Critical Perspectives on Human Rights and Disability Law

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Edited by

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FOREWORD

It gives me enormous pleasure to pen a few words about this splendid volume titled *Critical Perspectives on Human Rights and Disability Law*. Its editors, Marcia Rioux, Lee Ann Basser and Melinda Jones have in sixteen essays, gathered together the thoughts of themselves and a number of significant disability scholars to examine the interplay between disability rights and the law.

The approach of this book is to outline what the editors aptly describe as the foundational human rights principles of dignity, equality, inclusion and participation. Building upon this foundation, the essays unpack the relationship between human rights principles, domestic law and the experiences of we people with disabilities. We must never forget that these laws and policies operate on the lives of "flesh and blood" persons with disabilities, many of whom are vulnerable; and accordingly the operations of laws and practises will always require diligent study. This fine collection of papers fulfills this role with aplomb. While it is not the purpose of a foreword to summarise the book *per se* it is appropriate to note that in unpacking the operations of laws upon persons with disabilities, several of the essays examine important cutting-edge issues for we persons with disabilities. These issues include valuing all lives; the rights of children, parents and doctors; involuntary treatment; sterilisation; political participation; and children, reproductive rights and parenting.

On 8 May 2008, the United Nations Convention on the Rights of Persons with Disabilities came into force, and at the time of writing (March 2010) some eighty nations have ratified it. As one of the twelve foundation members of the treaty body for this Convention titled, the United Nations Committee on the Rights of Persons with Disabilities, I welcome the scholarship contained in this volume. I especially applaud the essay by María Soledad Cisternas from Chile who is also a foundation member of the treaty body.

The Convention adopts the social model of disability whereby physical, mental and sensory impairments are no longer perceived as simply medical problems. On the contrary, the social model of disability recognises that persons with such impairments are perceived as disabled by the State and by society. The social model seeks to end such paternal attitudes and stereotyping in order to enable persons with disabilities to lead fulfilled and fulfilling lives. On a more concrete level, the Convention grants we persons with disabilities civil, political, economic and cultural rights which have long been bestowed upon able bodied persons but which in many instances have not trickled down to significant numbers of my sisters and brothers with disabilities. At the international level, the Convention plays an important role by requiring countries to periodically report to the treaty body on what measures they have taken to implement the human rights set forth in the Convention.

Article 33 of the Convention is a relatively new and largely untried provision which requires countries to establish mechanisms to monitor the implementation of the Convention. Such mechanisms must ensure that persons with disabilities and persons with disabilities organisations fully participate in the implementation and in the monitoring of the Convention.

It is of equal importance to appreciate that we persons with disabilities are also able to rely upon the human rights provisions which are contained in other United Nations conventions, as well as in many supra-national covenants, charters and treaties. Lawyers and other advisors of we persons with disabilities should leave no stone unturned when examining and evaluating appropriate legal avenues of redress.

At the national level, however, it is essential to understand that the rights of persons with disabilities will be fully protected only when domestic laws, policies and practises are appropriate, adequate, sensitive and based upon justice. I venture to believe that the promotion and the protection of the human rights of we persons with disabilities requires cooperation from both the domestic and international spheres. Only then will we persons with disabilities attain true dignity, equality, autonomy, social inclusion and justice.

Professor Ron McCallum AO
2010 Chair
United Nations Committee on the
Rights of Persons with Disabilities
At Sydney, Australia,
March 2010

ACKNOWLEDGEMENTS

This book is a result of on an ongoing project on Law and Disability and the production of the text has been a lengthy process. During its development there have been significant changes in the recognition of the role of human rights and disability law, including the adoption of the *United Nations Convention on the Rights of People with Disabilities*. We would like to acknowledge the assistance and support of many people who have been a part of this process and have worked on or watched these changes.

We have been very fortunate to bring together this book in a highly encouraging environment with the support of the School of Health Policy and Management at York University as well as the York Institute of Health Research, the graduate program in Critical Disability Studies at York University, the School of Law and the Faculty of Law and Management at La Trobe University and the Australian Human Rights Centre at the University of New South Wales. The production of this book has been made possible by generous grants from York University, Disability Rights Promotion International and La Trobe University.

We would also like to thank the research assistants who contributed this book including doctoral student in York University Critical Disability Studies Joanna Rankin, (editing and introductions); research assistant Allyson Marsolais (bibliography) and La Trobe Law student Margaret Buchannan. Their assistance in bringing this project to fruition is greatly appreciated.

As the editors of this collection we also want to extend our greatest appreciation to all of the contributing authors who have made this final work a success and who have generously and patiently given their expertise in this collaborative process. Thank you Aaron, Angela, Christopher, Ena, Genevra, Janet, Kithure, Lora, María, Michael, and Michael, Paula, Rebecca, Rodrigo and Roxanne without whom this project would not have been possible. It has been our pleasure to work with you on this pioneering book.

Finally, we would like to recognize our publisher Lindy Melman at Brill Publishing for agreeing to publish this work and for all of the editorial work that she has contributed to the final product.

We hope that this book will be useful in disability law courses and to the students in disability law; to the legal community as they approach cases; to governments as they approach disability law; to disability organizations world-wide; and to the international human rights community.

Marcia, Lee Ann and Melinda

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INTRODUCTION

CRITICALLY APPROACHING HUMAN RIGHTS[1]

The relationship between law and disability has evolved over the past 30 years. The introduction of human rights laws and disability discrimination legislation have changed the landscape for people with disabilities.[2] The development of critical legal scholarship and critical disability studies have provided an impetus to the development of the field of critical disability legal scholarship.[3] In this volume we explore the relationship between human rights principles, human rights law, domestic law and the experience of people with disabilities. To understand the complex role of disability rights, it is important to recognize the ways in which legal constructions of knowledge are embedded in both understandings of the disabled person in law and in the ideology that is produced surrounding disability. Just as the relationship between disability and law has been under theorized, the relationship between human rights/international law, ethical theorizing about disability and legal constructions of justice has only relatively recently come onto the agenda, and has, until recently, rarely been analyzed critically.

From the perspective of international law, the adoption of an international human rights treaty specific to disability represents a legal outcome that is the result of non-binding law, Declarations, General Comments and Resolutions. From the perspective of the disability community, the adoption of the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD or the *Convention*) is a cause for celebration, as it is a statement from the international community that people with disabilities are valued members of society and are

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[1] We would also like to acknowledge the contributions made by Joanna Rankin, PhD candidate, York University, Canada.

[2] See for example Sweden: Act 2003:307; USA: *Americans with Disabilities Act* 1990; Canada: *Human Rights Act* 1977 and *Charter of Rights and Freedoms* 1982; UK: *Equality Act* 2010; Australia: *Disability Discrimination Act* 1992.

[3] Modeled on Critical Legal Studies, the first M.A. in Critical Disabilities Studies began in 2002 at York University in Toronto, Canada. It was followed by a PhD program in 2007, See: http://www.yorku.ca/gradcdis/ (visited Nov 8, 2010).

entitled to be treated as rights-bearers. The development of the CRPD was unprecedented in the speed with which it was drafted and adopted. The *Convention* lends a new urgency to the task of understanding the relationship between human rights and people with disabilities—a process begun with the development of domestic laws recognizing disability.

This volume begins by stepping back and looking at the meaning of human rights principles; to consider how they apply to various aspects of the lives of people with disabilities; and to further consider the relationship between this rights analysis and legal action. The articles in this volume recognize the way in which disability has been presumed to be a static state with too little attention paid to conceptualizing the impact of the legal construction of disability.

This book tackles some issues that are central to a critical approach to human rights and disability law. It surfaces the way in which there is a general misconception of the potential of law to undermine the value of people with disabilities. An underlying premise introduced by Professor Basser in chapter 1 is that people with disabilities "have not traditionally been seen as rights bearers." Jones unpacks that idea (chapter 3) recognizing what has become increasingly more apparent through the critical disability literature, that people with disabilities have been viewed, because of the nature of legal and social constructions of the status of disability, as objects of pity, as recipients of charity and welfare, rather than as entitled to rights. This reflects a generalized failure to "take into account the inherent value of each and every person." Rioux and Riddle explore this idea (chapter 2) arguing that broader social values and assumptions about disability are embedded in legal understandings, frameworks and jurisprudence. Whereas human rights principles point to the equality of individuals and the specific entitlements "possessed by all persons by virtue of their human and social dignity" (Kindiki, chapter 11), disability, is seen as outside this conception, adding "...additional layers of complexity to th[ese] basic principles" (Waterstone, chapter 13). To put in place a human rights perspective on disability law, an ideological shift is needed which questions the seemingly natural disparity built into the law in the treatment of people with disabilities. This way of applying rights is described by Brown and Lord, in chapter 10, as a means of promoting the recognition of people with disabilities as rights holders through the use of legally binding and non-discriminatory mandates. The application of these rights is upheld by three foundational characteristics: that rights are indivisible, inter-dependent and inter-related; that is, there can be no prioritization of rights.[4]

Though human rights are intended to be applicable to all people, people with disabilities globally continue to experience discrimination in relation to the protection and implementation of their rights. Current applications of law frequently negate the principles themselves and instead uphold premises of indignity, inequality and exclusion. As Rioux and Riddle argue, in chapter 2 "legal constructions of inequality are built into the nature of both the disabled person in law and into knowledge production in the field of disability…". At present, despite domestic laws, including disability discrimination law, human rights law and administrative law, laws have rarely been applied in ways which fully benefit people with disabilities and the application of these rights often fail to reflect lived experiences. While in many jurisdictions there are at least some legal or constitutional protections available to people with disabilities, people with disabilities continue to have limited access to education, adequate housing and choice in the way they live. They are frequently denied food, health care and supports and continue to be excluded from activities of daily living, as well as social and cultural pursuits.

One response to the exclusion of people with disabilities and the denial of rights is to have recourse to law and for legal interpretation to be considered in light of disability. Law may take the form of domestic legislation or a judicial decision within a particular legal system, or it may be an appeal to the human rights confirmed by international law. This volume provides tools with which to critically assess the exercise of law itself, using human rights principles. These tools are human rights principles which offer insight into justice for people with disabilities. Specifically it is argued that the principle of dignity, the principle of equality and the principle of inclusion and participation, independently and together, shed light on what is needed to give effect to the human rights of people with disabilities.

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[4] Interdependence is outlined in the CRPD Preamble Section (*c*) "*Reaffirming* the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination."

Part I: Human Rights Principles

Exploring human rights principles allows us to demonstrate the essential role that human rights principles can play in the experience of disability at its intersection with law. Part I explores in detail the principles of dignity, equality and inclusion/participation in the context of disability law, arguing the importance and interconnectedness of each of these principles in the lives of people with disabilities. Our objective is to demonstrate the way in which human rights principles can lead to outcomes that support people with disabilities and to demonstrate that the use of human rights principles can lead to new and empowering perspectives on the relationship between law, disability and the state.

In chapter 1, Basser provides a comprehensive account of dignity as a rights issue for people with disabilities, recognizing its foundation in individual value and the resulting empowerment. Outlining its history and theoretical development, dignity is proposed as a fundamental basis of analysis in both the operational and legal promise to establish and maintain human rights through national and international human rights codes, national laws and conventions and regional principles. Invoking the principle of dignity, Basser offers insight into the lived experience of the individual involved in legal action and of the impact of social policy on people with disability as a whole. Taking the dignity of the person into account allows us to understand what is at stake and to rethink decisions made under more global principles.

In Chapter 2 Rioux and Riddle focus on competing interpretations of the principle of equality, outlining three general ways in which equality has been framed in philosophy and law: the like treatment model; the equal opportunity model; and the substantive or equality of outcome model. The authors explore the effectiveness of the application of each conception of equality in relation to disability and demonstrate that, in law and legal interpretation, there is an inherent inequality present in law and knowledge production. Rioux and Riddle argue that the language of equality is used to defend a range of outcomes, some of which contradict basic objectives of the equality principle. Recognizing that human rights principles support substantive or outcome equality it is possible to revisit legal decisions and social policies in order to assess their consistency with an equal outcome approach.

In Chapter 3, Jones argues the principle of inclusion challenges views that people with disabilities should be merely tolerated or simply accepted. She argues that there are three dimensions of inclusion: non-discriminatory attitudes; access to participation; and facilitation to limit the impact of disability. These features are identified as traits of a just society, accessible through the implementation of human rights. Comparing re-distributive, social integrationist and moral understanding discourses, Jones provides an important challenge to the lack of justice identified through exclusionary practices.

The authors of the three chapters recognize that social or legal action should be considered in the light of all three principles. People with disabilities are only valued members of society to the extent that they are treated with dignity and respect, are provided with outcomes which are substantively equal with the outcomes of others and are fully included in all aspects of the life of society. These principles provide the framework with which to understand the interrelationship between disability law and rights.

Part II: Advancing Dignity

Part II focuses on human rights issues relating to the dignity of the person. The jurisprudence and legal statutes discussed in the following chapters make clear that persons with disabilities are frequently denied this right. They highlight the centrality of dignity in ensuring human rights as well as the implementation of the right to dignity as a principle from which to argue human rights cases.

Taking dignity as an ethical precept, Jones, in chapter 4, draws our attention to the legal conceptions of wrongful birth and wrongful life in torts relating to disability. The very idea of a "wrongful birth" or a "wrongful life" is contentious and, at first instance, appears to suggest that people with disabilities would be better off dead. People with disabilities have objected to the continuing recognition by the court of these torts, arguing that the language of law has far ranging influence and has an impact on the way in which people with disabilities are viewed. Jones argues that these torts may be justifiable and legitimate when brought by persons with disabilities.

In his chapter titled "Children at the Edge of Life: Parents, Doctors and Children's Rights," Freeman revisits questions related to life saving treatment of disabled infants and reconsiders legal cases in the light of the principle that all people should be treated with dignity and respect. Freeman argues that there is a fundamental problem in legal and medical decision making which fails to recognize the inherent value of new born children with disabilities. Freeman explores assumptions made about the quality of disabled lives. Despite the United Nations *Convention on the Rights of the Child*, which makes clear that children are rights-bearers, Freeman argues that this is often forgotten in the context of children and medical decision making. He demonstrates that while this is true for children generally, it is particularly problematic for children with disabilities.

Richardson considers a similar problem with respect to people with psychiatric disabilities in "Involuntary Treatment, Human Dignity and Human Rights." Focusing on the right to dignity, rather than the experience of disability, Richardson examines the way in which decisions are made "about" or "in the interest of" individuals. Of particular concern is the imposition of involuntary treatment on people with psychiatric disabilities, which, he argues, constitutes a denial of human dignity. Richardson views this issue in light of the jurisprudence of the European Court of Human Rights, in which there is an emphasis placed on physical integrity and self determination in the interpretation of human rights. This jurisprudence offers a perspective which may be helpful in the interpretation of the CRPD.

According dignity to any person requires recognition of their sexuality, sexual identity and their freedom to engage sexually. Dignity also requires respect for reproductive freedom and the right to family life. Respecting the dignity of disabled women requires an understanding both of the impact of disability and of the experience of being a woman, as is recognized in Article 6 of the *Convention*. Mykitiuk and Chadha explore this often neglected aspect of the lives of women with disabilities. In the process, they deconstruct the law relating to reproductive and parenting rights and argue that law is caught up in the denial of sexual health education and reproductive services to people with disabilities. Mykitiuk and Chadha argue that according dignity to people with disabilities requires that there be accessible sex education which emphasizes the entitlement to intimate relationships, the right to marry, the right to sexual and reproductive health, the right to have and maintain a family and the right to reproductive assistance. The complexity of this area suggests the importance of education, not just for people with disabilities but for the community at large, to understand the right to dignity.

While the preceding chapters have focused on matters intimate to the individual – reproductive rights and cutting edge questions about life, death and medical treatment, Laycock reminds us that questions of dignity arise in every situation in which people generally, and people with disabilities in particular, find themselves. In "Price v UK: The Importance of Human Rights Principles in Promoting the Rights of Disabled Prisoners in the United Kingdom," Laycock looks at how the dignity of a person can be compromised in prison, not just by the ordinary problems which arise, but also because of the complications associated with disability. Laycock illustrates the mistreatment of people with disabilities in the penal system and argues that there is a failure to recognize that accommodating the needs of a prisoner with a disability is essential if one is to provide equality and dignity of their treatment within the prison system.

Dignity is central to the recognition of a person as a rights-bearer. Whether the issue – either overt or covert discrimination—occurs in employment or education, leisure activities or accessing goods or services, mandates a consideration of whether the person has been treated with dignity and respect. This analysis provides not only insight into that person's situation but it is also a means of uncovering what is unjust in a broader range of situations. Denying dignity to a person with a disability is to deny that person's humanity. Ensuring dignity is essential to a meaningful guarantee of human rights.

Part III: Ensuring Equality

In Part III we move from a focus on the individual to a focus on the comparative position of people with disabilities and those without disabilities. The principle of equality, a foundational rights principle, requires that people with disabilities are recognized as equal members of society. Building on Rioux and Riddle's analysis of equality in Chapter 3, the chapters in this section of the book explore the extent to which inequality can be dressed up as equality through linguistic acrobatics and legal smokescreens. As Rioux and Riddle make clear, understanding equality is not as simple as it appears at first sight. Where people are differently situated, it is essential to establish the extent to which the difference needs to be taken into account if equality is to be fully realized. Ideas of equality range from formal equality, in which each person is accorded identical treatment independent of personal characteristics, to equality of opportunity, to equality of outcome and substantive equality.

These ideas of equality are explored by Rioux and Patton in "Beyond the Legal Smokescreen: Examining Equality Values in Sterilization Jurisprudence." The sterilization of women and girls with intellectual disabilities is a practice which is still common place and, in some countries, legally sanctioned by the State. As this remains contentious, applications have been made to the courts of a number of jurisdictions seeking to legitimate sterilization procedures and the role of the state under the *parens patriae* power. Rioux and Patton note that there have been very different outcomes in different courts on similar fact situations. While the language of equality is invoked in most cases, the meaning attributed to equality varies significantly, showing that the differing outcomes can be explained in terms of the different legal and ethical characterizations of equality. In order to make headway through the confusion about equality, the authors demonstrate the quite radically distinguishable ways in which Canadian, British and Australian courts have addressed this issue and the outcome for people with disabilities. Rioux and Patton maintain that equality of outcome is the only concept of equality which arguably can be held to be consistent with human rights principles.

Recognizing that the substantive equality of people with disabilities is a basic requirement of justice which claims to operate within a human rights framework, does not, in itself, provide a means of ensuring substantive or outcome equality. Brown and Lord in their chapter, "The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: The UN Convention on the Rights of Persons with Disabilities," argue that specific action is needed to mitigate against the potentially negative consequences of disability. The term "reasonable accommodation" is used in the CRPD and in some domestic laws, to describe the proactive measures to be taken and the social goods that need to be provided in order for people with disabilities to function as equal members of society. It is only when a person with a disability has been accorded reasonable accommodations that substantive equality can become a reality. This has consequences for the interpretation of the *Convention* in the rights of persons with disabilities, as well as other international and domestic guidelines and law. Brown and Lord argue that an understanding of reasonable accommodation provides a key to advocacy for people with disabilities. Further, they recognize reasonable accommodation as integral to successful enforcement mechanisms.

Kindiki lays out the operation of the legal protection of people with disabilities in Kenya. In his chapter, "Legal Protection of Persons with Disabilities in Kenya: Human Rights Imperatives," Kindiki considers the way in which the law operates in circumstances where there has been a failure to accord equality to people with disabilities. Focusing on the situation in Kenya, Kindiki concludes that much remains to be done both in terms of understanding the experience of disability and in terms of the law designed to protect people with disabilities. This chapter provides a critique which has wide application.

Demonstrating one way in which substantive equality can be given effect, Dhir, in "Corporate Selective Reporting of Clinical Drug Trial Results as a Violation of the Right to Health," draws our attention to issues of access to safe pharmaceuticals. The general principle of inclusion requires that people with disabilities have equal access to health care resources and that the medication that they are given is safe and suited for the purpose it is prescribed. Dhir argues that governments have a responsibility for regulating clinical drug trials and assuring full transparency to ensure the protection of people with disabilities from misdiagnoses or negative side effects.

Where there are laws proscribing discrimination and/or promoting the rights of people with disabilities, it is important that they have more than a symbolic effect. The objective of good law is good social practice, and while it is important that law be developed, it is more important to ensure that policies and practices are adopted which make a difference to the lives of people with disabilities. Equal outcome requires recognition that barriers are built into law and social policy and practice. Law may be ineffective if there is no concurrent recognition that inequality is a consequence of the organization of social and political institutions and the ways in which legal ideas of incompetence and incapacity have been entrenched. Where lawmakers adopt and apply the principle of substative or outcome equality, the human rights of people with disabilities can be protected. The strategic use of this notion of equality will mandate courts to consider, more comprehensively, the rights of people with disabilities.

Part IV: Promoting Inclusion and Participation

The principle of inclusion and participation encompasses the relationship between the individual and society at large, and the way in which individuals experience relationships in both the private and the public realm. Whatever is done to ensure the inclusion of one person will also have the possibility of providing a blueprint for the inclusion and participation of people with disabilities generally. Invoking the principle of inclusion and participation not only generalizes from what would be "right" for one person, it also shifts the focus from the experience of the individual's disability to the structures of society with which individuals must contend. Ethically, as Jones points out in Chapter 4, the principle of inclusion goes beyond tolerance and acceptance to facilitation and participation.

Waterstone illustrates the content of inclusion and participation in his chapter titled "Political Participation for People with Disabilities." As he points out, political participation is a basic requirement of a democratic society, and ensuring equality of political participation for people with disabilities is a complex matter. Waterstone considers how the requirements about voting may need adjusting if this right is to be provided on inclusive and participatory terms to people with disabilities.

Jiménez in this chapter, "The Right to Live a Life Free of Violence for People with Disabilities," provides a clear example of the principle of inclusion in his analysis of violence against people with disabilities in Latin America. Beginning with recognition of the extent of violence, Jiménez draws our attention to relevant international law which specifies the right to live free of violence. The problem which he describes is that where there is law, it operates in a manner which is exclusive of people with disabilities. While he points out that the domestic laws do not adequately reflect the rights found in international law, he is more concerned with the reality that the laws do not operate effectively for women and people with disabilities. He argues that exclusion takes two forms. First, there is a lack of access to justice, where a person with a disability has been the victim of violence, whether in the home or in the broader society. Secondly, where people with disabilities who are victims of violence do have access to the courts, they are insufficiently facilitated or accommodated through the legal process. He proposes that specific legislation about the rights of people with disabilities, which includes the right to an independent life free from harm, would be a means of giving effect to international human rights law. Further, Jiménez argues that there is a national responsibility to respond to this problem and that an inclusive attitude to people with disabilities is overdue.

The *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (*Standard Rules*) were developed as a guideline to government practices with respect to the inclusion of people with disabilities in the absence of a convention on disability. With the implementation of the *Convention,* Cisternas Reyes' interpretation of the relationship between reasonable accommodation and the principle of inclusion, along with the strategic use of the *Standard Rules*, provides illustrations of inclusive social practices. Reporting on a legal project in which people with disabilities and indigenous people were trained about their rights Cisternas Reyes demonstrates the various faces of inclusion and participation and the complexity of ensuring it. People with disabilities need to be empowered by understanding what rights they have. People without disabilities need to recognize what may be required for the inclusion of people with disabilities. Equally, public officials have a responsibility to include people with disabilities, whether as fellow employees or as service users.

The complexity of understanding disability and inclusion and participation requires knowledge about the lived experience of disability. The practice of inclusion varies from culture to culture and from society to society. Inclusive practices are consequent on an understanding not only of disability generally, but are grounded in research which informs us of the localized experience of disability and the strategies developed where there has been a denial of human rights. As Pinto argues in "Monitoring Human Rights: a Holistic Approach," monitoring disability rights involves a broad perspective on what is happening in society. It involves interpreting and researching individual experience, laws and policies but there also has to be an assessment of national and international programs and public attitudes to disability. Monitoring processes have the potential to be both educative and empowering. The outcome of monitoring projects, such as the Disability Rights Promotion International (DRPI) project, is a ready and rich source of data which can be used in human rights enforcement of international and national law and advocacy. DRPI's work is grounded in the recognition of the interconnectivity of individual experiences; systems, laws and policy; and public awareness (measured through media monitoring).

Each area is designed as a way of identifying violations, gaps and misrepresentations of the implementation of rights. Pinto argues that holistic monitoring can be used both for shadow reports to governments and the United Nations, as well as formal government submissions to make those reports more robust and incorporate the perspective of people with disabilities themselves.

The critical perspective on human rights and disability law presented in this volume are drawn from the experience of scholars and activists in a number of jurisdictions and legal systems. The core human rights principles of dignity, equality and inclusion and participation have been analyzed and applied with a view to understanding the way in which human rights principles can be applied in law and policy to achieve grounded outcomes for people with disabilities. A principled approach to international human rights law offers a tool for people with disabilities that transcends national boundaries. Using these principles to analyze facts whenever an action is brought to the courts has the potential to educate all the players involved, to provide an understanding of what is at stake for the person with a disability and to recognize what is required from governments and the legal community to meet the entitlements of people with disabilities as rights-bearers.

While each of the three principles used as the under-pinning for this volume – of dignity, equality and inclusion and participation – stand on their own, the concepts are interrelated and interdependent. Arguably, substantive equality is an objective that can be achieved by according dignity to the person and ensuring inclusive and participatory practices. Equally, it could be said that the institutionalization of dignity will ensure equality. The principle of inclusion found in the CRPD, while not historically seen as a foundational human rights principle, recognizes that substantive equality and dignity are only achievable when there is real inclusion of people with disabilities. They will be substantively equal to those without disability and their dignity will also be respected.

With respect to people with disabilities, these human rights principles are essential to the determinations of courts and transformative of the experience of society. Where policies are drafted or legal decisions made, the principles of dignity, equality and inclusion and participation offer criteria to be used in assessing the consistency with the human rights of people with disabilities. From the perspective of human rights, only those outcomes and processes which promote dignity, equality and inclusion and participation can be supported. The practical application of these analyses are explored throughout this volume.

PART I

HUMAN RIGHTS PRINCIPLES

HUMAN DIGNITY

Lee Ann Basser

> …Valuing human dignity means acknowledging the inherent worth of human beings; therefore violating dignity involves conveying the message that some are of less worth than others.[1]

> The recognition and protection of human dignity is one of the core values…of our society and, indeed, of all the societies which are part of the European family of nations and which have embraced the principles of the Convention. It is a core value of the common law, long pre-dating the Convention.[2]

People with disabilities have not traditionally been seen as rights bearers. For the most part people with disabilities have been recipients of charity and welfare, seen as objects of pity rather than as authors of their own destiny. This reflects an individual tragedy approach to disability and fails to take into account the inherent and ultimate value of each and every person. The ideological shift inherent in a human rights perspective requires that people with disabilities are recognised as rights bearers and entitled to the benefits which flow from membership in the human family. As family members we expect to accord each other dignity and as workers we expect our employers and colleagues to value us as human beings and to act accordingly. As citizens we expect to be treated with dignity by the state. Yet many people with disabilities experience indignity in both their public and private lives.

Recognition of human dignity is found in a range of legislative instruments which acknowledge the entitlements of people with disabilities. These include international and domestic human rights instruments – treaties, constitutions, charters and bills of rights – which apply to people with disabilities whether or not disability is specifically

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[1] Reaume, D.G. (2003). Discrimination and dignity. *Louisiana Law Review, 63*, 1–51.

[2] *R (Burke) v GMC* para 57 referring to *R(A B X & Y) v East Sussex CC and the Disability Rights Commission (No2)* [2003] EWHC 167 (Admin) per Mumby J. It goes without saying that human dignity is not limited to the European family of nations – it is a principle of international human rights law as well as a core value of many national legal systems.

referred to.[3] Also included are: disability discrimination laws, equal opportunity laws and affirmative action laws. The operation of these laws is designed to ensure that human dignity is respected. Excluding or discriminating against people with disabilities ignores the essential value and worth of the individual.

Meeting basic needs is the first step in securing human dignity and is necessary as a means of underwriting specific civil and political human rights. The idea of dignity is crucial to an understanding of human rights and is important to the individual, in the development of a sense of self and of self-esteem, providing a foundation for self-determination. An integrated sense of self, coupled with an appreciation of one's inherent worth, allows an individual to see him or herself as more than simply the sum of his or her limitations. Too often people with people with disabilities have seen themselves as others see and describe them, focusing on their "deficits" or "label." The promise of human rights is that *all* people are of equal worth and the implication of human dignity provides the basis for people with disabilities to reconstruct themselves as ordinary people. It is the experience of dignity which allows a person to recognise his or her own value. In this way human dignity becomes a tool of empowerment.

There is another important aspect of dignity. Dignity provides a framework of analysis, a context for unpacking social structures, the way people are viewed and the way policies are implemented. Dignity asks us to think: "how would it feel to stand in the shoes of the other person?"; "how would I like to be treated?". The attribution of dignity allows for the possibility of a claim to human rights entitlements at the same time as providing the content of those claims. When dignity is protected by law, status and recognition are conferred on the individual.

Until the adoption of the *Convention on the Rights of Persons with Disabilities* (CRPD)[4] "disability" only appeared as a status in one international human rights treaty – the *Convention on the Rights of the Child*. The reason that disability was included in the CROC was two fold, one reason was that by the time it was drafted disability had become an issue on the public agenda. The other was that the CROC brings together the gamut of human rights as they apply to one population (children). The *Universal Declaration of Human Rights* (UDHR),[5] the

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[3] See below beginning at page 31.

[4] A/C.3/64/L.24.

[5] General Assembly Resolution 217A (III) of 10 December 1948.

International Covenant on Civil and Political Rights (ICCPR)[6] and the *International Covenant on Economic Social and Cultural Rights* (IESCR)[7] do not make reference to people with disabilities. This could be seen as an indication that the international community considered people with disabilities to be of lesser worth than other people.[8] However, both the United Nations Human Rights Committee and the Committee on Economic, Social and Cultural Rights issued *General Comments* clarifying the inclusion of people with disabilities[9] and subsequently the General Assembly passed resolutions to this effect. Any residual doubt about the fundamental worth of people with disabilities and their entitlement to be treated with dignity have been resolved by the CRPD which almost all nations have adopted.[10] The fact that the dignity of people with disabilities has been recognised in international law is important for a number of reasons. Over and beyond the symbolic function of the law, by which it is made clear that people with disabilities are rights-bearers, the law plays an important role in education about disability and in raising awareness of the inherent worth of all people with disabilities. Although dignity is included as a basic principle in the CRPD and other international human rights instruments, the concept remains both illusive and undefined.

The Concept of Dignity

At the heart of modern human rights is the concept of human dignity. Dignity is an attribute of each person by virtue of his or her humanity. The idea of dignity has its roots in antiquity[11] and can be found in many

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[6] General Assembly Resolution 2200A (XXI) of 16 December 1966.

[7] General Assembly Resolution 2200A (XXI) of 16 December 1966.

[8] This was a motivating factor for the development of the Disability Convention see Darrow, M. (1996). International human rights law and disability: Time for an international conventionon the rights of people with disabilities? *South African Journal of Human Rights,* 3(1), 69–96.; see also Quinn, G. & Degener, T. (2002). *The current use and future potential use of United Nations human rights instruments in the context of disability.* New York & Geneva: United Nations.

[9] HRC *General Comment* 18 HRI/Gen/1/Rev.1 at 26 (1994) para 7; ESCR *General Comment* 5 UN.DE/C.12/1994/13 (1994).

[10] Of 192 member states of the United Nations 143 have signed (74 ratified) the CRPD and 87 have signed (47 ratified) the Optional Protocol as at 10 November 2009.

[11] For an outline of the development of the concept of human dignity see: Englard, I. (2000). Human dignity: From antiquity to modern Israel's constitutional framework. *Cardoza Law Review,* 21, 1903–1927.; Beyleveld, D. & R. Brownsword. (2001).

cultures, not all of them "rights respecting."[12] Human dignity has been conceptualised as a moral value, a principle underpinning human rights and as a human right.[13] The attribution of dignity is not dependent on social status, political affiliation, economic value, religion, ethnicity, race, gender, genetic make up, the ability to reason, physical or mental ability or merit. As Réaume puts it:

> To ascribe human dignity to human beings…that is, to treat it as an inherent aspect of humanity- is to treat human beings as creatures of intrinsic, incomparable, and indelible worth, simply as human beings; no further qualifications are necessary. In this basic sense, dignity is ascribed to human beings independently of their particular accomplishments or merits of praiseworthiness. It refers to a kind of worth that is not contingent on being useful, or attractive, or pleasant or otherwise serving the ends of others.[14]

This worthiness attaches to a person because of her humanity. It is not a privilege and cannot arbitrarily be encroached upon. Human dignity is therefore understood as inherent and inviolable, a quality that is intrinsic to the person. Each human being is deemed to be of inestimable value because of his or her inherent self-worth. Implicit in this acknowledgement of the inherent value of the human person, is an acknowledgement and acceptance of human diversity and difference.

Human dignity, along with the other concepts discussed in this book, is a foundational principle underpinning human rights with the potential to provide an interpretive lens through which to ascertain the content of specific rights. As with human dignity, the modern conception of human rights is that they attach to the person by virtue of being human. They are not the gift of States but are the "right" of human persons.[15] Understood in this way, rights are entitlements that ground

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Human dignity in bioethics and biolaw. Oxford: Oxford University Press.; McCrudden, C. (2008). Human dignity and judicial interpretation of human rights. *European Journal of International Law, 19*(4), 655–724.

[12] Howard, R. E. & J. Donnelly. (1986). Human dignity, human rights and political regimes. *American Political Science Review, 80*(3), 801–817.; Donnellly, J. (1982). Human rights and human dignity: An analytic critique of non-western conceptions of human rights. *American Political Science Review, 76*(2), 303–316.

[13] Grant, E. (2007). Dignity and equality. *Human Rights Law Review, 7*(2), 299–329.

[14] Reaume, D.G. (2003). Discrimination and dignity. *Louisiana Law Review, 63*, 1–51.

[15] Weinrib, L. (2005). Human dignity as a rights-protecting principle. *National Journal of Constitutional Law, 17*(3), 325–345.

claims against the State and found obligations on the part of the State. Many States protect human rights in their Constitutions or have enacted Bills of Rights with constitutional or legislative force. Each of these laws bolster a claim of entitlement to dignity.

The relationship between human rights and human dignity is complex. In its modern conception dignity is both a fundamental principle underlying human rights and a right in itself.[16] Human dignity can be seen as the "source" of human rights[17] and, at the same time, human rights are said to give effect to the principle of human dignity. Human rights are relational[18] – people live together in society and rights-entitlements of individuals are constrained by the need to give equal concern and respect to other human beings. Human dignity is similarly relational. Dignity comes into play in transactions between individuals and in dealings between individuals and the State. Human dignity can found a claim to the resources of society that are required for living a life with dignity. Equally, the extent to which any claim can be met will also be constrained by the need to give equal concern and respect to others.

Human dignity is particularly valuable because it reiterates and reinforces the idea that all people are rights-bearers. This is very important for those groups of people who have been traditionally denied a place in society. If rights are *special entitlements* and therefore, in Dworkin's words, "trumps,"[19] (or as Jones puts it – "the entry card into society"),[20] then dignity is the key that turns the lock and allows entry into society and requires that each person be treated with equal concern and respect in that society.

Giving effect to the principle of human dignity requires knowing something about the effect of difference in people's lives.[21] Equally as

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[16] For example Art 1 EU Charter of Rights of Fundamental Rights – proclaimed by the Presidents of the European Council, European Commission and the Commission of Justice and Home Affairs on 7th December 2000 in Nice. For a history of the Charter see http://www.eucharter.org/home.php?page_id=65 (last accessed 3 April 2006).

[17] Schachter, O. (1983). Editorial Comment: Human Dignity as a Normative Concept. 77 *Am J Int'l L*, 848–854, 848.

[18] Minow, M. (1990). *Making all the difference: Inclusion, exclusion and American law*. Ithaca, New York: Cornell University Press.

[19] Dworkin, R. (1977). *Taking rights seriously*. London: Duckworth Press.

[20] Jones, M. (1996). Balancing competing human rights. Communications Law Centre Proceedings of Conference on Free Speech in Australia, Sydney 10th September 1996, 45–49 at 47.

[21] Young, I.M. (1990). *Justice and the politics of difference*. Princeton, New Jersey: Princeton University Press.; Minow, M. (1990). *Making all the difference: Inclusion, exclusion and American law*. Ithaca, New York: Cornell University Press.

more is revealed about the nature of the differences experienced by people with disabilities, the more understanding we have of the meaning of dignity. For example, the principle of dignity is discharged by ensuring that people are not humiliated by the way in which they access services; understanding the diverse needs of people with disabilities for services provides information about the ways in which service users could be humiliated. Equally, dignity is affronted when a person with a communication and/or speech difficulty is shouted at on the assumption that the person is also deaf; dignity is respected when an individual is given the time and opportunity to "speak" using whatever mode of communication with which he or she is most comfortable. Similarly, dignity is affronted where children with physical disabilities are unable to participate in mainstream schooling because of the physical configuration of the buildings or lack of accessible toilets; dignity is maintained when a class is rescheduled to a ground floor class room to enable a child with physical disabilities to participate.

Satisfaction of the principle of dignity requires that all human beings are empowered to enjoy the benefits of society on an equal basis. This includes participation in political activity and in the social, recreational and cultural pursuits of the society. Dignity focuses on the person. Recognising the whole person, including aspects of the person that are "different" or "disabled," is a prerequisite to according dignity. While it is important to acknowledge the structural barriers which disable many people, it is impossible to accord dignity to a person with a disability without looking internally as well as externally. People are disabled, their lives made more challenging and difficult by their impairments and functional limitations of body and mind as well as by external systemic disadvantage. It is the requirement of dignity that ensures that "whole" people are seen and responded to.

Human dignity is a concept which resonates – it is one that is intuitively understood. Indeed, for all that the concept of human dignity has been theorised and has "come to be used as an expression of a basic value accepted in a broad sense by all people,"[22] what is meant by the concept of human dignity has been largely "left to intuitive understanding, conditioned in large measure by cultural factors."[23] This is

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[22] Schachter, O. (1983). Editorial comment: Human dignity as a normative concept. *American Journal of International Law, 77*, 848–854.

[23] Ibid., 849.

particularly true in legal texts such as international human rights treaties and declarations, national constitutions and domestic legislation where dignity is identified as a foundation value and sometimes as a right but is not usually defined. As Schachter puts it, there seems to be a general belief "that a violation of human dignity can be recognized even if the abstract term cannot be defined."[24] However, while legal instruments may be silent about the meaning of human dignity, it is possible to discern a meaning from both the instruments themselves and from various legal cases in which reliance has been placed on the concept in legal argument and in judicial reasoning.

As a principle informing the content of other human rights principles, dignity also has a role to play in the balancing process necessary to bring different rights and principles into harmony.[25] Dignity carries with it a transformative potential.[26] For people at the margins, as people with disabilities so often are, this transformative potential of human dignity (and of human rights more generally) is of particular importance. To a certain degree, that transformative potential has begun to be realised. For a long time many people with disabilities have been denied their basic humanity, shut out from society, treated as objects of charity and pity or perhaps of benevolent paternalism, and denied legal status.[27]

The transformative potential of the concept of dignity is not limited to this very important change in status for people with disabilities. That transformative potential extends into the substance and operation of law providing people with disabilities (together with other disadvantaged groups) with an important tool for affecting change and ensuring rights. Over and beyond this, invoking the concept of dignity requires an analysis of economic inequality, its impact on quality of life and may give rise to redistributive strategies.[28] The possibilities for dignity in this regard can be seen by its usage over time.

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[24] Ibid., 849.

[25] Chaskalson, A. (2000). The third Bram Fischer lecture: Human dignity as a foundational value of our constitutional order. *South African Journal of Human Rights, 16*(193).

[26] Cowen, S. (2001). Can 'dignity' guide South Africa's equality jurisprudence? *South African Journal of Human Rights,* 17.

[27] Jones, M. & L.A. Basser Marks. (1999). Law and social construction of disability. In M. Jones & L.A. Basser Marks (Eds.), *Disability, diverse-ability and legal change* (pp. 1–24). The Netherlands: Martinus Nijhoff.

[28] For a discussion of recognition and redistribution in the context of the principle of equality see Fredman, S. (2007). Redistribution and recognition: Reconciling

The Development of the Concept of Dignity

The modern understanding of dignity is informed by the ancient Roman ideas of *dignitas* and *dignatio*.[29] *Dignitas*, to the ancient Romans, signified a particular social and political status. Honour and respect were accorded to those worthy individuals who acquired the status of *dignitas*, perhaps through appointment to public office. Dignity accrued as a result of personal achievements and moral integrity.[30] This concept of dignity is to be distinguished from that connoted by *dignatio*, a distinction ascribed to Cicero. The term *dignatio* refers to the dignity or worth that attaches to a human being by virtue of being human.[31] Much later Pufendorf adopts this distinction in his secular version of natural law. Pufendorf's concept of *dignatio* is a precursor of modern ideas about dignity – it is inherent and therefore inalienable and all people are equal in dignity. For Pufendorf, human dignity is the basis for people having natural rights – in other words rights are derived from human dignity.[32] However, the entitlement to dignity is founded in the ascription of the common capacity for reason.[33] This, in itself, is problematic.

Another idea that underlies the modern conception of dignity is derived from the Bible. In the Judeo-Christian tradition[34] a person's

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inequalities. *South African Journal of Human Rights, 23*, 214–234.; Albertyne, C. (2007). Substantive equality and transformation in South Africa. *South African Journal of Human Rights, 23*(2), 253–276.

[29] Barrett, J. (2005). Dignatio and the human body. *South African Journal of Human Rights, 21*(4), 525–546.; Grant, E. (2007). Dignity and equality. *Human Rights Law Review, 7*(2), 299–329.

[30] Englard, I. (2000). Human dignity: From antiquity to modern Israel's constitutional framework. *Cardoza Law Review, 21*, 1903–1927.

[31] Englard, I. (2000). Human dignity: From antiquity to modern Israel's constitutional framework. *Cardoza Law Review, 21*, 1903–1927.; see also McCrudden, C. (2008). Human dignity and judicial interpretation of human rights. *European Journal of International Law, 19*(4), 655–724.

[32] Grant, E. (2007). Dignity and equality. *Human Rights Law Review, 7*(2), 299–329.

[33] Ibid., 304; Jones, M. & L.A. Basser Marks. (1994). The dynamic developmental model of the rights of the child: A feminist approach to rights and sterilisation. *International Journal of Children's Rights, 2*, 265–291.

[34] Although always referred to as the "Judeo Christian tradition" this is not an accurate representation of the Jewish perspective on dignity. The implication of being created in God's image is that all people must be valued independent of capacity or rationality. The Bible asks "whose blood is redder?" This means that no person is able to judge any other person because no one person is either superior or inferior. M. Jones. (2007). Jewish theology, disability and human rights. *World Journal of Religions 10*(4), 101–145;

dignity stems from the relationship with the divine, from being created in the image of God.[35] This conception of dignity is derived from "man's" special position in the world in which "he" is superior to other creatures, capable of self-reflection, possessing creative capacities and a rational soul.[36] This idea of "man's" inherent dignity was further developed by medieval philosophers such as Aquinas into natural law theory.[37] Modern theological thinkers tease out these ideas and acknowledge human dignity and worth as a fundamental value.[38]

An important source of the modern conception of dignity is to be found in Kant's philosophical writings. For Kant dignity is a quality of intrinsic worth and is tied up with morality.[39] Kant conceived of dignity as founded in autonomy and from this developed the categorical imperative:

> Act in such a way that you treat humanity, both in your person and in the person of each other individual, always at the same time as an end, never as a mere means.[40]

This conception of dignity as autonomy is a moral one, which attaches to all human actors. This means that when someone treats another with indignity, it is a moral failing; being treated with indignity is a moral abuse. If a person is to be treated as an end in themselves, that person must be accepted as they are, with no differential value being placed because of any particular characteristic. To treat people as ends in themselves requires that people be treated with dignity and respect.

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see also J. Sacks. (2007) *The home we build together: Recreating society.* London & New York: Continuum Publishers; J. Telushkin. (2006). *A code of Jewish ethics – Volume 1: You shall be holy*. Harmony/Bell Tower.

[35] What follows is the briefest of outlines of the evolution of the concept of dignity. For a more detailed discussion see McCrudden, C. (2008). Human dignity and judicial interpretation of human rights. *European Journal of International Law, 19*(4), 655–724; Barrett, J. (2005). Dignatio and the human body. *South African Journal of Human Rights, 21*(4), 525–546; Englard, I. (2000). Human dignity: From antiquity to modern Israel's constitutional framework. *Cardoza Law Review, 21*, 1903–1927.

[36] Englard, *supra* note 35 1908.

[37] Grant, E. (2007). Dignity and equality. *Human Rights Law Review, 7*(2), 299–329.

[38] Sacks, J. (2005). *To heal a fractured world: The ethics of responsibility*. London & New York: Continuum Publishers.

[39] "Hence, only morality and humanity, insofar as the latter is capable of the former, possesses [sic] dignity." Kant, E., *Foundations of the Metaphysics of Morals* cited in Englard, I. (2000). Human dignity: From antiquity to modern Israel's constitutional framework. *Cardoza Law Review, 21*, 1903–1927.

[40] Ibid.

One problematic aspect of the historical conception of dignity, from a disability perspective, is that it is often tied with the ascription of autonomy and the ability for practical reason. A human rights approach, which takes dignity to be a central element, cannot be dependent on the ability of the person to act independently of all others or to act rationally. Feminist legal scholarship challenged the liberal ideal of "rugged individualism" demonstrating unequivocally that we are all interdependent and all function in relation to one another.[41] So the fact that, often, people with disabilities find themselves in relationships of dependency is irrelevant to their inherent dignity and to their entitlement to be treated with dignity. Equally, the ability of a person to reason, think rationally or be intellectually "competent" has no bearing on the moral imperative of treating people with dignity and respect.[42]

At the heart of the right to dignity is respect for the inherent value of our own lives,[43] for the ability to treat others with dignity is circumscribed by the way in which we treat ourselves. Dworkin, in *Life's Dominion* considers two approaches to understanding dignity. He proposes an experiential theory of "indignity" as a means of understanding dignity. This theory focuses on the objective experience of the individual and assumes that "indignity" will lead the person to experience mental anguish and a loss of self-respect which could amount to self-loathing or self-hatred.[44] However, this approach to dignity does not account for the fact that the individual may not experience distress. This may mask the indignities arising from structural disadvantage and fails to take account of the circumstances where a person is brainwashed or socialised in a way that makes him or her blind to the indignity, for example, a slave who accepts his or her situation.[45] It also fails to take account of the situation of many people with disabilities.

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[41] See generally: Pateman, C. (1989). *The sexual contract*. Oxford: Polity Press; Smart, C. (1989). *Feminism and the power of law*. London: Routledge; Charlesworth, H. et al. (1991). Feminist approaches to international law. *American Journal of International Law, 85*, 613–645.; Minow, M. (1990). *Making all the difference: Inclusion, exclusion and American law*. Ithaca, New York: Cornell University Press.

[42] See generally: Stainton, T. (1994). *Autonomy and social policy*. Aldershot: Avebury; Nussbaum, M.C. (2006). *Frontiers of justice: Disability, nationality, species membership*. Cambridge, Massachusetts: Belknap University Press. See also Jones, M. & L.A. Basser Marks. (1994). The dynamic developmental model of the rights of the child: A feminist approach to rights and sterilisation. *International Journal of Children's Rights, 2*, 265–291.

[43] Dworkin, R. (1993). *Life's dominion*. London: Harper Collins.

[44] Ibid., 234.

[45] Ibid., 235.

The alternative approach, the one which Dworkin prefers, is that dignity is a rights-claim on others that they recognise what it means to be human. Dignity is far more than the individual experience of a particular life (Dworkin describes this as the passive aspect of dignity).[46] Respect for dignity also has an active voice which takes into account what Dworkin describes as "critical" interests. Critical interests have a self regarding aspect going to the individual's convictions about the intrinsic value of his or her life – his or her moral position, about leading a valuable life, but dignity also has an objective/external aspect. This involves the acknowledgement by others of the person, his or her moral standing and that his or her life is intrinsically and objectively important.[47] In this way: "Dignity is a central aspect of…the intrinsic importance of human life."[48]

What is clear is that dignity is an important human rights principle and while the conception of dignity varies between cultures and with time and place, it is possible to identify a "basic minimum" core content of human dignity. McCrudden argues that there are three such elements.[49] The first is that dignity is inherent to all human beings by virtue of their humanity – each person has an intrinsic worth. Secondly, other people should recognise and respect that intrinsic worth and either act or refrain from acting in certain ways out of respect for that intrinsic worth. Thirdly, as between the state and the individual, "recognising the intrinsic worth of the individual requires that the state should be seen to exist for the sake of the individual human being, and not vice-versa."[50] McCrudden identifies the first element as the ontological claim, the second element as the relational claim and the third element as the state-limited claim.

Adopting these elements of human dignity allows for an understanding of what it means in fact to be treated consistently with dignity. First is the absolutely crucial requirement that a person's physical integrity is respected.[51] This has consequences both in every day interactions and

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[46] Ibid., 235.

[47] Ibid., 236.

[48] Ibid., 236.

[49] McCrudden, C. (2008). Human dignity and judicial interpretation of human rights. *European Journal of International Law, 19*(4), 655–724.

[50] Ibid., 679.

[51] Jones, M. & L.A. Basser Marks. (2000). Valuing people through law: Whatever happened to Marion. *Law in Context Special Issue: Explorations of Law on Disability in Australia, 17*(2), 147–180.

in "extraordinary" situations such as those involving medical treatment, unwanted sexual advances and punitive measures. Secondly, human dignity means that every person has the inherent right to be treated as an individual with a personality.[52] This means that the right to freedom of opinion and belief, (including religion), inherent in the values of a liberal state are accorded to everyone. Thirdly, human dignity means that a person must be given voice about any issues which affect their lives and must have the ability wherever possible to exercise choice.[53] Finally, inherent dignity of any individual requires that he or she has access to a fair share of the goods of society.[54] This means that the availability of resources to any individual is dependent on the socio-economic environment in which they live, but dignity dictates that there is a fair distribution of those goods between members of the society.

Dignity under International Law

In the aftermath of WWII, with the establishment of the United Nations and the adoption of the *Universal Declaration of Human Rights* (UDHR), the concept of dignity was established as a foundation principle for human rights. The Preamble to the Charter of the United Nations affirms the commitment of the international community to human rights and to human dignity:

> We the peoples of the United Nations determined to reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small.

The UDHR gives prominence to the concept of dignity referring to it in two places. The Preamble to the UDHR recognises the "inherent dignity and…equal and inalienable rights of all members of the human family" and referring to the UN Charter goes on to reaffirm the faith of the UN "in the dignity and worth of the human person and in the equal rights of men and women…". Article 1 states:

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[52] Mill, J.S. (1869). *On liberty* (4th edition ed.). London: Longman, Roberts & Green.

[53] Yeatman, A. (2000). What can disability tell us about participation. In M. Jones & L.A. Basser Marks (Eds.), *Explorations on law & disability in Australia* (pp. 181–202). Australia: The Federation Press.

[54] See generally: Nussbaum, M.C. (2006). *Frontiers of justice: Disability, nationality, species membership*. Cambridge, Massachusetts: Belknap University Press.

> All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

At the time this was a radical new approach to human rights and to dignity.[55]

The place of human dignity as a cornerstone of human rights is cemented in the *International Covenant on Civil and Political Rights* (ICCPR) and the *International Covenant on Economic, Social and Cultural Rights* (ISECR). The Preamble to each of these Covenants confirms the recognition of the inherent dignity of all people and recognises that human rights derive from that inherent dignity. Dignity is also referred to in the text of particular articles, for example in Article 10 ICCPR – relating to deprivation of liberty -and in Article 13 ICSECR – the right to education. Subsequent UN Conventions also refer to human dignity in both the Preamble and the substantive Articles.[56]

In more recent years, the number of substantive articles referring to dignity in international instruments has significantly expanded:

> References to dignity have expanded to include not only rights relating to conditions of (and treatment during) detention and the right to education, but also other rights: rights in the criminal justice process, rights to be provided with minimum conditions of welfare, the right to health, the rights of disabled persons to be treated as autonomous individuals, the right of children to be treated with dignity following abuse, rights to reputation, rights of indigenous cultures, rights to control access and use of personal data, and the conduct of biomedical experimentation.[57]

This can be seen in the newest UN convention – the *Convention on the Rights of Persons with Disabilities* (CRPD) – where dignity comes into

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[55] Charlesworth, H. (2008). The universal declaration of human rights (1948) in R. Wolfrum (Ed.), *Max Planck encyclopedia of the public international law.* Oxford University Press. Online: http://www.mpepil.com/home (last accessed November 18, 2009); McCrudden, C. (2008), *supra* note 49; See Stainton, T. (1994). *Autonomy and social policy.* Aldershot: Avebury.; Jones, M. & L.A. Basser Marks. (2000). Valuing people through law: Whatever happened to Marion. *Law in Context Special Issue: Explorations of Law on Disability in Australia, 17*(2), 147–180.; Jones, M. & L.A. Basser Marks. (1994). The dynamic developmental model of the rights of the child: A feminist approach to rights and sterilisation. *International Journal of Children's Rights, 2*, 265–291. This is implicit in the CRPD.

[56] For a more detailed discussion of the history of the inclusion of dignity in International Law instruments see McCrudden (2008), *supra* note 49, pp. 668–671.

[57] Ibid., 670–671.

play not only in the Preamble but also in the substantive provisions of the Convention. The Preamble to the CRPD recalls the reference to the inherent dignity and worth of all people in the Charter of the UN and affirms the universality and indivisibility of human rights. It also recognises that "discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person." Dignity is also referred to in the Preamble with respect to the need for a comprehensive disability-specific convention which responds to the disadvantage and indignities experienced by people with disabilities. The underlying purpose of the Convention is spelt out in Article 1. It is to:

> ...promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Respect for dignity is a foundational principle of the CRPD (Article 3) and dignity is specifically referred to in a number of the Articles of the Convention – including Article 8 "Awareness Raising"; Article 16 "Freedom from Exploitation, Violence and Abuse"; Article 24, "Education"; Article 25 "Health."[58] This is in keeping with the centrality of the concept in the *Vienna Declaration and Programme of Action* (1993) which identified dignity as foundation to human rights in general[59] and adopted the concept of dignity in relation to particular rights such as the prohibitions on torture (Art 55), gender-based violence (Art 18), extreme poverty (Art 25) and the treatment of indigenous people (Art 20) and the issue of biomedical ethics (Art 11).

Human dignity is also an important principle in regional international human rights instruments both in the preambles and in the substantive human rights provisions. Indeed, as McCrudden notes, there is "a remarkable degree of consistency between the regional human rights instruments, and between these instruments and the international instruments…"[60] For example the preamble to the *Inter-American Convention on the Elimination of all forms of Discrimination against Persons with Disabilities* recognises that human rights "flow from the inherent dignity and equality of each person." Similarly, the *African*

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[58] This inclusion of dignity is in keeping with guidelines for new human rights instruments adopted by the UN General Assembly in 1986 Ibid., 669.

[59] A/CONF.157/23.

[60] McCrudden, *supra* note 49, 672.

Charter on the Rights and Welfare of the Child and the *Revised Arab Charter on Human Rights* refer to dignity in the context of people with disabilities while the *African Charter* and the *Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights* refer to it in relation to the right to education.[61]

Dignity under National Law

Reflecting its value in international law, dignity has a role to play in national law whether as a foundational value, a human rights principle, a constitutional or legislative right.[62] Even in the absence of an articulated constitutional or legislative right to dignity, or constitutional or legislative statement of dignity as a foundational value, the principle of dignity may be incorporated into domestic law through the judicial application of international human rights norms.

Dignity plays a particular role in countries such as Germany and South Africa where there has been an historical systemic denial of basic human rights. So, for example, Article 1 of the German Basic Law provides:

> 1. The dignity of man shall be inviolable. To respect and protect it shall be the duty of all state authority.
> 2. The German people therefore acknowledge inviolable and inalienable human rights as the basis of every community, of peace and justice in the world.
> 3. The following basic rights shall bind the legislature, the executive and the judiciary as directly enforceable law.[63]

As Klein explains, dignity under the German Constitution is both an objective legal norm and a basic right.[64] The State has a duty to respect

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[61] Further examples and specific articles found in McCrudden, *supra* note 49, 672.

[62] For a more detailed discussion see McCrudden Ibid.; Chaskalson, A. (2002). Human dignity as a constitutional value. In D. Kretzmer & E. Klein (Eds.), *The concept of human dignity in human rights discourse* (pp. 133–144). The Netherlands: Kluwer Law International.; Klein, E. (1994). Human dignity in German law. In D. Kretzmer & E. Klein (Eds.), *The concept of human dignity in human rights discourse* (pp. 145–159). The Netherlands: Kluwer Law International.

[63] *Basic Law for the Federal Republic of Germany*, Article 1.

[64] E. Klein (2002). Human dignity in German law. In D. Kretzmer & E. Klein (Eds.) *The Concept of Human Dignity in Human Rights Discourse*. The Netherlands: Kluwer Law International 145–159, 147.

and protect the dignity of all members of the community.[65] At the same time, dignity is a cornerstone or constitutive principle in the system of basic rights.[66] The Federal German Constitutional Court has held that human dignity refers not only to the dignity of the individual but to the dignity of "man" as a species so that any encroachment upon human dignity is a violation:

> There is, according to the jurisprudence of the courts, no way to balance other legal interests be they of other individuals or of the community, with the dignity of a person. The principle of proportionality does not come into play as long as an intrusion upon human dignity has been established.[67]

The importance of these laws can be seen in the light of the development of German law. The Constitution was enacted against the background of the Holocaust with the determination to clearly outlaw atrocities of the type that were committed during Nazi rule. From 1933 there was systematic degradation of people with disabilities who did not fit the idealised picture of the Aryan race.[68] Sterilisation, institutionalisation and murder (called "euthanasia") were progressive measures directed at people with disabilities.

While the South African experience of people with disabilities was not as overtly horrific as during the Nazi period, the indignities of apartheid are well known. In post-apartheid South Africa, the Constitutional Court stressed the importance of human dignity, even before the enactment of the 1996 Constitution:

> Respect for the dignity of all human beings is particularly important in South Africa. For apartheid was a denial of a common humanity. Black people were refused respect and dignity and thereby the dignity of all South Africans was diminished. The new Constitution rejects this past and affirms the equal worth of all South Africans. Thus recognition and protection of human dignity is the touchstone of the new political order and is fundamental to the new Constitution[69]

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[65] Ibid.

[66] Ibid.

[67] Ibid., 149.

[68] This is the least known of the Nazi atrocities which included the wholesale murder of millions of Jews, Roma and homosexuals.

[69] O'Regan J. in *S v Makawanyane* (1995) 6 BCLR 778 (CC), para 329 referring to the 1993 Interim Constitution.

The 1996 Constitution included dignity as a foundational value[70] and as a constitutional right.[71] Subsequent jurisprudence of the Constitutional Court has clarified the role of human dignity in South African law:

> The value of dignity in our Constitutional framework cannot therefore be doubted. The Constitution asserts dignity to contradict our past in which human dignity for black South Africans was routinely and cruelly denied. It asserts it too to inform the future, to invest in our democracy respect for the intrinsic worth of all human beings. Human dignity therefore informs constitutional adjudication and interpretation at a range of levels. It is a value that informs the interpretation of many, possibly all, other rights. This Court has already acknowledged the importance of the constitutional value of dignity in interpreting rights such as the right to equality, the right not to be punished in a cruel, inhuman or degrading way, and the right to life. Human dignity is also a constitutional value that is of central significance in the limitations analysis. Section 10, however, makes it plain that dignity is not only a *value* fundamental to our Constitution, it is a justiciable and enforceable *right* that must be respected and protected. In many cases, however, where the value of human dignity is offended, the primary constitutional breach occasioned may be of a more specific right such as the right to bodily integrity, the right to equality or the right not to be subjected to slavery, servitude or forced labour (O'Regan J para 35).[72]

Dignity is important in other jurisdictions even in the absence of a history of extreme violence. The Supreme Court of Canada has long recognised the protection of human dignity as an element of the protection of all the rights guaranteed by the *Charter of Rights and Freedoms*,[73] even though dignity is not a specified human right under the *Charter* and there is no articulated statement of values and principles in the

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[70] Section 1: "The Republic of South Africa is one, sovereign, democratic state founded on the following values: (a) Human dignity, the achievement of equality and the advancement of human rights and freedoms; (b) Non-racialism and non-sexism; (c) Supremacy of the constitution and the rule of law; (d) Universal adult suffrage, a national common voters roll, regular elections and a multi-arty system of democratic government, to ensure accountability, responsiveness and openness."

[71] Section 10: "Everyone has inherent dignity and the right to have their dignty respected and protected."

[72] *Dawood & Anor v Minister of Home Affairs & ors; Shalabit & Anor v Minister of Home Affairs & Ors; Thomas & Anor v Minister of Home Affairs & Ors* [2000] ZACC 8; 2000 (8) BCLR 837. See also *National Coalition for Gay & Lesbian Equality v Minister of Justice* 2000 (2) SA 1 (CC).

[73] *R v Kapp* [2008] SCC 41 para 21 per McLaughlin.

Canadian Constitution such as is found in the South African Constitution.[74] The principle of human dignity has played a role in the interpretation of the Charter and the development of Charter jurisprudence. As Dickson CJ commented in *R v Oakes:*

> The Court must be guided by the values and principle essential to a free and democratic society which I believe embody, to name but a few, respect for the inherent dignity of the human person, commitment to social justice and equality, accommodation of a wide variety of beliefs, respect for cultural and group identity, and faith in social and political institutions which enhance the participation of individuals in society.[75]

The importance of human dignity is illustrated by the interplay between the value/principle of human dignity and the equality guarantee in section 15(1) of the Charter. One of the distinct purposes of Section 15 is to express "a commitment…to the equal worth and human dignity of all persons."[76] At the same time, human dignity has been a constitutive part of the interpretation of section 15 as a guarantee of substantive equality. In developing its understanding of equality, the Supreme Court, in *Law v Canada*,[77] transformed human dignity into an element of the legal test for discrimination. In determining whether discrimination had occurred consideration had to be taken of the impact of a law or program on human dignity.[78] In so doing the Supreme Court explained the concept of dignity in the following, oft cited terms:

> Human dignity means that an individual or group feels self-respect and self-worth. It is concerned with physical and psychological integrity and empowerment. Human dignity is harmed by unfair treatment premised upon personal traits or circumstances which do not relate to individual needs, capacities or merits. It is enhanced by laws which are sensitive to the needs, capacities and merits of different individuals, taking into account the context underlying their differences. Human dignity

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[74] Unlike the South African Constitution, which is contained in one enactment, the Canadian Constitution is made up of a number of enactments including the *Constitution Act* 1867 *British North America Act* 1867and the *Constitution Act* 1982 which includes the Canadian *Charter of Rights and Freedoms*. None of these enactments articulate a set of interpretive principles in the way that the South African Constitution provides.

[75] *R v Oakes* [1986] SCR 103, 136.

[76] *Eldridge v British Columbia (Attorney General)* [1997] 3 SCR 624.

[77] *Law v Canada (Minister of Employment and Immigration)* [1999] 1 SCR 497.

[78] Ibid., paras 62–75.

> is harmed when individuals or groups are marginalised, ignored, or devalued, and is enhanced when laws recognize the full place of all individuals and groups in…society.[79]

Although the Supreme Court has recently resiled from the attempt in *Law* "to employ human dignity *as a legal test*" (emphasis added), the Court continues to recognise human dignity as an essential value underlying all the rights guaranteed under the *Charter*.[80] As a result, the concept of dignity remains important in the interpretation of substantive equality in Canada.

Despite the fact that Australia has no constitutional protection of human rights and no bill of rights, the jurisprudence of the High Court of Australia incorporates the principle of dignity.[81] Using international human rights norms in the interpretation of the common law, some High Court judges have applied the principle of dignity to resolve complex legal issues. For example, Brennan J in *Marion's case* found non-consensual sterilisation of an intellectually disabled minor to be unlawful because it was an assault on the dignity of the person:

> Human dignity requires that the whole personality be respected: the right to physical integrity is a condition of human dignity but the gravity of any invasion of physical integrity depends on its effect not only on the body but also upon the mind and self-perception.[82]

Impositions on physical integrity constitute an invasion of dignity. Even where a person with a disability is unable to articulate the extent of the affront to his or her person, protection of human dignity constitutes a means of safeguarding rights. This strategic use of the concept of dignity illustrates the potential of human rights principles to improve the position of people with disabilities in society.

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[79] *Law v Canada (Minister of Employment and Immigration)* [1999] 1 SCR 497 para 53 per Iacobucci J.

[80] *R v Kapp* [2008] SCC 41 para 21 per McLaughlin. For an example of the application of the test in *Law* see *Nova Scotia v Martin & Lasseur* [2003] 2 S.C.R. 504.

[81] Legislative charters of rights have been recently enacted in the ACT (*Human Rights Act* 2004) and Victoria (*Charter of Human Rights and Responsibilities* 2006) and a discussion is currently underway about the appropriateness of the introduction of a national charter.

[82] *Secretary, Department of Health and Community Services* v *JWB and SMB,* (1992) ALJR 300 418 per Brennan J.

Conclusion

Any account of human rights must start with the moral entitlement of all people to be treated with dignity. This means that people must be treated as ends in themselves, first as people and only then as people with particular characteristics. For people with disabilities this means asking the question about whether the treatment or interaction is predicated on preserving and protecting the moral worth of the individual, not on some idea about the person's disability. On the other hand, denying the importance of the disability and the needs arising as a result of the disability would itself be an affront to human dignity. The principle of dignity requires that the whole person is taken into account.

Human dignity is not only a moral value but is also a means of understanding what it is to be a rights-bearer. Dignity provides a moral basis for the relationship between individuals, by investing inherent worth into human interaction. The principle of human dignity can help unpack any given human right, to understand the impact of any denial on any given individual or to provide the basis for a claim to distributive justice. Each person has the same basic entitlement to dignity and so each person must act in such a way that their behaviour is consistent with the mutual respect of the other. Equally the State must facilitate the operation of rights by investing resources in individuals to ensure equality and participation.

International law makes provision for human dignity both as a moral precept and as an operational principle. Increasingly, dignity has begun to play a role in domestic law. Whether the right to dignity is protected by a constitution or a bill of rights, by legislation or by judicial practice, the legal articulation of human dignity offers enormous potential to people with disabilities. Because so often denial of rights to people with disabilities is predicated on the failure to accord dignity, legal protection of dignity is a useful tool in establishing and maintaining human rights. Moreover, the concept of human dignity – whether as a principle, value or right – provides a platform on which legal argument can be developed to redress wrongs or support claims.

VALUES IN DISABILITY POLICY AND LAW: EQUALITY

Marcia H. Rioux and Christopher A. Riddle

To understand the nature of disability rights, it is important to understand the way in which the legal construction of inequality is built into the nature of both the disabled person in law and into knowledge production in the field of disability, leading to the presumption that a positivist paradigm is essential to test the parameters of equality for this particular class of people.[1] Furthermore, it is necessary to explore the choices that are made to the limits and distribution of political power and the legal position of the disabled population in the face of that power. In developing an understanding of how cases are argued to recognize differences in the use of principles of equality for those with disabilities in society, one discovers that equality, and particularly substantive equality, is a fundamental principle of human rights that warrants a close examination in order to understand how to move ahead in entrenching the rights of people with disabilities. As Rawls contends:

> For us the primary subject of justice is the basic structure of society, or more exactly, the way in which the major social institutions distribute fundamental rights and duties and determine the division of advantages from social cooperation.[2]

People with disabilities have often failed to be included within the evolving concept of equality as it has shifted from an approach emphasizing the equal-treatment of individuals, to one more substantive in nature. Formal meanings of equality possess an element of what Sen would call "fetishism."[3] Material goods or resources are often discussed while ignoring the relationship between individuals and the goods being equalized. An approach to equality that emphasizes the private consumption of goods disregards the relationship between goods and the individual, and ignores what goods do for individuals. This

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[1] Rawls, J. (1971). *A Theory of Justice.* Cambridge, Massachusetts: The Belknap University Press, 7.

[2] Ibid.

[3] Sen, A. (1995). Equality of what?, in S. Darwall (Ed.) *Equal Freedom: Selected Tanner Lectures on Human Values*. Ann Arbor: University of Michigan Press.

"fetishism" is especially relevant when discussing equality for people with disabilities as assumptions are often made regarding the background conditions of individuals, ignoring inherent differences between members of society.

Equality as a human right must refocus to recognize the capacity of human beings to form purposes and choices and to become aware of options to acquire both control and knowledge of desires and motives.[4] It must be designed to recognize the capacity to think and to develop and maintain relationships free from external interference.[5] The fostering of self-development and the striving for excellence are other characteristics that form the basis on which we accord individuals respect.[6] A denial of such characteristics diminishes that respect and fails to promote autonomy and self-determination within substantive equality.

Many individuals require differing social arrangements, including varieties of care, in order to live integrated and productive lives.[7] Disability raises a unique and particularly important issue within distributive justice claims – how can individuals requiring differing measures to promote inclusion receive equal treatment?

Fortunately, others have gone before and paved the way for disability to be considered within the context of substantive equality rather than the less complex notion of equal treatment. There are differences and inequalities between people, that is a matter of objective fact; however, artificial distinctions need to be differentiated and there has to be a distinction between those inequalities that are the consequence of the organization of society, and those that stem from individual characteristics. The false assumption that people are starting in an equal position often leads to the further entrenchment of the inequality that is already disadvantaging people, and results in the introduction of further injustices. In other words, the social and legal construction of inequality is an important part of the understanding of the equality rights of people with disabilities.

While a single theoretical notion of equality may in-and-of-itself be difficult to achieve, many argue that it is the lack of a clearly developed

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[4] Lukes, S. (1974). Socialism and equality. In L. Kolakowski & S. Hampshire. (Eds.) *The Socialist Idea* London: Weidenfeld and Nicolson London.

[5] Ibid.

[6] Ibid.

[7] Nussbaum, M.C. (2006). *Frontiers of Justice: Disability, Nationality Species Membership.* Cambridge, Massachusetts: The Belknap University Press.

notion of equality in legal discourse that is especially troubling. However, upon closer examination of numerous cases and interpretations presented throughout this book, it becomes apparent that there are some clear conceptions of equality as well as methodologies for determining why some people should be treated unequally and, consequently, the basis on which people are entitled to equality. There are numerous cases that are clearly based on the notion of equal treatment that limit the participation and inclusion of people with disabilities. Conversely, there are some cases based upon the notion of substantive equality that lead to actual changes in material conditions for people with disabilities.

Equality as a Human Right

The application of the principle of equality leads to questions of the meaning of the notion itself, the nature of the social problems to which it is applied, the characterization of the relevant difference between persons and, finally, the proper manner to address such difference. As Sandra Fredman recognizes, "the appeal to difference was the key way in which contradictions between the liberal ideal of equality and the subordination of [people with disabilities] were addressed."[8]

Equality analysis involves the critical examination of how difference is recognized, given meaning, and valued:[9]

> It is not the denial of difference that is being argued but the need to take into account that difference in coming to determine how rights and privileges are assigned – that is, the fulfillment of the potential of every individual…[Additionally] all…are equally eligible for all honours, places and employments, according to their different abilities, without any other distinction than that created by their virtues and talents. [10]

The "infuriatingly elusive" concept of equality encompasses an elastic spread of meanings that range from legitimating and formalizing differences and unequal treatment, to incorporating broad environmental

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[8] Fredman, S. (2005). Disability equality: A challenge to the existing anti-discrimination paradigm?, In A. Lawson & C. Gooding. (Eds.) *Disability Rights in Europe: From Theory to Practice.* Oxford: Oxford University Press.

[9] Young, M. (1997). Sameness/difference: A tale of two girls. *Review of Constitutional Law 4*(1), 150–166.

[10] Declaration of Rights, prefixed to the French Constitution of 1793.

and institutional changes, services, policies, and programs to ensure equality is achieved.[11]

> The notion of "equality" must accommodate what is expressed in the French Declaration of Rights: it must allow for the fulfillment of the potential of every individual. From that starting point, certain propositions may be deduced…
> (i) Artificial, irrelevant distinctions cannot be the basis upon which rights and privileges are assigned.
> (ii) Equality does not involve uniformity. In particular, it does not involve uniformity by reference to the lowest common denominator.[12]

The scope of theories of equality extends from the equalization of material resources to the recognition of non-material human rights that require equal attention. Amartya Sen differentiated among equality as utilitarian equality, total utility equality and Rawlsian equality.[13] More pointedly, utilitarian equality, or the most fundamental version, according to Sen, relies upon utilitarian principles of goodness as applied to distribution.[14] The end goal of this version of equality in relation to distributive conceptions is to maximize the sum-total of utility, often failing to recognize the implications for individualistic distribution. Total utility equality, while still relying upon notions of utilitarianism, relies on factual, observable events and not a series of alternative options associated with how things *could* be, as in utilitarian equality. Total utility equality does not require hypothesis of what things could have been under various other circumstances but, instead, is concerned with the factual utility present within society. Finally, Rawlsian equality, often seen as the launching point for contemporary criticism and scholarship, is concerned with the upholding of fundamental social goods and liberties viewed to be of primary importance in the pursuit of justice.[15] Sen expanded upon Rawls' conception of justice and argued for a basic capabilities approach that consists of the notions of "functionings," value-objects, freedom, and well-being.[16] This version calls for the assurance of various functionings that represent parts of the

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[11] Hon. Justice Mary Gaudron, High Court of Austalia. (1990). The Mitchell Oration 1990 "In the Eye of the Law: The Jurisprudence of Equality," 24 August 1990 Equal Opportunity Commission Adelaide.

[12] Hon. Justice Mary Gaudron, 1990.

[13] Sen, 1995.

[14] Sen, A. (1999). *Commodities and Capabilities.* New Delhi: Oxford University Press.

[15] Ibid.

[16] The capabilities approach has been adopted and advanced by many contemporary theorists. Nussbaum, Sen, Wolff, and De-Shalit, Arneson, and Prah Ruger are

state of a person or, more particularly, the various things that he or she manages to do or be while leading a life. While the list of essential capabilities as endorsed by Nussbaum for example, is fluid, it has included such notions as life, bodily integrity, and practical reason.[17]

With an abundance of interpretations of equality as well as categorical distinctions, this paper uses three heuristic models (the like treatment model,[18] the equal opportunity model[19] and the substantive or equality of outcome model[20]) which most closely reflect the way in which law has interpreted equality in cases relating to distributive justice. The important issue is how to take difference and needs into account in arriving at equality while avoiding discrimination. A further challenge is to understand the relationships between persons and goods, recognizing that people have very different needs that differ with the type of disability, health, environment, location and work conditions associated with those individuals.

The three concepts of equality found in jurisprudence result in vastly dissimilar outcomes and social practices for people with disabilities. All raise issues of inclusion and exclusion in relation to the benefits of society. They draw between the justified and unjustified distinctions at different places, ranging between substantive changes to the material

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amongst those individuals and all propose what can be perceived as differing conceptions of the equality of capabilities. See Nussbaum, M.C. (2006). *Frontiers of Justice.,* Boston: Belknap Press; Sen, A. (1999). *Commodities and Capabilities.* India: Oxford India Paperbacks; Sen, A. (1997). *On Economic Inequality.* Oxford: Clarendon Paperbacks; Sen, A. (1995). Equality of What?, in S. Darwall (Ed.) *Equal Freedom: Selected Tanner Lectures on Human Values.* Ann Arbor: University of Michigan Press, 207–330; Wolff, J. & De-Shalit, A. (2007). *Disadvantage.* New York: Oxford University Press; Arneson, R. (2009). Two cheers for capabilities, in H. Brighouse & I. Robeyns (Eds.) *Measuring Justice: Primary Goods and Capability.* Cambridge: Cambridge University Press, 2009; and Prah Ruger, J. (2006). Toward a theory of a right to health: Capability and incompletely theorized agreements. *Yale Journal of Law and Humanities, 18:* 273–326, for various interpretations of the capabilities approach.

[17] Nussbaum, 2006.

[18] Aristotle in Sterba, J.P. (1980). *The Demands of Justice.* Notre Dame: University of Notre Dame Press.

[19] Dworkin, R. (1977). *Taking Rights Seriously.* London: Duckworth Press; Rawls, J. (1971). *A Theory of Justice.* Cambridge, Massachusetts: The Belknap University Press; Williams, B. (1960). The empty idea of equality. In P. Laslett & W.G. Runciman (Eds.) *Philosophy, Politics and Society.* Oxford: Basil Blackwell.

[20] Veatch, R.M. (1986). *The Foundations of Justice: Why the Retarded and the Rest of Us Have Claims to Equality.* New York: Oxford University Press; Lukes, S. (1974); Rawls, J. (1958). Justice as fairness. *The Philosophical Review, 67*(2) 162–194; Baker, C.E. (1983). Outcome equality or equality of respect: The substantive content of equal protection. *The University of Pennsylvania Law Review*, *131*(5), 933–998.

conditions of people with disabilities and re-legitimizing the prevailing inequalities founded on the values and assumptions of nineteenth century Liberalism. The latter rests on the traditional assumption that people with disabilities can claim equality only to the extent that they can approximate other citizens.

Additionally, there is an unstated endorsement within the various forms of equality of the numerous theoretical perspectives from which disability can be analyzed. It is the relationship between and surrounding the various interpretations of disability that can aid in gaining further insight into contextual difficulties and advantages surrounding the legal employment of such forms of equality. A distinction can be drawn between medical and rehabilitation services and those that focus on a social pathological approach to disability. Medically based conceptions of disability are aimed at curing or ameliorating disease and not at recognizing the oppressive nature of social, cultural, and legal structures.[21] It becomes clear that the meaning of equality will vary depending on the perspective of disability adopted.

The Equal Treatment Model of Equality (Formal Equality)

A minimal notion of equality, or the Aristotelian notion, is that, "equality consists of treating equals equally and unequals unequally."[22] Using this limited notion of equality the enforcement of laws and of legal and social rights are equally applied to all. Formal equality makes no attempt to clarify what makes people equal in any particular circumstances. Neutrality in the application of the law and the absence of different treatment are presumed to result in equality. Relying on this notion of equality would be appropriate and suitable if individuals were similarly situated, but becomes problematic when people are not.

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[21] For a more thorough elucidation of the various ways with which to conceptualise disability consult Barnes, Colin, et al. (1999). *Exploring disability: A sociological introduction.* Cambridge: Polity Press, pp. 10–38; Baynton, D.C. (2001). Disability and the justification of inequality in American history. in P.K. Longmore & L. Umansky, (Eds.) *The new disability history: American perspectives.* New York: New York University Press, pp. 33–57; Rioux, M.H. (1997). Disability: The place of judgement in a world of fact. *Journal of Intellectual Disability Research, 41*(2), 102–111; or Shakespeare, T. (1999). What is a disabled person? In M. Jones & L.A. Basser Marks (Eds.) *Disability, Divers-Ability and Legal Change.* New York: Kluwer Law International, pp. 25–34; Shapespeare, T. (2006). *Disability Rights and Wrongs.* London: Routledge.

[22] Warrington, A.J. (1963). *The Ethics Book III.* London: Dent.

For example, people who cannot fill out forms are denied the right to vote, while others, who can read and write, are afforded this right. The law is equally applied to all those who fulfill the established voting procedures; therefore, the fact that it has a differential impact on those with some disabilities is as insignificant as the extraneous causes for the lack of ability. The nature of equality being sought is what Walzer would identify as "simple" equality.[23] While simple or negative equality ignores inherent differences and promotes equality as equal treatment, complex or positive equality[24] provides provisions and recognizes differences as valuable and individuals as requiring different treatment to arrive at a similar result or outcome. Using this approach neither the systematic, legal exclusion of those with disabilities – for example, from the regular education system – nor the means of eliciting the information, which is in a manner less accessible to some than others, are taken into account in determining justified and unjustified distinctions.

In those circumstances where classes of people are identically situated with respect to opportunity sought, formal equality may lead to factual equality. Those who share fewer of the characteristics of the advantaged group do not gain, because the underlying substantive inequalities, including poverty, are not taken into account. Due to the entrenchment of ableist social and economic structures, poverty is experienced by the vast majority of people with disabilities.[25]

In the promotion of human rights, and particularly equality, it is helpful to recognize that a social group cannot be defined solely by a set of shared characteristics but instead, by the sense of identity that comes with being a member of a specific group.[26] It is equally important to acknowledge that group meanings have an impact on individuals and to therefore recognize the construction of an individual's identity through the cultural and historic forms the group members know as their own.[27]

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[23] Walzer, M. (1983) *Spheres of Justice: A Defence of Pluralism & Equality.* Oxford: Basil Blackwell.

[24] Ibid.

[25] For example, in Canada in 1996 the poverty rates for the total population was 19.69% while for people with disabilities it was 30.75%. Statistics Canada. (1996). Census of Canada.

[26] Young, I.M. (1990). *Justice and the Politics of Difference.* Princeton, New Jersey: Princeton University Press.

[27] Ibid.

If the goal is substantive equality, then treating all alike, including those with demonstrable social advantage, does not achieve the objective. The flaw in the like-treatment model is that it fails to recognize that the problem "resides in the structures (built to reflect and accommodate privileged norms) and not in the person who is judged different [and] popular prejudice can magnify the effects."[28]

Theories endorsing the equal treatment of individuals (or formal equality) rely heavily upon individual pathological approaches to conceptualizing disability. The reactive and cure-based approach of an individual pathology perspective to disability analysis is echoed in formal forms of equality. Equally treated citizens are encouraged to take action to insure themselves should the event arise that they are in a debilitating accident.[29] Similar to an individual pathology approach to disability, under formal equality considerations, emphasis is placed upon the tragedy of being disabled and individuals are viewed as anomalies albeit worthy of society's charity and benevolence. Disability is viewed as a natural occurrence and luck-based, emphasizing the requirement of a private and not societal, approach to addressing disability.

The Equal Opportunity Model

The premise underlying equality of opportunity is that everyone, regardless of race, gender, disability or other irrelevant personal characteristics, should have the equal opportunity and access to participate and exercise political, social, economic and cultural rights. Equal opportunity is understood as a consequence of removing the legal and institutional barriers that stand in the way of people. It is embedded in the assumption that when these barriers are removed, people who have historically faced discrimination on the basis of personal characteristics will be able to achieve substantive equality. It takes into account historical conditions of inequality. However, it does not address all the fundamental differences that have conventionally provided a basis for

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[28] Quinn, G. (1995). The International Covenant on Civil and Political Rights and Disability: A conceptual framework. In T. Degener & Y. Koster-Dreese. *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments.* London: Martinus Nijhoff Publishers.

[29] Dworkin, R. (2000). *Sovereign Virtue: The Theory and Practice of Equality.* Cambridge, Massachusetts: Harvard University Press.

disentitlement of those with disabilities. Recognition of the historic and systemic basis of the inequality of groups underlying the equal opportunity model can redress some of the persistent effects of discrimination. However it is still problematic for ensuring material equality in many cases.

Equality of opportunity exists in many forms. Nevertheless, the underlying values associated with this perspective remain focused upon responsibility and freedom. Various progressive forms of equality of opportunity present different emphasis, ranging from a concern with the rules that govern the competitive framework adopted for the distribution of goods, to a metric designed to allot these goods justly.[30] While non-competitive forms of the equality of opportunity do exist, these are often regarded by opportunity theorists as incomplete conceptions, incapable of presenting an opportunity perspective in its strongest form.[31]

Because of the underlying values of responsibility and competition, a hierarchy is created, often leaving people with disabilities to be oppressed by a paternalistic hand governing who is eligible to compete and on what grounds they are allowed to do so. Individual autonomy is neither respected nor recognized and value will inherently be placed upon one form of competition while ignoring the other. While measures are often taken to ensure that by virtue of acting within the arbitrary confines of the competition, no one individual receives an unfair portion of the rewards, an equality of opportunity perspective nevertheless fails to recognize that social marginalization and devaluation occur as a result of ranking individuals in a competitive framework.

The meaning and parameters of equality reflect a shift in emphasis from a desert-based perspective premised upon notions of self-reliance and independence, to recognizing the worth of the individual – a more nuanced understanding of need and social support. Similar to individuals without disabilities, people with disabilities possess unique talents and skills that can be situated on a spectrum of individual abilities and that require recognition in the pursuit of equality.[32] The recognition of differing talents and skills is often misinterpreted as an attempt

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[30] Jacobs, L. A. (2004). *Pursuing Equal Opportunities: The Theory and Practice of Egalitarian Justice.* New York: Cambridge University Press.

[31] Ibid.

[32] Lepofsky, D. (1998). The Charter's guarantee of equality to people with disabilities – How well is it working? *Windsor Yearbook of Access to Justice*, *16,* 155–214.

to measure and rank abilities, not as one designed to promote inclusion and accommodation, resulting in the use of merit-based arguments in determining equality within society.

Arguments that endorse the recognition of desert within theories of equality can often be disregarded as either a misinterpretation of the concept itself, or as a misrepresentation of the goal of the promotion of equality. Elements of entitlement or fairness are often misinterpreted as being component parts of conceptions of desert. In reality circumstantial luck most often determines the success of one's outcome. Nevertheless, people are often mistakenly said to deserve the outcome achieved when it is in fact, social arrangements or structures that are arbitrary to an individual's performance that determined the outcome.[33] Take for example, an individual who has achieved success in the business world. In order to be successful within such a world, one has to follow the arbitrary rules or confinements designed to govern competition in business. Such confines often limit the participation of people with disabilities in fair competitions. David Miller claims that if a hypothetical world can be devised wherein the exact actions that yield success would produce the opposite effect, then an individual can be said to be entitled to their rewards, but cannot be said to be deserving of them.[34] Thus, we cannot say of the successful businessman or woman that he or she deserves the wealth associated with his or her success. The reason this is not an instance of desert but is because of the arbitrariness of the rules of the competition that unjustly favour particular types of individuals, while disadvantaging others, like people with disabilities.

Similarly, inherent within the notion of desert is the idea of participation or action – in order to deserve a benefit, reward, or status, one must do or accomplish something to warrant such desert. One cannot deserve a reward without performing an action worthy of said reward.[35] However, the pursuit of equality under the law is an *a priori* consideration. While every individual should be treated equally in terms of their right to democratic participation, for example, such a right is upheld in a just society – not because individuals have done something to deserve such treatment – but for the sake of equality itself.

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[33] Miller, D. (1999). *Principles of Social Justice.* Cambridge, Massachusetts: Harvard University Press.

[34] Ibid.

[35] Macleod, A.M. (2005). Distributive justice and desert. *Journal of Social Philosophy 36*(4), 421–438.

When employing desert or merit-based arguments, notions of "reverse discrimination" have been used in reference to affirmative action and serve to further stigmatize and degrade individuals warranting compensatory action by virtue of society being unable to account for their specific aspirations.[36] In an attempt to equalize opportunities, affirmative action is introduced. However, individuals are either viewed as worthy of charity and pitiable or instead, seen as undeserving of the opportunities granted and viewed to be limiting other able-bodied individuals' options that may not require the recognition of difference.[37]

Traditional values of economic and social self-sufficiency, particularly in Western societies and increasingly in the developing economies that are entrenched in economic globalization, limit the social obligation of equality for persons with disabilities. The conventional basis of social obligation of those with disabilities has been beneficence and privilege as a consequence of charity by governments and the public.

Practices that incorporate notions of efficiency and fairness within the context of merit inevitably disadvantage those with disabilities. In order to promote a merit-based approach, individuals must have at some point in time enjoyed similar opportunities and had similar starting positions.[38] That said, it is the case that individuals with disabilities are oftentimes provided neither similar opportunities nor are they situated similarly to those able-bodied individuals not adversely affected by societal structures. The counter-argument raised by some egalitarians account for difference outside of equality considerations.

Fairness is seen as a barrier to equality and such injustices can be defended because people with disabilities are "disadvantaged" and their difference is accounted for through charity or acts of benevolence.[39] The central question is how to achieve a social agenda that can acknowledge difference (pluralism) without resulting in inequitable or unfair policies, while simultaneously ensuring the benefits of inclusion or assimilation into economic and social structures. A tension then arises once considerations move beyond abstractions or theoretical notions of rights and guarantees to account for the realities of disability (and gender, race, age etc.) and practices argued to be basic to the operation

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[36] Livingston, J.C. (1979). *Fair game? Inequality and Affirmative Action.* San Francisco: W. H. Freeman and Company.

[37] Ibid.

[38] Macleod (2005), *supra* note 35.

[39] Nozick, R. (1974). *Anarchy, State, & Utopia.* Oxford: Blackwell Publishing.

of the market economy and liberal democracy. It challenges the abstract conventions of modern Liberalism such as merit and anti-nepotism. Arguments against equality rooted in the controversial language of neo-liberals and the new right such as quotas, reverse discrimination, economic risk, non-competitiveness, and so on, have captured the public and the legal discourse.

These challenges are only compounded when one adopts conceptions of justice either founded upon, or heavily reliant on, ideas of desert. When the notion of desert is applied and is not done so erroneously, it often results in radically unjust social circumstances contingent upon a homogenous starting position, allocation of resources, and capabilities. Conversely, disability as a social phenomenon relies upon an acceptance of diversity and the value it affords society within the realm of equality and the pursuit of justice under the law.

While equality of opportunity assumes it is possible to situate individuals along a similar starting line, this proves to be, more often than not, false when examining the social situations of people with disabilities. Beginning from the same starting line (assuming one can determine when everyone is at that starting line) may be effective when the personal characteristics of the participants closely approximate the norm. For people with disabilities, there are physical and intellectual differences that make starting at the same point of little additional benefit than would not starting at all. Thus, the equality of opportunity cannot possibly lead to the equality of results in many situations. The major flaw in the model for enabling equality of opportunity for people with disabilities is that their differences are not solely the result of historic circumstances. In most cases they cannot, and should not, be expected to overcome natural characteristics and become like the "norm."

The basis for a claim to equality can be made solely on a person's citizenship or on their humanness on a general egalitarian value assumption – for example, that all people should be accorded equal respect by their government – rather than on their ability to compete in unequal circumstances.[40] The claim to resources is to enable participation with, in some cases, long-term support. This claim involves a redistribution of state resources, but it does not necessarily lead to the measurable

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[40] Greenawalt, K. (1983). *Discrimination and Reverse Discrimination.* New York: Knopf Press.

economic outcome that is foreseen for other disadvantaged groups. This model of equality does not address what characteristics ought to be regarded as irrelevant, as it is based on the simple assumption that equal opportunity is to provide access to the competitive, individualistic market, not to such non-comparable goods as services, activities, and information to enable the exercise of equality and autonomy in everyday life.

Equality of opportunity requires a form of on-going affirmative action to take into consideration the political economy of rights. It must recognize the barriers that cause or exacerbate claims to equality. It must avoid the problem of making disadvantage invisible by identifying only the most obvious distinctions and ignoring the issue of systemic or structural disadvantage.

Unlike equal treatment models, conceptions of equality premised upon equalizing opportunities for people with disabilities implicitly rely upon a notion of social pathology emphasizing environmental considerations. The notion of leveling background conditions or procedures guiding the competitive framework within an opportunity perspective is akin to a level of environmental awareness and the subsequent development of rules to ensure equality despite environmental barriers. More pointedly, the fundamental principles within an equality of opportunity perspective, while aimed at addressing and equalizing the physical or structural barriers one may encounter, do not address the social and attitudinal barriers from a human rights perspective. Inherent within an environmental approach to disability is the notion of equalizing the structures that situate individuals in society. The environmental approach to disability is concerned with the disestablishment of rules unjustly favouring individuals by virtue of natural or luck-based endowments. The principles within equality of opportunity are present to ensure similar rights.

Equality of Results or Outcome

A more expanded concept of equality is substantive equality or equality of outcome, with a recognition that, in order to make a real difference to people's well-being through a commitment to equal respect, equal dignity, equal humanness and autonomy, it is necessary to move beyond formal legalism. This has been variously called an "equality-of-outcome" model, an "equality-of resources" model and an "equality of respect" model.[41] Sen introduces the notion of "basic capability equality," which he claims is beyond utility (equality of opportunity) and the Rawlsian concern with primary goods.[42] Nussbaum expands upon this notion and argues that it incorporates the notion of an individual having the right to be able to do certain basic things, such as the ability to move, to meet nutritional and clothing requirements, to participate in social life and the community.[43] Additionally, while there are simple functionings, there are also complex, idiosyncratic, functionings necessary if one is to lead a valuable life that may not be relevant for another.

An equality of outcome perspective recognizes the limitations of the traditional legal justifications for excluding people legally, socially and economically. In *Andrews v Law Society of British Columbia,*[44] the Supreme Court of Canada proposed a broad and substantive notion of equality. In the first case in Canada[45] to interpret the notion of equality before and under the law after *the Charter of Rights and Freedoms*[46] came into effect, McLachlin signaled the breadth of the meaning of equality:

> …vacuity of the formalistic concepts of equality and emphasized the need to look at the reality of how differential treatment has an impact on the lives of the members of stigmatized groups. The purpose of the *Charter* Guarantee[47] of equality, the Court affirmed was not to guarantee

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[41] Dworkin, R. (1986). *Law's Empires.* Cambridge, Massachusetts: Cambridge University Press; Neilsen, K. (1985). *Equality and Liberty: A Defense of Radical Egalitarianism;* N.J. Rowmon and Allanheld Tutuwa; Dworkin, R. (1981). What is equality: Part 1, Equality of welfare. *Philosophy and Public Affairs, 10*(3) 185–246; Dworkin, R. (1981). Part 2, Equality of resources. *Philosophy and Public Affairs, 10*(4) 283–345; Dworkin, R. (1987). Part 3, The place of liberty. *Iowa Law Review, 73*(1) 1–54; Dworkin, R. (1987). Part 4, Political equality. *San Francisco Law Review, 22*(1) 1–30; Weston, P. (1990). *Speaking of Equality: An Analysis of the Rhetorical Force of Equality in Moral and Legal Discourse.* Princeton, New Jersey: Princeton University Press.

[42] Sen, 1995; Nussbaum, 2006.

[43] Ibid.

[44] *Andrews v Law Society of British Columbia* [1989] 1 SCR 143.

[45] Many important cases for disability rights and equality have come after the Andrews decision. Take for example, *Eldridge v British Columbia (Attorney General)*, [1997] 3 S.C.R. 624.; *Cameron v Nova Scotia* (1999), 177 D.L.R. (4th) 611 (N.S.C.A.).; and *Council of Canadians with Disabilities v VIA Rail Canada Inc.*, [2007] 1 S.C.R. 650, 2007 SCC 15.

[46] *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982 c. 11.

[47] s 15(1) of the *Canadian Charter of Rights and Freedoms* reads:
Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without

> some abstract notion of similar treatment for the similarly situated. It was not even to guarantee equal opportunity – opportunity that may mean nothing to those unable to exercise it by reason of lack of education or the social structures of society. The purpose of the *Charter's* guarantee was rather to better the situation of members of groups that had traditionally been subordinated and disadvantaged. Quality lies not in pious platitudes but in actually using the law to end the disadvantage and discrimination that people suffer because their personal characteristic and elites slot them into a non-privileged category.[48]

Equal outcome utilizes the law in ensuring equality by recognizing the fallacy of the assumption that existing distributions of power and wealth are a product of individual initiative rather than state action. Such a conception of equality allows for the reformation of services such as education and health and can ensure proper redistribution of resources by taking a critical perspective of what government and private bodies must do. It incorporates the notion of well-being and the implication for resource distribution that would require both the redistribution necessary to enable equal opportunity, as well as the redistribution necessary to take into account unequal needs because of physical, sensory, intellectual or psychiatric differences as well as the social, political and legal barriers that serve to highlight such differences. Entitlement is based on a comprehensive notion of intrinsic worth and need, not on status or on inequality of talent resources or social usefulness.

Unlike the two other models, equality of outcome starts not with an assimilationist view, but with a pluralistic perspective on how people with differences and similarities ought to see each other in a just society. It argues that formal barriers have placed groups in substantively different social positions, or that differences are sites of social disadvantage. Consequently, the removal of barriers without addressing the associated disadvantage does not result in any material change. It identifies the systematic discrimination against groups as an integral part of policies fostering a dominant social agenda, not as a mistake or a historic anomaly. To enable equality that takes into account immutable differences, differences have to be accommodated to neutralize them as barriers to personal achievement and to entitlement as fully

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discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

[48] McLachlin, B. (1996). The evolution of equality. *The Advocate, 54*(4) 559–566.

participating members of society. The emphasis has to be on accommodation or structural change of basic institutions, rather than affirmative action. An equal outcome approach is a model that incorporates the assimilationist model (basic claims, for example, to education, employment, community etc.) and a pluralist model (that is, accommodation for difference, for example, affirmative action, job adaptation, etc.) without losing the benefits of each. This shifts the legitimacy of the equality claim from need to outcome. The basis for disentitlement itself has to be addressed, recognising that the equality issue is not simply that there are those who have not been fairly tested or evaluated in terms of their right to participate, for example, in the labour market and to have a particular job, but instead, that classes of jobs have not been created for which people could legitimately qualify.

The premises of this model of equality are that all persons of distinguishable disadvantaged groups have the same needs for equality, respect and autonomy; that the capacity to exercise that right is not a distinguishing characteristic for the purpose of recognizing or denying that right; and that equality is consequent on the equal value, benefit and rights possessed in differences from the norm, not on overcoming natural characteristics and becoming as much like the norm as possible. This refocuses the concept of equality, both legally and socially, from the negative notion of discrimination to a positive means of integration. The former concentrates on removing obstacles, while the latter creates a common social space, setting a minimum of essential conditions of social inclusion and engagement and the redistribution of resources and legal claims to enable that to occur. The question of whether someone is similarly situated with non-disabled individuals as the normative standard becomes redundant in legal argument and replaced by the attempt to challenge non-participation.

Theories endorsing the equalization of outcome rely heavily upon ideas within a human rights, or interactionalist approach to disability. Inherent within a human rights approach to disability analysis is the notion that, despite the elimination of actual environmental barriers, societal and attitudinal barriers are nevertheless present and in need of attention. Implicit within an equality of outcomes approach is also an understanding that the subjective value one may place on a specific democratic entitlement is of prime importance and warrants just as much consideration as an opportunity or ability demanded by an able-bodied individual. A move from the toleration to the celebration of difference requires the recognition of the disabling barriers one can encounter aside from those addressed within an environmental paradigm.

Additionally, similar to the idea that disability is a social pathology, and not an individual tragedy, the responsibility to ensure that one's fundamental human rights or functionings are addressed is not borne by the individual but, rather, the social and political structures surrounding them. Unlike an individual pathology approach to disability, idiosyncratic needs are taken into account in the provision of supports. The enforcement of human rights recognizes the individual choices one makes, and avoids prescribing results seen to be in the individual's best interest that stem from paternalistic attitudes.

Conclusion

Equality has a long and noble tradition in law – it is entrenched in the constitutions of some countries and is accepted in many others as fundamental to the notion of governance. It assumes that certain basic problems are bound to occur and seeks to address the way in which rules are developed and applied and how institutions, power relations and rights and duties are organized. The notion of equality has been used as an organizing framework, at least nominally, to recognize that groups are disproportionately impacted by the nature of social structures and that it is the responsibility of the state to address those issues. Inequality has been accepted as a recurring social, legal, moral, religious and cultural problem. In 2007, The UN Convention on the Rights of Persons with Disabilities was ratified. While it mentions the equality of opportunity as well as practices of non-discrimination, it fails to make explicit how we should conceptualize and apply the notion of equality.

The issues that arise from an examination of equality in law are not just how it has been expressed in Constitutions, but the use in both case law and black letter law to spell out the way in which people can be treated unequally within the construction of the notion of equality. It is the issue of the relevance of the differences among people and if those differences are determined to be material differences justifying lesser outcomes. As equality requires distributive justice, it is a central issue for people with disabilities. They have, it could be argued, been the benchmark for deciding how equality is determined, what formulation of equality is used as a measuring tool, and the consequences.

The boundary between the entitlement or disentitlement to equal outcomes and the social responsibility for enabling the exercise of equality has fallen heavily on the shoulders of those with disabilities.

Coming to a realization of the principles of equality in case law originates in the abstract ideas that are found in these models. It is generally assumed that law is instrumental in providing a basis for a comprehensive process of legal change and that equality is a legal instrument for addressing social problems. However, while the courts have used equality of opportunity in cases of race and gender,[49] they have been much more reluctant to use it as a basis for decision-making in cases related to disability. There seems to have been reluctance to recognize that with disability, the difference is real and immutable and consequently, at a minimum, equality has to be interpreted from an equality of opportunity perspective and that for real equality before and under the law, equality has to be consistently interpreted more broadly, as the equality of outcome.

But the preponderance of cases are not found by the courts to be cases of equality but rather, are limited to a determination of access to services. They are reduced to issues of service delivery and service quality rather than issues of equality. The appeal to equality as a principle for social change, even in the current era in which the discrimination against people with disabilities is being outed, questions some privileged social positions. Until very recently, people with disabilities have had little shared, recognized cultural identity; they have largely been sharing normative opinions and attitudes of the non-disabled population. In terms of social change and pressure for equality, this tends to mask the legitimate character of the demands that can be made. As equality is appealed to in terms of social justice, and supported by legal arguments, vested interests will often be found to support the opposition to social change by resorting to economic or scientific arguments.[50] For example, arguments may be made that risks to safety and health will result if people with disabilities are in the labour force or that children with behavioural disabilities will disrupt the learning of

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[49] See for example, *Symes v Canada*, [1993] 4 S.C.R. 695.; *Vriend v Alberta*, [1998] 1 S.C.R. 493.; *British Columbia (Public Service Employee Relations Commission) v BCGSEU*, [1999] 3 S.C.R.; *Bear v Canada (Attorney General)*(C.A.) [2003] 3 F.C. 456.; and *Newfoundland (Treasury Board) v N.A.P.E.*, [2004] 3 S.C.R. 381, 2004 SCC 66.

[50] Rioux, M. (2002). Social disability and the public good. *Man and Development, 24*(4) 179–198.

others in the classroom. These arguments may be based on the medical characteristics of disabilities or may be made on the basis of the economic hardship that adaptation will cause. Sometimes those in opposition will point out the risks to justice in extending equality to people with disabilities. For example, schools have argued that by providing additional time for completing tests or assignments in school, they will be disadvantaging (or treating unfairly) the average child without a learning disability.

There has been little reluctance in law to accept the general principle of equality in its limited sense of formal equality, but in those cases, not unexpectedly, the courts find that there are relevant factual differences on which to base dissimilar treatment, without the principle of equality being broached. Even the case that felled the "separate but equal" provision in the United States, *Brown v Board of Education*[51] is not yet the precedent in most countries with respect to disability. There are a few cases that can be looked at as the first cracks in the wall – the *Eve* decision in Canada (decided on grounds of equality); and the *Marion* decision in Australia (decided on the grounds of autonomy). An abundance of important and precedent-setting legal cases in the field of disability are, however, nowhere to be found. The values and assumptions around disability are still clearly grounded in presumptions about disability as an individual pathology – as residing in the individual and not as a consequence of the political, social and economic conditions. A market driven perception of what is just and fair and what is discriminatory reins the creative potential of this legal instrument to effect social change and to radicalize the concept of equality for people with disabilities.

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[51] *Brown v Board of Education* 347 US483 (1954).

INCLUSION, SOCIAL INCLUSION AND PARTICIPATION

Melinda Jones

The principle of inclusion is simple – it is the opposite of exclusion and also of alienation. It is the principle that says that whatever benefits accrue to members of a society are the heritage of all people, not just those who are able-bodied. Inclusion means that all people are entitled to full membership of the human family. Within the large group of humanity, just as in any family, people play a number of different roles and bring to the community a variety of needs, vulnerabilities, skills and experiences. Each individual operates in relation with others and each of us is inter-dependent. Inclusion requires the recognition of self in other, and other in self.[1]

Fundamentally, inclusion is the principle that we are all entitled to participate fully in all aspects of society; that we all have the same rights and responsibilities; that we all have something to contribute. It is the principle which demands valued recognition of all people and the entitlement of all to meaningful interaction, involvement and engagement in every part of the complex, multifaceted societies in which we live. Whether at school or work, in clubs or cinemas, in playgrounds or at beaches, at the health centre or the supermarket, the right to inclusion requires that people with disabilities are not merely seen, but are heard and acknowledged.

Inclusion is the right of the individual and the responsibility of society as a whole. Inclusion requires the removal of barriers and social structures which impede participation. It requires proactive policy making, lateral thinking and on-going commitment. Inclusion is a realistic and pragmatic principle. It accepts the reality of disability and difference, and acknowledges that. While medical treatment and rehabilitation have a role to play in improving the physical position of people with disabilities, these can never, on their own, provide for the rights of equal citizenship and of social solidarity. Inclusion is about valued recognition, meaningful engagement and enabling social policy.

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[1] Habermas, J. (1987). *The philosophical discourse of modernity* (F.G. Lawrence Trans.). Cambridge: Polity Press.

THREE DIMENSIONS OF INCLUSION

In order for people with disabilities to be included in society, each of the three dimensions of inclusion must be operational. These are: a non-discriminatory attitude towards people with disabilities; the guarantee of access to participation in every area of life; and the facilitation of people with disabilities to limit the impact of disability.

Because inclusion ultimately depends on the acceptance of difference and the willingness to celebrate diversity, there must be an environment and political will to combat discrimination and to promote equality. While people with disabilities are shunned or locked away, stereotyped or viewed as outsiders, it is unrealistic to expect inclusion. Negative perception and treatment will not necessarily occur across all aspects of society or with respect to all types of disability. The inclusion of some people with disabilities may pave the way for a change of attitude with respect to other people with disabilities. An appropriate attitude to people with disabilities should not be taken for granted. Inclusion is predicated upon good interaction between people with and without disabilities. It is the attitude adopted by society which determines the extent to which inclusion will be achieved.[2]

One of the greatest hurdles confronting people with disabilities is the understanding of disability in terms of individual pathology. Described as the medical model of disability, this perspective considers disability to be a deficit in the individual which prevents the person from reaching the benchmark of "normal."[3] Disability is seen as a personal tragedy, presenting hurdles which only the individual can combat. Often the person is reduced to a condition or impairment, and the only assumed need is for medicine and rehabilitation. While not underestimating the importance of these, where appropriate, or discounting the reality that people with disabilities are disadvantaged by their bodies or minds, the focus on individual pathology has distracted society from the recognition of people with disabilities as people first, with the same needs and aspirations as anyone else. Rethinking the extent to which the barriers to inclusion are truly a result of different

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[2] See Morris, J. (1991). *Pride against prejudice: Transforming attitudes to disability*. Toronto: Women's Press.; Goggin, C. & C. Newell. (2005). *Disability in Australia: Exposing a social apartheid*. Sydney: University of New South Wales Press.

[3] On the various approaches to disability see: Jones, M. & L.A. Basser Marks. (2001). Law and people with disabilities. In N. Smesler & P. Baltes (Eds.), *International encyclopedia of social and behavioral sciences* (pp. 8475–8480). Oxford: Elsevier.

functioning, leads to recognition of people with disabilities as rights-bearers, rather than as people in need of charity or welfare. An attitude to people with disabilities which conflates impairment with personhood is itself a barrier to inclusion.[4]

One way of assessing the extent to which people with disabilities are thought of as equal members of society is by paying attention to the portrayal of disabilities in the media.[5] If people with disabilities are constantly positioned as villains and the epitome of evil, it can be assumed that fear of disability is extant. If people with disabilities are seen as super-human, like Helen Keller perpetually discovering language at the water-tank, rather than ordinary people sharing the struggle for an ordinary life, we can assume that people with disabilities continue to hold outsider status.[6] If disability is shown as personal tragedy, overcome by heroes who are always able to walk away from their wheelchairs by the end of the story, it can be assumed that disabilities can be overcome with the right attitude. These sorts of images both mould and reflect the values of a society and stand in the way of true inclusion.

The second dimension to the inclusion principle is access. This builds on the social model of disability which locates disability outside the individual. The social model seeks to identify and eliminate restrictions which prevent inclusion. Barriers may take the form of stairs or the way in which a building is constructed, affecting, for example those using wheelchairs; or it may be the way in which information is communicated, where small print or complex language may exclude those with vision impairments or intellectual disabilities respectively. It is the basic arrangements of the society which will often need to be reorganised. While individuals can locate and complain about structural impediments, it is the responsibility of the society (not just the government, but individual citizens such as shopkeepers, bartenders or headmasters) to dismantle or remove barriers. Most often this will require the taking of active steps, for the *status quo* is designed in the interest

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[4] See, for example, Rioux, M. (2003). On second thought: Constructing knowledge, law, disability and inequality. In S. Herr, L. Gostin & H. Koh (Eds.), *The human rights of persons with disabilities: Different but equal* (pp. 287–318). Oxford: Oxford University Press.

[5] See generally, Thomson, R.G. (1997). *Extraordinary bodies: Figuring physical disability in American culture & literature*. New York: Columbia University Press.

[6] Crow, L. (2000). Helen Keller: Rethinking the problematic icon. *Disability & Society,* 15(6), 845–859.

of dominant groups. Unless there is an attitude which empowers rather than represses people with disabilities, access will not be achievable.

Accessibility makes participation possible. Without access, people with disabilities are excluded from the life which those without disability take for granted. Simple things like catching a bus, using the local library, doing the shopping, seeing a film or going to church can be too difficult for a person with a disability. And if the person has been denied the right to an appropriate education, her chances in the labour market and her ability to relate to peers may be curtailed. Equally, being denied the right to participate in the labour market will not only have an impact on an individual's sense of well being, but will also limit his or her financial ability to take advantage of the social, leisure, cultural or religious activities available in the community in which they live. Access to participation in all aspects of the social, cultural and economic life of the society is a requirement of the human rights principle of inclusion.[7]

Ensuring access does not, by itself, guarantee inclusion. Rather, a third dimension to inclusion is required. For meaningful engagement to occur, it will often be necessary to facilitate the inclusion of people with disabilities. This may take the form of providing equipment or medicine. It may be that for a particular individual to participate, a support person will be required. More often it will involve an alternate strategy to achieve an end. Examples of this are a modified curriculum for a person with an intellectual disability; audio format for those for whom reading is difficult; captioning of visual media for the hearing impaired; and audio cues at pedestrian crossings. Not only is facilitation needed at a macro level, but individuals may need accommodation in all sorts of ways to ensure the highest level of independence and functioning. Where, for example, an individual is unable to button shirts or tie shoelaces, it should be easy enough to provide clothes with zips and shoes with velcro or buckles, even if this requires a deviation from a specified uniform. The cost to an organization is low and the gain to the individual immense. Facilitation of this sort makes a massive difference to the impact of disability and to the autonomy of the individual.

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[7] On the importance of accessibility for participation see Young, I.M. (1990). *Justice and the politics of difference*. Princeton, New Jersey: Princeton University Press.; and Yeatman, A. (2000). What can disability tell us about participation? In M. Jones & L.A. Basser Marks (Eds.), *Explorations on law & disability in Australia* (pp. 181–202). Australia: The Federation Press.

It is not only people with disabilities who benefit from facilitation when accessing the resources available in the society in which they live. Multicultural societies have embraced the need for interpreters and multilingual publications, recognising that without these the participation of people from non-English speaking backgrounds will be limited and their rights to social goods such as a fair trial may become meaningless. Equally, the provision of childcare is designed to facilitate women in the workforce and the provision of maternity leave is designed to accommodate working mothers. Facilitating people with disabilities changes the terms by which interaction with others is possible and discounts the impact of disability on ordinary existence.

Maimonides, a 12th century Jewish thinker, saw the virtue of inclusion in his discussion of the Jewish law of *tzedaka*, often translated as "charity" but actually meaning "justice." The highest and ideal form of *tzedaka* involves anonymously providing a poor person with the means by which to become independent.[8] It is a just society which recognises that providing support to enable independence is beneficial not just to the individual but to the society as a whole. Further, it should be recognised that establishing the right to be facilitated is a matter of self-interest as well as a means of supporting people with disabilities – statistically there is a very high chance that any given person, or one of their close relatives will become disabled at some point in their lives.[9]

Inclusion as a Human Right

Although human rights are a serious business, the analogies generally used to explain their function come from the world of game playing. Richard Dworkin, in his seminal account of the modern liberal conception of rights, describes rights as trump cards.[10] When someone has a trump, all the other players must defer to the power of the trump. When someone has a right, it puts an end to argument or discussion about the best decision in the case at hand. On this basis, having the

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[8] On Maimonides' eight levels of *tzedaka*, see Telushkin, J. (2009). *A code of Jewish ethics: Volume 2: Love your neighbor as yourself.* Harmony/Bell Tower. 187–191 . For discussion of the issue of *tzedaka* in Jewish law and practice, see Telushkin, 156–259.

[9] Basser Marks, L.A. (2008). Disentangling disability and health. In B. Bennett, T. Carney & I. Karpin (Eds.), *The brave new world of health* (pp. 218–236). Annandale, NSW: Federation Press.

[10] Dworkin, R. (1990). *Taking Rights Seriously.* London: Duckworth.

right to inclusion gives you an ethical trump card, which will allow you to direct the outcome of arguments of principle. This is the difference, according to Dworkin, between rights in the strong sense and rights in the weak sense. A strong claim is a claim which promotes the fundamental requirement of rights: that is, the treatment of all people with equal concern and respect.[11]

An alternative view of rights, developed by feminist legal scholars and critical race theorists, sees rights as providing entry into the discourse of society, helping to define the boundaries between people and structuring relationships.[12] Minow argues that rights, "are calls for communal dialogue: the language we use to try to persuade others to let us win this round."[13] From this perspective, rights are the cards we play with, and having a claim to rights, involves being welcome at the card table. Rights are matters to be negotiated. Being dealt a hand means that your voice can be heard and your perspective considered.

This second account of rights gives greater meaning to the concept of inclusion as a right. By being allowed to be participants in the discourse of rights we become entitled to "a basic equality among participants as participants."[14] Allowing people with disabilities to be players is a crucial prerequisite to inclusion. Disagreements are inevitable when there are 52 cards in play, but instead of the result being a win/lose situation, resolution is reached by communal discourse directed towards fundamental values.

The language used within social discourse can itself be indicative of the true level of commitment to the rights of people with disabilities. At one end of the spectrum is "tolerance" – where the society demonstrates a willingness to put up with presence of difference, but not to embrace it. When we are prepared to tolerate people with disabilities we do not object to their presence as viewers of the game, but we do not really want them to play. Beyond tolerance is the idea of "acceptance" – where people with disabilities are welcomed to the table and allowed to

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[11] Ibid., 184ff.

[12] Minow, M. (1990). *Making all the difference: Inclusion, exclusion and American law*. Ithaca, New York: Cornell University Press.; Williams, P. (1993). *The alchemy of race and rights*. London: Virago Press.; Jones, M. (1996). Balancing competing human rights. *Communications Law Centre Proceedings of Conference on Free Speech in Australia,* Australia. 45–49.

[13] Minow, M., ibid.

[14] Minow, M., ibid.

play. However, acceptance does not require an alteration of the rules or an adjustment of the cards. For inclusion to occur, it is necessary to move beyond toleration and acceptance. Including others requires a willingness to facilitate or accommodate difference: a willingness to make changes to the game, to the structural requirements of the game, to the playing pieces or even to the criteria for winning. Inclusion involves the amelioration of difference until it becomes irrelevant to the chances of success.

An example of the use of language with respect to the educational opportunities for children with disabilities indicates the importance of demanding inclusion. When the objective of education is "mainstreaming," there is no demand for equality. Rather, children with disabilities are tolerated on the same campus as others, and share some of the school's facilities. However, segregation in separate units or separate classes is not seen as contrary to providing rights. Children with disabilities are present in the school community, but not really a part of it. On the other hand, "integration" of children with disabilities is evidence of acceptance. When children with disabilities are integrated into the classroom, they become part of the class and part of the learning community. However, as the Canadian Supreme Court said in *Eldridge*, integration is "conditional upon their emulation of able-bodied norms."[15] If the child cannot operate firmly within the *status quo*, the child will simply miss out on the activity. It is the children with disabilities who must adapt themselves as well as they can, and who must participate as much as they are able.

When it is "inclusion," rather than "mainstreaming" or "integration," which is sought, much greater demands are being made of the system. When a child is included, the barriers to participation will be removed and active steps will be taken to ensure the child's social and academic well-being. It is the classroom and the learning processes that will have to be adapted to allow for meaningful participation and to allow the child the same educational opportunities as provided for other students.[16] As such, inclusion requires mitigation of the effects of difference.

Human rights, then, require more than the recognition of the equal worth of all people and the commitment to treating everyone with

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[15] *Eldridge v British Columbia* (1997) SCJ No 86 at 56.

[16] Basser Marks, L.M., & M. Jones (2002). Fostering inclusive societal values through law. *International Journal of Children's Rights, 10*(4), 371–402.

dignity and respect. Human rights are social tools for the achievement of a just society. Excluding some people is not only disrespectful: it involves holding some people to be less equal than others. Inclusion is the operational principle for ensuring that all people can be meaningfully involved in society and that all people can meaningfully engage in both the benefits and burdens of citizenship.

Social Exclusion and Social Inclusion

The discourse of "social exclusion" and "social inclusion" has hijacked the public policy debate about the idea of inclusion in Europe, Canada and Australia. While this debate rarely revolves around the rights or needs of people with disabilities, the implications of a social inclusion perspective are potentially wide-ranging and have the potential to support or undermine the rights of people with disabilities. Walker & Walker explain that social exclusion:

> … refers to the dynamic process of being shut out, fully or partially, from any of the social, economic, political or cultural systems which determine the social integration of a person in society. Social exclusion may therefore be seen as the denial (non-realization) of the civil, political or social rights of citizenship.[17]

Similarly, Teague & Wilson comment that social exclusion in not just a description of inequality, but:

> … a set of *processes,* including within the labour market and the welfare system, by which individuals, households, communities or even whole social groups are pushed towards or kept within the margins of society It encompasses not only material deprivation but more broadly the denial of opportunities to participate fully in social life. It is associated with stigmatisation and stereotyping …[18]

The term social exclusion was coined in France in 1974 in response to growing poverty and social unrest, not to describe the experience of

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[17] Walker, A. & C. Walker (Eds.) (1997). cited by Saloojee, A. (2003). *Social inclusion, anti-racism & democratic citizenship*. Toronto: Laidlaw Foundation, Working Paper Series at 11. Saloojee (at 4) considers that exclusion describes the process by which dominant group are able to secure the greater share of society's valued goods to use their advantages to reinforce their control over rights, opportunities and privileges in society.

[18] Teague, P. & R. Wilson. (1995). Towards an inclusive society, in *Democratic Dialogue: Social Exclusion, Social Inclusion* Report No. 2 Belfast, online: http://cain.ulst.ac.uk/dd/report2/report2m.htm#inclusive.

people with disabilities.[19] The idea of social inclusion took hold somewhat later, emerging as a core element of the Blair government's "Third Way."[20] Because, from the outset, the terms lacked conceptual clarity,[21] the language of social inclusion and exclusion has been used to justify a range of conflicting ideological positions. While some have attempted to distinguish social inclusion from social exclusion, arguing that the difference depends on the respective attribution of responsibility for the marginalisation to the state or to the members of the outsider group, this does not hold.[22] It is generally accepted that social exclusion and social inclusion involve the complex, multifaceted interaction between those at the centre and those at the margins. Beyond this, however, little can be predicted about the content of a claim of concern about those experiencing social exclusion. This is because the language of social exclusion has been co-opted by all sides of the political divide, with each group colouring the notion of social exclusion with its own perspective.

Levitas has characterised the alternative political usages of the terminology of social exclusion and social inclusion as a redistributive discourse [RED],[23] a social integrationist discourse [SID],[24] and a moral

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[19] See Saloojee, A., *supra* note 17.

[20] Giddens, A. (1998). *The third way: The renewal of social democracy*. Australia: Polity Press.; Collins, H. (2003). Discrimination, equality & social inclusion. *Modern Law Review, 66*(1), 15–43.

[21] Collins, H., ibid.

[22] See Mitchell, A. & E.R. Shillington. (2002). *Poverty, inequality & social inclusion*. Toronto: Laidlaw Foundation Working Paper Series.; Saloojee, A., *supra* note 17, at 13 who sees social inclusion as a radical response to exclusion. The contrasting position is held by Teague & Wilson, *supra* note 18, who argue social exclusion is the responsibility of the wider society. Levitas demonstrates the alternative positions held in the name of social inclusion and social exclusion (see note 23, below).

[23] RED was commonplace in critical social policy throughout the 1980s and 1990s, and is consistent with the right to inclusion. The redistributive discourse considers social exclusion to be a consequence of poverty. As such, increasing welfare to reduce poverty is crucial. Equally, reducing discriminatory and exclusionary practices that may be causes of poverty (which includes the inability to participate in the customary life of society) are central to RED. This discourse of social exclusion focuses on processes which produce inequality and implies a "radical reduction of inequalities and a redistribution of resources and power." Levitas, R. (1998). *The inclusive society? Social exclusion & the new labour*. London: MacMillan at 14.

[24] SID obscures the underlying causes of inequality and exclusion and undermines the legitimacy of non-participation in paid work. This casts moral aspersions about the value of those who stay home as carers (whether as parents or as supporting people with disabilities) and about the reality that some people may not be able to work (for example as a result of complex multiple disabilities, psychiatric disabilities or chronic

underclass discourse [MUD].[25] Those adopting RED consider the major barrier to participation to be poverty, which includes both lack of money and lack of financial capacity.[26] The solution proffered by RED is to increase welfare to reduce poverty and to deal with discriminatory and exclusionary practices. This perspective has something to offer people with disabilities.

While RED lays responsibility for dealing with exclusion firmly in the hands of the state, SID and MUD cast marginalised individuals in a more central role.[27] SID is concerned with the exclusion from paid work and the need for the moral integration of those outside the labour market. Its concerns are economic efficiency and social cohesion, which it considers can only be legitimately achieved through paid work. From this perspective, serious attention needs to be paid to problems created by those outside the paid workforce and coercive measures may be needed to bring these outsiders in. MUD, on the other hand, considers the problem of social exclusion to be the lack of moral responsibility on the part of the marginalised underclass, which is compounded by learnt dependency. By focusing on the behaviour of the poor, and the danger to social order posed by outsider groups – such as unemployed, potentially criminal, young men; single parents, especially unmarried mothers; and children who are truant from school – the MUD reduces social exclusion and social inclusion to an excuse for social control.

Saloojee suggests an alternative characterization of the different uses of the language of social exclusion and social inclusion.[28] He distinguishes between strong and weak positions on social exclusion/inclusion. The weak version is concerned with the integration of the excluded into society, which it claims will come about when the

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illness). Rather than empower those excluded from the workplace by providing alternative means of inclusion, SID de-legitimates anybody outside the labour market.

[25] Levitas, R. (1998), *supra* note 23; (2003). The idea of social inclusion. *Social Inclusion Research Conference,* Ottawa.

[26] Sen argues that this is only a new approach to the extent that earlier discourses of poverty often lacked the element of capacity, which he has argued for many years is central to a sophisticated analysis of poverty. Sen, A. (2000). *Social exclusion: Concept, application & scrutiny* No. 1. Social Development Papers). Manila: Asian Development Bank.

[27] According to SID, the responsibility for solving the problem lies both with the state, which must use a carrot/stick approach to weaning people off welfare, and the currently unemployed individuals who must change their attitude and get to work. According to MUD, social benefits are the cause of dependency and the state needs to regulate the behavior of those who lack moral character. MUD is a language of moralism and moral panic, which seeks mainstreaming through the labour market.

[28] Saloojee, A., *supra* note 17.

individuals involved change their behaviour and take greater responsibility for their own well-being. The focus of this weak idea of social exclusion is on individuals entering the paid workforce, which is to be encouraged through welfare reform. This notion of social exclusion considers that individuals will not only gain the economic advantages of a higher income when they join the paid workforce, but will also gain the concomitant benefits of self-esteem and of social engagement. Voluntary work may also provide benefits to those outside the paid workforce but if that work is domestic labour or childrearing responsibilities (usually falling upon women) the benefits of participation will not be achieved. This weak construct of social exclusion and social inclusion is similar to Levitas' social integrationist/moral underclass discourse, and poses a threat to the human rights of people with disabilities. It assumes that opportunities are available, if only people would take advantage of them. It is blind to the reality of structural impediments to participation and legitimises the reduction of benefits to an unviable level for those who are dependent on them.

Saloojee's strong version of social exclusion/social inclusion is more useful both as a description of the experience of people with disabilities and as a transformative tool. Like Levitas' RED, the strong version of social exclusion and social inclusion focuses on the relationship between those who are excluded and those responsible for their exclusion. This approach disentangles the various current and historical processes that reproduce oppression, discrimination and exclusion. According to Saloojee, the:

> [s]trong approaches to social inclusion discourse therefore are intimately concerned with rights, citizenship and restructured relations between radicalized communities and the institutions of the dominant society. The focus is on valued recognition and valued participation by those excluded from full participation in society and the benefits of society.[29]

Because it is open to a policy analyst, scholar or politician to adopt a weak or strong position, or to use the language of social exclusion/inclusion as a transformative principle or a crass ideological tool, it is essential to understand that adoption of the language of social exclusion or social inclusion does not guarantee a relationship with the human rights principle of inclusion. Nonetheless, the literature on social exclusion and social inclusion resonates with the experience of people with disabilities. Equally, the strong versions of social inclusion discourse

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[29] *Supra* note 17.

parallel the analysis of the rights of people with disabilities developed by disability scholars. In this respect, social exclusion discourse discloses the existence of structural constraints located in the very fabric of society. It points to the lack of access to social goods; lack of resources which prevents individuals becoming effective, contributing members of society; and to the reality that members of marginalised groups are not recognised as full and equal participants. Social inclusion, on these terms, offers a new approach to inequality and injustice,[30] critiques hierarchies of oppression and promotes a transformative agenda. To this extent social exclusion/inclusion may be able to be co-opted to promote the rights of people with disabilities.

Two issues raised in the context of social exclusion/social inclusion that bear further comment are poverty and social well-being/solidarity. Of the world's 650 million people with disabilities, 80% live in developing countries.[31] Both in those societies and in the north, people with disabilities are disproportionally among the poorest members of the society. Amartya Sen argues that poverty does not only relate to the level of income or the money available, but also relates to the capability that a person has to use that money to achieve full participation in society.[32] He argues that there are two ways in which poverty handicaps people with disabilities: an "earning handicap" and "conversion handicap." Attention needs to be paid to "earning handicap" because people with disabilities may find it harder to get a job or to retain it and may receive lower compensation for the work they undertake. Anti-discrimination law may be useful in addressing these problems and the constituents of inclusion – attitude, access and facilitation – will need to come into play. However, people with disabilities are not only disadvantaged in terms of income-producing capacity. The ability of people with disabilities to convert money into whatever is required for good living is limited by the "conversion handicap." A person with a disability may need more income to do the same things as someone without a disability. For example, to move or hear, a person with a disability may

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[30] Collins argues that social inclusion may provide a means of defending anti-discrimination laws and explaining deviations from the rules of formal equality. Collins, H., *supra* note 20, 15–43.

[31] UN Enable *Fact Sheet on Persons with Disabilities,* online: http://www.un.org/disabilities/default.asp?id=18.

[32] Sen, A., *supra* note 26. Sen, A. (1992). *Inequality reexamined*. New York: Russell Sage Foundation; Nussbaum, M. (2006) *Frontiers of justice*. Harvard University Press.

require assistance and whether this takes the form of a wheelchair, an hearing aid, an interpreter or personal support, this may cost a great deal of money to any given individual. As a result:

> [w]ith the same level of income a disabled person may be able to do far fewer things, and may be seriously deprived in terms of the capabilities that he or she has reason to value. For the same reason for which disability makes it harder to *earn* an income, disability also makes it harder to *convert* income into the freedom to live well.[33]

The implications of this are significant. If Sen is correct in finding that in the UK only a quarter of the poverty of people with disabilities can be attributed to "income handicap" and three-quarters to "conversion handicap," then any assessment of social supports required to achieve equality for people with disabilities must not only look to the generalised cost of living, but must focus on the cost of living with a disability. The personal cost of disability will also vary depending on the degree to which institutions and the infrastructure of the state are designed to facilitate the inclusion of people with disabilities.

Further, the radical discourse of social exclusion/social inclusion accepts that there is more to exclusion than poverty. Being excluded is also about social well-being, which includes, in addition to the basic provision of food and shelter, the opportunities to participate in the life of the society in a meaningful way. Access to non-material goods requires that the social organisation of society is such that these are potentially available to all. Collins argues that the emphasis on the distribution of non-material goods derives from the fundamental objective of social inclusion, that is, social solidarity:

> Although we have observed that social inclusion shares with equality a concern with the distributive allocations to groups and individuals in a society, its more fundamental objective is the outcome of social cohesion. Social inclusion is a theory of how society can be integrated and harmonious. At its simplest, the theory is that if everyone participates fully in society, they are less likely to become alienated from the community and will conform to its social rules and laws. Social inclusion fosters social cohesion or, to use an older concept, solidarity. The outcome sought by policies of social inclusion is therefore not merely justice for individuals but also a stable social order.[34]

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[33] Sen, A. (2004). Disability and justice. *Disability and Inclusive Development Conference – Keynote,* Washington, Page 3.

[34] Collins, H., *supra* note 20, 15–43.

There is no doubt that one consequence of exclusion from society is alienation, and that addressing exclusion may lead to meaningful engagement in society. The right to inclusion is about the right to be a full member of society. This means that people with disabilities are entitled to both the material and non-material goods that make participation possible. Each of the three dimensions of inclusion is at stake. The most critical of the elements; attitude, is not a material good. While material goods are important, people with disabilities cannot be included without the provision of non-material goods. Meaningful engagement and valued recognition depend on a social commitment to respond to all aspects of exclusion.

A Checklist Approach to Inclusion

One practical approach to the inclusion principle is to use a checklist to ensure that all matters have been taken into account. Assuming that there is a commitment to achieve substantive equality in the operation of policy, a process of thought that makes specific reference to the differential impact of policy and to the complex, diverse structure of needs and interests represented in the community, will be crucial. When it comes to the checklist of members of the community for whom a social policy is being devised, the checklist would provide the challenge of addressing the full range of stakeholders in the policy being developed. In particular, the list would commonly involve the following:

Step 1: Including the Whole Community

- Have you included the needs of women as well as men; children as well as adults?
- How will the policy impact on people whose sexual identity is not heterosexual?
- Have you taken into account the full diversity of cultural and religious groups that are part of the community?
- Have you considered the impact upon people from diverse ethnic and racial groups?
- Have you considered the impact of the policy on the homeless and the jobless?
- Have you taken into account the position of those living in rural as well as urban areas?
- Have you taken into account the position of migrant workers and their families?

- Have you considered the impact upon refugees and other non-citizens?
- Have you taken into account the effect of the policy on people with disabilities?

The inclusive attitude necessarily extends beyond disability and the models used to include other groups of people will have a flow-on effect to people with disabilities. However, when it comes to disability, it is not sufficient to consider people with disabilities as a class. Assessing the application of a policy to disability, and its potential impact, will require attention to different groups of people with disabilities and different experiences resulting from the degree of disability. It is therefore necessary to take a further step.

Step 2: Ensuring Inclusion for All People with Disabilities

- Are *all* people with disabilities going to be able to share the benefit of the policy?
- Does the policy impose physical structures that exclude people with mobility disabilities?
- Is accommodation made for people with visual or hearing impairments?
- Does the policy include a means with which to facilitate the inclusion of people with intellectual disabilities?
- Will the policy take into account the periodic absences of those with chronic illness or the instability of many people with psychiatric disabilities?
- What differential impact, costs or benefits will confront people with disabilities in the implementation of the policy?
- Is it taken for granted that that people with disabilities will be able to equally benefit from the policy, or have steps been taken to ensure inclusion?

The question must always be: can the policy be adapted to ameliorate the differential impact on disability and/or other “outsider” status? Taking into account the needs and experiences of people with disabilities goes a long way towards developing an inclusive society. It requires lateral thinking – going outside the box of the media-screened world – that may result in creative solutions to newly understood problems.

Step 3: Issue-Specific Considerations

A third checklist must be added to the others if we are to assess the inclusive quality of the social structure or of social institutions. This list will involve the deconstruction of the issue under consideration, such that the minutiae of policy can be checked against the community or disability checklist. As this third list will be specific to the issue under examination it is, perhaps, easiest to demonstrate the application of the checklist approach by working through two example areas.

a) The Right to Vote

The right to vote is the most basic of all political rights, and having the right to vote is a mark of membership of a community.[35] Those who are entitled to vote are those who matter to the society, whose opinion is valued, and whose judgement is respected. History has shown that even where there are claims of "universal sufferage," substantial groups within the society may be denied the vote. Women, indigenous peoples and the poor or indigent are the most likely people to be excluded from political participation.

Voting and political participation are not only intrinsically valuable as aspects of freedom, they are also of instrumental effect. Those engaged in governing tend to take notice of and listen to those whose opinion can affect their prospects of election or re-election and their access to power. It has been suggested that the difference between places in Europe where migrant workers riot, and those where there is a far greater degree of harmony (for example, between France and Germany) turns on the fact that in the former situation politicians gain no benefit from taking the needs of migrant workers into account. Equally, right wing/racist groups have no fear of defeat at the polls.[36]

In democracies, involvement in the political process through participation in elections is considered the fundamental right of all citizens. However, it is far more complex an issue than the physical act of casting a ballot.

The minimum content of the right to voting includes:

- The right to participate in the election on equal terms;
- The right to register to vote (where such a system exists);

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[35] On human rights and the right to vote, see Jones M. (1995). The right to vote and participate in political processes. *Human Rights, the Laws of Australia.* Law Book Co. 11–29; Gaze E. & M. Jones. (1990). *Law, Liberty and Australian Democracy.* Law Book Company at 73–114.

[36] Sen, A. (2000). Other people. *Proceedings of the British Academy,* 111, 319–335.

- Access to information about the electoral system, including how, when and where to vote;
- Access to information about competing policies, platforms or ideas of the respective candidates and/or political parties;
- The right to participate in public debate about the respective ideas being presented by candidates and/or political parties;
- The right for the vote to be by secret ballot; and
- The right to stand as a candidate and/or to hold political office.

The ability to have a political voice is underscored, as Sen points out,[37] by the concomitant transparency of information. Political freedom entails not only the freedom to be heard, but also the freedom to demand information. Teasing out the elements of the right to vote allows us to recognise the points of the process which may exclude people with disabilities, and to establish what needs to be done to ensure inclusion.

The checklist begins with the question: does the law specifically exclude any people with disabilities from participating in elections? For example, in some jurisdictions people with psychiatric disabilities and people with intellectual disabilities are specifically denied the right to vote. People with other sorts of disabilities may also find themselves excluded by law. This is clearly unacceptable.

Once all people with disabilities are granted the right to vote, the checklist continues:

- Are any people with disabilities excluded from participating because they are unable to access voting in the form it is presented? For example, are voting places physically accessible? Are there alternative ways of marking a ballot paper? (Is voting predicated on the ability to write or read?) Does voting require standing in a queue for an extensive period of time?
- Similarly, if voter registration is required, are there terms and conditions which some people are unable to meet because of their disabilities? Does voter registration require, for example, complex language skills or the ability speak?
- Do people with disabilities have access to information about the electoral system, including how, when and where to vote? Is electoral information available in accessible formats (Braille, big print, audio)?

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[37] Sen, A., *supra* note 26, 40.

Does the information take the form that it is intelligible to people with intellectual disabilities?)
- Can people with disabilities access and participate in public debate about the respective ideas being presented by candidates and/or political parties? (Are there issues of physical access? Are interpreters available?)
- Even where an aid is needed, are people with disabilities provided with the means to secretly record their votes? Is it possible for all people to enter their votes secretly?
- Are some people denied the right to be candidates in elections or to hold political office?

For people with disabilities, information about disability policies, about spending, about distribution of wealth and about the attitudes of candidates to disability is crucial to the exercise of political power. Equally, people with disabilities have a stake in all aspects of governance–even where these have nothing to do with disability *per se*. Failure to ensure the full range of political information to people with disabilities is tantamount to denying them their full personhood. Unless access to the electoral process is guaranteed, people with disabilities will continue to be marginalised. Once it is known that people with disabilities have a political voice, disability will become an issue of concern to politicians – voters count; non-voters don't.

b) *The Right to Education*

Education is another crucial area for inclusion. The language of inclusion is often used to describe the means of ensuring meaningful participation in the classroom. However, to fully implement the right of inclusion, every aspect of education must be considered.

The right to education has been said to consist of four elements: availability (to ensure no-one is excluded); accessibility (in terms of non-discrimination, physical accessibility and financial accessibility); acceptability (demonstrating a commitment to human rights); and adaptability (meeting the needs of all learners).[38] Further, there are four

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[38] Tomasevski, K. (2006). *Human rights obligations in education: The 4-A scheme*. Netherlands: Wolf Legal Publisher.; Tomasevski, K. (2003). *The right to education* (Report submitted by the Special Rapporteur No. U.N. Doc E/CN.4/2004/45). New York: United Nations.

cornerstones of the right to education and each of the elements of the right to education must be applied in each area: the composition of the school community; the classroom and the curriculum; the concern of the teacher; and the values of the education system. This means that attention must be paid to whether the school community is inclusive in the sense that the full range of traditionally excluded people are given a place and a voice. The classroom must be inclusive in its physical manifestation and in the way learning is arranged. The curriculum must be suitable, but also must give recognition to the reality of diversity. The teachers must demonstrate an inclusive attitude in both their teaching methods and in their classroom management.

Considerable work has been done on the right to education, particularly with respect to physical inclusion and curricula adaptability. However, the full picture is often out of focus. One area, for example, has received relatively scant attention. This is inclusion in the curriculum in the sense that people with disabilities are portrayed as ordinary people entitled to valued recognition. Perhaps the simplest response to the latter is to include books with characters with disabilities in the curriculum. Examples of these are two Australian children's novels, *Jodie's Journey* by Colin Thiele[39] and *Blabber Mouth* by Maurice Glietzman.[40] *Jodie's Journey* is about a girl who develops juvenile arthritis and has to come to terms with being unable to compete in show jumping. *Blabber Mouth* deals with a mute child, whose problems are not with her inability to speak but with her father who intervenes inappropriately. Each of these are strong characters and real people dealing with real problems facing children generally.

While it is not realistic to assume that every school can make provision for every abstracted child with a disability, there are some general and specific accommodations that can be expected. When a facility is being built, there is no reason why it cannot be designed with the needs of mobility-impaired people in mind. Especially in developing countries, but also elsewhere, children are excluded from school due to building design. Adapting existing buildings is neither difficult nor expensive. It may be that the position of a particular classroom may need to be changed or the library relocated. The cost involved in measures of this sort cannot be compared to the cost of exclusion from education. Similarly, adapting the difficulty of teaching material to meet

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[39] Thiele, C. (1988). *Jodie's journey*. Australia: Walter McVitty Books.

[40] Glietzman, M. (1992). *Blabber mouth*. London: Pan Macmillan.

the needs of different groups of learners is simply good teaching practice. With the use of computers, it is easy to produce material in large print or to modify a worksheet. The main issue is the willingness of the teacher, school and community to respect the rights of all children.

Because success in education is crucial to success in other areas of life, failure to provide adequate appropriate education to all children is tantamount to perpetual exclusion. It is not enough for children to be physically present, although this is a good start. Children with disabilities must be meaningfully engaged in the full range of benefits available through education. The relevant questions with respect to education are:

- Is any child excluded from school (whether due to financial, physical or intellectual constraints)?
- Is any child excluded from any aspect of school-life (including learning, assemblies, excursions, playtime, sport and extra-curricular activities)?
- Is the teaching programme relevant to all learners?
- Are the education system, the school and the teacher committed to inclusion?
- Has teacher training taught flexibility to respond to diversity amongst the student body?
- Are the teaching materials accessible to all?
- Is the classroom designed with the needs of all learners in mind?
- Are all children facilitated in such a way that the learning is meaningful?
- If support is required for a student to be included, is this available? (Support may take the form of personal assistance, modification of materials or equipment).
- Is support or assistance designed to enhance the valued recognition of the child?

The checklist approach to inclusion offers practical guidance in ensuring that the educational needs of all children are met. While this discussion has focused on questions relevant to primary school, the issues are also pertinent to pre-school, secondary school, tertiary institutions and adult education programmes. Wherever educational opportunities exist, it must be open to all members of the community to participate fully. It is particularly important to ensure access to participate in vocational training programmes, as the inability to participate in work-related learning affects the work and earning potential of the individual.

Given the centrality of education to every aspect of life, and the correlation between substandard or no education and poverty, ensuring that people with disabilities have equal opportunities for education is crucial. To be included in education, each of the three dimensions of inclusion must be present. There must be a commitment to equality and an inclusive attitude; there must be access, and there must be facilitation. Only then will the rights of people with disabilities be respected.

Inclusion and the Law

The *International Convention on the Rights of Persons with Disabilities [Disability Convention],*[41] which clarifies the position of people with disabilities in international law, was adopted by the United Nations on 13 December 2006 and entered into force on 3 May 2008. The extent to which the treaty is law in any country will depend on whether that state has ratified the Convention, and then, where required, if it has been incorporated into the law of the country.[42] As at the end of 2009, 143 states had signed the Convention and it had been ratified by 76 nations. Even where the treaty has not become part of the law of a country, the principles enunciated and the rights protected are nonetheless clear statements of support for people with disabilities. For the present purpose, it is significant that 2 of the 8 General Principles governing the operation of the *Disability Convention*, principles encoding the most basic requirements necessary for the rights of people with disabilities to be met, are concerned with inclusion. These general principles, listed in Article 3 of the Convention, are: (c) full and effective participation and inclusion in society; and (f) accessibility. Article 9, which deals with accessibility, outlines steps that parties must take if they are to accord human rights to people with disabilities. Article 9(1) reads:

> To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

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[41] *International Convention on the Rights of Persons with Disabilities* A/RES/61/106.

[42] On international law and human rights, see Smith, R.K.M. (2007). *International human rights*. New York: Routledge.

Article 19, relating to "living independently and being included in the community," takes this one step further:

> States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and *shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community*…(emphasis added).

A number of other articles in the *Disability Convention* are relevant to the principle of inclusion. These include: Article 8—Awareness-raising; Article 13—Access to justice; Article 20—Personal mobility; Article 24 – Education; Article 25 – Health; Article 27—Work and employment; Article 29—Participation in political and public life; and Article 30—Participation in cultural life, recreation, leisure and sport.

The *Disability Convention* does not replace other relevant international law, but sits alongside the other human rights treaties and other international instruments. It is important to understand that state obligations to accord human rights to people with disabilities do not begin or end with the *Disability Convention*. There is a great deal of other international law specifically relevant to people with disabilities and there is a substantial body of human rights law applicable to people with disabilities. The *Disability Convention* updates some of that law and clarifies the position of people with disabilities with respect to human rights generally. Both guidance and leverage can be gained for people with disabilities though knowledge of the law generally, and can be used strategically in any campaign for inclusion.

With respect to access and participation of people with disabilities, the most significant instrument developed prior to the *Disability Convention* is the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules).*[43] Building on the *World Programme of Action Concerning Disabled Persons,*[44] the *Standard Rules* emphasise that people with disabilities have the right to the same opportunities as other citizens and to an equal share in the improvements in living conditions resulting from economic and social development. The *World Programme of Action* had defined equalisation of opportunities to mean:

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[43] United Nations General Assembly Resolution 48/96, adopted at the 48th session of the General Assembly on 20 December 1993.

[44] United Nations General Assembly Resolution 37/52 (1982).

> the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all.[45]

The *Standard Rules* specify that general awareness of the rights of people with disabilities, and the provision of appropriate medical care, rehabilitation and support services, are prerequisites to access and participation. States are called upon to recognise the importance of accessibility to the process of equalisation of opportunity. Specific areas of life are then targeted as focal points for beginning the process of providing full rights to people with disabilities. In particular, there are rules relating to access to the physical environment, access to education, and access to employment. States are held to be responsible for, among other things, the provision of social security and income maintenance, and to ensure equality with respect to family life, culture, religion, sport and recreation.

While equalisation of opportunity does not specifically cover the third dimension of inclusion, the *Standard Rules* do make reference to the need for facilitation of people with disabilities if the access provided is to be successful. Rule 4 requires states to provide equipment and assistive devices, personal assistance and interpreter services. Acknowledging the potential financial barriers to access, Rule 4 also specifies that assistive devices should be provided by the state free of charge or at a very low cost. With respect to inclusion in education, some aspects of accommodation requirements are demanded of states, which are to provide appropriate support services as well as access.[46] Equally in the context of employment, the *Standard Rules* insist that states should adopt measures to design and adapt the workplace. States should also play a leading role in the development and use of technical means of making the arts accessible to all.

With respect to the attitudinal and non-discriminatory dimension of inclusion, many instruments proclaim that *all* people are equal[47] and that the specific rights provided for by the instrument shall apply

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[45] Ibid., at Para 12.

[46] *Standard Rules*, Rule 6 Para 2.

[47] See for example the Preamble and Articles 1 & 2 of the *Universal Declaration of Human Rights,* Adopted and proclaimed by *General Assembly resolution 217 A (III) of 10 December 1948*; see also *International Convention on the Rights of Persons with Disabilities*, Article 5.

without discrimination of any kind. As such, the International Bill of Rights – comprising the *Universal Declaration of Human Rights* [UDHR], the *International Covenant on Civil and Political Rights* [ICCPR] and the *International Covenant on Economic, Social and Cultural Rights* [ICSECR] – are all applicable to people with disabilities, even in the absence of reference to disability. This is recognised by various treaty bodies. For example, General Comment 5 of the Committee on Economic, Social and Cultural Rights (which monitors the operation of ICESCR states that, "since the Covenant's provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognised in the Covenant."[48] The Committee goes on to explain that:

> [t]he absence of an explicit, disability-related provision in the Covenant can be attributed to the lack of awareness of the importance of addressing this issue explicitly, rather than only by implication, at the time of the drafting of the Covenant over a quarter of a century ago…[I]t is now very widely accepted that the human rights of persons with disabilities must be protected and promoted through general, as well as specially designed, laws, policies and programmes.[49]

The Human Rights Committee, which supervises the operation of the ICCPR, clarifies that any law adopted by a state which is a party to the Covenant must not be discriminatory.[50] Although disability is not amongst the listed grounds, it is now well understood that disability is included. The World Conference on Human Rights, in 1993, adopted the *Vienna Declaration and Programme of Action* which states that:

> all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities. Every person is born equal and has the same rights to life and welfare, education and work, living independently and active participation in all aspects of society. Any direct discrimination or other negative discriminatory treatment of a disabled person is therefore a violation of his or her rights. The World Conference on Human Rights calls on Governments, where necessary, to adopt or adjust legislation to assure access to these and other rights for disabled persons.[51]

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[48] Committee on Economic, Social and Cultural Rights (1994) *General Comment No. 5: Persons with Disabilities* UNDocE/C.12/1994/13 Para 5.

[49] Ibid., Para 6.

[50] Human Rights Committee, (1989) General Comment 18, Non-discrimination HRI\GEN\1\Rev.1 at 26 (1994) Para 12.

[51] World Conference on Human Rights (1993) *Vienna Declaration and Programme of Action* A/CONF.157/24, 25 June 1993 Para 63.

Just as there is international law incorporating the principle of inclusion of people with disabilities, so too is there law at domestic level implementing aspects of the principle of inclusion. Domestic anti-discrimination laws, such as the Australian *Disability Discrimination Act* 1992 and the US *Americans with Disability Act* 1990, give effect to the core ideas of inclusion when they outlaw discrimination and require that "reasonable accommodations" be made.[52] The objective of these laws is to eliminate barriers to inclusion through the rules pertaining to direct and indirect discrimination and to facilitate inclusion by requiring that steps be taken to make it possible for the person with a disability to participate on equal terms with others.

"Accommodations" required by anti-discrimination laws have included kerb-cuts (creating a ramp-effect at street crossings to allow wheel chair mobility); Braille symbols on Automatic Teller Machines; captioning on films; and adaptations to schools and workplaces. Most laws do not demand complete inclusion of people with disabilities, however. This is because accommodation is generally only required with respect to a limited number of specified areas of life and because any requirement that accommodations be made is always limited by a defense that making the adjustment would impose "undue burden" or "unjustifiable hardship." This means that the cost to the institution, organization or individual engaged in discrimination are balanced against the benefits to people with disabilities. Occasionally the court administering the law will take the big picture and, for example, consider the budget and assets of the school system or business as a whole, rather than focus on the particular shop or on the given school. At other times, the decision-maker's focus will be on the burden that would be imposed on the individual or the business unit if it were required to make the proposed accommodations.

Law, then, provides for the practical implementation of the right to inclusion. However, the particular application of a law to a specific issue will always be open to debate. So long as all three dimensions of inclusion are present – a non-discriminatory attitude to people with disabilities, access to participation and facilitation of that participation – the action in question will be legitimate. More often than not, people with disabilities have to work to demand and achieve full and meaningful engagement in every aspect of life. Nonetheless, the existence of human

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[52] Jones, M. & L.A. Basser Marks. (2000). A bright new era of equality, independence and freedom – casting an Australian gaze on the ADA. In L. Francis & A. Silvers (Eds.), *Americans with disabilities* (pp. 371–386). New York: Routledge.

rights law provides a basis for the claim that we are all entitled to equality and to be treated with dignity and respect. It is the principle of inclusion, however, that provides the key to what it means for a disabled person to be treated respectfully and what action is necessary for a person to be an equal member of society.

Conclusion

The principle of inclusion, like all human rights principles, is aspirational and its full implementation requires a transformation of society. Nonetheless, by determining social policy through the lens of inclusion we can begin to shift perception about the difference of disability. As the Vienna Declaration and Programme of Action says, "[t]he place of the disabled is everywhere."[53] Essentially we are all the same, equal in value and worthy of dignity and respect. However it is not always clear what is required of us if we are to demonstrate our valuing of all people. The right to inclusion provides both the means of deconstructing action and a description of a just society.

Inclusion is the principle at stake when we reject the common-sense view that people with disabilities are primarily disabled by their bodies. It provides a means with which to respond to the systemic and structural impediments to full participation in society. The inclusion principle comes into play when we demand the fulfilment of the human rights of all people in all aspects of social, cultural, religious, economic and political life. Inclusion clarifies what it is that is being demanded by people with disabilities in a claim for entitlement to human rights.

An inclusive society is a just society. Unless there is an attitude which takes equality seriously and which is committed to non-discrimination, justice will not pertain. Unless there is provision for access of all sorts and in all contexts, people with disabilities will remain outsiders living on the fringes of society. Unless there is facilitation to limit the impact of disability, accommodation that makes inclusion possible and support where it is needed, people with disabilities will be relegated to the margins. Using an inclusion check-list provides a means of articulating the issues and of ensuring all potential sites of exclusion are challenged. Inclusion calls for the right to valued recognition through meaningful engagement. This is what is sought by all people.

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[53] *Vienna Declaration and Programme of Action*, para 64.

PART II

ADVANCING DIGNITY

INTRODUCTION: DIGNITY

As Basser describes it in Chapter 1, human dignity is a complex principle which involves a positive interpretation of "humaneness" and of what it means to be a rights bearer. Adopting the principle of human dignity leads to action which reflects the inherent worth of each individual. This section provides examples of the application of the principle of dignity and explores the benefits of approaching legal questions from this perspective. The chapters build on Basser's work which teases out the idea of dignity and elucidates how a person should be treated if they are to be treated with dignity. She writes:

> First is the absolutely crucial requirement that a person's physical integrity is respected. This has consequences both in every day interactions and in "extraordinary" situations such as those involving medical treatment, unwanted sexual advances and punitive measures. Secondly, human dignity means that every person has the inherent right to be treated as an individual with a personality. This means that the right to freedom of opinion and belief, (including religion), inherent in the values of a liberal state are accorded to everyone. Thirdly, human dignity means that a person must be given voice about any issues which affect their lives and must have the ability wherever possible to exercise choice. Finally, inherent dignity of any individual requires that he or she has access to a fair share of the goods of society. This means that the availability of resources to any individual is dependent on the socio-economic environment in which they live, but dignity dictates that there is a fair distribution of those goods between members of the society.[1]

Application of the principle of dignity results in a new critical perspective on law.

The purpose of this section is to demonstrate the radical role human rights principles generally, and dignity specifically, can play in the experience of disability in its intersection with law. Bringing dignity to bear on the subject of law, allows scholars and legal advocates to understand how rights have been accorded and denied, and to demand that the outcomes of legal cases and the development of law is consistent with the recognition of the inherent dignity of the person. This section explores topics as diverse as prenatal genetic testing, abortion, medical

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[1] Part I, Basser, Human Dignity, Pages 27–28.

decision making, life saving treatment, psychiatric problems and imprisonment. Recognizing that the fundamental entitlement of all people to be treated with dignity and accorded respect is an inalienable right, and approaching legal problems with this in mind provides new insights with which to address the problems faced by individuals with disabilities.

VALUING ALL LIVES – EVEN "WRONGFUL" ONES

Melinda Jones

The most basic principle of human rights is that all people are of infinite value, independent of gender, race or ability. Yet there exists an area of law which revolves around the idea that certain (disabled) lives are not worth living and that certain (disabled) people should never have been born. Known as the birth torts, legal actions for "wrongful life" and "wrongful birth" are recognised in almost every jurisdiction in the world. They are, it is true, highly contested. The torts give rise to judicial opinion about the sanctity of life, the immeasurable love of parents for their children, the law of abortion (and the ethics of selective abortion) and current developments in the field of human genetics. Some commentators have labelled these actions as endorsing a new form of eugenics, a "legitimate" means of disposing of people with disabilities before they are even born.[1] Others have argued that their concern is with preventing pain and human misery.[2] Others still, argue that this is a matter of technical legal consideration, borne of the courts' desire to right wrongs and to spread the financial burden of disability.[3]

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[1] See, for example, Shakespeare, T. (1998). Choices and rights: Eugenics, genetics and disability equality. *Disability & Society, 13*(5), 665–682.; Wolbring, G. (2001). Where do we draw the line? Surviving eugenics in a technological world. In M. Priestley (Ed.), *Disability and the life-course: Global perspectives* (pp. 38–49). Cambridge: Cambridge University Press.; Field, M.A. (1993). Killing the handicapped – before & after birth. *Harvard Women's Law Journal, 16*, 79–138.; Hubbard, R. (1997). Who should and who should not inhabit the world? In L. Davis (Ed.), *The disability studies reader* (pp. 187–202). London: Routledge; King, D. (2001). Eugenic tendencies in modern genetics. In B. Tokar (Ed.), *Redesigning life? The worldwide challenge to genetic engineering* (pp. 171–194). Kingston: McGill-Queens University Press.

[2] See, for example, Green, R. (1996). Prenatal autonomy and the obligation not to harm one's child genetically. *Journal of Law and Medical Ethics, 25*(1), 5–16.; Green, R. (1996). Prenatal autonomy and the obligation not to harm one's child genetically. *Journal of Law and Medical Ethics, 25*(1), 5–16. Margaret Shaw takes it one step forward, arguing that allowing a child with a genetic condition is tantamount to "fetal abuse" (sic). Per Botkin, J.R. (2003). Prenatal diagnosis and the selection of children. *Florida State University Law Review, 30*, 265–294.

[3] See, for example, Pollard, D.A. (2004). Wrongful analysis in wrongful life jurisprudence. *Alabama Law Review, 55*, 327–375.; Stretton, D. (2005). The birth torts: Damages for wrongful birth and wrongful life. *Deakin Law Review, 10*(1), 319–364; Stretton, D. (2006). Wrongful life and the logic of non-existence. *Melbourne*

Actions for wrongful birth and wrongful life are initiated in situations where it is claimed that there has been medical malpractice involving the birth of the child. Claims are brought either by a person with a disability or by the parents (usually the mother) of a child (usually with disability). The alleged failure on the part of the medical practitioner is to allow a particular child to be born. Had the practitioner taken the woman's reproductive rights seriously, the child would not have come into the world, either because, on the facts of the given case, the child would not have been conceived or because the woman would have discontinued the pregnancy. In the cases to be examined there is generally a finding that a doctor or a genetic counsellor has in fact been negligent and so his/her legal culpability is not in issue. The question that arises is whether attributing legal liability for the "damage" of the birth of a child is an acceptable legal and social outcome. Practitioner/defendants argue that they should not be held accountable for their actions because, independently of the parents' views, a child is of infinite value and can therefore not constitute "damage." Furthermore, they argue that granting a remedy for their negligence could only be sustained by the court accepting that some (disabled) lives are not worth living.

Consider the case of Nicholas Perruche, born in France in 1983, whose story is typical of those brought before the courts in wrongful life actions.[4] In 1982, Mrs Perruche visited her local doctor, because her four year old daughter had come down with rubella (also known as German measles) and she was four weeks pregnant. She was aware that the rubella virus attacks and ravishes foetuses, causing serious damage to an unborn child, which can include brain damage, heart defects, deafness and eye problems. She did not want to continue with the pregnancy if she was infected. It was sufficiently early in the pregnancy that abortion would be lawful, and she had not yet attached emotionally to the foetus. Mrs Perruche made it clear that she would have an

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University Law Review, 31(3), 972–1001; and Robertson, H.B. (1978). Toward rational boundaries of tort liability for injury to the unborn: Prenatal injuries, preconceptions injuries and wrongful life. *Duke Law Journal,* 1401–1456.

[4] *Perruche*, Cass. ass. plén., 17 nov. 2000, no 99–13.701, no 457P, Conclusions de M. l'Avocat Général Sainte-Rose; Rapport de M. Pierre Sargos, http://www.courdecassation.fr/agenda/arrets/arrets/99–13701arr.htm; *Gaz. Pal.* no 24, 24–25 janv. 2001, 4, note J. Guigue. According to Lysaught, this was the first French wrongful life case. Lysaught, Therese M. (2002) Wrongful life? The strange case of Nicholas Perruche. 28 *Human Life Review* 165–170 at 166.

abortion if there was any risk of the child being disabled as a result of her contact with the rubella.

The doctor took two blood samples two weeks apart and sent them off to a pathology laboratory for testing. The laboratory gave contradictory results, which required further investigation. Instead of following this up, the doctor assured Mrs Perruche that she was fine and could safely proceed with the pregnancy. The doctor negligently told Mrs Perruche that she was immunised and that the baby was safe. When Nicholas was born with a range of severe problems resulting from congenital rubella his parents commenced legal action both for themselves (as a “wrongful birth” action) and on Nicholas’ behalf (as a “wrongful life” action). The *Cour de Cessation*, the highest court in the French legal system, granted Nicholas a remedy. A lower court had found in favour of his parents.[5]

The decision of the *Cour de Cessation* outraged the disability community, doctors and laboratory technicians.[6] Speaking on behalf of the doctor, a lawyer commented: “This is making a distinction between lives that merit living and those who don’t…that’s a slippery slope.”[7] On behalf of the medical community another lawyer declared “The ruling means that the handicapped have no place in our society.”[8] In the New York Post a journalist wrote: “The truth is, this is not about the rights of the handicapped. This is about society wishing to establish a right by any means necessary not to be burdened with caring for them.”[9] Members of the French National Syndicate of Gynaecologists and Obstetricians went on strike and began refusing to perform routine ultrasound scans for fear of litigation. Parliament was lobbied by doctors and an emergency session of the French National Assembly was called. In early 2002, legislation was enacted denying legal redress to “one who is harmed solely by being born.”[10]

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[5] Ewing, J. (2002). Case note: The Perruche. *Journal of Family Studies, 4*, 317–321.; Duguet, A.M. (2002). Wrongful life: The recent French Cour de Cassation decisions. *European Journal of Health Law, 9*, 139–163.

[6] Lewis, P. (2005). The necessary implications of wrongful life claims: Lessons from France. *European Journal of Health Law, 18*, 135–152.

[7] Quoted in Reynolds, D. (2000). Couple sue doctor for son’s birth. *Inclusion Daily Express,* 6 November 2000.

[8] Quoted in Reynolds, D. (2001). New high court ruling upholds ‘wrongful birth decision’. *Inclusion Daily Express,* 16 July 2001.

[9] Quoted in Reynolds, D. (2001). New high court ruling upholds ‘wrongful birth decision’. *Inclusion Daily Express,* 16 July 2001.

[10] Lewis, P. (2005). The necessary implications of wrongful life claims: Lessons from France. *European Journal of Health Law, 18*, 135–152. 135 at 134.

Clearly these cases excite passion. The public is right to be outraged at the suggestion that someone's life is not worth living, and to show solidarity with people with disabilities. However, this approach to the subject is wrong-headed. It confuses the outcome and the negligence and shifts the focus of the case from the real legal issue – the culpability of a negligent doctor – to emotional appeals about disability and the lives of people with disabilities; prenatal testing, abortion and selective abortion; and women, motherhood and birth. Using a human rights approach – one that focuses on the dignity of the person, equality between people, and inclusion of all people in society – this chapter attempts to deconstruct "wrongful life" and "wrongful birth" actions in order to determine whether these actions are consistent or inconsistent with human rights principles.

1. Wanted Pregnancy; Unwanted Child

It is possible to divide wrongful life and wrongful birth cases into two classes. The first class are often referred to as wrongful conception or wrongful pregnancy cases as they involve an unwanted pregnancy leading to the birth of an unwanted child – even if once born the child is loved and valued.[11] Where a medical practitioner has been negligent in the performance of a sterilisation procedure, it is relatively unproblematic to provide a remedy as the tortious action is akin to medical malpractice. The second class of cases, wrongful birth are those cases in which *a child* is very much wanted, but the particular child's disability results in the *particular disabled child* being unwanted. The unifying feature of these cases is the disappointment of disability and the claim that, but for the negligence of the medical practitioner involved, the child would not have been born. All the legal actions, in the second class, concern children with disabilities. As such, the outcome of the cases and

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[11] Commentators who have relied on this distinction include Granchi, J.R. (2002). The wrongful birth tort: A policy analysis and the right to sue for an inconvenient child. *South Texas Law Review, 43*, 1261.; Jackson, E. (2000). Abortion, autonomy and prenatal diagnosis. *Social and Legal Studies, 9*(4), 467–494.; and Donnelly, M. (1997). The injury of parenthood: The tort of wrongful conception." *Northern Ireland Legal Quarterly* 48, 10–23. However, Hoyano concludes that, in the aftermath of *Parkinson v St James' & Seacroft University Hospital N.H.S. Trust* [2001] 3 All E.R. 97 and *Rees v Darlington Memorial Hospital N.H.S. Trust* [2002] 2 All E.R. 177 (C.A.), that this distinction is no longer viable – see Hoyano, L. (2002). Misconception about wrongful conception. *Modern Law Review, 65*, 883–906. at 903.

the approach to disability incorporated in the judgments is of interest not just to the parties, but also to people with disabilities as a whole.

The majority of these cases involve negligence during the course of a woman's pregnancy. This may be a failure to undertake appropriate testing, a failure to appropriately interpret the medical information available, and/or a failure to properly inform or advise the woman about matters relevant to her pregnancy. There are two possible classes of plaintiffs in these cases – the woman (and possibly husband) who lost the opportunity to abort an unwanted pregnancy, and the child who has to live with the consequence of the failure to abort. When the action is brought by the parent, the action taken will be a wrongful birth action; when the child brings the action it is a wrongful life action. Wrongful life cases pose more difficulty than the other categories of cases, although they are based on exactly the same fact situations as the other birth torts. While all sorts of emotive pleas and appeals to idealised public policy arise in wrongful birth cases, judges reserve their best cards for wrongful life litigants. Once negligence has been established, the cases turn on whether damages will be payable and if so, how they are to be assessed and quantified. Many jurisdictions will simply not entertain wrongful life actions[12] and legislation banning these actions has been widely enacted. I believe this is a mistake, and, if anything, contrary to the interests of people with disabilities.

1.1. *Modern Birth Technology*

The professional standards with which medical practitioners and health professionals must comply when engaged in reproductive medicine include the appropriate application of modern birth technologies such as prenatal testing and pre-implantation genetic screening. Prenatal testing includes the use of ultrasound technology, blood tests to determine the presence of a range of antibodies that could affect a foetus and to detect genetic diseases and amniocentesis. Pre-implantation genetic screening, involving the screening of the ovum or sperm prior to implantation to ensure that they are free from genetic or other disorder,

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[12] In the USA, for example, wrongful life actions are only available in 3 states – California, New Jersey and Washington. For information about legislation in the USA see Crockin, S. (2005). Reproduction, genetics and the law. *Reproductive Biomedicine Online, 10*(6), 692–704. For a more general survey of this issue see Stretton, D. (2005). The birth torts: Damages for wrongful birth and wrongful life. *Deakin Law Review, 10*(1), 319–364.

arises in the context of *in vitro* fertilisation (IVF), which must itself be performed to professional standards. Professional standards are not static and medical practitioners are expected to keep abreast of developments in genetics and the availability of prenatal genetic testing:

> With over 500 prenatal genetic tests currently available, and many more entering the consumer medical market each year, prenatal genetic testing is rapidly becoming routine practice in the medical management of pregnancy.[13]

Further, in the context of IVF, the failure to test an ovum or sperm, or to inform the prospective parents of genetic defects in the ovum or sperm, could result in legal liability.

> Today, genetic tests are clinically available for 1,000 diseases; several hundred more are available in a research setting…Mistakes in testing, failure to test, or failure to accurately convey test results are inevitable, and as options have multiplied, so have the chances of error. For anyone seeking a legal remedy to these new "reproductive wrongs," the challenge has been to try to fit them into, or find ways to expand, existing legal theories.[14]

Doctors are not the only potential defendants in this context. There are hundreds of genetic laboratories around the world which specialise in genetic testing and which could be held legally liable for mistakes that should not have been made. The consequence of errors can be both devastating and expensive. For this reason most health professionals have professional indemnity insurance. The purpose of tort law is to ensure that costs associated with residual damages are borne by the wrongdoer rather than the family that has to live with the consequence of the error.

1.2. *Preconception Negligence – Decisions to Become Pregnant*

Scientific advances in bioethics, egg and sperm donations and IVF have provided opportunities for those who cannot easily reproduce. Preimplantation genetic screening allows for significant information about

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[13] Ekberg, M. (2007). Maximizing the benefits and minimizing the risks associated with prenatal genetic testing. *Health, Risk & Society, 9*, 67–8 at 67.

[14] Crockin, S. et al. (2006). Genetic tests are testing the law: The fast-growing field of genetic testing has raised new legal questions: Who is responsible when a child is born with a severe genetic defect? and what theories, standards, and choice of law apply to these new technologies? *Trial, 42*(10), 44–51 at 46.

the embryos, providing would-be parents with the means to be selective about which embryos are to be implanted. Organisations which fail to undertake appropriate testing, or fail to pass on relevant information about their products to prospective parents, may be found to be negligent. *Johnson v Superior Court of Los Angeles County*[15] provides an illustration of such a negligence action. The case involved a sperm donor who passed on a serious genetic condition, autosomal-dominant polycystic kidney disease, to a baby girl. The donor had noted on his intake form that he had a family history of kidney disease, but the sperm bank failed to act on that knowledge or inform the prospective parents of the risk. Similarly, in *Paretta v Medical Offices for Human Reproduction*[16] a New York medical program recommended the use of a pre-screened egg donor, but failed to advise the Paretta's that their chosen egg donor had tested positive as a carrier for cystic fibrosis. Not only was no information or advice given regarding the carrier status of the biological mother, but neither was Mr Paretta advised that if he too was a carrier there was a serious risk that the child would, as she did, have cystic fibrosis.

Another strategy has been developed which is particularly valuable to high risk genetic groups. This is population carrier-status screening which allows a couple to establish, prior to conception, whether their child would be at risk of serious disability because of their genetic compatibility. Carrier status screening for Tay-Sachs disease, a cruel and ultimately fatal degenerative neurological disorder, has been developed for high risk populations such as Ashkenazi Jews. Genetic testing of the carrier status of each potential parent is recommended, so that it will be possible for a couple to establish whether they are both carriers (which is the only way a child can be conceived with Tay-Sachs disease). Should this be the case, the couple are advised to avoid having children together. The only reason to patronise such a service is to receive accurate information about carrier status. So, when the Curlenders sought genetic screening for Tay-Sachs and were advised that they were not carriers of the causative gene, they proceeded to conceive a child. [17] Due to the negligence of the Bio-Science Laboratories, their daughter was born with Tay-Sachs disease (which would not have been possible had the information they'd been given been accurate).

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[15] *Johnson v Superior Court of Los Angeles County* 124 Cal. Rptr. 2d 650 (2002).

[16] *Paretta v Medical Offices for Human Reproduction* 760 N.Y.S.2d 639 (2003).

[17] *Curlender v Bio-Science Laboratories* 165 Cal Rptr 477 (1980).

Their daughter had a life expectancy of 4 years, during which time she would suffer greatly and require a substantial amount of expensive care.

1.3. *Negligence and Abortion – Decisions to Discontinue Pregnancy*

The second group of cases of wanted pregnancy, unwanted child, specifically deals with selective abortion – where a finding of disability is the basis of the decision to abort. In order to make such a decision, women need information about the status of the foetus. The negligence alleged in these cases is the failure of a medical practitioner or relevant health professional to ensure that the woman has sufficient information on which to make a decision whether or not to proceed with a pregnancy. Typical cases of this sort are brought as a result of women who receive negligent advice about the status of the foetus, where there is a failure to carry out routine testing or testing specifically requested in the light of family history, and when there is negligent misdiagnosis about the status of the foetus.

Many cases of negligent advice arise in the context of contact with rubella during the early stages of foetal development. The *Perruche* case, discussed above, is one such case. As is shown by the number of women who seek medical advice because of contact with rubella, the affect of the virus in early pregnancy is common knowledge among women as well as among the medical community. A great many of the wrongful birth cases are brought by women who are negligently advised that there would be no undue effect on the foetus despite contact with rubella in early pregnancy.[18] Other actions have been brought by women who came into contact with rubella and had been negligently misdiagnosed. In the English case of *McKay*[19] the medical practitioner had sent samples to their laboratory, but the tests were wrongly carried out. Mrs McKay was negligently told that she had not contracted the virus and that it was safe to proceed with the pregnancy. When her child was born it was apparent that she was significantly affected by the virus and was multiply disabled. A recent Australian case,[20] involved a woman who visited her doctor because she was concerned that she

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[18] Two such cases featured in this chapter are from France, *Perruche*, Cass. ass. plén., 17 nov. 2000, no 99–13.701, no 457P and Australia, *Harrinton v Stephens* (2006) 226 ALR 391; [2006] HCA 15 (9 May 2006).

[19] *McKay v Essex Area Health Authority* [1982] QB 1166.

[20] *Harriton v Stephens* (2006) 226 ALR 391; [2006] HCA 15 (9 May 2006).

had fever and rash which might have been rubella. She thought she may be pregnant and was worried about the possible impact of rubella on foetal development. Blood tests confirmed the pregnancy, but were inconclusive for the rubella. The test results stated: "[i]f no recent contact or rubella-like rash, further contact with this virus is unlikely to produce congenital abnormalities." She was seen by a second doctor in the practice. He confirmed the pregnancy and, on listening to the woman's history, reassured her that her illness was not rubella, and referred her to a gynaecologist for management of the pregnancy. The reassurance was negligent, as the woman had recently had a "rubella-like rash" and a further blood test for rubella antibodies should have been ordered. This would have disclosed the risks of congenital abnormalities for the foetus, and the allowed for the pregnancy to be terminated.[21]

Wrongful birth actions are also brought when there has been a failure to carry out routine testing or testing specifically requested as a result of family history. In one such case, K's mother attended a Medical Centre when she became pregnant, and was placed under the care of a midwife and obstetrician. The pregnant woman told both the doctor and midwife about a chromosomal abnormality that was in her husband's family and specifically asked to be tested for this condition. She knew testing was available as other family members had been able to rule out the condition or abort an affected foetus. She was told this was unnecessary and the medical professionals declined to run the genetic tests which they had requested. The mother was very clear that she would have an abortion had the tests revealed a high risk for this condition. The child was born with the disorder and brought an action for wrongful life.[22]

Another such case[23] occurred in California, which has state-mandated screening to test for conditions such as Down's syndrome and spina bifida. This information was not shared with a pregnant woman, who attended a medical practice for antenatal care. When her

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[21] *Harriton v Stephens* (2006) 226 ALR 391; [2006] HCA 15 (9 May 2006).

[22] *Leids Universitair Medisch Centrum v Kelly Molenaar* Horge Raad 18 March 2005. See Heindriks, A. (2005). Wrongful suits? Suing in the name of Terri Schiavo and Kelly Molenaar. *European Journal of Health Law, 12*, 97–102.; and Nys, H.F. & Dute, J.C.J. (2004). A wrongful existence in the Netherlands. *Journal of Medical Ethics, 30*, 393–394.

[23] Reynolds, D. (2004). Parents sue doctor for not testing baby for spina bifida. *Inclusion Daily Express,* 14 September 2004.

daughter was born with spina bifida the mother brought an action against the medical practitioner, claiming damages for the failure to provide information necessary for her to exercise her fundamental right to reproductive choice. Similarly, in Singapore, a woman was not advised that it was possible to test for Down's syndrome, nor given information that at her age there was a high risk that a foetus would be so affected. Failure to inform about the possibility of testing and of the risk to older women was clearly contrary to professional standards. The doctor was found liable, as the birth of a child with Down's syndrome was found to be the direct result of this negligence.[24]

2. Genetic Testing, Selective Abortion and Eugenics

A major reason for prenatal testing is to allow women to abort a foetus should it have "undesirable" characteristics.[25] However, the degree to which the information is routinised and confined to a medical setting often results in *uninformed* consent to an abortion. Further, the risk of miscarriage increases with prenatal testing, independent of any finding of abnormality, but this has become an acceptable side-effect.[26] Women are not often given information that the main purpose of screening or testing is abortion,[27] although in some places doctors are urged to refuse women testing unless they agree in advance to abort the foetus on the finding of a "defect."[28] There are other reasons for undertaking prenatal testing. There is a great deal to be said for information being made available to pregnant women, to allow them to *choose to keep a*

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[24] *Ju v See Tho Kai Yin* [2005] 4 SLR 96 cited in Fordham, M. (December 2005). A life without value. *Singapore Journal of Legal Studies,* 395–406.

[25] See footnote 1 above.

[26] Deirdre Little comments: "We forget that for women in their mid forties the false positive rate from prenatal screening [for Down's syndrome] is set much higher at close to 50%, to maximise the detection rate so that none slip through. For every 100 pregnant women aged 44 who have the prenatal screening test for Down syndrome, 52 will be told that their screening test is positive, but only about 4 or 5 of them will actually have a Down syndrome child... the next step imperils the baby's life." Little, D. (2009). Prenatal diagnosis – benefit or betrayal. *Quadrant, 53*(2), 74–76 at 75.

[27] Little, D. (2009). Prenatal diagnosis – benefit or betrayal. *Quadrant, 53*(2), 74–76 at 74.

[28] Per Elias, S. & F.J. Annas. (1994). Generic consent for genetic screening. *New England Journal of Medicine, 330*, 1611–1613., cited by Shepherd, L. (1995). Protecting parents' freedom to have children with genetic differences. *University of Illinois Law Review, 4*, 761–812 at 776–78.

child that medicine might wish to throw away.[29] This information will allow women to prepare for the birth of a child with disabilities, particularly if there is a likelihood that the child will need urgent medical attention. The advance notice will also present an opportunity to learn about the different ways the disability might affect a child, and the strategies adopted by other parents. It is important to note however, that until the child is born (and often not until quite some time later) nothing can be assumed about the impact of the condition on the child. It is important that prospective parents understand that it is impossible to assess how disabling a condition will be, as this will depend not only on the severity of any impairment but also of the resources available and accessed, for these may lead to quite a different picture than painted by doctors and other health professionals.[30]

2.1. *Abortion and Selective Abortion*

From a woman's rights perspective, reproductive freedom is of central importance. This includes freedom to have control over one's own body – to have children or not to have children; to have access to contraception; to have access to safe abortion, at least until the point of development when the foetus could be said to be a viable life; and, importantly, the right not to abort a foetus. If abortion is illegal in all circumstances, it will not only constitute an offence to one's human rights, but it will also mean that there will be no place for actions of wrongful birth. In Ireland, for example, there is very little prenatal testing as the unborn child is specifically protected by the constitution.[31]

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[29] See Rapp, R. (1998). Refusing prenatal diagnosis: The meanings of bioscience in a multicultural world. *Science, Tehcnology and Human Values, 23*, 45–70.; Dixon, D.P. (2008). Informed consent or institutionalized eugenics? How the medical profession encourages abortion of fetuses with Down syndrome. *Issues in Law & Medicine, 24*, 3–60; Tankard Reist, M. (2006). *Defiant birth: Women who resist medical eugenics.* Melbourne: Spinifex Press.

[30] On a personal note, I was told in all earnest that my daughter (with a genetic condition Cohen's syndrome) would never walk or talk, and that, as I had other children, I should place her in an institution and forget about her. This would have been a self-fulfilling prophecy. With massive early intervention and quite a lot of ongoing medical management, my daughter is a very fine young woman, with values I am proud of, and who, despite significant limitations, is so high functioning that her disability is not necessarily the first thing people see in her.

[31] Daly, B. (2005). Wrongful birth, wrongful conception and the Irish constitution. *European Journal of Health Law, 12*, 57–76.; Kancler, M. (2009). To be or not to be born? Civil liability for damage resulting from birth in a comparative context: Recent Polish and Irish caselaw concerning wrongful birth and wrongful conception.

This means that not only is it unlawful to procure an abortion in Ireland, but it is also unlawful to travel for the purpose of procuring an abortion. There is no discrimination. All life, whether disabled or "wrongful," is equally valued and all life is considered sacrosanct. Spain also guarantees the rights of the unborn child in its constitution, but it seems that unborn children with disabilities are not as equal as others. Selective abortion appears to be available in Spain.[32]

Where health professionals are negligent in advising women about the status of the foetus, it is at least arguable that, if an abortion would not be legal in a particular jurisdiction, then no damage has resulted from the negligence. This line of reasoning was adopted by the trial judge in the Australian case, *CES v Superclinics*.[33] In that case, a 21 year old student was negligently and repeatedly told that she was not pregnant until it was too late for her to have an abortion. Newman J found that, although the defendants were grossly negligent and caused a great deal of harm, the plaintiff was not entitled to damages. This was because: "her case depended upon a claim that she had lost an opportunity to do something he determined was illegal (viz, have her pregnancy terminated) and therefore the law did not permit her to claim damages."[34] Under the law of the Australian State of NSW, it is an offence to terminate a pregnancy "unlawfully."[35] However, an abortion will not be unlawful in NSW if a doctor believes on reasonable grounds that continuation of the pregnancy poses a threat to the physical or mental health of the woman, which is to be determined by taking into account economic and social considerations as well as physical and psychological grounds. There has been only one successful prosecution for unlawful abortion in NSW,[36] so while it was tecnichally possible that the

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Electronic Journal of Comparative Law, 13(3), 5–7. Kancler, at 5–7, provides an example of the Irish courts entertaining a wrongful birth action where a sterilisation was performed negligently: *Byrne v Ryan* [2007] I.E.H.C. 207.

[32] Per Daly, B. (2005). Wrongful birth, wrongful conception and the Irish constitution. *European Journal of Health Law, 12*, 57–76.

[33] *CES v Superclinics (Australia) Pty Ltd* Unreported Newman J, Supreme Court of NSW, 18 April 1994.

[34] Graycar, R. & J. Morgan. (1996). Before the high court: Unnatural rejection of womanhood: Pregnancy damages and the law. *Sydney Law Review, 18*(3), 323–341 at 332. See also Petersen, K. (1996). Wrongful conception and birth. *Sydney Law Review, 18*(4), 503–522.

[35] Section 83 *Crimes Act* 1900 (NSW).

[36] *K v Minister for Youth & Community Services* [1982] 1NSWLR 311. The successful prosecution was for an abortion which caused injury to the woman resulting in hospitalisation. The matter was appealed, but the subject of the prosecution, Dr Smart was

abortion in this case could have been illegal, there was no evidence that the plaintiff would have had an unlawful abortion. The reality of the availability and frequency of abortion was accepted by the High Court, which overturned the initial decision. Kirby A-CJ commented that:

> [t]aking that reality into account would permit commonsense to intrude into the Court's deliberations. It would allow the Court to take into account the fact that it would be most unlikely that any medical practitioner, still less the first appellant, would have been prosecuted and taken to trial. There is an air of unreality about the contrary approach…[37]

The relevance of the law of abortion to wrongful birth actions is illustrated by another Australian case, *Viviers v Connolly*.[38] The judge considered that it was possible but not probable that the abortion denied would have been unlawful, so he reduced the damages he awarded by 5%. In many countries abortion is unlawful or only permitted to save the life of the pregnant woman. Another large number of countries outlaw abortion after a specified gestational age, usually between 12 and 14 weeks. The latest specified gestational age appears to be 24 weeks in Singapore and the United Kingdom(Northern Ireland excluded).[39] The law of a great many jurisdictions make exceptions for "foetal defects," allowing abortion well over the time-limit otherwise specified. While selection on the basis of sex is roundly condemned, selection on the basis of disability is widely applauded.[40]

2.2. *The "Disability Rights Critique" of Selective Abortion*

Disability scholars and activists have developed a response to selective abortion and to prenatal testing widely referred to as the "disability rights critique" [DRC]. The DRC is not a human rights response to these issues; rather, it primarily offers a disability perspective on the Human Genome Project and the use of prenatal testing to facilitate

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ill, and subsequently died, prior to the matter being heard. See Cica, N. (1989). *Abortion law in Australia* No. Research Paper No 1. Australia: Parliamentry Libary, Australian Parliament, http://www.aph.gov.au/library/Pubs/rp/1998–99/99rp01.htm.

[37] (1995) 38 NSWLR 47 at 70, cited by Graycar & Morgan, *supra* note 34 at 333.

[38] *Viviers v Connolly* [1995] 2 Qd R 326.

[39] See United Nations Department of Economic and Social Affairs, Population Division. (2007). World abortion policies, online: www.unpopulation.org/esa/population/unpop.htm and Harvard University. Annual review of population law: Abortion laws, online: www.hsph.harvard.edu/population/abortion/abortionlaws.htm.

[40] See Wolbring, G. (2005). A disability rights approach towards sex selection. *Development, 48*(4), 106–112.

selective abortion. The DRC is constructed through the lens of the social model of disability, which locates disablement outside the individual and looks for social barriers which interfere with the full inclusion of people with disabilities in society.[41] Although the DRC does not critique prenatal testing and selective abortion from an human rights perspective, it does raise issues that an human rights analysis needs to take into account.

The disability rights critique makes two claims – that prenatal testing followed by selective abortion is morally problematic; and that prenatal testing and selective abortion are driven by misinformation. From these claims it is concluded that "permitting and practising the selective termination of disabled foetuses amounts to colluding with (and perhaps also encouraging) discrimination against people with disabilities."[42] Further, supporting the practise of selective abortion and facilitating it through prenatal testing may constitute a new form of eugenetics.[43]

The DRC considers the position of people with disabilities to be fragile, and that the gains that have been made through the legal developments such as antidiscrimination law are only just beginning to bring about change. The DRC takes the view that selective abortion and prenatal testing threaten these improvements because they are regressive, relying as they do on the medical model of disability and on a very narrow view of disability.[44] Prenatal testing and selective abortion will not

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[41] On the human rights model of disability see Jones, M. & L. Basser Marks. (2001). Law and people with disabilities. In N. Smesler & P. Baltes (Eds.), *International encyclopedia of social and behavioral sciences* (pp. 8475–8480). Oxford: Elsevier; Title 3.8.133; Discipline: Law; Basser Marks, L. (2008). Disentangling disability and health. In B. Bennett, T. Carney & I. Karpin (Eds.), *The brave new world of health* (pp. 218–236). Annandale, NSW: Federation Press.; and Rioux, M. (2003). On second thought: Constructing knowledge, law, disability and inequality. In S. Herr, L. Gostin & H. Koh (Eds.), *The human rights of persons with disabilities: Different but equal* (pp. 287–318). Oxford: Oxford University Press.

[42] Sheldon, S. & S. Wilkinson. (2001). Termination of pregnancy for reason of foetal disability: Are there grounds for special exception in law? *Medical Law Review, 9*, 85–109 at 102.

[43] Ekberg, M. (2007). Second opinions: The old eugenics & the new genetics compared. *Social History of Medicine, 20*, 581–593. Dixon, D. P. (2008). Informed consent or institutionalized eugenics? How the medical profession encourages abortion of fetuses with Down syndrome. *Issues in Law & Medicine, 24*, 3–60.; Pritchard, M. (2005). Can there be such a thing as a 'wrongful birth'? *Disability & Society, 20*(1), 81–93.

[44] The medical model is the term used to describe historical treatment of people with disabilities, which has predominantly focused on the limitations posed by bodies and minds and to equate disablement with indivdual impairment.

"cure" disability, nor are they the way to improve the position of people with disabilities. The DRC stresses that the rhetoric around the Human Genome Project places an undue emphasis on "birth defects," thereby removing focus from the significant issues for people with disabilities.

Further, the DRC points out that advocates of prenatal testing base their arguments on a number of false assumptions about living with a disability. First of all, the medical paradigm constructs "biology as destiny." It assumes that all the negative experiences in the life of a disabled person are somehow attributable to the condition the person has, rather than to external factors. So if a disabled person experiences isolation, poverty, unemployment, powerlessness or low social status, these are seen to be the inevitable consequences of biological limitation. As Asch puts it: "The paradigm of medicine concludes that the gaps in education, employment, and income that persist between adults with disabilities and those without disabilities are inevitable because the impairment precludes study or limits work."[45]

Another assumption about disability attributed to those who support prenatal testing and selective abortion is "genetic determinism." This is the view that by knowing about the genes of a person, you somehow know that person. This involves an emphasis on the "defect" and a paternalism which assumes that "defect" tells you something meaningful about the person. Further, genetic determinism assumes that the "defect" is a totally dominant aspect of the person, and subsumes all the other characteristics which generally constitute personhood. This is simply wrong and is also quite offensive. To deny an individual personality is character assassination! This mistake has two elements. First, establishing that a foetus is affected by a given condition does not provide any information about how the condition will affect the person. Genetic conditions are not experienced in the same way by all individuals who have the condition. There is a broad range of possibilities. Even medicine recognises this when it categorises conditions as mild, moderate or severe. Yet the worst case scenario is often presented without recognition that not all people with any given "defect," within any given category, will be "impaired" in the same way. Secondly, being able to establish that a person has a genetic condition does not provide any insight into his or her personality – their preference for chocolate

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[45] Asch, A. (1999). Prenatal diagnosis and selective abortion: A challenge to practice and policy. *American Journal of Public Health, 89*(11), 1649–1657.

ice-cream over strawberry; their passion for football or ice-skating; their love of jazz or hatred of opera; their great skills as a board game player or as a computer whiz; their temperament as a serious scholar or as a party animal. While some "defects" may limit some individuals in some areas of life, short of discrimination and lack of access to services, it is unimaginable that a person would be so disabled that they can be reduced to their diagnosis.

A final problem exposed by the DRC is the assumption made by proponents of prenatal testing and selective abortion that the life of a disabled person is full of "pain and suffering" and that people with disabilities live in misery. This is simply not true for the majority of people with disabilities. Asch comments:

> Chronic illness and disability are not equivalent to acute illness or sudden injury, in which an active disease process or unexpected change in physical function disrupts life's routines. Most people with conditions such as spina bifida, achondroplasia, Down syndrome, and many other mobility and sensory impairments perceive themselves as healthy, not sick, and describe their conditions as givens of their lives–the equipment with which they meet the world. The same is true for people with chronic conditions such as cystic fibrosis, diabetes, haemophilia, and muscular dystrophy. These conditions include intermittent flare-ups requiring medical care and adjustments in daily living, but they do not render the person as unhealthy as most of the public–and members of the health profession–imagine.[46]

Most disabilities are not experienced as "pain and suffering," nor are people with disabilities "harmed" by their condition. Nonetheless, this misconception allows commentators like John Harris to argue that, just as it is morally wrong to harm another, it is morally wrong to bring a disabled person into the world.[47] He argues that to do so, adds to the sum of human suffering and makes the world a worse place for us all to live in. Harris continues with the utilitarian argument that avoidable pain should be avoided, and because he considers that the burden of pain and suffering carried by people with disabilities is unacceptable, disability can be seen to be incompatible with a good life. This leads to the conclusion that it is a kindness to prevent the birth of a person with

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[46] Asch, A. (1999). Prenatal diagnosis and selective abortion: A challenge to practice and policy. *American Journal of Public Health, 89*(11), 1649–1657.

[47] Harris J. (1990). The wrong of wrongful life. *Journal of Law & Society*, 17, 90–105.

a disability.[48] Yet, as Saxton observes, the suffering experienced by people with disabilities is "primarily a result of not enough human caring, acceptance and respect."[49]

This leads to the most fundamental position of the disability critique of prenatal testing and selective abortion. Its position is that the very availability and use of these techniques undermines and devalues people with disabilities. It is argued that it is not possible to hold people with disabilities in high esteem (or at least equal to their non-disabled counterparts) at the same time as convincing hundreds of thousands of women that they should abort "defective" babies. The purpose of prenatal testing and the ready availability of selective abortion is quite specifically to weed out foetuses with disabling traits. If disabling traits are seen as features of a foetus that would render its life not worth living, we must also subscribe to the corollary – that existing people with those same attributes are not just different, but are abhorrent.

It is a small step from here to characterising the practice of prenatal testing and selective abortion as a new form of eugenics.[50] Certainly it is true that the whole enterprise of the Human Genome project is aimed at the perfection of the human race by way of the eradication of imperfections. The old eugenics targeted vulnerable groups – members of minority races, women and people with disabilities. The new genetics targets women as the receptacles of future generations and people with disabilities who are reduced to their genetic origins. Of course, modern genetics does not cover the whole picture of disability, but in staking its claim to improve human stock by eradicating "faulty" genes it suggests that the main or at least most important cause of disability is genetic.

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[48] Harris, J. (1998). *Clones, genes and immortality*. Oxford: Oxford University Press. He states that "to bring a child into being who will have a life so terrible that death is preferable is morally wrong." And again: "Where the disability is so great that people are incapable themselves of forming anything so sophisticated as a preference about life or death, and where again their life is so terrible that mere existence is a cruelty, then we should give them a humane death by legalizing euthanasia in such cases" (p. 118) (cited by Marzano-Parisoli, M.M. (2001). Disability, wrongful-life lawsuits and human difference: An exercise in ethical perplexity. *Social Theory and Practice, 27*(4), 637–659). For a refutation of this position see Marzano-Parisoli, M.M. (2001). Disability, wrongful-life lawsuits and human difference: An exercise in ethical perplexity. *Social Theory and Practice, 27*(4), 637–659.

[49] Saxton, M. (1988). Prenatal screening and discriminatory attitudes about disability. *Women and Health, 13*(1), 217–24 at 222.

[50] See footnotes 1 and 41 above.

This fails to recognise that people with disabilities are not all born with disabilities but acquire them through accident and injury, from war and landmines, from lack of access to basic goods like housing, food and clean water, and through disease (often which could have been dispelled by the provision of readily available medication). Even if the Human Genome project is successful beyond the dreams of geneticists, it will not remove disability from society. In the meantime, women will be coerced or cajoled into aborting "defective" foetuses and will lose even more control over their reproduction. At present "pregnant women are expected to optimise the health of their foetuses and this includes testing their foetuses for genetic risk,"[51] even though there is some risk to the healthy foetus from the process of testing.

These misconceptions about people with disabilities fuel proponents of modern genetics to search for more "cures" for more disabilities. The logical consequence of the eugenic state of mind is that existing people with disabilities are devalued, and that this could well interfere with the objectives of the disability movement – the treatment of people with disabilities with dignity and equality, and the promotion of full inclusion in all aspects of society.

2.3. *Response to the "Disability Rights Critique" of Prenatal Testing and Selective Abortion*

Not all disability scholars subscribe to the disability rights critique. There are two points of departure. First, there is the internal critique that challenges the hold and explanatory power of the social model of disability. Secondly, there is the external response which accepts the argument about the mistaken assumptions about disability, but which rejects the conclusion that prenatal testing and selective abortion cannot be supported without undermining the value of people with disabilities. The internal objection to the disability rights critique is a challenge to the social model of disability which does not necessitate a return to a medical model of disability. The external view of prenatal testing and selective abortion takes a pragmatic approach, acknowledging the reality of modern science and taking into account the position of people with disabilities, without concluding that the one poses an inherent threat to the other.

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[51] Shepherd, L. (1995). Protecting parents' freedom to have children with genetic differences. *University of Illinois Law Review, 4*, 761–812 at 783.

At least some problems encountered by people with disabilities are attributable to the disadvantages intrinsic to "impaired" bodies or minds. Richard Hull differentiates between socially-induced disability (arising from, among others, the social, political, economic structures of society) and impairment-induced disability (where limitation of ability or opportunity is due to impairment).[52] The latter types of constraints are not disadvantages caused by others. To the extent that abortion is sought with reference to impairment-induced disability, it may hold sway. But socially-induced disability will inevitably impact upon the disadvantage experienced, and this lowers the veracity of the parental-interest claim.

Even the most ardent proponent of the disability rights critique accepts that it is possible, even if not probable, that prenatal testing could be carried out in such a way that it may function without devaluing people with disabilities.[53] Adrienne Asch's concession comes from the possibility that prenatal testing could be conducted without coercion to abort a "defective" foetus. This would involve a new type of informed consent – a consent to selective abortion in the light of information about how people experience particular disabilities and the barriers they encounter and the opportunities they enjoy.

In an early publication of the Hasting Centre[54] an example is given of full disclosure and non-directive genetic counselling with respect to foetuses diagnosed with Down's syndrome. Instead of a discussion with an obstetrician, the women (and their partners) meet with paediatricians who specialise in genetics and with families who are raising infants, children and young adults with Down's syndrome. Instead of selective late term abortions performed on all the women coming through the programme, only 62% of women chose to terminate their pregnancies. Asch's objections to prenatal testing and selective abortion would be met if this were the universal model of genetic practice.[55]

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[52] Hull, R.L. (2006). Cheap listening? Reflections on the concept of wrongful disabilities. *Bioethics, 20*(2), 55–63 at 58.

[53] Asch, A. (2003). Disability, equality and prenatal testing: Contradictory or compatible. *Florida State University Law Review, 30*(2), 315–342. See also Steinbock, B. (2000). Are prenatal testing and selective abortion morally acceptable ways of preventing disability? In E. Parens & A. Asch (Eds.), *Prenatal testing and disability rights* (pp. 108–123). Washington: Georgetown University Press.

[54] Hastings Center. (1991). *The context: What frames the discussion about prenatal testing?* Hastings Center Report. New York: Hastings Center.

[55] Asch, A. (2003). Disability, equality and prenatal testing: Contradictory or compatible. *Florida State University Law Review, 30*(2), 315–342.

What this shows is that it is not inevitable that the processes of prenatal testing and selective abortion will result in discrimination against existing people with disabilities. On the contrary, a model of genetic counselling that involves people with disabilities who have a relevant "impairment" will result in many more members of the community learning about disability and gaining some understanding that people with disabilities are people first. Further, the multi-dimensional approach to genetic counselling of this type will help parents and prospective parents see the whole child. In this scenario, "genetic determinism" and "biology as destiny" will be shown to be shallow, one dimensional accounts of people with disabilities. While it is probably a pipe dream for the service described to be replicated universally, it at least provides evidence that prenatal testing and selective abortion are not inherently discriminatory.

3. Human Rights and "Wrongful" Lives

Wrongful birth actions brought with respect to unwanted children are relatively straightforward to deal with. When a child is conceived after one parent or another has undergone a sterilisation procedure, a course of action specifically taken in order to prevent pregnancy, there is a probability that the child is born as a direct result of medical negligence.[56] However, once we stepped into the realm of wanted pregnancies that give rise to unwanted children, we entered the world of modern medical technology and selective abortion. It is, therefore, essential to understand the disability rights critique of prenatal testing and selective abortion before we could consider a human rights perspective on wrongful birth actions. Had I concluded that the practice of prenatal testing and selective abortion was inherently undermining of people with disabilities, then I would have had to object to wrongful birth actions. This is because wrongful birth actions involving unwanted children cannot be sustained, or found to be consistent with human rights, if they reinforce inherently discriminatory values about people with disabilities.

It is now possible to assess wrongful birth actions themselves, and to determine whether they interfere with the rights of people with disabilities. Having considered the effect of wrongful birth actions involving

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[56] In such cases, the disabled status of the child should be irrelevant to the finding of the failure of duty of care, but central to the assessment of damages.

unwanted children, the solution that I propose, to be consistent with human rights, is to award the same range of damages to all applicants, independent of their ability status. If an action is available with respect to a healthy, unwanted child, it must also be available to a disabled unwanted child. No special case must be made out for people with disabilities – people with disabilities are ordinary actors in these wrongful birth actions. By determining that there is one law for all, wrongful birth suits are supportive of the inclusion of people with disabilities in society, treat people with disabilities equally to others, and ensure that the dignity of people with disabilities is respected. The elegant simplicity of the solution with respect to unwanted children is not replicated with respect to the class of wanted-unwanted children.

3.1. *What is Wrong with "Wrongful Life"?*

An additional complexity now needs to be brought into play – the situation in which the action is brought by, or on behalf of, the disabled child. The action is then called "wrongful life", rather than wrongful birth. It may be that the most offensive feature of wrongful life actions is the suggestion in the name of the tort, that some births or lives can be, in themselves, wrongful. It is true that the law of torts is the area of law covering legal wrongs, and that in every tort action there is an allegation that some behaviour or other is wrongful. But as a general rule, the wrong done to the victim is not considered to be the legal wrong. So, for example, in an industrial action, the action is not known as "wrongful worker" or "wrongful machinery." What is *wrong* is the behaviour of the tortfeasor (the wrong-doer). Similarly, an action involving a person who became ill after drinking ginger ale with a snail in it is not referred to as a "wrongful snail" or "wrongful ginger ale" – again the wrong is the negligent behaviour of the manufacturer of the drink. Naming the damage done in the course of medical treatment as wrongful birth or wrongful life sounds a little like the law is blaming the victim.[57]

Wrongful life and wrongful birth actions are identical, with only one exception. The exception is that wrongful life actions are brought by

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[57] See Kirby J in *Harriton v Stephens* (2006) 226 CLR 52 paragraphs 8–14; Teff, H. (1985). The action for "wrongful life" in England and the United States. *International and Comparative Law Quarterly, 34:* 423 at 425; and McHugh and Gummow JJ in *Catternach v Melchior* (2003) 199 ALR 131 at 68.

the child born consequent to the negligent behaviour of a medical practitioner or health professional. In most cases this will not be necessary, for the parents will be available to seek damages themselves. However, there are a number of reasons why it may be appropriate for a child to bring an action before the courts. The most common reason relates to the amount of time available to launch an action. Statutes of limitation, which most commonly specify that an action must be brought within 3–6 years of the wrongdoing, have the effect of preventing tardy parents from challenging the negligent behaviour. Another reason, which is more likely to be relevant to people with disabilities than to others, is that the biological parents, who were victims of the wrongdoing, are no longer involved in the life of their child. Where the child has been adopted, fostered or institutionalised, the only possible way of accessing damages that may provide urgently needed resources for the child, is for an action to be brought in his or her name. Equally, if the parents are no longer living, the potential for an action may be in the hands of the child. Finally, the parents may not be able to afford the cost of litigation, emotionally or financially, and a philanthropic organisation or the like may be willing to support the child to bring an action.

"Wrongful life" actions are generally considered to be a distinct class of actions which should be distinguished from "wrongful birth" actions.[58] Commentators have suggested that this distinction allows us to draw a "line in the sand"[59] between ethically supported wrongful birth cases and morally problematic wrongful life cases. But this is a "false dichotomy."[60] Using the terminology of wrongful life has shifted the focus from the legal wrong – the negligence of the medical practitioner or health professional – to the "wrongful" life. Approaching the birth torts as analytically distinct has led to objections specific to wrongful life cases, and entirely misses the point that the wrongdoing in both cases

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[58] See Stretton, D. (2005). The birth torts: Damages for wrongful birth and wrongful life. *Deakin Law Review, 10*(1), 319–364 for a thorough account of jurisdictional responses to wrongful life and wrongful birth actions respectively.

[59] This was one of the arguments by the majority of the Australian High Court in *Harriton v Stephens. See also* Neville, W.J. & B. Lokuge. (2006). Wrongful life claims: Dignity, disability and "a line in the sand." *Medical Journal of Australia, 185*(10), 558–560, and Canellopoulos Bottis, M. (2004). Birth and wrongful life actions. *European Journal of Health Law, 11*, 55–59.

[60] Hensel, W.F. (2005). The disabling impact of wrongful birth and wrongful life actions. *Harvard Civil Rights-Civil Liberties Law Review, 40*, 141–196.

is identical.[61] It has allowed scholars such as Adrienne Asch to support wrongful birth actions because they acknowledge the women's right to self-determination, while rejecting wrongful life actions on the basis that life cannot be an injury.[62]

Those who object to the false dichotomy between wrongful birth and wrongful life actions usually do so in order to support wrongful life actions, on the assumption that wrongful birth and wrongful life actions should stand or fall together.[63] However, Wendy Hensel argues that is incorrect to characterise wrongful birth actions as cases about the reproductive rights of the mother, because to do so ignores the salient feature of wrongful birth cases – the disabled child.[64] Her conclusion is that both actions are contrary to the principles of "therapeutic justice" and so both should be abolished.[65] Others such as Thomas Faunce[66] take the opposite position and argue that ordinary principles of justice require that the distinction between the actions be abandoned and that wrongful life actions succeed.

The courts have, in many jurisdictions, rejected wrongful life actions on three grounds. First, they claim that the actions depend on acceptance of the proposition that some people would be better off dead. Secondly, judges reject wrongful life actions because of their belief that establishing damages requires them to compare existence with non-existence, which they claim to be impossible. Finally, the position is put

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[61] Asch, A. (2001). Disability, bioethics and human rights. In G. Albrecht, K. Seelman & M. Bury (Eds.), *Disabilities studies handbook* (pp. 297–326). UK: Sage.

[62] Asch cited by Hensel, W.F. (2005). The disabling impact of wrongful birth and wrongful life actions. *Harvard Civil Rights-Civil Liberties Law Review, 40*, 141–196 at 165.

[63] See, for example, Stretton, D. (2006). Wrongful life and the logic of non-existence. *Melbourne University Law Review, 31*(3), 972–1001.; Stretton, D. (2005). The birth torts: Damages for wrongful birth and wrongful life. *Deakin Law Review, 10*(1), 319–364.; and Pollard, D.A. (2004). Wrongful analysis in wrongful life jurisprudence. *Alabama Law Review, 55*, 327–375.

[64] Hensel, W.F. (2005). The disabling impact of wrongful birth and wrongful life actions. *Harvard Civil Rights-Civil Liberties Law Review, 40*, 141–196 at 164–170.

[65] Hensel states: "Tort law should not serve as a tool of injustice under the guise of benevolent intervention on behalf of individuals with disabilities. Because relief to individual litigants in wrongful birth and wrongful life actions is purchased at a cost to society as a whole, neither action should be recognized by state legislatures or the courts." Hensel, W.F. (2005). The disabling impact of wrongful birth and wrongful life actions. *Harvard Civil Rights-Civil Liberties Law Review, 40*, 141–196 at 145.

[66] Faunce, T. (2007). Abandoning the common law: Medical negligence, genetic tests and wrongful life in the Australian High Court. *Journal of Law and Medicine, 14*(4), 469–477.

that, even if it were possible to make that comparison, it is nonetheless impossible to quantify damages in wrongful life cases. This last claim is inconsistent with the experience of courts, which regularly make assessments of damages similar to those sought in wrongful life actions, and is not sustainable.[67] The first two claims, on the other hand, are taken to be definitive of the question before the courts. What is more, one effect of a judicial finding in favour of the child in wrongful life cases, has been for legislatures to become involved and ban wrongful life actions. The question is, do justice and the human rights of the individual involved require an alternative response?

Any suggestion that some people with disabilities would be "better off dead," is clearly unacceptable. Just because the injury – that is, the consequence of the wrongdoing – could be characterised as the life of the disabled person, it does not follow that the very existence of that person is being challenged or undermined. Quite correctly, courts have refused to make a finding that any person would be better off dead and have refused remedies in wrongful life actions because of their assumption that granting a remedy would inherently involving endorsing such a claim. However, when the focus is shifted from the wronged individual to the wrongdoing, there is no reason to come to this conclusion. On the contrary, however, awarding damages in a wrongful life action proves that the person before the court would not be better off dead, but would be better off with access to resources.

Similarly, the argument about existence and non-existence is untenable – finding for a child in a wrongful life suit does not require such a metaphysical consideration. The argument is that existence is always preferable; the comparison odious. However, dissenting judges and scholars have not considered this a real or even logical barrier to action.[68] Kirby J in *Harriton v Stephens*[69] considered this objection to

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[67] See ; Stretton, D. (2005). The birth torts: Damages for wrongful birth and wrongful life. *Deakin Law Review, 10*(1), 319–364.

[68] For an excellent analysis of this problem see Stretton, D. (2006). Wrongful life and the logic of non-existence. *Melbourne University Law Review, 31*(3), 972–1001. Stretton comments (at 50) about the decision in *Harriton v Stephens* (2006) 226 ALR 391; [2006] HCA 15 (9 May 2006) that "[t]he High Court had an opportunity to display bravery and integrity by reaching, as it managed to do for wrongful birth a controversial but legally correct decision on a matter of considerable social importance. Instead the Court regressed, depriving the plaintiffs of a legally justified remedy by resort to inconsistent logic and ill-considered policy."

[69] *Harriton v Stephens* (2006) 226 ALR 391; [2006] HCA 15 (9 May 2006) at [97]–[101].

wrongful life to be comparable to the arguments accepted by some courts in the early days of sex discrimination law. There it was argued that a pregnant woman could not succeed in an action where she alleged that she was discriminated against by dismissal from employment as a result of her pregnancy. The reasoning was that the law required that discrimination be proved by a comparison with the way men would be treated in the same circumstance. As it was impossible for her to prove that she was treated less favourably than a pregnant man would be, her action failed. Here, too, the logic is unassailable but the task of the judge is not identical to the logician. As Kirby J says, this is a red herring.[70] No one is seriously suggesting that the applicant should not exist – it is the very fact of his or her existence that makes the action compelling. The solution of the Israeli Supreme Court in *Zeitzoff v Katz* is preferable.[71] The appropriate comparison is not between existence and non-existence but between the life now lived and the life that the child would have experienced had he or she not been affected by rubella or a "faulty" gene. This is the child that the negligent medical practitioner had led the mother to believe she was carrying. The child, not a replicable and therefore expendable model, was wanted, just without any of the disabling characteristics – which after all may be significant but nonetheless are only one aspect of the person.

3.2. *The Impact of Wrongful Life and Wrongful Birth Actions on People with Disabilities*

Although none of the above reasons for denying wrongful life litigants is valid, there remains one very significant objection to wrongful life actions. The argument is that wrongful life and wrongful birth actions seriously undermine people with disabilities, and that they should therefore be prohibited. If this is the case, we must conclude that the actions should be abolished. Wendy Hensel, in a seminal piece on the subject, comments:

> Wrongful birth and wrongful life suits may exact a heavy price not only on the psychological well-being of individuals with disabilities, but also on the public image and acceptance of disability in society. Rather than

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[70] *Harriton v Stephens* (2006) 226 ALR 391; [2006] HCA 15 (9 May 2006) at [108].

[71] *Zeitzoff v Katz* [1986] 40(2) PD 85 (Supreme Court of Israel). See also Shapira, A. (1998). "Wrongful life" lawsuits for faulty genetic counselling: Should the impaired newborn be entitled to sue?" 24 *Journal of Medical Ethics*, 369–376.

> focusing on a defendant's conduct, as in a traditional tort action, both wrongful birth and wrongful life suits ultimately focus on the plaintiff's disability, a status that is at least partially a societal construction…Any benefits secured by individual litigants in court are thus taxed to the community of people with disabilities as a whole, placing at risk, in the drive for individual compensation, the gains secured by collective action and identity.[72]

This is a more sophistocated version of the argument put by the French disability community in *Perruche.* It is also the reiteration of the position claimed then conceded as incorrect by proponents of the disability rights critque. But where is the evidence? Judges who support wrongful life as a tool for those who are seriously disabled to recover some financial support, consider and then reject this argument.

Hensel is legitimately concerned about the gains of the disability community since the 1990 enactment of the ADA, which she considers to be both insubstantial and tenuous. However, all the evidence is to the contrary. While there is no doubt a long way to go, people with disabilities are much better off than they were 20 years ago. Many jurisdictions have introduced anti-discrimination laws since the introduction of the ADA, which, although not a panecea, do herald some positive change. Further, the international community has widely endorsed the new *Convention on the Rights of Persons with Disabilities.* Surely these legislative developments overshadow minor torts like wrongful life and wrongful birth. When common law developments are understood in the context of significant social and legal support for people with disabilities, this objection disappears.

4. Conclusion: How To Be Respectful of People With Disabilities

While there is concern about the negative impact of wrongful life and wrongful birth actions, successful actions are small victories for people with disabilities. There is room for improvement, as is discussed below, but where damages are awarded to people with disabilities they provide a "degree of practical empowerment."[73] It would be naive to believe that

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[72] Hensel, W.F. (2005). The disabling impact of wrongful birth and wrongful life actions. *Harvard Civil Rights-Civil Liberties Law Review, 40*, 141–196 at 144 and *passim.*

[73] Kirby J *Harriton v Stephens* (2006) 226 ALR 391; [2006] HCA 15 (9 May 2006) at [122].

disability is inexpensive. For people with high support needs, the cost may be very high. Expenses may include medical costs (surgery, medication, allied health/ paramedical support etc); the cost of equipment (wheelchairs, shower stools, modified vehicles etc); costs associated with personal care (the employment costs of carers); and the cost of inclusive education (modified material, teacher support, changes to the physical environment etc). These costs should not primarily be a matter of individual responsibility and should not depend on the private financial resources available to an individual. However, in almost all places in the world, the burden falls on the shoulders of people with disabilities and their families. To the extent to which an award of damages will alleviate some of the financial stress, and improve the life of one person by facilitating his or her inclusion, success in wrongful life and wrongful birth cases is beneficial.

This is far from an ideal solution. Some sort of universal scheme which provides for the financial needs of people with disabilities would be vastly superior.[74] If the inclusion of people with disabilities was facilitated by the broader community such that it was unnecessary to look to solutions in the law of torts, people with disabilities would be in a much better position than they are almost anywhere in the world today. It may be ironic that some severely disabled people will be lucky enough to have access to the courts, because there is someone or some wrongdoing to blame for their disability, while the majority of people with disabilities are not similarly advantaged. Still worse, it is arguable that it is the least morally worthy of all parents, those who would abort a foetus as a result of disability and are happy to declare to the world that their child is unwanted, who have access to these torts. Parents, or prospective parents, who choose to nurture whatever child they have, and would not abort a foetus just because medical practitioners have told them that their child is "defective," have the same financial burdens as those who practice, or would practice, selective abortion. This injustice, too, would be addressed by a universal compensation scheme.

The crucial issue, from an human rights perspective, is that whatever strategy is adopted with respect to people with disabilities is respectful of them. Wrongful life and wrongful birth suits have been contentious in this regard. In the light of the analysis in this chapter, it is possible to

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[74] Such as the *National Compensation Scheme of New Zealand* per Thomas, C. (2003). Claims for wrongful pregnancy and damages for the upbringing of the child. *University of New South Wales Law Journal, 26*(3), 125–158.

conclude that the availability of these actions does not inherently entail a finding that some lives are less valuable than others or that some people would be better off dead. Yet there is a great deal of dicta in the courts and writings of scholars that is uncertain about this and some that objects to the torts because of their belief that wrongful birth and wrongful life actions involve public declarations that devalue people with disabilities. In recognition of this, I suggest that reform of the law is warranted. Wrongful life and wrongful birth suits must not only be consistent with the human rights of people with disabilities; they must also be seen to be consistent with human rights.

First of all, it is crucial that the dignity of the litigants is maintained at all times. This appears not to be the case while the title "wrongful life" is maintained. The title suggests that it is the life of the disabled person which is wrongful, rather than the wrongful position that the disabled person has been placed in due to the negligence of another. The name of the tort has misled judges and scholars alike, and has led the disability community to be distressed by courts awarding damages for wrongful life. While I suggested earlier that we had no alternative but to continue to use the language of the courts in these actions, perhaps a way can be found around this. Recognition that the torts of wrongful birth and wrongful life are analytically inseparable leads to the possibility of collapsing the torts into one action – the action for wrongful birth could be brought both by women (parents) and their offspring.

Secondly, the courts should acknowledge that focussing to the extent they do on the specifics of the disability of the child, risks regressing to a medical model of disability. As a result of subscribing to a medical model of disability, the courts more often than not fail to see the whole person and make the assumption that the person is consumed by suffering. However severe the disability may be, the disability remains only one feature of the person. The risks are the stereotyping of people with disabilities as one-dimensional and the endorsement of a disabled culture of helplessness. The language of the court should be appropriate, and the discussion of metaphysical questions about existence and non-existence should be left to philosophers.

Thirdly, the actions should operate in the same way as other tort actions. This requires focussing on the wrongdoer rather than the victim of the wrongdoing. The characteristics of the particular person are only relevant in the assessment of damages – after a finding of a breach of the duty of care. The law of torts developed as a means of deterring wrongdoers and spreading the costs associated with the wrongdoing.

It is clear that treating someone in a negligent fashion constitutes a failure to accord dignity to that person. The law restores that dignity by recognising that the person has been wronged and by providing a remedy to compensate for both the way she or he was treated and for the consequent damage. It is rare in the reported wrongful birth decisions for the negligence to be in issue – defendants generally concede that their behaviour did not comply with professional standards and was taken without sufficient regard to the plaintiff. So why is it that plaintiffs tend to be unsuccessful in their claims? Perhaps this is a result of the differential power of the players – people with disabilities are one of the most vulnerable groups; medical practitioners amongst the most powerful. In the aftermath of the *Perruche* judgment, it was obstetricians who went on strike and the medical community which lobbied the government to introduce law banning wrongful life actions. Failure to recognise this, together with other factors such as the commodification of pregnancy and the commercial interests (of radiologists, pathologists and drug companies and others) in decisions about pregnancy leads to a misplaced assumption of medical benevolence.

Finally, those who advocate putting an end to wrongful life and wrongful birth actions need to give pause and consider the problem of the baby and the bathwater. There are a number of important gains for women, and potentially people with disabilities, that will be lost by the abandonment of these torts. First, there are all the actions relating to unwanted children. Surely the medical practitioners involved in those cases should be responsible for their negligence and carry any costs which were foreseeable. These costs are not just about the upbringing of the child but also whatever expenses the particular child brings. Paying for disability in this context involves applying ordinary torts principles. Secondly, while current actions of negligent information, diagnosis or testing result in denying the woman the opportunity to abort the foetus, in the future exactly the same behaviour on the part of tortfeasor will cause disabilities that may have been prevented *in utero*. In this situation, the health professional could be said to have caused the disability. Whether the actions are brought by the parent or the child, the existence of the current torts will smooth the way for future accountability. Thirdly, the fact that a major class of detractors of the law are medical, para-medical or bio-medical organisations who fear litigation, suggest that the deterrent effect of the torts may be real. The cases rarely involve an innocent mistake that anyone could make – mostly the behaviour of the tortfeasor defies imagining. Only those who provide sub-standard medical care for pregnant women are at risk of being sued.

In conclusion, then, the torts of wrongful life and wrongful birth should be retained, preferably as one action. This would resolve the ambiguity created by the name of the tort, wrongful life, and make it clear that no people are wrongful. It is essential that any law ensure that people with disabilities are treated with dignity, respected and valued as are all other members of society. By granting damages in the new combined action for wrongful birth tort, the courts are valuing people with disabilities by recognising that whoever is unlawfully wronged is entitled to a remedy. This is confirmation that all lives are valuable, including those wrongfully described as "wrongful."

CHILDREN AT THE EDGE OF LIFE: PARENTS, DOCTORS AND CHILDREN'S RIGHTS

Michael Freeman

There are many children at the edges of life. This paper is about one group of them: premature newborn babies who live at life's margins. The recent cases in England of Charlotte Wyatt[1] and Luke Winston-Jones[2] are evocative images of their plight. I offer a perspective on these cases and on premature newborns generally, which is all too easy to neglect or, indeed, dismiss. I will therefore start with an assertion: they are persons and they have rights. Both of these statements are controversial and fly in the face of current orthodoxy. I will justify both in due course. But first I need to make a number of preliminary points, and outline a context.

Introduction – The Context

As a result of advances in medical science, most children are born healthy. Indeed, even children who are born under 26 weeks of gestation have a good chance of life at a level or quality which most of us would consider reasonable.[3] However, there are some babies born who are so profoundly handicapped that ethical issues about their treatment must be addressed. Charlotte Wyatt and Luke Winston-Jones are two recent English examples of the babies whose plight I am addressing. The situation of the severely disabled newborn child has tested both ethicists and courts. With the increase in sophistication of medical technology, infants can be kept alive where once there was no such expectation. Recent evidence[4] suggests that there is an approximate

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[1] *Portsmouth NHS Trust v Wyatt and Wyatt* [2005] 1 FLR 21. But this case continues with further references to the court. The latest is reported at [2005] 2 FLR. 480. A further referral is in *The Guardian*, 25 February 2006.

[2] *Re L* [2005] 1 FLR 491.

[3] Marlow, N., et al. (2005). Neurologic and developmental disability at six years of age after extremely preterm birth. *New England Journal of Medicine, 352*(1), 9–19.

[4] Muraskas, J., et al. (1998). Neonatal viability in the 1990s: Held hostage by technology. *Cambridge Quarterly of Healthcare Ethics, 8*(2), 160–172.

20 per cent survival chance for babies born after 23 weeks' gestation, rising to 90 per cent plus at 28 weeks. But, as the authors of this study point out, the line between ordinary and extraordinary treatment has become blurred; and the distinction between standard care and experimental care has all but disappeared. They note, "As technology continues to progress, the envelope of viability could very well be pushed back further and further."[5]

THE DECISION-MAKER

Most of the existing discussion centres on who should make the decision. Raymond Duff and A. G. M. Campbell observe in an oft-cited article:

> Can families in the shock resulting from the birth of a defective (*sic*) child understand what faces them? Can they give truly "informed consent" for treatment or with-holding treatment? Some of our colleagues answer no to both questions. In our opinion, if families regardless of background are heard sympathetically and at length and are given answers to their questions in words they understand, the problems of their children as well as the expected benefits and limits of any proposed care can be understood clearly in practically all instances. Parents *are* able to understand the implications of such things as chronic dyspnea, oxygen dependency, incontinence, contractures, sexual handicaps and mental retardation.[6]

Kuhse and Singer agree: "When it is the parents who will be looking after the infant if it (*sic)* lives, it should be the parents who have the principal say in the decision."[7]

There is general agreement that parents are the appropriate decision-makers. They are assumed to have the best interests of their children at heart. But, clearly, this is not always so: a striking instance is the English case of "Baby Alexandra," in which a baby with Down Syndrome with

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[5] Ibid., 167.

[6] Duff, R. & A.G.M. Campbell. (1973). Moral and ethical dilemmas in the special-care nursery. *New England Journal of Medicine, 289*(17), 890–894, at 893. This article was published the day my special needs son was born!

[7] Kuhse, H. & P. Singer. (1985). *Should the baby live? The problem of handicapped infants*. Oxford: Oxford University Press. For empirical evidence to this effect see McHaffie, H. et al. (2001). Deciding for imperiled newborns: Medical authority or parental autonomy. *Journal of Medical Ethics, 17*, 104–109.

an intestinal blockage would not have had life-saving surgery had the parents' wishes prevailed.[8] They did not do so. Wardship proceedings were taken and the Court of Appeal, applying a "best interests" test, refused to conclude that Alexandra's life would be so "demonstrably awful" that she should be "condemned to die."[9] The case is a remarkable insight into societal attitudes towards disability and to Down Syndrome in particular a generation ago. Thus, concern focused not on Alexandra, but on how much it was going to cost to raise her. An organisation was formed shortly after the "Alexandra" decision to promote the rights of parents to make decisions as to whether severely handicapped newborn babies should live or die.[10] A commentator in *The Times* describes the Court of Appeal's decision as "the cruel folly."[11] She wrote, "Those who call for legal intervention in preference to the quickly reached decisions between parents and trusted doctors seem to me to lack understanding of the moral capacities of ordinary people."[12] She called for parents to be able to make their decisions "privately and peacefully and with people whose goodwill [they] can trust."[13] A survey at the time of 250 pediatricians showed that in cases where parents rejected the child, only 36 per cent would recommend surgery for a baby with Down Syndrome needing an intestinal operation to live, but where parents accepted the baby, the percentage favouring surgery rose to 64 per cent.[14]

QUALITY OF LIFE

It is generally agreed that if the quality of life of the newborn is extremely poor and the prognosis is that it cannot improve, s/he need not be kept

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[8] *Re B* [1981] 1 WLR 1421. She subsequently (at about 10 months) returned home, although, if her parents' wishes had prevailed, she would have died. This "end" to the story (would that we actually knew the "end"!) is found in *The Observer*, 5 December 1982.

[9] This emotive language of Templeman, L. J. was subsequently repudiated – and rightly so – in a later case: see *Re J* [1991] 1 FLR 366, at 382.

[10] *The Times*, 14 September 1981.

[11] Tomalin, C. A. (1 September 1981). The cruel folly. *The Times*.

[12] Ibid.

[13] Ibid.

[14] See Harbridge, E. (1981). Life or death – who decides? *Community Care*, 4–5. I wrote on the Alexandra decision in *inter alia* Freeman, M.D.A., note 40.

alive, but may be allowed to die.[15] But what is meant by "quality of life" is far from clear. Although one writer has attempted to express this mathematically,[16] it is clear that it is not an easy concept to grasp. One way of looking at it is to ask (but ask whom?) whether it would have been better not to have been born. One way of approaching this – but it is circular – is to consider what is meant by "better off dead." Bonnie Steinbock has suggested this.[17] It means, she argues, "life is so terrible that it is no longer a benefit or a good to the one who lives."[18] In the case of a competent adult (or competent child) the criteria by which to judge whether a person is better off dead is ordinarily whether the person himself (or herself) considers life not worth living. This is surely why we allow a competent adult to refuse life-saving treatment,[19] recognise advance directives[20] and give due consideration to a patient's desire to receive continuing treatment.[21] "In the final analysis," Munby J observed in Leslie Burke's case, "it is for the patient, if competent, to determine what is in his own best interests."[22]

With children, this issue is less clear than with adults. Despite the *Gillick* ruling more than 20 years ago,[23] we deny competent children the right to refuse treatment.[24] We in England would certainly not permit a child to make an advance directive though the Dutch now do. Babies, of course, have never been legally competent. They cannot understand the choice between living with a severe disability and no existence

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[15] See Doyal, L. & D. Wilsher. (1994). Towards guidelines for withholding and withdrawal of life prolonging treatment in neonatal medicine. *Archives of Diseases in Childhood, 70*, 46–70.

[16] Shaw, A. (1977). Defining the quality of Life: A formula without numbers. *Hastings Center Report, 7*(5), 11. His equation is $QL = NE \times (H + S)$. Quality of life is equal to one's natural endowment multiplied by the sum of the contributions to the individual by his/her family/home and society. The practical application of Shaw's formula would lead to a zero quality of life for an encephalic baby, whilst the quality of life of an infant with Down Syndrome would depend on the way s/he was cared for by family and the society into which s/he is born.

[17] Steinbock, B. (1992). *Life before birth*. New York: Oxford University Press.

[18] Ibid., 120.

[19] *Re C* [1994] 1 WLR 290 (a paranoid schizophrenic Broadmoor patient).

[20] *HE v A Hospital NHS Trust* [2003] 2 FLR 408 (a case which exemplifies some of the difficulties with such directives). See also Mental Capacity Act 2005.

[21] *R (Burke) v General Medical Council* [2004] 2 FLR 1121.

[22] Ibid., 1197. But this decision has now been reversed: see [2005] 2 FLR. 1223.

[23] *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112. In November 2005 this decision was challenged, particularly in relation to abortion. The challenge failed.

[24] See *Re R* [1992] Fam 11; *Re W* [1993] Fam 64; *Re S* [1994] 2 FLR 1065; *Re C* [1997] 2 FLR 180.

at all. Nor I suspect can many so-called competent adults. Of course, a life that a "normal" individual might find intolerable might may be perceived differently by a baby or small child who has experienced nothing else. As Robertson argued:

> One who has never known the pleasures of mental operation, ambulation and social interaction surely does not suffer from the loss as much as one who has. While one who has known these capacities may prefer death to a life without them, we have no assurance that the handicapped person, with no point of comparison, would agree. Life and Life alone, whatever its limitations, might be of sufficient worth to him.[25]

How is "quality of life" to be measured? Should it be looked at objectively or should the focus be on the experiences of the individual or should an attempt be made to combine the objective and the subjective? In the leading English case of *Re J,* Taylor L. J. attempted the combined test. He said:

> The correct approach is for the court to judge the quality of life the child would have to endure if given the treatment, and decide whether in all the circumstances such a life would be so afflicted as to be intolerable to that child. I say "to that child" because the test should not be whether the life would be tolerable to the decider. The test must be whether the child in question, if capable of exercising sound judgment, would consider the life tolerable.[26]

It is ironic that the doctrine of "substituted judgment," having been rejected by the English courts,[27] should be invoked here. I previously described Taylor L. J.'s attempt to get inside the baby's mind as a "palpable fiction."[28] For reasons I will give in due course I am not so sure that the exercise Taylor L. J. had in mind cannot be done. Hedley J. in the *Charlotte Wyatt* case described the task as "daunting," though not "one from which the judge [can] turn aside."[29] Hedley J. also made the point – amply illustrated also in the *Glass* litigation[30] – that "those who have cared for a disabled child often have different perceptions of 'quality of

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[25] Robertson, J. A. (1974). Involuntary euthanasia of defective newborns: A legal analysis. *Stanford Law Review, 27*(2), 213–269.

[26] *Re J* [1991] 1 FLR 366. 383–384.

[27] Although there are often instances of it being used: e.g. *Re D* (1997) 38 BMLR1 and *Re G* (2001) 65 BMLR 6. And see also the *Mental Capacity Act* 2005.

[28] Also see: Freeman, M.D.A (1997). *The moral status of children*. The Hague: Martinus Nijhoff.

[29] *Supra* note 1.

[30] See *Glass v United Kingdom* [2004] 1 FLR 1019.

life' and 'intolerability' to those who have not." In his view both "quality of life" and its "intolerability" have "strong subjective elements."[31]

Some Possible Approaches

There are a number of strategies that can be employed. One can "wait until certainty," continuing active treatment until death or irreversible coma is almost certain. This gives maximum possible protection to each infant's right to live. But it also maximizes the number who will die slowly over a period of months.[32] A second approach is that of "statistical prognosis." This withholds treatment from infants whose prognoses are statistically grim. This minimizes the number of infants who die slow deaths and sacrifices some potential survivors to achieve this goal, which in turn makes decisions psychologically easier. In the view of those who favour this approach, withholding treatment is morally preferable to withdrawing it. Of course, this approach is only as good as the statistical data on which it relies.[33] A third approach strikes a balance between the two. Under this, "the individualized prognostic strategy," doctors start treatment and re-evaluate the decision taken on each infant, based on clinical indications of death or severe brain damage. This allows for a wide variation in treatment decisions and minimizes unnecessary suffering or waste of life. However, much depends on the accuracy of medical prognosis, and also on the ways doctors exercise their discretion.

Death or Disability?

Even the severely disabled newborn baby may have the potential to lead a fulfilling life in the future. Obviously, "fulfilling" is a relative term, but many will be capable of valuing their own lives as we do ours. How critical should this potential future be when making decisions in the days, weeks, months after birth? Can we justify inflicting suffering

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[31] *Supra* note 1, 29.

[32] On this approach see Mason, J.K. (1986). Parental choice and selective non-treatment of deformed newborns. *Journal of Medical Ethics, 12*(2), 67–71.

[33] This approach is particularly associated with practice in Sweden: see further, Rhoden, N. (1986). Treating Baby Doe: The ethics of uncertainty. *Hastings Center Report, 16*(4), 34–42.

now to protect the possibility of this future life? The infants we are referring to are sentient beings, able to experience pain and discomfort, and therefore have an interest in not experiencing this. Although some doctors hold the view that infants cannot remember or anticipate the pain,[34] this does not justify our actions in inflicting painful experiences on them without regard to their immediate well-being. Can such pain and suffering be outweighed by future benefits? Does inflicting pain and suffering on an infant undermine the whole argument of acting in the "best interest" of the infant? Can an infant be compensated for his/her suffering by the benefits that may be bestowed at some time in the future?

On the other hand, there are many reasons for deciding that death, not a severely handicapped life, may be in the best interest of the infant. Robert Weir puts forward the following reasons why this might be the case.[35] First, despite aggressive treatment and the use of sophisticated medical technology, survival of such infants is often for a very short period. Secondly, there are often no curative or corrective treatments for the conditions for which these infants suffer, so that little can be done for them other than marginal life prolongation, palliative care and institutionalisation in a long-stay ward. Thirdly, since most of the conditions of the infants in question are due to serious neurological complications, those who survive invariably end up with severe to profound intellectual disabilities and thus a much-reduced potential for a life that is socially regarded as valuable. And, fourthly, there are often many other concomitant medical problems associated with serious disability on birth, including congenital heart failure, poor muscle tone, respiratory failure and seizures.

The prevailing orthodoxy says that babies – it does not distinguish premature from full term – are not persons. And it would accord them few, if any, rights. I have always thought intuitively that Tooley,[36] Kuhse and Singer[37] and Harris[38] were wrong: anyone who thinks he can justify

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[34] A view which has been questioned: see e.g. Fitzgerald, M. (1995). *Foetal pain*. London: Department of Health.

[35] Weir, R. (1984). *Selective non treatment of handicapped newborns*. New York: Oxford University Press.

[36] Tooley, M. (1972). Abortion and infanticide. *Philosophy and Public Affairs, 2*(1), 37–65.

[37] Kuhse, H. & P. Singer. (1985), *supra* note 7.

[38] Harris, John. (1992). *The Value of Life* (revised edition). London: RPK.

infanticide just has to be. An examination of the literature reveals just how wrong they are.

THE DEFICIT MODEL

Before I look at the deficit model, I will make a preliminary observation. This is about children generally, not babies. It is striking just how much of the literature about children is similar to that about women. It is as easy to construct children as non-competent as it was to portray women in this way only a matter of years ago. The so-called deficit model sees children as pre-rational, as ignorant and as therefore incapable of contributing to decisions.[39] They are viewed as social problems not social participants, objects of intervention, not persons in their own right.[40] It is no surprise that both recent media attention and journals of philosophy have been focused on disenfranchised prisoners, when there has been little concern about children, the largest group denied the vote.[41] It is in the interests of adult society to keep children in prolonged dependence. But evidence from around the world and from the past shows this is neither inevitable nor essential.[42] As Berry Mayall recently and most pertinently observed, "the concept of generation is key to understanding childhood."[43]

CHILDREN AS AGENTS

Evidence stretching back 20 years or more – interestingly roughly contemporaneous with the *Gillick* decision[44] – shows young children, younger than those envisaged in that decision, can be highly competent: technically, cognitively, socially and morally.[45] They can be agents,

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[39] And therefore as "becoming" rather than "being," a view that goes back to Locke. See also Combs, A.W. (1999). *Being and becoming*. New York: Springer.

[40] See Freeman, M.D.A. (1983). *The rights and wrongs of children*. London: Frances Pinter.

[41] During the 2005 General Election much concern was voiced that prisoners did not have the vote but virtually none focused on children. On children and citizenship see Archard, D. (2004). *Children: Rights and childhood* (2nd Edition ed.). London: Routledge.

[42] And see John, M. (2003). *Children's rights and power*. London: Jessica Kingsley.

[43] Mayall, B. (2002). *A sociology of childhood*. London: Routledge Falmer.

[44] See note 23.

[45] See Gardner, H. (1993). *Children's consent to surgery*. Buckingham: Open University Press.; Hutchby, I. & E.J. Moran. (1998). *Children and social competence*. London: Falmer.

people who negotiate with others, and alter relationships or decisions or the making of social assumptions and constraints.[46]

Many who will accept this in regards to older children (teenagers, adolescents) may now be coming to accept that this applies to younger children too. For many, Priscilla Alderson's work on children's consent to surgery was revelatory[47] and as convincing as her monograph on young children's rights.[48] But babies, premature babies, small infants with special needs, the very people (if I'm allowed to use that word) who we are told are not even persons are excluded from this acknowledgement.

Psychologists recognise newborn babies as "agents creating their own environments in interactions with their caretakers."[49] Babies contribute to the parent – infant dyad and to their own development.[50] Alderson, Hawthorne and Killen in a recent paper wrote:

> Babies…seek comforting stimuli, and avoid and shut out unwanted stimuli by habituation (getting used to and coming to ignore repeated stimuli) and by going to sleep. They have a range of self-soothing behaviours, and they "speak" in an expressive language of sounds, facial expressions and body movements that can be "read". Babies vary greatly in how far they have a robust capacity to learn to handle multiple stimuli, to organise themselves to interact with the complex environment, and to control their states so that they can avoid becoming overwhelmed and disorganised. Babies also vary in how cuddly they are by nestling or moulding themselves against the carer's body, and in how readily they take part in social interactions, turning to sounds, tracking, gazing, smiling and becoming excited or irritable, as well as how soon they become exhausted, which they signal by becoming pale or mottled, with altered breathing, hiccoughs, yawns and regurgitating or gagging or crying'.[51]

This is enough, in my view, to establish babies as persons. It takes us away, of course, from the distanced objective view, at the root of orthodoxy, which sees the baby as an object. It may be objected that all that

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[46] See Mayall, B., *supra* note 43, 21.

[47] Alderson, P. (1993). *Children's consent to surgery*. Buckingham: Open University Press.

[48] Alderson, P. (2008). *Young children's rights*. (2nd ed). London: Jessica Kingsley.

[49] Bell, R. (1968). Reinterpretation of the direction of effects in studies of socialization. *Psychological Review, 75*(2), 81–95.

[50] See Wolke, D. (1989). Environmental neonatology. *Archives of Disease in Childhood, 62*(10), 987–988.

[51] Alderson, P., et al. (2005). The participation rights of premature babies. *International Journal of Children's Rights, 13*(1), 31–50, at 34. I derive enormous assistance from this excellent paper.

has been described here is biological. To this there are two responses: first, that should be enough (I appreciate this has implications for animals,[52] which I would not want to pursue). More significantly, it is more than biological, it is social, learned and responsive. Research interest is growing in how babies "participate" in their learning and social relationships, how they are even partners in their learning.[53]

The Newborn Individualized Developmental Care and Assessment Programme (NIDCAP) uses naturalistic observations of even the most fragile premature babies from birth to record their strengths and sensitivities – not note deficits.[54] Their behaviour or language is understood in three sub-systems: autonomic (breathing, heart rate etc); motor (body tone, posture, facial and body movements); and state (patterns of transferring between the states described earlier).[55] NIDCAP sessions last 60 – 90 minutes and observe the environment and the baby's behaviours and interactions with carers. This is done to educate and support caregivers and to plan care that will enhance the baby's wellbeing and competence. But it also offers important research evidence (as well, it may be added, assistance to NICUs, if only they take notice of it).

PREMATURE BABIES' RIGHTS

What rights do these babies have? Even for those prepared to countenance older children's rights, this may seem an outrageous question. I do not think it is. Let me take the obvious rights which may impact upon premature newborn babies. I'll use the statement in the *United Nations Convention on the Rights of the Child* (CRC) (though, of course, many of the rights to which I will refer are also in the European Convention on Human Rights). First, most obviously they are children within Article 1 of the CRC. Discrimination on grounds of "disability" is not countenanced (see Article 2). And decisions about all children are governed by a "best interests" criterion – this is clearly laid down in Article 3.

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[52] The writings of Peter Singer and Tom Regan may be consulted on this.

[53] See Greenfield, S. (2000). *The private life of the brain*. London: Penguin.

[54] See Als, H. (1981). *Manual for the naturalistic observation of the newborn (preterm and full term)*. Boston: Children's Hospital. See also Als, H. (1999). Reading the premature infant. In E. Goldson (Ed.), *Nurturing the premature infant* (pp. 18–85). New York: Oxford University Press.

[55] See Als, H., ibid.

The right to life is in Article 6 of the CRC: "every child has the inherent right to life (and) to the maximum extent possible survival and development."[56] Of course, for premature babies this right may conflict with the right to protection from torture (in Article 37), and with the right (in Article 6 itself) to the maximum extent possible of development, to the highest attainable standard of health (in Article 24) and to an adequate standard of living (in Article 27). Survival may mean a lifetime of suffering. This is why doctors and parents consider withholding treatment and subsequently withdrawing it. Withdrawing treatment may include withdrawing fluids and nutrition.[57]

Medical ethics is influenced by high expectations for a "reasonable" quality of life free from impairment and for an intellectual form of personhood, accompanied by low expectations of babies' capacities and awareness. As I have already indicated, many leading ethicists believe that babies are non-persons and therefore without human rights. Singer, for example, asserts they lack five "ethically relevant characteristics": consciousness; the capacity to interact with others; having conscious preferences for a continued life; having enjoyable experiences; and having relatives who will grieve at their death.[58] Read John Wyatt, on the other hand, and you will see a description of parents who relate to their premature baby as a unique, precious member of the human community, an individual with a history, an identity and a name, not a thing but a person to be treated with respect, a beloved child.[59]

The law (in England as elsewhere, and also as indicated already in the U. N. Convention) recognises premature babies are persons. Importantly, this reflects babies' own experiences and responses and adults' perceptions of these, as found in the research of Priscilla Alderson and her colleagues,[60] and others.[61] It is easy to dismiss the right to life "as if this is something that adults allow or support, and babies receive,"[62] But as Alderson et al report, "many premature babies

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[56] The right to life begins at birth and not, for example, at conception. Not all States Parties are happy with this, least of all the Holy See.

[57] See McHaffie, H. (2001). *Crucial decisions at the beginning of life*. London: Routledge.

[58] Singer, P. (1995). *Rethinking life and death*. Oxford: Oxford University Press. Contrast his views on animals.

[59] Wyatt, J. (1998). *Matters of life and death*. Leicester: Inter-Varsity Press.

[60] See note 51. Other articles are forthcoming.

[61] For example, Wyatt, J., *supra* note 59.

[62] See Alderson et al, *supra* note 51, 39.

put much energy and concentration into surviving as if consciously or not, they value their life."[63] The researchers cite one case – a baby born at 30 weeks – who soon after birth gazed at his mother's face, as if he depended on her loving support. They note: "The pleasure or reassurance that some babies evinced when held by their parents or by nurses they know well showed that, to some degree, that had all five of Singer's…'ethical' characteristics."[64] This baby's mother is quoted as describing "the life thing" as being "so strong, they'll fight and fight and fight and you start respecting them for that…they kind of keep going and you end up feeling really quite in awe of that."[65]

There are other rights too: name and nationality (see Article 7) and identity (Article 8) which are also important to this discussion.[66] This refers to personal characteristics and agency and to personhood. Included within this are emotions and memories. Though some might prefer to think that infants do not have these capabilities, research by Brazelton,[67] Als[68] and others[69] records emotional capacities, and Alderson et al saw or heard adults describe "babies who appeared to express hurt, misery, calm, contentment, relief, pleasure and excitement."[70] They quote a counsellor's view:

> Yes, I definitely think they have emotions and memories. I think they definitely know the difference between the touch of a parent and the touch of a nurse or doctor.…You can see the difference in the reaction when the parent arrives there is excitement it's incredible.[71]

There are many other rights,[72] but I will concentrate only on the key to understanding the baby as a person in the decision-making process. Article 12 of the Convention (CRC) endorses the child's right to express views freely in all matters affecting the child. The view of the child is to

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[63] Ibid.

[64] Ibid.

[65] Ibid.

[66] See the excellent discussion by Alderson, P. et al, *supra* note 51, 40.

[67] Brazelton, T. & J. Nugent. (1995). *Neonatal behavioral assessment scale*. London: Cambridge University Press.

[68] Als, H. (1999). Reading the premature infant. In E. Goldson (Ed.), *Nurturing the premature infant* (pp. 18–85). New York: Oxford University Press.

[69] For example, Murray, L. & L. Andrews. (2000). *The social baby*. Richmond: Children's Project Publishing.

[70] *Supra* note 51, 40.

[71] *Supra* note 51, 41.

[72] In relation to disabled children, see Article 23.

be given due weight according to the age and ability of the child.[73] Obviously, the absence of language inhibits the exercise of this right by babies and small children. Babies however, can cry and exhibit other behavioural characteristics to express distress, discomfort and pain and some are better at interpreting these "expressions" than others. We cannot be certain that babies "choose" to live or die. But we do not know that they have no views on how long they continue the effort to survive when they are extremely weak and ill. This calls into question why some babies are more resilient and why some can surmount greater problems than others. We cannot ignore a baby's agency. Alderson et al quote a neonatologist who thought there were qualities that enabled very sick children to cling to life. To quote Alderson et al again:

> Countless observed and reported examples in the four NICU showed that many adults were convinced that they were not mechanically caring for the unconscious organisms that some philosophers allege babies to be. Indeed, they were interacting within human relationships influenced by the babies' views.[74]

Understandings and Practices

There is, I believe, a chasm between what children's rights advocates believe, some continuing attitudes of well-known philosophers and some prevailing practices. I will concentrate here on the latter.

It is not surprising that the medical profession should be in some confusion. It can terminate the life of a severely handicapped foetus – in England at full term[75] – but killing babies with the most significant disabilities constitutes the crime of murder. Indeed, contemporaneous with "Baby Alexandra" was the trial of Dr Arthur.[76] This case centred on a baby, John Pearson, also with Down Syndrome, but lacking the physical issues from which Alexandra suffered which in her case

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[73] See Franklin, A. & P. Sloper. (2005). Listening and responding? Children's participation in health care within England. *International Journal of Children's Rights, 13*(1), 11–29.

[74] *Supra* note 51, 46.

[75] Under the *Abortion Act* 1967, s1 (1)(d). On the meaning of severe handicap see Scott, R. (2005). Interpreting the disability ground of "The Abortion Act". *Cambridge Law Journal, 64*(2), 388–412.

[76] *R v Arthur* (1981) 12 BMLR 1; and see Gillon, R. (1985). An introduction to philosophical medical ethics: The Arthur case. *British Medical Journal, 290*(6475), 1117–1119.

required surgery. But, as in Alexandra's case, the child was rejected by his parents. Dr Arthur, a paediatrician of high repute, wrote in his notes: "Parents do not wish it to survive. Nursing care only." John Pearson died 69 hours later. Dr Arthur was acquitted of attempted murder.[77]

It is difficult to understand why he was not convicted. This was not a medical decision to withhold treatment but a social one. Courts rarely contradict clinical decisions but this decision had no clinical basis. John Pearson was expressing in the only way he could a determined will to live. Yet the President of the Royal College of Physicians commented:

> Where there is an uncomplicated Down's case and the parents do not want the child to live…I think these are circumstances where it would be ethical to put it upon a course of management that would end in its death…I say that with a child suffering from Down's and with a parental wish that it should not survive, it is ethical to terminate life.[78]

Observe the language used here. The child is an "it"[79] and medical non-treatment is "a course of management."

The case law has moved on but practice has not necessarily done so. It is at its most inflexible in the Netherlands where, under the so-called Groningen model, babies of 23 and 24 weeks gestation are allowed to die and those who have reached 27 weeks are resuscitated.[80] Those in between, live or die according to their parents' wishes. In Britain practice is variable: some, more specialist institutions like University College Hospital, take a robust interventionist position, others a more laissez-faire "wait and see" approach. Of course, this means that life or death for these most vulnerable of our citizens – I use this word deliberately – is dependent on a geographical lottery. Decisions are informed by empirical data on such matters as the relationship between survival at a particular point of gestation and disability, but, of course, it is as a result of such ethical decisions that we have the data to start with. The circularity of the decision-making process is not, I fear, always appreciated.

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[77] He was originally charged with murder but the charge was reduced when it became clear that the child had not been physically healthy.

[78] (1981). *Butterworths Medico-Legal Reports 12:*1, 21–22. An insight into practices 20 years on is Kmietowick, Z. (2001). Down's children received "less favourable" hospital treatment. *British Medical Journal, 322:* 815: it is not so very different.

[79] On which see Saunders, B. J. & C. Goddard. (2001). The textual abuse of childhood in the English-speaking world: The contribution of language to the denial of children's rights. *Childhood, 8*(4), 443–462.

[80] See *The Times*, 26 April 2005, 6.

Case Law Post–Arthur

There are many discussions of the case law of the last quarter of a century.[81] I can therefore be brief. The template was set by *Re B* (Baby Alexandra).[82] The ruling was succinctly put by Dunn L. J.: "She should be put in the position of any other mongol (*sic*) child and given the opportunity to live an existence."[83] The test is clearly one of best interests of the child, though this does not tell us very much. Indeed Templeman L.J. noted, "There may be cases…of severe proved damage where the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion."[84]

Re B was an easy case to decide – or should have been. So was *Re C* in 1989.[85] The child here was moribund. The hospital was given authority to treat her so as to allow her to die peacefully and with dignity. The test was her best interests.

More difficult was *Re J* a year later, because J was not dying.[86] He had brain-damage, suffered from repetitive seizures and periods when he stopped breathing for which he required ventilation. The question was what was to be done if he suffered a further collapse. The Court of Appeal ruled that, "it would not be in J's best interest to reventilate him in the event of his stopping breathing unless to do so seems appropriate to the doctors caring for him given the prevailing clinical situation."[87]

The court made four significant points. First, whilst there is a strong presumption in favour of a course of action that will prolong life, the decision-maker must look at it from the perspective of the patient, that is undertake a "substituted judgment." Secondly, it was necessary to look to quality of life, including pain, suffering and distress. Thirdly, the court saw the decision-making as a co-operative effort between the doctors and parents (or where the child, as commonly, had been warded, between the doctors and the court with the views of the parents

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[81] A good recent one is Read, J. & L. Clements. (2004). Demonstrably awful: The right to life and the selective non-treatment of disabled babies and young children. *Journal of Law and Society, 31*(4), 482–509.

[82] *Re B* [1981] 1 WLR 1421.

[83] Ibid., 1425.

[84] Ibid., 1424.

[85] *Re C* [1989] 2 All E R 782.

[86] *Re J* [1990] 3 All E R 930.

[87] Ibid., 933.

being taken into consideration). The decision was to be taken in the best interests of the child. And, fourthly, it was stressed, as it so often is in end of life decisions about adults, that the debate was not about terminating life but about withholding treatment designed to prevent death from natural causes.[88] Thus, Taylor L.J. stressed:

> The court never sanctions steps to terminate life.…There is no question of approving, even in a case of the most horrendous disability, a course aimed at terminating life or accelerating death. The court is concerned only with the circumstances in which steps should not be taken to prolong life.[89]

In 1992 in (another) *Re J*[90] the Court of Appeal emphasised clinical autonomy.[91] Balcombe L.J. could conceive of "no situation where it would be a proper exercise of the jurisdiction…to order a doctor, whether directly or indirectly, to treat a child in a manner contrary to his or her clinical judgment."[92] And he would go further: "I find it difficult to conceive of a situation where it would be a proper exercise of the jurisdiction to make an order positively requiring a doctor to adopt a particular course of treatment in relation to a child."[93]

A problem occurs where parents and doctors cannot agree on the appropriate course of action. And this has happened in several high profile cases. In *Re C*[94] the parents were Orthodox Jews who believed that life should always be preserved. The child, 16 months old, had incurable spinal muscular atrophy, but was conscious, able to recognize her parents and to smile. Parents and doctors disagreed as to what should happen if she suffered a further respiratory relapse: the doctors did not want to reventilate her, but the parents could not agree to this. To follow the parents' wishes "would be tantamount to requiring the doctors to undertake a course of treatment which they are unwilling to do. The court could not consider making an order which would require them to do so."[95] The medical evidence was clear – spinal

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[88] But note Shaw A's comment on this in "Doctor, Do We Have A Choice?" *New York Times Magazine*, January 30 1972, 54.

[89] *Re J, supra* note 86, 943.

[90] *Re J* [1992] 2 FLR 165.

[91] As it had done in *Re R* [1992] Fam 11, 26.

[92] *Supra*, note 90, 175.

[93] Ibid.

[94] *Re C* [1998] 1 FLR 384.

[95] Ibid., 390.

muscular atrophy is a "no-chance situation."[96] The court gave leave to the hospital to withdraw treatment and not attempt resuscitation in the event of respiratory arrest. This was in C's best interests.

There was conflict between parents and doctors also in *A National Health Service Trust* v *D*.[97] This is the first reported case in which the European Convention on Human Rights was raised. There was held to be no infringement of Article 2 of this Convention because the order was made in the best interests of the child. The judge also confirmed that Article 3 of the Convention embraced the right to die with dignity, a phrase of enormous significance, though not one upon which the judge expanded.

This brings me back to the two cases with which I started this article: Charlotte Wyatt and Luke Winston-Jones.[98] Both cases received enormous media coverage: Charlotte Wyatt in particular was front page news. But the principles applied are merely a re-affirmation of those established in the line of cases previously discussed. Luke Winston-Jones, who had an incurable genetic condition resulting in severe cardio-respiratory dysfunction, died shortly after the litigation. Charlotte Wyatt defied her prognosis of her surviving for 12 months, and lived well beyond her second birthday.[99]

Initially, in the *Wyatt* case, the hospital was permitted to cease further aggressive treatment, since even though it might prolong life, it was not in the child's best interests.[100] But by the time of the appeal,[101] nearly 11 months later, there appeared to be major changes in Charlotte's condition. In October 2004 she was said to be in constant pain: in late August 2005 she was said to be pain-free most of the time. In October 2004 it was believed that she could derive no pleasure from life: in August 2005 she was believed to enjoy her bath and being tickled.

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[96] And see Royal College of Paediatrics and Child Health. (1998). *Withholding or withdrawing life saving treatment in children: A framework for practice*. London: Royal College of Paediatrics and Child Health.

[97] *A National Health Service Trust* v *D* [2000] 2 FLR 677.

[98] Discussed in Meyers, D. W. (2005). *Wyatt* and *Winston-Jones:* Seriously ill babies and who decides to treat or let die? *Edinburgh Law Review, 9*(2), 307–316. ; and Brazier, M. (2004). Letting Charlotte die. *Journal of Medical Ethics, 30*(6), 519–520.

[99] Media reports on the 24th February 2006 suggest she is dying. In the meantime the strain posed by the case has led to her parents marriage breaking down and an attempt at suicide by her father.

[100] *Supra* note 1.

[101] *Wyatt v Portsmouth Hospital NHS and Wyatt (by her Guardian) (No 3)* [2005] 2 FLR 480.

In October 2004 it was said she could not see: in late August 2005 she was looking at toys above her head and deriving pleasure from following objects in front of her. In October 2004 she had, it was said, no sense of sound: in late August 2005 it was thought that she might well have relatively good hearing. In October 2004 it was said she could make no deliberate actions: in late August 2005 it was believed she had attempted to hold a bauble. Whereas once she had been a "prisoner" in an oxygen box that fed her 95% oxygen because of her fragile lungs, at the time of the appeal she was spending several hours a day with just a nasal tube, could sit in a chair and was sometimes taken outside the hospital.[102]

The parents returned to court in 2005 and asked that the declaration for non-treatment be set aside. Once again the court was persuaded by the medical opinion that Charlotte should not be resuscitated if she suffered a serious respiratory collapse. Hedley J gave three reasons. First, there was a doubt that Charlotte could survive even with full ICU treatment. Secondly, even if she did, it would result in a significant deterioration in her condition. Thirdly, the whole experience of ICU treatment would, "imperil a peaceful death."[103]

The case returned to court – each time to the same judge[104] – in late February 2006.[105] Hearing that there had been a significant deterioration in Charlotte's condition, the court ruled that doctors could let her die: "Medical evidence speaks with one voice, that ventilation simply will not achieve the end for which no doubt the parents would wish." As at the point of writing, she is still alive. It seems unlikely there will be further applications.

In all these cases the courts have sided with the doctors. But suppose it were to prefer the parents' assessment of the child's best interests? It may be a doctor's duty to refer such a situation to a colleague. But if s/he does not do this? The clearest example of such a conflict is the *Glass* litigation, which was pursued to the European Court of Human Rights.[106] The case centred not on a baby, but on a severely mentally and physically handicapped adolescent, who had required ventilation.

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[102] See *The Guardian*, 26 August 2005.

[103] [2005] All ER (D) 278 (April).

[104] Hedley J.

[105] *The Guardian*, 25 February 2006.

[106] *Supra* note 30 and see Huxtable, R. & K. Forbes. (2004). *Glass v UK*: Maternal instinct v medical opinion. *Child and Family Law Quarterly, 16*(3), 339–354.

The mother opposed the use of morphine or drugs to relieve distress in the future treatment of her son and expected him to receive resuscitation should his heart stop. When his condition deteriorated, the doctors, who believed the boy was dying, wanted to administer diamorphine as pain relief. A "do not resuscitate" order was put on his notes without the mother's consent. The mother believed her son was being covertly euthanised. It led to a fight between the family and the doctors. The mother successfully resuscitated her son, who later improved and was discharged home. It was alleged that English law (and practice) failed to ensure effective respect for the child's right to physical and moral integrity within the meaning of "private life" under Article 8 of the European Convention. The court agreed. However, there would not have been a breach if the doctors had applied to the court, rather than bringing in the police. Had they done so, it is likely that the court would have granted a declaration authorizing non-treatment. David Glass would have died, it would seem, unnecessarily. The *Glass* case thus offers a mixed message: encouraging in showing the potential of human rights legislation, but less promising in offering doctors a way out.

Concluding Comments

There are no easy answers. And there can be no easy conclusion. We have undervalued the lives of babies with disabilities and high care needs. Of that there can be no doubt. Pre-"Baby Alexandra," only a generation ago, they were not given exposure to argument in a court. She was not the first baby with Down syndrome who had an intestinal blockage. Clearly many Alexandras just died, either on a doctor's advice or a parent's request. That there is a spate of litigation now is, therefore, reassuring. The focus must be on the child. It is important that not only are the child's best interests considered, but that they are the only consideration. It is all too easy to defer to convenience or employ utilitarian considerations (it is obviously costly to keep these babies alive). A children's rights approach to this subject will emphasise that even the most premature are persons within the meaning of the UN Convention and that discrimination against them because of their disabilities is unacceptable, and that decisions must be taken in their best interests.[107]

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[107] See Davis, A. (1983). Right to life of handicapped. *Journal of Medical Ethics, 9*(3), 181.

It will also not ignore their participation rights[108] and, as we have seen, even the most premature and perhaps even the most handicapped are capable of exercising some agency. But if we accept that adults have the right to die with dignity, that dying is part of the living process and that therefore the right to life includes a right to choose death, we must acknowledge that there will be situations where we should not impose life on babies whose only experience is pain.[109]

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[108] See Cavet, J. & P. Sloper. (2005). Participation of disabled children in individual decisions about their lives. *Children and Society, 18*(4), 278–290.

[109] On quality of life see Boddington, P. & T. Podpadec. (1992). Measuring quality of life in theory and in practice: A dialogue between philosophical and psychological approaches. *Bioethics, 6*(3), 201–217; Campbell, N. (1994). When Care Cannot Cure: Medical Problems in Seriously Ill Babies. In Beller, F.K. & R.F. Weir (Eds.) *The Beginning of Human Life*, Kluwer, Dordrecht.

INVOLUNTARY TREATMENT, HUMAN DIGNITY AND HUMAN RIGHTS

Genevra Richardson

Respect for individual autonomy emerged as the dominant principle of Western bioethics during the second half of the twentieth century. From autonomy grew consent. Involuntary treatment administered in the absence of consent, stands in apparent opposition to these prevailing values. In the context of involuntary treatment, consent may be absent either because the patient lacks the capacity to make the necessary decisions or because treatment is imposed despite a capable refusal. While both cases raise issues of personal autonomy, they do so in rather different ways. This chapter will consider the question of involuntary treatment against a background of general human rights principles. While the provision of treatment for mental disorder[1] will provide the main focus, because it is here that many of the most sensitive issues have arisen, reference will be made to treatment for other forms of disorder where relevant. By way of introduction a brief account of the relevant international instruments will be provided. The law will then be considered, first in relation to adults who lack capacity and then, more controversially, in relation to those who retain capacity but are still vulnerable to the imposition of medical treatment.

A. Human Rights Principles

In relation to the provision of medical treatment, as in so many other areas, the relevant human rights principles do not invariably pull in the same direction. Certainly the importance of self-determination and respect for personal autonomy has been recognised since the early years of the last century. In 1914 Cardozo J was able famously to claim,

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[1] Editors' Note: The language describing psychiatric disability used in this chapter is the language of the law in the UK at the time the chapter was written. This predates the introduction of the Mental Health Act 2007 and the UN Convention on the Rights of Persons with Disabilities. The analysis of the law in this chapter remains sound, despite the changes which have been made to the law since this chapter was submitted.

"Every human being of adult years and sound mind has a right to determine what shall be done with his own body."[2]

The same principle has been reflected internationally in the rights guaranteed by article 17 of the *International Covenant on Civil and Political Rights* (ICCPR) and article 8.1 of the *European Convention on Human Rights* (ECHR): article 8.1 states, "Everyone has the right to respect for his private and family life, his home and his correspondence."

In the European context it is now well established in the jurisprudence of the European Court of Human Rights (ECtHR) that these article 8 rights extend to physical integrity and self determination and would be engaged by the imposition of medical treatment without consent (see below). The *European Convention on Human Rights and Biomedicine* 1997 (CHRB) is even more specific. According to article 5 of that Convention, "An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it."

Similarly, article 12 of the *International Convention on Economic, Social and Cultural Rights* (*ICESCR*) provides for the right to the highest standard of physical and mental health, and in elaborating on that article the Committee on the (*ICESCR*) has observed "The right to health contains both freedoms and entitlements. The freedoms include…the right to be free from…non-consensual medical treatment and experimentation."[3]

Against this background must be set the increasing emphasis on human dignity. According to article 1 of the European CHRB:

> Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.

And in *Pretty v United Kingdom,* the ECtHR explained, in relation to the ECHR, that, "The very essence of the Convention is respect for human dignity and human freedom."[4]

The renewed emphasis on human dignity in rights discourse has led to some speculation about its precise relationship to self-determination, a debate which has particular relevance in bioethics.[5] In essence human

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[2] *Schloendorff v Society of New York Hospitals* (1914) 105 NE 92 at 93.

[3] ICESCR 2000, para 8.

[4] *Pretty v UK* (2002) 35 EHRR 1 at para 65.

[5] Beyleveld, D. & R. Brownsword. (2001). *Human dignity in bioethics and biolaw.* Oxford: Oxford University Press.

dignity can be regarded as an empowering notion linked to individual autonomy and self-determination. A respect for human dignity implies respect for the choices and preferences of individuals.[6] Or, alternatively, it can be seen as constraining, as placing limits on individual choice in order to protect some more general notion of human dignity such as the sanctity of human life.[7] In bioethics this distinction carries particular significance in the context of the debates surrounding for example, end of life decisions, or human embryonic stem cell research and therapeutic cloning. With regard to embryonic stem cell research and therapeutic cloning the constraining approach to human dignity may be seen to underpin the restrictive attitudes adopted in many European and American jurisdictions. Arguably it may also be seen in the paternalistic approach which has dominated attitudes towards the provision of treatment for mental disorder in many jurisdictions (see below).

In the specific context of treatment for mental disorder there are a number of international statements to be noted. In 1991 the General Assembly of the United Nations adopted *Principles for the Protection of Persons with Mental Illness and for the improvement of Mental Health Care*.[8] Principle 11 deals with treatment and sets out the general principle of informed consent (11(1)). However, Principle 11(6) provides that treatment without consent may be given, subject to the usual safeguards, if the patient is "held as an involuntary patient." This immediately appears to deny the right of self-determination to all involuntary patients whatever their level of decision making capacity and whatever their own individual preferences.[9] More recent statements from the Council of Europe reflect a rather different approach.

Standards published by the Committee for the Prevention of Torture (CPT) in 2004 state in paragraph 4 that:

> Patients should, as a matter of principle, be placed in a position to give their free and informed consent to treatment. The admission of a person to a psychiatric establishment should not be construed as authorising

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[6] Hale, B. (2005). What can human rights do for my mental health? *Journal of Mental Health Law, 12*, 7–16.

[7] Feldman, D. (1999). Human dignity as a legal value – part 1. *Public Law, 44*, 682–702.

(2000). Human dignity as a legal value – part 2. *Public Law, 45*(61), 76.; Beyleveld & Brownsword (2001), *supra* note 5.

[8] United Nations. (1991). *Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care.* UN Doc. G.A. Res 46/119.

[9] Gendreau, C. (1997). The rights of psychiatric patients in the light of the principles announced by the United Nations. *International Journal of Law and Psychiatry, 20*(2), 259–278.

> treatment without his consent. It follows that every competent patient, whether voluntary or involuntary, should be given the opportunity to refuse treatment or any other medical intervention. Any derogation form this fundamental principle should be based on law and only relate to clearly and strictly defined exceptional circumstances.

Further, in September 2004 the Committee of Ministers of the Council of Europe published a Recommendation to member states *Concerning the protection of the human rights and dignity of persons with mental disorder*. In the first place, article 3 of that recommendation prohibits "any form of discrimination on grounds of mental disorder." Article 12 concerns consent and provides that "treatment may only be provided to a person with mental disorder with his or her consent if he or she has the capacity to consent." However, this is made subject to a number of further articles which deal with involuntary treatment in certain situations. Article 18, for example, provides that involuntary treatment can be given under the following conditions:

> i. the person has a mental disorder;
> ii. the person's condition represents a significant risk of serious harm to his or her health or to other persons;
> iii. no less intrusive means of providing appropriate care are available;
> iv. the opinion of the person concerned has been taken into consideration.[10]

These statements of the Council of Europe are not directly binding on domestic courts. Even the CHRB, signed by a majority of members of the Council of Europe, has yet to be fully ratified. The CHRB has, however, been referred to directly by the ECtHR and it is certainly possible that its provisions will be used increasingly by the Court in the interpretation of article 8.2 of the ECHR which describes the circumstance in which the right to self-determination can be overridden.[11]

B. Treatment in the Absence of Consent: Adults Who lack Capacity

In most developed jurisdictions the law respects the treatment decisions of adult patients. Individuals are free to refuse medical treatment

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[10] Available online: https://wcd.coe.int/wcd/ViewDoc.jsp?id=775685&BackColorInternet=DBDCF2&BackColorIntranet=FDC864&BackColorLogged=FDC864

[11] Plomer, A. (2005). *The law and ethics of medical research*. London: Cavendish Publishing.

for whatever reason. In this way the law recognises and reflects the principle of autonomy, but only those adults deemed capable of making the relevant decisions will be regarded as capable of making autonomous choices worthy of respect. Treatment choices made in the absence of capacity will not be respected as autonomous decisions by the law. Thus most developed jurisdictions make specific legal provision for treatment decisions to be made on behalf of adults who lack the necessary capacity to make those decisions themselves.[12] Typically a two-stage process will be adopted.[13] Firstly, the individual's decision-making capacity will be assessed and secondly, if capacity is found to be lacking, an appropriate treatment intervention will be identified. For the purposes of the assessment, the relevant concept of capacity or competence (the terms are being used interchangeably here) will be that defined by law. The law provides the definition of capacity against which an individual's ability to make decisions is assessed. This is no easy task and there is an extensive literature discussing the relationship between legal, ethical and medical notions of capacity and the difficulties encountered in its practical assessment.[14] In England and Wales the most recent statutory formulation of decision-making capacity in this context is that found in the *Mental Capacity Act* 2005. According to that Act, a person lacks capacity if, due to "an impairment of, or a disturbance in the functioning of, the mind or brain" he is unable to make a decision for himself[15] and:

> a person is unable to make a decisions for himself if he is unable:
> a) to understand the information relevant to the decision,
> b) to retain that information,
> c) to use or weigh that information as part of the process of making the decision, or
> d) to communicate his decision.[16]

These statutory criteria, which are to be interpreted disjunctively, evolved following a lengthy consultation initiated by the Law

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[12] Richardson, G. (2002). Autonomy, guardianship and mental disorder: One problem, two solutions. *Modern Law Review, 65*(5), 702–723.

[13] McCubbin, M. & D. Weisstub. (1998). Towards a best interest model of proxy decision making for incompetent psychiatric patients. *International Journal of Law and Psychiatry, 21*(1), 1–30.

[14] Hotopf, M., et al. (2005). *Mental capacity: A systematic review of empirical research.* London: Department of Health.

[15] section 2(1).

[16] section 3(1).

Commission in the 1990s and they largely, but not entirely, reflect the principles developed through the case law. They are intended to provide a working definition of decision-making capacity which can be readily understood and applied and which is not so demanding that few of us would ever be assessed as capable. It is too early to know whether they have succeeded in these aims, but the concerns expressed to date relate mainly to their application to psychiatric disorders (see discussion below).

Once the first stage has been completed and a lack of capacity has been established, the law will typically provide for decisions relating to medical treatment to be made on behalf of the individual in his or her best interests. Again the notion of best interests has been the subject of much debate. Essentially the choice lies between notions of best interest, which emphasise the doctor's ability to determine, paternalistically, what is in the best interests of the patient, and those which seek to reflect as far as possible the individual's own preferences and values. In recent years the tendency has been to encourage the latter approach. The approach adopted by the *Mental Capacity Act* 2005 in England and Wales (section 4) can be seen as an attempt to combine the two. As the Explanatory Notes[17] explain, "best interests is not a test of "substituted judgment" (what the person would have wanted), but rather it requires a determination to be made by applying an objective test as to what would be in the person's best interests." But the list of factors which have to be taken into account include the person's past and present wishes, beliefs and values.[18]

As far as the common law in England and Wales is concerned, the courts have made it clear that professional medical judgment is simply the starting point: established medical opinion alone cannot define an individual's best interests. Once it is established that a particular intervention is acceptable according to a body of responsible medical opinion it is then necessary to determine whether the intervention is also in the individual patient's best interests and this determination will involve, "broader ethical, social, moral and welfare considerations."[19] In the sensitive context of the sterilisation of adults who lack capacity this

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[17] TSO (The Stationery Office). (2005). *Mental Capacity Act 2005, Explanatory Notes*, TSO, London.

[18] section 4(6).

[19] *Re S (adult patient: sterilisation)* [2001] Fam 15 per Dame Butler-Sloss.

enables the court to consider the full cultural and social background to each individual case.[20]

Arguably, it is in the determination of best interests that a tension can emerge between self-determination and autonomy on the one hand, and a constraining approach to human dignity, as represented for example by the principle of the sanctity of life, on the other. This is particularly evident in the context of end of life decisions. In recent years the courts in England and Wales have tended to elevate self-determination above the sanctity of life when the two have been in apparent conflict. In *Bland,*[21] a case involving the withdrawal of treatment from a young adult who had suffered severe brain damage in a football stadium accident and had relapsed into a persistent vegetative state, Lord Goff declared that just as the sanctity of life must yield to the principle of self-determination in the case of a competent refusal of life saving treatment, so must the doctor's duty to act in the best interests of the incapable patient. In the opinion of the House of Lords, since it was not in the patient's best interests to prolong his life, it would be lawful to withdraw treatment.

In a rather different context the ECtHR has had to consider the application of article 3 (prohibiting torture and inhuman or degrading treatment) to the forcible treatment of an incapable patient detained in a psychiatric hospital. In *Herczegfalvy v Austria*[22] the ECtHR held that there was no breach of article 3 where a patient was forcibly fed and sedated and handcuffed to the bed. The Court had accepted that the "position of inferiority and powerlessness which is typical of patients confined in psychiatric hospitals call for increased vigilance," and that the protections of article 3 applied and "permit of no derogation."[23] Nevertheless the Court was satisfied that the treatment of Mr Herczegfalvy was justified on the grounds of therapeutic necessity and could not therefore be regarded as inhuman or degrading. Further, the same principle of medical necessity was applied to the alleged breach of article 8, in the context of which the Court attached "decisive weight" to the state and hospital's opinion that Mr Herczegfalvy was, "entirely incapable of taking decisions for himself."[24] It is interesting to

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[20] Mason, J.K. & R.A. McCall Smith. (2002). *Law and medical ethics* (6th ed.). London: Butterworths., chapter 4 and Practice Note 2001.

[21] Airedale NHS Trust v Bland [1993] 1 All ER 821, 864.

[22] *Herczegfalvy v Austria*, *supra* note 21.

[23] Ibid., at para 82.

[24] Ibid., at para 86.

examine the significance of incapacity here. Had Mr Herczegfalvy been capable and refusing it must be assumed that a breach of article 3 would have been found. As Baroness Hale has asked, "Why should it be acceptable to treat an incapacitated person in a way which would be degrading if done to a capacitated person?"[25] If an intervention is inhuman or degrading when applied to a capable person against his or her will, why is it any less so when the recipient is incapable? Then there is the possible distinction between treatment for mental disorder and treatment for physical disorder, particularly in relation to article 8. Had Mr Herczegfalvy been incapable and given treatment for a physical disorder, would such a generous test of "medical necessity," to be judged simply according to the "psychiatric principles generally acceptable at the time,"[26] have been applied by the Court? Certainly according to current English common law principles the test of best interests which would now be applied in cases of incapacity would have to take account of the "broader ethical, social, moral and welfare considerations" referred to by Dame Butler-Sloss, above.

C. Treatment in the Absence of Consent: Adults Who Have Capacity and Who Refuse Treatment

Any power to impose medical treatment on capable individuals in the absence of their consent would constitute an immediate breach of the central principles of self-determination and respect for patient autonomy. Therefore, in order to justify any such powers their use would need to be restricted to the most exceptional circumstances. It is unfortunately necessary in this context to distinguish treatment for physical disorder from treatment for mental disorder.

1. *Treatment for Physical Disorder*

In relation to involuntary treatment for physical disorder, the UK courts are clear that a capable adult is free to refuse medical treatment even if her death will inevitably result.[27] A similar approach is reflected in the judgment of the ECtHR in *Pretty*[28] (see below). Neither the

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[25] Hale (2005), *supra* note 6, 11.

[26] *Herczegfalvy v Austria supra* note 21, 83.

[27] Re B v NHS Hospital Trust [2002] 2 All ER 449.

[28] *Pretty, supra* note 4.

principle of the sanctity of life nor the desire to protect the patient herself from harm can be allowed to override the principle of self-determination. In relation to the protection of the rights of others the position is not so clear. Many jurisdictions do make, or have made, provision for the compulsory treatment of certain infectious diseases, and some have introduced compulsory vaccination schemes for diseases such as smallpox. However, as a recent survey of selected European jurisdictions shows, there is no uniform pattern[29] and some countries have a strong tradition of reliance on a voluntary and consensual approach to the control of infectious disease.[30] Indeed the current statutory framework providing public health powers in relation to communicable disease in England and Wales, the *Public Health (Control of Disease) Act* 1984, makes no provision for compulsory treatment, as opposed to compulsory detention in hospital, and broadly similar powers exist in Scotland and Northern Ireland. In the UK, at least, there appears to be a greater reluctance to infringe the right to physical integrity in the interests of public health than to infringe the right to liberty of the person through hospital detention. However, the growing public health fears concerning both new pandemics, such as SARS and avian flu, and the re-emergence of old diseases, such as tuberculosis, in a more potent guise, have led to some reconsideration of these powers.

With regard to international instruments, the provisions of the ECHR (article 8) and the CHRB (article 5), which enshrine the principle of informed consent, have already been referred to. Article 26 of the CHRB, in language reminiscent of article 8 of the ECHR, describes the circumstances in which the right to informed consent may be restricted. In relation to treatment for physical disorder the Explanatory Report notes that, "the exceptions defined in the article are aimed at protecting collective interests (public safety, the prevention of crime, and the protection of public health) or the rights or freedoms of others,"[31] and provides the "compulsory isolation of a patient with a serious infectious disease, where necessary," as, "a typical example of an exception for reason of the protection of public health."[32] Significantly the Explanatory Report refers to involuntary treatment, as opposed to isolation, only in

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[29] Martin, R. & R. Coker. (2005). *Public health powers and infectious disease: A European study*. London: Paper presented at the W.G. Hart Workshop.

[30] Baldwin, P. (2005). *Disease and democracy: The industrialised world faces AIDS*. Los Angeles: University of California Press.

[31] Ibid., at para 149.

[32] Ibid., at para 150.

relation to treatment for mental disorder. Both international instruments and many domestic codes, it seems, display considerable reluctance to restrict the principles of self-determination and autonomy in relation to the provision of medical treatment for physical disorder even when it comes to the protection of others. The attitude to treatment for mental disorder is significantly different.

2. *Treatment for Mental Disorder*

While jurisdictions are typically reluctant to provide for the compulsory imposition of treatment for physical disorder, there is rarely any such reluctance in the case of treatment for mental disorder. Specialised legislation commonly provides for the involuntary treatment of people with mental disorder of the required severity and rarely stipulates that lack of capacity must be established before any such powers are used. Thus treatment for mental disorder can be imposed despite the patient's capable refusal. *The Mental Health Act* 1983, which currently applies in England and Wales, constitutes a clear example of such a legislative provision. Part IV of the *Act* allows for the administration of medical treatment for mental disorder despite the patient's capable refusal. Until quite recently this was not perceived as raising any particular difficulties, provided the necessary safeguards were in place. The values of beneficence and social protection were simply allowed to prevail. However, in the light both of the debate surrounding mental health law reform in the UK and of the incorporation of the ECHR into domestic law, the received wisdom is increasingly subject to question.[33] While some of the current discussion is specific to England and Wales, it raises fundamental questions of general relevance about the justification for imposing treatment on people with mental disorder despite their capable refusal. If the principles of patient autonomy and self-determination require that respect be given to a patient's competent refusal of treatment for physical disorder, why are these principles not

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[33] Expert Committee (1999) *Review of the Mental Health Act 1983,* Department of Health, London; Szmukler, G. (2001). A new mental health (and public protection) act. *British Medical Journal, 322*(7277), 2–3.; Zigmund, A. & A. Holland. (2000). Unethical mental health law: History repeats itself. *Journal of Mental Health Law, 3*, 49–56.; Richardson, G., *supra* note 11; Richardson, G. (in press). Balancing access, autonomy and public protection. In T. Carney & D. Weisstub. (Eds).

given the same weight in the context of treatment for mental disorder? What is the justification for affording less respect to patient autonomy and self-determination in relation to mental disorder? Can the apparent discrimination on grounds of mental disorder be justified?

In terms of the ECHR these questions engage articles 3, 8 and 14. Article 3 prohibits torture and inhuman or degrading treatment and it is certainly possible that the forcible treatment of a capable and objecting patient could be sufficiently severe to constitute a breach of that article. To date the jurisprudence of the ECtHR has set a relatively high hurdle which might in reality limit the potential relevance of article 3 to extreme cases, such as *Herczegfalvy*.[34] In *Pretty v UK*[35] the Court explained that the existing case-law, "refers to "ill-treatment" that attains a minimum level of severity and involves actual bodily injury or intense physical or mental suffering."[36]

However, in *Keenan v UK*,[37] a case involving a young man who had committed suicide in prison, the ECtHR had emphasised the need to consider the whole context in which the alleged ill-treatment had occurred:

> The Court recalls that ill-treatment must attain a minimum level of severity if it is to fall within the scope of Article 3. The assessment of this minimum is relative: it depends on all the circumstances of the case, such as the duration of the treatment, its physical and/or mental effects and, in some cases, the sex, age and state of health of the victim.[38]

In particular the Court reiterated the point made in *Herczegfalvy* that in the case of mentally ill persons it should "take into consideration their vulnerability and their inability, in some cases, to complain coherently or at all about how they are being affected by any particular treatment."[39] The Court also saw article 3 in terms of the protection of human dignity and explained that treatment could be in breach even though the mentally ill person may not be able to point to any specific ill-effects.[40]

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[34] *Herczegfalvy v Austria*, *supra* note 21.
[35] *Pretty*, *supra* note 4.
[36] Ibid., para 52.
[37] *Keenan v UK* [1998] EHRLR 648.
[38] Ibid., para 108.
[39] Ibid., para 110.
[40] Ibid., para 112.

The domestic courts in England and Wales have reiterated the need to take the whole context into account but no domestic case concerning the forcible treatment of a psychiatric patient in the UK has yet found that the circumstances have been sufficient to amount to a breach of article 3. In *R (PS) v W*[41] the High Court held that the oral application of anti-psychotic medication where there was no evidence of serious side effects did not meet the minimum level of severity required to establish a breach of article 3.[42]

Article 8 on the other hand, which guarantees respect for private life, is regarded as having considerable potential relevance in relation to autonomy and involuntary treatment. According to article 8(1), "everyone has the right of respect for his private and family life, his home and his correspondence," and it is now clear that this guarantee of respect for private life covers the physical and moral integrity of the person.[43] And, to quote from the ECtHR's decision in *Pretty v UK*, a case involving a terminally ill patient's right to die, "the imposition of medical treatment, without the consent of a mentally competent adult would interfere with a person's physical integrity in a manner capable of engaging the rights protected under article 8.1."[44] Similarly in a case involving the competent objections of the mother of a "severely handicapped child" the Court held that the decision to impose treatment on the child in defiance of the mother's objections, "gave rise to an interference with the [child's] right to respect for his private life, and in particular his right to physical integrity."[45]

Similarly, in the domestic context, the judiciary in England and Wales are becoming increasingly aware of the relevance of article 8(1). In 2002 the Court of Appeal accepted the argument that treatment of an adult against his or her competent wishes could constitute a breach of article 8(1) and, in a claim for judicial review of the legality of the decision to treat under powers provided by the Mental Health Act, held that the patient was entitled to call medical witnesses to give evidence and to be examined.[46] Later that year the Court of Appeal held that the second opinion doctor who approves the provision of treatment against

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[41] *R (PS) v G and W* [2003] EWHC Admin 2335.

[42] See also *Haddock* (2005).

[43] *X and Y v The Netherlands* (1985) 8 EHRR 235.

[44] *Pretty, supra* note 4, para 63.

[45] *Glass v United Kingdom* [2004] 1 FLR 1019 at para 70.

[46] *R (Wilkinson) v Broadmoor Special Hospital Authority* [2001] EWCA Civ 1545.

the competent wishes of a patient under the 1983 Act, "sanctions the violation of the autonomy of a competent adult patient," and must at least provide reasons.[47] In that context Lord Justice Sedley drew attention to the affirmative protection of personal autonomy recognised by article 8[48] (para 47). In effect article 8.1 might create a presumption in favour of the protection of personal autonomy which can only be rebutted on the part of the hospital authorities if they let the patient know "as a matter of right…in useful form and at a relevant time" what the reasons are for the "proposal to override his will."

As the judgments in the two cases described above indicate, the rights guaranteed by article 8.1 are not absolute. They are subject to the conditions contained in article 8.2:

> There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

It is therefore necessary to consider in what circumstances the involuntary treatment for mental disorder of competent adults might be considered as being, "in accordance with the law" and "necessary in a democratic society in the interests of…public safety," for example, or possibly, "the protection of health."

In the present state of the law it is certainly not possible to provide a definitive answer to these questions, but a few essential points can usefully be made. In the first place it is important to consider what might be meant by the term "necessary." Again *Pretty* (2002) provides some guidance: "according to the court's established case-law, the notion of necessity implies that the interference corresponds to a pressing social need and, in particular, that it is proportionate to the legitimate aim pursued."[49] If a similar approach is adopted in the context of mental disorder, then what might constitute a sufficiently "pressing social need?" It must be safe to assume that the protection of the life of others would and so, probably, would the protection of the life of the patient, but in the latter case the assumption might be more qualified. It is clear from cases like *Keenan v The UK* (1998) that article 2 (the right to life)

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[47] *R (Wooder) v Feggetter* [2002] EWCA Civ 554.

[48] Ibid., at para 39.

[49] *Pretty, supra* note 4, para 70.

can impose an obligation on states to take steps to preserve life, especially when the vulnerable person is in custody. But it is also clear that even such life-saving steps must respect the restraints imposed by article 8. The recognition by the court of the relevance of article 8 as a counterweight to a state's obligations to preserve life under article 2 suggests that an empowering notion of human dignity is being preferred over a more constraining approach. The state's interference with the privacy and autonomy rights of the individual under article 8 must not extend too far, even in the interests of the preservation of life.

The position becomes much more uncertain when the "pressing social need" is not the protection of the patient from suicide or death, but simply the protection of his or her "health or safety," as in section 3 of the *Mental Health Act* 1983 (England and Wales) or "the protection of other persons," where no level of gravity is specified as was in section 3 and in clause 9(4)(b) Draft Mental Health Bill 2004.[50] If the patient is incompetent to make treatment decisions herself, then presumably article 8.2 can be applied to permit the necessary steps to be taken to preserve her health. This was certainly the assumption made by the English Court of Appeal in *N v Dr M*.[51] In cases where the patient retains decision-making competence and refuses treatment the position is much more difficult. It is interesting here to recall the principles contained in the CPT Standards and the Council of Europe Recommendation described above. The CPT Standards require "exceptional circumstances" as a condition of any derogation from the fundamental principle of informed consent, while the Recommendation talks in terms of, "significant risk of serious harm to his or her health or to other persons" before involuntary treatment is acceptable. Certainly these statements are not directly binding on the ECtHR but a similar approach is taken by the CHRB. According to article 7 of that Convention a person who has a mental disorder of a serious nature may only be subject to involuntary treatment for that disorder in order to avoid *serious harm* to his health (my emphasis). As explained above, the ECtHR has been prepared to cite the CHRB in the context of its discussion of article 8.2, so the importance attached to self-determination by that Convention and the other statements from the Council of

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[50] Department of Health (2004) *Draft Mental Health Bill,* Cm 6305–1, The Stationery Office, London.

[51] *N v Dr M* [2002] EWCA Civ 1789.

Europe may yet influence the interpretation of article 8.2 in relation to the involuntary treatment of capable people with mental disorder.

It is certainly legitimate to argue that, if the protection from involuntary medical treatment afforded to competent adults by article 8.1 is to have any real force in the context of mental disorder, then the proviso contained in article 8.2 must be strictly drawn and the instruments cited in the previous paragraph would support such an interpretation. In the context of physical ill-health it seems highly unlikely that article 8.2 would permit the forcible administration of antibiotics in order to preserve the physical health of a competent adult, in the absence of truly exceptional circumstances. That being so it is hard to justify a different interpretation of the article in the context of mental ill-health. In the English High Court case of *R (PS) v W,*[52] referred to above, Silber J appears to import the common law test of best interests into the context of forcible medication under the *Mental Health Act* (1983) and suggests that treatment in the patient's best interests would be "in accordance with the law" and potentially acceptable under article 8(2).[53] This, however, represents a strange application of the English common law doctrine of best interests. In domestic law the notion of best interests would not be relevant in the case of a competent patient refusing treatment for physical disorder. In such a case respect for autonomy and self-determination would prevail and the refusal would be accepted, however contrary it might be to the patient's "best interests" as perceived by the medical profession. It is hard therefore to understand the basis on which Silber introduces the notion in relation to the competent refusal of treatment for mental disorder. If the argument is simply that best interests must be implied as a necessary component of the English statutory scheme, then forcible treatment of a psychiatric patient in her own best interests may be "according to law" in terms of article 8.2, but that alone cannot be sufficient to ensure compliance with the article. Why should the forcible medication of a competent adult simply to preserve her mental health be permitted under article 8.2 if forcible medication in the interests of her physical health would not be, however much it might be "according to law" and in her assumed "best interests?"

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[52] *R (PS) v W*, *supra* note 41.

[53] Bartlett, P. (2004). Capacity, treatment and human rights. *Journal of Mental Health Law, 10*, 52–65.

Of course the intensity of some mental disorders can vary over time and a patient's level of competence may fluctuate over the course of the disorder and its treatment. It may therefore be necessary to interpret the nature of the protection provided by article 8 in that light. The presence or absence of competence could not be contested at each drug round. However, in this context it is interesting to note the ECtHR's decision in *Glass*[54] where the Court found a breach of article 8 on the basis that the hospital authorities had overridden the mother's objection to the proposed treatment without first seeking authorisation from the domestic courts. There is no clear indication in the judgment of the precise circumstances in which such authorisation would be required when treatment in apparent breach of article 8(1) is proposed. But this ECtHR decision in combination with the domestic cases of *Wilkinson* (2002) and *Wooder* (2002) might suggest that any treatment plans which override competent refusals will have to be carefully justified. It is also relevant here to consider the doctrine of the state's margin of appreciation which might be used to provide the authorities with some flexibility.[55] But it is hard to believe that this doctrine could be employed simply to approve the provision of a forcible treatment power exclusively to the case of mental disorder, and in the absence of a threat of serious harm either to the patient or to others. It is also hard to believe that the exercise of such a power would be regarded as proportionate, particularly if the medication involved had significant side effects and the risks of non-treatment were not severe and had been understood and accepted by the competent patient.[56] In *R (PS) v W* Silber J placed considerable significance on the fact that the medication in question appeared to cause no adverse side effects in the patient.

Finally, in relation to the ECHR, the relevance of article 14 must be considered. Article 14 provides that Convention rights and freedoms, "shall be secured without discrimination on any ground." There follows a list of prohibited grounds which does not expressly include disability, but culminates with the words, "or other status." In *Pretty,* in the House

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[54] *Glass* [2004], *supra* note 44.

[55] Pannick, D. (1998). Principles of interpretation of convention rights under the human rights act and the discretionary area of judgement. *Public Law,* 545–551. Singh, S. et al. (1999). Is there a role for the margin of appreciation in national law after the human rights act? *European Human Rights Law Review, 1*, 4.

[56] Singh, R. (1997). *The future of human rights in the United Kingdom*. Oxford: Hart Publishing.; *Wilkinson* (2002), *supra* note 45.

of Lords, Lord Hope held that article 14 could extend to discrimination on grounds of physical or mental capacity, and it can be assumed that it would also extend to mental or physical disability. For the purposes of article 14 a difference in treatment is discriminatory, "if it has no objective and reasonable justification, that is if it does not pursue a legitimate aim or if there is not a reasonable relationship of proportionality between the means employed and the aim sought to be realised."[57] The ECtHR also remarked that Contracting States enjoy a margin of appreciation whether differences in treatment are justified.[58] However, article 14 does not provide a free standing prohibition on discrimination; it relates solely to discrimination in relation to the rights and freedoms guaranteed by other articles in the Convention. Further, in order to establish a breach of article 14, the individual must provide a comparator group whose situation is sufficiently similar to convince the court.[59] This can prove difficult – as in the English case of *R (PS) v W* – where the court refused to accept that patients with mental disorders who were not subject to formal statutory powers provided a suitable comparator group. In practice, therefore, although a breach of article 14 is frequently claimed, it seldom contributes conclusively to the determination of the case.

In the absence of definitive case law, of course all these arguments in relation to the ECHR remain speculative. Nevertheless, the jurisprudence of the ECtHR, particularly in relation to article 8, contains quite enough respect for patient autonomy to suggest that domestic policy makers should seriously reassess the traditional approach to involuntary treatment in the case of capable individuals with mental disorder. More specifically the government in England and Wales should reconsider its apparent refusal to countenance incapacity, in any shape or form, as an element within the criteria for the use of compulsory powers.[60] It has been consistently argued that it would be wrong in principle and unworkable in practice for the government to introduce new legislation perpetuating the denial of respect for patient autonomy.[61] It may

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[57] *Pretty, supra* note 4, para 88.

[58] Ibid.

[59] *Wandsworth LBC v Michalek* [2003] 1 WLR 617.

[60] Department of Health. (2005). *Government response to the report of the joint committee on the draft mental health bill 2004.* Cm 6624, The Stationery Office, London.

[61] Szmukler, G., *supra* note 32; Szmukler, G. & F. Holloway. (2000). Reform of the Mental Health Act: Health or safety. *British Journal of Psychiatry, 177*, 196–200.;

now be legitimate to add that to do so is likely to lead eventually to an embarrassing confrontation with the European Convention.

This is not to deny that the implementation of a capacity test in the context of mental disorder can be extremely difficult, as the Canadian Supreme Court case of *Starson*[62] has illustrated.[63] There are the practical problems of assessment referred to above. But in addition there is some reluctance to accept that a formal legal notion of capacity can reflect all the subtleties and complexities of mental disorder. Most legal definitions of capacity have been evolved in the context of guardianship and are designed to apply in relation to people with either severe communication difficulties or cognitive problems: learning disability, for example, or dementia and other organic brain syndromes.[64] Mental health legislation, by contrast, is typically concerned with the needs of patients with psychiatric disorders. In these circumstances it may not be sensible simply to adopt in mental health legislation a definition of capacity designed to be applied in a different context. In particular there is the question of insight. A patient might be legally competent yet might still fail to appreciate her illness and consequent need for treatment. While many would argue that this problem can be avoided with careful construction of a legal definition, it is evident that some see the problem of the lack of insight as a real hurdle to the application of self-determination in the field of mental disorder.[65]

In the United States, Grisso and Appelbaum have developed a descriptive definition of capacity to be used by clinicians in the context of psychiatric disorders.[66] Crucially this definition includes the notion of appreciation: to have capacity the person must have the ability to appreciate the significance of the treatment information for his or her own situation. In this way it seeks to meet the problem of insight. Yet some might argue that even this notion of appreciation fails to capture

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Zigmund, A. & A. Holland, *supra* note 32. Richardson, G., *supra* note 11; Richardson, G. (2005). The European and mental health law in England and Wales: Moving beyond process? *International Journal of Law and Psychiatry, 28*, 127–139.

[62] *Starson v Swayze* 2003 SCC 32.

[63] Rudnick, A. (2002). Depression and competence to refuse psychiatric treatment. *Journal of Medical Ethics, 28*, 151–155.; Van Staden, C. & C. Kruger. (2003). Incapacity to give informed consent owing to mental disorder. *Journal of Mental Health Law, 29*, 41–43.; Bartlett, P., *supra* note 52.

[64] Hotopf, M., et al., *supra* note 13.

[65] *R(B)* (2005).

[66] Grisso, T. & P. Appelbaum. (1998). *Assessing competence to consent to treatment.* New York: Oxford University Press.

the consequences of the delusional beliefs or unusual value systems present in some mental disorders.[67] In essence there is a difficult balance to be struck between definitions of capacity which are set so high that few of us would ever satisfy them, and those which are set so low that people with a pressing need for medical treatment would evade the imposition of the treatment they so evidently need. But, however difficult it might be to find that balance, respect for patient autonomy is central both to our understanding of the limits of state powers of intervention in health care and to the developing Strasburg case law on article 8 in relation to physical health care. In which case it becomes incumbent upon states either to explain why the rules should be different in relation to care and treatment for mental disorder or to abandon their discriminatory approach to mental disorder.

D. CONCLUSIONS

Any provision of medical treatment in the absence of the patient's consent comes into immediate conflict with the fundamental principles of self-determination and respect for individual autonomy. However, in the case of individuals who lack the capacity to make treatment decisions themselves the law has to provide a mechanism through which those decisions can be made on their behalf. If it did not do so it would be condemning incapable people to remain untreated. Typically the law will require that any treatment intervention in the case of an incapable adult be demonstrably for that individual's benefit or in his or her best interests. While in the past notions such as best interests were often understood in terms of professional judgment there is now much more emphasis on the need to reflect the individual's own values, preferences and wishes as far as they can be determined. It is an empowering rather than a constraining approach to human dignity that now prevails, even in the context of end of life decisions.

In the case of individuals who retain capacity, the principles of self-determination and autonomy should only be breached in exceptional circumstances and, in relation to treatment for physical disorder, the law would seem generally to reflect this imperative. We may refuse treatment even if death will inevitably result: self-determination will

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[67] Tan, J. (2003). The anorexia talking? *The Lancet, 362*, 1246.

trump the sanctity of life. Only in the case of immediate harm to others, as in relation to certain infectious diseases, do some jurisdictions allow for compulsory treatment, and even here countries such as the UK restrict their public health powers to hospital detention, not treatment.

In relation to treatment for mental disorder, however, the position is very different. Traditionally the otherwise universal principles have not been applied to mental disorder. The values of beneficence and social protection have prevailed. Treatment for mental disorder can be imposed in the face of a capable refusal in the interests of the patient's health or safety or for the protection of others. As is currently the case in England and Wales there is no requirement that the risk to the patient or to others be significant nor the harm serious. Increasingly the justification for this apparent discrimination against mental disorder is being questioned. Policy makers are being urged to reduce the gap between mental and physical disorder by introducing some requirement of incapacity or impaired decision-making before involuntary treatment for mental disorder can be considered. Such a solution is not without difficulty. The concept of capacity is far from straightforward and raises particular problems when applied in relation to certain psychiatric disorders.

Nonetheless, the current debate cannot be ignored. For too long those with mental disorders have suffered stigma and discrimination. Governments must be urged to reconsider laws which, by denying the application of universal ethical and human rights principles to the treatment of mental disorder, only serve to entrench this discrimination. If mental disorder is to be treated differently from physical disorder then the justification for that apparent discrimination must be specifically and expressly spelt out. The silent denial of human rights principles to those with mental disorder cannot be allowed to continue unchallenged.[68]

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[68] The law discussed in this chapter is correct as of October 2005.

SITES OF EXCLUSION: DISABLED WOMEN'S SEXUAL, REPRODUCTIVE AND PARENTING RIGHTS

Roxanne Mykitiuk and Ena Chadha

I. Introduction

"Women with disabilities commonly find themselves precluded from performing the major life functions commonly assigned to women."[1] This is nowhere more true than in the areas of sexuality, reproduction and parenting. While women generally are identified with, and indeed valorized for, their nurturing roles, sexual attractiveness and reproductive capacities, women with disabilities are all too often regarded as lacking in each case. Disability affects whether and how women are permitted to participate in sexual, reproductive and nurturing activities. In a culture where women are still defined, to a significant extent, as sexual beings, reproducers and nurturers, the "general culture limits disabled women's maternal occupation and leaves them 'roleless.'"[2] Thus, even in contemporary society, women with disabilities are denied the roles most commonly assigned to their gender and the characteristics most valued in women.

There is increasing awareness within the international human rights community about the sexual and reproductive health needs of women. International human rights law has expressly recognised women's rights to intimate relations and reproductive choice by promulgating protections and obligations with respect to marital status, access to contraceptives, family planning, pre and post-natal care, sexual violence and sexually transmitted diseases. For example, one United Nations Human Rights Committee has acknowledged that "[t]he realization of women's right to health requires the removal of all barriers interfering with access to health services, education and information, including in the area of sexual and reproductive health."[3] Yet, despite

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[1] Silvers, A. (1998). Reprising women's disability: Feminist identity strategy and disability rights. *Berkeley Women's Law Journal, 13*, 81–116.

[2] Ibid.

[3] UN Committee on Economic, Social and Cultural Rights (2000) General Comment No. 14: "The Right to the Highest Attainable Standard of Health (Article 12 of the

the particular relevance of these topics for women with disabilities, the international community has given scant attention to barrier removal and the promotion of rights for women with disabilities in the areas of sexual and reproductive health.

The failure of States to apprehend the interests of women with disabilities has been noted: "persons with disabilities are sometimes treated as genderless human beings, and as a result, the double discrimination suffered by women with disabilities is often neglected."[4] That women with disabilities are routinely regarded as asexual implies that they do not, or should not, have any aspirations to motherhood. In theory, women with disabilities, like all people, enjoy the full spectrum of human rights guaranteed by international law. However, in order for women with disabilities to secure meaningful inclusion and participation in society, special attention must be accorded, as a matter of human rights, to enhancing the dignity and self-determination of women with disabilities as sexual citizens, and to facilitate their equal access and opportunity to sexual and reproductive health services.

We use as a starting point the fundamental human rights values of equality, dignity and inclusion, and we explore the promotion of these values in the areas of sexual citizenship, reproductive care and decision-making and parenting for women with disabilities. We argue that self-determination about reproductive health and sexual well-being are integral human rights for women with disabilities. We begin with a brief overview of the various international human rights instruments that speak to sexual health and reproductive rights. Next, we examine barriers existing in education, law and health services that hinder the sexual, reproductive and parenting rights of women with disabilities in Canada. Through this analysis, we seek to articulate how the interests of women with disabilities regarding their bodies, sexuality and reproductive capacities must be informed by the human rights values of equality, dignity and inclusion. By focusing on sexuality, reproduction and parenting in the lives of women with disabilities, we seek to gain additional purchase in understanding how gender and disability intersect, and aim to call attention to new practices, attitudes

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International Covenant on Economic, Social and Cultural Rights)" Doc. E/C.12/2000/4 para 21.

[4] UN Committee on Economic, Social and Cultural Rights (1994) General Comment No. 5: "Persons with Disabilities" Doc. E/1995/22 para 19.

and institutional arrangements which will enable women with disabilities to participate fully and experience intimate fulfillment in our society.

II. International Standards Regarding Sexual, Reproductive and Parenting Rights

The legal interests of women with disabilities to sexual and reproductive health have been described as the "new frontiers for the advancement of human rights."[5] Complicating the advancement of these rights is the lack of consensus as to what sexual and reproductive rights might entail for women with disabilities; nowhere are they captured in a single, explicit, legally codified provision. Rather they must be traced from various freedoms, entitlements, and principles that address an array of human rights issues, such as bodily integrity, privacy and non-discrimination.

Promoting and protecting the interests of women with disabilities, in regards to parenting and sexual and reproductive health, involves a myriad of positive and negative legal, social, economic and political rights.[6] The Center for Reproductive Rights (CRR) describes sexual and reproductive rights as "embedded in" and "supported by" a number of internationally recognised human rights principles that relate to health and self-determination.[7] Consequently, a broad range of international instruments, declarations and covenants, reflecting human rights standards must be consulted to ascertain the legal rights of

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[5] Cook, R.J. et al. (2003). *Reproductive health and human rights: Integrating medicine, ethics and law*. Oxford: Clarendon Press 209.

[6] Traditionally, negative rights constitute civil and political rights, which are considered to be guarantees of "freedom from" state interference, such as non-consensual sterilisation. Positive rights are affirmative obligations, usually in the area of social and economic rights, whereby state action is required to protect and promote human rights, such as a minimum level of health care.

[7] Center for Reproductive Rights. (2002). *Bringing rights to bear: An advocate's guide to the work of UN treaty monitoring bodies on reproductive and sexual rights*. New York: Center for Reproductive Rights, online: http://www.reproductiverights.org/pdf/pub_bp_brb.pdf.

[8] *Universal Declaration of Human Rights* (*Universal Declaration*); the *International Covenant on Civil and Political Rights* (*ICCPR*); the *International Covenant on Economic, Social and Cultural Rights* (*ICESCR*); the *Declaration on the Rights of Disabled Persons*; the *Convention on the Elimination of All Forms of Discrimination Against Women* (*CEDAW*); the *Convention on the Rights of the Child* (*CRC*); the *Principles for*

women with disabilities to sexual citizenship and reproductive health.[8] According to Cook, Dickens and Fathalla, "rights are interactive, in that each depends to a greater or lesser degree on the observance of others," and therefore this assortment of international rights and principles needs to be "read interactively" and "applied cumulatively" to advance the interests of women in sexual and reproductive health.[9]

Among the international human rights principles that encompass legal, social, economic and political rights and which may therefore give legal force to fundamental human rights to parenting, sexual citizenship and reproductive health, are:

- the right to life, liberty and security of the person;[10]
- the right to equality and non-discrimination;[11]
- the right to marry and found a family;[12]
- the right to highest standard of attainable health;[13]
- the right to reproductive health, including family planning and maternal health services;[14]
- the right to information and education about sexual health, family planning and reproductive services;[15]

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the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (*Mental Health Principles*); the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (*Standard Rules*); and *Convention on the Rights of Persons with Disabilities* (*CRPD*).

[9] Cook et al. (2003)., *supra* note 5 at 159.

[10] Guaranteed by Articles 3 & 5 of the *Universal Declaration of Human Rights* (UN 1948), Articles 6 & 9 of the *ICCPR* (UN 1996a) and Articles 10 & 14 of *CRPD* (UN 2006).

[11] Guaranteed by Article 7 of the *Universal Declaration of Human Rights* (UN 1948), Articles 2 & 3 of the *ICESCR* (UN 1996), Article 26 of the *ICCPR* (UN 1966), paragraph 3 of the *Declaration on the Rights of Disabled Persons* (UN 1975), Rule 5 of the *Standard Rules* (UN 1993), Principle 1.4 of the *Mental Health Principles* (UN 1991) and Articles 5 & 6 of *CRPD* (UN 2006).

[12] Guaranteed by Article 16.1 of the *CEDAW* (UN 1979), Article 22 of the *Universal Declaration of Human Rights* (UN 1948), Article 23 of the *ICCPR* (UN 1966), Article 10 of the *ICESCR* (UN 1966), Rule 9 of the *Standard Rules* (UN 1993) and Article 23 of *CRPD* (UN 2006).

[13] Guaranteed by Articles 10 & 12 of the *ICESCR* (UN 1966b), Article 25.1 of the *Universal Declaration of Human Rights* (UN 1948), Rule 2 of the *Standard Rules* (UN 1993) and Article 25 of *CRPD* (UN 2006).

[14] Guaranteed by Article 25(2) of the *Universal Declaration of Human Rights* (UN 1948), Articles 10, 12 & 16 of the *CEDAW* (UN 1979), paragraph 41 of the *Vienna Declaration and Programme of Action* (World Conference on Human Rights 1993) and Article 25 of *CRPD* (UN 2006).

[15] Guaranteed by Article 10 of the *CEDAW* (UN 1979), Article 13 of the *ICESCR* (1966b), Rule 6 of the *Standard Rules* (UN 1993) and Article 23 of *CRPD* (UN 2006).

- the right to privacy;[16] and
- the right to not be exploited, subjected to inhuman or degrading treatment, or non-consensual medical treatment.[17]

As this list suggests, the rights of women with disabilities with respect to parenting, and sexual and reproductive health are related to and dependent upon the observance of a diverse range of complementary human rights principles[18] that are articulated in several international instruments and consensus documents ranging from the 1948 *Universal Declaration of Human Rights* to the recent 2006 *Convention on the Rights of Persons with Disabilities*.[19]

While most of these international instruments address rights related to broad principles of physical and psychological integrity and non-discrimination, one document draws particular attention to the parenting, sexual and reproductive concerns of the disability community. The *Standard Rules* begin by emphasising that States must promote the right of people with disabilities to "personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood."[20] The *Standard Rules* further provide that "[p]ersons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood."[21]

In addition to the foregoing declarations and covenants, international human rights committees have put forward a number of important statements and recommendations salient to issues of sexual and reproductive self-determination and parenting rights of women with disabilities.[22]

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[16] Guaranteed by Article 17 of the *ICCPR* (UN 1966), paragraph 12(d) of the CEDAW Committee *General Recommendation 18* (CEDAW 1991), Principle 13 of *Mental Health Principles* (UN 1991) and Article 22 of *CRPD* (UN 2006).

[17] Guaranteed by Article 7 of the *ICCPR* (UN 1966), paragraph 10 of the *Declaration on the Rights of Disabled Persons* (UN 1975) and Articles 16 &17 of *CRPD* (UN 2006).

[18] Petchesky, R.P. (2000). Human rights, reproductive and sexual health and economic justice – why they are indivisible. *Reproductive Health Matters, 8*(15), 12–17.

[19] Note this analysis simply reviews major United Nations human rights documents and does not constitute a comprehensive survey of international instruments. In particular, we do not discuss the import of regional documents or treaties, such as the European Convention.

[20] Rule 9 of the *Standard Rules* (UN 1993).

[21] Rule 9.2 of the *Standard Rules* (UN 1993).

[22] As international monitoring bodies, these Committees evaluate and comment about how States uphold their obligations under a ratified treaty or covenant. The General Comments/Recommendations produced by the Committees clarify and

In 1994, the CESCR Committee issued *General Comment No. 5*, a document devoted entirely to elucidating the human rights of people with disabilities.[23] The Committee noted that the rights of people with disabilities to marry and have their own family "…are frequently ignored or denied, especially in the case of persons with mental disabilities."[24] The Committee further reinforced the principles regarding sexual and reproductive health, first articulated in the *Standard Rules,* by emphasizing that "[w]omen with disabilities also have the right to protection and support in relation to motherhood and pregnancy," and that their sexual, "needs and desires…should be recognized and addressed in both the recreational and the procreational contexts."[25] The Committee emphasised that non-consensual sterilisations and abortions on women with disabilities are serious violations of the right to health under Article 12.[26]

Six years later, in *General Comment No. 14*, the CESCR Committee elucidated that the "right to health" consists of the freedom to control one's body, which also entails sexual and reproductive self-determination.[27] The Committee highlighted that the "right to health" must be interpreted to include equality and non-discrimination in the delivery of health services, physical accessibility, affordability and, "access to health-related education and information, including on sexual and reproductive health."[28] The Committee concluded that these components of the right to health are fundamental human rights indispensable for the exercise of other human rights.

The recent *Convention on the Rights of Persons with Disabilities* (*CRPD*) provides that States Parties need to ensure that persons with disabilities have equality with respect to fertility, independent decision-making and responsibility regarding the number and spacing of their

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interpret the nuances of specific covenant provisions and suggest future steps for States to promote the realisation of particular obligations.

[23] UN Committee on Economic, Social and Cultural Rights (1994) General Comment No. 5: "Persons with Disabilities" Doc. E/1995/22.

[24] Ibid.

[25] Ibid., para 31.

[26] Ibid.

[27] UN Committee on Economic, Social and Cultural Rights. (2000) General Comment No. 14: "The Right to the Highest Attainable Standard of Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights)" Doc. E/C.12/2000/4 para 8.

[28] Ibid., para 11.

children.[29] The *CRPD* further elucidates that the right of persons with disabilities to appropriate and affordable health must include sexual and reproductive health and population based public health programmes.[30]

It is apparent from the above survey that sexual and reproductive rights encompass a broad range of human rights issues, and a variety of international instruments and statements can be read to embrace the interests of women with disabilities to parenting, sexual citizenship and reproductive health. While the identified documents are not an exhaustive inventory of the potential legal foundations upon which sexual, reproductive and parenting rights can be built, these documents indicate that the integral components of the right to equality and physical and psychological integrity are built on the values of dignity, inclusion and self-determination. Rooted in the fundamental principles of equal citizenship, sexual and reproductive rights for women with disabilities seek to enhance the ability of women with disabilities to access, participate in and control safe and satisfying intimate relations and promote their freedom to choose and capacity to reproduce.

III. Right to Sexual Health Education

It is widely accepted that education is an essential tool for promoting healthy attitudes and beliefs about sexual identity, intimacy and reproduction, as well as a means to prevent and protect against sexual abuse and exploitation. In commentaries regarding the significance of sex education to the rights of women, children and racialized communities, numerous United Nations Committees have urged governments to prioritise sexual and reproductive health education and systematise sex education in schools.[31] Rule 9(2) of the *Standard Rules* state that "[p]ersons with disabilities must have the same access as others to family planning methods as well as to information in accessible form on the sexual functioning of their bodies." Although such human rights

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[29] Article 23 (*CPRD*, UN 2006).

[30] Article 25 (*CPRD*, UN 2006).

[31] See for example, Center for Reproductive Rights (2002), *supra* note 7 which details the numerous published statements by four United Nations human rights committees, including the CEDAW Committee, Committee on the Rights of the Child, Committee on the Elimination of Racial Discrimination and the Human Rights Committee, all of which have encouraged States to implement sexual education.

instruments are unequivocal about the importance of the right to education in areas of sexual health and reproduction, the enshrined principles are far removed from the reality of sex education for people with disabilities. Research substantiates that women with disabilities do not receive accessible and non-judgmental information and counselling responsive to their sexual and reproductive health needs.

In Canada, while all provinces currently have school curricula that address sexual health, due to conservative social and religious ideology, sex education has been a contentious issue until recent decades. The controversy and shortcomings in the provision of sex education historically have been aggravated for the disability community because of the erroneous perception that sex education is inappropriate and unnecessary for people with disabilities.[32] A World Health Organization (WHO) document indicates that society, families and educational institutions tend to openly "ignore or repress" the needs and self-realisation of youths with disabilities regarding their sexuality and that sexual education for adolescents with disabilities "remains in nobody's land."[33]

According to research findings regarding the general population, people normally learn about sex from their peers, although among young people it is becoming more common to learn about sex from school and parents.[34] With increased inclusive education in Canada,

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[32] Crawford and Ostrove indicate that general cultural attitudes characterise the sexuality of disabled persons as "inappropriate" or "nonexistent." See Crawford, D. & J.M. Ostrove. (2003). Representations of disability and the interpersonal relationships of women with disabilities. *Women and Therapy, 26*(3–4), 179–194. See also Irwin, M.M. (1997). *Sexuality and people with disabilities*. Bloomington: Indiana Institute on Disability and Community. Irwin notes that, "myths about people with disabilities and sex abound. One view is that people with disabilities are either not interested in sex or are not capable. At the other end of the spectrum, people with disabilities are sometimes viewed as being overly interested in sex and out of control in their sexual behaviour. Accurate information, free of stereotypical perceptions, must be available to each person who is disabled so he/she can develop a healthy view of who he/she is as a sexual being." Available online: http://www.iidc.indiana.edu/cedir/sexuality.html.

[33] Montero, F. (2006). *Sexual and reproductive health for persons with disabilities*. Switzerland: Geneva Foundation for Medical Education and Research in Human Reproduction (slide presentation) 36–37, online: Geneva Foundation for Medical Education and Research, World Health Organization (WHO) Collaborating Centre in Education and Research in Human Reproduction: http://www.gfmer.ch/400_Publications_En.htm.

[34] Nosek, M.A. (2003). *National study of women with physical disabilities: Final report 1992–1996*. Houston: Baylor College of Medicine, online: Baylor College of Medicine http://www.bcm.edu/crowd/?pmid=1408.

disabled girls today have more informal opportunities to learn about sex from school friends.[35] However, girls with disabilities continue to face significant barriers to obtaining formal sex education. As sex education continues to be a component of physical education classes, young women with disabilities who are not included in these classes or who are in segregated educational settings often do not receive this information.[36] Sex education is also taught in other inaccessible ways or fails to address the needs of people with disabilities. For example, generic teaching materials that document the physiological functions of able-bodied women may not include accurate information or depict images about bodily differences in women with disabilities, such as episodic menstrual cycles, loss or lack of sensation or prosthetic limbs.[37] Further, sex education relies to a significant extent on the presentation of visual illustrations, graphs and diagrams, but persons with vision disabilities require materials in alternate formats, which are not readily available.[38] Persons with learning disabilities in particular often do not receive thorough information, because they are often infantilised and overprotected.[39] Moreover, prejudicial social mores persist to cast doubt on the propriety and necessity of providing girls with disabilities with comprehensive and candid sex education.[40]

In a study about women with disabilities, sexual health and rehabilitation services, the United States Center for Research on Women with Disabilities (CROWD) observed that women who received sex education in rehabilitation programs noted that the rehabilitation programs

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[35] Ibid., at 11–12.

[36] Notwithstanding integration in regular classes, students with disabilities are routinely withdrawn from non-core classes, like gym, to receive special education instruction.

[37] For example, amputations, catheters, prostheses or other equipment are rarely, if ever, represented.

[38] Irwin. (1997)., *supra* note 32. See also Collier, B., et al. (2004). *Reducing the risk of sexual abuse for people who use augmentative communication: A community response*. Toronto: The Speak Up Project. Available online: Augmentative Communication Community Partnerships-Canada http://www.aacsafeguarding.ca/SUPSummaryReport.pdf which documents how symbols, graphics and other visual aids regarding sexuality are not available for people relying on augmentative communication systems.

[39] Shakespeare, T. et al. (1996). *The sexual politics of disability: Untold desires*. London: Cassell.

[40] See Collier, et al. (2004)., *supra* note 38. A recurring theme highlighted in the ACC report was the prejudicial attitudes of health and service providers. One female participant expressed feeling degraded and humiliated when her attendant saw her sexuality vocabulary and referred to it as "dirty pictures" (at 4).

did not address their needs because they predominantly dealt with men's issues, and were offered too early during their recovery, at a time when they had more pressing concerns.[41] Very little Canadian research has specifically examined the nature and extent of sex education available to women with disabilities. A 2004 report studying issues of sexuality and abuse amongst persons with severe speech impairments, however, signals the systemic inadequacy of sex education for people with disabilities.[42] This study documented that amongst people who use augmentative and alternative communication (AAC) systems there were extensive gaps in the knowledge and experience related to the expression of healthy sexuality.[43] Thirty-four per cent of the participants identified that they required assistance to simply locate and access sexual health education, and this was a particular obstacle for older participants who were excluded from educational programs because of age restrictions.[44] The majority of the AAC participants (73–88%) had no vocabulary (pictures or symbols) to communicate about sexual matters, such as privacy, body parts, feelings, sexual activities, as well as issues of abuse.[45] Most participants reported that they received no sex education from their parents, at school or from their health care professionals and, "expressed an overwhelming need to learn about and discuss aspects of healthy sexuality."[46] The report documented that the lack of information compounded the participants' communication difficulties and heightened their exposure to sexual abuse.

The importance of sex education for women with disabilities is underscored by the fact that women with disabilities experience disproportionate physical and sexual abuse.[47] A recent WHO report

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[41] CROWD. (2003)., *supra* note 34 at 11–12.

[42] Collier et al. (2004)., *supra* note 38.

[43] Ibid., 7.

[44] Ibid., 16. Note that this finding showed almost equal numbers of men and women.

[45] Ibid., 10.

[46] Ibid., 7–8.

[47] Elman, R.A. (2005). *Confronting the sexual abuse of women with disabilities.* Harrisburg: National Resource Center on Domestic Violence. Available on-line: VAWnet Applied Research Forum http://www.vawnet.org/SexualViolence/Research/VAWnetDocuments/AR_SVDisability.pdf, citing Stimpson, L. & M.C. Best. (1991). *Courage Above All: Sexual Assault Against Women with Disabilities.* DisAbled Women's Network, Toronto. After analysing numerous studies regarding sexual abuse and women with different types of physical and mental disabilities, these Canadian researchers concluded, "that more than 70% of women with a wide variety of disabilities have been victims of violent sexual encounters at some time in their lives."

highlights that "[f]actors, such as increased physical vulnerability, the need for attendant care, life in institutions, and the almost universal belief that disabled people cannot be a reliable witness on their own behalf make them targets for predators."[48] Women with disabilities are 1.5 to 10 times as likely to be abused as non-disabled women,[49] and likely to experience longer durations of abuse than women without disabilities.[50] Research reveals that women with developmental disabilities face the highest risks of sexual abuse and "studies further indicate that women who are unable to have children because of sterilization or birth control use might be at higher risk for sexual abuse if perpetrators know their actions will not be detected through pregnancy."[51] Although it is widely recognised that a key component for prevention of sexual abuse is sex education, a recent report confirms that sex education courses tend to take place in venues not accessible to people with disabilities and, "the lack of information on sexuality and women with disabilities makes such discussions more difficult."[52] Thus, despite the explicit provision in the *Standard Rules* that people with disabilities should be educated about how to protect themselves from abuse,[53] society remains oblivious to how the absence of timely and relevant sex education systematically heightens the vulnerability and victimisation of women with disabilities.

Health Canada recently disseminated *Canadian Guidelines for Sexual Health Education (Guidelines)*, a teaching tool promoting comprehensive sex education to encourage positive outcomes such as self-esteem, respect for others, non-exploitative and rewarding sexual relations.[54] The *Guidelines* are based on a philosophy that emphasises balancing personal desire, the rights and needs of others, and societal expectations, as well as the absence of discrimination based on race, gender,

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[48] Montero. (2006)., *supra* note 33 at 26.

[49] Sobsey, D. (1988). Sexual offences and disabled victims: Research and practical implications. *Vis-a-Vis, 6*(4), 1–2.

[50] Young, M.E. (1997). Prevalence of abuse of women with physical disabilities. *Archives of Physical Medicine and Rehabilitation, 78*(Suppl.), s34-s38.

[51] Dotson, L.A. et al. (2003). People tell me I can't have sex: Women with disabilities share their personal perspectives on health care, sexuality, and reproductive rights. *Women and Therapy, 26*(3–4), 195–209.

[52] Elman, R.A. (2005)., *supra* note 47 at 7.

[53] Rule 9.

[54] Health Canada (2003) *Canadian Guidelines for Sexual Health Education* Centre for Infectious Disease Prevention and Control, Health Canada, Ottawa, online: Health Canada http://www.phac-aspc.gc.ca/publicat/cgshe-ldnemss/pdf/guidelines_e.pdf.

sexual orientation, religion, ethno-cultural background or disability. This philosophy is that effective sex education, "[p]rovides accurate information to reduce discrimination."[55] The *Guidelines* recognise the importance of education that occurs in conjunction with access to clinical services, counselling and social services, community support, and physical resources that are required to support individual efforts to enhance sexual health and avoid sexual problems.

Thus, a vital component of appropriate sex education is not just teaching disabled individuals about their own sexual health, but also educating non-disabled people, including family members, counsellors, health care and other service providers, to respect the sexuality of people with disabilities. The 2004 AAC report noted that, due to inadequacies of information and education, non-disabled people hold significant misconceptions about the sexuality of persons with speech disorders. In order to promote healthy sexuality and prevent abuse, the report recommended that family and service providers must also be educated about the sexual needs of people with disabilities.[56] The recent WHO document indicates that families often avoid reference to sexuality in relation to their adolescent children with disabilities, refuse to reply to questions regarding puberty and developing bodies or "even worse…project their own fear and anxieties in their replies."[57]

It is well-established in Canadian disability rights jurisprudence that inequality can manifest both from differential treatment that results in exclusion or because of a failure to take into account a group's already disadvantaged position within society.[58] We see that both forms of discrimination occur due to deficiencies in the provision of sex education to women with disabilities. Inadequate sex education discriminates against women with disabilities by disregarding their right to equal treatment in education and simultaneously rendering them vulnerable to sexual abuse. This lack of comprehensive and accessible sex education undermines the human rights interests of women with disabilities, particularly in regards to their right to make informed choices about their personal health and bodies, and further exacerbates their disadvantaged status as a population systemically at risk of sexual violence.

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[55] Ibid., 8.

[56] Collier et al. (2004)., *supra* note 38.

[57] Montero. (2006)., *supra* note 33 at 38.

[58] See *Eaton v Brant County Board of Education*, [1997] 1 S.C.R. 241 at para 66.; *Quebec (Commission des droits de la personne et des droits de la jeunesse) v Montréal (City)*, [2000] 1 S.C.R. 665; and *Granovsky v Canada*, [2000] 1 S.C.R. 703.

Women with disabilities must be guaranteed a right to equal access to, and benefit from, sex education, including education about sexual and reproductive health, sexual orientation, contraceptives and sexually transmitted diseases. Failure to provide sex education perpetuates the marginalisation of women with disabilities, diminishes their capacity for self-determination, exposes them to risk of sexual abuse, and accordingly constitutes a form of systemic discrimination that jeopardises their physical and psychological integrity.

IV. Right to Intimate Relationships

Social inclusion is recognised as an integral component of the individual's and society's well-being.[59] Moreover, the principle of social inclusion lies at the heart of all rights and freedoms articulated for and about people with disabilities in international human rights law. Despite the myriad of international documents and declarations that seek to promote the full and effective participation of people with disabilities in social life, we see that women with disabilities continue to experience tremendous isolation, exclusion and marginalisation in one important area of social inclusion, specifically, involvement in emotional, personal and intimate relationships.

Women with disabilities encounter significant obstacles to social participation, including negative attitudes and physical barriers, which hinder their opportunity to meet people and form friendships, and thereby limit their capacity to enjoy social relationships and sexual expression. As one author points out:

> [t]he degree to which an individual with a physical, sensory, or cognitive disability is capable of exploring and expressing her/his sexuality can depend upon the ability to meet potential partners. Environmental and monetary factors (e.g., architectural barriers to social gatherings, lack of money for transportation and/or sign-language and voice interpreters) can prevent people with disabilities from exploring sexual relationships.[60]

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[59] United Nations (2001) *Human Rights of Persons with Disabilities* Background Paper, Division for Social Policy and Development, online: UN Enable http://www.un.org/esa/socdev/enable/rights/humanrights.htm.

[60] Mona, L.R. (2003). Sexual options for people with disabilities: Using personal assistance services for sexual expression. *Women and Therapy, 26*(3–4), 211–221.

Most activities in which adults participate to meet others are simply inaccessible to women with disabilities. Research confirms that accessible transportation is a serious problem throughout Canada and that women with disabilities experience barriers in using local conventional and specialised transit up to twice as much as men.[61] Recreational venues and sports clubs popular for group-based social activities, such as restaurants, clubs, bowling alleys and movie theatres, are routinely inaccessible to people with physical disabilities.[62] Barriers to employment that women with disabilities face also limit their social interaction. Employment is a source of independence. It generates the money to afford social activities, as well as providing a social context within which to meet potential friends, partners and lovers, but also the sense of worth and accomplishment required to form healthy relationships.[63] However, Canadian statistics indicate that, in the year 2000, only 23.2% of women with disabilities held full-time, full year employment.[64]

Difficulties in accessing adequate housing create further barriers. Limited housing opportunities force women to live relatively far from their friends and acquaintances and result in fewer chances to socialise.[65] Women who live in institutional settings face barriers to developing intimate relationships because they often do not have the possibility of expressing their sexuality.[66] Those who live independently, but who require the services of personal assistants, may face additional difficulties in building relationships and intimacy given that their privacy is impacted.[67]

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[61] Chadha, E. (2005). Running on empty: The "not so special status" of paratransit services in Ontario. *Windsor Review of Legal and Social Issues, 20.*

[62] See for example, *Turnbull v Famous Players Inc.* (2001) 40 C.H.R.R. D/333 (Ont. Bd. Inq.); *Brock (Litigation Guardian of) v Tarrant Film Factory Ltd.* [2000] O.H.R.B.I.D. No. 5, wherein two human rights tribunals found that popular movie cinemas discriminated against persons with disabilities by having theatres that were inaccessible to wheelchair users or barred admission to wheelchair users; and *Youth Bowling Council of Ontario v McLeod* (1990), 75 O.R. (2d) 451 (Div. Ct.), aff'd (1994) 20 O.R. (3d) 658 (C.A.) where the Ontario Court of Appeal affirmed the right of a young girl with a disability to play in a bowling league. See also Shakespeare et al *supra* note 39 at 30.

[63] Ibid., at 32.

[64] Canadian Council on Social Development (2005) *Disability Information Sheet No. 18*, online: http://www.ccsd.ca/drip/research/drip18/drip18.pdf using data from Statistics Canada's 2001 Census.

[65] Shakespeare et al., *supra* note 39 at 31.

[66] Ibid., at 33–34.

[67] Lesbians in this situation have the additional problem of either hiding their sexual orientation or risk losing their assistant because of prejudice and homophobia: Ibid., at 167–168.

All of the foregoing barriers, compounded by stereotypes and myths, limit social interaction, curtailing opportunities for women with disabilities to form sexual and intimate relationships. Assumptions also abound about the sexual orientation of women with disabilities, who are viewed as uniformly heterosexual. If a woman is known to be lesbian, her sexuality is perceived as her failure to be a real woman.[68] Lesbian women with disabilities face even more difficulties establishing relationships as a minority within a minority and often feel they belong in neither group. They may feel unwelcome in the disability movement where they sometimes experience prejudice and homophobia.[69] On the other hand, they are also excluded from the lesbian social arena. They are excluded in the same manner that heterosexual disabled women are socially excluded (transportation and architectural barriers, exclusion from employment, lack of housing, etc.) and, in addition, are not considered "proper" lesbians because it is believed that their disabilities preclude them from having an independent sexuality. As a result, they often feel lonely and isolated in a community that celebrates sexuality and physical appearance.[70] This situation presents greater complications for women who are not accepted in their families and need to create a "chosen family" for themselves.[71]

The right to freely express and exercise one's sexuality is a developing area of law. In 2004, the United Nations Commission on Human Rights affirmed that an, "understanding of fundamental human rights principles, as well as existing human rights norms, leads ineluctably to the recognition of sexual rights as human rights."[72] The previous year Health Canada similarly confirmed that "[s]exuality is a central aspect of being human throughout life," and that "[s]exual health is a state of physical, emotional, mental and societal well-being related to

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[68] Because she is not a real woman, the only person who can fall in love with her is another woman: Ibid., at 154–155. See also O'Toole, C.J. (1996). Disabled lesbians: Challenging monocultural constructs. In D.M. Krotoski, M.A. Nosek & M.A. Turk (Eds.), *Women with physical disabilities: Achieving and maintaining health and well-being.* Toronto: Paul H. Brooks Publishing, pp. 137.

[69] Shakespeare et al., *supra* note 39 at 165.

[70] Ibid., 163–165.

[71] O'Toole *supra* note 68 at 139.

[72] United Nations Commission on Human Rights (2004) *The Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health: Report of the Special Rapporteur, Paul Hunt* 60th Sess, UN Doc. E/CN.4.2004/49 para 54 online: http://www.unhchr.ch/Huridocda/Huridoca.nsf/(Symbol)/E.CN.4.2004.49.En?Opendocument.

sexuality."[73] Thus, Health Canada adopts the notion that "[f]or sexual health to be attained and maintained, the sexual rights of all persons must be protected and fulfilled."[74] Cook, Dickens and Fathalla point out that, "human sexuality serves more than the purpose of reproduction. It enhances human bonding, spouse or partner attraction, intimacy, affection and fidelity, and social stability, thereby maximizing human development and security."[75]

This acknowledgement of the fundamental nature of sexuality to human identity is the central justification for extending human rights protection to intimate relationships and activities concomitant with sexual expression. Given that sexual health is a critical dimension of human identity, failure to respect, or unjustifiable interference with, this aspect of a person's identity is inconsistent with human rights principles regarding the physical and psychological integrity of people with disabilities. Accordingly, for women with disabilities, an important feature of this right to sexual health involves protecting and promoting their ability to control and exercise sexual expression on their own terms. This conception of human sexuality however, is in stark contrast with the reality that women with disabilities face. Anne Finger argues: "[s]exuality is often the source of our deepest oppression; it is also the source of our deepest pain."[76] Women with disabilities, like children and elderly people, are generally seen as dependent persons who are not fully active participants in society. As such, their sexuality is undermined and their capacity for sexual feeling and activity denied.[77]

The right to sexual expression and assisted sexual activity is an emerging issue for people with disabilities. One author posits, "[r]eceiving Personal Assistance Services (PAS) for sexual activity is becoming of increasing importance to the disability community and to mental health professionals."[78] The World Health Organization has argued that all persons should be able to enjoy and control their sexual and reproductive behaviour, and that sexuality should be part of health

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[73] Health Canada. (2003). *Canadian Guidelines for Sexual Health Education* Centre for Infectious Disease Prevention and Control, Health Canada, Ottawa, 4–5, online: Health Canada http://www.phac-aspc.gc.ca/publicat/cgshe-ldnemss/pdf/guidelines_e.pdf.

[74] Ibid., 5, citing French, J. (1990). Boundaries and horizons: The role of health education within health promotion. *Health Education Journal, 49*(1), 7–10.

[75] Cook et al., *supra* note 5 at 173.

[76] Finger, A. (1992). Forbidden fruit. *New Internationalist, 233*, 8–10.

[77] Shakespeare et al., *supra note* 39 at 10.

[78] Mona, *supra note* 60 at 211.

care.[79] The issue of assisted sexual expression raises a multitude of complicated questions and ethical tensions regarding private and public interests. As McSherry and Somerville suggest for people with disabilities, "[t]he existence of a right to freedom of sexual expression is more controversial than that of a right to marry or a right to physical integrity. No legal document enshrines such a right."[80] However, given existing human rights protection for sexual health, privacy, personal relationships[81] and the right to equality for people with disabilities, a right to assisted sexual expression is grounded in human rights principles that promote the physical and psychological autonomy and integrity of people with disabilities and guarantee their equal treatment in services.

The *Canadian Charter of Rights and Freedoms*[82] and the various human rights codes enacted by the provinces and the federal government prohibit discrimination on the basis of disability in the provision of services, including disability-related health services and social programs.[83] Thus, it is well-established in Canadian human rights law that people with disabilities are entitled to receive equal access to treatment and accommodation in services, and this freedom from discrimination applies to both private and public sector services. The Supreme Court of Canada has stressed the importance of the role of accommodation in advancing the inclusion and participation of people with disabilities in society has recognised that achieving meaningful equality in receipt of services often requires accommodation in the provision of the service.[84] The Supreme Court has described disability accommodation as a highly

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[79] Earle, S. (2001). Disability, facilitated sex and the role of the nurse. *Journal of Advanced Nursing, 26*(6), 433–440.

[80] McSherry, B. & M.A. Somerville. (1998). Sexual activity amongst institutionalized persons in need of special care. *Windsor Yearbook of Access to Justice, 16*, 90–131.

[81] Sheppard, C. (2004). Intimacy, rights and the parent-child relationship: Rethinking freedom of association in Canada. *National Journal of Constitutional Law, 16*(1), 103.

[82] *Canadian Charter of Rights and Freedoms,* Part I of the *Constitution Act, 1982,* being Schedule B to the *Canada Act 1982* (U.K.) 1982 c. 11. Section 15(1) provides: "Every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination and in particular, without discrimination based on…mental or physical disability."

[83] See for example, *Eldridge v British Columbia (Attorney General)* [1997] 3 S.C.R. 624. See also *Rojas v British Columbia (Ministry for Children and Families* [2001] B.C.H.R.T.D. No. 17 and *Hutchinson v British Columbia (Ministry of Health)* [2004] B.C.H.R.T.D. No. 55.

[84] *British Columbia (Superintendent of Motor Vehicles) v British Columbia (Council of Human Rights)* [1999] 3 S.C.R. 868 at para 44, wherein the Court stated, "those who provide services subject to the Human Rights Code must adopt standards that

individualised process, which must be sensitive to the unique needs and interests of individuals with disabilities in order to respect and promote their dignity, integrity and empowerment.[85]

Approximately 22% of adult Canadians with disabilities receive supports and services from public and private agencies and organisations that provide assistance in the home for carrying out everyday activities.[86] In the context of attendant supports for people with disabilities, the right to equal treatment in services may involve augmenting the service and/or adapting delivery methods in order to assist the client to receive and benefit from the service. The Supreme Court of Canada has held that when a service provider, such as a local government agency, chooses to supply a service or accord a benefit, they must do so on a non-discriminatory basis.[87] If sexuality is an integral component of human identity, and personal attendant care is a service provided to facilitate independence and meaningful inclusion, it may be argued from a disability rights perspective that in order to benefit from the service and achieve equal citizenship, the person involved must be provided access to, and accommodation in, care services so that they may enjoy intimate fulfilment and sexual expression.[88]

It has been argued that assisted sexual expression comes within the ambit of personal care attendant services and therefore the provision of such services must be conferred in a non-discriminatory manner.[89] Howe contends that care providers should help their clients prepare for social situations, and that an equity argument can be made to support public financing for sexual facilitation and sexual surrogacy.[90]

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accommodate people with disabilities where this can be done without sacrificing their legitimate objectives and without incurring undue hardship".

[85] *Nova Scotia (Workers' Compensation Board) v Martin*, [2003] 2 S.C.R. 504.

[86] Statistics Canada. (2003). *Disability Supports in Canada, 2001,* Catalogue No. 89–580-XIE, Statistics Canada, Ottawa, 7 online: http://www.statcan.ca/english/freepub/89–580-XIE/89–580-XIE03001.pdf.

[87] *Eldridge, supra* note 83.

[88] Mona. (2003)., *supra* note 60, 213, citing the World Institute on Disability (1999) *Personal Assistance Services 101: Structure, Utilization and Adequacy of Existing PAS Programs*, Oakland, CA, which defines personal assistance services as, "involving a person assisting someone with a disability to perform tasks aimed at maintaining well-being, personal appearance, comfort, safety, and interaction with the community and society as a whole". In the Canadian context, Kerzner (2004) indicates examples of attendant services include bathing, transfers, toileting, essential communications and meal preparation.

[89] Ibid., 251–252; Earle, *supra* note 79 at 437.

[90] Howe, E.G. (2004). Disability. *Journal of Clinical Ethics, 15*(4), 239.

The range of services encompassed by assisted sexual expression are as broad and varied as the range of impairments for which attendant services are provided, and may include: sex education, transportation, removal of clothing, transferring from wheelchair to bed, purchasing or applying birth control, etc.[91] As one author asserts, "[b]ased on general notions of PAS, sexual positioning certainly appears to be a component of personal daily life activity."[92]

In seeking assisted sexual expression, people with disabilities are simply invoking their right to equal treatment with respect to service provision and are availing themselves of an existing benefit; namely attendant services, a program explicitly created to provide support in daily living and personal care to enhance the integration and independence of people with disabilities into mainstream society.[93] According to human rights principles, if assisted sexual expression was accepted as part of the right to equality in services, then the only exemption that would permit the proscription of this service would be the exception of reasonable accommodation short of undue hardship.[94] This means that the right to equal treatment in services, and the duty to accommodate in such services, is qualified only to the extent that the service provider experiences "undue hardship." Given the fundamental importance of ensuring that people with disabilities achieve equality, the Supreme Court has articulated a high standard for proving undue hardship.[95]

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[91] Mona *supra* note 60 at 213.

[92] Ibid., 214.

[93] In the provincial human rights context, see for example, *Rojas v British Columbia (Ministry for Children and Families*, *supra* note 90, where the Tribunal found that government funded personal care delivered in the person's home by a personal caregiver constituted, on a *prima facie* basis, a "service" to which the obligation of equal treatment applied. See also the recent decision of *Hutchinson v British Columbia (Ministry of Health)*, *supra* note 90, wherein the Tribunal held that the provincial government's policy prohibiting the hiring of family members as caregivers constituted discrimination regarding a "service."

[94] *Eldridge v British Columbia (Attorney General)*, *supra* note 83.

[95] Ibid., Only a limited number of factors have been identified in Canadian human rights jurisprudence as appropriate considerations for evaluating undue hardship. Under Ontario human rights law, the key factors are: (1) costs of accommodation, including the availability of outside sources of funding; and (2) health and safety issues with respect to accommodation, including issues of assumption of risk. Claims of business convenience, contractual agreements, staff morale and third party preference (other employees, customers, etc.) are not valid considerations. These factors are not relevant considerations and are deemed to diminish and detract from the dignified accommodation of persons with disabilities.

The basic problem that people with disabilities in Canada face, before even securing attendant services to facilitate sexual expression, is simply ascertaining their rights and their agency's policies and procedures regarding assistance with sexual practices.[96] For example, the 2004 AAC study involving persons with speech disabilities revealed that a number of adult participants living in group homes did not know if they were "allowed" to have sexual relationships within that setting.[97] The AAC study revealed that 65% of the participants had questions about an attendant's role in assisting them with sexual activities, such as preparation, positioning, using safer sex supplies, birth control, bathing after sex and masturbation.[98]

Due to prevailing social prejudices that negate the sexuality of people with disabilities, most service agencies have either largely overlooked this issue or deliberately refused to address the concerns of people with disabilities to assisted sexual activity. A survey of clinicians' attitudes on sexual relations between patients showed that attitudes were primarily influenced by prejudices around the nature and location of the sexual act, as well as the gender of the patients. The researchers found that competence and consent were not correlated to staff attitudes, even though those are the norms of law and due process.[99] Similarly, group homes and other disability housing units also have failed to address the issue of sexual activity amongst residents and on the premises. A content analysis of policies on sex between inpatients in psychiatric hospitals found that only 16% dealt with staff training.[100]

It is critical that attendant agencies and assisted living centres develop policies and guidelines to address these issues so as to foster a healthy living environment and ensure that their services are provided in a discrimination-free manner. As McSherry and Somerville posit, "[h]aving a policy at the very least helps to establish a consensus regarding the way staff members should behave toward sexual activity among persons in their care, and reduces the problem of individuals in

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[96] Collier et al., *supra* note 38.

[97] Ibid.

[98] Ibid., at 8.

[99] Commons, M.L., et al. (1992). Professional's attitudes towards sex between institutionalized patients. *American Journal of Psychotherapy,* 46(4), 471.

[100] Buckley, P.F. & T. Robben. (2000). A content analysis of state hospital policies on sex between hospital inpatients. *Psychiatric Services, 51*(2), 243–245.

institutions having constantly to adjust their behaviour to differing attitudes of staff members".[101] Mechanisms and policies must be created to assist people with disabilities to make decisions and access services that enhance their independence and capacity to engage in sexual expression.

V. Right to Marry

Contemporary Western society has observed significant changes regarding the concept of marriage, the right to marry, who is considered "marriageable" and what are considered to be proper intimate relationships. For example, in North America, legal prohibitions against inter-racial or inter-religious marriage no longer exist and, in some jurisdictions, legislation has been enacted recognising the validity of same-sex marriages.[102] Social attitudes are more tolerant of different types of relationships, such as common law relationships, care relationships, age differences between partners, marriage amongst seniors and even matters of consanguinity. However, while social and legal understandings of marriage and personal relationships are dramatically evolving, society continues to hold negative ideas about the propriety of marriage for people with disabilities, and in particular, people with mental disabilities.[103]

The decision to marry and found a family is a right enshrined in Article 16 of the *UDHR* and this right is reinforced in other international human rights instruments.[104] Rule 9 of the *Standard Rules* requires States to ensure that laws do not discriminate against people with disabilities with respect to marriage and further exhorts, "[t]aking into

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[101] McSherry et al., *supra* note 80 at 131.

[102] *An Act respecting certain aspects of legal capacity for marriage for civil purposes* ("*Civil Marriage Act*") S.C. 2005, c. 33, as assented to 20 July 2005.

[103] We use the phrase "mental disability" here and in other parts of the chapter to refer to a broad category of mental disabilities, including intellectual, cognitive, neurological, emotional and psychiatric disabilities. If a specific term or label is employed, as opposed to mental disability, the particular identification is used to reflect the language of the cited research.

[104] For example, Article 10 of the *ICESCR* mandates that States must accord "[t]he widest possible protection and assistance…to the family". The CESRC Committee has interpreted this provision to mean that States are obligated to ensure that laws, social policies and practices do not impede the realisation of the rights of people with disabilities to marry and form a family, UN Committee on Economic, Social and Cultural Rights (1994) General Comment No. 5: "Persons with Disabilities" Doc. E/1995/22.

account that persons with disabilities may experience difficulties in getting married and setting up a family, States should encourage the availability of appropriate counseling." Given these international pronouncements seeking to promote self-determination and dignity for people with disabilities with respect to marriage, restrictions on the right to marry must never be imposed based on stereotypical and discriminatory notions about people with disabilities. The decision to marry is a deeply personal matter that involves the individual in a socially honoured pledge and legally recognised contract.

The stereotype that people with disabilities lack mental capacity to understand the nature of marriage is invoked frequently and globally to deprive people with disabilities of their right to marry and found a family.[105] For example, marriage and guardianship laws in certain parts of the United States prohibit the marriage of individuals with intellectual and mental disabilities.[106]

However, this stereotypical presumption and its enactment in legislation conflicts with international human rights values of equality and full citizenship. The *Principles for the Protection of Persons with Mental Illnesses* clearly provide that a determination of mental illness does not equate with wholesale lack of capacity and that persons with mental illness have equal legal, economic, social and political rights as guaranteed to all persons in human rights law.[107] The right to marry and found a family, as well as the right to privacy and family life, are entitlements guaranteed to people with disabilities in a variety of international treaties. A number of human rights documents have recognised that the rights to marry and found a family have particular relevance to people with mental disabilities because of society's tendency to correlate mental disability with lack of capacity. As McSherry and Somerville posit, "[i]t is one thing to have a requirement that marriage be fully consensual, but another matter entirely to have a provision restricting

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[105] Amnesty International. (2004). Albania: Disability and the Right to Marry. (Press Release, 11 November) Amnesty International, London, online: news.amnesty http://news.amnesty.org/index/ENGEUR110052004.

[106] Churchill, M.A. (2001). Marriage laws discriminate against the disabled. *Michigan Bar Journal, 12,* online http://www.michbar.org/journal/pdf/pdf4article249.pdf.

[107] United Nations *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care,* adopted by General Assembly Resolution 46/119, 17 December 1991, online: Office of the United Nations High Commissioner for Human Rights http://www.ohchr.org/english/law/principles.htm.

the right of individuals with intellectual disabilities or mental illness to marry."[108]

Marriage laws that directly or indirectly presume persons with mental illness lack capacity to marry are discriminatory. Such laws violate the psychological integrity of people with mental disabilities by interfering with a profoundly intimate and personal choice and undermining the individual's basic freedom and autonomy to make life decisions about their future. By linking incapacity to marry with mental disability, such marriage laws not only deny people with mental disabilities autonomy in a profoundly personal matter, but appear to suggest that such persons are not entitled to the respect and rights accorded to others. This is inconsistent with the fundamental values of inherent dignity and equality for people with disabilities recognised in international human rights law.

Furthermore, by spotlighting people with mental disabilities and treating them differently, any marriage legislation that does so, effectively implies that the mental condition renders the person "unmarriageable" and in so doing, stigmatises and demeans their human dignity. A WHO report points out that "[e]xtreme poverty and social sanctions against marrying a disabled person mean that they are likely to become involved in a series of unstable relationships,"[109] thereby exacerbating their vulnerable status.

The right to marry is one example of where social prejudices about disability, gender and sexuality intersect and adversely impact on the power of women with disabilities to enjoy intimate relations and experience the rights and responsibilities concomitant with marriage. There are strong misconceptions about the relationships of women with disabilities: if a woman with a disability is single or living alone, this cannot be by choice but rather because no one wants her; if she is in a relationship with a non-disabled person, he or she must be a special person who takes care of her or, conversely, a person who has a suspicious desire to hide his or her own inadequacies or some other form of neurosis; if she lives with a disabled partner, they must have chosen each other simply because they are both disabled rather than for any

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[108] McSherry et al., *supra* note 80 at 111.

[109] Montero, *supra* note 33 at 25.

other qualities they might have, and their relationship must be non-sexual.[110]

The prevalence of negative stereotypes that question the mental capacity of those with disabilities to enter into a marriage are especially problematic for women with disabilities. Women with disabilities are disproportionately and routinely labelled as incompetent, particularly with respect to issues of consent, sexuality and reproduction.[111] Feminist and disability research highlights that women generally, and women with disabilities in particular, are at "special risk" of being constructed as incompetent.[112] The leading Supreme Court of Canada case on sterilization, *E. (Mrs.) v Eve*,[113] provides a clear example of this problem. Despite the positive outcome of the decision which endorsed a disability-rights approach to sterilization, the Supreme Court nevertheless accepted the lower court's characterisation of Eve, an adult female with an intellectual disability, as incompetent. Notwithstanding evidence that the young woman was fully integrated in her community, regularly attended a school for adults with disabilities and was interested in a romantic relationship with a peer pupil, the lower court found, and the Supreme Court did not question, that Eve was incapable of making

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[110] Shakespeare et al., *supra* note 39 at 9; Disabled Women's Network. (1993). *Women with disabilities talk about sexuality*. Toronto: DAWN.

[111] Stefan highlights how capacity doctrine is premised on a false neutrality, which assumes that capacity is internal to the individual (that is, mental illness or alcoholism) and therefore wrongly concludes that lack of competence can be objectively assessed: Stefan, S. (1993). Silencing the different voice: Competence, feminist theory and law. *University of Miami Law Review, 47*(3), 763–815. Feminist disability theorists urge the recognition of social factors that engender and exacerbate competence concerns, in particular the powerlessness, abuse and violence experienced by women with disabilities.

[112] See Secker (1999) who argues that competence is a gendered and relational construct and that women, due to their subordinate status in society, are susceptible of being labeled incompetent.

[113] *E. (Mrs.) v Eve*, [1986] 2 S.C.R. 388. Eve's mother applied for a court order seeking that her 24-year-old "mentally retarded" daughter, Eve, be sterilised to prevent the possibility of pregnancy. The Court of Appeal approved a full-scale hysterectomy for Eve. The Supreme Court refused to authorise non-medically necessary sterilisation and overturned the Court of Appeal. Eve was described as "mildly to moderately retarded" and involved in a relationship with a male, who she met at her school for adults with mental disabilities. The Supreme Court noted, at paras 2–4, that Eve and her male friend talked about marriage, however the matter was brought to an end when the situation was identified by school authorities. The Supreme Court held that sterilisation should never be authorised for non-therapeutic purposes. The irreversible nature of the intervention, the ensuing physical damage and the grave intrusion on the individual's basic rights all outweighed the highly questionable benefits of a non-therapeutic sterilisation.

decisions regarding her personal relations and reproductive health. Discriminatory laws regarding marriage reinforce and further entrench such negative stereotypes about women with disabilities, while simultaneously violating their human rights.

Marriage laws can no longer operate on the paternalistic assumptions that people with mental disabilities and women with disabilities do not have capacity to understand personal and intimate relationships and that therefore it is in their best interests for society to ensure that they refrain from engaging in such arrangements and forging such a bond. Such stigmatisation, loss of autonomy and interference with personal relationships violates the psychological integrity of people with disabilities and is contrary to human rights principles which seek to, "break down the barriers that stand in the way of equality for all."[114] As stipulated by the *Standard Rules*, governments need to develop and institute social and legal measures that enable people with disabilities, by means of education, counselling and appropriate services, to make informed choices with regard to intimate relations and marriage. A presumption of incapacity present in marriage laws offends the dignity of people with disabilities. To be in harmony with other disability rights protections entrenched in international human rights law, marriage legislation must be interpreted to promote independence and dignity of people with disabilities and therefore should operate on a presumption that people with disabilities have the capacity to make personal decisions.[115]

VI. RIGHT TO SEXUAL & REPRODUCTIVE HEALTH

International human rights law recognises, through Article 12 of the *ICESCR*, the "right of every person to the highest attainable standard of physical and mental health." This right to health has been interpreted to include the right to "a system of health protection which provides

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[114] *British Columbia (Superintendent of Vehicles) v British Columbia (Council of Human Rights), supra* note 84 at para 2.

[115] Generally, the law treats issues of capacity on a case by case basis and incapacity must be proven with respect to the specific choice and inherent risks in the specific decision. Thus, an individual with a disability may be incompetent for certain matters, for example, financial decisions, while remaining competent for other matters, such as health decisions. See Kerzner, L. (2006). Mental capacity through a disability lens. In M. A. McColl & L. Jongbloed (Eds.), *Disability and social policy in Canada* (2nd ed., pp. 336–369). Toronto: Captus Press.

equality of opportunity for people to enjoy the highest attainable level of health."[116] In Canada, section 3 of the *Canada Health Act* states that, "[i]t is hereby declared that the primary objective of Canadian health care policy is to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers."[117] Concomitantly, provincial health insurance plans provide universal, comprehensive and accessible health care to all Canadian residents.

However, while the majority of Canadians receive the medical services they need, women with disabilities experience significant barriers in accessing sexual and reproductive health services. Physicians often lack knowledge about sexuality issues particular to women with disabilities and do not know how to adapt their practices in order to serve them better. Despite laws and policies that prohibit discrimination in services on the ground of disability,[118] medical facilities are often physically inaccessible,[119] or services are provided in an inaccessible manner.[120] One author describes how women with disabilities are denied necessary health services because of numerous:

> environmental, attitudinal and information barriers. For example, many physically disabled women can't access standard diagnostic equipment. We can't stand before scanners, climb onto high tables, or wrench our legs into stirrups. Consequently, we are less likely to have mammograms and regular Pap tests.[121]

Moreover, because women with disabilities are seen as asexual and unable to procreate, the sexual and reproductive aspects of their health care are often neglected.

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[116] UN Committee on Economic, Social and Cultural Rights (2000) General Comment No. 14 explains at para 8, "The right to health is not to be understood as a right to be healthy. The right to health contains both freedoms and entitlements. The freedoms include the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation. By contrast, the entitlements include the right to a system of health protection that provides equality of opportunity for people to enjoy the highest attainable level of health."

[117] *Canada Health Act*, R.S. 1985, c. C-6.

[118] See discussion of Right to Intimate Relations, above.

[119] See for example, *Quesnel v London Educational Health Centre* (1995) 28 C.H.R.R. D/474 (Ont. Bd. of Inq.).

[120] See for example, *Eldridge v British Columbia (Attorney General) supra* note 83.

[121] Hershey, L. (2003). Rights, realities and issues of women with disabilities. In R. Morgan (Ed.), *Sisterhood is forever: The women's anthology for the millennium* (pp. 233). New York: Washington Square Press.

In accordance with the right to health and human rights principles, women with disabilities in Canada must be provided equality in accessing and benefiting from health care services. This is consistent with the equality rights values articulated by the Supreme Court of Canada in a variety of cases about disability services and health care. The Court has stated that public officials must be sensitive to differences in the actual needs of vulnerable groups in order to protect their equality rights and the government is under a positive duty to provide accommodation to address those differences.[122] The Supreme Court has also held that discrimination may accrue from a failure to ensure that the people with disabilities benefit equally from services offered to the general public.[123] We see that women with disabilities are routinely denied these rights in the area of contraception, obstetrical care and reproductive health.

(i) *Contraception*

Women with disabilities experience difficulty in accessing accurate information about contraceptive options and gaining access to contraceptives. While it is standard practice for gynaecologists to ask their patients of reproductive age about birth control, this matter is not automatically put to women with disabilities, especially those who have physical disabilities, as it is often assumed that they are not sexually active.[124] Women with disabilities therefore are compelled to raise

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[122] *Eaton v Brant County Board of Education*, *supra* note 58; *Eldridge v British Columbia (Attorney General) supra* note 83; *British Columbia (Superintendent of Motor Vehicles) v British Columbia (Council of Human Rights) supra* note 84.

[123] *Eldridge* v *British Columbia (Attorney General) supra* note 83 is a landmark decision for the application of a positive right in the allocation of health care and disability services. The Supreme Court held that the provincial government's failure to fund sign language interpreters for deaf patients in a hospital constituted discrimination on the basis of a disability. The Court held that once the state provides a benefit, it is obliged to do so in a non-discriminatory manner. Writing on behalf of a unanimous court, Justice LaForest held that, in certain circumstances, governments may be, "require[d]… to take *positive action*, for example by extending the scope of a benefit to a previously excluded class of persons" [emphasis added] (para 73). The Court concluded that the provincial government had not reasonably accommodated the claimants' disabilities to the point of undue hardship.

[124] While the Society of Obstetricians and Gynaecologists of Canada (SOCG) has published a set of guidelines for contraception, which includes specific reference to counselling and treatment of individuals with mental and intellectual disabilities, they do not address the needs of women with other types of disabilities, Society of Obstetricians and Gynaecologists of Canada. (2004). Canadian contraception consensus: Clinical practice guidelines no. 143. *Journal of Obsteterics and Gynaecology Canada, 26*(2), 143 (Part 1 of 3), 26(3) *JOGC* 219 (Part 2 of 3), 26(5) *JOGC* 347 (Part 3 of 3),

the subject themselves, which can be uncomfortable for some individuals.[125]

Research indicates that, as with other issues of gynaecological care, when prescribed contraceptives, such as birth control pills and Depo-Provera injections, women with disabilities are routinely given little or no explanation and description about why and how contraceptives are to be used, the side effects, or alternative forms of contraception.[126] Doctors, parents and caregivers often fail to provide adequate education regarding birth control. Consequently, not only are women with disabilities deprived of important information about contraception usage, they can be unaware of what it is that they are using and even left ignorant about the fact that that they are, indeed, using it.[127] For women with disabilities this situation, "serves to perpetuate a lack of control over reproductive choices just as forced sterilization did in the past."[128] This failure to ensure fully informed access to appropriate birth control undermines the ability of disabled women to control their fertility, impinges on their right to self-determination and strikes at their physical and psychological security.

There is also a lack of information among health care professionals about the most appropriate contraceptive methods for women with disabilities.[129] The impact of hormonal agents such as non-estrogenic contraceptives (for example, Norplant) on underlying disabilities has not been well studied.[130] It is believed that estrogen-containing oral contraceptives may not be appropriate for women with mobility impairment because of their increased risk of thrombotic predisposition.[131] According to some researchers, estrogen and progesterone have

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online: SOGC http://www.sogc.org/sogcnet/sogc_docs/common/guide/index_e.shtml #gynaecology.The guidelines do however address issues particular to the prescription of oral contraceptives to women who have chronic diseases such as lupus erythematosus, diabetes mellitus and sickle cell disease, and conditions such as epilepsy: see Part 2 of 2, pp. 245–246.

[125] Welner, S. (1996). Contraception, sexually transmitted diseases and menopause. In D.M. Krotoski, M.A. Nosek & M.A. Turk (Eds.), *Women with physical disabilities: Achieving and maintaining health and well-being* (pp. 81–90). Toronto: Paul H. Brooks Publishing.

[126] Dotson et al., *supra* note 51 at 198.

[127] Ibid., 198.

[128] Ibid., 198.

[129] Welner, *supra* note 125 at 81.

[130] Ibid., 84.

[131] Ibid., 81; Basson, *supra* note 110 at 362.

an impact on seizure thresholds.[132] These issues require further research in order to establish guidelines for contraception methods for women with disabilities.

The Supreme Court of Canada issued a strong pronouncement in *Eve* that non-therapeutic and non-consensual surgical sterilisation must never take place. However, women with disabilities continue to experience the same pervasive social prejudices and attitudes that shaped and justified past sterilisation practices with respect to their sexual and reproductive capacity. In most cases, these attitudes are a reflection of the concerns of society, and in particular the individual's family, about the impact of a pregnancy on the disabled woman and her caregivers. The fear is that the disabled woman will not be able to manage her own fertility to prevent pregnancy or, especially in an institutional setting, that her vulnerability will make her an easy target of sexual abuse leading to pregnancy. In both cases, the woman with a disability is regarded as an object of care and reconfiguration. To literally carve out the reproductive capacity of the body of the disabled woman is viewed as the better and more convenient option rather than placing responsibility on those who are entrusted with her care and protection.

While it is clear that Canadian courts will not approve the non-therapeutic sterilisation of persons who are mentally disabled, courts appear to accept less intrusive methods to secure similar results. In an Alberta case called *Re C.M.L.*,[133] the Surrogate Court determined the propriety of the Public Guardian's decision to consent to the insertion of an Intrauterine Device (IUD) for C.M.L, a 45 year-old sexually active woman, who was under guardianship. According to the judgment, C.M.L. stated that she did not want to get pregnant but was having difficulty with birth control pills and condoms. The Court concluded that the insertion of an IUD was the best and least intrusive method of complying with C.M.L.'s wish to avoid a pregnancy. Regarding the criteria to be applied however, the Court suggested that there was a lower threshold concerning consent when dealing with "functional sterilization" of an IUD as opposed to surgical sterilization. The Court stated the consideration was simply the best interests of the dependent adult.[134]

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[132] Welner, *supra* note 125 at 84.

[133] *Re C.M.L.* [2001] A.J. No. 331 (Surrogate Ct. Alta.) (para 20) online: QL (AJ).

Despite the lack of consent, the Court appears to conclude that non-therapeutic "functional sterilization" was in C.M.L.'s best interests. The Court's finding clearly implies that the reproductive rights and rights to bodily integrity of adults with mental disabilities may be infringed more easily in cases where less drastic means than surgical sterilisation exist.

This line of reasoning leaves open the possibility that Norplant implants, for example, could be justified on this basis, notwithstanding the multitude of complications and side effects that are often associated with their use. We need to question why medical interventions, even those less invasive than surgery, should ever be justified on the basis of best interest unless there is a reason for the intervention beyond the existence of disability. And, when the procedure in question is one which affects the reproductive capacity of non-consenting women with mental disabilities we need to be particularly vigilant to ensure that it is carried out for therapeutic reasons only. Although the language of the Court implies a paternalistic prejudice against a woman with disability exercising reproductive choice, *Re C.M.L.* can instead be viewed as the Court respecting the reproductive wishes of a dependent woman, thus enhancing her dignity.

(ii) *Obstetric Care*

Consistent with human rights legislation, the *Code of Ethics* of the Canadian Medical Association (CMA) imposes a duty on physicians to not discriminate against a patient in providing medical services. Section 17 of the Code provides that while a physician may refuse to accept a patient for legitimate reasons, a doctor must not discriminate against a patient on protected grounds, such as medical condition, physical or mental disability.[135] These laws and policies confirm the right of women with disabilities to have access to the services and support of health care professionals when they are, or wish to become, pregnant. However, the reality that women with disabilities experience is entirely different. In addition to the physical inaccessibility of doctors' offices, hospitals and birthing centres, women with disabilities contend with degrading

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[134] Ibid., para 20.

[135] Canadian Medical Association. (2004). *Code of ethics (update 2004)*. Ottawa: Canadian Medical Association, online: http://policybase.cma.ca/PolicyPDF/PD04–06.pdf.

messages and stereotypes about their ability to fulfil the role of a parent. The pervasive biases that women with disabilities face include:

> fears that a disabling condition may be passed on to a child; assumptions that disabled women cannot nurture, care for, or discipline children; the belief that mobility is essential for childrearing; and notions that a mother's disability would be a hardship to her children.[136]

Health care professionals and others routinely opine that a woman with a disability should not get pregnant or continue the pregnancy if there is a risk that the child could inherit the disability.[137] These pejorative assumptions and judgments undermine women's sense of self-worth and intensify their insecurities about motherhood.[138]

The difficulty that women with disabilities experience in gaining access to meaningful obstetrical care also reflects the paucity of knowledge and research about the specific issues related to pregnancy and birth for them.[139] Though the SOGC and the CMA have established guidelines for obstetrical care, these do not address the particular needs of women with disabilities.[140] This omission signals at least three misapprehensions about women with disabilities and their reproductive health needs. Firstly, disabled women will not, or do not, get pregnant. Secondly, disabled women who are pregnant, or who are contemplating pregnancy, have needs and interests that are generic to all women. Lastly, since disabled women have no needs or interests that ought to be considered by obstetricians and gynaecologists, there is no reason to fashion guidelines specific to the condition of women with disabilities. However, while women with disabilities who are pregnant share concerns with all prospective mothers – concerns about their own health maintenance and that of their future child, in addition to concerns

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[136] Hershey, L. (2000). Women with disabilities: Health, reproduction and sexuality. In C. Kramarae & D. Spender (Eds.), *International encyclopedia of women: Global women's issues and knowledge*. Scarborough: Routledge Press.

[137] Carty notes that "[s]ome women have reported being offered termination of pregnancy before any assessment of their desires or abilities." Carty, E.M. (1998). Disability and childbirth: Meeting the challenges. *Canadian Medical Association Journal, 159*(4), 363–369.

[138] Rogers, J.G. (1996). Pregnancy and physical disabilities. In D.M. Krostoski, M.A. Nosek & M.A. Turk (Eds.), *Women with physical disabilities: Achieving and maintaining health and well-being* (pp. 101–108). Toronto: Paul H. Brooks Publishing.

[139] Carty, *supra* note 137 at 367.

[140] Society of Obstetricians and Gynaecologists of Canafa. (2000). *Healthy beginnings: Guidelines for care during pregnancy and childbirth*. Ottawa: SOGC, online: http://policybase.cma.ca/PolicyPDF/PD98–07.pdf.

about their ability to care for their babies – some women with disabilities must also contend with the, "possible interactions between pregnancy and disability."[141] This failure to address the unique needs of women with disabilities in securing obstetrical care suggests pregnant disabled women are unworthy of care and attention, reinforces stereotypical assumptions about their ability to become parents and denies them equality in health services.

Because physicians remain the primary source of information about pregnancy, childbirth and parenting, and because they are the primary arbiters of care, physicians need further and better information about the unique implications of pregnancy for women with disabilities. The particular risks of pregnancy for women with various disabilities, the mutual impact of the disability and pregnancy and, in particular, the accommodations necessary to make care physically accessible and more supportive all require further exploration and research.

Given the multitude of attitudinal and physical barriers that women with disabilities face in reproductive services, they need, not only physically accessible, but also psychologically supportive, obstetrical care. This approach views women with disabilities as knowledgeable about their own bodies, health needs and experiences. It is also an approach where women with disabilities who wish to enjoy the experiences of pregnancy, childbirth and parenting are not prejudged as incapable mothers, but are supported in meeting the challenges that these experiences inevitably bring. This approach is consistent with disability rights and equality principles in that it shifts the focus away from the so-called expertise of the medical professional to respecting and accommodating the needs, interests and decisions of the woman as integral to providing her with the best obstetric care.

(iii) *Reproductive Assistance*

Though most disabilities do not directly impact fertility, many women with disabilities have difficulty in achieving pregnancy. And just as they struggle to find an obstetrician who will take them on as a patient during their pregnancy, women with disabilities also face barriers when trying to find a specialist who will help them become pregnant.[142]

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[141] Carty, *supra* note 137 at 364.

[142] Basson, *supra* note 110 at 362.

In Canada, the *Assisted Human Reproduction Act* (*AHR* Act)[143] regulates the use of assisted human reproductive technologies. This legislation is particularly relevant to women with disabilities in at least two respects, each of which is found under the Act's statement of principles. First, the *AHR* Act recognizes that, "women more than men are directly and significantly affected," by these technologies,[144] and that, "the health and well-being of women must be protected in the application of these technologies."[145] Second, the *AHR* Act declares that "human individuality and diversity" must be preserved and protected.[146] This principle could be relied upon by women with disabilities who wish to avail themselves of assisted reproductive technology. At the same time, the first principle declares that the health and well-being of children created through these technologies must be given priority in any decision-making regarding their use. While this principle has not been interpreted by any court, it could be construed negatively against women with disabilities if the social perception prevails that their potential children would be at a disadvantage, either due to the risk of inheriting a disability themselves, or the alleged challenges of having a parent with a disability. The *AHR* Act is also problematic in that it explicitly proscribes certain uses of reproductive technology, including sex-selection, while implicitly allowing the use of technology to test for and abort foetuses with genetic markers for certain conditions or to select against embryos identified with genetic markers for undesired traits or conditions. Women with disabilities in particular may feel pressure to make use of reproductive services for these ends.[147]

The *Canadian Charter of Rights and Freedoms* and provincial human rights statutes also apply to assisted reproductive services, and mandate that there be equal access to such services without discrimination.[148] The *Joint Policy Statement on Social Screening and Reproductive*

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[143] *Assisted Human Reproduction Act* (2004) S.O. c.2.

[144] section 2(c).

[145] section 2(e).

[146] section 1(g).

[147] Mossof, J. (1993). Reproductive technology and disability: Searching for the rights and wrongs in explanation. *Dalhousie Law Journal, 16*, 98–124.

[148] See for example, *Korn v Potter* (1996) 134 D.L.R. (4th) 437, wherein the British Columbia Supreme Court affirmed a human rights complaint against a physician for failing to provide artificial insemination services to a lesbian couple as a violation of the right to be free of discrimination in health services as protected under provincial human rights law.

Technologies[149] adopted by the SOGC and the Canadian Fertility and Andrology Society provides some guidance regarding when physicians can refuse to provide access to reproductive services to a woman. It states that no groups of individuals should be denied, as a group, access to reproductive technologies. However, individuals who are believed to be potentially incapable parents should be denied. The policy states: "The primary concern should always be, not for the ability of a person to have a child, but for the prospective child to have a responsible parent."[150] Though the policy prohibits blanket discrimination against groups of persons, it does offer a physician the option to refuse to provide services to a woman with a disability should he or she believe that the individual lacks the capacity to be a responsible parent. Given the biases that women with disabilities face when they want to become mothers, the possibility for physicians to refuse their assistance seems very real. In effect, the policy entitles a physician to exercise extra scrutiny in determining the potential for parenthood of women who are disabled, something which is not immediately apparent with others.

A further barrier to access to assisted reproductive services is the characterisation of these services as not medically necessary, and therefore not covered by provincial health insurance programs. In all provinces (except for Ontario which covers the cost of three treatment cycles of *in vitro* fertilisation (IVF) in cases of bi-lateral fallopian tube blockage[151]) patients (or their private health insurance plans) must bear the cost of assisted reproductive services and of the required fertility drugs and hormones. As few women with disabilities have the financial resources to assume such costs, their access to these services is even further limited.[152]

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[149] Society of Obstetricians and Gynaecologists of Canada. (1999). Joint policy statement: Social screening and reproductive technologies. *Journal of the Society of Obstetricians and Gynaecologists of Canada, 21(1),* 36,36.

[150] Ibid., 38. The policy also states "If a physician cannot accept the inclusion of a certain group of individuals based on social factors because of personal conscience, the physician is obligated to inform the patient, and to refer him or her to other qualified medical professionals who will assist the patient in addressing the medical problem" at 39.

[151] *Health Insurance Act General Regulation,* R.R.O. 1990, Reg. 552 at para 24(1)(23). The cost of the drugs is not covered however.

[152] See *Cameron v Nova Scotia (Attorney General)* (1999) 204 N.S.R. (2d) 1, leave to appeal to S.C.C. refused [1999] S.C.C.A. No. 531 [QL (SCCA)] wherein a Nova Scotia couple brought an action against the province to recover the cost of IVF related treatments received outside of the province arguing that the province's refusal to provide hospital insurance coverage for the treatments was a breach of their constitutional

The struggle for reproductive choice was one of the primary political battles of feminism in the twentieth century. Yet, for women with disabilities the struggle for reproductive choice is still far from over. Matters which have long been affirmed as areas of private and intimate decision-making in the wider society – access to and choice of contraceptive methods, and decisions about becoming a parent, for example – must still be fought for in public by women with disabilities. Moreover, matters which are widely regarded as social rights in Canada, such as access to quality reproductive health and antenatal care, are not routinely provided to women with disabilities; still less available are access to leading edge technologies and therapies for infertility treatment. For there to be a meaningful right to exercise self-determination with respect to sexual and reproductive health, women with disabilities should, like their non-disabled cohorts, be able to freely choose to be sexually active without fear of pregnancy, as well as be able to choose if, when and how to become pregnant. In order to achieve equality with respect to reproductive rights and sexual citizenship, women with disabilities must be given equal opportunity to and benefit of contraceptive options, obstetric care and reproductive support services.

VII. Right to Found a Family

The myths and assumptions that hamper efforts of women with disabilities to access sexual and reproductive health services also impose barriers to their parenting activities. Indeed, while society generally views family life and parenting as desirable roles for women, it is less understanding of, and much less accommodating to, women with disabilities who wish to parent. According to Anita Silvers, "[w]hile other women

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right to equal treatment under health insurance law, discriminating against them on the basis of their physical disability, namely infertility. The Majority of the Court of Appeal recognised infertility as a disability and that the plaintiffs' equality rights had been infringed, but found the infringement justified as a reasonable and proportionate limit due to rationed health care funding. See also *Auton (Guardian ad litem of) v British Columbia (Attorney General)* [2004] 3 S.C.R. 657, wherein the province's failure to fund a specific type of autism treatment was challenged as a violation of the constitutional right to equality. The Supreme Court concluded that the treatment was not a "core" medical benefit and thereby not provided under Canada's health care laws, arguing that there was no evidence that the government's refusal to fund the autism therapy was any different from the approach the government would take in regards to other emerging, novel therapies.

are expected to become mothers and may even be called upon to defend their choice to remain childless, women with disabilities are criticized for becoming pregnant."[153] Once they do have children, women with disabilities are, "expected to prove that retaining their maternal roles is compatible with their children's welfare."[154] Often it is assumed that women with disabilities are incapable of caring for their children because they are perceived as passive and dependant. The assumption is that rather than being caregivers to their children, they must be cared for by them.[155]

Some women with disabilities report that even when they are with their children, their motherhood is denied. The people they meet assume that the children are not their own: that they are their personal attendants or someone else's children. Moreover, their decision to have children may be judged as selfish or unfair given their perceived shortcomings as disabled persons, but also given the possibility that they would give birth to a disabled child.[156] In addition to these attitudinal barriers, women with disabilities face various challenges in their roles as parents. These may be linked to a multitude of factors including: the nature of their disability; changes to their health status; relationships with their partners (or lack thereof); the security or precariousness of their economic status; the (un)availability of supports and services; their child's unique needs; and changes in their children as they mature.

Various international instruments speak of the right to found a family, the importance of the parent-child relationship, and the need of *all* parents to be supported in their efforts to nurture and care for their children.[157] Rule 9(2) of the *Standard Rules* emphasises that States should promote the full participation of people with disabilities in family life and, in particular, disabled persons must not be denied the opportunity to experience parenthood. Rule 9(3) of the *Standard Rules* provides that, "States should promote measures to change negative attitudes towards marriage, sexuality and parenthood of people with disabilities, especially of girls and women with disabilities, which still

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[153] Silvers, *supra* note 1 at 92.

[154] Ibid.

[155] Shakespeare et al., *supra* note 39 at 107.

[156] Ibid., 107–108.

[157] Article 16(3) of the *Universal Declaration* states that, "[t]he family is the natural and fundamental group unit of society and is entitled to protection by society and the State."

prevail in society." One international document even addresses the rights of children who have parents with disabilities. The *Convention on the Rights of the Child* recognises that the family is "the fundamental group of society and the natural environment for the growth and well-being…of children," and that children should not be discriminated against because of their parents' identities, including when the parent has a disability.[158] By recognising that parenting is a challenging responsibility for everyone and that a diverse range of supports are crucial in order to succeed in this role, international human rights principles implicitly endorse the rights of people with disabilities to support services to facilitate their parenting duties. However, even within international human rights discourse and literature, greater recognition must be paid to the linkages between social prejudices, systemic discrimination and barriers that cause the isolation and marginalisation of parents with disabilities and thereby contribute to the victimisation of their children.

Mothers with disabilities confront challenges in accessing the services and assistance they need to enable their parenting activities. These challenges reflect the myth of the self-sufficient family perpetuated in western culture. In this view of the family, dependence on external resources is not normal; it is exceptional and generally must be temporary in nature. Parents must therefore be self sufficient and able to fulfil the needs of their children on their own. As society accepts this myth, mothers with disabilities are penalised if they cannot achieve self-sufficiency without having recourse to external assistance for their parenting activities. They risk being identified as neglectful or abusive and having their children removed from their care. They may also face discrimination as they attempt to form a family, either in forming a relationship, bearing their own children or in trying to adopt.

Just like non-disabled mothers, women with disabilities require supports to be good parents. Unfortunately, unlike non-disabled mothers, women with disabilities are viewed as less maternal and unfit to parent and reliance on social supports is perceived to be a sign of weakness. In *Eve v Eve,* the Supreme Court of Canada expressly highlighted the need to infuse human rights values into society's understanding of what it means to be a "fit" parent. Responding to the government's argument that sterilisation may be necessary where the disabled individual's

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[158] CRC Preamble and Article 2.

"fitness to parent" was in doubt, Justice La Forest confronted negative stereotypes regarding the ability of persons with mental disabilities to be suitable parents and explicitly acknowledged that this inquiry is "value-loaded."[159] La Forest J. further recognized that, while disability has a tendency to correlate with poverty, the problem of lack of financial resources to be a proper parent "is a social problem, and one, moreover, that is not limited to incompetents."[160] These *obiter* comments reveal the Supreme Court's sensitivity to the fact that childhood deprivation has more to do with household poverty, and less to do with whether the parent has a mental disability.

One of the principal areas where mothers with disabilities confront systemic discrimination is in their interaction with the child protection system. Mothers with disabilities are often subjected to increased scrutiny from child protection agencies as they are often assumed to be incapable of caring for children, believed to be "unfit," or viewed as poor role models. In addition, child protection workers, who may have little or no training in disability, may transfer their negative assumptions about the parenting abilities of women with disabilities into their encounters with the women they are investigating.[161] Furthermore, the child protection system can be insensitive to the socioeconomic context of the family, including lack of supports, poor health, unemployment and abuse, which place parents with disabilities and their children at increased risk of neglect and harm.

Pursuant to Canadian child welfare legislation,[162] if a child is thought to be in need of protection because the child has suffered or risks suffering at the hands of his or her caregiver, a warrant may be issued authorising a child protection worker to remove the child from his or her home and bring him or her to a place of safety until a hearing is conducted to determine whether the child is in need of protection.[163] A variety of actors and circumstances may therefore initiate the child protection process.

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[159] *E. (Mrs.) v Eve*, *supra* note 113 at 431.

[160] Ibid.

[161] Shakespeare et al., *supra* note 39 at 111–112.

[162] While the child welfare regime is similar across the Canadian provinces, for purposes of this chapter the specific example of Ontario *Child and Family Services Act*, R.S.O. 1990. c. C.11 will be used.

[163] This risks include physical and emotional harms resulting from neglect, failure to adequately care for, provide for, supervise or protect the child, or from a pattern of neglect in caring for, providing for or supervising a child. *Child and Family Services Act,* R.S.O. 1990. c. C.11, ss. 37(2), 40(2) & 40(6).

The case of 27-year old single, deaf mother whose newborn child was apprehended illustrates how the system can work to the detriment of women with disabilities. The deaf woman was the subject of a negligence complaint by her landlord, who complained to the local Children's Aid Society (CAS) that the mother did not respond to her infant's crying and that her baby-monitoring device was not functioning. The police and CAS workers apprehended the infant and because the authorities were not accompanied by an interpreter, they were unable to communicate with the mother. She did not understand why or where they were taking her child. She was merely handed a business card. The mother, arguing that her baby, like many others, simply cried more during the night, obtained help from social agencies for the deaf. Her child was eventually returned to her after a hearing before the Family Court.[164] These events are disturbing in their illustration of the prejudices that mothers with disabilities must endure: because she was perceived as a suspect mother from the start, her credibility was judged inferior to that of the landlord and consequently, there was little need to ensure due process by obtaining her version of the events or informing her of the reasons for the apprehension of her child. The authorities' biases against and indifference to the mother's rights is evidenced by their failure to bring a trained interpreter to explain the process and legal basis and ramifications of the apprehension. Clearly, the deaf mother had already been judged unfit.

A determination by the courts on the question of whether a child is in need of protection under the *Child and Family Services Act* involves a consideration of the available evidence about the parent's skills and ability to care for and to meet the child's needs. In *Nova Scotia (Minister of Community Services) v F. (B.)*, a 2003 case involving two parents with mental disabilities, the Court held that the parents' disabilities should not be a concern if they can provide a loving, caring and risk-reduced home.[165] The parents were found to have limited cognitive ability, and after several years of involvement with home care support services and parenting skills programs, the Minister of Community Services sought to place their children under permanent care and custody. The Court found that it would not be in the children's best interests to remove them from their parents' care and recognised that there were external,

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[164] Keung, N. *The Toronto Star* (March 5, 2002) at p. B.03.

[165] *Nova Scotia (Minister of Community Services) v F(B)* (2003) 219 N.S.R. (2d) 67.

informal supports that contributed to the children's upbringing. This approach represents an example of where the legal system was prepared to eschew disability stereotypes and undertake a contextual analysis of the situation. The majority of cases, however, do not explicitly question the suitability of support services for women with disabilities and rarely do the courts delve into the question whether the support services provided to the disabled parent correspond to her needs and capacities, and truly enable her to care for her children.

Time is a factor that may pose an additional challenge to mothers with disabilities involved with a child protection society. Many women with disabilities may require long-term or ongoing support, an option which may be rejected by the courts and the child protection societies who hold the view that parents should be self-sufficient. Once their child has been apprehended, disabled mothers may have difficulty securing the child's return. Under the *Child and Family Services Act*, a child may be kept as a ward up to 12 months for children who are less than 6 years old and to 24 months for children aged 6 and over (section 70). The objective of these provisions is to provide as much stability as possible to the children who are under the state's care. However, this may place women with disabilities in general, but particularly those who have mental disabilities, at a disadvantage given that they may need longer to develop the abilities deemed necessary to care for their children.

Examples of such situations include *Children's Aid Society of the Niagara Region v M.C.*,[166] wherein the Court recognised that, the intellectually disabled mother had made some progress "[b]ut time is her enemy. [Her children] need a stable relationship now. They cannot wait."[167] Similarly in the case of *Children's Aid Society of the County of Simcoe v S*, the mother, who had cognitive limitations and personality disorder, lost her children even though she had taken steps to stabilise her life and undergone treatment. The Court found that the necessary changes with respect to mother's abilities could not be concluded in the necessary time frame which would permit the child to be returned to

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[166] *Children's Aid Society of the Niagara Region v M.C.* [2000] O.J. No. 3268 (O.C.J.) online: QL (FAMQ).

[167] Ibid., para 113. See also *Children's Aid Society of Simcoe v L.A.M.* [2000] O.J. No. 389 (S.C.J.) online: QL (FAMQ); *Children's Aid Society of Owen Sound and the County of Grey v B.H.* [2000] O.J. No. 5308 (O.C.J.) online: QL (FAMQ); *Children's Aid Society of Ottawa-Carleton v A.* [2001] O.J. No. 2887 (S.C.J.) online: QL (FAMQ).

his mother's care. The Court concluded that the importance of the biological relationship and the child's development of a bond in relationship with his mother are outweighed by the need to promote his overall development in a safe environment.[168]

The foregoing analysis reveals that disabled mothers, especially those with mental disabilities, often find themselves embroiled in a surveillance system that is ill equipped to address their disability-related needs. Not only is their competence to mother already questioned by operation of myths and stereotypes about disability, but often services and supports which might be of assistance in carrying out their parenting role are not available or are inadequate to meet their specific needs. This is not to suggest that the involvement of child welfare officials in the lives of disabled mothers is never appropriate or that orders in favour of the state for guardianship are never warranted. The experience of women with disabilities suggests quite plainly that an adversarial relationship with the state and state agencies does not meet the needs of children or those of mothers with disabilities. The problem is how to redirect the attention of the state and state agencies towards an enabling role, which recognises the abilities of women with disabilities as mothers and enters into dialogue with them over the most appropriate supports to assist them in devoting the kind of care and attention to their children they are capable of giving.

VIII. Conclusion

International human rights law has endorsed women's rights to sexual education, reproductive health services and the right to found a family. Indeed, several international Human Rights Committees have recognised the integral connection between the right to access and benefit from sexual and reproductive information, counselling and health services and the ability of women to enjoy equal citizenship in society. However, this understanding has not translated into advancing and protecting the rights of women with disabilities. Due to the tendency to view women with disabilities as genderless and sexless, society has marginalised the social and economic issues that are critical to promoting their parenting, sexual and reproductive rights, including

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[168] *Children's Aid Society of Simcoe v L.A.M.* [2000] O.J. No. 389 (S.C.J.) paras 184 & 196.

access to sexual education and reproductive services. Further, strong myths continue to prevail about the sexual and intimate lives of women with disabilities. Because women with disabilities are seen as asexual (or sexually inadequate), not desirable, and incapable of ovulating, menstruating, conceiving or giving birth, it is imagined that women with disabilities do not need information or services with respect to contraception, safe sex, or childbearing.

In many instances with respect to nurturing, sexual and reproductive rights, the law in Canada does not actively discriminate against women with disabilities. Instead, we see that the law imposes burdens or erects barriers which adversely affect or impede women with disabilities from exercising and enjoying sexual and reproductive citizenship. The harmful effects of such indirect discrimination must not be underestimated. Canadian disability and equality rights jurisprudence makes clear that failure to accommodate the needs and interests of the disability community undermines the capacity of people with disabilities to participate in society and constitutes a violation of their human rights. Little scholarship, and even less jurisprudence, has tackled the concerns of discrimination experienced by women with disabilities in relation to their sexual and reproductive rights. The disability rights movement itself has not prioritised issues of sexuality and reproduction, instead focusing on the elimination of discrimination in employment, education and housing.[169]

Thus, despite international pronouncements enshrining women's rights in these areas, we see that in most situations involving their sexual, parenting, and reproductive interests, women with disabilities are denied the benefits and services that are ordinarily available to other women. This differential treatment often springs from the conception that disabled women are genderless and sexless, and is further precipitated by negative views about the propriety and ability of women with disabilities to engage in intimate relations and to become parents. The time has come to see women with disabilities differently and to recognise the fundamental role of parenting rights and sexual and reproductive health in enabling women with disabilities to secure full citizenship.

In an environment that already restricts the social interaction of women with disabilities through barriers to mobility and communication, women with disabilities find their social isolation compounded

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[169] Shakespeare et al., *supra* note 39 at 5–6.

by the denial of their sexuality and by the deprivation of opportunities for intimacy. Health professionals and family members appear acutely uncomfortable with the prospect of educating and enabling women with disabilities to fulfil themselves as sexual and reproductive human beings. It is as if society's gaze cannot encompass the capacity of women with disabilities for intimate fulfilment as sexual partners and parents. By erasing intimate relations from the lives of women with disabilities, broader society detaches them from the important bonds through which members of society relate to one another.

Women with disabilities have inherent dignity and worth and are entitled to equal access and opportunity to the supports and services that meaningfully enable their full participation in intimate relations and social inclusion. This involves recognising that sexuality is essential to identity, social and personal interaction and physical and mental health. The right of women with disabilities to sexual and reproductive citizenship includes the right to exercise and express sexuality freely; to be safe from sexual abuse and discrimination; to have access to reproductive health information and services; to make informed decisions about one's own body; and, if one choose to do so, to experience parenting. Upholding these important rights requires sensitivity to the unique challenges women with disabilities experience in participating in sexual and reproductive activities, ensuring accessible sexual education and reproductive health services and parenting supports and services. Further, the right to self-determination and autonomy in deciding whether to engage in intimate contacts and establish long-term relationships or marriage are fundamental rights of all citizens. These rights must be promoted and protected to ensure that women with disabilities can reach their full potential as equal and valued members of society.

PRICE V UK: THE IMPORTANCE OF HUMAN RIGHTS PRINCIPLES IN PROMOTING THE RIGHTS OF DISABLED PRISONERS IN THE UNITED KINGDOM

Angela Laycock

There has been a significant change in the position of prisoners with disabilities in the United Kingdom (UK) during the first decade of the twenty-first century, much of which can be attributed to the influence of human rights principles on UK law. It is indeed no coincidence that this change has coincided with the passage of the *Human Rights Act* 1998 which, when it came into force on 2nd October 2000, was *Bringing Rights Home*[1] by incorporating the majority of the articles of the *European Convention for the Protection of Human Rights and Fundamental Freedoms* 1950 (ECHR) into domestic law. Perhaps, however, a more significant contribution to the promotion of the rights of disabled prisoners occurred in international law, under the jurisdiction of the European Court of Human Rights (ECtHR) in *Price v UK*,[2] when Article 3 of the ECHR was mobilised to gain recognition for the needs of prisoners with disabilities at a time when the existing law left this group of human beings without civil protection. Subsequent changes to the *Disability Discrimination Act* 1995 through the *Disability Discrimination Act 1995 (Amendment), Regulations* 2003 and the *Disability Discrimination Act* 2005 will probably ensure that such a case remains unique in UK jurisprudence. *Price v UK*'s importance, however, will remain undiminished as a demonstration of the legal potential of a human rights approach as a vehicle for promoting the rights of people with disabilities, who otherwise might have found themselves outside the protection of the law.

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[1] "Before the General Election the Labour Party published a consultation document, *Bringing Rights Home*, setting out in some detail the case for incorporation, and its preliminary proposals for the way this should be done." *Rights Brought Home: The Human Rights Bill* Government White Paper Cm3782, 1997, introduction and summary, para 2.

[2] (33394/96) (2002) 34 E.H.R.R. 53 11 B.H.R.C. 401 (2002) 5 C.C.L. Rep. 306 Times, August 13, 2001, 2001 WL 825435.

The aim of this chapter is to provide an analysis of the effect of a human rights approach on the treatment of disabled prisoners in the UK and to explore its potential for promoting the legal rights of disabled people. The chapter opens with an examination of *Price v UK*, in which it is argued that the case demonstrates the effective mobilisation of human rights principles in case law to promote the rights of disabled prisoners. This theme is developed through an examination of cases brought before the ECtHR since 2001, involving prisoners with disabilities and medical conditions, which have further developed the jurisprudence of human rights and disability. This is followed by a discussion of the recent inclusion of disabled prisoners in UK disability legislation and their gradual acquisition of equality of treatment in the domestic law of the United Kingdom, since *Price v UK*. It is argued that these changes can be attributed to a change in the rights paradigm – from acceptance of the legal exclusion of disabled prisoners to a positive duty to include and promote their human rights to dignity and equality – a change in fact from a civil to a human rights approach.

Price v UK: Mobilising Human Rights Law

Though judgment in *Price v UK* was not given until 10th July 2001, the period of imprisonment which gave rise to this action in the ECtHR was, in fact, three days in January 1995.[3] Coincidentally, this occurred during the same year as the enactment of the *Disability Discrimination Act* 1995, the first statute in the UK to grant civil rights to people with disabilities. On 23rd July 1996, Ms Adele Ursula Price lodged her application against the United Kingdom of Great Britain and Northern Ireland with the European Commission of Human Rights under former Article 25[4] of the ECHR[5] alleging that, "her committal to prison and her treatment in detention violated Article 3 of that Convention."[6]

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[3] *Price v UK* (33394/96) (2002) 34 E.H.R.R. 53 paras. 7 & 10.

[4] Now Article 34 of the ECHR as amended by Protocol No. 11 of 1998: "The Court may receive applications from any person, non-governmental organisation or group of individuals claiming to be the victim of a violation by one of the High Contracting Parties of the rights set forth in the Convention or the Protocols thereto. The High Contracting Parties undertake not to hinder in any way the effective exercise of this right."

[5] *Price v UK*, *supra* note 3, para 1.

[6] Ibid., para 3.

The court's account of the circumstances of the case not only highlights the degree of ill-treatment that could be suffered by disabled prisoners at the time but, more importantly, their exclusion – both express and implied – from legal protection under UK law. It is possible to identify mistreatment by three public authorities: Lincoln County Court (whose judge arguably failed in his duty to Ms Price by committing her to prison for contempt of court); the authorities of Lincoln Police Station; and New Hall Women's Prison, Wakefield. In the latter, Ms Price was held in conditions which the ECtHR found to be "degrading" and which, as Judge Greve observed, "violated not only specific provisions but the entire spirit of the *Standard Minimum Rules for the Treatment of Prisoners* adopted on 30 August 1955 by the First United Nations Congress on the Prevention of Crime and the Treatment of Offenders."[7] While Lincoln County Court was exonerated by statute, the principles of negligence failed to provide a remedy at common law for Ms Price's treatment by the police and prison authorities.

When Ms Price refused to answer questions about her financial position during civil proceedings against her for recovery of a judgment debt, the trial judge committed her to New Hall Women's Prison for seven days for contempt of court. Judge Bratza, on agreeing with the verdict of violation of Article 3, took the opportunity with Judge Costa to comment separately because he wished "to make clear that in my view the primary responsibility for what occurred lies not with the police or with the prison authorities…but with the judicial authorities who committed the applicant to an immediate term of imprisonment for contempt of court,"[8] explaining that he could "see no justification for the decision to commit the applicant to an immediate term of imprisonment without at the very least ensuring in advance that there existed both adequate facilities for detaining her and conditions of detention in which her special needs could be met."[9] A justification did, however, exist in the form of statute law: Section 12(1) of the *Prison Act* 1952 provides that "a prisoner, whether sentenced to imprisonment or committed to prison on remand or pending trial or otherwise, may be lawfully confined in any prison."

Ms Price's attempts at common law to gain redress for her treatment at Lincoln Police Station and New Hall Women's Prison were equally

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[7] *Price v UK, supra* note 3, Separate opinion of Judge Greve para 7.

[8] *Price v UK, supra* note 3, Separate opinion of Judge Bratza joined by Judge Costa para1.

[9] Ibid., para 2.

unsuccessful. Because her case had been heard in the afternoon, it was too late for her to be taken directly to Wakefield. Instead, she was "lawfully confined" under s 12 of the *Police Act* 1952, to a cell at Lincoln Police Station. However:

> [t]his cell, which contained a wooden bed and a mattress, was not specially adapted for a disabled person. The applicant alleges she was forced to sleep in her wheelchair since the bed was hard and would have caused pain in her hips, that the emergency buttons and light switches were out of her reach, and that she was unable to use the toilet since it was higher than her wheelchair and therefore inaccessible.[10]

The evidence from the notes written by the doctor who examined her around midnight on 20th/21st July 1995 seems to support these allegations:

> Patient complained of feeling cold, headache and queasy, (no food since admission – offered but refused)…Talking quite sensibly, not obviously hypothermia, seated in wheelchair. Tells me unable to lie flat and sleeps on sofa, sitting up, at home. On Erythromycin for ear infection. On examination ears NAD Nystigmus J36. Unfortunately the facilities available in the cells for this type of disabled person (sic). Really requires a room temp in the high 70's as not moving/not able to move around.[11]

Part of the reason for her not being able to move around to any great extent was that a court officer had refused her permission to take with her the battery charger for her wheelchair on the grounds that "this would be considered a luxury item."[12]

On 21st July, Ms Price was taken to New Hall Women's Prison where she was detained until the afternoon of 23rd July1995.[13] Though accommodated in a cell in the prison's Health Care Centre, which had a wider door for wheelchair access, hand pulls in the toilet recess and a hydraulic hospital bed, the conditions of her detention were inadequate for the needs of a person with her disabilities. Dr Kidd, the prison doctor who examined Ms Price on her committal, made the following observations:

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[10] Ibid., para 8.

[11] Ibid., para 9.

[12] Ibid., para 7.

[13] The remission provisions in sections 45 and 33 of the *Criminal Justice Act* 1991 meant that the applicant had only to serve half the sentence imposed, i.e. three and a half days. (Ibid., para 17).

> New reception.
>
> Thalidomide victim with numerous deformities…At home she is relatively independent tho' has numerous services including electric wheelchair – which may need recharging over W/E [weekend].
>
> In hospital has difficulty with
>
> - bed – too high
> - sink – unable to reach
> - mobility – battery running down
> - fluid intake – likes to take juice and there is none
> - diet – vegetarian
> - general hygiene – needs help
>
> Needs fluid intake
> - batteries recharged
> - adequate temperature.[14]

On being advised on 21st July by the medical staff of "the numerous problems staff may encounter with this inmate," the duty Governor agreed that, if a suitable place in an outside hospital could be found, he would license Ms Price to go. The medical records, however, reveal a further problem, stating that "[w]e do not have any medical condition to admit her with." It would seem that prevention of a medical condition was not sufficient. The medical records continue, "Dr Kidd will review Adele tomorrow, as he thinks there is a likelihood she will develop a UTI [urinary tract infection]."[15]

Ms Price's remedy at common law would be in negligence. That all three public authorities – the Lincoln County Court; Lincoln Police Station; and New Hall Women's Prison – owed her a duty of care was not in doubt. What would be harder to prove was that any of these authorities had breached their duty of care or indeed that Ms Price had suffered any damage from those particular breaches. As has already been indicated, Lincoln County Court was not liable in negligence having executed its duty according to the requirements of the *Police Act* 1952, and, in the unlikely event of Ms Price being able to establish that the Lincoln Police Authority had fallen below its standard of care, it would be even harder to prove that the ill health Ms Price claimed to have suffered following her detention resulted from the conditions of the one night she spent in the police cell. Indeed, in outlining the

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[14] Ibid., para 12.

[15] Ibid., para 13.

circumstances of the case, the ECtHR observed, "[s]he claims to have suffered health problems for ten weeks as a result of her treatment in detention, but has not provided direct medical evidence in support of this claim."[16] As for the prison authorities, it would be unlikely that resulting damage would even become relevant since it would be difficult to establish a breach of duty on their part: the two reasons for this were pointed out by Ms Price's counsel in his opinion of 6th March 1996. The first was that there were "difficulties which…[she] was likely to face in proving that she had suffered the ill-treatment which she alleged." The second was that the precedent of *Knight and Others v Home Office and Another,*[17] in which the High Court held that, "given the lack of resources, the standard of care required of a prison hospital was lower than that which would be required in an equivalent outside institution,"[18] would lead to a similar ruling in Ms Price's case.

Counsel concluded his advice by saying that he believed that her claim had a limited prospect of success and that, even if she did succeed, damages were not likely to exceed £3,000.[19] As a direct result of his advice, Ms Price suffered a further blow to her planned action when a week later her legal aid certificate was discharged. Municipal law may certainly have left Ms Price without either remedy or recognition of the indignities she had suffered but international human rights law had not. The evidence Ms Price could offer might be insufficient to prove liability in torts but it was more than adequate to establish a violation of her rights under Article 3 of the ECHR and, in so doing, to improve the lives of disabled people detained at Her Majesty's pleasure as well as those detained in the prisons of other High Contracting Parties of the ECHR.

The ECHR is an international regional instrument of human rights law, which provides for "the collective enforcement of certain of the rights stated in the Universal Declaration."[20] The preamble to the *Universal Declaration of Human Rights* 1948 begins with a statement of "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family" as "the foundation of

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[16] Ibid., para 18.

[17] [1990] 3 All England Reports 237.

[18] *Price v UK*, *supra* note 3, para 19.

[19] Ibid., para 19.

[20] *European Convention for the Protection of Human Rights and Fundamental Freedoms* 1950, Preamble.

freedom, justice and peace in the world." The concept of the "inherent dignity…of all members of the human family," is a fundamental principle of international human rights law and informs the decision on an application brought before the ECtHR. Consequently, the ECtHR plays a different role from the domestic courts when considering evidence. The nature of that role was defined in the 2005 case of *Mathew v The Netherlands,* when the ECtHR stated that:[21]

> [t]he Court's role, it should be remembered, is to rule not on criminal guilt or civil liability but on Contracting States' responsibility under the Convention. The specificity of its task under Article 19 of the Convention – to ensure the observance by the Contracting States of their engagement to secure the fundamental rights enshrined in the Convention – conditions its approach to the issues of evidence and proof. In the proceedings before the Court, there are no procedural barriers to the admissibility of evidence or predetermined formulae for its assessment. It adopts the conclusions that are, in its view, supported by the free evaluation of all evidence, including such inferences as may flow from the facts and the parties' submissions. According to its established case-law, proof may follow from the coexistence of sufficiently strong, clear and concordant inferences or of similar unrebutted presumptions of fact. Moreover, the level of persuasion necessary for reaching a particular conclusion and, in this connection, the distribution of the burden of proof are intrinsically linked to the specificity of the facts, the nature of the allegation made and the Convention right at stake. The Court is also attentive to the seriousness that attaches to a ruling that a Contracting State has violated fundamental rights.[22]

Instead of considering the evidence put forward by Ms Price in the light of breach of duty and resulting damage, the judges of the ECtHR would be considering whether she had provided enough evidence to establish treatment sufficiently degrading to deprive Ms Price of that "inherent dignity" guaranteed to every human being.

Price v UK was in fact the third case to come before the ECtHR in 2001 relating to the treatment of prisoners with a disability or other condition[23] to which special attention would have to be paid by the

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[21] (24919/03) (2006) 43 EHRR 23 para 154–6; see below for discussion of case.

[22] Ibid., para 156.

[23] Drug addiction (*Peers v Greece* see below fn 27*)* is not recognised as a disability in UK law. Nevertheless, the case is included here on the grounds that a drug addict is disabled by his condition and according to human rights discourse the standard is that of human dignity regardless of the characteristics that human, or, for the purposes of the current discussion, that prisoner, might have.

detaining authorities. Although the applicant in the first case, *Keenan v UK,*[24] was the parent of a prisoner who had committed suicide and therefore the case was argued largely under Article 2 – the right to life – the applicants in all three cases were successful in their applications for recognition of a violation of Article 3. That article states "[n]o one shall be subjected to torture or to inhuman or degrading treatment or punishment."

The Court[25] held that the mode of imposition of segregation in the punishment block imposed on Mark Keenan, who suffered from paranoid schizophrenia, was "not compatible with the standard of treatment required in respect of a mentally ill person. It must be regarded as constituting inhuman and degrading treatment and punishment within the meaning of Article 3 of the Convention."[26]

The second case, *Peers v Greece,*[27] was brought by a British national, who was addicted to drugs. He was arrested at Athens Airport on drug-related charges and then taken as a remand prisoner to Koridallos Prison in Greece. He was first detained in the prison's psychiatric hospital before being moved to the segregation unit of Delta wing and, then, Alpha wing. In Delta wing, he claimed, he shared a small cell with one other prisoner, with an open toilet, which often failed to work, in hot, cramped conditions with little natural light and no ventilation. In Alpha wing conditions were also cramped and unhygienic. In addition, he had no access to vocational courses or activities or a library. Mr Peers alleged that such conditions amounted to "inhuman and degrading treatment." While the Court considered that "there was no evidence of a positive intention of humiliating or debasing the applicant," it noted that "the absence of any such purpose could not conclusively rule out a finding of a violation of Article 3."[28] It certainly believed that "the fact that the competent authorities took no steps to improve the objectively unacceptable conditions of the applicant's detention… denoted lack of respect for the applicant."[29]

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[24] *Keenan v UK* (27229/95) (2001) ECHR 242.

[25] An alternative abbreviation to ECtHR used in case reports for the European Court of Human Rights; see quotation from *Mathew v The Netherlands* above at page 5 referenced in note 22.

[26] Ibid., para 116.

[27] *Peers v Greece* (28524/95) (2001) 33 EHRR 51 19th April 2001.

[28] Ibid., para 74.

[29] Ibid., para 75.

The two areas of treatment that the ECtHR found particularly damning were: firstly, the two months in which Mr Peers had been obliged to stay confined to his bed for "a considerable part of each 24 hours," in a cell, "with no ventilation and no window, which would at times become unbearably hot," and secondly, having to use the toilet in the presence of another cell mate. The judge's opinion was as follows:

> The prison conditions complained of diminished the applicant's human dignity and aroused in him feelings of anguish and inferiority capable of humiliating and debasing him and possibly breaking his physical or moral resistance. In sum, the Court considers that the conditions of the applicant's detention in the segregation unit of the Delta wing of Koridallos Prison amounted to degrading treatment within the meaning of Article 3 of the Convention. There has thus been a breach of this provision.[30]

Bringing her case before the court in July, Ms Price was able to benefit from the success a few months earlier of *Peers v Greece,* since there were parallels which could be drawn between the treatment of Mr Peers and her own. Just as had happened in *Peers v Greece,* the Court could find "no evidence in this case of any positive intention to humiliate or debase the applicant."[31] Recalling that "ill-treatment must attain a minimum level of severity if it is to fall within the scope of Article 3," it then went on to cite *Peers v Greece,* observing that:

> [i]n considering whether treatment is "degrading" within the meaning of Article 3, one of the factors which the Court will take into account is the question whether its object was to humiliate and debase the person concerned, although the absence of any such purpose cannot conclusively rule out a finding of violation of Article 3.[32]

Although not expressly recognised by the ECtHR, there were factors in the treatment of Mr Peers and Ms Price which could be said to be similar. In *Peers*, the Court had expressly highlighted having to go to the toilet in front of a cell mate as "degrading." In *Price*, one of Ms Price's most disturbing allegations, which the Government did deny, was that, having been lifted onto the toilet by a female prison officer, Ms Price was left there for over three hours until she agreed to allow a male nursing officer to clean her up and help her off the toilet. Discomfort caused

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[30] Ibid., para 75.

[31] *Price v UK*, *supra* note 3, para 30.

[32] Ibid., para 24.

by temperature and immobility were other factors which the Court took into account in *Peers v Greece*. These also played an important part in Ms Price's allegations; though in her case the problem was being too cold, not being subject to stifling heat:

> The Court considers that to detain a severely disabled person in conditions where she is dangerously cold, risks developing sores because her bed is too hard or unreachable, and is unable to go to the toilet or keep clean without the greatest of difficulty, constitutes degrading treatment contrary to Article 3. It therefore finds a violation of this provision in the present case.[33]

The Court unanimously held that the State should pay the applicant in respect of non-pecuniary damage £4,500 – £1500 more than her counsel had anticipated for a successful outcome to an action under UK law. She was also awarded costs.[34] Perhaps more importantly, she had acquired legal recognition that the failure to cater adequately for prisoners with disabilities was an unacceptable infringement of the rights of a human being. *Price v UK* had demonstrated that human rights law could be mobilised to promote the rights of disabled people.[35]

Since *Price v UK*, there have been several cases brought before the ECtHR concerning prisoners with disabilities which have developed the jurisprudence of disability and human rights under the ECHR. There has been most development in the law relating to the rights

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[33] Ibid., para 30.

[34] Though these were reduced in order to ensure payment:
"(ii) GBP 4,000 (four thousand pounds sterling) in respect of costs and expenses, less FRF 5,300 (five thousand three hundred francs) to be converted into pounds sterling at the rate of exchange applicable on the date of delivery of this judgment;

(b) that simple interest at an annual rate of 7.5% shall be payable from the expiry of the above mentioned three months until settlement" (Ibid., para 35).

[35] See *Vincent v France* (2007) (6253/03): A wheelchair user made a successful application under Article 3 of the ECHR, the main reason was that he was held for four months in a cell which he could not leave unaided as each time one of the wheels of his chair had to be rmoved and replaced so that he could pass through the door. "En l'espèce, rien ne prouve l'existence d'une intention d'humilier ou de rabaisser le requérant. Toutefois, la Cour estime que la détention d'une personne handicapée dans un établissement où elle ne peut se déplacer et en particulier quitter sa cellule, par ses propres moyens constitue un «traitement dégradant» au sens de l'article 3 de la Convention. » para. 103 (Report in French only); *Ostrovar v Moldova* (2005) (35207/03) a prisoner claimed successfully infringement of Article 3 for the "cumulative effects of conditions in the cell" (para. 89) which included *inter alia* the failure of the prison authorities "take any steps to separate him from smokers" when they "were aware of his condition." (para. 85).

of prisoners with disabilities under Article 3. In *Mathew v The Netherlands,*[36] the ECtHR, quoting from *Kalashnikov v Russia,*[37] restated the principles relating to Article 3:

> The Court reiterates that Article 3 of the Convention enshrines one of the most fundamental values of democratic society. It prohibits in absolute terms torture or inhuman or degrading treatment or punishment, irrespective of the circumstances and the victim's behaviour…
>
> The Court further reiterates that, according to its case-law, ill-treatment must attain a minimum level of severity if it is to fall within the scope of Article 3. The assessment of this minimum is relative; it depends on all the circumstances of the case, such as the duration of the treatment, its physical and mental effects and, in some cases, the sex, age and state of health of the victim.[38]

The "separate opinions" in *Price v UK* raised two matters in relation to Article 3 which have been developed in later ECHR case law. The first has already been mentioned: Judges Bratza and Costa's suggestion that a failure by the authorities to provide satisfactory conditions for detention for disabled prisoners is a violation of Article 3. This could be interpreted as paving the way for a positive duty to build into the planning of any place of detention facilities to cater for prisoners with disabilities. Secondly, Judge Greve's observation that "to avoid unnecessary hardship – that is, hardship not implicit in the imprisonment of an able-bodied person – she has to be treated differently from the other people because her situation is significantly different."[39] This has led some applicants to question whether imprisonment itself is an infringement of their rights under Article 3.

While arguing that the responsibility for the violation of Ms Price's rights under Article 3 lay with Lincoln County Court, Judges Bratza and Costa also observed that there had been "certain failings in the standard of care provided by the police and prison authorities," and that these "stemmed in large part from the lack of preparedness on the part of both to receive and look after a severely handicapped person in conditions which were wholly unsuited to her needs."[40] Two years later,

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[36] *Mathew v The Netherlands* (2005) (24919/03).

[37] 47095/99, § 95, ECHR 2002-VI.

[38] *Mathew v The Netherlands*, *supra* note 36, para 175 quoting the ECtHR in *Kalashnikov v Russia*.

[39] *Price v UK, supra* note 3, "Separate Opinion of Judge Greve" para 5.

[40] Ibid., "Separate Opinion of Judge Bratza joined by Judge Costa" para 2.

the ECtHR in *McGlinchey & Others v UK*[41] expressly recognised "the responsibility owed by prison authorities to provide the requisite medical care for detained persons."[42] Like Ms Price, the applicants, who were the parent and children of Judith McGlinchey, a heroin addict who had died in prison, had been advised that there was "insufficient evidence to establish the necessary causal link between her death and the allegedly negligent care afforded to her in custody."[43] Like Ms Price, they had sought redress by means of a claim under Article 3 of the ECHR in the ECtHR. In giving judgment the Court stated:

> Under this provision the State must ensure that a person is detained in conditions which are compatible with respect for her human dignity, that the manner and method of the execution of the measure do not subject her to distress or hardship of an intensity exceeding the unavoidable level of suffering inherent in detention and that, given the practical demands of imprisonment, her health and well-being are adequately secured by, among other things, providing her with the requisite medical assistance.[44]

The Court found that the loss of weight and dehydration, which resulted from vomiting and which the authorities had failed to monitor, had posed very serious risks to Mrs McGlinchey's health. These findings, together with the fact that the prison service had failed to comply with their duty to provide Mrs McGlinchey with the necessary medical treatment for her condition, amounted to a breach of the prohibition against inhuman and degrading treatment found in Article 3 ECHR.

Judge Greve, in *Price v UK*, argued that to avoid violating Article 3, it may sometimes be necessary for the detention authorities to provide additional services:

> In a civilised country like the United Kingdom, society considers it not only appropriate but a basic humane concern to try to ameliorate and compensate for the disabilities faced by a person in the applicant's situation. In my opinion, these compensatory measures come to form part of the disabled person's bodily integrity. It follows that, for example, to prevent the applicant, who lacks both ordinary legs and arms, from bringing with her the battery charger to her wheelchair when she is sent to prison for one week, or to leave her in unsuitable sleeping conditions so that she has to endure pain and cold – the latter to the extent that eventually a

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[41] *McGlinchey & Others v UK* (2003) (50390/99).

[42] Ibid., para 57.

[43] Ibid., para 39.

[44] Ibid., para 46.

> doctor had to be called – is in my opinion a violation of the applicant's right to bodily integrity. The applicant's disabilities are not hidden or easily overlooked. It requires no special qualification, only a minimum of ordinary human empathy, to appreciate her situation and to understand that to avoid unnecessary hardship – that is, hardship not implicit in the imprisonment of an able-bodied person – she has to be treated differently from other people because her situation is significantly different.[45]

In Judge Greve's opinion, only by making arrangements to compensate for Ms Price's disabilities could it be "ensured that her treatment was equivalent to that of other prisoners."[46] Her assertion that each of the authorities "could and should have ensured that the applicant was not put into detention until [these] special arrangements had been made,"[47] and that failure to do so, "gave rise to violations of the applicant's personal integrity…as well as to inhuman and degrading treatment,"[48] has to be interpreted, at least, as providing a justification for the demand for making specific adjustments to places of detention to accommodate disabled prisoners, and, perhaps more ambitiously, as the beginnings of a positive duty to do so.

The argument for treating disabled prisoners differently, in order to ensure equal treatment with other prisoners and so to avoid a violation of Article 3, was further developed in *Mouisel v France*.[49] The applicant, who had leukaemia,[50] successfully argued that it was a violation of his rights under Article 3 to be handcuffed while undergoing treatment at an outside hospital. Even though handcuffing prisoners when on visits outside the prison was accepted practice, the ECtHR considered that there had been a violation of Article 3:

> In the instant case, having regard to the applicant's health, to the fact that he was being taken to hospital, to the discomfort of undergoing a chemotherapy session and to his physical weakness, the Court considers that

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[45] *Price v UK, supra* note 3, "Separate Opinion of Judge Greve" para 4.

[46] Ibid., para 5.

[47] Ibid., para 6.

[48] Ibid., para 6.

[49] (2002) (67263/01).

[50] In the UK, under the *Disability Discrimination Act* 2005, the definition of disability has been widened to include persons with progressive conditions such as cancer, multiple sclerosis or HIV where the impairment has an effect on the individual's ability to carry out normal day-to-day activities. (See discussion below pages) For the purposes of this study, however, as stated at note 23 above, it is the infringement of human dignity rather than recognition in law that has dictated the inclusion of these authorities.

> the use of handcuffs was disproportionate to the needs of security. As regards the danger presented by the applicant, and notwithstanding his criminal record, the Court notes the absence of any previous conduct or other evidence giving serious grounds to fear that there was a significant danger of his absconding or resorting to violence. Lastly, the Court notes the recommendations of the European Committee for the Prevention of Torture concerning the conditions in which prisoners are transferred to hospital to undergo medical examinations – conditions which, in the Committee's opinion, continue to raise problems in terms of medical ethics and respect for human dignity…The applicant's descriptions of the conditions in which he was escorted to and from hospital do not seem very far removed from the situations causing the Committee concern in this area.[51]

The test for "degrading treatment" remains the infringement of human dignity, "for this the health and well-being of a prisoner must be adequately secured."[52] In *Matthew v The Netherlands*, the ECtHR found that depriving a prisoner who suffered from curvature of the spine from access to a wheelchair after he had used it as a weapon against a prison officer did not amount to a violation of Article 3 in the absence of evidence to suggest "that the applicant was incapacitated to the point of immobility."[53] "Article 3," the Court explained, "cannot be interpreted as requiring a prisoner's every wish and preference regarding medical treatment to be accommodated. In this as in other matters, the practical demands of legitimate detention may impose restrictions which a prisoner will have to accept."[54]

The Court also rejected Mr Mathew's allegation that the authorities' refusal to release him to be treated by a civilian medical specialist was a violation of his rights under Article 3, particularly, he claimed, as he had not yet been convicted. While the judges agreed that depriving a person of his or her liberty may often involve an element of "suffering and humiliation" which goes beyond that "connected with a given

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[51] Ibid., para 47.

[52] *Matthew v The Netherlands*, *supra* note 36, para 186; The ECtHR did, however, find a violation of Article 3 for other reasons: "There has been a violation of Article 3 of the Convention in that the applicant was kept in solitary confinement for an excessive and unnecessarily protracted period, that he was kept for at least seven months in a cell that failed to offer adequate protection against the elements, and that he was kept in a location from which he could gain access to outdoor exercise and fresh air only at the expense of unnecessary and avoidable physical suffering" (para 217).

[53] Ibid., para 172.

[54] Ibid., para 186.

form of legitimate treatment or punishment," they went on to note that:

> it cannot be said that detention on remand in itself raises an issue under Article 3 of the Convention. Nor can that Article be interpreted as laying down a general obligation to release a detainee on health grounds or to place him in a civil hospital to enable him to obtain specific medical treatment.[55]

Prior to *Matthew v The Netherlands*, there had been two attempts by applicants to establish that imprisonment *per se* could, depending upon the disability of the prisoner, be sufficient to be a violation of Article 3. In 2002, Mr Mouisel argued that "detention was in itself incompatible with the condition of prisoners suffering from life-threatening diseases."[56] He argued that:

> imprisonment should merely entail depriving a person of his freedom of movement and that all other fundamental rights remained intact during detention. The Court should therefore, in his opinion, set out to determine whether the suffering he had endured in the course of his illness while in prison had attained a sufficient level of severity to fall within the scope of Article 3 of the Convention.[57]

While the ECtHR, referring to the judgments in *Keenan v UK* and *Price v UK*, agreed that it had held that certain types of treatment could infringe Article 3, the Article could not be "construed as laying down a general obligation to release detainees on health grounds."[58] However, in his particular case it agreed that the national authorities had not taken sufficient care of Mr Mouisel's health to ensure that he did not suffer treatment contrary to Article 3 of the Convention and that there was a violation of that Article:

> His continued detention, especially from June 2000 onwards, undermined his dignity and entailed particularly acute hardship that caused suffering beyond that inevitably associated with a prison sentence and treatment for cancer. In conclusion, the Court considers that the applicant was subjected to inhuman and degrading treatment on account of his continued detention in the conditions examined above.[59]

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[55] Ibid., 175.

[56] *Mouisel v France* (2002) (7263/01) para 33.

[57] Ibid., para 32.

[58] Ibid., para 40.

[59] Ibid., para 48.

A year later, the question of whether imprisonment for persons with certain disabilities amounted to treatment sufficiently severe to lead to a violation of Article 3, was raised by Mr Gelfmann, who was suffering from AIDS and who had applied under French Law for a pardon and then for parole for treatment. These applications had been refused. Once again, the ECtHR observed that the minimum level of severity for a violation of Article 3 was relative and that "regard is to be had to the particular circumstances of each specific case." The Court further noted:

> Thus, the Court has been called upon to examine, *inter alia*, whether it is compatible with Article 3 for the following categories of persons to be detained: persons suffering from mental disorder (*Kudła* cited above; and *Keenan v. the United Kingdom*, no. 27229/95, ECHR 2001-III) or serious illness (*Mouisel* cited above, *Matencio v. France*, no. 58749/00, 15 January 2004; and *Sakkopoulos v. Greece*, no. 61828/00, 15 January 2004), the disabled (*Price v. the United Kingdom*, no. 33394/96, ECHR 2001-VII), the elderly (*Papon* decision cited above) or drug addicts suffering withdrawal symptoms (*McGlinchey and Others v. the United Kingdom*, no. 50390/99, ECHR 2003-V).[60]

Referring closely to the judgment in *Mouisel v France*, the ECtHR left no doubt that Article 3 did not lay down a general obligation to release a detainee on health grounds or to transfer him to a civil hospital but nevertheless the High Contracting Party was required:

> to ensure that prisoners are detained in conditions which are compatible with respect for human dignity, that the manner and method of the execution of the measure do not subject them to distress or hardship of an intensity exceeding the unavoidable level of suffering inherent in detention and that, given the practical demands of imprisonment, their health and well-being are adequately secured by, among other things, providing them with the requisite medical assistance.[61]

In 2006, the case of Jean-Luc Rivière[62] provided the first "circumstance" when the ECtHR would conclude that a prisoner's disability would

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[60] *Gelfmann v France* (2003) (25875/03) para 49.

[61] Ibid., para 50; see also *Kotsaftis v Greece* (2008) (39780/06), – successful application for inhuman treatment: "The Court concluded that the Greek authorities, during the period in question, had not fulfilled their obligation to safeguard the applicant's physical integrity, in particular by providing him with the appropriate medical care. Taking the view that that omission amounted to inhuman treatment, it held that there had been a violation of Article 3." European Court of Human Rights 431 12.06.2008 Press release issued by the Registrar, Chamber Judgment, *Kotsaftis v Greece* (Case report in French only).

[62] *Riviere v France* (2006) (3383403).

render continued detention in prison incompatible with respect for human dignity and failure to transfer him to hospital would be a violation of Article 3. Though sentenced to death for murder in 1980, the Court of Cassation, in 1982, commuted Mr Rivière's sentence to life imprisonment without parole for a minimum of 15 years. Thus, when in August 2002, a psychiatrist from the Val-de-Reuil Regional Medical and Psychiatric Department issued a certificate stating that the applicant was psychotic with suicidal tendencies and that his condition required hospital treatment, Mr Rivière was already eligible for parole. He was, however, admitted to hospital for only one month. In 2004, Mr Rivière applied to be released on licence but the parole board refused his application. Having made the now customary observation, "selon sa jurisprudence, pour tomber sous le coup de l'article 3, un mauvais traitement doit atteindre un minimum de gravité,"[63] and that a decision as to what that minimum was depended on all the circumstances of the case, "notamment de la durée du traitement et de ses effets physiques et mentaux," the ECtHR pointed out that in *Price v UK* detention of a quadriplegic in conditions which were not adapted for her disability were deemed to constitute "degrading treatment."[64]

The Court first outlined the breaches of French municipal law,[65] brought about through the continued detention of Mr Rivière, then went on to consider the implications of continued detention under the ECHR. Building on its own decisions in *Mouisel v France* and *Gelfmann v France,* the ECtHR suggested that it was possible to argue that Article3 imposed on the State a positive obligation to ensure that all prisoners

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[63] Ibid., para 59; report in French only; see for example.

[64] Ibid., para 61: "Dans l'arrêt *Price c. Royaume-Uni*, la Cour a jugé que le fait d'avoir maintenu en détention la requérante, handicapée des quatre membres, dans des conditions inadaptées à son état de santé, était constitutif d'un traitement dégradant (n° 33394/96, § 30, CEDH 2001–VII)."

[65] Ibid., para 71–2; European Court of Human Rights, 417, 11.7.2006: Press release issued by the Registrar, Chamber Judgment, *Rivière v France*.

"(T)he Court noted that Article D. 398 of the Code of Criminal Procedure provided that prisoners with mental disorders could not be held in an ordinary prison but were to be compulsorily admitted to hospital by order of the prefect. That provision was confirmed by Article L. 3214–1 of the Public Health Code, which stated that detainees suffering from mental disorders should be admitted to a specially designed wing of an ordinary health-care institution. The Court further observed that Recommendation No. R (98) 7 of the Committee of Ministers of the Council of Europe concerning the ethical and organisational aspects of health care in prison provided that prisoners suffering from serious mental disturbance should be kept and cared for in a hospital facility that was adequately."

were cared for in a manner that protected their human dignity and that this included the provision of the required medical care:

> Elle réitère que, si l'on ne peut déduire de l'article 3 de la Convention une obligation générale de libérer un détenu pour motifs de santé ou de le transférer dans un hôpital civil, même s'il souffre d'une maladie particulièrement difficile à soigner, cet article impose en tout cas à l'Etat l'obligation positive de s'assurer que tout prisonnier est détenu dans des conditions qui sont compatibles avec le respect de la dignité humaine, et que, eu égard aux exigences pratiques de l'emprisonnement, la santé et le bien-être du prisonnier sont assurés de manière adéquate, notamment par l'administration des soins médicaux requis.[66]

Thus, it followed that prisoners with serious mental disorders and suicidal tendencies should be provided with special care irrespective of the gravity of their crimes.[67] It was the opinion of the Court that the continued detention of the applicant without medical supervision "entailed particularly acute hardship and caused him distress or adversity of an intensity exceeding the unavoidable level of suffering inherent in detention."[68] In short, the applicant had suffered "l'etraitement inhumain et dégradant."[69] Consequently, the detention of this prisoner with diagnosed mental disabilities without the medical treatment he needed, violated Article 3.[70]

The following year, Mr. Vladimir Kutcherek, who suffered from schizophrenia, made a successful application to the ECtHR for violations of his rights under Article 3 for "lack of adequate medical treatment and assistance provided to the applicant while he was detained on remand, amounting to inhuman and degrading treatment."[71] In addition, the ECtHR found that the "unjustified" use of truncheons "amounted to inhuman treatment,"[72] while "the handcuffing of the mentally ill applicant for a period of seven days without any psychiatric

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[66] Ibid.

[67] *Riviere v France* (2006) (3383403) para 75: . "Au vu de cette jurisprudence, la Cour considère que l'état d'un prisonnier dont il est avéré qu'il souffrait de graves problèmes mentaux et présentait des risques suicidaires, même si jusqu'à présent ceux-ci ne se sont pas réalisés, appelle des mesures particulièrement adaptées en vue d'assurer la compatibilité de cet état avec les exigences d'un traitement humain, quelle que soit la gravité des faits à raison desquels il a été condamné."

[68] European Court of Human Rights, 417, 11.7.2006: Press release issued by the Registrar, Chamber Judgment, *Rivière v France.*

[69] Ibid., para 76.

[70] Ibid., para 77.

[71] *Kucherek/Koutchereouk v Ukraine* (2007) (2570/04) para 152.

[72] Ibid., para 132.

justification, or any medical treatment for injuries sustained during his forced restraint and self-inflicted during the confinement in the disciplinary cell, must be regarded as constituting inhuman and degrading treatment."[73] *Kucheruk/Koutcherouk v Ukraine's* contribution to Strasbourg jurisprudence goes far beyond additions to the list of recognised violations of Article 3 ECHR for two reasons. Firstly, it demonstrates the successful mobilisation of Article 5 to prevent the authorities from prolonging detention:

> The applicant's continued detention in the Hospital after the court order committing him to compulsory psychiatric treatment was revoked could not be regarded as a first step in the execution of the order for his release and therefore did not come within sub-paragraph 1 (e), nor did it fall within any other sub-paragraph, of Article 5. Accordingly, there has been a violation of Article 5 § 1 on that account.[74]

It confirmed the decision in *Gorshkov v Ukraine* "that a key guarantee under Article 5 § 4 is that a patient compulsorily detained for psychiatric treatment must have the right to seek judicial review on his or her own motion."[75] Secondly, it established a positive obligation to investigate the effects of detention procedures on prisoners with a medical condition; in this case, the effect of the use of truncheons by prison guards on a detainee suffering from schizophrenia which the ECtHR described as "a procedural violation of Article 3 of the Convention."[76]

Three months later, the case of *Dybeku v Albania*[77] provided the ECtHR with an opportunity to clarify the obligation under Article 3 ECHR to investigate the effects of detention on a mentally disabled patient:

> There are three particular elements to be considered in relation to the compatibility of an applicant's health with his stay in detention: (a) the medical condition of the prisoner, (b) the adequacy of the medical assistance and care provided in detention,and (c) the advisability of

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[73] Ibid., para 145.

[74] Ibid., paras 193–4.

[75] *Gorshkov v Ukraine* (2005) (67531/01) para 44 quoted in *Kucherek/Koutchereouk v Ukraine* (2007) (2570/04) para 197.

[76] *Kucherek/Koutchereouk v Ukraine*, *supra* note 70, para 163; see also Index to the Information Notes on the Court's case-law 2007.

[77] (2007) (41153/06).

> maintaining the detention measure in view of the state of health of an applicant."[78]

The Albanian Government, by treating Dybeku in the same manner as any non-disabled criminal convicted of homicide and sentenced to life imprisonment, had failed to take into account the fact that "his psychological condition may have made him more vulnerable than the average detainee,"[79] while "a lack of resources cannot in principle justify detention" and lack of proper medical treatment.[80]

The most recent addition to the Human Rights legal arsenal for the protection of disabled prisoners was the mobilization of Article 2, though by definition too late to protect the detainee. Helene Renolde "alleged that the French authorities had not taken the necessary measures to protect the life of (her brother) Joselito Renolde and that his placement in a punishment cell for forty-five days had been excessive in view of his mental fragility."[81] By this failure, they had not only violated Article 3 by submitting him to inhuman and degrading treatment but also his right to life under Article 2. On the grounds that "the vulnerability of mentally ill persons calls for special protection," especially "where a prisoner suffering from severe disturbance is placed, as in the instant case, in solitary confinement or a punishment cell for a prolonged period, which will inevitably have an impact on his mental state, and where he has actually attempted to commit suicide shortly beforehand,"[82] the ECtHR concluded that "the authorities in the instant case failed to comply with their positive obligation to protect Joselito Renolde's right to life, and that there has been a violation of Article 2 of the Convention."[83] Moreover, "such a penalty is not compatible with the standard of treatment required in respect of a mentally ill person and constitutes inhuman and degrading treatment and punishment"[84] and so the French authorities had also violated Article 3.

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[78] Ibid., para 42.

[79] Ibid., para 47.

[80] Ibid., para 50.

[81] *Renolde v France* (2009) (5608/05) para 3.

[82] Ibid., para 109; Judge Villigerin his concurring opinion that there was a violation of Article 2 simply because the authorities had failed to supervise the taking of medication.

[83] Ibid., para 110.

[84] Ibid., para 129.

In 2008, the ECtHR, in the case of *Yakovenko v Ukraine*,[85] confirmed that lack of provision of "timely and appropriate medical assistance to the applicant in respect of the condition (in this case, his HIV and tuberculosis infections) amounted to inhuman and degrading treatment within the meaning of Article 3 of the Convention,"[86] while failure to provide appropriate transport to and from treatment, could, and indeed in this case, had, "exceed(ed) the minimum level of severity" for the Court to find "there has been a violation of Article 3 of the Convention."[87]

Though most developments in European human rights law relating to disabled prisoners have been under Article 3, the cases of *Price v UK* and *McGlinchey & Others v UK* have demonstrated the potential of Articles 14 and 13 of the ECHR respectively. Judge Greve, in her separate opinion in *Price v UK,* suggested that there had been a violation of Article 14, which states:

> The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

Though not expressly mentioned in Article 14, disabled people would come under the category of "other status" when matters of discrimination were considered. Judge Greve certainly took this view. Quoting from the judgment in *Thlimmenos v Greece,*[88] she pointed out that the right not to be discriminated against under the Convention is "violated when States without an objective and reasonable justification fail to treat differently persons whose situations are significantly different."[89] Having pointed out that at night Ms Price, because of her disability, was unable to move enough to keep a normal human temperature if the room was not specially heated or she was not wrapped in a space

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[85] (2008) (15825/06).

[86] *Yakonvenko v Ukraine*, 2008) (15825/06), para 101; see footnote l regarding definition of disability.

[87] Ibid., para 113.

[88] Ref *Thlimmenos v Greece* (2000) (34369/97 § 44).

[89] (2000) (34369/97 § 44) as quoted in *Price v UK*, *supra* note 3, "Separate Opinion of Judge Greve" para 3.

blanket, she argued that such treatment was not only a violation of Article 3 but was also discriminatory:

> It is obvious that restraining any non-disabled person to the applicant's level of ability to move and assist herself, for even a limited period of time, would amount to inhuman and degrading treatment – possibly torture…It requires no special qualification…to appreciate her situation and to understand that to avoid unnecessary hardship – that is, hardship not implicit in the imprisonment of an able-bodied person – she has to be treated differently from other people because her situation is significantly different.[90]

The prohibition of discrimination under Article 14 has a more limited application than the other guarantees in the ECHR, since its reach is only as far as the "enjoyment of the rights and freedoms set forth in the Convention." The procedural implications of this are that a violation of Article 14 must be argued in conjunction with the violation of another Article in the ECHR. Despite this provision, it is surprising that in *Price v UK* an application was not made under Article 14 in conjunction with Article 3 for, as Lidia Lai, a member of the Disabled Rights Promotion International *Legal Education and Research Project*, pointed out in her report, "a complaint of discrimination about the treatment of a disabled person will fall within the ambit of Article 3 as well as Article 14 ECHR."[91] She went on to observe:

> It may have been effective for Ms. Price to argue that the degrading treatment she experienced was a direct result of discrimination against her disability…There is a direct correlation between the prohibition from torture under Article 3 and the prohibition from discrimination under Article 14. Where somebody has been subjected to torture or to inhuman or degrading treatment or punishment, it may be a result of discrimination concerning his or her sex, race, gender or status. In *Price*, the discrimination was a result of the applicant's status, her physical disability.[92]

None of the prisoners with disabilities or disabling conditions in the cases following *Price v UK* have attempted to mobilise Article 14. This may be because a successful application relating to discrimination

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[90] *Price v UK*, *supra* note 3, "Separate Opinion of Judge Greve" para 4.

[91] Centre for Empirical Studies in Law and Regulation, University of Greenwich. (2004). Mechanisms Available for Improving the Rights of Disabled Prisoners. *Building a Human Rights Monitoring System in the Field of Disability: Comparative Evaluation of rights Mechanisms UK 2003–5* Interim Report, p149.

[92] Ibid., p 149.

depends not only on establishing the violation but also on establishing that the "other status" of the applicant is one which can be recognised under Article 14. The decision, however, to keep the same non-discrimination grounds as Article 14 in Article 1, taken when drafting Protocol No. 12 of the ECHR, the aim of which is "to take further steps to promote the equality of all persons through the collective enforcement of a general prohibition of discrimination,"[93] would suggest that establishing membership of the category of "other status" is not generally perceived as problematic. Indeed, this is confirmed by the Council of Europe's comments in its *Explanatory Report* on Protocol No. 12:

> The list of non-discrimination grounds in Article 1 is identical to that in Article 14 of the Convention. This solution was considered preferable over others, such as expressly including certain additional non-discrimination grounds (for example, physical or mental disability, sexual orientation or age), not because of a lack of awareness that such grounds have become particularly important in today's societies as compared with the time of drafting of Article 14 of the Convention, but because such an inclusion was considered unnecessary from a legal point of view since the list of non-discrimination grounds is not exhaustive, and because inclusion of any particular additional ground might give rise to unwarranted *a contrario* interpretations as regards discrimination based on grounds not so included. It is recalled that the European Court of Human Rights has already applied Article 14 in relation to discrimination grounds not explicitly mentioned in that provision (see, for example, as concerns the ground of sexual orientation, the judgment of 21 December 1999 in the case of *Salgueiro da Silva Mouta v Portugal*).[94]

More likely, it can be explained by the dependency of the success of an application involving Article 14 on the proof of a violation of an additional Article. Indeed the *7th International Colloquy on the European Convention on Human Rights,*[95] looking to broaden:

> through the development of the Strasbourg case-law, the protection offered by Article 14 of the Convention…recognised that there was little scope for further expansion of the case-law on this score since the prohibition in Article 14 is clearly accessory to the other, substantive guarantees in the Convention.[96]

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[93] "Preamble", *Protocol No. 12 to the Convention for the Protection of Human Rights and Fundamental Freedoms Explanatory Report* (ETS No. 177).

[94] *Protocol No. 12 to the Convention for the Protection of Human Rights and Fundamental Freedoms Explanatory Report* at 20 (ETS No. 177).

[95] Copenhagen, Oslo and Lund, from 30 May to 2 June 1990.

[96] Reported in *Protocol No. 12 to the Convention for the Protection of Human Rights and Fundamental Freedoms Explanatory Report* at 3 (ETS No. 177).

Thus, the general prohibition of discrimination under Article 1 of Protocol No.12 is not limited to the rights in the Convention. Indeed, the guarantee is that, "the enjoyment of any right *set forth by law* shall be secured without discrimination."[97] Consequently, when a High Contracting Party ratifies Protocol No. 12, the principle of non-discrimination will extend to rights guaranteed under national law as well as under the ECHR itself. Furthermore, the second part of Article 1 – "No one shall be discriminated against by any public authority on any ground such as those mentioned in paragraph 1" – provides for the challenging of public authorities in relation to any acts or omissions, the carrying out of any obligations under national law and the manner of exercising their discretionary powers.

Article 1 of Protocol No. 12 has the potential to widen the scope of the protection offered by Article 14. However, Protocol No. 12 is an additional protocol and therefore does not amend or replace Article 14, which will continue to apply to States Parties to the Protocol. At present, its use by disabled prisoners in the UK is purely hypothetical, since though the Protocol gained the requisite ten ratifications from High Contracting Parties for it to come into force on 1st April 2005, the UK Government has yet to sign the Protocol, let alone to ratify it.[98]

Article 13, in contrast to Article 14, has been the subject of a successful action–*McGlinchey & Others v UK*, in the ECtHR. Article 13 provides: "[e]veryone whose rights and freedoms as set forth in this Convention are violated shall have an effective remedy before a national authority notwithstanding that the violation has been committed by persons acting in an official capacity."

The applicants claimed that under UK law there was "no adequate remedy for their complaints about the treatment of Judith McGlinchey in prison, or a remedy that would address the defects in management and policy which allowed the neglect and ill-treatment,"[99] and that,

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[97] Author's emphasis.

[98] Information accessed on 4th January 2009 from the Chart of Signatures and Ratifictions Protocol No. 12 to the Convention for the Protection of Human Rights and Fundamental Freedoms.

CETS No.: 177, online, http://conventions.coe.int/Treaty. Though the UK Government is in a minority of ten in not having signed the Convention, the fact that it took five years to come into force and that five years later only seventeen High Contracting Parties have ratified while a further twenty have failed to follow their signature with a ratification is arguably an indication of the governments' recognition of the potential for enforcing guarantees and the subsequent expenditure.

[99] *McGlinchey & Others v UK*, *supra* note 41, para 60.

under Article 13, they were entitled to a remedy. The ECtHR agreed: "In the case of a breach of Articles 2 and 3 of the Convention, which rank as the most fundamental provisions of the Convention, compensation for the non-pecuniary damage flowing from the breach should in principle be part of the range of available remedies,"[100] it stated. It also stated that "the remedy required by Article 13 must be "effective in practice as well as in law"[101] and consequently:

> that Judith McGlinchey, or the applicants acting on her behalf after her death, should have been able to apply for compensation for the non-pecuniary damage suffered by her. As there was no remedy which provided a mechanism to examine the standard of care given to Judith McGlinchey in prison and the possibility of obtaining damages, there has, accordingly, been a breach of Article 13 of the Convention.[102]

Thus, even though the "right to an effective remedy" could not be successfully mobilised in the UK domestic courts because Article 13 of the ECHR was not part of the *Human Rights Act* 1998, it was still a right in international human rights law that could be claimed by a UK national and enforced by the ECtHR.

Changing the UK Disability Paradigm from Civil Rights to Human Rights

Price v UK marked a turning point in the law relating to disabled prisoners in the UK. Not only did it ensure that in practice the police and prison authorities would address the needs of disabled prisoners but also it heralded a new approach to promoting their rights, a move away from the use of domestic common law and statutory principles to the application of human rights principles. Ms Price had fought and won her application in the ECtHR. Under Article 46 of the ECHR, the UK Government, as a High Contracting Party, had undertaken "to abide by the final judgment of the Court." This was clearly demonstrated in August 2001 when the Home Office agreed to an out of court settlement of £3,500 plus legal costs for a subsequent action brought by a

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[100] Ibid., para 63.

[101] Ibid., para 62.

[102] Ibid., para 67. Also argued successfully by applicant in *Yakovenko v Ukraine*: "The Court finds that there was no effective and accessible remedy in respect of the applicant's complaints about the conditions of the his detention. There was, therefore, a violation of Article 13 of the Convention," para 127.

disabled prisoner who claimed mistreatment under the *Disability Discrimination Act* 1995.

The prisoner, who weighed 22 stone and suffered from arthritis and a heart condition, was sentenced to nine months imprisonment for handling stolen goods. For this offence he should have been held in an open prison. According to normal practice, he began his imprisonment in HMP Horfield and was then transferred to Leyhill Open Prison. However, the Governor of Leyhill, because of the prisoner's disability, insisted on returning him to HMP Horfield where he served the remainder of his sentence. HMP Horfield was for prisoners who had committed serious offences and who were subject to a much stricter regime than existed in an open prison. "One of the more disturbing aspects of the case," wrote Paul Daniels, his solicitor, "was that he could easily have been accommodated at Leyhill."[103] As a result, the prisoner, because of his disability, suffered a term of imprisonment much harsher than another convict for a similar crime without a disability. For example, he had fewer opportunities to associate with other prisoners, more limited recreation and entertainment facilities and fewer visits than he would have had at Leyhill. Matthew Harris, in his report for the DRPI Education and Research Project, made the following observation:

> According to the Prison Service Order 2855's definition of discrimination, he was treated differently because of his disability in that an able bodied prisoner would not have been transferred to a more secure prison in order to accommodate him. The fact that this case was settled out of court indicates that the Prison Service felt as though they would have lost.[104]

At first, the Home Office had tried to claim that the disability legislation did not apply to prisons but the prisoner's solicitors managed to obtain internal Home Office documents which acknowledged that the *Disability Discrimination Act* 1995 did apply to prisons. The solicitors hailed the settlement as "a landmark decision:"

> It is the first case in which a prisoner has obtained compensation from a prison following disability discrimination. The way the prisoner was

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[103] *Russell Jones & Walker.* (16 August 2001). Website, online: http://www.rjw.co.uk/.

[104] Harris, M. (2004). Monitoring the mechanisms for the promotion of the rights of prisoners with disabilities in the United Kingdom. *Building a Human Rights Monitoring System in the Field of Disability: Comparative Evaluation of rights Mechanisms UK 2003–5 Interim Report* Centre for Empirical Studies in Law and Regulation, University of Greenwich, 130.

> treated was a gross affront to his personal dignity and should never have been allowed. All he wanted was equal treatment, not special favours. Instead, he had to face much worse prison conditions simply because of his disability. This case will have a major impact on the rights of disabled prisoners.[105]

The out of court settlement may have been made under the banner of civil rights and the *Disability Discrimination Act* 1995 but the law that achieved that settlement was human rights law. Indeed, the solicitors' discourse is of the human rights principles of dignity and equality: the prisoner's treatment was "a gross affront to personal dignity" and "all he wanted was equal treatment."[106]

Had the case come before the domestic courts, a very different set of circumstances would have existed from those in which Ms Price had first attempted to take her case before the UK courts. *Price v UK* had established that inadequate facilities for disabled prisoners could amount to a violation of Article 3. Moreover, now that the *Human Rights Act* 1998 was in force, not only did a UK court under section 2(1)(a) have to "take into account" any judgment or advisory opinion of the ECtHR but, as an expressly recognised public authority,[107] the *Human Rights Act* 1998 made it unlawful for a UK court or tribunal or any person carrying out a public function "to act in a way which was incompatible with a Convention right."[108] In the light of the *Price v UK* judgment and the Government's obligations under Article 46, if the Home Office had persisted in its claim that the *Disability Discrimination Act* 1995 did not apply to prisons, then, under section 4(2),[109] the court might have been obliged to make a "declaration of incompatibility" with the ECHR of the *Disability Discrimination Act* 1995. Though, as established in s 4(6)(a), such a declaration "does not affect the validity, continuing operation or enforcement of the provision in respect of which it is given; and (b) is not binding on the parties to the proceedings in which it was made," such a development would have been a public and formal indication to the executive that the Home Office's practices would have to change if it were to discharge its obligations to disabled prisoners under the ECHR. By settling out of court, the Home

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[105] Ref *Russell Jones & Walker, supra* note 103.

[106] Ibid.

[107] s6(1)(3)(a) *Human Rights Act* 1998.

[108] s6(1) *Human Rights Act* 1998.

[109] *Human Rights Act* 1998.

Office had at this stage avoided a full-blown public commitment to making immediate adjustments for the detention of disabled prisoners. Though Frances Crook, the Director of the Howard League for Penal Reform, claimed that the League was "delighted at the result in this case, which shows that disabled prisoners have a right not to be treated less favourably because of their disability," she was less than certain about its consequences in practice: "The Home Office will hopefully now do something about the unacceptable treatment of disabled prisoners."[110]

However, the influence of *Price v UK* on UK law on the treatment of disabled prisoners should not be underestimated. On 6th August 2001, Ben Summerskill reported in *The Observer*:

> After *Price v UK* and the out of court settlement achieved by Paul Daniels, the Prison Service undertook to "treat prisoners as ordinary 'customers'" in future. It has given an undertaking to "remove or alter physical barriers that prevent a disabled person gaining access" to all prisons by 2004.

Moreover, it would seem that the responsibility of the judges identified by Judge Greve of "ensuring in advance that there existed both adequate facilities for detaining [a disabled prisoner] and conditions of detention in which her special needs could be met," could now under UK law have become a legal reality. Four days after Ben Summerskill had reported the changes promised by the UK prison authorities, Steve Foster raised this question in an article published in the *New Law Journal*. If, he argued, "under section 6 of the *Human Rights Act* 1998, courts are defined as public authorities for the purpose of liability for breaching convention rights," then "a violation could take place by the act of sentencing."[111] A corollary to Steve Foster's argument could be that a UK court in 2010 faced with similar facts to those in *Price v UK* might find itself forced to declare that the provision under Section 12(1) of the *Prison Act* 1952 that any prisoner "may be lawfully confined in any prison," was incompatible with Article 3 of the ECHR.

The contribution of the *Human Rights Act* 1998 in providing a legal mechanism to challenge the treatment of prisoners with disabilities in the domestic courts has been important. However, its contribution has

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[110] Quoted in "News and Events" *Russell Jones & Walker, supra* note 103.

[111] Foster, S. (2001). Inhuman and degrading prison condition. *New Law Journal, 151*(6996), 1222 at 1223.

been more fundamental in that it has provided the ideological framework for a change in the perception of disability. On 1st October 2000, the day before the *Human Rights Act* 1998 came into force, in an interview with the BBC, Professor Francesca Klug outlined her hopes for the Act:

> My personal vision is that this Act becomes part of the national dialogue, much as race and gender equality legislation has infiltrated the national dialogue in an effective way. I hope that the *Human Rights Act* will do so in a much broader context.[112]

Disability legislation is notable by its absence from Professor Klug's statement. In 2000, the dominant view was that disability belonged more to the realms of medical, welfare and discrimination law than to equality and human rights. Yet it is in the field of disability that there has been most change and nowhere is this change more marked than in the instruments determining the treatment of prisoners. The development in the UK law relating to disabled prisoners is a clear demonstration of the truth of Professor Starmer's claim that "the *Human Rights Act* 1998 represents a new beginning and a fundamental shift to a rights-based system of law."[113]

In 2001 the author of an editorial on *Price v UK* in the *Disability Tribune* wrote:

> Like many others not born with our impairments, I was pushed into a world defined by majority opinions: the problems were mine, I was now deficient, handicapped, crippled, a burden, a patient, one of those people "on welfare."[114]

Prisoners with disabilities suffered even greater marginalisation for, before the decision in *Price v UK* and the intervention of Paul Daniels, the prison authorities were thought not to be subject to the *Disability Discrimination Act* 1995 and thus disabled prisoners would not qualify to benefit from the "reasonably comprehensive (although far from exhaustive) set of positive rights to supplement welfare provisions."[115] Indeed, under the original Prison Service Order 2855, the Prison

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[112] Klug, F. (October 1, 2000). Analysis. *BBC Radio 4*. King's College, London.

[113] Keir Starmer (Autumn 1999). *Legal action.*

[114] Disability Tribune. (2001). *Newsletter of the Disability Awareness in Action*, online, http://www.daa.org.uk/.

[115] O'Brien, N. (September 10, 2004). *Accentuating the positive: Disability rights and the idea of a commission for equality and human rights*. Oxford: St Catherine's College.

Service undertook to "ensure that prisoners with physical, sensory and mental disabilities are able…to participate equally in prison life," only "as far as practicable," while the obligation on the Governor was limited to a requirement "to consider what reasonable adjustments, if any, are necessary to meet the needs of the disabled prisoner."[116] Even as late as 2004, the *Information Book for Disabled Prisoners*, published by the Prison Reform Trust, persisted in this view. After quoting PS02855 1999: 1, it identified "the key phrase of the Prison Service statement" as being "as far as is practicable," observing:

> In some prison establishments it will be easier to help and support you than in others depending on:
> - the design of the building
> - the level of security needed
> - how crowded it is
> - how many staff there are available to help you.[117]

The new Prison Service Order (PSO) 2855 issued on 27th July 2005 was unequivocal:

> This PSO updates and replaces the previous PSO on the management of prisoners with physical sensory or mental disabilities. It sets out required actions and good practice relating to all aspects of prison life relating to prisoners with disabilities.
>
> This PSO applies to all prisoners, and it will usually be best to assume that a prisoner has a disability rather than not.[118]

Disabled prisoners were no longer to be left on the margins of the prison community but must be enabled to take part in prison life:

> It is Prison Service policy, in line with developing legislation, that disabled prisoners are not discriminated against in any aspect of prison life and that equality of opportunity in accessing all parts of prison life, and in particular to address their offending behaviour and be resettled is offered to all prisoners.[119]

The provisions set down for putting such a policy into practice, read like a manual on how to avoid the mistakes of the authorities in the cases brought before the ECtHR. Two examples here will suffice:

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[116] Prison Service Order Number 2855 issued 20/12/99: *Management of Prisoners with Physical, Sensory or Mental Disabilities.*

[117] Ibid., page 7.

[118] H M Prison Service Order 2855 *Prisoners with Disabilities,* p 1.

[119] Ibid., p. 4.

> Prisoners with disabilities need to be allocated to accommodation suitable to their needs. It is best practice where possible not to routinely accommodate prisoners with disabilities within healthcare depts, but on normal location otherwise they can miss out on access to all aspects of the prison regime.[120]
>
> It is important that staff are sensitive to the need to allow prisoners to retain in possession items which they need to use in respect of a disability unless there is a clear and defensible reason for an exception, – for example walking sticks, spare batteries for hearing aids etc.[121]

The catalyst for such a change in policy was undoubtedly the *Disability Discrimination Act* 2005 which, through the addition of s 21 B, made it, "unlawful for a public authority to discriminate against a disabled person in carrying out its functions,"[122] and, by omitting the prison authorities from the list in subsection (3) of those public authorities exempted from the obligations of the Act, brought the Prison Service within the reach of the disability discrimination legislation.[123] However, such a change would not have occurred without a change in the domestic legal paradigm from discrimination to human rights principles. Dame Anne Owers, the Chief Inspector of Prisons, described this change in a public lecture she gave in 2003, a year after coming into office:

> Almost exactly three years ago, the *Human Rights Act* came into effect, bringing into UK law the provisions of the ECHR. I was part of the Task Force…The aim was prevention and dialogue, rather than simply litigation and conflict: to train authorities, and discuss with them what amendments might be needed to laws and practices. These discussions were not just about compliance: they were driven by Francesca Klug's description of human rights as a value system for a godless age, something that "does not require a belief in anything more than the dignity of each person."[124]

"The dignity and safety of prisoners," Dame Anne argued, "are absolutely central to a proper custodial environment and therefore to a prisons inspectorate."[125] It was these principles that led to the development of the Prison Inspectorate's "Healthy Prison" concept. As Dame Anne explained in the same lecture:

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[120] Ibid., p. 16.

[121] Ibid., p. 18.

[122] s 21B(1).

[123] The original draft of the Disability Discrimination Bill had included the following exemption: "an act done in relation to carrying out a function of allocating prisoners to a prison; or allocating prisoners to accommodation within a prison."

[124] Owers, A. (October 22, 2003) BIHR Human rights lecture: *Prison Inspection and the Protection of Human Rights,* Version 1.

[125] Ibid.

> It is based on the World Health Organization's four tests of what constitutes a healthy custodial environment; and that is based upon international human rights principles, set out in the various UN and Council of Europe instruments and guidelines. Those four tests are: that prisoners are held in safety; that they are treated with respect and dignity as human beings; that they are able to engage in purposeful activity; and that they are prepared for resettlement.

The strength of the duty to promote disability equality set out in the *Disability Discrimination Act* 2005 lies in the fact that it combines human rights principles with discrimination law. The importance of such a combination was first acknowledged by the drafters of Protocol No. 12 of the ECHR:

> While the equality principle does not appear explicitly in the text of either Article 14 of the Convention or Article 1 of this Protocol, it should be noted that the non-discrimination and equality principles are closely intertwined. For example, the principle of equality requires that equal situations are treated equally and unequal situations differently. Failure to do so will amount to discrimination unless an objective and reasonable justification exists.[126]

Nick O'Brien, who was the Legal Director of the UK's Disability Rights Commission at the time the *Disability Discrimination Act 2005* came into force, identified the UK's disability discrimination legislation as a new departure in anti-discrimination law because it differed significantly from other statutes such as the *Sex Discrimination Act 1975* or the *Race Relations Act 1976* since:

> …it requires more than simple equality of treatment by creating obligations upon potential perpetrators of discrimination to make 'reasonable adjustments' to their practices, policies and procedures…What matters is that the result for the disabled person is the same as it would have been for an otherwise similarly placed non-disabled person: they get the job, keep the promotion, escape dismissal (equal outcome)…Equality is, paradoxically, about being treated differently, not the same.[127]

This was certainly true of the disabled prisoner in *Price v UK*. Failure "to ensure that her treatment was equivalent to that of other prisoners," by making special arrangements to compensate for her disabilities, "foreseeably gave rise to violations of the applicant's personal

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[126] *Protocol No. 12 to the Convention for the Protection of Human Rights and Fundamental Freedoms*: *Explanatory Report* at 15.

[127] O'Brien, N., *supra* note 115.

integrity – physical and psychological – as well as to inhuman and degrading treatment."[128]

Section 7 *Human Rights Act 1998* empowers the disabled prisoner, "if he is a victim of an unlawful act", to "(a) bring proceedings against the authority…in the appropriate court or tribunal, or (b) rely on the Convention right or rights concerned in any legal proceedings." There have, however, been relatively few challenges from disabled prisoners under the Act and even fewer have succeeded.[129] The main area of litigation has been in relation to the handcuffing of prisoners undergoing medical treatment[130] "taking into account"[131] the ECtHR's judgment in *Mouisel v France.*[132] In *R (on the application of Clive Spinks) v Secretary of State for the Home Department,*[133] Mr Spinks failed in his claim that the Secretary of State had breached Article 3 by refusing to allow his release after he was diagnosed with terminal cancer because, unlike the applicant in *Mouisel*, there had been no recommendation to move him to hospital and he remained reasonably fit. He also failed in his claim of degrading treatment when he continued to be handcuffed while undergoing medical treatment because of the likelihood of him escaping and causing danger to others. However, Buxton LJ repeated the trial judge's recommendation that "the authorities will no doubt wish to reflect on the implications of the *Mouisel* decision and in particular the observations of the European Committee of Prevention of Torture to which the court made reference."[134] Mr Graham, in contrast, who was suffering from Hodgkins' lymphoma and very weak, was successful in his appeal:

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[128] *Price v UK* (2002), *supra* note 3, (33394/96) "Separate Opinion of Judge Greve".

[129] *R v Anthony James Drew* [2003] UKHL 25, HL held that automatic life sentence for a mentally ill offender was not incompatible with Article 3 of the ECHR as long as he received the necessary treatment.; *R v Ashworth Hospital Authority ex parte Munjaz* [2005] UKHL 58, seclusion not contrary to Article 3; see also *R (on the application of Mackenzie) v Governor of Wakefield Prison* [2006)] EWHC 1746 (Admin) Inspection of Category A prisoner, who suffered from prostate cancer and post traumatic stress disorder, at regular intervals during the night to ensure that he was still in his cell and that he had made no attempt to escape, may cause inconvenience and nuisance but it fell below that which could be said to be a breach of Article 3. Para. 9.

[130] See note 51 above on the definition of disability.

[131] Human Rights Act 1998 s.2(1).

[132] (2002) (7263/01).

[133] [2005] EWCA Civ 275.

[134] At para. 47 quoting Elias J *R (on the application of Clive Spinks) v Secretary of State for the Home Departmen* [2004] EWHC 2916 (Admin) para. 53.

> The restraining by handcuffs of a man receiving chemotherapy is, at a minimum, degrading. I would also hold it to be inhumane unless justified by other considerations. There were none here. He posed, on any sensible view, no risk whatever of escape, while being treated and no risk of causing harm to the public were he to do so.[135]

The *Human Rights Act* 1998's second decade of existence seems set for an escalation of challenges from disabled prisoners. In February 2009, in response to the publication of the *HM Chief Inspector of Prison's Annual Report 2007–8*, Leigh Day & Co solicitors stated that they were: "currently acting for a number of disabled prisoners with a range of disabilities" (including a profoundly deaf prisoner, a blind prisoner, a wheelchair using prisoner and prisoner with significant concentration and memory problems) in legal claims against the Prison Service: "Unfortunately, our clients' experiences echo the Chief Inspector's findings in that our clients' disabilities have neither been adequately assessed nor addressed with the result that they are far less able to participate in day-to-day prison life.[136]

In November 2009, Benjamin Burrows, co-incidentally a practitioner from the same firm, in an article in *Learning Disability Today,* argued that it was "almost inevitable that there (would) be further legal challenges by prisoners whose learning disability needs have not been adequately met."[137] His firm had already launched an action against the Secretary of State for Justice and Serco Home Affairs Ltd – the private company that ran the prison – for an alleged failure to make the necessary adjustments to enable a prisoner with severe learning disabilities to access and participate in an Offending Behaviour Programme (OBP). OBPs are designed to form a part of a prisoner's rehabilitation by encouraging him to consider the effect of his behaviour on himself and others and to learn and adopt constructive techniques to avoid situations which could lead him to reoffend. Prisoners are given a sentence plan designed to enable them to demonstrate that they are less likely to reoffend and so "move down the categorisation level and prepare for their eventual release."[138] The sentence plan will set certain objectives

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[135] *R (On the Application of (1) Graham (2) Allen v Secretary of State for Justice* [2007] EWHC 2940 (Admin) para. 34; distinguished in *R (on the application of Vaclovas Faizovas) v Secretary of State for Justice* [2009] EWCA Civ 373.

[136] *Leigh Day shares Prison Chief's concerns of treatment and care of disabled prisoners, 2nd February 2009, http://www.leighday.co.uk/news/news-archive.*

[137] Burrows, B. (2009). Extra time. *Learning Disability Today, 9*(8), 26–28.

[138] Ibid., 27.

for the prisoner. Frequently, these include attendance on particular OBPs relevant to the prisoner's offence. A successful completion of an OBP could contribute to an earlier release. There is, however, only one OBP, the sex offenders' treatment programme, which has been adjusted for prisoners with severe learning difficulties. Burrows outlined the arguments of the action as follows:

> (F)ailure to make the necessary adjustments deprived John[139] of the opportunity to successfully complete the OPB and, in turn had an adverse impact on the sentence progression and the prospects of him being released from prison.
>
> Specifically, it is argued that this failure is unlawful and contrary to stated HM Prison Service policy that "prisoners with disabilities will be offered equal opportunity to address their offending behaviour" as set out in PSO 2855.
>
> It is also argued that failure is a breach of their requirements under the DDA and a breach of John's Article 8 (respect for family life) and Article 14 (prohibition of discrimination) convention rights in accordance with the European Convention on Human Rights.[140]

The case was settled out of court; the Secretary of State accepted that he "unlawfully delayed in assessing and addressing the claimant's neurological condition and needs" and agreed to pay an equivalent to compensation and legal costs.

In the introduction to *Disabled Prisoners: A short thematic review on the care and support of prisoners with a disability,* published in March 2009, the Chief Inspector of Prisons observed that the results were "not encouraging:"

> To begin with, there is considerable under-reporting of the extent of disabilities. Prisons' own recording systems tell them that only 5% of

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[139] The name used in the article but not the real name.

[140] Burrows, B. (2009). Extra time. *Learning Disability Today, 9*(8), 26–28 at 28. It seems this case was settled out of court between the writing and publication of the article. On 12th October 2009 Leigh Day & Co published the following on their website: "We have successfully concluded a judicial review challenge on behalf of Edward Szuluk against the Secretary of State for Justice, the Government Minister with responsibility for the Prison Service, and Serco Home Affairs Ltd, the private company who run HMP Dovegate, in relation to the failure to adequately assess and address Mr Szuluk's disability needs during his imprisonment between November 2001 and November 2008." Available online: http://www.leighday.co.uk/news/news-archive/disabled-prisoner-victory/?searchterm=prison service order (accessed on 26th January 2010).

> prisoners have a disability. Yet in our surveys 15% of prisoners reported a disability, and there must be more who don't realise they have one…. Within prisons themselves, from the moment of reception to the time of discharge, prisoners with disabilities reported poorer experiences than those without disabilities in all areas, except for healthcare.[141]

What is "encouraging" is the recognition by prison authorities that disabled prisoners have a legal right to expect a service equal to their non-disabled detainees and that right is supported by law. Indeed, the Chief Inspector of Prisons opens the thematic report with this reminder to the Prison Service:

> The National Offender Management Service, like all public authorities, is now subject to the requirements of the Disability Discrimination Act. It is required to promote disability equality and unlawful discrimination in all the prisons in England and Wales.[142]

More importantly, the National Offender Management Service had already issued Prison Service Instruction 31/2008 to Prison Governors and Directors "to ensure that prisoners with disabilities are allocated to appropriate accommodation as soon as possible after reception and on recategorisation." The following improvements were mandatory:

> 11. Governors (and Directors of Contracted Prisons) must put in place arrangements to ensure that any problems in allocating a prisoner with a disability to appropriate accommodation are raised at the earliest opportunity with the Area Manager and PMS.
> 12. Governors (and Directors of Contracted Prisons) must ensure that prisoners with disabilities are able to access the regime and appropriate interventions. Where this is not possible at a particular establishment because appropriate accommodation is not available, and reasonable adjustments cannot be made, the prison should contact the PMS to identify another establishment with the appropriate accommodation and courses.
> 13. Governors (and Directors of Contracted Prisons) must ensure that prisoners are not prevented from being transferred, either as a result of recategorisation or in order to access particular courses as part of their sentence plan, solely because they have a disability.
> 14. Governors (and Directors of Contracted Prisons) must ensure that transfer requests to their establishment are not refused solely on the

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[141] Owers, A. Introduction, *Thematic Report by HM Inspectorate of Prisons*, *Disabled Prisoners: A short thematic review on the care and support of prisoners with a disability*, 5.

[142] Ibid., p. 5.

> basis of a disability unless the prison legitimately cannot provide the appropriate accommodation and care.[143]

These improvements may now be enforced by statutory rights but they reflect a change in paradigm from discrimination and a negative acceptance that disability would inevitably lead to exclusion from many of the facilities open to non-disabled prisoners on the grounds that adjustments could not be made easily, to human rights and a positive duty to promote the rights of all prisoners equally, regardless of ability. Even as early as four years after the *Human Rights Act* 1998 came into force, the change was noted by commentators:

> The broad interpretation of the *European Convention of Human Rights* and the *Human Rights Act*, through the emerging case law on disability-related issues constitutes a…human rights jurisprudence that prioritizes notions of dignity, community and participation at the expense of narrower conceptions of individual civil liberty.[144]

The adoption by the UN of the *International Convention on the Rights of People with Disabilities* in 2006 provides further proof of the change in paradigm in the field of Disability. Richard Light, the UK's representative on the UN Ad Hoc Committee, was keen to emphasize that the aim of this Convention was not to grant new rights but to ensure access to old ones. This Convention prioritises all three "notions of dignity, community and participation," outlined by Nick O'Brien, all of which were considered in *Price v UK*. Article 25 of the Convention guarantees human dignity through the imposition of a positive duty on the authorities to provide health services relating to impairment, something Ms Price was denied – she could be admitted to hospital only to cure, not to prevent an illness.[145] Article 19 guarantees a right to independent living. The right includes the right to choose to live in the community and to have the support to enable her to do so. Dr Kidd who examined Ms Price on the night of her arrival at New Hall Prison was very conscious of this need, commenting on her relative independence at home as opposed to her dependency in prison due to the lack of preparedness of the New Hall Prison authorities.[146] Article 5

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[143] Available online: http://www.insidetime.org/info-rules-results.asp?rID=25&c=psi2008031_allocation_for_prisoners_with_disabilities

[144] O'Brien, N., *supra* note 115.

[145] *Price v UK* para. 14.

[146] Ibid., para. 13.

guarantees equality and non-discrimination. All signatory states must implement anti-discrimination law and reasonable adjustment where necessary so that disabled people can participate equally. Although a female officer was appointed to care for Ms Price at night, this was insufficient to enable her to participate as she needed two officers to lift her and the cell was not adapted for her needs.[147]

The pattern of developments in UK law relating to disabled prisoners in the first decade of the twenty-first century seems to continue to confirm Nick O'Brien's contention that there has been a "gradual shift of emphasis away from discrimination towards a broader notion of participation," which "invites a rebalancing of the strategies needed to mobilise the law purposefully."[148] The history of *Price v UK* and the changes brought about through the *Human Rights Act* 1998 and the *European Convention for the Protection of Human Rights and Fundamental Freedoms* 1950, together with the UK Government's very recent ratification of the *International Convention on the Rights of People with Disabilities* 2006[149] would suggest that the mobilisation of human rights law and principles should remain a key strategy in promoting the rights of the disabled men and women currently detained in Her Majesty's prisons.

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[147] Ibid., para 15.

[148] O'Brien, N, *supra* note 115.

[149] 8th June 2009.

PART III

ENSURING EQUALITY

INTRODUCTION: EQUALITY

As Rioux and Riddle point out, equality has long been recognized as a principle of human rights. However, the legal meaning of the concept is contested. As they point out:

> The "infuriatingly elusive" concept of equality encompasses an elastic spread of meanings that range from legitimating and formalizing differences and unequal treatment, to incorporating broad environmental and institutional changes, services, policies, and programs to ensure equality is achieved.[1]

Rioux and Riddle outline a range of different ways in which equality has been interpreted in law – including formal equality, equality of opportunity and substantive equality or equality of outcome. They argue that to be consistent with human rights the principle of equality for people with disabilities must turn on a recognition of "difference." This section builds on the authors observation that:

> Many individuals require differing social arrangements, including varieties of care, in order to live integrated and productive lives. Disability raises a unique and particularly important issue within distributive justice claims – how can individuals requiring differing measures to promote inclusion receive equal treatment?[2]

While in other areas of human rights it is clear that only substantive equality can address systemic discrimination, with respect to disability the problem is more complex. This is because disability is the interaction of an individual impairment and the interaction between disability and the social structures of society. For equality to be applied as a principle protecting the human rights of people with disabilities and empowering people with disabilities as participants in society, equality must be a principle which guides social action and legal decision making.

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[1] Hon. Justice Mary Gaudron, High Court of Australia (1990) The Mitchell Oration 1990 "In the Eye of the Law: The Jurisprudence of Equality" 24 August 1990 Equal Opportunity Commission Adelaide.

[2] Rioux & Riddle, Part I, page 38.

Rioux and Riddle observe that

> There are differences and inequalities between people, that is a matter of objective fact, however, artificial distinctions need to be differentiated and there has to be a distinction between those inequalities that are the consequence of the organization of society, and those that stem from individual characteristics. The false assumption that people are starting in an equal position often leads to the further entrenchment of the inequality that is already disadvantaging people, and results in the introduction of further injustices. In other words, the social and legal construction of inequality is an important part of the understanding of the equality rights of people with disabilities.[3]

In this section the way in which people with disabilities experience equality and the way in which the law applies theories of equality are explored through the analysis of a wide range of issues, ranging from the sterilization of intellectually disabled women to the experience of political participation by people with disabilities generally. Laws invoking the principle of equality are relatively common but usually use the equal treatment standard. However, in disability discrimination legislation and in human rights legislation the notion of equality is more broadly interpreted. Adopting the human rights principle of equality as a strategic tool of analysis allows the authors in this section to adopt a critical perspective on law and disability.

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[3] Ibid., 38.

BEYOND LEGAL SMOKE SCREENS: APPLYING A HUMAN RIGHTS ANALYSIS TO STERILIZATION JURISPRUDENCE

Marcia H. Rioux and Lora Patton

How a society labels difference and then assigns or removes legal rights based on that label can reveal the underpinnings of social structure, policy and law. The courts, in their role as arbiters of individual disputes, reflect the existing social perspectives of difference and the resulting societal hierarchies, and bring those values to their decision-making. Not just passive commentators on policy, the courts also play a significant role in policy development, although rarely is this role explicitly acknowledged. Rather than directly tackling the difficult issues of equality, difference and individual human value, legal decisions employ seemingly neutral constructs that do not remove judgment about social policy but, instead, veil those judgments in legal rhetoric. Once we recognize and pierce the layers of legal doctrine that provide a legal framework for decision-making, the fundamental social values implied in case law are revealed. In understanding the underlying framework of legal decisions, we are able to approach argument before the courts, infusing our positions with human rights analyses that better address clients' stories and the reality of difference and discrimination.

Sterilization jurisprudence provides a rich basis for examining the legal constructs that disguise social policy considerations. The recent case of Ashley X[1] highlights the ongoing unresolved issues affecting the bodies of women with intellectual disabilities. Two years before the publication of the case in a medical journal, Ashley was a 9 year-old girl. She was described by her physicians as being "non-ambulatory" with "severe, combined developmental and cognitive" delays that would not improve as she grew.[2] The medical decisions made by her parents

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[1] Gunther, D.F. & D.S. Diekema. (2006). Attenuating growth in children with profound developmental disability: A new approach to an old dilemma. *Archives of Pediatrics and Adolescent Medicine, 160*(10), 1013–1017, online, www.archpedi.ama-assn.org/cgi/content/full/160/10/1013.

[2] Ibid., 1013.

and her physicians are informative about the value placed on the body of a woman with intellectual disabilities. Ashley's growth was artificially attenuated to minimize any further growth, keeping her "of manageable size"[3] so she could be more easily moved, cuddled and fit into a standard bathtub.[4] Beyond growth attenuation, Ashley was given a hysterectomy and underwent the removal of her breast buds.[5]

Ashley's physicians argued that the combined treatments provided Ashley with "the best possible quality of life," allowing her to be more easily cared for by her family[6] while her parents noted that the procedures would allow her to "retain more dignity in a body that is healthier, more of a comfort to her, and more suited to her state of development."[7] In other words, her body would reflect her intellectual development. The removal of breast buds was explained by the desire to remove a possible source of discomfort while her parents noted that "Ashley has no need for developed breasts since she will not breast feed and their presence would only be a source of discomfort."[8] Similarly, Ashley was seen as having "no need for her uterus since she will not be bearing children."[9] Her physicians noted that there were benefits to hysterectomy in controlling the side effects of growth attenuation therapy but the primary reason given was to "eliminate the complications of menses."[10]

Ashley's case was not adjudicated. Instead, the physician's involved, having obtained direction from her parents, took the matter to an internal ethics board which ultimately approved the procedures.[11] Regardless, the language used to describe the procedures and the purposes for which they were conducted reveal deep assumptions about the worth of Ashley's body: rather than maintaining her bodily integrity – keeping her "whole" – modifying her physical attributes to better fit the environment was prioritized. Her best interest was equated with her parents' ability to maintain her at home and being easily able

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[3] Ibid., 1014.

[4] "Pillow Angel" website, developed by Ashley's parents, online, http://ashleytreatment.spaces.live.com/blog/cns!E25811FD0AF7C45C!1837.entry (visited November 11, 2010).

[5] *Supra* note 1.

[6] Ibid.

[7] *Supra* note 4.

[8] Ibid.

[9] Ibid.

[10] *Supra* note 4.

[11] *Supra* note 4.

to carry and move her. Her uterus and breasts were seen as unnecessary given her intellectual disability – and removed to improve her comfort. Ashley's "dignity" was determined to be enhanced by keeping her body size consistent with her imputed mental development.

Issues impacting the bodily rights of women with intellectual disabilities have been adjudicated by the highest courts in England, Canada and Australia. Despite similar facts, the courts analyzed the individual situations using different legal constructs, and came to divergent conclusions about the rights of women with intellectual disabilities. All three cases deal with issues of competence, of *parens patriae* power, of substitute decision-making, of rights and of well-being, as well as with discrimination, equality and difference. All three cases raise issues of inclusion and exclusion in relation to the traditional presumption that women control their own bodies and specifically the access to decision-making around child bearing to which non-disabled women have access. Only one young woman, Eve, was not sterilized. From an analytical perspective, the models of judicial inquiry applied found legitimacy from very different places. Different legal "boxes" or constructs were applied, but underneath the rhetoric, notions of sameness and difference, and the values assigned by that determination, are explored, although somewhat covertly. The decisions do, however, provide a means of developing legal jurisprudence from a human rights perspective, and a basis for considering which framework might provide the best possible solution in moving towards equality and inclusivity.

THREE YOUNG WOMEN

In Canada, *Eve's* case[12] arose in the following manner. In 1986, Eve's mother requested that the court confirm her ability to have her twenty-one-year-old daughter undergo a hysterectomy to prevent potential pregnancy. Eve was described as "mildly to moderately mentally retarded" with expressive aphasia which made it difficult to determine the degree to which she understood various concepts. At the time Eve was attending a residential school during the week, away from her mother's community. Eve "struck up a close friendship with a male student; in fact, they talked of marriage." Eve's mother believed that

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[12] *Eve* (Mrs.) *v Eve* [1986] 2 S.C.R. 388 ("Eve's case").

Eve might become pregnant. She felt that her daughter could not cope with being a mother and feared that care of any child would fall to her. Eve's mother believed the only means of preventing pregnancy was sterilization.[13]

In England, Jeanette[14] was a minor, a seventeen-year-old at the time, with an intellectual disability and epilepsy. As a child, she had been placed under the care of the local authority in England to enable training and medical support, though her mother maintained involvement in her life. The local authority, upon noting Jeanette was "showing signs of sexual awareness and sexual drive"[15] sought court intervention to authorize sterilization by occlusions of the fallopian tubes (a "tubal ligation"). The authority argued that pregnancy would pose significant emotional risks for Jeanette. Her mother supported the application but Jeanette's interests were argued by an appointed guardian *ad litum*. The matter was treated as urgent as Jeanette would become of legal age within six months of the hearing and the court acknowledged that there was some doubt as to whether "residual *parens patriae* jurisdiction remains in the High Court after majority."[16] Although it is difficult to know what the characterization means, the court noted that Jeanette had a "moderate degree of mental handicap," the "mental age" of five or six and spoke "only in sentences limited to one or two words."[17] She was, according to the court, able to dress and bath herself and had been "taught to cope with menstruation."[18] At the time of the application, Jeanette had exhibited some sexual awareness and masturbation. The court found that although she had effective supervision in the institution in which she lived, Jeanette's needs were not so great that she would need to be permanently institutionalized.

Marion,[19] in Australia, was a fourteen-year-old girl at the time of the last court intervention. She lived with both an intellectual disability and physical disabilities including severe deafness and epilepsy. She was found to be unable to care for herself. Very little else is evident

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[13] Ibid., paras 2–3.

[14] *Re B* [1987] HLJ 21 ("Jeanette's case").

[15] Ibid., 209.

[16] Ibid., 212.

[17] Ibid., 212.

[18] Ibid., 209.

[19] *Secretary, Department of Health and Community Services v JWB and SMB* [1992] 106 ALR 385 (QL) ("Marion's case").

about her circumstances from the facts of her case. Her parents, concerned with future menstrual management and fertility control, sought a confirmation of their ability to consent to a hysterectomy and ovariectomy. If they were found to lack the power to consent to the requested procedure, they wished the court to authorize the sterilization procedures. The hysterectomy was sought to prevent pregnancy and the "psychological and behavioural consequences" of menstruation while ovariectomy would manage hormonal shifts.[20]

All cases are remarkable in their failure to examine the voices and the wishes of the young women involved. Instead, experts provide analysis of their intellectual and emotional ability and the potential benefits and risks arising from the proposed surgical interventions. Generalized statements about human rights are noted, but the individual desires were either never canvassed or not deemed important enough to include in the final legal analysis. Ironically, in decisions that focus on what is best for each of the women, legal discussion has silenced the very voices of those most directly impacted by the decisions.

Regardless, on the basis of expert testimony and evidence, the cases proceeded. Each of the three decisions are argued in dissimilar manners, although they touch on the same type of fact situation – and the courts based their decisions on different underlying legal premises. There are a number of areas in which the courts diverge and converge. Each of the decisions will be discussed here, looking specifically at: whether the sterilization was argued to be an issue of public policy; whether and which human rights principles must be infused in best interest principles; and the implications of the cases for the rights of dignity, equality and inclusion of people with disabilities.

An Issue of Public Policy?

In the early nineteenth century, sterilization of persons with disabilities was undertaken by a number of governments for eugenic purposes. Based on rudimentary understanding of genetics, it was felt that intellectual disability was genetic and sterilization would reduce the numbers of the

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[20] Ibid., para 1.

"feebleminded" and prevent the birth of degenerates including those who were "imprisoned, incarcerated or institutionalized."[21]

That sterilization has a history of abuse in many jurisdictions is perhaps best exemplified by a United States decision to involuntarily sterilize a young woman who had been institutionalized to hide her pregnancy; a pregnancy that had resulted from rape. Until *Buck v Bell*[22] in 1925, sterilization laws were routinely struck down by the courts on the basis that they were "unconstitutional as cruel and unusual punishment, violations of due process, or violations of equal protection."[23] With *Buck*, however, the U.S. Supreme Court shifted thought significantly on the issues and ruled in favour of the constitutional powers that they believed did not violate the due process clause of the Fourteenth Amendment. Carrie Buck was committed to a state institution for epileptics where her mother was also a patient. She was said to have a "mental age" of 9 years and Carrie's own daughter was said to "have a look" that was "not quite normal."[24] Medical experts testified that Carrie, her mother and her daughter were "feebleminded" and that it was "unquestionably hereditary." In the eugenic reasoning of the time, the court allowed the state to sterilize Carrie Buck under a program providing for the involuntary sterilization of a "probable potential parent of socially inadequate offspring." Writing for the Court, Justice Holmes stated:

> Carrie Buck is a feeble minded white woman…She is a daughter of a feeble minded mother in the same institution and the mother of an illegitimate feeble minded child…We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already zap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute the degenerate offspring for crime, or to let them starve for their imbecility, society can

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[21] Gewirtz, D. S. (1994). toward a quality population: China's eugenic sterilization of the mentally retarded *New York Law School Journal of International Comparative Law, 15*(1), 139–162, at 152.

[22] *Buck v Bell* [1927] 274 US 200.

[23] Diekema, D.S. (2003). Involuntary sterilization of persons with mental retardation: An ethical analysis. *Mental Retardation and Developmental Disabilities, 9*(1), 21–26, at 22. And see Burgdorf, R. & M. Burgdorf. (1977). The wicked witch is almost dead: *Buck v Bell* and the stelization of handicapped persons. *Temple Law Quarterly, 50*(4), 995–1034.

[24] Kevles, D.J. (1985). *In the name of eugenics: Genetics and the uses of human heredity*. New York: Penguin Books.

> prevent those who are manifestly unfit from continuing their kind…. Three generations of imbeciles are enough."[25]

The *Buck* decision led to a dramatic rise in involuntary sterilization for persons with intellectual disability throughout North America.[26]

After the Second World War, Western perceptions of eugenic practices gradually began to change, initially in *Skinner v Oklahoma*[27] with a determination that "the right to procreate was fundamental, requiring a compelling state interest to justify interfering with it."[28] Procreative and bodily rights began to take hold. By 1981, the U.S. Supreme Court held that:

> The societal harms, envisioned by the eugenicists, if these exist at all, were not sufficient to justify either the violation of an individual's fundamental right to make reproductive decisions without the interference of others or the unconsented bodily invasion inherent in involuntary sterilization.[29]

As eugenic and public interest justification for the sterilization of persons with disabilities waned, parents and guardians began shifting the argument, seeking sterilization to the best interest of their children.[30] Arguments before the courts began to reflect the change. Paternalistic notions of protection of a person with an intellectual disability replaced societal concerns of eugenics. Instead of removing the procreative ability of people with disabilities for the protection of society, sterilization was seen as a mechanism to protect individuals. Courts began to be presented with the difficulties of menstruation and the inability to care for a child as reasons to perform sterilization. The cases of Eve, Jeanette and Marion reflect these new arguments. Yet, only Canada and Australia recognized the importance of historical treatment of people with intellectual disabilities and issues of public policy within their decision-making. While Jeanette's case reflects a paternalistic conceptualization of best interest, the courts in both the Eve and Marion cases import

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[25] *Supra* note 22, para 4.

[26] Park, D.C. & J.P. Radford (1998). From the case files: Reconstructing a history of involuntary sterilisation. *Disability & Society, 13*(3), 317–342.

[27] (1942) 316 U.S. 535.

[28] *Supra* note 23, 22.

[29] *Re Grady* [1981] 426 A.2d 467.

[30] *Supra* note 23, 23.

human rights notions into their judgments directly challenging historical policy, though they ultimately result in different findings.

Despite the obvious history of abuse, the House of Lords, on appeal of Jeanette's case, dismissed the notion that there was any issue of public policy and dealt only with application of the criteria of the welfare or "best interests" of the ward. As it was put by Lord Hailsham of St Marylebone LC:

> This is no doubt that, in the exercise of the wardship jurisdiction the first and paramount consideration is the well being, welfare, or interests (each expression occasionally used, by each, for this purpose synonymous) of the human being conceived, that is the ward herself or himself. In this case I believe it to be the only consideration involved. *In particular there is no issue of public policy other than the application of the above principle which can conceivably be taken into account, least of all (since the opposite appears to have been considered in some quarters) any question of eugenics….*"[31] (emphasis added).

Likewise, Lord Oliver of Aylmerton similarly concludes that the case "…*involves no general principle of public policy*"(emphasis added) and that it "has nothing whatever to do with eugenics." These conclusive statements were made despite the acknowledged "extensive public interest shown"[32] and that "the very word 'sterilisation' has come to carry emotive overtones."[33] The dismissal of the opportunity to consider the history and impact of disabling theories is troublesome in light of the significant decision the court makes about Jeanette and the irreversibility of her sterilization.

The High Court in Marion's case took the opportunity to comment on the historic dispossession of people with disabilities, weaving the development of public policy into the disposition of the case. Importantly, the court held that people with disabilities "are entitled to individual inviolability…that the lives of people with disabilities are as valuable as those who are 'normal.' "[34] The court specifically finds that sterilization can have a tremendous impact on a person's perception of him or herself and involuntary sterilization, as found in a Canadian Law Reform Paper, may be seen "as a symbol of reduced or degraded status."[35]

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[31] *Supra* note 14, 212 (*Jeanette*).

[32] Ibid., 211.

[33] Ibid., 215.

[34] *Supra* note 19, 7.

[35] Ibid., 22.

In holding that authorizing involuntary sterilization is a special case of medical intervention, the court based its finding on the fundamental right to dignity, the right to bodily integrity, and the "gravity of the procedure and its ethical, social and personal consequences."[36] More importantly, however, the clear statement by the court that individuals with intellectually disabilities are entitled to equal protection by the law was important. The court declared that those with disabilities were as valuable to society as those without.

In Canada, the Supreme Court unanimously held that people who have an intellectual disability cannot be required to undergo a non-therapeutic sterilization authorized by any third party including parents or next-of-kin, the Public Trustee or the administrator of a facility. The court refused to acknowledge any consideration other than what was in the "therapeutic" interest of the individual involved. In this way the court ensured that third parties, such as parents and guardians, could not authorize sterilization for their own convenience or protection. Eve's mother brought the original application in *Eve* under the Province of Prince Edward Island's guardianship legislation, which did not provide the specific legislative authority to permit the procedure on the basis of a third party consent. There was no legislation in any jurisdiction in Canada that permited a guardian, court appointed committee or next-of-kin to consent on behalf of a person with an intellectual disability to a non-therapeutic sterilization. The Supreme Court of Canada clearly stated in its decision that if legislation were to be introduced in Canada to authorize this type of procedure it would have to do so explicitly, and that such legislation would be subject to constitutional scrutiny under the *Charter of Rights and Freedoms*.[37] As *Eve*'s case was initiated prior to the introduction of the *Charter*, the court did not directly consider principles of constitutionality. Nonetheless, its acknowledgment of the new individual rights embodied by the *Charter* made it relatively clear that future legislation would not succeed.

Unlike the court in England, the Canadian Court clearly situated the case within the context of public policy:

> There are other reasons for approaching an application for sterilization of a mentally incompetent person with utmost caution. To begin with, the

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[36] Ibid., 20.

[37] No legislation enabling this has been introduced in any province in Canada subsequent to this decision.

> decision involves *values in an area where our social history clouds our vision* and encourages many to perceive the mentally handicapped as somewhat less than human. This attitude has been aided and abetted by now discredited eugenic theories whose influence was felt in this country as well as the United States. Two provinces, Alberta and British Columbia, once had statutes providing for the sterilization of mental defectives.[38] (emphasis added).

In all of the cases, issues of eugenics were introduced, although unlike the courts in Canada and Australia and in similar cases in the United States, the English dismissed the issue of eugenics out of hand. Both the Canadian and the Australian courts were mindful of the abuses that occurred under sterilization programs that had operated within their jurisdictions for a good part of the 20th Century which were directed towards people with disabilities. In recognizing the historical policy, the courts tacitly acknowledged their role in challenging that policy and impacting future social understanding of women with disabilities.

Do Rights Principles Trump Welfare Issues?

How society understands disability is fundamental to how that society will then develop policies impacting those persons seen as disabled. Social constructs of people with disabilities are "neither mutually exclusive nor temporally chronological,"[39] rather, those constructs blend within one another. One means of understanding difference is commonly referred to as the medical model, an idea that grounds the disease or disability within the individual and then seeks to "cure" the individual by eliminating the difference through medical or biological means. Thus the disabled individual is fixed in a way that is seen to be in her best interest, making her better able to function within the community. Contrast this construct with a human rights analysis. In such a model, the individual is not seen as diseased or wrong, but different. The difference is not to be remedied but instead recognized as an inherent human diversity. Acknowledging and accepting that diversity requires the community to adjust to the difference to best accommodate the individual needs. Whereas the latter construct recognizes

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[38] *Supra* note 12, para 78.

[39] Rioux, M. & E. Zubrow. (2001). Social disability and the public good. In D. Drache (Ed.), *The market or the public domain? Global governance and the asymmetry of power* (pp. 148–189). London: Routledge, 169.

the inherent value in individuals and promotes maintaining the rights that would otherwise accrue to any person, a best interest approach may well deem those rights unnecessary as the person is in some way damaged.[40]

In England, cases involving the wardship of children are determined on the basis of a "welfare" principle. Originating in the principle of *parens patriae*, the court had a role in protecting persons who could not act for themselves, including children and persons with disabilities. Considering Jeanette's situation, the court turned it's mind to the role of rights in the case of women with intellectual disabilities and applied the legal construction of "best interest" in determining welfare. Instead of acknowledging the importance of individual rights and situating the "best interest" decision within such an analysis, the court fell back to the paternalistic reasoning that often infects decisions for those seen as different and globally incompetent.

The English decision, coming as it did after the Canadian decision in *Eve*, took account of La Forest J's decision. Lord Hailsham stated that he found LaForest's outline of the history of the *parens patriae* jurisdiction (in the Canadian case) "extremely helpful"[41] to him. However, he found that:

> …his [LaForest's] conclusion that the procedure of the sterilization "should never be authorized for non-therapeutic purposes" [is] totally unconvincing and in startling contradiction to the welfare principle which should be the first and paramount consideration in wardship cases. Moreover, for the purposes of the present appeal I find the distinction he purports to draw between "therapeutic" and "non-therapeutic" purposes of this operation in relation to the facts of the present case above as totally meaningless and [if it were meaningful, it would still be an incorrect application of the welfare principle]. To talk of the "basic right" to reproduce of an individual who is not capable of knowing the causal connection between intercourse and childbirth, the nature of pregnancy, what is involved in delivery, unable to form maternal instincts or to care for a child appears to me wholly to part company with reality.[42]

Lord Bridge, while not disputing the *Eve* decision on the facts, was critical of the rights-based approach of the Canadian Supreme Court in its conclusion that:

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[40] *Supra,* note 39.

[41] *Supra* note 14, 213.

[42] Ibid., 213.

> [t]he grave intrusion on a person's rights and the certain physical damage that ensues from non-therapeutic sterilization without consent, when compared to the highly questionable advantages that can result from it, have persuaded me that it can never safely be determined that such a procedure is for the benefit of that person. Accordingly, the procedure should never be authorized for non-therapeutic purposes under the *parens patriae* jurisdiction.[43]

Lord Bridge's criticism of this statement is categorical and revealing.

> This sweeping generalisation seems to me, with respect, to be entirely unhelpful. To say that the court can never authorize sterilization of a ward as being in her best interests would be patently wrong. To say that it can only do so if the operation is "therapeutic" as opposed to "non-therapeutic" is to divert attention from the true issue, which is whether the operation is in the ward's best interest, and [turn it into a] debate as to where the line is to be drawn between "therapeutic" and "non-therapeutic."[44]

He rejected the Canadian Supreme Court's rights analysis and focused on the insignificance of rights in this context and the potential harm that could result. He dismissed the argument by stating that:

> [t]he Supreme Court of Canada in *Re Eve,* 31 D.L.R. (4th) 1 at 5, refers… to "the great privilege of giving birth", the sad fact in [this] case is that the mental and physical handicaps under which the ward suffers effectively render her incapable of ever exercising that right or enjoying that privilege.…I find it difficult to understand how anybody examining the facts humanely, compassionately and objectively could reach any other conclusion.[45]

Lord Oliver interpreted the *Eve* decision to have challenged the notion that the best interest of the woman concerned was the primary concern. He comments that:

> [LaForest J's] conclusion was that sterilization should never be authorized for non-therapeutic purposes under the *parens patriae* jurisdiction. If in that conclusion the expression "non-therapeutic" was intended to exclude measures taken or the necessary protection from harm of the person over whom the jurisdiction is exercisable, then I respectfully dissent from it for it seems to me to contradict what is the sole and paramount

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[43] Ibid., 214.

[44] Ibid.

[45] Ibid., 212.

> criterion for the exercise of the jurisdiction, viz. the welfare and benefit of the ward.[46]

For the English court, then, whenever an individual is found unable to exercise a right, the right itself does not exist. In other words, without the ability to make decisions about her own procreation, and her presumed inability to develop such decision-making capacity, the court found that to argue that Jeanette had fundamental rights of this nature, was "wholly to part company with reality."[47]

Regardless of whether Jeanette had individual rights, the English court indicated such a consideration should not exist apart from a "best interest" paternalistic approach, inherent in determining the issue. They considered a number of factors relevant to Jeanette's condition but failed to set out general guidelines to weigh before implementing what might be the "best" result and failed to include her individual rights in the analysis at all. Significant emphasis was placed on the fact that Jeanette was considered unable to appreciate the changes to her body that would occur during pregnancy and labour would cause her to be "terrified, distressed and extremely violent."[48] Caesarian delivery was also noted to be problematic as she previously had interfered with the healing of wounds.[49] Based on the evidence that successful labour could not occur, the court also considered the possibility of terminating any pregnancy prior to full term but noted that existing medical conditions made it impossible to discover the pregnancy before it was too late to perform abortion.

Some consideration was given to other forms of birth control that would not be permanent, although most were dismissed out of hand. Counsel representing Jeanette's interests recommended a progesterone pill and suggested the intervention be attempted for a trial period before moving to the permanent sterilization sought. The court, however, found that, given a reduced chance of success and potential problems with maintaining a daily dosage, the less intrusive option was not appropriate. Interestingly, the court also noted that a further reason for rejecting the contraceptive was because the potential long-term effects of the drug were unknown. In contrast, sterilization was found to be

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[46] Ibid., 215.
[47] Ibid., 213.
[48] Ibid., 212.
[49] Ibid., 210.

"a relatively minor operation carrying a very small degree of risk to the patient, a very high degree of protection and minimal side effects."[50]

Without raising the issues directly, the court also appeared to place at least some importance on what it saw as the ability to increase Jeanette's quality of life. As noted in the facts, Jeanette was at the time in a facility but "her degree of incapacity is not such that it would be thought right that she should, effectively, be institutionalised all her life."[51] Yet the court failed to provide what may have been an interesting analysis of Jeanette's competing rights to maintain her bodily integrity and to procreate as opposed to her liberty rights and ability to exercise sexual freedom. By imposing a paternalistic best interest test within the welfare analysis, important considerations were left unaddressed.

The best-interest principle, on which the British court relied, results in some conventional built-in biases and value judgments disguised as legal principles. Jeanette's best interests do not include any analysis of her own perception of the surgery and how sterilization may impact on her understanding of her own personhood. Jeanette was found to be unable, at the time of the decision, to make an informed decision about procreation. This, together with her impending eighteenth birthday (which may, as acknowledged by the court, have left the court without jurisdiction to make a decision) created a situation of emergency in the mind of the court. The underlying notion that Jeanette was unable and apparently disinterested in actually becoming a mother was seen as a reason to remove her right to maintain the ability to do so. Clearly such an analysis does not attach to a woman's right to maintain procreative ability where she is not diagnosed with an intellectual disability. Rather, such a right should be recognized as inviolable, regardless of whether a woman has any desire or intent to have children. Jeanette's ability to live outside of institutions was traded for her physical integrity.

Safeguarding Individual Rights in Best Interest Analysis

The welfare of the individual has similarly been used to undermine fundamental rights of women with intellectual disabilities in U.S courts. "Best interest" principles have been central to the determinations to provide the moral and legal authority for the court to remove what is

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[50] Ibid., 217.
[51] Ibid., 216.

normally considered a fundamental right of an individual. American law sways toward the determination of whether someone can be sterilized in the face of presumptions about their capacity to consent and presumptions of the individual capacity to bear and raise children and to make the decisions required about having a child.

In a case in the United States[52] in which the Supreme Court of New Jersey provided a "nonexclusive" list of guidelines, the court, as it has in other cases in U.S. jurisdictions, tended to be cautious with respect to issues of sterilization and those with intellectual disability, recognizing a history of overzealous eugenic decisions. In the Superior Court of Pennsylvania, for example, the court saw two prerequisites to authorizing sterilization: that the individual be found to lack the capacity to make a decision and there was some predictability to the permanence of the in capacity; and that the woman or girl be capable of reproduction.[53] The court found that the best interest determination depended on a finding that sterilization was the only feasible method of contraception and that it was the least intrusive intervention to protect the interests of the individual. In *Terwilliger*, the court provided a "nonexclusive" list of procedures to guide courts in their deliberation, a list of guidelines adapted from another decision of the Supreme Court of New Jersey.[54]

The list included:

a. The possibility that the incompetent person will experience trauma or psychological damage if she become pregnant or gives birth, and conversely, the possibility of trauma or psychological damage from the sterilization operation.
b. The likelihood that the individual will voluntarily engage in sexual activity or be exposed to situations where sexual intercourse is imposed on her.
c. The inability of the incompetent person to understand reproduction or contraception and the likely permanence of the inability.
d. The ability of the incompetent person to care for a child, or the possibility that the incompetent may at some future date be able to marry and, with a spouse, care for a child.

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[52] *The Matter of Terwilliger* [1982] 450 A.2d 1376.

[53] Ibid.; see also *In Re Hayes* [1980] 93 Wash. 2d 228, a decision of the Supreme Court of Washington.

[54] Ibid., quoting *Re Grady (supra,* note 29*).*

e. Evidence that scientific or medical advances may of occur within the foreseeable future which will make possible either improvement of the individual's condition or alternative and less drastic sterilization procedures.
f. A demonstration that the proponents of sterilization are seeking it in good faith and that their primary concern is for the best interests of the incompetent person rather than their own or the public's convenience.[55]

While the decision of the court in this case was that there was no need to sterilize the twenty-five-year-old woman involved, the court developed a rather detailed record of the relevant issues to be used in such cases. Several years later the Superior Court of Pennsylvania in a similar case[56] relied on the same standards.

The Supreme Court of Washington also provided detailed guidelines on procedural protections in In *Re Hayes*,[57] including a requirement for the determination that the person be incapable of making the decision and unlikely to develop that ability in the foreseeable future. The court went further to suggest that there must be no alternative to sterilization available.

Most recently, the Illinois appellate court affirmed *Terwillinger* and *Hayes* when it refused to permit the tubal ligation of a 29-year-old woman with an acquired brain injury that left her "mentally disabled."[58] *K.E.J.* is unique in that it quotes extensively from the evidence of the young woman herself, as well as the thoughts and wishes she had expressed to family and caregivers. Despite K.E.J.'s position, the court held that her current wishes were not relevant to the best wishes finding as she was incapable of making decisions regarding sterilization and reproduction. As she had "sustained the head injury leading to her current lack of competence when she was eight years old" and therefore, "there [was] no way to determine what she would choose for herself,"[59] the court engaged in a detailed consideration of the elements of best interest from *Hayes*. As there were alternatives available, the court did not order sterilization.

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[55] Ibid.

[56] *Estate of C.W.* [1994] 640 A.2d 427.

[57] [1980] 93 Wash. 2d 228.

[58] *In re Estate of K.E.J.* [2008] 887 N.E.2d 704 (Ill. App. 1 Dist.).

[59] Ibid.

Focused on Rights Analysis

Overruling an earlier provincial decision[60] that dismissed public policy issues and found that "issues of the rights of the handicapped in general, or questions of women's right to reproduce, were not relevant,"[61] the Canadian Supreme Court in *Eve* rejected the paternalism inherent in the best interest test. The court took the position that the "best interests of the woman" must be framed in terms of her fundamental rights, including her right to bear children. Acknowledgement and preservation of individual rights were seen as an essential element of the analysis.

The court went on to introduce the construction of "therapeutic" or "non-therapeutic" procedures, legal determinations that would have a profound impact on the ultimate decision. LaForest J acknowledged that *parens patriae*, the court's residual power to protect vulnerable persons, could be used "to authorize the performance of a surgical operation that is necessary to the health of a person…I mean mental as well as physical health."[62] Conversely, and in an important restriction of *parens patriae* power, courts could not intervene to authorize actions that were non-therapeutic.

In reality, the Canadian court's distinction of therapeutic and non-therapeutic procedures is not strictly dissimilar from the idea of "best-interest" held paramount in England. Jeanette's situation, after all, was in some ways dissimilar to that of Eve. Whereas Eve's guardian sought a hysterectomy largely for the ease of the guardian in protecting Eve from pregnancy, the medical situation Jeanette faced was much more serious. The Canadian decision noted that there was "no evidence that giving birth would be more difficult for Eve than for any other woman"[63] while the evidence in Jeanette's case indicated significant stress could result from menstruation and any potential pregnancy.[64] Further, Eve's mother sought a hysterectomy, while Jeanette's proposed tubal ligation: "[H]ysterectomy…is not only irreversible; it is major surgery."[65]

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[60] *Re K. and Public Trustee* [1985] 19 D.L.R. (4th) 255.

[61] Norrie, K.M. (1989). Sterilisation of the mentally disabled in English and Canadian law. *International and Comparative Law Quarterly, 38*(2), 387–395, at 388.

[62] *Supra* note 12, para 76.

[63] Ibid., para 21.

[64] *Supra* note 14, 216–217.

[65] *Supra* note 12, para 21.

Thus the legal constructions could be seen as not particularly distinct while the "therapeutic" distinction provides a legal basis for what is largely a policy statement by the court. Rather than making the rights analysis explicit, the determination is guarded in legal language obscuring the broader issue. There is rather clear evidence that the English court was so bound and fettered by its understanding of intellectual disability as a medical and static condition that it could not even consider a rights analysis. The Canadian court was open to the recognition of intellectual disability as a condition that did not preclude the exercise of rights and it proceeded with extreme caution.

In the final analysis, the importance in the Canadian decision is not the legal tool used to justify the determination but the insistence on confirming the procreative rights of women with intellectual disabilities, regardless of their ability to exercise those rights. Even if the "therapeutic" versus "non-therapeutic" analysis may be read by some, as it was by the English court, as a "best interest" analysis, the Canadian court clearly embedded individual rights elements in the determination.

Rights and Consent-Based Procedures

In Marion's case, the Court in Australia outlined 2 major issues: the threshold question of consent to medical procedures and the capacity of the child to consent. The court was the first to analyze the importance of determining whether or not the individual was able to make her own decisions about the proposed procedures – or whether she would later become able to consent. In both Canada and England, the consent issue was assumed (both young women were seen as globally incompetent for decision-making) and little time was spent on assessing their capacity or future capacity.

The Australian court also drew a distinction between a functional approach and a status approach to competence.[66] In looking at issues relating to children's rights, the Court held that determining individual capacity to make decisions regarding medical treatment could not be

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[66] Jones, M. & L.A. Basser Marks. (2000). Valuing people through law: Whatever happened to Marion. *Law in Context Special Issue: Explorations of Law on Disability in Australia, 17*(2), 147–180.

made solely on the basis of that individual's membership of a group. Marion could not be found incapable simply because she was a person with a disability; rather, an assessment of her actual ability to understand the procedure and its results must be implemented. By analogy, her status as a person with a disability could not alone result in a finding of incapacity. Thus the court "rejected the categorisation of people according to status and adopted the imperative of looking behind the label to the person."[67]

People who have been diagnosed with intellectual disability have been virtually excluded from the process of providing informed consent. The label of intellectual impairment has created a presumption for health care professionals which excludes people who have been labeled from being involved in personal medical decisions.

The medical label of intellectual disability in many cases automatically implies the legal label of mentally incompetent. In other words, the medical label gets interpreted without further consideration or reflection to a legal conclusion by defining intellectual disability in terms of lack of competence to learn, and by defining informed consent in terms of being mentally competent to understand. The informed consent test itself creates a discriminating barrier for those with disability. In order to declare a person legally incompetent, it is standard procedure for the courts to rely simply on the affidavits of two or three physicians.

The presumption of incapacity of those who have intellectual disabilities is pervasive in hospitals and court rooms and operates independently of the individual's demonstrated or potential abilities. The presumption of incompetence is commonly held even in the absence of any specific court order declaring incompetence. It is held without regard to the nature of the proposed procedure, treatment or surgery. For people who are labeled as intellectually disabled all of the variables ordinarily taken into account by physicians are disregarded as unnecessary because of the medical label compounded by the legal presumption. There has been little in the way of a medical or legal tradition in which people with intellectual disabilities have been substantially involved in the decision-making process. Physicians have found legal protection and moral solace in the legal presumption and designation.

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[67] Ibid., 153.

What was created in law, to wrap protection around those found to be disabled, has created an unrecognized and unquestioned justification for differential and disrespectful treatment. Marion's decision challenged this practice, while the British decision about Jeanette, reinforced it.

Understanding competence as an individual ability rather than a categorical status strengthened the position of women with intellectual disabilities in Australia to control their own bodies – and maintain their own dignity. Competence in and of itself, however, is yet another legal construct that provides a basis for granting rights to some persons – while providing the basis to remove those rights from others. Competence moves the disability rights analysis ahead several steps but again can obscure the issue of whether a person retains her rights. Marion was determined to be incompetent and the court later made the decision to proceed with sterilization, although it did so by using a rights analysis, based on a right to dignity.

In *Eve*, the concept of equality was used to promote individual value, regardless of difference. Interestingly, using the right of dignity, the court in Marion's case considered whether providing women with intellectual disabilities greater dignity actually promoted sterilization. In an analysis similar to that in Jeanette's case, the Australian court suggests that the right to dignity must be balanced against the individual's right to greater freedom. In that case, the court specifically held that it is "inviolability that is protected"[68] and that basis does not hold that sterilization can never occur. In particular, the court found that in some circumstances, competing personal rights may mitigate in favour of imposing non-consensual sterilization. Thus the rights analysis in Canada led the court to conclude that no "non-therapeutic" sterilizations could occur without individual consent, leaving open the ability for medical or other circumstances to allow for therapeutic procedures determined to be in the best interests of the person, albeit within the context of equality. In Australia, the rights analysis created circumstances where competing personal rights may allow for sterilization. The choice of how to best situate a rights analysis, and which rights to emphasize, may be critical in moving towards a true understanding of equality and inclusion for persons with disability.

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[68] *Supra* note 19, 24.

Fundamental Principles from the Cases

The Right to Reproduce

In *Re Eve*, the Canadian court focused a great deal on the right to procreate. In framing the decision, significant consideration was given to the fundamental importance of a woman's right to become pregnant and give birth – a right that exists regardless of the individual's ability to exercise the right or her disability. Similar reasoning compelled the English court to refuse consent to sterilize an 11-year-old girl in 1976. *In Re D,*[69] the court referred to the "irreversible nature of such an operation and the deprivation, which it involves, of a basic human right, "namely the right of a woman to reproduce."[70] Interestingly, that case also turned on the fact that the minor was likely to become capable of giving consent on her own with time, suggesting the functional competency analysis that were later clearly articulated in Australia.

In Jeanette's case, however, Lord Hailsham dismissed the reasoning in both the *Re D* and *Eve* cases – both of which had raised the issue of sterilization without consent in the context of the right of a woman to reproduce as a basic human right. In his judgement, Lord Hailsham limited the right to reproduce, arguing that the right is valuable only if the individual can exercise autonomy. He concluded that: "[t]his right is only such when reproduction is the result of informed choice of which this ward is incapable."[71] Similarly, Lord Bridge of Harwich on the same point held that:

> The sad fact in the instant case is that the mental and physical handicaps under which the ward suffers effectively render her incapable of ever exercising that right [of a woman to reproduce] or enjoying that privilege.[72]

Jeanette's "best interest," then, was determined without consideration of her being a woman. Her disability made that component of personhood less important if not entirely irrelevant to the court. The cloak of "best interest" removed the need to see Jeanette as a whole person of equal value to other women.

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[69] *Re D. (A Minor)* [1976] 1 All E.R. 326.

[70] *Supra* note 14, 213.

[71] Ibid.

[72] Ibid., 214.

The best interest doctrine eliminates broader societal values and public policy underpinnings for an apparently neutral consideration of individual circumstances. In situating the argument in the analysis of Jeanette's best interests, the court dismissed considerations of underlying assumptions about women with intellectual disabilities. While individual judgments may seem to provide fairness, the analysis fails to include broader issues that may impact a person's best interest including how they may perceive their attributed difference. Further, the community of people with disabilities may also be directly affected by the removal of the rights of one of its members.

Unlike the British case, in *Eve* the Canadian court found that the distinction between "therapeutic" and "non-therapeutic" procedures provided a loophole in which to move beyond best interest and insert a right-based analysis. By focusing on the "right" of an individual to reproduce, rather than the best interest of Eve (or her potential child), the court could equate women with intellectual disabilities with other women. Drawing a distinction between therapeutic versus non-therapeutic interventions allowed the court to eliminate the medical and legal considerations of interest that were implied to be neutral in the other cases[73] and that failed to place women with intellectual disabilities on equal footing, as being rights holders regardless of their ability to exercise those rights.

Bodily Integrity and Dignity

Rather than focusing on the right to reproduce in Marion's case, the Australian court concentrated instead on the right to bodily integrity and a basic human right to dignity in making decisions about one's own body. The court found that the common law right to bodily integrity, "the right in an individual to choose what occurs with respect to his or her own person,"[74] could support the general rights of people with disabilities. "The effect of the decision is that bodily integrity is accepted as a fundamental human right, protected by both the criminal and civil law."[75] Wrapped in issues of dignity, however, the court also

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[73] Rioux, M. (2003). On second thought: Constructing knowledge, law, disability and inequality. In S. Herr, L. Gostin & H. Koh (Eds.), *The human rights of persons with disabilities: Different but equal* (pp. 287–318). Oxford: Oxford University Press.

[74] *Supra* note 19, para 10.

[75] *Supra* note 66, 152.

seems to consider what it poses as an equal but competing right of women with disabilities: the right to have decisions made about their reproduction when they are unable to make those decisions themselves. In other words, the court appears to consider "dignity" to cut both ways and to permit sterilization where such could provide the individual with greater freedom. To that degree, situating equality analyses within concepts of dignity weakens the argument, allowing "dignity" to override bodily integrity and value inherent in humanness. Although the court seemingly adopts the analysis of the Canadian court by discarding paternalistic "best interest" doctrine, it expands the criteria of "therapeutic" procedures to include elements of "freedom" that may arise from sterilization.[76]

Allowing for sterilization in some cases, as a means of preserving the dignity of women with intellectual disability allows for "substituted decision-making." A third party would be in a legal position to step in, when the individual was incapable, and make a decision reflective of the individual's own decision, if he or she were capable. Substitute decision-making is a popular concept in the United States jurisprudence. *Eve* specifically considered and rejected such a notion by eliminating third party consent for non-therapeutic procedures. Providing for third party consent presumes that non-therapeutic procedures are ever valued in any circumstances for individuals – that those with intellectual disabilities would ever, themselves, consent to sterilization. Further, allowing a substituted decision suggests that another person could ever truly place themselves in the position of the individual under consideration: that they could appreciate all of the circumstances and feelings of the person involved and actually determine the position that he or she would take, if able. While Marion's case explicitly rejected substitute consent, the court ultimately attempted to place itself in her shoes – and determined that her interest in dignity would be greater than bodily integrity.

Both the Australian and English cases permitted sterilization. By using best interest doctrine and the concept of dignity in choosing sterilization, the courts weakened the position of persons with disabilities but from very different positions. While best interest tests remove the importance of individual rights in the equation, the element of dignity tries too hard to find equality by imposing the need to determine the

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[76] *Supra* note 19, 37.

question of sterilization when such a concern should have been unnecessary.

Implications of the Cases: Why the Outcomes Matter

The United Nation's Women's Committee of the *Convention on the Elimination of All Forms of Discrimination against Women* made several recommendations to its members regarding the rights of women. Recommendation 22 indicates, in part, that health services should be provided in a manner that provides equality to women and, in particular in a manner "that ensures that a woman gives her fully informed consent, respects her dignity, guarantees her confidentiality and is sensitive to her needs and perspectives. States parties should not permit forms of coercion, such as non-consensual sterilization."[77] The rights of women with intellectual disabilities require additional scrutiny given the more complex situations, as noted in the general principles of the recommendations. The more recent *Convention on the Rights of Persons with Disabilities* may also provide tools, requiring that signatory states ensure that "persons with disabilities, including children, retain their fertility on an equal basis with others."[78] Yet the value of international law and equality provisions generally, rest on the ability of courts to incorporate and validate the rules provided. Where general concepts of equality are hidden in legal tests, doctrine and analyses, without an equality analysis at the forefront, the true nature of societal willingness to support issues of equality are lost. International law provides standards upon which member states are responsible but a failure to clearly enunciate fundamental equality statements results in legal smokescreens to hide perceptions of difference.

The legal tools used to evaluate women with intellectual disabilities and determine the course of their procreative future result in vastly convergent analyses that mask societal values respecting difference. Ignoring the social values implicit in all decisions to remove procreative rights led the English court to base its findings on the specific facts

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[77] CEDAW, *General Recommendation No. 21 (13th session, 1994) Article 16(1)(e)*, online http://www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm visited November 11, 2010).

[78] Article 23(1)(c), online, http://www.un.org/esa/socdev/enable/rights/convtexte.htm#optprotocol (visited November 11, 2010).

of Jeanette's situation, failing to fully articulate matters of equality, integrity and dignity. The Canadian court protected Eve from nonconsensual sterilization by first grounding its review in public policy and acknowledging the significant failures of a system that sought to apply "best interest" to sterilization applications. The Canadian court found that Eve, a woman of equal value to society as any other woman, regardless of her intellectual disability, was entitled to protection from non-consensual sterilization that was not strictly required to protect her health. Marion, though ultimately sterilized, was recognized by the Australian court as a right holder, entitled to the same rights of bodily integrity and dignity as other women. Unlike the Canadian court, however, the Australian decision opens the possibility of non-consensual sterilization through its analysis: the court suggests that a woman with intellectual disability may have an equal right to sterilization despite lack of capacity, as though the procedure is the opposing right to bodily integrity.[79]

To some degree, the different fact situations could explain the differences in the court rulings. In Eve's situation, her mother sought a hysterectomy, but with little evidence to support the need for such an intrusive surgery. The court did not find that it would have been more difficult for Eve to carry a child to term or to give birth. On the other hand, Jeanette's situation was clearly different. The court held that Jeanette was likely to become psychologically distressed by pregnancy and birth itself may have been seriously traumatic and potentially physically dangerous for her. Very little information is available regarding Marion's circumstances, in part because the court was not authorizing the procedure itself but determining how such a decision should be made outside of the court system. Therefore we are lacking the facts

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[79] In *Re: Angela* ([2010] FamCA 98), a 2010 decision of the Family Court of Australia, a hysterectomy was ordered for a twelve year old girl. The court ordered the hysterectomy because of the reduced quality of life Angela reportedly experienced because of "pain and suffering" and "hygiene discomfort" from menstruation (Angela was unable to communicate so the pain and suffering was reported by her mother). There was some likelihood that Angela would also suffer fewer epileptic seizures. The Court determined that because Angela could never consider pregnancy and because she would not experience a negative psychological reaction, her welfare would improve because of the hysterectomy. No Independent Children's Lawyer was appointed to advise the court of Angela's rights because it was decided that there would be no value added in having a lawyer to address her legal interests. Unlike the decision in Marion's case, this decision does not reflect an analysis of dignity or value, but instead reverts to a "best interest" analysis more similar to the English decision.

that would allow us to consider her position more clearly. An important point for consideration and further analysis in similar cases is whether the courts were simply reflecting their own perception of the limitations of a person with an intellectual disabilities in how they characterized the ability of the three women. Medical records have been found to exaggerate the incapacity of people with intellectual disabilities because they frame it from within a medical diagnosis and fail to take into sufficient account the social and environmental conditions that have an impact on ability.[80] Thus the use of terms such as mild, moderate, severe and profound are still used in medical and service literature although there is no scientific criteria for making such determinations. Those are subjective terms and the actual distinction among these three women can hardly be gleaned from the legal facts.

However, it is not unusual to have descriptions of people with disabilities that emphasize their incapacities without considering their capacities. They will be described very differently depending on the purpose that one is trying to achieve or rather the general attitude that is held. For example, a young woman named Lelani Muir was institutionalized for many years and sterilized, under the *Eugenic Sterilization Act* of Alberta but was subsequently found by the court to have had no intellectual disability. She received significant damages from the court.[81] The perception is often more in the eyes of the beholder (the court, administrative tribunal or social welfare agency) rather than being an arguable objective description of the individual. Particularly lacking in all cases examined above is the opinion of the young women around whom the decisions revolve. Instead of the voices of Eve, Jeanette and Marion, the cases reduce their situation to the reports of their lives and abilities by others.

Despite the differences in the facts, however, it is clear that each court approached the issue of sterilization from a different bias. Both the Canadian and Australian cases acknowledged the long history of discrimination against persons with disabilities, particularly as it relates to eugenics. In consciously moving away from history, the courts embraced rights theory to elevate women with intellectual disability to

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[80] World Health Organization. (2001). International Classification of Functioning, Disability and Health (ICF). Geneva: WHO.

[81] *Muir v Alberta* [1996] 132 D.L.R. (4th) 695.

the same status as other rights holders. Although the rights considered are distinct – the right to procreate and the right of bodily integrity – both courts firmly placed equality analysis at the centre of the legal issues being considered. Neither court expressly dealt with equality, however. Instead, the Canadian court used the legal dichotomy of therapeutic and non-therapeutic procedures to situate the right to procreate at the forefront of the discussion. Australia instead used the concept of dignity to maintain a woman's bodily integrity. The legal principles unnecessarily hide the real issue under consideration – whether a woman with intellectual disabilities has the same societal value as other women and, consequently, the same right to equal outcome. Nonetheless, the decisions go beyond the English position of "best interest" which fails to acknowledge any equality analysis.

Recent Decisions

Recent practice in all jurisdictions is telling as to the impact of the cases. Savell, in her article regarding sexuality in persons with disabilities notes that in Australia, the state has acknowledged that in the five years after the Marion decision, "two hundred young learning disabled women were illegally sterilized…and this may be a conservative estimate" based on the fact that more than one thousand sterilizations were performed with parental consent.[82] Meanwhile data collated by the health insurance commission shows that at least 1045 girls have been sterilised over this same period."[83] In Canada, civil cases challenging non-consensual sterilizations continue to succeed as evidenced by the case of Leilani Muir[84] and A.R.[85] In Belgium, a 2004 study found

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[82] Savell, K. (2004). Sex and the sacred: Sterilization and bodily integrity in English and Canadian law. *McGill Law Review, 49*(4), 1093–1141, at 1099 and note 15. And see Dutter, B. (1989, 25 August 1998). 200 impaired girls illegally sterilized in Australia (quoted in Savell).

[83] Brady, S. et al. (2001). *The sterilization of girls and young women in Australia: Issues and progress*. Sydney: Sex Discrimination Commissioner and the Disability Discrimination Commissioner at the Human Rights and Equal Opportunities Commission, online, http://www.wwda.org.au/brady.htm (visited November 11, 2010).

[84] *Supra* note 81.

[85] From Savell, *supra* note 82.: For a selection of media reports on the case, see Jacobs, M. (2 June 2002). Sterlization issue in court's hands. *Edmonton Sun,* pp. 27.; Gifford, J. (8 October 2002). Sterlization can be decision of a loving mother. *The Halifax Daily News,* pp. 28.; Henderson, H. (8 June 2002). Case reignites debate on

that sterilization rates among women with intellectual disabilities "exceeded three times that of the general population" and seemed more likely when the woman resided in an institution.[86]

In early 2007, Ashley's case received international notice and reignited the debate on the value to be placed on the bodies of persons with disabilities. While the hormonal treatment has received a great deal of commentary, the removal of her breast tissue and her uterus has been less often debated. Ashley's parents, who consented to the interventions on behalf of their daughter argued that "preventing her from going through puberty means she won't experience the discomfort of having periods or growing breasts that might develop breast cancer, which runs in the family."[87] The severity of the interventions, or the somewhat bizarre suggestion that Ashley may experience "discomfort" from developing breasts, recalls the paternalistic best interest arguments of the British court. As with Jeanette, the caregivers who spoke on behalf of Ashley lauded the value of the interventions without acknowledging the severe risks of the surgeries or less intrusive measures that could accomplish the same goals.Without hearing Ashley's voice in the debate, decisions were made about the value of her disabled body and what was the best use of that body as it matured.

More disturbingly, some of Ashley's treatment was justified under a veil of increasing her dignity. As in Marion's case, Ashley's, caregivers interpreted dignity to include a right to have one's body cut open and radically changed. Arguing that the hormone treatment intended to stunt her growth was providing Ashley with greater dignity, her caregivers argue that the intervention is "a medical method of enabling profoundly disabled children to remain in the care of their parents when they become adults."[88] Keeping Ashley's body in the state of childhood would allow her to remain in the care of her parents.

Absent in Ashley's case is a discussion of her fundamental value as a human being and how her body has intrinsic value. The *Eve* decision clearly noted that non-consensual sterilization could "never safely be

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forced sterilization. *The Toronto Star,* pp. M15. ; Jamieson, A. (5 June 2002). Parents wrestling with sterilization issues deserve compassion. *Vancouver Sun,* pp. A15. ; Smith, J. (1 June 2002). Burden of care v. burden of proof. *The National Post,* pp. A23.

[86] Servais, L. et al. (2004). Sterilisation of intellectually disabled women. *European Psychiatry, 19*(7), 428–432.

[87] *Supra*, note 4.

[88] Ibid.

determined [to be] for the benefit of that person"[89] and it rejected the benefit to Eve's mother in protecting against possible pregnancy. In Ashley's case, however, the benefits to the caregivers morphs into an alleged benefit to Ashley herself – in allowing her to be more easily cared for at home. Ashley's case has never been examined by a court and thus we are lacking a clear understanding of how legal doctrine may be applied. Nonetheless, it is obvious that the arguments about her best interest fail to preserve Ashley's bodily integrity or her value as a woman.

Conclusion

The use of legal terminology and doctrine often can be used to mask unpleasant societal truths. In the cases of Eve, Jeanette and Marion, legal concepts overshadowed the pivotal issue of equality for women with intellectual disabilities.

By framing arguments in terms of consent, best interests and court jurisdiction, like *parens patriae*, the rights or lack of rights of those with difference can be lost. Looking beyond legal terms reveals the fundamental and competing values that society places on persons with disabilities. Equality analyses can provide the most effective means of addressing historic discrimination. As we have seen in the Canadian case of *Eve*, creating a rights-based understanding of individuals may provide the most equitable outcome by preserving the importance of the individual within the historical perspective of difference.

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[89] *Supra* note 12.

THE ROLE OF REASONABLE ACCOMMODATION IN SECURING SUBSTANTIVE EQUALITY FOR PERSONS WITH DISABILITIES: THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Janet E. Lord and Rebecca Brown

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD or Convention)[1] elaborates for the first time in a legally binding international human rights convention the concept of reasonable accommodation, explicitly linking it to the realization of *all* human rights – civil, political, economic, social, cultural – and embedding it within the non-discrimination mandate. In so doing, the CRPD animates both theoretical as well as practical discussions about rendering all rights meaningful for some 650 million persons with disabilities worldwide. The Optional Protocol to the CRPD (OP-CRPD),[2] adopted at the same time as the Convention, together with the newly adopted Optional Protocol to the International Covenant on Economic, Social and Cultural Rights (OP-ICESCR)[3], provide new entry points for claimants with disabilities and their representative organizations with the opportunity to enrich human rights advocacy through the application of reasonable accommodation across all spheres of life. The progressive application of reasonable accommodation through these new complaints mechanisms should likewise rouse – and one hopes considerably stimulate – the somewhat sluggish development of this concept in other human rights realms, including in the European Court of Human Rights and other regional systems.

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[1] Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106 (2007) [hereinafter CRPD or Convention].

[2] Optional Protocol to the Convention on the Rights of Persons with Disabilities *opened for signature* Mar. 30, 2007, G.A. Res. 61/106 (2007) [hereinafter CRPD Optional Protocol or OP-CRPD].

[3] Optional Protocol to the Covenant on Economic, Social and Cultural Rights *opened for signature* Sept. 24, 2008 G.A. Res. A/RES/63/117 (2008) [hereinafter OP-ICESCR].

This chapter reviews the concept of reasonable accommodation as it is articulated in the CRPD, the human rights treaty where it makes its first appearance. This analysis is then set against the more timid manifestation of the reasonable accommodation duty in other human rights realms, including its application in the UN and regional human rights systems. The CRPD, it is hoped, will help enliven the reasonable accommodation duty and thereby give impetus for its further development in international as well as national human rights practice. This possibility, we argue, is genuine given the procedural mechanisms now in place for advancing disability discrimination and reasonable accommodation claims under the two new Optional Protocols to the CRPD and ICESCR respectively.

I. Reasonable Accommodation under the CRPD

The CRPD, in its design, is a roadmap for the re-integration of all human rights – civil, political, economic, social and cultural. The Convention places the substantive equality of persons with disabilities as its purpose[4] and embodies the interrelationship of all rights, thereby challenging the bifurcation of the Universal Declaration of Human Rights[5] into two Covenants.[6] The CRPD also achieves a reorientation of disability issues as rights claims (as opposed to medical or charitable concerns),[7]

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[4] CRPD, *supra* note 1 at art. 1 (identifying the "purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities."). *Id.*

[5] Universal Declaration of Human Rights, G.A. Res. 217A (III), , U.N. GAOR, 3d Sess., U.N. Doc. A/810 (Dec. 12, 1948). The UDHR encompasses civil, political, economic, social and cultural rights in one, holistic instrument. Academic commentary on the subsequent separation of civil and political rights on the one hand and economic, social and cultural rights on the other in the two Covenants and the ensuing debate on negative and positive liberty is ubiquitous. *See especially* Carter, I. (2007). Negative and positive liberty. *Stanford Encyclopedia of Philosophy, available at:* http://plato.stanford.edu/entries/liberty-positive-negative/#Bib visited on November, 12, 2010).

See also MacCallum, C. (1967). Negative and positive freedom. *Philosophical Review, 76*, 312–334.;Young, R. (1986). *Beyond negative and positive liberty*. New York: St. Martin's Press.; Berlin, I. (1969). Two concepts of liberty. In I. Berlin (Ed.), *Four essays on liberty* (pp. 118–172). London: Oxford University Press.

[6] International Covenant on Civil and Political Rights, G.A. Res. 2200A (XXI), U. N. GAOR, Supp. No. 16 at 52, U.N. Doc. A/6316 (1966) [hereinafter ICCPR]; International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI), U.N. GAOR, Supp. No. 16, U.N. Doc. A/6316 (1966) [hereinafter ICESCR].

[7] *See generally,* Stein, M.A. (2007). Disability human rights. *California Law Review, 95*(1), 75–122.; Lord, J.E. (2002). *Understanding the role of an international*

and creates a framework for analyzing the role of the State in terms of legal obligations embedded within a substantive equality framework.[8]

Transcending Formal Equality Frameworks

Formal models of equality require all similarly situated people receive the same treatment and for laws and policies to be formulated in a neutral manner.[9] This model ignores human difference, and, more importantly, the societal barriers that inhibit rights enjoyment and full participation. Anna Lawson usefully summarizes the consequences of a formal model of equality approach in relation to the rights of marginalized groups:

> Its focus is therefore on requiring identical treatment. It would insist, for instance, that a university treat identically qualified applicants in the same way regardless of the fact that they might have different genders, racial background, or physical impairments. It would insist that employers offer promotion to identically situated people on the same basis regardless of such differences; that hospitals offer them beds on the same basis; that electoral authorities allow them to vote on the same basis; and that public housing services offer them accommodation on the same basis. Clearly, the application of a system of formal equality begs the question of what should be regarded as relevant difference and who should be treated as similarly situated.[10]

Substantive equality is, by contrast, less concerned with equal treatment and more focused on equal access and equal benefits.[11] This requires more than restraint on the power of the state; positive action or positive measures and an allocation of resources may be necessary to ensure

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convention on the human rights of people with disabilities. Washington: National Council on Disability.

[8] Lord, J.E. & Stein, M.A. (2010), Assessing economic, social and cultural rights: The Convention on the Rights of Persons with Disabilities, in Malcolm Langford & Eibe Reidel (Eds.), *Equality and economic and social rights* 4–5.

[9] The literature on the limitation of formal models of equality – particularly in relation to securing the rights of marginalized groups – is significant. Of particular note are the following: Fredman, S. (2002). *Discrimination law*. Oxford: Hart Publishing.; Hendricks, A. (1995). The significance of equality and non-discrimination for the protection of disabled persons. In T. Degener, & Y. Koster-Dreese (Eds.), *Human rights and disabled persons: Essays and relevant human rights instruments* (pp. 40–53). The Netherlands: Martinus Nijhoff Publishers.

[10] Lawson, A. (2008). *Disability and equality law in Britain: The role of reasonable adjustment*. Portland: Hart Publishing.

[11] Lawson, *supra* note 10 at 19. *See also*, Brodsky, G. & Day, S. (2002). Beyond the social and economic rights debate: Substantive equality speaks to poverty. *Canadian Journal of Women and the Law, 14*, 184–219, 206–207.

all people are equally able to realize their human rights.[12] In contrast to formal equality, substantive equality requires that the State not only fulfill its obligation of conduct, but also the obligation of result in the process of implementing human rights.[13] Sandra Fredman has proposed four specific goals of substantive equality including: (1) breaking the cycle of disadvantage associated with marginalized groups; (2) promoting respect for equal dignity as a strategy for remedying stereotyping, stigma and violence associated with marginalized status; (3) positive affirmation and recognition of marginalized identity; and (4) facilitation of full participation in society.[14]

A core goal of substantive equality is to ensure the equal distribution of benefits among members of society and to transform the unequal power relations between persons that may inhibit equal access to human rights.[15] In some circumstances, this may require treating persons with disabilities differently, where treating them the same would fail to recognize critical needs, ignore barriers to full inclusion and undermine realization of human rights.[16] As the Committee on Economic, Social and Cultural Rights stated in relation to persons with disabilities:

> The obligation in the case of such a vulnerable and disadvantaged group is to take positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities. This almost invariably means that additional resources will need to be made available for this purpose and that a wide range of specially tailored measures will be required.[17]

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[12] Fredman, S. (2005). Providing equality: Substantive equality and the positive duty to provide. *South African Journal of Human Rights, 21*(2), 163–190, 163.

[13] Alston, P. & Quinn, G. (1987). The nature and scope of states parties' obligations under the International Covenant on Economic, Social and Cultural Rights. *Human Rights Quarterly, 9*(2), 156–229, 185.

[14] Fredman, *supra* note 12, 167.

[15] Liebenberg, S. & Goldblatt, B. (2007). The interrelationship between equality and socio-economic rights under South Africa's transformative constitution. *South African Journal of Human Rights, 23*(2), 335–361, 342.

[16] Lawson, *supra* note 10, 22–23.

[17] Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 5, Persons with disabilities* (Eleventh session, 1994), U.N. Doc E/1995/22 at 19 (1995), reprinted in Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, U.N. Doc. HRI/GEN/1/Rev.6 at 24 (2003) at para 9.

The point of departure for developing a robust disability discrimination law is thus the recognition that substantive equality for persons with disabilities requires steps beyond embedding bald discriminatory proscriptions in laws and policies. It necessitates positive action to ensure inclusion and participation of disabled persons who have been subjected to historic discrimination and isolation through physical, social and attitudinal barriers,[18] as well as a failure to make appropriate accommodation in workplaces and education, among other domains of life.[19] The substantive equality framework also reflects on both the process and results of positive measures: it compels an inquiry as to whether those efforts taken have adequately involved affected groups and facilitated the actual realization of human rights through the positive measures taken. The inclusion of the reasonable accommodation requirement in the CRPD recognizes that affirmative steps must be taken beyond the guarantee of formal legal equality to move toward equality in fact, as discussed in more detail below.[20]

Reasonable Accommodation as a Substantive Equality Facilitator

The inclusion of reasonable accommodation within the framework of non-discrimination and equality in the CRPD constitutes a considerable advance in the re-unification of human rights obligations. Or, as Anna Lawson suggests, reasonable accommodation in the CRPD serves a "peculiar bridging role."[21] In this sense, its application across all rights – civil, political, economic, social and cultural – draws together and thus re-aggregates human rights law.

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[18] *See generally* Lord & Stein, *supra* note 8.

[19] CESCR, *supra* note 17 at para 15.

[20] Lawson observes that in arguing for the reunification and interdependence of all human rights, it is vital not to conflate overarching legal obligations of states with legal requirements which arise in particular circumstances. Specifically, reasonable accommodation is a non-discrimination obligation and as such, the non-discrimination obligation requires the implementation of reasonable accommodation measures. Lawson argues that these measures generally require positive action, but only the failure to implement the reasonable accommodation duty, and not the failure to undertake positive measures, is actionable as a violation of the right to non-discrimination. Further, the failure to accord reasonable accommodation measures should be understood as one manifestation of discriminatory conduct, akin to direct discrimination or indirect discrimination. Lawson, *supra* note 10, 222–225.

[21] Lawson, A. (2009). The UN convention on the rights of persons with disabilities and European disability law: A catalyst for cohesion? In O. Arnardottir & G. Quinn (Eds.), *The United Nations Convention on the Rights of Persons with Disabilities: European and Scandinavian perspectives* (pp. 320). Leiden: Martinus Nijhoff, 103.

The concept of reasonable accommodation, which was initially expressed in the domestic disability law of the United States,[22] first appeared at the international level in General Comment 5 of the Committee on Economic, Social and Cultural Rights (CESCR).[23] Drawing on that language, the CRPD defines reasonable accommodation in Article 2 as:

> [N]ecessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.[24]

As a structural matter, obligations of equality and non-discrimination, including reasonable accommodation, are expressed in Article 5, within the group of provisions that have general application across the CRPD. Article 5(2) obliges States Parties to "prohibit all discrimination on the basis of disability."[25] Disability discrimination is defined in Article 2 to mean:

> [A]ny distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.[26]

Denial of reasonable accommodation is thus a separate and distinct basis upon which to found a claim for disability discrimination under the CRPD. Moreover, the integration of reasonable accommodation into the formal definition of non-discrimination in Article 2 of the CRPD establishes that the realization of fundamental civil and political rights requires implementation through positive measures in order to address ongoing systemic discrimination against persons with

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[22] *Rehabilitation Act* 1973, 29 USC s. 701 et seq & 28 CFR part 41 (Department of Justice); 29 CFR Part 32 (Department of Labor); 45 CFR Part 84 (Department of Health and Human Services).

[23] CESCR, *supra* note 17. For useful background on the adoption of this General Comment, *see* Alston, P. (1995). Disability in the international covenant on economic, social and cultural rights. In T. Degener & Y. Koster-Dreese (Eds.), *Human rights and disabled persons: Essays and relevant human rights instruments* (pp. 94–105). The Netherlands: Martinus Nijhoff Publishers.

[24] CRPD, *supra* note 1, at art. 2.

[25] Ibid., at art. 5(2).

[26] Ibid., at art. 2.

disabilities. In addition, Article 5 requires that States “take all appropriate steps to ensure that reasonable accommodation is provided” in taking measures “to promote equality and eliminate discrimination.”[27] As Anna Lawson has argued persuasively, this provision, along with Article 8 (awareness-raising) requires not only the provision of reasonable accommodation but also positive steps in relation to raising awareness of the duty to accommodate, measures that can be taken, and compliance mechanisms.[28]

The duty to provide reasonable accommodation in the CRPD extends to a broad array of social actors, including the State, employers, education providers, health care providers, testing and qualification bodies, providers of goods and services and private clubs. The duty requires these actors to reasonably adjust policies, practices and premises that impede the inclusion and participation of persons with disabilities.[29] While the reasonable accommodation duty falls within the articles of general application and therefore applies across all of the articles, it is also specifically referenced in the specific substantive articles on liberty and security of the person (Article 14(2)), education (Article 24), employment (Article 27), as well as Article 12 which references, within the access to justice realm, the “provision of procedural and age appropriate accommodations.”[30]

Reasonable accommodation requires positive measures to address the unique needs of persons with disabilities in order to ensure the equal right to work, education, health and to an adequate standard of living – these are usually programmatic in nature. In this sense, the obligation to reasonably accommodate the unique needs of persons with disabilities merges with the obligation under the ICESCR and under the economic, social and cultural rights (ESC rights) provisions in the CRPD, to apply the maximum of available resources to realizing the substantive rights in question. The CRPD offers an exceptional model of “convergent paradigms of rights and remedies and the importance of the standard of reasonableness in in reviewing the right to positive measures in light of available resources in the context of both equality rights and ESC rights.”[31]

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[27] Ibid., at art. 5(3).

[28] Lawson, *supra* note 10, 32.

[29] Ibid., at p. 222.

[30] CRPD, *supra* note 1 at art. 13(1).

[31] Porter, B. (2009). The reasonableness of articles 8(4) – Adjudicating claims from the margins. *Nordic Journal of Human Rights, 27*(1), 39–53. Special issue: Perspectives on a new complaint and inquiry procedure: The Optional Protocol to

The link between reasonable accommodation and disability discrimination in the CRPD thus creates an obligation of immediate effect.[32] Accordingly, the CRPD ensures that reasonable accommodation is equally required in relation to civil and political rights and ESC rights.[33] The precise implications of this remain somewhat unclear.[34] Anna Lawson suggests that the language the concept of "reasonableness" and "undue burden" serve to introduce some notion of progressive realization into the non-discrimination calculus. While this language can allow for some interpretation of the temporal implications of the duty to accommodate, even a conservative reading of this obligation would conclude that, at a minimum, there is the immediate requirement to take steps through legislative and other measures to realize disability rights to available resources. The implementation of reasonable accommodation over the long term will be required to meet comprehensively the obligations of the right to equality and non-discrimination.[35]

The consequence of this explicit coupling of non-discrimination and reasonable accommodation in the CRPD is that the right to non-discrimination (understood as a civil right) can only be realized through its application to *all* human rights. This version of substantive equality, essential for gaining human rights traction for socially, economically and historically marginalized groups, thus requires more than formal

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the International Covenant on Economic, Social and Cultural Rights (Malcolm Langford, guest editor) pp. 39–53, 42.

[32] Lord & Stein, *supra* note 8, 7. *See also* Lawson, *supra* note 22, 103. ("States are therefore required to prohibit such failure [to provide reasonable accommodation] by Article 5(2) and to do so immediately as the right to be free from discrimination is a civil and political right to which the principle of progressive realization does not apply.). *Id.*

[33] CRPD, *supra* note 1 at art. 5.

[34] Lawson points out that the integration of civil and political rights with economic, social and cultural rights in the CRPD met with some controversy during the drafting of the CRPD and that one aspect of the compromise reached was the inclusion of "reasonableness" and "undue burden" into the text, which, she asserts, re-introduces, to some extent, concepts of progressive realization and a margin of discretion. Lawson, *supra* note 21, 104. However, as Bruce Porter notes, the concept of "margin of appreciation" has been rarely discussed within UN treaty bodies and appears in no treaty text and further that it has been associated with the abandonment of effective judicial remedies for ESCR claims relating to poverty, *See,* Porter, *supra* note 31 at 47.

[35] ICESCR, *supra* note 6, art. 2. *See also* Committee on Economic, Social and Cultural Rights, *General Comment 3, The nature of States Parties' obligations* (Fifth session, 1990), U.N. Doc. E/1991/23, annex III at 86 (1991), reprinted in Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, U.N. Doc. HRI/GEN/1/Rev.6 at 14 (2003)at para 1–2.

equality in the application of human rights law. It also undermines the untenable and increasingly rejected position that civil and political rights are "negative" and require little positive action or investment of resources on the part of the State.[36]

The CRPD therefore makes explicit the interconnectedness and interdependence of all human rights. Civil and political rights of non-discrimination and participation are required to disrupt the patterns of exclusion, and economic and social rights are needed to address the legacy of marginalization including poverty and inaccessibility.[37] The CRPD serves to re-conceptualize and unite civil and political rights and economic, social and cultural rights in the realization of equality for persons with disabilities by requiring reasonable accommodation through positive measures in all areas of life.[38] This innovative application of reasonable accommodation under the CRPD offers new opportunities for disability rights advocates seeking justice for violations of the rights of persons for disabilities under its Optional Protocol and indeed for disability advocates seeking to press economic, social and cultural rights claims under the newly adopted Optional Protocol to the ICESCR.

II. The Nascent Development of Reasonable Accommodation in Human Rights Law

The CRPD gives full expression to the legal obligation to provide reasonable accommodation for persons with disabilities. This concept was in use in various international and regional fora and at work in domestic legal frameworks prior to the adoption of the CRPD. Its invocation was made explicit in international human rights law through the adoption of *General Comment 5* on persons with disabilities by the Committee on Economic, Social and Cultural Rights, as noted above.[39] Thus, for example, the duty to accommodate was applied implicitly in cases involving disabled prisoners before the UN Human Rights Committee and the European Court of Human Rights and also in relation to the provision of support systems and the design of educational

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[36] Lawson, *supra* note 10, 32.

[37] Lord & Stein, *supra* note 8, 4–5.

[38] Porter, *supra* note 31, 42.

[39] CESCR, *supra* note 17.

environments and curricula for disabled children and adults under the European Social Charter.[40] Therefore, although the adoption and entry into force of the CRPD represents a watershed moment in the development and recognition of this critical concept, it has been evolving at all levels for many years.

In this section, we will review some threshold cases which apply reasonable accommodation in a manner that is implicit or underdeveloped. We will examine those cases and use them as a basis to reevaluate the ways in which the more explicit and legally binding nature of reasonable accommodation under the CRPD might have offered greater relief for the complainant and a coherent method for applying the substantive equality framework to address current and past discrimination. This analysis will provide the foundation for some preliminary observations as to the role that the CRPD may play in enriching disability discrimination cases at regional and international levels. Finally, the legal standards required under the ICESCR will also be integrated where the case involves economic and social rights in an attempt to posit what a holistic examination and recognition of economic and social rights of persons with disabilities might look like under the CRPD.

The Duty to Accommodate Prisoners

An early and fertile ground for the application of reasonable accommodation in cases concerning rights violations against persons with disabilities was, not surprisingly, in the realm of mistreatment of prisoners. The paradigmatic case in this context is *Price v United Kingdom*,[41] decided by the European Court of Human Rights (ECtHR), where the court found that the complainant had experienced degrading treatment, in violation of Article 7 of the European Convention on Human Rights[42] through the failure to accommodate for her disability in the prison setting. The complainant, Ms. Price, had foreshortened limbs

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[40] *Autism Europe v France*, Complaint No. 13/2002, decision on the merits of 4 November 2003.

[41] *Price v UK,* European Court of Human Rights, App. No 33394/96 (2001) 34 EHRR 1285.

[42] Convention for the Protection of Human Rights and Fundamental Freedoms, 213 U.N.T.S. 222, *entered into force* Sept. 3, 1953, *as amended by* Protocols Nos 3, 5, 8, and 11 *which entered into force* on 21 September 1970, 20 December 1971, 1 January 1990, and 1 November 1998 *respectively.*

and also had a serious kidney condition. Owing to her refusal to respond to questioning about her financial position in a debt recovery proceeding, Ms. Price was sentenced to three nights in jail. During this time, she was forced to sleep in a very cold cell, she was not allowed access to her battery charger for her wheelchair, her bed was inaccessible to her and she had to rely on male prison staff to assist her in using the toilet after she had been left there for three hours waiting for a female attendant. Following her release, she required medical treatment due to her inability to use the toilet facilities.

The Court held that the conditions faced by the complainant amounted to degrading treatment notwithstanding any evidence of an intention to humiliate Ms. Price.[43] While the Court rendered a positive decision in this case, it did not take up the opportunity presented to explicitly discuss the duty to afford prisoners with disabilities reasonable accommodation in the context of their prison confinement. While the case demonstrates the willingness of the Court to take into account the different needs of differently situated prisoners on the basis of impairment or health status, it did not go as far as it might in its reasoning. Thus, while *Price* discloses some element of reasonable accommodation at work, it is not specifically defined and does not appear as a stand-alone claim, rather, it is implicit and contingent on its application to a specific substantive right, in this case, inhuman and degrading treatment or punishment.

The ECtHR and other courts in Europe have issued similar judgments in cases where the traditional prison setting has a degrading and dehumanizing impact on persons with disabilities.[44] So too have treaty bodies, in as much as the Human Rights Committee, the body that monitors implementation of the International Covenant on Civil and Political Rights (ICCPR),[45] found that standard accommodations for a death row inmate who experienced paralysis violated Article 10 of the ICCPR (rights of prisoner to dignity and respect) on the basis that he

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[43] Price, *supra* note 41 at para. 30.

[44] *See Mouisel v France*, European Court of Human Rights App No 67263/01 (2002) ECHR 740. *See also Napier v Scottish Ministers* (2004) Scottish Law Times 555 p. 41–42. For discussion of these cases, see O'Cinneide, C. (2009). Extracting protection for the rights of persons with disabilities from the human rights framework – Established limits and new possibilities. In G. Quinn, & O. Arnadottir (Eds.), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian perspectives*. The Netherlands: Martinus Nijhoff Publishers.

[45] ICCPR, *supra* note 6.

was unable to clean out his cell or climb onto his bed.[46] Finally, the Inter-American Commission of Human Rights has held that in the case of persons with mental disabilities, prison settings must also be appropriate for their mental and physical needs.[47]

All of these cases are limited, however, both in requiring a violation of an underlying substantive right, as well as limiting the discussion of the violations to those relating to the rights to life, dignity and humane treatment and not as a denial of the right to be free from discrimination and to be accommodated as part of the non-discrimination obligation. The CRPD, in contrast, offers a legal framework which can embrace both the substantive rights involved in these cases, and, crucially, adequately address the underlying discrimination, which has created or exacerbated the violations. Therefore, if *Price* had been brought forward in a claim before the CRPD Committee, the failure of the State to ensure Ms. Price was immediately accommodated in accessible and appropriate prison facilities would have constituted a *prima facie* violation of Article 5.[48] If the Court in *Price* had the CRPD as a tool of interpretation, and assuming it chose to use it, it could have avoided the inquiry as to whether any substantive rights had been violated and it might have grounded its finding in the failure to provide reasonable accommodation thus situating its decision within the non-discrimination obligation.[49]

While *Price* might have been decided on non-discrimination grounds alone of course, the CRPD incorporates a full range of civil, political, economic, social and cultural rights into its text. Indeed, on the facts in *Price*, the substantive rights of non-discrimination and equality, accessibility,[50] freedom from cruel, inhuman and degrading treatment or punishment,[51] physical and mental integrity of the person,[52] and right to health[53] were all at play as a basis for claiming a rights violation. In claiming any one of these substantive rights under the CRPD,

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[46] *Hamilton v Jamaica*, Communication No 616/1995, Views adopted by the Committee on 28 July 1999 (CCPR/C/66/D/616/1995).

[47] *See Victor Rosario Congo v Ecuador*, Case 11.427, Report No. 63/99, Inter-Am. C.H.R., OEA/Ser.L/V/II.95 Doc. 7 rev. at 475 (1998).

[48] CRPD, *supra* note 1 at art. 5.

[49] Lawson, *supra* note 10, 224.

[50] CRPD, *supra* note 1 at art. 9.

[51] Ibid., at art. 15.

[52] Ibid., at art. 17.

[53] Ibid., at art. 25.

it will be important for the Committee on the Rights of Persons with Disabilities to recognize that many components of ESC rights are subject to immediate obligations and that often the positive measures required in relation to ESC rights are concomitantly required on the basis of civil and political rights obligations. The concept of what is "reasonable" will have to be developed in a manner which is not allowed to erode in any way the non-derogability or immediacy of certain obligations, such as the obligations to refrain from cruel or unusual treatment and to take positive measures to afford prisoners access to adequate healthcare, food, shelter, sanitation and other necessities.

In relation to the right to health for example, the Committee could require the State Party to show that steps toward ensuring reasonable accommodations had been made with regards to the substantive provision of Article 25 (health) to meet its immediate obligations to ensure non-discrimination, as well as showing that steps were being taken to progressively realize these rights within maximum available resources.[54] Article 25 requires that persons with disabilities have the right to the highest attainable standard of health without discrimination and that all appropriate measures should be taken to ensure access to health services that are gender sensitive.[55] Consequently, because Ms. Price had kidney problems, and she was not provided accessible toilet facilities and was not attended by a female assistant, her substantive right to health was also violated in this case.

The CRPD therefore, is much more inclusive of the human rights of persons with disabilities than the framework offered in the traditionally bifurcated human rights framework and capable of addressing the various dimensions of discrimination and violations of rights. It allows increased flexibility in terms of the claims which can be sent to the Committee and it broadens the opportunity for rights bearers to claim their full spectrum of rights. Under the CRPD, Ms. Price could find relief even without a showing of degrading treatment as it recognizes that denial of reasonable accommodation in itself is a violation of fundamental rights. Ms. Price could also make the connection between the discrimination she experienced in terms of lack of reasonable accommodation and the unique and disproportionate impact it had on her right to health, therefore possibly increasing the liability of the State for its failure.

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[54] CESCR, General Comment 5, *supra* note 18 at para 9.

[55] Ibid.

The Duty to Accommodate in the Spheres of Sport, Recreation and Play

The duty to accommodation persons with disabilities in the realm of sport, recreation and play as it is reflected in the CRPD breaks new ground in offering the most detailed expression of such rights in any international human rights instrument. This augers well for applying concepts of disability discrimination and equality to this realm of social life given the peculiar hostility such claims have garnered in human rights cases.

In *Botta v Italy*,[56] the applicant, Mr. Botta, an Italian national, claimed a violation of his rights under the European Convention on Human Rights, including discrimination on the basis of disability. Mr. Botta, who was physically disabled, vacationed at Lido degli Estensi, a seaside resort in 1991, and found that the resort did not have accessible facilities to enable persons with mobility impairments to access the beach and the sea. Moreover, the resort failed to comply with Italian legislation on access insofar as it lacked special access ramps, lavatories and washrooms. The statute in question included provisions intended to guarantee persons with disabilities effective access to private buildings and establishments and the removal of architectural obstructions. A further government decree required that all future contracts awarding concessions to private beaches include a clause obliging the beaches to install at least one changing cubicle and one lavatory specially designed for the use of disabled people as well as a special ramp enabling access to the beach and the sea.

In March 1991, Mr. Botta complained to the mayor of Commachio, the municipality where the resort was located, and requested that the resort's facilities be made accessible in conformity with the legislation and decree. Later in the same year, Mr. Botta returned to the resort and found that no changes to facilitate accessibility had been made. Thereafter, he lodged a complaint against the minister for merchant shipping, the harbor-master and the local mayor, alleging they failed in their official duty to require the private beaches to install facilities for people with disabilities. In July 1992, Mr. Botta applied to the European Commission of Human Rights following the discontinuation of the proceedings by the local prosecutor's office and district court. Although by the time the application was submitted, in July 1997, some of the

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[56] *Botta v Italy*, 26 EHRR 241 (1998).

private beaches in question had installed accessible changing cubicles and lavatories, none of them had built a ramp designed to permit persons with disabilities to gain access to the beach and the sea.

Mr. Botta, in his application, asserted that his private life had been impaired, along with the development of his personality, on account of the Italian State's failure to take appropriate measures to ensure that the private bathing establishments at the resort in question were accessible to him. He asserted that he was unable to enjoy social relations on an equal basis with others which would enable him to participate in the life of the community and to exercise essential rights. He stressed that the failure of the State in this regard was not interference, but rather failure to discharge its positive obligations to adopt measures and to monitor compliance with domestic provisions relating to private beaches.

Relying on Article 14 (non-discrimination), together with Article 8 (privacy), Mr. Botta asserted that he was the victim of disability discrimination. He admitted that there was no longer any such *de jure* discrimination, since Italian legislation not only contained various provisions designed to ensure equality, but also required "positive measures" in favor of persons with disabilities. The disparity continued to exist in fact, however, given the facts in this particular case. Moreover, he noted the Court's practice to consider the particular circumstances of a given case in order to decide whether there had been any discriminatory treatment and the need for the Court to focus on the specific manner in which the impugned domestic rules were applied to the person concerned, rather than how they may be exercised in the abstract.

The Government argued that Mr. Botta's interpretation of Article 8 was too broad and would inexorably alter the meaning of the provision to require positive obligations to ensure the satisfactory development of each individual's recreational activities. The Government likewise rejected the argument that Mr. Botta had experienced disability discrimination in the case.

The Court found that Article 8 of the Convention did not apply in this case; instead, it determined that the right asserted by Mr. Botta (to gain access to the beach and sea at a place distant from his normal place of residence during his holidays) under Article 8 concerned interpersonal relations of such broad and indeterminate scope that there could be no conceivable direct link between the measures the State was urged to take and his private life. The Court noted that Article 8 could require the State to take positive measures which may include regulating private conduct, but that these obligations are present only where there is a direct and immediate link between the positive measures sought and the applicant's private or family life, a requirement which was not fulfilled in the present case. Regarding Article 14, the Court found that as the facts of the case did not fall within the ambit of a specific substantive provision of the Convention, Article 14 could not apply.

This case perhaps best exemplifies the perils of segregating rights into separate instruments. The applicant in this case was attempting to fit his social rights claim into an ill-fitting civil rights suit. Privacy rights were an uncomfortable fit and the Court was, in any case, unwilling to find a stand-alone disability discrimination violation. Traditional human rights framings are in this sense inimical to ESC rights and reinforce their devalued status in human rights practice.

The CRPD, in contrast to the ECHR, includes social rights and, in particular, guarantees to persons with disabilities the right to participate in sport, recreation, leisure and play. Article 30(5) requires States to encourage and promote the inclusion of persons with disabilities in mainstream sporting activities, "at all levels."[57] Applying the requirement of Article 5 that reasonable accommodation be provided, States must take specific measures to ensure that persons with disabilities are able to access mainstream sport.[58] Article 30(5) further requires States to provide opportunities for participation in both disability-specific sport and recreation and mainstream sport programming – a requirement that likewise triggers the duty to accommodate.[59] It also recognizes and affirms the rights of persons with disabilities to organize, develop and participate in sport and recreation with other persons with disabilities in disability-specific and mainstream programs which again requires that reasonable accommodations be provided.[60] Article 30 further ensures the rights of persons with disabilities to access and to use sporting, recreational and tourism facilities which, in keeping with Article 5 as well as Article 9 (accessibility) requires specific measures to facilitate access.[61] States also must take measures to ensure that persons with disabilities are included as recipients of services and programming

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[57] CRPD, *supra* note 1 at art. 30(5)(a).

[58] Ibid., at art. 5(3).

[59] Ibid., at art. 30(5)(b).

[60] Ibid., at art. 30(5)(b).

[61] Ibid., at art. 30(5)(c); art. 5(3); art. 9.

by organizers.[62] Finally, Article 30 recognizes the right of children with disabilities to play and to participate in recreation, leisure and sporting activities in the school system.[63]

The CRPD thus offers much to disability rights advocates and other human rights advocates interested in making claims in relation to sport, recreation and play. Article 30(5), as the most comprehensive expression of the right to participate in sport, recreation and play in human rights law, provides a solid framework for achieving substantive equality in this realm. The scant attention paid to recreation and leisure rights in both human rights law and practice[64] and its highly skeptical reception in the *Botta* case, suggest that there is ample room for the CRPD to help transform human rights work in this area.

The Duty to Accommodate Children with Disabilities in Educational Settings

In *MDAC v Bulgaria*,[65] the European Committee of Social Rights (European Committee) considered a collective complaints claim raised by the Hungarian-based Mental Disability Rights Advocacy Center and the Bulgarian Helsinki Committee. The complaint argued that children with disabilities (ranging from moderate, severe to profound) who were residing in certain social care home institutions in Bulgaria, received no education on account of their disabilities and that this constituted a violation of Article 17(2) of the Revised European Social Charter.[66] That provision requires States "to take all appropriate and necessary measures designed to provide to children and young persons a free primary and secondary education as well as to encourage regular attendance at schools." The collective complaint further alleged

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[62] Ibid., at art. 30(5)(e) & (c).

[63] Ibid., at art. 30(5)(d).

[64] *See* Lord, J.E. & Stein, M.A. (2009). Social rights and the relational value of the rights to participate in sport, recreation and play. *Boston University International Law Journal, 27*, 249–281(arguing that "even under an energized progression of social rights cases in international and domestic courts, rights relating to sport, recreation, leisure and play remain on the sidelines of human rights practice."). *See also* Stein, M.A. & Lord, J.E. (2007). Jacobus tenBroek, participatory justice and the UN Convention on the Rights of Persons with Disabilities. *Texas Journal of Civil Liberties and Civil Rights, 13*.

[65] *MDAC v Bulgaria*, Complaint No. 41/2007, European Committee of Social Rights, Decision of 3 June 2008.

[66] European Social Charter (revised), (ETS No. 163), *entered into force* January 7, 1999.

disability discrimination in violation of Article E of the Revised European Social Charter which protects against discrimination.

The complaint argued that nothing occurring inside the institutions constituted education for these children. The complaint averred that legislation guaranteeing the right to education for all children was not implemented in respect of these children residing in the social care institutions and referenced evidence to support their claim, including, for example, government data indicating that only 6.2% of children living in the relevant institutions were enrolled in schools. The complaint further stated that mainstream schools were not adapted to accommodate the needs of such children and that staff in those institutions were provided either no education at all, or inadequate education. The complaint also alleged that a lack of resources or the progressive realisation of rights could not, in this case, serve as a valid defence on the facts.

The European Committee found that there was a violation of Article 17(2) (right to education) as a stand-alone right and, when coupled with Article E (non-discrimination), a further violation grounded in disability discrimination. In particular, the Committee found that the children with disabilities in question were denied an effective right to education on account of disability discrimination.

With regard to the violation of the right to education, the European Committee found that, although the Bulgarian government had undertaken measures to respect the right to education for children with disabilities living in institutions, for example through legislation and action plans, those laws and policies had not been effectively implemented. They also found that there were inadequate standards for the right to education and equality of educational opportunities. Specifically, the Committee found that Bulgarian educational standards were inadequate because mainstream educational institutions and curricula were not accessible in practice as only 2.8% of children with intellectual disabilities residing in institutions were integrated in mainstream primary school. In addition, only 3.4% of the children attended special classes, which also indicated that special education was not accessible to children living in the institutions at issue. Finally, the Committee found that mainstream schools were not adapted to the specific needs of children with intellectual disabilities, teachers were not properly trained and resources were not developed to cater to the educational needs of children with disabilities. Moreover, due to the absence of primary educational opportunities, children with disabilities were ineligible to enter secondary education.

The European Committee rejected the claims of the Bulgarian government that there were inadequate resources to implement the right and determined that the government had failed to fulfil the three core criteria consistent with progressive realisation of rights, namely, (1) a reasonable timeframe, (2) measurable progress and (3) financing consistent with the maximum use of available resources. More particularly, the Committee noted the slow progress in implementation and the failure to undertake even the most basic measures, such as staff training or providing information on education requirements to institutions.

On the disability discrimination claim, the European Committee found that although disability is not explicitly listed as a prohibited ground of discrimination in Article E, it was indeed captured by the term "other status." Moreover, the Committee noted that the failure to take appropriate measures to take account of existing differences may also amount to discrimination. In that regard, the Committee articulated the principle that the obligation to provide evidence in support of the claims should be appropriately adjusted when it comes to matters of discrimination. Thus, given the evidence provided that showed the low percentage of children receiving an education in the institutions at issue, as compared to other children, the burden shifted to the government to refute such evidence. Finding no such evidence and no legal justification for the denial of access to education, the Committee determined that the disparity between the two groups of children was so great that it constituted discrimination against the children with disabilities.

Similarly, in another education complaint before the European Committee on Social Rights, *Autism Europe v France*,[67] the applicant, Autism Europe, asserted that France was failing to meet its obligation under, *inter alia*, Article 15(1) of the revised European Social Charter. This claim essentially alleged that children and adults with autism were not able to exercise the effective enjoyment of the right to education in mainstream school settings or in specialized educational institutions due to inadequate support. In other words, the school system was failing to accommodate their individual needs. The Committee found that France had failed to meet its obligations under the Charter insofar as it had failed to demonstrate that it was taking reasonable steps towards the fulfillment of Article 15 and other associated rights, including Article 17 (the right of children to social support) and Article E (equality).

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[67] *Autism Europe v France, supra* note 40.

The *MDAC v Bulgaria* case and the *Autism Europe v France* case reflect a progressive trend in recognizing and applying the right to an education for children with disabilities and, further, in animating the non-discrimination and equality provision of the Charter. Yet, the framework for non-discrimination and equality and reasonable accommodation in education in the CRPD offers additional tools for the European Committee on Social Rights (and indeed other treaty monitoring bodies) to draw upon in such cases. This is promising given the openness of the Committee to be guided by other standards and treaty body jurisprudence (e.g., General Comments on the ICESCR) in its work.[68] The level of detail provided on the right to education in the CRPD should be helpful in guiding the Committee in future cases involving the education of children and adults with disabilities.

Article 24 of the CRPD requires States Parties to ensure that persons with disabilities have access to an inclusive education system at all levels, as well as to lifelong learning opportunities, including to tertiary, vocational and adult education. Article 24 specifically requires States Parties to ensure the elimination of discrimination on the ground of disability from all aspects of education. Notably, it also requires States Parties to ensure that reasonable accommodation of impairment and disability related needs is provided at all levels of the education system. Reasonable accommodation is thus applicable to education both as a result of the general obligation of non-discrimination and equality in Article 5 and as an aspect of Article 24. Significantly, Article 24 requires States Parties to ensure that education is directed towards a number of fundamental goals, which include the development of human personality and potential, a sense of dignity and self-worth, respect for human rights, fundamental freedom and human diversity and effective participation in a free society. The provision has a strong thrust towards the provision of inclusive education and requires States Parties to provide the individualized services, such as individualized educational plans, and supports necessary to facilitate inclusion.

Finally, Article 24 addresses the learning and social development needs of children and young persons with sensory disabilities. In this particular context, States Parties are required to facilitate the learning

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[68] The European Social Rights Committee has a fairly strong record of looking to treaty body jurisprudence to guide its work. See, e.g., *MDAC v Bulgaria*, Complaint No. 41/2007, *supra* note 65 at para. 37 (citing the Committee on Economic, Social and Cultural Rights). *Id.*

of Braille and other alternative modes, means and formats of communication, and orientation and mobility skills and are required to facilitate peer support and mentoring to assist children and young persons with sensory disabilities to develop a positive self-image and social networks. Children who are deaf or deafblind must be provided with the opportunity to learn sign languages, and the linguistic identity of the deaf community must be promoted. Educational instruction must be delivered in the most appropriate languages and modes and means of communication for the child with sensory disability, and in environments that maximize their academic and social development. In order to realize these rights, States Parties are required to ensure that teachers are employed who are qualified in sign language and/or Braille, and to provide training to ensure that all staff working in the education system are sensitive to the needs of persons with disabilities, and are able to effectively use augmentative and alternative communication, and adapt and use educational techniques and materials appropriate for children with disabilities.

The detailed articulation of the right to education for children as well as adults with disabilities in the CRPD, inclusive of the duty to accommodate, provides a highly contextualized, disability-specific understanding of this right. As such, it would be surprising if Article 24 did not serve as a prominent guide for regional and international human rights procedures. Given that the facts in *MDAC v Bulgaria* and in *Autism v France* are, very unfortunately, not at all isolated instances of violations in the area of education for persons with disabilities, it is to be hoped that the Optional Protocols to the CRPD and ICESR serve as catalysts to action and advocacy.

The Duty to Accommodate Persons with Mental Disabilities

In *Purohit and Moore v The Gambia*,[69] mental health advocates witnessed the inhuman treatment of mental health patients in a hospital psychiatric unit. In their complaint to the African Commission on Human and Peoples' Rights on behalf of the mental health patients detained in the unit, the principal legislation governing mental health, the *Lunatics Detention Act of 1917*, was challenged. The complaint detailed that the Act contained no guidelines for making a determination and

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[69] *Purohit and Moore v The Gambia*, Communication No. 241/2001 (2003), AHRLR 96.

diagnosis of mental disability, there were no safeguards required during the diagnosis, certification or detention of the person, there was no requirement for consent to treatment, no independent examination of hospital conditions and no provision was made for legal aid or for compensation in the case of a rights violation. Finally, persons in the psychiatric unit were denied their right to vote.

The complaint also argued that the failure to include the provisions above resulted in a violation of Articles 2, 3, 5, 7(1)(a) and (c), 13(1), 16 and 18(4) of the African Charter on Human and Peoples' Rights.[70] The complainants argued that by ratifying the African Charter, a State undertakes the obligation to take immediate steps to align its domestic laws and practice with that required under the Charter and that The Gambia failed to do so in this case. The Act in question was adopted in 1917 and had not been amended since 1964, during which time extensive progress had been made in the understanding of human rights requirements. The complaint also argued that because the Act condemned any person declared a "lunatic" to automatic and indefinite detention, Articles 2 (non-discrimination) and 3 (equal protection) of the Charter were violated. Finally, because a person found to have a mental disability was detained indefinitely without due process, this also constituted discrimination on the ground of disability. The State responded that domestic remedies had not been exhausted and although no appeal procedure existed in the Act itself, a Constitutional complaint could have been brought to seek remedies and, further, that amendments were currently underway.

The Commission found that the type of remedy offered by the State was in reality only available to wealthy people and thus not an "available remedy" and ordered the Government to replace the Act with a new legislative scheme for mental health that was compatible with the African Charter on Human and Peoples' Rights, as well as more specific international standards for the protection of persons with disabilities. It noted that the rights to be free of cruel and degrading treatment, to liberty and security of person, to political participation as well as a showing of a legal basis for the detention and an opportunity for an appeal, were not adequately protected under the existing Act. The Commission also held that The Gambia failed to comply with

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[70] African (Banjul) Charter on Human and Peoples' Rights, (Adopted 27 June 1981, OAU Doc. CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982), entered into force 21 October 1986).

requirements of Articles 16 (best attainable standard of physical and mental health) and 18(4) (right to special measures for disabled persons with regards to moral and physical needs) and that States Parties were required to take concrete and targeted steps to ensure the right to health.

The African Commission, however, took it upon itself to read into Article 16 the obligation on the part of States Parties "to take concrete and targeted steps, while taking full advantage of their available resources, to ensure that the right to health is fully realised in all its aspects without discrimination of any kind."[71] This could be seen as an attempt to narrow the obligations of States to realize the right to health in relation to the duty to take immediate steps to progressively realize the right to health within maximum available resources under the ICESCR, to which The Gambia is also a party. The African Charter itself does not limit State obligations in this way.[72]

In *Purohit*, following a CRPD analysis, it could be argued that the failure to repeal or amend the *Lunatics Detention Ac*t itself was a denial of reasonable accommodation. The Act's provisions had the purpose and effect of creating barriers in many aspects of life for those deemed to fall under its purview, therefore the Act itself was discriminatory and, as a consequence, in violation of the CRPD. Also, the Act did not prevent the State from providing appropriate therapeutic and other supportive care, which could be interpreted as a failure to ensure substantive equality. The framework for determining when positive measures are required should be in a "comparison…not between those who are provided a benefit and those who are denied it, as in the traditional paradigm of under- inclusion…[r]ather it is between those who need a benefit in order to enjoy equality and those who do not."[73] Accordingly, it could be argued that The Gambia's failure to provide the appropriate adjustments in their legislation to ensure equality and human rights for persons with disabilities amounted to discrimination and a violation of Article 5 of the CRPD.

Secondly, the Act failed to reasonably accommodate persons with mental disabilities in terms of numerous substantive rights. The Act did not include a right to challenge a finding of mental disability and

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[71] *Purohit, supra* note 69 at para. 84.

[72] African Charter *supra* note 70.

[73] Porter, B. (1998). Beyond Andrews: Substantive equality and positive obligations after Eldridge and Vriend. *Constitutional Forum, 9*(2), 71–82, 78.

did not include the provision of legal aid to challenge this finding by other means such as a Constitutional challenge. Articles 12 and 13 of the CRPD affirm the legal recognition of persons with disabilities and the right to exercise legal capacity, as well as the support to do so through legal aid and procedural accommodations. Further, safeguards must be in place to ensure that any denial of legal capacity respects human rights and the will of the person, is proportional, and subject to review by a competent, independent body, among other criteria.[74] In this case, persons found to fall under the Act were subject to automatic detention and this would be a violation of Article 14 of the CRPD, which requires the detention be in compliance with international law, including the right to appeal and reasonable accommodation. Also, this policy of automatic detention would violate the right to live independently and be included in the community under Article 19.

The Act also failed to meet even the most basic standards with regard to the right to health. As the African Commission noted, there were no therapeutic objectives nor programs or resources allocated to realize the right to health for persons with mental disabilities.[75] Under the CRPD, the Committee would be able to find numerous violations of the right to health. State parties are required to "[p]rovide those health services needed by persons with disabilities because of their disabilities" and "provide care…on the basis of free and informed consent,"[76] neither of which were done in this case. Further, because this is an economic and social right, the State would have been required to show it had used maximum available resources to realize the highest attainable standard of health on a basis of non-discrimination.[77] The CRPD's recognition of reasonable accommodation for persons with mental disabilities combined with the right to health and other substantive rights would provide support for a more progressive interpretation of the duties of the State in this case. Explicit requirements of reasonable accommodation, non-discrimination and the immediate duty to take steps to progressively realize the right to health within maximum

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[74] Ibid., at art. 12(4).

[75] Communication No. 241/2001 (2003) at para 83.

[76] CRPD, *supra* note 1 at art. 25(b) and (d).

[77] Committee on Economic, Social and Cultural Rights, General Comment No. 14, *The Right to the Highest Attainable Standard of Health*, UN Doc. E/C.12/2000/4 (2000) at paras 30–32.

available resources would rebut watered-down interpretations of State obligations such as those that resulted in *Purohit*.

The Duty to Accommodate – Moving Forward

The foregoing case analysis suggests that the CRPD's substantive equality framework, including its reasonable accommodation concept, offers promise and indeed greater human rights protection for persons with disabilities than that which existed in general instruments of human rights law. Indeed, *Glor v Switzerland* is suggestive of this promise. In that case, decided by the ECtHR, the Court made major steps toward ensuring the human rights of persons with disabilities.[78] Swiss law requires all men to engage in military service or alternative civilian service.[79] Glor, a person with Type 1 diabetes, was declared unfit for military service by an army doctor and was then assigned to civil protection services, but he claimed that he was never called upon to perform his duties. Based on the Swiss tax code, all men not having a "major disability"(defined by domestic case law as meaning the individual's physical or mental integrity was affected by at least 40%) are subject to a service exemption tax of about 3% of net salary. Based on a medical examination, it was determined that Glor did not meet this 40% threshold and was subject to the exemption tax. Glor appealed the tax as he claimed he was always prepared to engage in military service and that he was the subject of discriminatory treatment.

The Court's decision recognized disability, for the first time, as a basis for discrimination under article 14 of the European Convention on Human Rights (ECHR).[80] The Court also detailed the numerous ways in which Switzerland could have provided reasonable accommodation (although this particular terminology was not invoked) for the complainant in light of his disability. The Court specifically explained that Switzerland could have been more responsive to Mr. Glor's individual circumstances, such as by assigning him to activities which required less physical effort.[81] Perhaps most importantly, the Court

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[78] *Glor v Switzerland,* European Court of Human Rights, Application No. 13444/04, 30 April 2009.

[79] Switzerland Const. art. 59 § 1.

[80] European Convention for the Protection of Human Rights and Fundamental Freedoms, Article 14, 213 U.N.T.S. 222, *entered into force* Sept. 3, 1953, *as amended by* Protocols Nos 3, 5, 8, and 11 *which entered into force* on 21 September 1970, 20 December 1971, 1 January 1990, and 1 November 1998 *respectively*.

[81] *Glor, supra* note 78 at paras. 91, 94 and 95.

cited the CRPD as the most contemporary understanding of the content of disability rights, to which it should look in interpreting the ECHR.[82]

The *Glor* case provides an example of how the CRPD can influence interpretation of the human rights of persons with disabilities, specifically the obligation of reasonable accommodation. The CRPD's integration of all human rights and its textual recognition of substantive equality through the duty of reasonable accommodation create a coherent framework for understanding and addressing discrimination against persons with disabilities. In the next section, this chapter will outline two mechanisms for adjudicating the duty of reasonable accommodation at the international level and how the understanding of the rights as defined under the CRPD can be effectively claimed by disability advocates.

III. The Optional Protocols under the CRPD and ICESCR

CRPD Optional Protocol Procedures

The Optional Protocol to the CRPD, adopted at the same time as the Convention itself and also entered into force on the same day, provides a mechanism for individual and group communications and an inquiry procedure. These present rich opportunities for developing the concept of reasonable accommodation in relation to CRPD rights and expanding disability rights claims.[83] The CRPD's communications and inquiry procedures are similar to other such procedures within the human rights system.[84] Interestingly, however, the drafters excluded inter-state communication procedures on the basis that such procedures are little used and thus would add little value to the Convention.[85]

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[82] Ibid., at para. 53.

[83] *See* CRPD Optional Protocol, *supra* note 2. As of this writing, there are 87 signatories and 47 ratifications to the CRPD Optional Protocol.

[84] See, e.g., Optional Protocol to the Convention on the Elimination of Discrimination against Women, G.A. res. 54/4, annex, 54 U.N. GAOR Supp. (No. 49) at 5, U.N. Doc. A/54/49 (Vol. I) (2000), *entered into force* Dec. 22, 2000 [hereinafter OP-CEDAW] and OP-ICESCR, *supra* note 3.

[85] Under the inter-state complaints procedure of the ICCPR, for example, a State must consent to the procedure before another State can launch such a complaint, rendering the procedure a particularly blunt one in practical terms. See, e.g., ICCPR, *supra* note 6, at art. 41(1) ("A State Party to the present Covenant may at any time declare

The CRPD's treaty monitoring body, the Committee of the Rights of Persons with Disabilities (the CRPD Committee), is empowered to review individual and group communications which allege violations of the Convention by participating States Parties. Communications may also be submitted *on behalf of* aggrieved individuals. This paves the way for disabled peoples organizations and, it is to be hoped, mainstream human rights groups, to take on disability rights claims under the CRPD.

Under the CRPD Optional Protocol, the admissibility of communications follows standard practice.[86] Thus, communications are inadmissible when they are submitted anonymously[87] or when the alleged events in question have occurred *prior* to and did not continue after, State Party ratification of the Optional Protocol.[88] Likewise, communications are rendered inadmissible: (1) when the "same matter" has been considered previously by the CRPD Committee; (2) when it is being reviewed simultaneously "under another procedure of international investigation or settlement;"[89] (3) where the complainant has failed to exhaust domestic remedies (unless these can be shown to be futile);[90] (5) where the communication is unfounded or unsubstantiated;[91] or (6) where it abuses the right to submit under, or conflicts with, the provisions of the CRPD.[92]

The Committee may, at any time after receiving a communication but before determining its merits, request a State Party to adopt sufficient interim measures "to avoid possible irreparable damage" to the

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under this article that it recognizes the competence of the Committee to receive and consider communications to the effect that a State Party claims that another State Party is not fulfilling its obligations under the present Covenant."). During the course of the CRPD negotiations, a study prepared by the Office of the High Commissioner for Human Rights found that inter-state communications had fallen into desuetude, with the only exception being their use in the European human rights system. See OHCHR *Expert paper on existing monitoring mechanisms, possible relevant improvements and possible innovations in monitoring mechanisms*, (submission to the 7th Session of the Ad Hoc Committee), UN Doc. A/AC.265/2006/CRP.4, at p. 14, para. 51, *online,* http://www.un.org/esa/socdev/enable/rights/ahc7docs/ahc7unedchrmonitor.doc.

[86] See, e.g., OP-CEDAW, *supra* note 84; OP-ICESCR, *supra* note 3 and the International Convention for the Protection of All Persons from Enforced Disappearance, E/CN.4/2005/WG.22/WP.1/Rev.4 (2005).

[87] ICCPR, *supra* note 6, at art 2(a).

[88] Ibid., at art. 2(f).

[89] Ibid., at art. 2(c).

[90] Ibid., at art. 2(d).

[91] Ibid., at art. 2(e).

[92] Ibid., at art. 2(b).

alleged victims of its actions;[93] such action does not, however, imply the ultimate admissibility or merits of the given communication.[94] The possibility of such precautionary measures is important and has been clearly demonstrated in a petition concerning the rights of persons with mental disabilities before the Inter-American Commission on Human Rights of the Organization of American States.[95] That case also illustrated the proactive role that can be played by certain monitoring bodies, with the Commission converting an original individual complaint to one that encompassed all individuals institutionalized in the State facility.[96] Given that the CRPD is authorized to hear group complaints[97] (as well as to make inquiries regarding systemic CRPD violations under the inquiry procedure[98]) it would follow that similar action would fall within its purview.[99] In addition, although the Ad Hoc Committee did not take up the suggestion of the Office of the High Commissioner for Human Rights for the inclusion of a specific provision allowing the Committee to address urgent situations through early warning measures, it is submitted that the Committee would be empowered to do so.[100]

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[93] Ibid., at art. 4(1).

[94] Ibid., at art. 4(2).

[95] In December 2003, in a landmark decision on a petition, the Inter-American Commission on Human Rights approved a petition for precautionary measures to protect the lives and physical integrity of people detained in a psychiatric institution in Paraguay and requested that the Government of Paraguay adopt all necessary measures to protect the lives, health, and the physical, mental and moral integrity of the 460 people detained in the institution, with special attention to the situation of women and children. *See Precautionary measures granted or extended by the Commission during 2003: Paraguay, on behalf of the patients of the Hospital Neurosiquiátrico (Neuro-psychiatric Hospital), in* ANNUAL REPORT OF THE INTER-AMERICAN COMMISSION ON HUMAN RIGHTS 2003, OEA/Ser./L/V/II.118, doc. 25., rev. 2 (2001), ch. III.C, para. 60.

[96] Ibid.

[97] CRPD Optional Protocol, *supra* note 2, at art. 1(1).

[98] Ibid., at art. 6.

[99] For example, in *International Association Autism – Europe (IAAE) v France*, 3 CoE. 12 (10 March 2004), the European Committee on Social Rights engaged in a far-reaching investigation of the extent to which children with autism were mainstreamed into France's school system.

[100] See, e.g., OHCHR Expert Paper, *supra* note 85, p. 15, para. 55. CERD developed early warning and urgent action measures in 1993, which may be invoked by the Committee or interested parties. See CERD, *Working Paper on Prevention of Racial Discrimination, including Early Warning and Urgent Action* Procedures, A/48/18, annex III online, http://www2.ohchr.org/english/bodies/cerd/docs/A_48_18_Annex_III_English.pdf (visited November 12, 2010).

States Parties are to be confidentially apprised of admissible communications by the CRPD Committee, and are required to respond in writing thereto with explanations or clarifying statements within six months.[101] The Committee will consider communications in closed meetings, and transmit any suggestions or recommendations to both the concerned State Party and the petitioner.[102] Thus, as with other communication procedures, communications under the Optional Protocol are confidential and recommendations issued in relation to communications are not enforceable. Nonetheless, it will be within the power of the CRPD Committee to craft follow-up procedures to fortify the recommendatory nature of its findings.

The Optional Protocol to the CRPD includes an inquiry procedure,[103] similar to those employed by other human rights monitoring mechanisms, to allow the initiation of investigations, particularly regarding egregious or systematic human rights violations.[104] A procedure of inquiry is triggered in cases where the Committee receives "reliable" information relating to "grave or systematic violations" of Convention obligations by a State Party.[105] In such cases, the CRPD Committee must call on that State Party to collaborate in an investigation of the information and submit its observations.[106] Thereafter, the Committee reviews the information submitted by the State Party and reliable information submitted by other parties.[107]

The Committee may choose to authorize one or more of its members to conduct an inquiry and report "urgently" to the Committee.[108] Such an inquiry may include a visit to the territory of the State Party subject to consent of the State Party (consent being a standard principle of international legal process). The findings of the inquiry are sent to the State Party, along with Committee "comments and

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[101] CRPD, *supra* note 1, at art. 3.

[102] Ibid., at art. 5.

[103] CRPD Optional Protocol, *supra* note 2, at art. 6.

[104] See, e.g., *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment,* G.A. res. 39/46, [annex, 39 U.N. GAOR Supp. (No. 51) at 197, U.N. Doc. A/39/51 (1984)], *entered into force* June 26, 1987 at art. 20 [hereinafter CAT]; *See also* the Charter-based 1503 http://www2.ohchr.org/english/bodies/chr/complaints.htm communications procedure, now administered under the Human Rights Council pursuant to HR Council Res. 5/1, UN Human Rights Council: Institution Building, 18 June 2007.

[105] CRPD Optional Protocol, *supra* note 2, at art. 6.

[106] Ibid., at art. 6(1).

[107] Ibid., at art. 6(2).

[108] Ibid., at art. 6(2).

recommendations."[109] The State Party is given an opportunity to respond within six months.[110] As with other inquiry mechanisms, the procedure is confidential and is thus closed to the public; written findings are similarly not made public.[111] The Committee may follow-up with the State Party after six months and invite the State to indicate what measures it assumed in reply to the inquiry.[112] In addition, the Committee may solicit the State Party to include details of these measures in its regular reporting cycle.[113]

ICESCR Optional Protocol Procedures

On December 10th, 2008, on the 60th Anniversary of the Universal Declaration of Human Rights, the United Nations adopted the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights (OP-ICESCR).[114] The adoption of this Optional Protocol represents historic progress in the full realization of all human rights by providing an opportunity for redress for economic, social and cultural rights, four decades after the adoption of the Optional Protocol to the ICCPR. The human rights contained in the ICESCR have been historically marginalized and the previous High Commissioner on Human Rights, Louise Arbour, noted that the adoption of the OP-ICESCR represents "human rights made whole," by reuniting the rights originally enshrined in the Universal Declaration of Human Rights and by providing the opportunity for redress for violations of human rights "typically linked to poverty, discrimination, and neglect that victims frequently endure in silence and helplessness."[115] Therefore, the new opportunity for an effective remedy provided by the OP-ICESCR is critical in ensuring all human rights of persons with disabilities are addressed and it provides an alternative forum for raising ESC rights violations of disabled persons. As jurisprudence develops under the OP-ICESCR, it must be flexible enough to meet the particular needs of groups and individuals who have experienced violations of ESC

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[109] Ibid., at art. 6(3).

[110] Ibid., at art. 6(4).

[111] Ibid., at art. 6(5).

[112] Ibid., at art. 7(2).

[113] Ibid., at art. 7(1); CRPD, *supra* note 1, at art. 35.

[114] OP-ICESCR, *supra* note 3.

[115] Arbour, L. (8 July 2008). Human rights made whole. *Policy Innovations,* online, http://www.policyinnovations.org/ideas/commentary/data/000068/:pf_printable (visited November 21, 2010).

rights in order to ensure it serves more than a merely formal mechanism for complaint, but it also must offer effective and appropriate remedies and therefore serves as a forum to seek substantive equality.[116]

Like the OP-CRPD, the OP-ICESCR provides for both individual and group communications, as well as inquiry procedures initiated by the Committee, and it generally follows those procedures developed under other, similar mechanisms.[117] In contrast to the OP-CRPD, the OP-ICESCR retains the inter-state inquiry procedure, allowing for the greatest range of possible complaints.[118] The admissibility requirements under the OP-ICESCR closely match those enumerated under the OP-CRPD[119] and the request for interim measures.[120] The process for examining a communication[121] also mirrors those under the OP-CRPD, detailed above.

The OP-ICESCR contains three unique provisions not found in other international treaties. The first is in article 4, which gives the Committee discretionary authority in exceptional circumstances to decline to consider a communication that "does not reveal the author has suffered a clear disadvantage."[122] There is little guidance from the *travaux preparatoires* of the Working Group on the OP-ICESCR on how this article should be applied and it is still unclear how the ESCR Committee will interpret this provision.[123] Another distinctive provision contained in the OP-ICESCR is contained in article 7, which allows for the offices of the Committee to be used for the negotiation of a friendly settlement, "on the basis of respect for the obligations set forth in the Covenant" and an agreement "closes consideration of the communication" by the Committee.[124] The civil society response to this addition has generally been favorable. It is seen as increasing the possibility of more fully addressing the systemic roots of the issue which gave rise to the case; however, there is an equally keen awareness of the need to address

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[116] Porter, *supra* note 31, at 41.

[117] See, e.g., OP-CEDAW, *supra* note 84.

[118] OP-ICESCR, *supra* note 3 at art. 10.

[119] Ibid., at art. 3.

[120] Ibid., at art. 5.

[121] Ibid., at art. 8.

[122] Ibid., at art. 4.

[123] *See,* International NGO Coalition for an Optional Protocol to the International Covenant on Economic, Social and Cultural Rights, *Considerations of the International NGO Coalition for an Optional Protocol to the International Covenant on Economic, Social and Cultural Rights in relation to the OP-ICESCR and its Rules of Procedure* (Sept. 2009) at 12.

[124] OP-ICESCR, *supra* note 3 at art. 7.

inequality of arms (an imbalance of power between a complainant and the responding State) and to maintain continuous follow up on the implementation of agreements.[125]

The third unique provision, which will be of particular importance for emerging jurisprudence under both the OP-CRPD and the OP-ICESCR, is Article 8(4) of the OP-ICESCR. This provision integrates a "reasonableness" standard of review, allowing the ESCR Committee to assess whether steps have been taken by the State to use maximum available resources in conjunction with Article 2(1) of the Covenant.[126] This standard of review reveals the compatibility of approaches under both the CRPD and the ICESCR in assessing the positive measures that must be undertaken in particular circumstances to ensure reasonable accommodation.

Standards of reasonableness under the OP-ICESCR must also be allowed to interact with the emerging standards of reasonableness elsewhere, such as under the new CRPD and its Optional Protocol. Reasonable accommodation for persons with disabilities is a very contextual and individualized approach to reasonableness review, which may provide a useful framework to ensure reasonableness review of rights claims under the OP-ICESCR is also framed around individual dignity and equality, and should thus not be confused with abstract policy review disconnected from rights claiming.[127]

Buttressing Reasonable Accommodation Duties and Disability Rights Advocacy under the Optional Protocols

The two Optional Protocols are likely to buttress the path-breaking work of disability rights advocates in pressing disability rights claims in regional and international human rights procedures. Ideally, the procedures offered in the Optional Protocols may well open up advocacy in relation to some of the most marginalized members of the disability community. The CRPD inquiry procedure, for example, has the potential to advance the major work of disability rights organizations that have exposed, particularly through monitoring and reporting practices, egregious abuses against children and adults with disabilities in institutions which are too often shielded from public

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[125] See NGO Coalition, *supra* note 123 at 12.
[126] OP-ICESCR, *supra* note 3, at art 8.
[127] Porter, *supra* note 31, 52.

scrutiny.[128] One might well imagine, for example, an inquiry concerning the institutionalization of persons with disabilities in abusive and squalid conditions and absence of community living arrangements, systematic exclusion of disabled children from schools, or the widespread failure to accommodate persons with disabilities in health prevention programs, such as HIV/AIDS education outreach or child immunization programs. The concept of reasonable accommodation, made applicable across the CRPD, can in such cases serve as an additional device with which advocates can press not only for the cessation of abuse, but for accommodations required in respect of Article 19 (living independently and in the community), Article 24 (education), Article 25 (health) and Article 28 (adequate standard or living), among others. Moreover, the Protocols can serve to protect not only persons with disabilities, but also those associated with disabled persons. The CRPD prohibits discrimination against "any person" on the basis of disability, thereby opening the door to claims not only by persons with disabilities themselves, but by those who have been discriminated against because of a mistaken assumption of disability, or due to their association with a disabled person.[129]

The OP-ICESCR should also be viewed as a viable forum for the submission of claims of violations of economic, social and cultural rights of persons with disabilities. Persons with disabilities around the world experience such violations of their economic, social and cultural rights, including violations to their right to adequate housing, food, water and sanitation, health, work and education. Discrimination and failure to accommodate for the needs of disabled persons in accessing public services, such as health, education or food distribution systems, are only a few examples of the unique and disproportionate impact such violations of economic, social and cultural rights can have on persons with disabilities. In many countries, many or all economic, social and cultural rights are not recognized or enforceable by law, leaving people with little hope of an effective remedy.

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[128] See, e.g., Mental Disability Rights International, *Human Rights & Mental Health: Mexico* (2000), *Children in Russia's Institutions: Human Rights and Opportunities for Reform* (1999), *Human Rights & Mental Health: Hungary* (1997); (2003); *Human Rights & Mental Health: Uruguay* (1995); Amnesty International Press Release, *Bulgaria: Disabled Women condemned to "Slow Death"*, AI Index: EUR 15/002/2001; Mental Disability Advocacy Center, *Liberty Denied: Mental Disability Detention in Hungary* (2003).

[129] Lord & Stein, *supra* note 8, 6–7.

In addition to the normative framework that the ICESCR provides for claiming ESC rights generally, the adoption of General Comment 5 by the Committee on Economic, Social and Cultural Rights of General Comment 5, as noted above, allows for greater understanding of the particular impacts that a lack of ESC rights have on persons with disabilities. The Committee's embrace of reasonable accommodation[130] and the explicit recognition and full elaboration of the concept in the CRPD – intended by the drafters to clarify the human rights obligations already set forth in the two Covenants through disability specific contextualization – provide tools through which ESC rights can be advanced and made meaningful.

Conclusion

The CRPD, in expressing for the first time in a legally binding human rights instrument the requirement that reasonable accommodation be accorded to persons with disabilities in the actualization of their rights, firmly situates disability rights within a progressive substantive equality rights framework. In so doing, it challenges outmoded characterizations about disability issues as belonging to medical or charitable spheres of action and thus grounded in paternalistic, welfare-oriented claims of beneficence. It offers opportunities not only for disability rights advocates to press their claims in human rights terms by invoking reasonable accommodation duties in respect of civil, political, economic, social and cultural rights, but potentially carves out new space for advocacy in other parts of the human rights movement. For example, the CRPD's non-discrimination and reasonable accommodation framework can animate HIV/AIDS discrimination claims, advance economic, social and cultural rights advocacy (in particular sidelined rights such as the right to sport, recreation and play) and potentially press forward the rights of other marginalized groups, such as religious minorities.[131]

The new procedural mechanisms offered up by the CRPD's Optional Protocol and the new ICESCR Optional Protocol, in addition to the 1995 Additional Collective Complaints Protocol to the *European Social*

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[130] CESCR, General Comment 5, *supra* note 17.

[131] Anna Lawson has usefully pointed to the historical connection between the development of reasonable accommodation and religious minority protection. Lawson, *supra* note 10, 5.

Charter provide fertile ground for fully elaborating the reasonable accommodation duty. In addition, the CRPD offers opportunities for regional human rights systems in Europe, Africa and the Americas to augment their consideration of disability rights cases under the existing regional human rights treaties. It is to be hoped that the international administrative tribunals of international organizations, such as the World Bank Administrative Tribunal or the Administrative Tribunal of the ILO, will likewise use the tools of the CRPD in their settlement of disability rights claims between management and staff members. Finally, as an impetus for domestic level change, the CRPD stands to usher in an unprecedented level of human rights reform in law, policy and practice.

LEGAL PROTECTION OF PERSONS WITH DISABILITIES IN KENYA: HUMAN RIGHTS IMPERATIVES

Kithure Kindiki

To treat unequals identically would be as unjust
as to treat equals differently.[1]

Part A: Law and the Challenge of Human Rights

1. *Disability and the Philosophical Underpinnings of Human Rights*

This chapter examines the normative framework for the protection of persons with disabilities in Kenya. Using human rights as the lens for analysis, the chapter pinpoints the deficiencies in the existing law and policies and proffers necessary legal, policy and institutional reforms and their justification. The chapter also draws inspiration from the international legal regime governing the rights of persons with disabilities and the emerging practice at the African regional level.

In ensuring the protection of persons with disabilities within any socio-cultural context, the near-universalistic imperatives are that persons with disabilities ought to be treated with equality and human dignity. Moreover, affirmative action, differential treatment, equalization of opportunities, resource allocation and rehabilitative programmes and measures, buttress this protection.[2]

Human rights mean the entitlements or moral powers possessed by all persons by virtue of their humanity and human dignity irrespective of age, gender, sex, race, ethnicity, colour creed or other similar immutable characteristics. The rationale for equal treatment sprouts

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[1] Bayefsky, A.F. (1987). Defining equality rights under the charter. In S.L. Martin & K.E. Mahoney (Eds.), *Equality and judicial neutrality*. Toronto: Carswell.

[2] Ibid., 7. The writer notes that disability is a development issue. This means that until disabled people are involved in national development, their needs and aspirations will continue to be neglected. More often than not, they are not involved in policy-making, in the deliberations on the national development plan, and many other issues.

from the nature and character of human rights, including: universality, inalienability and indivisibility.[3]

Mental, physical or sensory impairments experienced that persons with disabilities have coupled with the consequential effects of these impairments cumulatively constitute a "silent crisis" which affects not only those who live with disabilities and their families, but also the economic and social development of entire societies, where a significant reservoir of human potential in people often remains untapped.

From its early days, the United Nations (UN) sought to advance the status of persons with disabilities and to improve their lives. The concern of the UN is rooted in its founding principles, which are based on human rights, fundamental freedoms and equality of all human beings as affirmed by the UN Charter, the Universal Declaration of Human Rights (UDHR),[4] the International Covenant on Civil and Political Rights (ICCPR)[5] and the International Covenant on Economic Social and Cultural Rights (ICESCR).[6] These instruments emphasize that all persons, including the disabled, are entitled to exercise their civil, political, social and cultural rights on an equal basis with "ordinary" people.

The UN General Assembly has defined a person with disability as one who is:

> [u]nable to ensure by himself or herself, wholly or partly, the necessities of a normal human individual and/or social life, as a result of a deficiency, either congenital or not, in his or her physical or mental capabilities.[7]

Perceiving disability as a condition similar to illness and exclusively as a functional limitation, implies that disability is considered as an individual problem rather than a societal problem, and that solutions are searched in the individual sphere, through therapy and technical or personal support.[8]

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[3] The Vienna Declaration and Programme of Action, UN Doc. A/CONF. 157/23 para 5.

[4] UN General Assembly Resolution 217(III) of 10 December 1948.

[5] Adopted on 16 December 1966, entry into force 3 January 1976.

[6] Adopted on 16 December 1966, entry into force 3 January 1976.

[7] Resolution No. 3447 (XXX) Declaration of Persons with Disabilities of 9 December 1975. See also Resolution 2856 (XXVI) Declaration on the Rights of Mentally Retarded Persons of 20 December 1971.

[8] Degener, T. & Y. Koster-Dreese. (1995). *Human rights and persons with disabilities: Essays and relevant human rights instruments*. Dordrecht: Martinus Nijhoff Publishers, 13.

The statistics on, and conditions of, persons with disability in the world and in Kenya, in particular, paint a grim picture about their status and welfare. According to the 1999 census carried out by the Ministry of Planning and National Development, out of the Kenyan population of 28 million people, 5 million were persons with disabilities. Thus, they comprise a substantial and cognizable part of the total Kenyan population. In the United States of America (US), the Census Bureau estimates at the end of 1994 indicated that an approximated 54 million Americans had some type of disability; 26 million, a severe disability.[9]

The plight of persons with disabilities calls for a special policy and legal regime that assures them of the enjoyment of basic human rights. Such rights range from fundamental freedoms, dignity and worth of the human person, to the right to social and economic advancement.

A two-pronged approach to alleviate the disadvantages faced by persons with disabilities would, thus, emphasize prevention of disability on the one hand and the welfare and equalization of opportunities for the physically and mentally disadvantaged on the other. Several countries including Kenya have established separate structures to enforce the rights of disabled people. As shall be seen shortly, Kenya has a special legal framework for the protection of disabled people, isolated provisions in the Constitution and other references in a handful of statutes.

2. *A New Approach in Legislation and Policy on Disability*

In the last few years, the approach to disability legislation has altered considerably. Seto and Buhal have documented the different phases of the disability theory in the US. They classify the paradigms into four epochs: the affliction paradigm; the medical/charity paradigm; the civil rights paradigm; and the emergence of a variation paradigm. Concerning the affliction paradigm, they note that:

> Until that late nineteenth or early twentieth century, Americans commonly viewed disability as a punishment or test imposed by God. God in His mysterious wisdom, had afflicted someone with this peculiar burden, and they were supposed to bear it with patience and faith…Disabilities were the external expression of an individual's sinfulness and moral impurity. Disability was brought by sin.[10]

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[9] Seto, T.P. & S. Buhai. (2006). Tax and disability: Ability to pay and the taxation difference. *University of Pennsylvania Law Review, 154*(5), 1053–1146, 1055.

[10] Ibid., 1058.

The affliction epoch paved way to the medical/charity paradigm, which viewed persons with disabilities "as objects of pity, philanthropy, and paternalistic rehabilitation."[11] They were to be sympathized with and, if possible, were to receive monetary donations from well-wishers. That paradigm gave way in the 1970s to the civil rights paradigm, which asserted that disability, like race, was in significant part a social construct – a series of decisions by society to make disability matter. Under the civil rights model, people with disabilities were not necessarily different from anyone else in any way that ought to matter. Instead, society had constructed a world that made disabilities unnecessarily relevant. The disability was not the barrier; the stairs were the barrier because they had been built as the result of a societal decision to favor use of stairs over ramps – to favor those who walked over those using wheelchairs.[12] While the social model based its support for equal treatment on social justice requirements, the civil rights paradigm was hinged on the human rights ideals, arguing that all human beings irrespective of any immutable characteristic (including disability) possessed inalienable, inherent entitlements at law to be treated equally with others.

The world is currently discerning an emerging "variation" paradigm, which believes that equality is not enough. Persons with disabilities, the emerging school argues, still face a lot of difficulties. For instance, there are particular jobs that they may not be able to perform due to their disabilities. Indeed, some may never get to work due to many factors including the attitude shown to them. This is the "human variation" model which views persons with disabilities as the consequence of social institutions, having been constructed to deal with a narrower range of variation than is in fact present in any given population, thus those individuals whose mobility, communication, medical needs, or cognition differs from social norms find themselves confronting institutions not well suited to their abilities and potential.[13]

Currently, the prevailing position lays emphasis on persons with disabilities managing their own affairs. In this regard, for example, the *Zimbabwe Persons with Disability Act* (1992) provides for a National Disability Board comprising not more than 20 persons. Of these, 10 (half) are appointed by the relevant minister from a "panel of names

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[11] Ibid.

[12] Ibid., 1062.

[13] Ibid., 1071, 1072.

submitted to him by organizations or associations which he considers to represent disabled people." In the United Kingdom (UK) the *Disability Rights Commission Act* (1999) established the UK Disability Rights Commission whose ¾ majority comprises persons with disabilities or their representatives. The same approach can be discerned in the *Americans with Disabilities Act* (1992).[14]

A marked deviation in policy is notable in the equalization of opportunities for persons with disabilities. Even here, there has been a departure in the recent past from a "charity" oriented approach to a "rights" approach. Persons with disabilities are entitled, as of right, to most of the services that were hitherto treated as gifts of charity to them. This in turn has created correlative duties for them and "as disabled people achieve equal rights, they should also have equal obligations."[15] With the increased respect of the personal integrity and human rights of disabled people, so also is a heightening in the expectations of society from disabled people. This is a major departure from the tone and scope of earlier legislation and policy such as the *Rehabilitation Act* (1973, US). The new approach to legislation and policy reflect more rational thinking that gives better meaning to the cause of disabled people.

3. *International and Regional Normative Developments Applicable to Kenya*

This section summarizes landmark international and regional (African) norm-seeking relevant to persons with disabilities. In 1971, the General Assembly adopted the *Declaration on the Rights of Mentally Retarded Persons* proclaimed through General Assembly Resolution 2856 of 20th December 1971. This Declaration stipulates that mentally retarded persons are to be accorded the same rights as other human beings, as well as specific rights corresponding to their needs in the medical, educational and social fields. Emphasis was put on the need to protect disabled people from exploitation and provide them with proper legal procedures.

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[14] Kimondo, K. & Kibwana, K. (1997). Rehabilitation and equalization of opportunities for the disabled: A study of the policy and legislative framework in Kenya. In S. Wanjala & K. Kibwana (Eds.), *Democratization and law reform in Kenya*. Nairobi: Claripress.

[15] General Assembly, United Nations. (1982). *World Programme of Action Concerning Disabled People*, Gen. Res. 37/52, online: http://www.un.org/disabilities/default.asp?id=23 (visited December 5, 2010).

Four years later, in 1975, the General Assembly struck a normative blow for persons with disabilities by adopting the *Declaration on the Rights of Persons with Disabilities,*[16] which proclaims the equal civil and political rights of disabled people. This Declaration sets the standard for equal treatment and access to services, which help to develop capabilities of disabled people and accelerate their social integration.

The following year (in 1976), the General Assembly proclaimed 1981 as the International Year of Disabled People (IYDP). It called for a plan of action at the national, regional and international levels, with an emphasis on equalization of opportunities, rehabilitation and prevention of disabilities. This way, the World Programme of Action concerning Persons with Disability came to be adopted by the General Assembly in December 1982.[17] In order to provide a timeframe during which governments and organizations could implement the activities recommended in the World Programme of Action, the General Assembly proclaimed 1983–1992 the United Nations Decade of Disabled People.

Adopted by General Resolution 46/119 of December 1991, the *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Healthcare* are to be applied "without discrimination of any kind such as on grounds of race, colour, sex, language, age, social status, property or birth." Among the provisions are a set of fundamental rights which accrue to persons with disabilities, including the right to health and social care systems; the right to be treated with dignity and respect; the right of protection from all forms of exploitation, economic, physical, sexual or other abuse and degrading treatment; the right of protection from discrimination on grounds of mental illness; and the right to civil and political rights as enshrined in the UDHR and other human rights instruments such as the ICCPR and the ICESCR.

On December 20, 1993, the UN General Assembly at its 48th Session, and by General Resolution 48/96, adopted the *Standard Rules on the Equalization of Opportunities for Disabled People* (Rules).[18] The Rules

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[16] General Assembly Resolution 3447 (XXX).

[17] *Supra*, note 15.

[18] United Nations General Assembly. (1993). *Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Gen. Res.* 48/96, online: http://www.un.org/esa/socdev/enable/rights/wgrefa3.htm (visited December 5, 2010).

mark meaningful progress towards a general convention on the rights of persons with disabilities or, at the very least, a breeding ground for development of international customary law. They mark the end of a preliminary process of standard setting on human rights and disability within the UN's human rights division.

The Rules go beyond mere declaration of rights by calling for a strong moral and political commitment by states to equalization of opportunities for persons with disabilities. The Rules further identify areas of co-operation among states, especially in economic and technical areas, co-operation with the UN and other organizations, and provide a detailed policy-making framework for states and other organizations.

An interesting concept in the Rules is the setting out of obligations for disabled people. The Rules emphasize that equal rights for disabled people must carry the correlative duties: "those rights are being achieved … societies should raise their expectations of disabled people." This in turn calls for enhanced efforts to assist disabled people to assume their full responsibilities as members of society.

In a broad summary, the Rules address awareness-raising strategies, better medical care, rehabilitation and creation of support services. The Rules then target certain keys areas where equal opportunities are called for. These include accessibility to the physical environment and communication, education, employment, social security, culture, family life, religion, recreation and personal integrity.

The most important feature of the Rules is a detailed implementation section calling for information and research, the need for states to take into account disability in policy-making and planning, responsibility to legislate for rights of disabled people and an obligation to ensure adequate training of personnel at all levels involved in disabled people's programmes. The Rules emphasize the need for international co-operation, national monitoring and evaluation of disability and the importance of organizations of disabled people.

A monitoring mechanism is envisaged with a special rapporteur to be appointed for a three year period to monitor implementation of the Rules and to review, advise and provide feedback to the relevant UN agency. A Voluntary Fund on Disability is envisaged to which member states are encouraged to contribute for purposes of further and better implementation of the Rules.

However, the Rules are not compulsory but imply a strong moral and political commitment on behalf of states to take action. In addition, they provide a basis for technical and economic cooperation among States, the UN and other international organizations.

Finally, the UN in 2007 adopted the *Convention on the Rights of Persons with Disabilities* (Convention) to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by disabled people and to promote respect for their inherent dignity. The governing principles of the Convention, provided for under article 3, include respect for inherent dignity, non-discrimination, full and effective participation, respect for difference and acceptance of disability as part of human diversity and humanity, equality of opportunity, accessibility and equality. It is imperative that these principles be implemented at the international and national levels.

The difference between the Rules and the Convention lies in the legal character of the instruments. Unlike a Convention, the Rules are non-legally binding because they cannot be signed and ratified by member states. However, they can attain binding character as international customary rules when they are applied by a great number of states with the intention of respecting a rule in international law. But until then they only serve as a strong moral commitment on behalf of states to take action for the equalization of opportunities.

4. *The Protection of the Rights of Persons with Disabilities at the Regional (African) Level*

The political outfit that hosts the African regional human rights system is the African Union (AU). The AU has enacted a number of treaties aimed at protecting the various entitlements guaranteed at the international level and even certain novel ones. The main human rights treaty is the *African Charter on Human and Peoples' Rights* (African Charter)[19] which stipulates such rights as equality[20] and non-discrimination,[21] both critical to the protection of persons with disabilities. The African Charter has a specific provision addressing disability at article 18(4). To monitor the implementation of this human rights treaty, the African Commission on Human and Peoples' Rights (the African Commission) is established. Recently, a Protocol to the African Charter has entered into force to further secure the implementation of the

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[19] Adopted by the Assembly of Heads of State and Government of the Organisation of African Unity in Nairobi, Kenya, on 17 June 1981, entered into force on 21 October 1986.

[20] Ibid., Article 2.

[21] Ibid., Article 3.

African Charter. The African Commission has had occasion to adjudicate on disability issues.

The Commission's decision in *Purohit and Another v The Gambia*[22] represents three cardinal aspects of disability that are of relevance to the current study. Firstly, the decision illustrates that a human rights approach to the plight of the persons with disabilities is often all encompassing. Secondly, it demonstrates that human rights for all persons are interrelated, interconnected and indivisible. Put another way, human rights are one inviolable whole. In this respect, the right to dignity is the common denominator around which all other fundamental rights hinge. Thirdly, the decision accentuates the fact that most domestic jurisdictions in Africa fall way behind their international obligations. It does, therefore, illustrate the significance of the international plane as the ideal norm-setting scene.

In the instant communication, the complainant alleged that the respondent State, The Gambia, had violated various internationally accepted entitlements relating to persons with mental disabilities. The principle entitlements allegedly violated by the State included the right to equality, non-discrimination and, most importantly, the right to human dignity. The complainants decried the *Lunatics Detention Act* (LDA), legislation that, according to the evidence adduced before the African Commission, allowed the detention of the cognitive disabled without their cause being heard. Certificates issued by two medical practitioners, it was adduced, were sufficient to send the cognitive disabled to detention. There was no appeal to the certifications issued by medical practitioners under the LDA. Such detained people were not allowed to vote; the reason given by the State being that they were of unsound mind. The right to health of these unfortunate detainees were equally not up to the required international standards. As regards the right to equality and non-discrimination, the African Commission held as follows:

> Clearly the situation presented above fails to meet the standards of anti-discrimination and equal protection of the law as laid down under the provisions of articles 2 and 3 of the African Charter and principle 1(4) of the United Nations Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Illness and the Improvement of Mental Health Care.[23]

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[22] *Purohit and Another v The Gambia* (2003) AHRLR 96 (ACHPR 2003).

[23] Ibid., para 54.

The Commission also found that the LDA violated article 5 of the African Charter pertaining to human dignity stating that:

> Human dignity is an inherent basic right to which all human beings, regardless of their mental capabilities or disabilities as the case may be, are entitled to without discrimination. It is therefore an inherent right which every human being is obliged to respect by all means possible and on the other hand it confers a duty on every human being to respect this right.[24]

In the end, the Commission held the Republic of The Gambia in violation of articles 2 (right to equal treatment); 3 (right to non-discrimination); 5 (right to dignity); 7(1)(a) and (c) (right to have one's cause heard); 13(1) (right to participate in governance); 16 (right to the best attainable state of physical and mental health); and 18(4) (rights of the disabled) of the African Charter. In reaching this decision, the quasi-judicial tribunal also made certain pronouncements that are pertinent to the protection of the rights of disabled people. For instance, it decried the use of derogatory terminologies referring to the cognitive disabled, stating that such terminologies violate the right to dignity, a very interesting observation. The tribunal lamented that under the LDA, persons with mental illness had been branded "lunatics" and "idiots," terms which, without doubt, dehumanized and denied them dignity, in contravention of article 5 of the African Charter.[25]

Inspiration was drawn from the United Nation's *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Illness and the Improvement of Mental Health Care* and hence enriched the African regional jurisprudence. What is even more encouraging about this decision is the fact that only one stipulation of the African Charter (article 18(4)) has express mention of persons with disabilities and yet the African Commission interpreted the text so purposefully as to accommodate all the other rights enshrined by the regional testament. Of fundamental significance is how the equality and dignity provisions were employed innovatively. There is no evidence as yet that the jurisprudence in this 2003 decision has trickled down to Kenya, or any other African state for that matter. Moreover, it is instructive that decisions of the African Commission are not binding even to the concerned state although they have the weight of persuasiveness.

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[24] Ibid., para 57.

[25] Ibid., para 59.

PART B: THE KENYAN LEGAL FRAMEWORK

5. *International Law and Domestic Law*

The application of international norms on the domestic front has been the subject of protracted debates. Two schools of thought have emerged to explain the relationship between international norms and domestic law. One school of thought – monism – holds that international law and domestic law are simultaneous and that norms enacted on the international plane in fact apply to domestic jurisdictions automatically without the engagement of any additional processes. Consequently, this school of thought opines that a judge acting in the domestic court is bound by international law so long as that law is ratified by the state in question. Though not always, the Constitution of the US typifies this scenario given that in the US, once international law is ratified by the state, it applies automatically even on the domestic domain.

The dualists, on the other hand, hold that laws enacted on the international plane are not applicable on the domestic plane unless such laws have been downloaded through a process of domestication. A judge acting on the domestic plane may, therefore, decline to apply international law unless he is aware of a legislative enactment domesticating such international law (the technical term for bringing international law into national law in dualist countries is "transformation"). This is the position in the United Kingdom and, indeed, most commonwealth jurisdictions. Kenya is one such jurisdiction where international laws have to undergo a process of transformation before applying on the domestic front. The position in Kenya was asserted by the decision in the case of *Okunda v Republic*[26] where a superior court of record stated that international norms remain illusions unless they have been domesticated.

6. *The Rights of Persons with Disabilities in Kenya's Legal System*

6(i) *The Bill of Rights in the Constitution of Kenya*

The Kenyan Constitution, the supreme law of the land, gives every person, irrespective of colour, sex, creed or origin, fundamental rights and

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[26] *Okunda v Republic* (1970) EA 453.

freedoms. All rights in the Bill of Rights (Chapter V) are enforceable in the High Court under section 84 of the Constitution. Section 82 of the supreme law expressly states that discrimination of any kind shall not be permitted although it permits "fair discrimination" in cases, for instance, of persons with disabilities. Such vulnerable people may, thus, justifiably receive an advantage over and above an ordinary person without it being described as discrimination.

From a positive point of view, the Kenyan Constitution intended to give equal rights to all Kenyans. This is clear from other provisions in the Constitution that specifically allude to disability. Section 34, for example, provides that:

> …a person shall be qualified to be elected as a member of the National Assembly…if at the date of his nomination for election he is able to speak and unless incapacitated by blindness or other physical cause, to read the Swahili and English languages well enough to take an active part in the proceedings of the National Assembly…

The section would seem to allow persons with disabilities to contest elections. However, it has been the subject of misinterpretation in the past. In 1988, Mr. Munyi wa Gachomba, a visually disabled person, was denied nomination to contest the Mathare parliamentary seat through an ambivalent interpretation of section 34 of the Constitution as barring a person with visual disabilities.

It is contended, however, that the spirit of Chapter V of the Constitution and especially section 82 which disallows discrimination, show that it could not have been the intention of the legislature to expurgate the visually disabled or those disabled "by other causes" from contesting seats in the National Assembly. This ambiguity needs to be removed.[27]

6(ii) *The Persons with Disabilities Act 2003*

The UN initiatives captured under the international normative framework given above, embraced the growing international concept of human rights of persons with disabilities and equalization of opportunities for them. It is against the backdrop of this series of the UN

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[27] See Sinyo, J.O. (2001). *Constitutionalization of the rights of people with disabilities,* No. 13 September 2001. Mombasa: Constitition of Kenya Review Commission. She argues in favour of the express recognition of the rights of disabled people in the Constitution.

declarations, resolutions, rules and principles that the Kenyan *Persons with Disabilities Act* 2003 (the Act)[28] must be understood. The Act was published on January 9, 2004 and came into operation *vide* legal notice number 64 of June 16, 2004.

The Act is divided into eight parts. As is the case with any other Act of Parliament in Kenya, Part I contains the short title of the Act and the interpretative section. Part II establishes the National Council for Persons with Disabilities (the Council) as the main enforcement agency of the rights and privileges of persons with disabilities provided for under Part III. Part IV enshrines the civic rights while Part V establishes the National Development Fund for Persons with Disabilities (the Fund). Part VI provides for relief and incentives while Part VII contains miscellaneous provisions on, *inter alia*, the access to the legal systems by disabled people. Finally, Part VIII creates various offences and their respective penalties.

The preambular section of the Act states that it is an "Act of Parliament to provide for the rights and rehabilitation of persons with disabilities; to achieve equalization of opportunities for persons with disabilities; to establish the National Council for Persons with Disabilities; and for connected purposes."

Under the interpretative section,[29] "disability" is defined as the physical, sensory, mental or other impairment, including any visual, hearing, learning or physical incapacity, which impacts adversely on social, economic or environmental participation. "Discrimination," on the other hand, is defined as according different treatment to different persons solely or mainly as a result of their disabilities and includes using words, gestures or caricatures that demean, scandalize or embarrass a person with a disability.

Under this regime, persons with disabilities are accorded rights as well as privileges. For instance, they are guaranteed an equal right to employment,[30] as well as a privilege to be exempted from paying all manner of taxes pegged on the income accruing from their employment.[31] The Council is mandated to endeavor to secure reservation of 5% of all casual, emergency and contractual positions in employment

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[28] The Laws of Kenya, Chapter 14, online: http://www.kenyalaw.org/kenyalaw/klr_app/frames.php (visited December 5, 2010).

[29] Ibid., section 2.

[30] Ibid., section 12(2).

[31] Ibid., section 12(3).

in the public and private sectors for persons with disabilities.[32] In this regard, employers of persons with disabilities are entitled to a tax exemption amounting to 25% of the salary of each person with disability they engage.[33] Discrimination in education is equally outlawed and the State is required to establish special schools for persons with disabilities where that is called for; however, an integrated education system is recommended.[34]

The right to health is also protected. In particular, the Council is required to be represented in the implementation of the national health programme established under the ministry responsible for health for purposes *inter alia* of: preventing disability; early identification of disability; early rehabilitation of persons with disabilities; enabling persons with disabilities to receive free rehabilitation and medical services in public and privately owned health institutions; availing essential services to persons with disabilities at an available cost; and prompt attendance by medical personnel to persons with disabilities.[35] The Act entitles persons with disabilities to a barrier-free and disability friendly environment to enable them to have access to buildings, roads and other social amenities, and assistive devices and other equipment to promote their mobility.[36] The right to accessibility and mobility is to apply to public buildings[37] and also public service vehicles[38] within a specified period of the Act coming into force.

The civic right to vote has for the first time been given practical meaning to persons with disabilities in Kenya. The legislation under review requires them to be assisted during voting in presidential, parliamentary and civic elections.[39] It is also required that polling stations be accessible to them.[40] To foresee the implementation of these very noble provisions, offences are created under the Act to deter breach.

The Act makes a credible attempt to enact and codify the human rights imperatives of persons with disabilities. For instance, section 7(1)(b)(i) provides for equalization of opportunities while subsection

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[32] Ibid., section 13.
[33] Ibid., section 16(1).
[34] Ibid., section 19.
[35] Ibid., section 20.
[36] Ibid., section 21.
[37] Ibid., section 22(1).
[38] Ibid., section 23.
[39] Ibid., section 29.
[40] Ibid., section 30.

(iv) envisages the elimination of discrimination in order to ensure equality. Rehabilitation is provided for under subsection (vi).

To ensure the realization of the rights of persons with disabilities, the Act sets up the National Development Fund for Persons with Disabilities to be administered by the Council. The Fund envisions deposits by annual budgetary allocation by Parliament and other donations, which the Council may receive.[41] The Trustees of the Fund may also make investments.[42] All monies deposited in the Fund shall be used for the benefit of disabled people including the costs incurred in the protection of their entitlements.[43]

6(iii) *Other Laws Impacting Disabled People*

There are other terse and scattered references to persons with disabilities in many other statutes. One such Act is the *Kenya Society for the Blind Act (Cap 251)*[44] dealing mainly with administrative aspects of the society. The objects of the Society, enumerated in section 4, are:

a) To promote the welfare, education, training and employment of the blind,
b) To assist the government, or society or any person in all matters relating to the blind,
c) To advise on all things necessary or required in any matter relating to or connected with the blind.

No other substantive provision exists in the Act regarding people with visual impairments. Suffice it to state that the Act is not comprehensive even on the matters that it seeks to address.

A most ridiculous provision on persons with disabilities is found in the *Vagrancy Act,*[45] which equates a person with disabilities with vagrancy and begging. Section 2 refers to a vagrant who, "whether by reason of physical or mental disability, is unable to maintain himself otherwise than by vagrancy…". Such a provision is an indication of negative societal attitudes towards disabled people.

The *Penal Code*[46] makes it an offence for a person to have carnal knowledge of an imbecile or a cognitive disabled person. Penal

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[41] Ibid., section 33(1)(a) & section 33(1)(c).
[42] Ibid., section 33(1)(b).
[43] Ibid., section 33(2).
[44] The Laws of Kenya, Chapter 251.
[45] Ibid., Chapter 58.
[46] Ibid., Chapter 63.

provisions can be built into an Act of Parliament to deal with discrimination or abuse of the modesty of a disabled person in terms similar to those of the Code.

The *Civil Procedure Act,*[47] under Order XXXI, classifies minors and people with intellectual disabilities as "disabled" persons. A cognitively disabled person (the Act speaks of a person of unsound mind) can bring proceedings before a court of law through his or her guardian *ad litem*. Such a provision, like that of the Penal Code, is useful as it protects the rights, for example, to property of a cognitively disabled person.

The *Mental Health Act*[48] does not clearly define a person of unsound mind but generally refers to persons unable to take care of themselves due to diseases of the mind. The Act makes provisions for treatment of such cases.

The *Income Tax Act*[49] under section 32 provides that a person who proves that he is maintaining an incapacitated person shall be entitled to tax relief on personal income known as special single relief. The provision is meant to encourage society to take care of disabled people without incurring heavy financial burdens.

Section 46 of the Act provides that:

> The income tax of an incapacitated person shall be assessed on, and the tax thereon charged on, that person in the name of his trustee, guardian, curator, committee or receiver appointed by a court, in the same manner and to the same amount as that an incapacitated person would have been assessed and charged if he were not incapacitated.

Such a provision, in my view, does not assist a person with disability as it sanctions continued tax payment by his trustees when he or she is incapacitated. The Act can be amended to give better relief to persons with disabilities.

The *Customs and Excise Act*[50] has useful provisions for the welfare of persons with disabilities. The third schedule to the Act provides for exemption from import duty, suspended duty or dumping duty on "goods…consigned to or imported by organisation if the Commissioner is satisfied that they are for free distribution to poor and needy persons or for use in medical treatment or rehabilitation work in charitable institutions."

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[47] Ibid., Chapter 21.

[48] Ibid., Chapter 248.

[49] Ibid., Chapter 472.

[50] Ibid., Chapter 412.

Rules 15 and 16 further provide for similar duty exemption on "motor vehicle controls and equipment specially designed for the use of disabled people" and on "materials and articles specially designed for the educational, scientific or cultural advancement of the blind, for the use of an organization approved by the Government for the purpose of this exemption."

7. *Towards Reform of the Kenyan Law*

Besides implementing the policy changes suggested above, the Kenyan Government should undertake the following legislative measures to eliminate the deficiencies high-lighted earlier:

- The Kenyan Constitution should be amended to specifically provide that persons with disabilities shall enjoy all the rights in the Constitution and shall not be discriminated against on the basis of disability. Specific provisions on rights of persons with disabilities, if built into the Bill of Rights, would clear the ambiguity in section 34 that was once misinterpreted as barring the disabled from political office. This is instructive as the Constitution is the supreme law of the land and would thus logically make unconstitutional any discriminatory provisions in other statutes or policy documents.
- There should be a major review of all the existing legislation that is relevant to persons with disabilities in order to harmonize them with the *Persons with Disabilities Act*. For example, statutes such as the *Mental Health Act* and the *Kenya Society for the Blind Act* should be amended to provide more than just administrative norms and emphasize rehabilitation, prevention, health and equalization of opportunities.
- There should also be amendment of other relevant Acts in the areas of education, housing, employment, health, transport, planning and others: for example, the *Education Act,*[51] the *Public Health Act,*[52] the *Local Government Act,*[53] etc. This should specifically highlight the rights of persons with disabilities to an education, appropriate housing, and access to the physical environment, a convenient transport system, equal opportunities in employment, and so forth.

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[51] Ibid., Chapter 211.
[52] Ibid., Chapter 242.
[53] Ibid., Chapter 265.

- There is need for enactment or amendment to existing urban planning law, building laws and related laws. For example, the *Local Government Act* should be amended to ensure that no public building is licensed or approved unless it has special facilities that allow access to the physical environment by persons with disabilities. Such legislation must provide for accessibility codes, rules on public housing and so forth.

Other reform areas include:

- Amendment of Kenya's transport law to prohibit licensing of public transport that does not offer easy access by persons with disabilities and that is not safe for disabled people, in the spirit of the *Persons with Disability Act*. Examples of related legislation are present in Libya and New Zealand.
- Enactment of or amendment to tax laws and insurance laws or through establishment of some form of social security benefits for disabled people or tax exemption on their total income and not just employment income. A good example is the *Zakat* system in Islam, which levies a religious tax on personal property for distribution to disabled people.
- Reviewing the *Customs and Excise Act*'s provisions on duty-free importation of equipment for persons with disabilities, with an eye to implementing more comprehensive provisions and trimming the bureaucracy. The *Income Tax Act* should be amended to remove provisions that allow taxation of, say, a mentally ill person, through his trustees. It would make more sense to invest the taxed sums in health care for the person.
- Amendments to the Kenyan health laws, including the *Public Health Act* and *Mental Health Act,* to emphasize a healthy and secure environment for persons with disabilities and prevention of disabilities, for example through prosecution of those neglecting immunization, supply of equipment (such as prosthetics) for the disabled and provision for training and research.
- Enactment of proper law to provide for independent living centres, social rehabilitation centres, home care centres, etc, within the country's economic reach and along the legislative framework in place, for example, in Australia or the United States.
- Encouraging public education and awareness through, for instance, amendments to the objects of the *Kenya Broadcasting Corporation*

Act,[54] to create a specific duty to educate people on disability; or the creation of a national committee, local authority or individual holding a certain office whose duties require periodically sensitising, or educating the public on disability, its major causes, prevention, rehabilitation and the need for equalization of opportunities for disabled people. This could be effected through newsletters, media, a directory for disabled people, etc.

- Amendment to the penal laws and especially the *Penal Code* to criminalize discrimination in the workplace or public service; to penalize for conduct that abuses the modesty of a disabled person like abuses or slurs or disrespect for a person on grounds of disability, etc. The current provisions in the Penal Code, for instance those outlawing rape of imbeciles or those mentally ill, should be a guiding light to further amendments making it criminal to abuse or deprive or take undue advantage of a disabled person, etc.
- Amendments to the *Civil Procedure Act;* specifically Order XXXI, to ease procedure for mentally ill persons to protect their rights in court. A simple memorandum by that person or his guardian should move the court, without recourse to its form or technicalities of procedure.

These suggestions are by no means exhaustive. It is hoped that they will ignite sharp thought on the lives of persons with disabilities and the barriers they face and how to alleviate the same in the future.

Part C: Responding to the Underlying Imperatives

8. *The Imperatives*

A human rights approach to protecting persons with disabilities demands a number of paradigmatic considerations that must inform the legal framework for protecting disabled people. These considerations include justice, dignity, equality (the concomitant notion of equalization of opportunities and affirmative action), resource allocation and participation/inclusion.

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[54] Ibid., Chapter 221.

8(i) *Justice*

One of the most interesting attempts to defend the principles of justice is found in John Rawls' *A Theory of Justice*.[55] The conception of justice for which Rawls argues demands the maximization of liberty, subject only to such constraints as are essential; for the protection of liberty itself. He argues for equality for all, both in basic liberties of social life and also in distribution of all other forms of social goods, subject only to the exception that inequalities may only be permitted if they produce the greatest possible benefit for those least well off in a given scheme of inequality ("the difference principle"). He also argues in favor of "fair equality of opportunity" and the elimination of all inequalities of opportunity based on birth or wealth.[56]

Rawls' second limb of the idea of justice clearly adverts to the issues of distributive justice and affirmative action, which lie at the core of realizing the human rights imperatives of persons with disabilities in any socio-cultural context. It is only just that disabled people are recognized as requiring specific attention through equality and equalization of opportunities programmes.

8(ii) *Dignity*

The right to human dignity is one of the core constitutional rights.[57] Besides, the right is intricately linked with other human rights. This linkage was enunciated by O'Regan J in the South African case of *S v Makwanyane*[58] in the following words:

> Recognizing a right to dignity is an acknowledgement of the intrinsic worth of human beings: human beings are entitled to be treated as worthy of respect and concern. This right therefore is the foundation of many of the other rights that are specifically entrenched in…[the Bill of Rights].[59]

The point was reiterated by Chaskalson P:

> The rights of life and dignity are the most important of all human rights, and the source of all other personal rights in the Bill of Rights. By

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[55] (1971). Cambridge: Belknap University Press.

[56] Freeman, M.D.A. (2001). *Lloyd's introduction to jurisprudence* (7th ed.). London: Sweet & Maxwell, 523–524.

[57] De Waal, J., et al. (2000). *The Bill of Rights handbook*. Juta: Kenwyn, 208–209. See for instance Section 10 of the South African Constitution.

[58] 1995 (3) SA 391 (CC) para 144.

[59] Ibid., para 328.

> committing ourselves to a society founded on the recognition of human rights we are required to value these rights above all others.[60]

S v Makwanyane concerned a dispute where two persons sentenced to death had contested the sentence, citing the fact that such a sentence was inconsistent with the spirit of the Constitution of South Africa even though the supreme law had no explicit provisions on the same. It is in the course of this matter that the Constitutional Court took occasion to pronounce on the question of human dignity. South Africa, as a social, cultural and political context, provides a scenario where the resolve to protect human dignity is an urgent imperative. The decision alluded to above must be understood from a background where apartheid, as a government policy, had kept in abeyance respect for human rights for a significant portion of the population and therefore the dignity of these people. Black people in South Africa had been denied even the most basic entitlements such as freedom from torture, equality and non-discrimination, let alone such entailing rights as socio-economic rights. The results were a majority of people living in deplorable conditions necessitating judicial activism, a task that the Constitutional Court has very ably performed. Chaskalson P has painted this picture perhaps more succinctly:

> We live in a society in which there are great disparities in wealth. Millions of people are living in deplorable conditions and in great poverty. There is a high level of unemployment, inadequate social security, and many do not have access to clean water or to adequate health services. These conditions already existed when the Constitution was adopted and a commitment to address them, and to transform our society into one in which there will be human dignity, freedom and equality, lies at the heart of our new constitutional order. For as long as these conditions continue to exist that aspiration will have a hollow ring.[61]

It is worth elaborating briefly on the philosophical basis for these contentions. In liberal moral philosophy, human dignity is considered to be what gives a person their intrinsic worth. As a consequence, dignity is "above all price and so admits of no equivalent."[62] It is the source of a person's innate rights to freedom and to physical integrity, from which a number of other rights flow. Human dignity, accordingly, also provides

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[60] Ibid., para 144.

[61] *Soobramoney v Minister of Health, KwaZulu Natal.* (1998). 1 SA 765 (CC); (1997) 12 BCLR 1696 (CC), para 8.

[62] Jones, B. (1971). *Kant's principle of personality,* 127.

the basis for the right to equality – inasmuch as every person possesses human dignity in equal measure, everyone must be treated as equally worthy of respect.[63]

8(iii) *Equality*

At its most basic and abstract, the idea of equality is a moral idea that people who are similarly situated in relevant ways should be treated similarly. Its logical correlative is the idea that people who are not similarly situated should not be treated alike.[64] In this regard, equality connotes such related concepts as equality of opportunity and affirmative action.

However, it is not the basic and abstract idea of equality that is so difficult and controversial. Instead, it is two issues ancillary to the idea of similar treatment for similar people that prove so taxing. The first is the issue of what counts as relevant when it comes to determining the similarity of people's situations. The second issue is what constitutes similar treatment of people who are similarly situated. For example, we might think it immoral to deny education to children with visual impairments. All children stand in the same position before the law and should be given similar treatment when it comes to access to education. But is it sufficient simply to give children with visual impairments the right of access to the same schools as sighted children? Or does our commitment to equality (which includes the idea that people who are different in significant ways should not be treated the same as everyone else) require us to create special schools or special programmes which take into account the particular needs of children with visual impairments?

A distinction is made between formal and substantive equality. Formal equality simply requires that all persons are equal bearers of rights. In this view, inequality is an aberration, which can be eliminated by extending the same rights and entitlements to all in accordance with the same "neutral" norm or standard of measurement. Formal equality does not take actual and economic disparities between groups and

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[63] *National Coalition for Gay and Lesbian Equality v Minister of Justice.* [1999]. (1) SA 6 (CC), para 30.

[64] The most famous expression of this idea is that of Aristotle (384–322 BC): "Equality in morals means this: those things that are alike should be treated alike, while things that are unlike should be treated unalike in proportion to their unlikeness" *Nicomachean Ethics* V.3.1131a–1131b (Ross, W. (trans.) (1925)).

individuals into account. Substantive equality, on the other hand, requires an examination of the actual social and economic conditions of groups and individuals in order to determine whether the Constitution's commitment to equality is being upheld.

The equality requirements do not prevent the government from making classifications and from treating some people differently from others. Not every act of differentiation can therefore amount to unequal treatment. In other words, differentiation is permissible if it does not amount to unfair discrimination.

To this end, special measures may be taken to ensure the protection or advancement of people who have been disadvantaged by discrimination in the past, such as disabled people.

This equality mode implies the notion of indivisibility, interrelation and interdependence of the two sets of human rights: civil and political rights on the one hand and economic, social and cultural rights on the other. This is the human rights concept of the United Nations, as has been quoted so often and emphasized at the 2nd World Conference on Human Rights in Vienna in June 1993.

8(iii)(a) *Equalization of Opportunities*

Equalization means the "process through which the general system of society, such as the physical and cultural environment, housing and transportation, health services, education and employment, social life, including sports and secretariat facilities, are made accessible to all."[65]

The World Programme of Action concerning Disabled People, and the proposals for its implementation, developed a number of policy guidelines for equalization of opportunities:

- Disabled people should remain within their own communities and share in an ordinary lifestyle, with the necessary support.
- Disabled people should take part in decision-making at all levels, both in general community affairs and in matters that particularly concern them as people with disabilities.
- Disabled people should receive assistance as needed within the ordinary structures of education, health, social services etc.
- Disabled people should take an active part in the general social and economic development of society and their needs should be

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[65] *Supra* note 16 at 18.

> included in national planning. Disabled people should have adequate opportunity to contribute to national development.[66]

The World Programme of Action also recognizes women's needs as requiring special attention. The consequences of disablement are particularly serious for women because women with disabilities are discriminated against on double grounds: gender and disability. Therefore, they have less access to essential services such as health care, education and vocational rehabilitation.[67]

Women are also specially affected by disability because they are often entrusted with the responsibility of caring for disabled people in the community. Furthermore, women are more exposed to the risk of becoming less able because of neglect and certain forms of abuse and harmful traditional practices directed against them.[68]

The World Programme of Action, and its proposals for implementation, recommended change of policy in the following areas:

(1) That governments should encourage the formation of organizations for disabled people, help in the organization and coordination of the representation of their interests;
(2) That legislation of national human rights be passed that assures disabled people of their human worth and outlaws discrimination on the basis of disability. That as much as possible such legislation should follow the international human rights covenants providing rights and degrading treatment;
(3) That the physical environment should be made accessible to all by providing means that guarantee access by disabled people;
(4) That, as regards education:
    - Laws should be passed providing for compulsory education for children with all ranges of disabilities including the most severely disabled;
    - Education services for disabled children and adults "should be individualized, locally accessible, comprehensive and should offer a range of choices;"

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[66] Proposals for the implementation of the World Programme of Action concerning Disabled Persons, online: http://www.un.org/disabilities/default.asp?id=24#proposals (visited December 5, 2010).

[67] *Supra* note 4.

[68] Ibid.

- Special facilities which are not available in general schools should be offered.[69]
- Parents of disabled children should be involved in the process in order to provide a normal family environment;
- There should be public education on disability, its chief causes, prevention, rehabilitation and equalization of opportunities.

(5) Under the area of work and employment, the World Programme of Action and its implementation proposals recommended that:

- Laws should wipe out barriers to the employment of disabled people;
- The central and local governments should promote the employment of disabled people. (This can, for example, be done through a manpower services commission, as in the United States, or other forms of vocational rehabilitation);
- Equal opportunities for gainful employment for disabled people in both urban and rural areas be ensured;
- Affirmative action programmes be developed to ensure integration of disabled people into open employment. (This, as has been seen, can be done through legislation as in the case of *The Rehabilitation Act* of 1973 in the United States or even through Civil Rights legislation);
- There be a tri-partite strategy for the employment of disabled people through the Government, employers and trade unions;

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[69] In the area of education, emphasis is necessary on the need for special care for disabled children. Integration in the ordinary school system must go hand in hand with proper training for special teachers sensitised to the special needs of such children, without traumatizing or labeling the children or attracting prejudices against them. Such integration or "mainstreaming" should be incorporated into the college and university systems. Mainstreaming means inclusion of persons with disabilities into the normal or general education process. A student is considered "mainstreamed" where he spends any part of a school day in the regular classroom with other students. At the postsecondary level, it would be useful for government to produce guidance materials for college students on admission, special facilities and placement after college. The Open University in a paper on *Special Needs in Education* states that the basic policy of the Government should be to mix disabled people children or adults with the rest of the society in the general school system. But this principle must "not frustrate the aim of giving the child or student, within the limits of what is practicable, the greatest possible opportunity to benefit from the education process." To make this more meaningful, the training of special teachers should be integrated with that of ordinary teacher training.

- Measures be taken to prevent injuries at the workplace and ensure reintegration of such injured workers into the industry. (This can be done through appropriate legislation);
- Governments support the development of tools and facilities for disabled people;
- There should be development of counseling, guidance, vocational training and follow-up facilities for disabled people; and
- Where it is not possible for the severely disabled to compete in the regular industry there should be sheltered employment, for example, in workshops, self-employment schemes, home working, etc.

  It is suggested that there should be studies to solve the problem of disabled people at the workplace through adaptations, guidance or support services by professional or formal government agencies. Such a framework can be incorporated in industrial or employment legislation.

  A similar employment policy emphasizing the rights of job seekers with intellectual disabilities must be put in place. Such jobs should be tailored to the particular abilities of those individuals. There is a wide variety of skills among people with intellectual disabilities and they range across a spectrum of types of employment and needs for accommodation. In every case they should attract equal pay for equal work.

(6) The World Programme of Action further enjoins member states of the United Nations to develop income maintenance and social security frameworks for disabled people, ensure standard health care as a community-based system and provide social services through counselling by social and community workers on the special needs of disabled people.

The member states should also guarantee religious freedom for disabled people, ensure access to religious activities, and offer recreational, cultural and sports facilities for disabled people through provision of the facilities and proper organisation of the beneficiaries. The World Programme of Action further mandates research that can lead to alleviation of the plight of disabled people and continued sensitisation of the community through information and public education on disability, its causes, prevention and the special needs of disabled people.

The policies enumerated above can be put into place at the national level. Financing can be through donors, self-help projects or a tax levied by the government through relevant amendments to the existing tax laws.

An example of this type of funding is the *Zakat* system in Islam, where a religious tax is levied on certain types of personal property and the proceeds disbursed to individuals or organizations working for disabled people. The *Zakat* system is possible in Kenya's legal system because the Constitution allows for freedom of religion and religious practice and Islam is one of the main religions. The same Constitution at section 82 also allows for equality, nay, nondiscrimination in certain enumerated grounds and a broad and purposeful interpretation of this piece of supreme law should necessitate a policy framework that caters to the welfare of disabled people even in Kenya's current constitutional order.

The United Nations Standard Rules emphasize the goal of equalization of opportunities as a fundamental concept in disability policy. According to the Rules, "equalization of opportunities" means the process through which the various systems of society and environment, such as services, activities, information and documentation are made available to all, particularly to persons with disabilities.[70]

The principle of equal rights and opportunities implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way to ensure that every individual has equal opportunity for participation. Persons with disabilities are members of society and have a right to remain within their local communities. They should receive support they need within the ordinary structures of education, health, employment and social services as provided for under the World Programme of Action.

In addition, persons with disabilities are described as citizens with equal rights and equal obligations, who should receive assistance in assuming "their full responsibility as members of society."[71]

These guidelines could largely streamline Kenyan policy to reflect attitudes towards rehabilitation and equalization of opportunities for disabled people.

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[70] *Supra* note 18.

[71] Ibid. Introduction, online: http://www.un.org/disabilities/default.asp?id=26 (visited December 5, 2010)., para 24–27.

8(iii)(b) *Affirmative Action*

Affirmative action means taking into account the systemic disadvantage that some groups have faced. Persons with disabilities fall in this category. Typically, an affirmative action programme will require a member of the disadvantaged group to be given some preference for the distribution of some benefit over someone who is not member of that group.

Affirmative action programmes can be seen either as an exception to the right to equality or as part of the right to equality. The former view sees affirmative action as "reverse discrimination," a practice of favouring those discriminated in the past and discriminating against those favoured in the past. The latter view sees affirmative action as a means to the end of a more equal society. This view treats equality as a long-term goal, to be achieved through measures and programmes aimed at reducing the current inequality.

Like the South African Constitution,[72] the Kenya Constitution does provide for an affirmative action framework, albeit tacitly. This tacit approval of the concept of affirmative action is evidenced by section 82(4)(d) of the Constitution which exempts, say, persons subject to disabilities, from the general nondiscrimination clause in section 82(3). Thus in Kenya, like in South Africa, the concept of fair discrimination is entertained; an avenue that is open to affirmative action crusaders especially as it relates to disabled people, women, children, the aged or the vulnerable in society.

Affirmative action programmes must therefore be seen as essential and integral to the goal of equality and not as limitations of, or exceptions to, the right to equality. Practically this means that when a measure has been challenged in court as a violation of the equality right, the

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[72] The South African Constitution favours the latter view, that is to say, affirmative action is not an exception to equality, but is a means of achieving equality as understood in its substantive or restitutionary sense. Section 9 (2) of the South African Constitution states that "equality includes the full and equal enjoyment of all rights and freedoms," and that to, "promote the achievement of equality," affirmative action measures may be undertaken. In South Africa, one of the government's most ambitious affirmative action programme to date, *the Employment Equity Act 55 of 1998*, aims to redress inequalities in the public and private sector markets. The Act obliges employers to take steps to increase the representation of members of the so-called "designated groups" in their workforce. The designated groups are black people, women and people with disabilities.

state or institution responsible for the measure can defend it by showing that the programme: (1) promotes the achievement of equality; and (2) is designed to protect and advance persons disadvantaged by unfair discrimination.

Affirmative action is justified by its consequences. A measure that favours relatively disadvantaged groups at the expense of those who are relatively well off is not discriminatory because the consequences of such a measure are, in the end, a more equal society. But this means that the measure must be intended to achieve those desirable consequences.

In a memorandum presented to the Constitution of Kenya Review Commission by the Kenya National Disability Caucus, disabled people in Kenya advocated for the following measures as part of an affirmative action programme enshrined in the Constitution:

(1) express recognition of disabled people as marginalised and disadvantaged category of the citizenry requiring special measures for their progression;
(2) guarantee of free and compulsory education for all children with disabilities, and state-subsidised tertiary training for disabled people certified as incapable of meeting the cost of career training;
(3) reservation of at least 10% of all employment opportunities in the public service for disabled people, with provision for policies that will encourage the private sector to adopt similar measures. Such could include tax rebates to enterprises with a proven track record of promoting employment of disabled people;
(4) adoption of an electoral mechanism of proportionate representation under special seats at all levels of governance, including the local government, and the national legislative assembly, that would be exclusively reserved for special interest groups (disabled people, the youth and ethnic minorities) expressly recognized under the Constitution;
(5) a constitutional obligation placed upon all parliamentary political parties to ensure that at least 10% of the total number of nominated MPs are disabled people; and
(6) a review of the legal provisions on public finances and establishment of an appropriate mechanisms for allocating sufficient resources to the interests of disabled people and other marginalized categories of citizens.

8(iv) *Resource Allocation*

In the words of the UN General Assembly:

> The principle of equal rights for disabled people and non-disabled implies that the needs of each and every individual are of equal importance, that these needs must be made the basis for planning of societies, and that *resources must be employed in such a way as to ensure, for every individual, equal opportunity for participation.*[73] (Emphasis added).

Resource allocation becomes even more critical with the realization of the socio-economic rights of persons with disabilities. In this regard, the present author has pointed out elsewhere[74] that:

> The ICESCR is…explicit: It asks state parties 'to take steps individually and through international assistance and co-operation' to 'the maximum of its resources,' to progressively realize socio-economic rights…The use of the phrase 'to the maximum of its available resources' in the ICESCR is arguably designed to ensure that should a state fail to meet its minimum core obligations citing lack of resources, it must demonstrate that all effort has been applied to use the resources at its disposal. International cooperation and assistance must also have been sought for the purposes of securing the resources necessary for achieving the realization of socio-economic rights.[75]

It is crucial that when resource allocations are made in the national budget, those sections of the society who have been victims of marginalization in the past be accorded priority through affirmative action and reasonable accommodation in decision-making and resource-sharing positions.[76] In Kenya, budgetary issues remain the domains principally of the Executive and Parliament. Ideally, the Legislature is envisioned to impart democratic values unto the budget process. These values as of necessity involve affirmative action, equality and other related aspects. Unfortunately for Kenya, the Legislature is ill-equipped to perform this very entailing task with the inevitable result that the

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[73] General Assembly Resolution 37/52 (3 December 1982) para 25.

[74] Kindiki, K., (2005). Broadening the horizons: The draft constitution of Kenya and the protection of socio-economic rights. In Kindiki, K. & Ambani, O. (Eds.) *The anatomy of Bomas: Selected analyses of the 2004 draft Constitution of Kenya.* Nairobi: Claripress, 1–24.

[75] Ibid., 12.

[76] See generally, Liebenberg, S. (2002). South Africa's evolving jurisprudence on socio-economic rights: An effective tool for challenging poverty. 6(2) *Law, Democracy & Development,* 159.

concerns of vulnerable groups are neglected even at the budgetary level. A fiscal analyst in Kenya has thus lamented this irking position:

> …the legal framework is quite robust. It is outlined in the Constitution and various Acts of Parliament. However, it is quite old and out of date and does not cover critical areas such as extra budgetary funds. This framework is quite procedural and does not build in robust mechanisms for oversight and accountability. The legislature, which approves the budget, does not have sufficient time or resources that enable it to influence the outcomes.[77]

A legal framework that is amenable to people's participation is therefore called for in Kenya, and the impending Constitution review offers a golden chance for this reform.

8(v) *Participation/Inclusion*

Inclusion means a:

> goal-oriented and time-limited process aimed at enabling an impaired person to lead an optimum mental, physical and/or social functional life, thus providing him or her with the tools to change her or his own life. It can involve measures intended to compensate for a loss of function or a functional limitation (for example by technical aids) and other measures intended to facilitate social adjustment or readjustment.[78]

This is the process through which, "the remaining physical and mental capacities of the physically disabled are utilized and developed to their highest efficiency."[79]

The better and wider definition is that of "social rehabilitation" from the World Health Organization, that is:

> the combined and coordinated use of medical, social, educational, and vocational measures for training or re-training the individual to the highest possible level of functional ability…a process aimed at integration or reintegration of a disabled person into society by helping him to adjust to the demands of family, community, and occupation, while reducing any economic and social burdens that may impede the total rehabilitation process.[80]

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[77] Maina, B. (2005). Public finance management in Kenya: A review of the draft Bill of the Constitution of Kenya Review Commission. In Kindiki, K. & Ambani, O. (Eds.) *The anatomy of Bomas: Selected analyses of the 2004 draft Constitution of Kenya.* Claripress Nairobi, 137.

[78] *Supra* note 15.

[79] Ibid.

[80] Hogarth, James. (1978). *Glossary of health care terminology*. Copenhagen: World Health Organization.

The main hindrance to rehabilitation has "not so much been the lack of funds as the lack of technical know how and materials that prevent the improvement of services."[81]

The United Nations Economic and Social Council has thus recommended legislative and other measures on education, employment, prevention of disability and the development of appropriate technology for disabled people.[82]

9. *Conclusion*

Some countries have made tremendous progress in positive re-adjustment of their policies and legal frameworks in the area of rehabilitation and equalization of opportunities from a disability-human rights perspective. In Kenya, despite the laudable adoption of the *Persons with Disability Act* of 2003, a lot of reforms and alignment of the protection of persons with disabilities with human rights remains to be done.

The reform measures outlined throughout this chapter, and the policy framework that has been suggested, will certainly involve a lot of political goodwill on the part of the government, leaders and eventually the Legislature. It has been seen that the economic burden of altering the existing facilities to the comfort and advantage of persons with disabilities is immense. Noteworthy though, the *Persons with Disability Act* is the first serious piece of legislation to that end. By and large, this law is a reflection of the standards set by most international instruments, both on human rights, and, in particular, the rights of persons with disabilities. However, norm-setting is the easier part: the more challenging responsibility lies in norm-enforcement, in the implementation of the legal and policy pronouncements. Without implementation, the normative framework would remain nothing but an assemblage of hollow promises.[83]

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[81] Ibid.

[82] Ibid.

[83] *Supra* note 8, 14.

CORPORATE SELECTIVE REPORTING OF CLINICAL DRUG TRIAL RESULTS AS A VIOLATION OF THE RIGHT TO HEALTH

Aaron A. Dhir

Introduction/Context

In September 2004 pharmaceutical giant Merck announced that it was removing the multibillion-dollar drug Vioxx from the market.[1] Vioxx, a COX-2 selective nonsteroidal anti-inflammatory drug, was commonly used in the treatment of arthritis-related disabilities. A long-term clinical trial showed that some consumers, after taking the drug for 18 months, developed potentially lethal cardiovascular problems. Documents obtained under subpoena in litigation suggest that Merck actually knew about Vioxx's potential side-effects as early as 2000 and conspired to keep this information secret. The New England Journal of Medicine claimed that Merck intentionally deleted data regarding heart attacks sustained by Vioxx users prior to submitting a Merck-funded study in 2000.[2] It was further alleged in litigation that Merck "bullied outside researchers who questioned the drug's safety, and that it schooled its army of salesmen to 'dodge' tricky questions about Vioxx from doctors."[3]

Zyprexa and Risperdal are two of the leading drugs used in the treatment of schizophrenia and other psychiatric disabilities. Recently leaked internal documents of drug manufacturer Eli Lilly reveal that the company "engaged in a decade-long effort to play down the health risks of Zyprexa," concealing crucial information from physicians pertaining to the drug's connection with diabetes risk factors (e.g. increased blood sugar levels, obesity).[4] In June 2004, Janssen Pharmaceutica wrote to health care providers, warning them that promotional material had minimized potentially fatal risks associated with Risperdal and

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[1] This text is current up to the submission date of October 2008.

[2] Curfman G.D. et al. (2006). Expression of concern reaffirmed. *New England Journal of Medicine*. 354: 1193.

[3] *The Economist* (2004). Big trouble for Merck., online: http://www.economist.com/node/3360175 (visited November 19, 2010).

[4] Berenson, Alex. (2006). Eli Lilly said to play down risk of top pill. *New York Times*. (17 December 2006), online: http://www.nytimes.com/2006/12/17/business/17drug.html (visited November 19, 2010).

misleadingly claimed that the medication was safer in treating mental disability than other drugs in the same category.[5] Along similar lines, in 2008 the New England Journal of Medicine published a groundbreaking study examining the data submitted by drug companies to regulators when seeking approval for 12 different antidepressants. The authors concluded that industry's selective reporting of trial results, or mischaracterization of results, led to the published literature suggesting that 94% of trials conducted had been positive. In reality, however, this was the case for only 51% of trials.[6]

The industry practice of selectively reporting clinical drug trial results and related information is of great significance when considered in the context of disability rights. Safe, effective medications are of the utmost importance for numerous persons with disabilities who rely on the advice of healthcare providers and on publicized information in deciding on a particular course of treatment. As noted by the Council of Canadians with Disabilities, "[m]edications are an essential part of life for many persons with disabilities, for many they are the difference between life and death."[7]

For some commentators, the practice of selective reporting represents another example of malfeasance committed by large corporate actors that wield unmitigated power.[8] The depth and breadth of pharmaceutical corporations' strength and influence is undeniable – approximately 600 publicly traded biotechnology and pharmaceutical corporations are capitalized at over $1.5 trillion globally.[9] While governments have encouraged academia/industry collaboration as a means of furthering economic development, this influence and power imbalance has led to the commercialisation of academic medical research. From 1980 – 2000, industry funding of research and development at U.S. institutions increased by 875 per cent.[10] When medical academics have tried to intervene, the tensions between academic freedom and

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[5] Letter of Ramy Mahmoud (2004).

[6] Turner, Erick H., et. al. (2008). Selective publication of antidepressant trials and its influence on apparent efficacy. *New Eng. J. Med.*, 358(3) 252.

[7] Council of Canadians with Disabilities. (2002). CCD appears before Romanow Commission, online: http://www.ccdonline.ca/publications/health-inspector/0402.htm (visited November 2008).

[8] Angell, M. (2004). *The truth about the drug companies: How they deceive us and what to do about it.* New York: Random House.

[9] Huber, Peter W. (July/August 2006). Of Pills and profits: In defense of big pharma. *Commentary,* July/August 2006, 21.

[10] Lemmens, T. (2004). Leopards in the temple: Restoring scientific integrity to the commercialized research scene. *Journal of Law, Medicine and Ethics*, 32(4), 645.

corporate interests have been particularly pronounced. For example, in 2000 Dr. David Healy (a prominent psychopharmacologist and historian of psychiatry at the University of Wales) was hired to head the Mood Disorder Program at the University of Toronto's Centre for Addiction and Mental Health. The program received approximately 40 per cent of its funding from the pharmaceutical industry and had close research ties with Eli Lilly. After Healy delivered a paper expressing his concern about the risk of suicide in patients taking antidepressant drugs such as Prozac (which is manufactured by Eli Lilly), the University of Toronto rescinded his appointment.[11]

However, while attractive at one level, selective reporting cannot be explained as a function of corporate misconduct alone. Indeed, insufficient regulatory regimes actually perpetuate the impugned corporate conduct. Drawing on the Canadian experience, it is argued that this element of government facilitation serves to undermine the human rights of persons with disabilities. In that regard, this chapter proceeds with an overview of the domestic regulatory framework and an analysis of its limitations. The next section adds a layer of complexity by situating the industry conduct at issue within the context of corporate law theory. The balance of the chapter addresses how persons with disabilities, and the public interest organizations that represent them, can employ human rights principles to advance their fundamental rights. Specifically, it discusses how in struggling for reform Canadian advocates might advance a litigation strategy that relies on the international human rights framework. It argues that the right to health as found in Article 12 of the *International Covenant on Economic, Social and Cultural Rights* (ICESCR)[12] can be of assistance in attempting to achieve a judicial declaration of the current regulatory regime's unlawfulness.

THE REGULATORY PROCESS

In order to explore how the international human rights framework can be engaged by disability rights advocates in domestic litigation, it is essential to first understand the existing regulatory framework and its limitations.

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[11] Ibid., 642–643.

[12] International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI), U.N. GAOR, Supp. No. 16, U.N. Doc. A/6316 (1966) [hereinafter ICESCR].

Before a drug is authorized for sale in Canada, it is subject to scrutiny by the Therapeutic Products Directorate (TPD) of Health Canada's Health Products and Food Branch. The TPD review process is meant to assess, *inter alia*, the quality, efficacy and safety of the proposed drug.[13] The purpose of the manufacturer's clinical drug trial is to amass necessary information respecting these factors through the participation of consenting individuals and under the organizing principle of "good clinical practices."[14] These trials are regulated by Canada's *Food and Drugs Act* and the accompanying *Food and Drug Regulations* (*Regulations*). A Clinical Trial Application is submitted by the sponsor of the trial (i.e. the pharmaceutical company) and the government responds with either a "Not Satisfactory Letter" or a "Letter of No Objection" (although, technically, trials may begin after 30 days unless the applicant has received a Not Satisfactory Letter).[15] Assuming a Letter of No Objection is received, the trial proceeds and if the results demonstrate a therapeutic value that exceeds any potential detrimental risks, the manufacturer files a "New Drug Submission" with the TPD which includes information such as clinical trial results, potential therapeutic and negative effects, and packaging/labelling details.[16]

Based on the information submitted, the TPD conducts its own evaluation. If, in its opinion, the positive aspects outweigh any risks (which are capable of being mitigated) and the requirements found in Canada's *Food and Drugs Act* are met, the drug is assigned a "Notice of Compliance" and a "Drug Identification Number" which indicate governmental approval and allow the drug to be marketed in Canada.[17]

It should be noted that the TPD places heavy reliance on the material provided by the sponsor of the proposed drug and does not grant marketing authorization if "there is insufficient evidence to support the safety, efficacy or quality claims."[18] Thus, assuming sufficient evidence is present, the drug will receive approval. However, the regulatory process does not adequately address the *extent* of the sponsor's disclosure. In other words, it does not ensure that *all* clinical drug trial results,

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[13] Health Canada. Therapeutic Products Directorate. (2001). How drugs are reviewed in Canada., online: http://www.hc-sc.gc.ca/dhp-mps/alt_formats/hpfb-dgpsa/pdf/prodpharma/reviewfs_examenfd-eng.pdf (visited November 19, 2010), 1.

[14] Ibid., 2.

[15] Klein, A.V. & Tomalin, A.M. (2005). Clinical trial applications in Canada. *Canadian Journal of Clinical Pharmacology*. 12(3), 246.

[16] *Supra* note 12, 3.

[17] Ibid., 4.

[18] Ibid.

positive *and* negative, are provided. This regulatory deficiency was recently acknowledged by the Director of Health Canada's Marketed Pharmaceuticals Division:

> Dr. Bethiaume also noted that drug companies do not necessarily make regulators aware of all the studies they might be conducting on a particular drug, or what safety information might have flowed from such trials. "There is some discussion taking place [within Health Canada] about how can you make sure the drug company is sharing all the information it has on trials," he said.[19]

During the conduct of a clinical trial, section C.05.012(3)(c) of the *Regulations* requires the sponsor to "maintain complete and accurate records in respect of the use of a drug in a clinical trial, including… records respecting all adverse events in respect of the drug." However, under section C.05.014, only adverse drug reactions that are considered *both* "serious" and "unexpected" are subject to expedited reporting to Health Canada. The sponsor's ability to exercise discretion in the interpretation of the data is key. For the process to be effective, results "must be subject to analysis by independent experts who are alert to conflicts of interest that may distort the interpretation of data."[20] Further, under C.05.001, many problematic reactions will fall short of the definition of "serious adverse drug reaction," which refers to "an adverse drug reaction that requires in-patient hospitalization or prolongation of existing hospitalization, that causes congenital malformation, that results in persistent or significant disability or incapacity, that is life threatening or that results in death."

The practice of selective reporting also relates to the politics of knowledge production. Because the information submitted in the drug approval process is considered commercially sensitive, it is deemed confidential under Canadian access to information legislation. For example, in *Merck Frosst Canada & Co. v Canada (Minister of Health)* (2004 [2004] F.C.J. No. 1178 (FCTD))., Merck provided chemical and manufacturing information (including the results of clinical studies) to Health Canada in order to seek regulatory approval of the asthma drug Singulair. The disclosure included both confidential financial information and trade secrets. Health Canada received a request from a Merck

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[19] Abraham, C. (2005). Weak law blamed in Vioxx case. *Globe and Mail* (February 22, 2005).

[20] Garland, J.E. (2004). Facing the evidence: Antidepressant treatment in children and adolescents. *Canadian Medical Association Journal*, 170(4), 491.

competitor under Canada's *Access to Information Act* for records regarding the new drug submission. In response, it disclosed certain information that it did not consider confidential and notified Merck that it intended to disclose other pieces of information, but sought Merck's submissions on the issue.

Merck sought judicial review, arguing that disclosure would prejudice its competitive position. In finding in Merck's favour, the Court noted the distinction drawn in the *Access to Information Act* between information that government generates itself and information it receives from third parties, such as Merck. The latter is confidential in nature and cannot be disclosed. As such, although Health Canada could disclose the Notice of Compliance, the court reasoned that other information requested, including the notes of departmental reviewers and outside experts consulted, were confidential third-party information that would not exist but for the applicant's new drug submission. Although some of the information was in the public domain, the Court held that as long as it was not public in the same form as it appeared in the Health Canada records, the confidentiality of the information was not lost.

It should be noted that the Federal Court of Appeal disagreed with the latter aspect of this decision, holding that information is no longer confidential when it is in the public domain, even if it differs in form. The appellate court returned the matter to the lower court for redetermination so that this revision could be taken into account. This reversal would not be of assistance in our situation, however, given that the detrimental effects documented in unpublished clinical trials "disappear without a trace."[21] In fact, in the U.S., it has been estimated that just 50% of the approximately one million clinical drug trials conducted over the course of the last 56 years have been disclosed by sponsors.[22]

Correspondingly, absent consent from the drug manufacturer, the TPD will not disclose safety-related information found in unpublished clinical trials to academics, healthcare providers and persons with disabilities/consumers. As a result, the latter two groups are left with a gap in information that can lead to the uninformed prescription and use of these drugs. Further, academics are unable to subject the information to peer-review.

This lack of disclosure, and the resulting information gap, has significant repercussions. It is generally accepted that "the standard basis for

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[21] Rennie, Drummond. (2004). Trial registration: A great idea switches from ignored to irresistible. *JAMA* 292:11, 1359.

[22] Ibid.

treatment guidelines is systematic literature reviews or meta-analyses of all randomised controlled trials."[23] However, these reviews are generally limited to information that is available to the public. If neither the clinical trial information, nor the TPD reviewers' evaluations, are subject to independent scientific scrutiny, the Canadian public is forced to rely on the opinion of the TPD with respect to the efficacy and safety of the drugs it consumes.[24] This is problematic given that research has demonstrated that "[w]ithout access to all studies (positive as well as negative, published as well as unpublished) and without access to alternative analyses…any attempt to recommend a specific drug is likely to be based on biased evidence."[25] Further, seemingly neutral articles endorsing new drugs that currently appear in scholarly journals are often questionable. Although they are frequently published under the name of an academic, some have been found to be "ghost-written" (in other words, written by medical communication agencies that are paid by drug manufacturers). This occurred, for example, with prominent medications such as the selective serotonin reuptake inhibitor (SSRI) Zoloft[26] and the COX-2 inhibitor Vioxx.[27] The practice is attractive because it permits academics to increase their volume of publication while guaranteeing drug companies a favourable tenor for the article.

In 2000, a Health Canada Science Advisory Board Committee on the drug review process found Canada's review process "unnecessarily opaque" and suggested that the lack of transparency "is inconsistent with public expectation and contributes to a public cynicism about the integrity of the process." The Committee recommended that "new standards of access to information at all stages of the drug review process [should be set], enhancing transparency and public confidence."[28] Further, in 2004, a House of Commons Standing Committee on health "supported the development of mechanisms to enable greater public disclosure of information about clinical trials."[29] These calls for change were

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[23] Melander, H., et al. (2003). Evidence b(i)ased medicine – selective reporting from studies sponsored by pharmaceutical industry: Review of studies in new drug applications. *British Medical Journal* 326:1171.

[24] Lexchin, J. & Mintzes, B. (2004). Transparency in drug regulation: Mirage or oasis? *Canadian Medical Association Journal*. 17(11), 1363.

[25] Melander et al., *supra* note 22, 1173.

[26] Healy, D. & Cattell, D. (2003). Interface between authorship, industry and science in the domain of therapeutics. *British Journal of Psychiatry*. 183, 22–27.

[27] Wilde Mathews, Anna. (2005). Ghost story. *Wall Street Journal*, (December 13, 2005), A1.

[28] as cited in Lexchin & Mintzes, *supra* note 23, 1363.

[29] Ibid.

most recently echoed in a Health Canada external working group report, which recommended that "[a]ll clinical trial types should be registered with the exception of those that meet a few explicit exclusion criteria."[30]

In order to address criticisms, the TPD revised the process in 2004, requiring a "Summary Basis of Decision" (SBD) for each review. This document provides the TPD's reasons for conferring market authorization on a particular drug. As noted by Lexchin and Mintzes, the most important aspect of the SBD is the inclusion of clinical trial results relating to the drug's safety and effectiveness. However, the authors' study reveals that the SBD provides insufficient information to ensure the safe use of medications. Specifically, the authors analysed 3 groups of medications for which "unpublished data submitted to drug regulators contained important clinical information that was either unavailable or misrepresented within the published literature" to determine if this information would have been revealed via the SBD mechanism.[31] With respect to COX-2 inhibitors, antidepressants and hormone replacement therapy, they concluded that "the information available in the published literature failed to reflect the full body of scientific knowledge about a drug's effects…[and that] [t]hese problems would not have been discovered using Health Canada's SBDs, which lack detailed information on clinical trial design, methods and outcomes."[32]

In general, the response of Health Canada has been unsatisfying. For example, although concerns over the potential heart-attack risks posed by Vioxx existed for years, regulators insist that they lack the legislative authority to compel pharmaceutical corporations to conduct research on safety issues once a drug is available on the market.[33] At one level, this response is certainly of assistance as it reveals that problems in Canada's drug approval process exist not only at the pre-approval stage, but also with respect to post-marketing surveillance:

> the current safety system is inadequate…Health Canada does not know which drugs have been withdrawn because they were unsafe; there is no systematic information about what triggers a safety withdrawal; safety warnings do not appear to affect prescribing practices.[34]

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[30] External Working Group on the Registration and Disclosure of Clinical Trial Information. (December 2006). Options for Improving Public Access to Information on Clinical Trials of Health Products in Canada.

[31] As cited in Lexchin & Mintzes, *supra* note 23, 1363.

[32] Ibid., 1365.

[33] Abraham, *supra* note 18.

[34] Lexchin, J. (2005). Drug withdrawals from the Canadian market for safety reasons 1963–2004. *Canadian Medical Association Journal*, 172(6), 767.

In order to address concerns such as these, Bill C-51 was introduced to Parliament in April 2008. The Bill, if adopted, will amend the *Food and Drugs Act* to implement a "progressing licensing" framework. Such a framework involves the assessment of a therapeutic product's risks and benefits over its entire life cycle as opposed to primarily in the pre-market period.

While this is positive in some respects, commentators have expressed preliminary concerns that the threshold for initial market authorizations will be lowered in exchange for ongoing reporting requirements[35] and that such reform could actually lead to "more Vioxxes."[36] Indeed, there is a real danger that a singular focus on post-marketing surveillance will obfuscate the fact that corporations fail to disclose the totality of studies conducted with respect to particular drugs – and the resulting risk implications – before a drug goes to market. This lack of fulsome disclosure is a function of a flawed regulatory approval process. Further, the lack of transparency takes place within an unhealthy relationship of dependence. In 1994, the TPD began charging drug manufacturers fees for drug approval submissions. Within 5 years, these fees accounted for approximately 70% of the costs associated with operating the TPD, and, "[i]n return, the industry asked for action on the speed with which new drugs are approved."[37]

Corporate Law Theory

The practice of selective reporting implicates the issue of corporate social responsibility and its relation to profit maximization. Drug companies are reticent to disclose clinical trial results in an effort to safeguard their economic interests – they want to move a drug to market as soon as possible without regulatory hurdles. They also want to remain in control of data. In other words, with respect to issues of unfair competition in the marketplace, there is a concern that trade secrets will leak or that a competitor will appropriate patient networks. This, in addition to broader detrimental exposure to the integrity of the corporate product, would affect the immediate profitability of the business as reflected in its quarterly earnings reports.

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[35] Kondro, W. (2007). Health Canada proposes new regulatory regime for drugs. *Can. Med. A. J.,* 176: 1261.

[36] Wiktorowicz, M. (2008). Submission to the House of Commons Standing Committee on Health. No. 023 (15 April 2008), 7.

[37] Lexchin, *supra* note 33, 765.

While this chapter argues for a stringent regulatory framework, I would further argue that pharmaceutical corporations should, in fact, disclose the results of all clinical trials (both positive and negative) in the broader public interest. Quite simply, while the tangible data is still emerging, it has become increasingly clear that the lack of full disclosure has had a direct effect on the health of consumers (for example, the recent Vioxx scandal discussed above). Such a suggestion engages the issue of corporate social responsibility, the precise contours of which are constantly reshaped in keeping with the evolving narrative of the corporation's societal role.

This discussion is informed by two seemingly opposed theoretical models. Under the shareholder primacy model, championed by the Chicago school of monetary economics,[38] the corporation is viewed as private property owned by its shareholders. Its purpose is to maximize the wealth of these owners and the role of directors is to facilitate the owners' financial interests.[39] In contrast, the social entity/communitarian model views the corporation as a social entity, not as the private property of shareholders. Under this approach, the corporation carries a public purpose. It is born and operates as a legal construct only with governmental approval. Government's granting of the corporation's juridical personality is seen as warranted by the State's desire to promote social welfare (in other words, corporations have the potential to benefit society). Thus, as an extension, "the corporate purpose can be seen as including the advancement of the general welfare," and, "the making of a contribution to the public life of [the corporation's] communities."[40]

The debate between the shareholder primacy and social entity models as traditionally presented often presupposes a sharp dichotomy and, in that regard, reflects a deep conceptual incoherence. In attempting to negotiate the tensions between these two models, we are often forced to choose between either maximizing shareholder wealth or advancing social welfare. But the argument can be made that this divide is fallacious and that shareholder interests are, in fact, best served by pursuing social welfare.

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[38] See Friedman, M. (13 September 1970). The social responsibility of business is to increase its profits. *New York Times Magazine*.

[39] Allen, W.T. (1992). Our schizophrenic conception of the business corporation. *Cardoza Law Review*, 14(2), 265.

[40] Ibid., 271.

Academic studies establishing a positive correlation between a company's social performance and its financial performance have emerged.[41] The business case for social responsibility is rooted in a complex understanding of the short and long-term pressures that stakeholder groups put on businesses. Their heightened expectations create real pressures on companies for increased transparency and responsiveness. Taking into account factors such as positive employee relations and customer/supplier loyalty, it is now often argued that a company's corporate social responsibility record has an impact on its bottom line through its effect on the company's "reputational capital."[42] and that there is an empirical connection between reputation/goodwill and firm market value.[43] Studies analysing the effects of ethical business activity on share prices have indicated that a corporation's social performance and its share value have a positive correlation.[44] One inquiry found "overwhelming evidence of a positive relationship between social and financial performance indicators in a sample of large and important U.S. corporations," and concluded that "financial performance either precedes or is contemporaneous with social performance."[45] Another found that "shareholder wealth is decreased when firms act in a socially irresponsible or illegal manner," and that, for business enterprises, "acting in a socially responsible and law-abiding manner can be seen as a necessary (though not sufficient) condition for increasing shareholder wealth, all other things equal."[46]

The acceptance of one of these competing models over another (and of the supposed dichotomy between the two theoretical models), and thus of a particular normative model respecting the role of corporations

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[41] See Freeman, M. (2001). Doing well by doing good: Linking human rights with corporate self-interest. *International Business Law Journal*, 6: 741; Griffin, J.G. & J.F. Mahon (1997). The corporate social performance and corporate financial performance debate: Twenty-five years of incomparable debate. *Business and Society*, 36(1); Orlitzky M. & J.D. Benjamin (2001). Corporate social performance and firm risk: A meta-analytic review. *Business and Society*, 40(4).

[42] See Fombrun C.J., et al (2000). Opportunity platforms and safety nets: Corporate citizenship and reputational risk. *Business and Society Review*, 105(1).

[43] See Chauvin, K.W. & M. Hirschey (1994). Goodwill, profitability and the market value of the firm. *Journal of Accountability and Public Policy*, 13(2).

[44] Riahi-Belkaoui, A. (1991). Organizational effectiveness, social performance and economic performance. *Research in Corporate Social Performance and Policy*, 12.

[45] Preston, L.E. & D.P. O'Bannon (1997). The corporate social-financial performance relationship: A typology and analysis. *Business and Society*, 36(4), 428.

[46] Frooman, J. (1997). Socially irresponsible and illegal behavior and shareholder wealth: A meta-analysis of event studies. *Business and Society*, 36(3), 221.

in society, has a direct bearing on the subject at issue. In focusing on the long-term financial repercussions of the corporate conduct at issue, it is possible to undercut the position that acting in the public interest (that is, disclosing all clinical drug trial results) would necessarily be antithetical to profit maximization.

The Vioxx scandal serves as a preliminary example of how the failure to act in a socially responsible manner early on can result in detrimental long-term financial consequences for a corporation. After Merck disclosed the previously suppressed side-effects of Vioxx, the company's share price has nearly halved, taking $30 billion off the value of the world's fourth-biggest drug company.[47] The company is also currently named as a defendant in over 7,500 Vioxx-related lawsuits and has already been found liable in one piece of litigation. In that case, a Texas jury found Merck liable for the death of a 59 year-old Vioxx consumer and awarded the victim's widow $253.4 million in punitive and compensatory damages.[48] In the face of declining profits and legal costs, Merck recently announced that it is eliminating 7,000 jobs globally (which amounts to approximately 11 per cent of its work force) including 235 in Canada.[49] Further, in the U.S., Merck's shareholders recently brought a derivative suit arising from the Vioxx scandal. Although ultimately unsuccessful, this litigation is noteworthy given the nature of a derivative claim. Unlike other shareholder remedies that are personal in nature, this action alleges that harm has been done *to the corporation*. In this case, shareholders argued that the directors breached their fiduciary duty to the corporation by directing Merck to deny the existence of known cardiovascular health risks – the result of which was billions of dollars in losses.[50]

AVENUES FOR REFORM

Domestic Litigation

Domestic litigation is one strategy available to address the problem of selective disclosure. Most notably, it has been used with respect to

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[47] *The Economist*, *supra* note 2.

[48] Kaufman, M. (20 August 2005). Merck found liable in Vioxx case. *Washington Post*, pp. A01.

[49] Mckenna, Barrie. (Tuesday, November 29, 2005). Merck to Axe 7,000 jobs, 235 in Canada. *Globe and Mail.*

[50] *In Re Merck & Co. Inc. Derivative & ERISA Litigation* (5 May 2006), New Jersey 3: 05cv02368 (D.N.J), 2006 WL 1228595 (WL).

SSRIs. SSRI medications (including Paxil, Prozac and Zoloft) are prescribed in relation to psychiatric disabilities such as depression and have the effect of blocking the reuptake of serotonin, an important chemical neurotransmitter in the brain. In June 2004 New York State filed a novel suit against GlaxoSmithKline, accusing the company of:

> repeated and persistent fraud by misrepresenting, concealing and otherwise failing to disclose to physicians information in its control concerning the safety and effectiveness of its antidepressant medication paroxetine HCL…[that is, "Paxil"] in treating children and adolescents with Major Depressive Disorder ("MDD")."[51]

The specific allegations made in the litigation are both striking and germane to the present discussion. They outline how the pharmaceutical giant both suppressed the results of various clinical trials of Paxil and subsequently engaged in a deceptive marketing campaign:

> GSK's studies showed the possibility of a link between paroxetine and an increased risk of suicidal thoughts and acts in adolescents. Combined, studies 329, 377 and 701 showed that certain possibly suicide-related behaviors were approximately two times more likely in the paroxetine group than the placebo group…
>
> …
>
> Because its studies failed to demonstrate efficacy for paroxetine in treating MDD in children and adolescents and suggested a possible increased risk of suicidal thinking and acts for these youth, GSK sought to limit physicians' access to only the most favorable aspects of the data from these studies. To accomplish this, GSK embarked on a campaign both to suppress and conceal negative information concerning the drug and to misrepresent the data it did reveal concerning the drug's efficacy and safety.
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> …
>
> An internal GSK document from 1998 concluded that, in light of the mixed efficacy outcomes from study 329 and the entirely negative results of study 377, GSK's "target" was "[t]o effectively manage the dissemination of these data in order to minimise any potential negative commercial impact."
>
> As part of its campaign to "manage the dissemination of these data," the document recommended that GSK prepare and cause the publication of a full article on the only study with some favorable conclusions, study 329.
>
> Thereafter, and in accordance with the recommended plan, an article that described and analyzed the results of study 329 was published in a

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[51] *People of the State of New York* v *GlaxoSmithKline* (2004) 1, online: news.findlaw.com/cnn/docs/glaxo/nyagglaxo60204cmp.pdf (visited November 30, 2010).

> professional journal. The authors of this article included two GSK employees who authored GSK's final clinical report for study.
>
> Although it allowed the data from study 329 to be published, GSK concealed and suppressed studies 377 and 701, which failed to show that paroxetine was more effective than placebo in treating MDD in children and adolescents.
>
> While information from study 377 was presented at a medical convention in 1999, neither study 377 nor study 701 has ever been published, and they remain unavailable to physicians…
>
> …
>
> GSK has repeatedly misrepresented the safety and efficacy outcomes from its studies of paroxetine as a treatment for MDD in a pediatric population to its employees who promote paroxetine to physicians. These sales representatives are the GSK personnel who routinely have personal contact with the physicians who decide whether to write prescriptions for paroxetine.
>
> On a cover memo that transmitted the published article concerning study 329 to "All Sales Representatives Selling Paxil," Zachary Hawkins, GSK Paxil Product Management, stated, "*PAXIL demonstrates remarkable efficacy and safety in the treatment of adolescent depression*."…
>
> Study 329 did not demonstrate remarkable efficacy and safety in treating adolescent depression. Although the memo contained the boiler-plate language, "FYI *Article will be stamped: This article is for pharmaceutical consultants' Information only. Do not use it with, or distribute it to physicians*," it is clear that this was the intent. GSK would have had no reason to provide this information to sales representatives other than to use it to falsely characterize study 329 in their communications with physicians. Indeed, it appears that these sales representatives had paroxetine "targets" for psychiatrists who treat only children and adolescents, because GSK informed its sales force that these targets would be eliminated in 2003 (emphasis in the original).[52]

Recent academic analysis of the documents required to be produced during the course of the litigation has confirmed the allegations of selective reporting against GlaxoSmithKline.[53] It should be noted that global revenues for Paxil in 2003 were just under $4.97 billion.[54] Given this economic reality, the content of an internal GlaxoSmithKline memorandum is even more troubling, as it "explicitly states that

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[52] Ibid., 6–9.

[53] Jureidini, J.N., et al. (2008). Clinical trials and drug promotion: Selective reporting of study 329. *International Journal of Risk & Safety in Medicine* 20:73.

[54] Kondro, *supra* note 34, 783.

'the efficacy data are insufficiently robust to support a regulatory submission' and that reporting such a statement to the regulatory authorities would be 'commercially unacceptable' since it would undermine the overall status of the drug."[55] In other words, confirming Paxil's potential negative side-effects *vis-à-vis* children could undermine the drug's credibility with respect to the treatment of adults.[56] GlaxoSmithKline's response when the confidential memorandum was leaked is illustrative of the problematic gap in the domestic regulatory framework: "GSK spokeswoman Jill McKinlay-Morris…went on to say [that] 'GSK abided by all regulatory requirements for submitting safety data.' "[57]

The New York State litigation eventually settled, with GlaxoSmithKline agreeing to summarize the results of all clinical drug trials it sponsors and to place these summaries in a register to be posted on its website.[58] Other drug companies (for example Merck, Eli Lilly, and Johnson & Johnson) have expressed support for the idea of trial registers.[59] This compromise, however, has been met with skepticism since "previous experience suggests that, because of inherent conflicts of interest, it is unlikely that industry will ever be able to establish a large, common, complete, useful, trustworthy, up-to-date, and easily accessible register maintained over the long term."[60]

Rather, it is clear that, "[t]he most significant power to counterbalance the power of pharmaceutical companies lies with the drug regulatory agencies."[61] For regulatory involvement to be effective, however, reform is needed. Hand-in-hand with its capitulation to industry pressure to increase the pace of the drug approval process, domestic regulatory agencies' process of evaluating a drug's effectiveness and safety is flawed in that too much reliance is placed on the sponsors of the proposed drug. As noted with respect to the U.S. Food and Drug Administration, "[i]t has little control over how research subjects are recruited, where they are recruited, where the research is taking place, who is involved in the conduct of the trials, and so on."[62] Most importantly,

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[55] Lemmens, *supra* note 9, 641–642.
[56] Ibid., 642.
[57] Kondro, *supra* note 34, 783.
[58] Rennie, *supra* note 20, 1361.
[59] Ibid., 1360.
[60] Ibid., 1361.
[61] Lemmens, *supra* note 9, 650.
[62] Ibid.

there is nothing in the regulatory framework that prevents sponsors from manipulating clinical trials to show only positive results.

Large drug companies obviously have a clear financial interest in the outcome of the approval process. The fact that they have the ability to finance expensive clinical drug trials should not obfuscate their motivation to influence the results of clinical trials and, in that regard, the establishment of an independent drug evaluation agency that would administer clinical trials is strongly preferred.[63] A recent Royal Commission report in Canada makes this recommendation, *inter alia*, in order to address the role of pharmaceutical companies in the evaluation process.[64] It should be noted that the report does not prohibit the independent "National Drug Agency" from receiving any financial contribution from the pharmaceutical industry, but instead provides that:

> the industry's contribution should not be directly tied to paying for any particular service. In effect, a "firewall" must be established between the industry's financial contribution and the Agency's work. Very stringent guidelines for pharmaceutical industry contributions should be in place to ensure the Agency's independence from the industry it regulates.[65]

The International Human Rights Framework

Rather than pushing for regulatory reform, current Canadian litigation has focused on seeking monetary remedies from drug manufacturers arising out of their alleged negligence (for example, lawsuits launched against Merck *vis-à-vis* the Vioxx scandal). To date, no verdict has been rendered. As further litigation progresses, it will be interesting to see whether claims against Health Canada will emerge.[66] In other words, can it be argued that Health Canada should attract civil liability under the theory that in providing regulatory approval of noxious drugs, the federal government failed to adequately test the proposed drug or to require such testing? The answer remains to be seen, though such an argument is not without precedent. In *Harrington v Canada (Minister of Health)* (2003)[67] a plaintiff in a proposed class action claimed damages

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[63] Ibid., 653.

[64] Commission on the Future of Health Care in Canada. (2002), 201.

[65] Ibid., 203.

[66] CBC News, (2005).

[67] 20 C.C.L.T. (3d) 17 (B.C.S.C.). But see *Attis* v *Canada (Minister of Health)* (2003) 29 C.P.C. (5th) 242 (Ont. Sup. Ct.), where the Court declined to strike out a similar claim.

against the Canadian Minister of Health, arguing that the Minister had approved unsafe breast implants and that the granting of regulatory approval in itself constituted a governmental representation of the implants' safety. The Court, however, did not accept the argument, reasoning that the relevant regulatory framework did not actually impose any mandatory testing obligations on the government.

A strong first step in the establishment of the independent, institutional safeguard advocated above (and, in any event, in the formulation of an independent, mandatory clinical trials registry) would be a judicial declaration of the current regulatory regime's unlawfulness. Upon securing an appropriate plaintiff for litigation purposes, domestic public interest advocates might seek such a remedy by filing an application (and accompanying notice of constitutional question) before the courts, arguing that the regulatory regime, as presently constituted, violates sections 7 and 15(1) of the Canadian *Charter of Rights and Freedoms* (*Charter*). In other words, that the impugned regulatory regime violates the right to "life, liberty and security of the person" and also denies the right to equal protection and equal benefit of the law without discrimination on the basis of disability.

The Right to Health

In seeking such a remedy, advocates should consider how the federal government's insufficient regulatory regime engages the international human rights framework. Before discussing this point, a relevant new strategy in the protection of international human rights should be mentioned: "a shift…from nearly exclusive attention on the abuses committed by governments to close scrutiny of the activities of business enterprises, in particular multinational corporations."[68] In fact, it has now become trite to say that corporations have been complicit in violations of international human rights. As such, it has become common in present currents of legal thought to argue that the answer to the question of business enterprise responsibility can only be found in the transnational system and there has been a recent flurry of academic interest in the relationship between the international system and multinational corporations, the regulation of which "represents a fundamental challenge to the international legal order, [traditionally] premised on the

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[68] Ratner, S.R. (2001). Corporations and human rights: A theory of legal responsibility. *Yale Law Journal*, 111(3), 446.

centrality of states."[69] Given the complexities and evolving nature of arguments that would seek to assign direct responsibility to corporate entities (in this case, to pharmaceutical companies), the focus of the present chapter is on the role of the domestic state. In other words, using the example of Canada, I will now discuss how the federal government's regulatory shortcomings do not resonate with its international human rights treaty obligations *vis-à-vis* the right to health.

While recognised in various international and regional human rights instruments, the right to health is most authoritatively articulated in Article 12 of the ICESCR, to which Canada has acceded ("accession" is the formal acceptance of a treaty by a State which did not take part in negotiating and signing it and has the same effect as ratification). Specifically, under Article 12.1, States Parties recognise "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."

It should be noted that commentators have persuasively argued that Canadian courts have an obligation to interpret domestic law in a manner that conforms to binding international law norms.[70] That being said, international instruments are not considered directly applicable domestically unless they have been "transformed" to apply in Canada. In other words, they must be incorporated into Canadian law by a provincial legislature or federal Parliament. However, the act of determining whether or not international norms have been explicitly implemented via domestic legislation is by no means a straightforward process.[71] Indeed, the domestic status of international human rights treaties, in particular, has been left unclear by Parliament.[72]

Canada's domestic law (whether in the *Charter* or otherwise) has no express provision recognising the right to health. As such, it can be argued that advocates are not able to directly invoke Article 12 of the ICESCR as a self-standing positive right. Indeed, as noted by Porter, "[a] consistent recommendation of CESCR [the Committee on Economic, Social and Cultural Rights] in its most recent reviews of Canada has been that human rights legislation be amended to include

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[69] Chesterman, S. (2004). Oil and water: Regulating the behavior of multinational corporations through law. *New York University Journal of International Law and Politics*, 36, 307.

[70] Brunnée, J. & S. Toope (2002). A hesitant embrace: The application of international law by Canadian courts. *Canadian Yearbook of International Law*, 30, 6.

[71] Ibid., 20–21.

[72] Ibid., 23.

the right to housing and other social and economic rights."[73] By contrast, in its reporting to the Human Rights Committee, Canada has claimed implementation of the *International Covenant on Civil and Political Rights* through the *Charter*[74]—a fact that emphasises the second class status the Canadian government affords economic and social rights.

However, despite the lack of an explicit guarantee of the right to health, of critical importance to domestic advocates is the Supreme Court of Canada's recognition that non-binding international human rights law instruments can be used as an interpretive framework for domestic legislation (that is, the regulatory framework discussed above). Indeed, in some instances, the Court has been open to the migration of ideas across the borders of legal disciplines and systems, which is currently the subject of a lively scholarly debate.[75] As held by the Madam Justice L'Heureux-Dubé for the majority in *Baker v Canada (Minister of Citizenship and Immigration)* (1999):

> International treaties and conventions are not part of Canadian law unless they have been implemented by statute…Nevertheless, the values reflected in international human rights law may help inform the contextual approach to statutory interpretation and judicial review. As stated in R. Sullivan, Dreidger on the Construction of Statutes (3rd ed. 1994), at p. 330:
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> the legislature is presumed to respect the values and principles enshrined in international law, both customary and conventional. These constitute a part of the legal context in which legislation is enacted and read. In so far as possible, therefore, interpretations that reflect these values and principles are preferred.[76]

To date, the right to health has not played a significant role in Canada's domestic litigation. On rare occasions where the right has been invoked, it has not been incorporated into the Court's analysis, underscoring the uphill battle facing disability rights advocates. This is best revealed in *Chaoulli* v *Quebec (Attorney General)* (2005), where the Supreme Court of Canada considered excessive waiting periods for medical treatment

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[73] Porter, B. (2004). Homelessness, human rights, litigation, law reform: A review from Canada. *Australian Journal of Human Rights*, 10(2), 142.

[74] Brunnée & Toope, *supra* note 69, 23–24.

[75] Choudhry, Sujit. (Ed.) (2007). *The migration of constitutional ideas.* Cambridge: Cambridge University Press.

[76] *Baker v Canada (Minister of Citizenship and Immigration).* [1999] 2 S.C.R. 817, paras 69–70.

in Canada's public health care system. The Court held that the waiting periods endangered both individuals' health and lives. As a result, it reached the troubling conclusion that legislated prohibitions on the purchase of private health care insurance were in violation of the right to life in Quebec's human rights legislation (thus declaring a right to make such purchases). The interveners Charter Committee on Poverty Issues and Canadian Health Coalition supported a remedy that would address the rights violations of all Canadians, not just those who have the financial means to purchase private health insurance. In doing so, they argued that "[a]n interpretation of sections 7 and 15 [of the *Charter*] that recognizes the right to health, including access to health care without financial barriers, is consistent with and dictated by Canada's international human rights obligations."[77] This was supported with reference to Article 12 of the ICESCR, which, unfortunately was not referred to in the Court's decision.

At the provincial level, in *MacKeigan* v *Department of Community Services*, the Nova Scotia Assistance Appeal Board refused a claimant's social assistance appeal request for special needs funding to have necessary dental surgery. The Court ultimately quashed the tribunal decision and sent the matter back to the Board for reconsideration. In its Order, the Court specifically instructed the Board to exercise its discretionary authority in accordance with "Canada's international human rights obligations, especially including the right of everyone "to the enjoyment of the highest attainable standard of physical and mental health as provided for in the *International Covenant on Economic, Social and Cultural Rights*."[78] Although the claimant was ultimately successful, the second Board decision, unfortunately, did not reference the ICESCR.

At times, the ICESCR has been invoked by the Courts, but in a retrogressive manner. For example, in *Gosselin v Québec (Attorney General)* (2002), the Supreme Court of Canada heard a *Charter* challenge to social assistance legislation in Quebec that imposed insufficient welfare rates for people aged under 30 who did not participate in programs aimed to facilitate entry into the workforce. The challenge was brought on the basis of age discrimination and a violation of the

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[77] Charter Committee. (2005), para. 31. See also the Charter Committee on Poverty Issues' factum in *Eldridge* v *British Columbia (Attorney General)* (1997).

[78] *MacKeigan* v *Department of Community Services* (2004) Consent Order, August 17, 2004, 2.

section 7 *Charter* right to "life, liberty and security of the person" (the amount provided by the legislation was insufficient to cover basic needs). Despite a strongly written dissent by Justice Arbour (who was supported by Justice L'Heureux-Dubé), the Supreme Court rejected the claim. Chief Justice McLachlin, for the majority, invoked the ICESCR as a means of distinguishing the Quebec legislation:

> Was s. 45 intended to make the adequacy of a social assistance regime's specific provisions subject to judicial review, unlike the neighbouring provisions canvassed above? Had the legislature intended such an exceptional result, it seems to me that it would have given effect to this intention unequivocally, using precise language. There are examples of legal documents purporting to do just that. For example, Article 11(1) of the *International Covenant on Economic, Social and Cultural Rights*, 993 U.N.T.S. 3, recognizes "the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions"…
>
> In contrast…s. 45 of the *Quebec Charter* is highly equivocal. Indeed, s. 45 features TWO LAYERS of equivocation. Rather than speaking of a right to an acceptable standard of living, s. 45 refers to a right to MEASURES. Moreover, the right is not to measures that ensure an acceptable standard of living, but to measures that are SUSCEPTIBLE OF ENSURING an acceptable standard of living. In my view, the choice of the term "susceptible" underscores the idea that the measures adopted must be oriented toward the goal of ensuring an acceptable standard of living, but are not required to achieve success. In other words, s. 45 requires only that the government be able to point to measures of the appropriate KIND, without having to defend the wisdom of its enactments. This interpretation is also consistent with the respective institutional competence of courts and legislatures when it comes to enacting and fine-tuning basic social policy.[79]

The reticence of both the Canadian government and courts to incorporate international law respecting economic and social rights domestically, however, should not thwart the efforts of domestic disability advocates to push the boundaries of the regulations in question. In doing so, what relevant international legal principles are at their disposal?

In its General Comment No. 14, the Committee on Economic, Social and Cultural Rights (the Committee) delineated the normative content of the right to health. In particular, it clarified that the right does not

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[79] 4 S.C.R. 429, para 93.

imply that individuals have a right to be *healthy*.[80] In that sense, the idea of "the highest attainable standard of health" recognises that neither individuals nor governments can ensure a particular level of health, "which is determined by the individual's heredity and environment, and can be moulded by health interventions only to a limited degree."[81] As a result, the right to health is to "be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health."[82] Further, the Committee interpreted the right to health as an inclusive right that extends not only to appropriate and timely health care, but also to the underlying determinants of health, which, *inter alia*, includes access to health-related information.[83] Most importantly for present purposes, the Committee articulated that the right to health consists of four elements, including the following:

> (b) *Accessibility*. Health facilities, goods and services have to be accessible to everyone without discrimination, within the jurisdiction of the State party. Accessibility has four overlapping dimensions…[including]…
>
> INFORMATION ACCESSIBILITY: ACCESSIBILITY INCLUDES THE RIGHT TO SEEK, RECEIVE AND IMPART INFORMATION AND IDEAS CONCERNING HEALTH ISSUES…
>
> (d) *Quality*. AS WELL AS BEING CULTURALLY ACCEPTABLE, HEALTH FACILITIES, GOODS AND SERVICES MUST ALSO BE SCIENTIFICALLY AND MEDICALLY APPROPRIATE AND OF GOOD QUALITY. This requires, *inter alia*, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation.[84]

With respect to the general obligations imposed on States parties, the ICESCR provides that governments "undertake to take steps…with a view to achieving progressively the full realization of the rights recognized in the present Covenant."[85] Despite the notion of progressive realisation (and the accompanying recognition of limited available

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[80] General Comment No. 14, the Committee on Economic, Social and Cultural Rights, Para 8.

[81] Tomasevski, Katarina. (1999). The right to health for persons with disabilities. In Deneger, T. & Y. Koster-Dreese (Eds.) *Human rights and disabled persons: essays and relevant human rights instruments*, 135.

[82] General Comment No. 14, the Committee on Economic, Social and Cultural Rights, para 9.

[83] Ibid., para 11.

[84] Ibid., para 12, emphasis added.

[85] ICESCR Article 2(1).

resources) it is understood that States parties are also under some level of immediate obligation, to the maximum of its available resources.[86] Further, "States parties have a specific and continuing obligation to move as expeditiously and effectively as possible towards the full realization of article 12."[87] Last, as with all human rights, the right to health imposes three levels of obligations on States Parties – to respect, protect and fulfill the rights in question:

> The obligation to *respect* requires States to refrain from interfering directly or indirectly with the enjoyment of the right to health. The obligation to *protect* requires States to take measures that prevent third parties from interfering with article 12 guarantees. Finally, the obligation to *fulfil* requires States to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realization of the right to health.[88]

With respect to the specific obligations imposed on States parties, paragraph 34 of General Comment No. 14 provides that the obligation to respect the right to health includes the State's responsibility to refrain from "marketing unsafe drugs," a requirement which is clearly not being met in the current circumstances. It further prohibits the application of coercive medical treatments "unless on an exceptional basis for the treatment of mental illness." In such exceptional situations, both international standards and best practices are to be respected and particular mention is made of the UN's *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care* (MI Principles).

This reference to forced psychiatric treatment is germane to the present discussion. Admittedly, the MI Principles have been criticised by various groups for putting forth a paternalistic model of healthcare and for being weak on the right to refuse often harmful antipsychotic treatment. However, Principle 10(1) is particularly interesting for our purposes. Under it, "[m]edication shall meet the best health needs of the patient," and "mental health practitioners shall only administer medication of known or demonstrated efficacy."[89] Following from this, governments that allow forced treatment interventions with

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[86] General Comment No. 14, the Committee on Economic, Social and Cultural Rights at para. 31. See also *General Comment No. 3*, Committee on Economic, Social and Cultural Rights, 5th Sess., U.N. Doc.E/1991/23 (1991).

[87] Ibid.

[88] Ibid., para 33.

[89] This is subject to Principle 11(15), which is not germane to the present discussion.

medications that have had negative clinical trial results suppressed (for example, SSRIs) are neither meeting the best health needs of the patient nor administering medications of known or demonstrated efficacy. With respect to the latter, it can be argued that suppressed information regarding the side-effects of medications does not relate to their ability to produce the desired effect. However, I would argue that the efficacy of a medication is severely compromised if the medication carries with it side-effects so serious as to be potentially fatal.

There are additional obligations that are relevant to the question at issue. Under paragraph 35 the obligation to protect the right to health includes the responsibility of States to "ensure that third Parties do not limit people's access to health-related information and services." Under paragraph 37, the obligation to fulfil the right to health includes the responsibility of States to "foster…recognition of factors favouring positive health results, e.g. research and provision of information," and ensure that obligations are met "in the dissemination of appropriate information relating to…the availability of services," and "support…people in making informed choices about their health." Under paragraph 42, while acknowledging that States are ultimately responsible for compliance with the ICESCR, the Committee recognises that:

> non-governmental organizations, civil society organizations, as well as the private business sector – have responsibilities regarding the realization of the right to health…[and that] State parties should therefore provide an environment which facilitates the discharge of these responsibilities.

Further, paragraph 50 enumerates various violations of the obligation to respect the right to health, including:

> the deliberate withholding or misrepresentation of information vital to health protection or treatment…and the failure of the State to take into account its legal obligations regarding the right to health when entering into bilateral or multilateral agreements with other States, international organizations and other entities, such as multinational corporations.

Last, paragraph 51 provides the following violations of the obligation to protect the right to health: "the failure to regulate the activities of individuals, groups or corporations so as to prevent them from violating the right to health of others…[and] the failure to discourage production, marketing and consumption of tobacco, narcotics and other harmful substances."

Conclusion

To date, the intersection of States parties' international human rights obligations with the activities of pharmaceutical corporations has been primarily discussed *vis-à-vis* the role such corporations play in providing affordable access to drugs in developing countries. Indeed, "[t]he most prevalent criticism of the pharmaceutical industry has related to the high prices charged for life-prolonging drugs, particularly drugs which combat and relieve the symptoms of HIV/AIDS."[90] Currently under-explored, however, is the legal landscape surrounding the selective reporting of negative clinical drug trial results and the right to health of persons with disabilities.

In September 2005, representatives of pharmaceutical company Novartis reiterated the standard industry position. Namely, while the industry can contribute to the realisation of the right to health, its role is merely ancillary to that of the state: "[o]nly the state can guarantee *a priori* ownership across the whole of society and foster development in the sense of public welfare."[91] However, a further point was made. In discussing the role that the industry can play, it was emphasized that:

> [i]n its business activities, Novartis *respects* (in that it does not abuse) the right to health by complying with all international and national laws and regulations, such as those…on the safety of its products and ethical principles in the performance of clinical studies.[92]

Thus, the industry has set forth a simple "we act in harmony with the law" justification. While Health Canada approves medications that are manufactured by the pharmaceutical industry, it has said that drug companies carry "the primary responsibility for the safety of any product they sell, manufacture, import or distribute to the Canadian public," and that they "must comply with all legislative and regulatory requirements."[93] However, as discussed above, the regulatory regime governing the drug approval process actually facilitates the impugned

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[90] Joseph, S. (2003). Pharmaceutical corporations and access to drugs: The 'fourth wave' of corporate human rights scrutiny. *Human Rights Quarterly*, 25(2), 427.

[91] Breuer, M. & A. Schulze (2005). Supplement rather than substitute – the abstract right to health and appropriate action at Novatis. *Ethical Perspectives on Balancing Business and Public Interests*, 22–24 Sept., 4.

[92] Ibid., 5.

[93] Health Canada, *supra* note 12.

corporate conduct by not requiring the submission of all positive and negative drug trials. This, in turn, has repercussions for the health and well-being of disabled drug consumers and undermines their right to safe, effective medications.

Consequently, in tandem with lobbying efforts for policy reform, litigation launched by domestic advocates can have an important role in the establishment of an independent drug evaluation agency and a corresponding independent and mandatory clinical trials registry. In seeking a judicial declaration of the current regulatory regime's unlawfulness, advocates should incorporate an analysis that engages the international human rights framework. Used as an interpretative mechanism, the right to health as found in the ICESCR, and interpreted by the Committee, can be a useful tool in the public interest advocacy arsenal.

Persons with disabilities make up one of the largest global minority groups. Without question, their rights have been systematically violated in virtually all societies. If we accept the social model of disability, the logical progression is a rights-based paradigm that focuses on the responsibility of the State to address socially-created impediments and to ensure that the provision of health care, including medications, is respectful to the dignity and equality of persons with disabilities. A rights-based approach must inform the regulatory framework in order to empower and recognise persons with disabilities as active rights-bearing individuals. As it stands, current corporate practices and the Canadian federal government's lack of meaningful regulation arguably reinforce and perpetuate the medical model of disability – stripping persons with disability of agency and reducing them to passive, uninformed subjects of clinical intervention.

PART IV

PROMOTING INCLUSION AND PARTICIPATION

INTRODUCTION: INCLUSION AND PARTICIPATION

Inclusion is the principle that all people have the right to take part in all facets of the society in which they live. Where human rights are accorded, people with disabilities will not live on the margins of society but will have meaningful interaction, involvement and engagement in the workforce, in leisure, in education and in their private lives. Whatever goods a society has to offer will, according to the principle of equality, be accessed by people with disabilities on the same terms as they are available to those without disabilities. This section is structured around the principles of inclusion outlined by Jones in chapter 3. She explains:

> Fundamentally, inclusion is the principle that we are all entitled to participate fully in all aspects of society; that we all have the same rights and responsibilities; that we all have something to contribute. It is the principle which demands valued recognition of all people and the entitlement of all to meaningful interaction, involvement and engagement in every part of the complex, multifaceted societies in which we live.[1]

Jones argues that there are three aspects to inclusion: there must be an inclusive attitude towards people with disabilities; people with disabilities must have access to the benefits of society; and people with disabilities must be facilitated to ensure their ability to participate in society. She argues that it is not sufficient that people with disabilities are tolerated, nor even that they are accepted as members of society. Inclusion indicates a willingness to facilitate or accommodate difference and to make changes to the requirements of entry necessary to allow that participation.

The authors in this section explore what is needed for people with disabilities to be included in a number of social circumstances. Whether the focus is on the rules of engagement or disability specific matters; on the implementation of rules or the application of human rights at the intersection of disability and law; or where legal governance at first appears to be disability neutral, bringing inclusory principles into play provides a radical and critical perspective on the the right to inclusion and participation for people with disabilities beyond traditional legal constructions of inequality.

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[1] Jones, Part I, page 57.

POLITICAL PARTICIPATION FOR PEOPLE WITH DISABILITIES

Michael Waterstone

Looking at disability through a human rights lens necessitates a discussion of equality and difference. A fundamental human rights principle is that individuals are inherently equal. Disability adds additional layers of complexity to this basic principle. Is the goal of human rights principles to eliminate discriminatory barriers keeping people with disabilities out of employment, public access, educational and other elements of public life, or are additional steps needed to ensure access? Put simply, is it enough to ensure that doors are open, or do we need to take the affirmative step of placing a ramp to acknowledge that not everyone can climb stairs?

As two of the pioneers of a rights-based approach to disability, Theresia Degener and Gerard Quinn, have explained, equality can be viewed in three ways: (1) formal or juridical equality; (2) equality of results; and (3) equal opportunity or structural equality.[1] This essay discusses equality for people with disabilities in political participation, itself a recognised international human right. I argue that the preferable rights-based approach to equality in political participation for people with disabilities should follow Degener and Quinn's third conception of equality. Specifically, elections must be structured in a way that allows people with disabilities to vote in the same way as their fellow citizens, to the greatest extent possible. This includes taking steps to protect the ability of people with disabilities to vote secretly and independently and in polling places, when these voting options are available to the general citizenry. This is consistent with larger rights-based notions of disability, which focus on equality of opportunity.

As a practical matter, democratic elections are increasingly the medium by which the international human right of political participation is met. It is indisputable that the past two decades have seen a

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[1] Degener, T. & G. Quinn. (2002). A survey of international, comparative and regional disability law reform. In M.L. Breslin & S. Yee (Eds.), *Disability rights law & policy: International and national perspectives*. Transnational Publishers, 7–8.

dramatic increase in the number of newly democratic states.[2] The United States appears committed to a policy of spreading democracy throughout the world.[3] Some academics go so far as to suggest that democracy itself is now a human right, while others, conceding that democratic government and the human right of political participation have a close relationship, argue that democracy is not necessary to guarantee the right of political participation.[4]

Whatever the ultimate merits of this debate, I take it as a given that democratic elections are often at least one of the ways that states meet their obligations to guarantee the human right of political participation. The question, then, becomes under what conditions this right is meaningful for people with disabilities. As a starting place, people with disabilities must be guaranteed the right to vote. Formal exclusions are unacceptable under any version of equality. But merely being guaranteed the right to a vote is not enough. Rather, to truly provide equality in political participation, a state must explicitly protect the ability of people with disabilities to vote in the polling places and by secret ballot, to the same extent as other citizens. In this way, difference is acknowledged, because without modification, people with certain disabilities may not be able to vote by secret ballot or in a polling place. But equality of opportunity is also protected because, when voting experiences are equalised to the greatest extent possible, all people have the same ability to influence the political process.

This essay proceeds in four parts. First, I discuss how both political participation and disability have evolved as human rights issues. Second, I make the argument that from a rights-based perspective, it is preferable that the right to political participation for people with disabilities be expressed in a way that specifically protects their rights to

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[2] See Marshall, M. G. & R.R. Gurr. (2003). Center For International Development & Conflict Management, Peace and Conflict, 17 ("There were eighty-three countries (83) classified as democracies in early 2002, nearly double the number of democracies counted in early 1984 (42)."); *see also* Maley, M. (2003). Transplanting election regulation. *Election Law Journal, 2*(4), 479–497. ("In the last fifteen years, a large number of multi-party elections have been held either in third world countries with little previous history of them, or in post-conflict environments as parts of peace settlements.").

[3] This position is supported by the writings of commentators like Natan Sharansky, who advocate foreign policy approaches that emphasise making international policy decisions with democracy-fostering effects. *See* Sharansky, N. (2004). *The case for democracy: The power to overcome tyranny & terror*. New York: Public Affairs Books.

[4] *See* Marks, S. & A. Clapham. (2005). *International human rights lexicon*. Oxford: Oxford University Press.

participate in elections in the same way as their fellow citizens, to the maximum extent possible. Third, I use the American legal and policy experience in voting for people with disabilities to demonstrate the parameters of this argument. Finally, I will offer observations on how domestic law in the United States and emerging international law fare under a rights-based approach in providing equal access in political participation.

Political Participation and Disability as Human Rights Issues

The right to political participation is an internationally recognised human right. The first human right instrument touching on political participation is the *Universal Declaration of Human Rights,* adopted by the United Nations General Assembly in 1948. This was not created for the purpose of establishing binding legal obligations but, instead, as a common standard of achievement to which all states aspire. It provides that, "Everyone has the right to take part in the government of his country…" and that, "this will [of the people] shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures."[5] Specifically, while citizens are guaranteed a secret ballot, this is qualified by, "equivalent free voting procedures," a term which is not defined.

The *International Covenant on Civil and Political Rights* is the principal treaty declaring a right to political participation. It creates binding legal obligations with respect to state parties. Article 25 of this Covenant provides that:

> Every citizen shall have the right and the opportunity, without any of the distinctions mentioned in Article 2[6] and without unreasonable restrictions…to vote and to be elected and at genuine periodic elections which

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[5] *See* GA Res. 217A(III), U.N. GAOR, 3d Sess., U.N. Doc. A/810 (1948).

[6] Article 2 of the Covenant provides that, "each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status." *Covenant on Civil and Political Rights*, G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No.16, at 52. U.N. Doc. A/6316 (1966).

> shall be by universal and equal suffrage and shall be held by secret ballot, guaranteeing the free expression of the will of the electors.[7]

By providing rights to "every citizen," the Covenant's protections should extend to people with disabilities. This falls within Degener and Quinn's first level of equality: that is, a formal exclusion from the voter rolls of people with disabilities would plainly violate the Covenant. But the Covenant stops there and makes no specific mention of voting issues for people with disabilities, nor acknowledges their differences in exercising their political participation rights. Making a voting accommodation (like third-party assistance) that does not guarantee secret voting might not be viewed as an "unreasonable restriction." Polling place access is not mentioned.

Traditionally, disability was not conceived of as a human rights issue, and people with disabilities were left behind as human rights were expanded and guaranteed in various treaties.[8] Over time, however, this has changed and disability issues have increasingly become recognised as belonging in the family of international human rights. The primary blueprint for the world community's disability rights and policy is the non-binding U.N. *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (Standard Rules). Adopted in 1993, the Standard Rules, among other things, provide:

> The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation. Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment, and social services.[9]

Non-governmental organisations took the initial lead in formulating standards about the human rights of people with disabilities regarding voting. The International Foundation for Electoral Systems has been active in setting forth international standards for the participation of

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[7] *International Covenant on Civil and Political Rights*, G.A. Res. 2200A, 21 U.N. GAOR, Supp. No. 16, at 52, U.N. Doc. A/6316 (1966).

[8] See Degener & Quinn, *supra* note 1, at 6; see also Herr, S.L. Gostin & H. Koh (2003). *The human rights of persons with intellectual disabilities*. Oxford: Oxford University Press, at 3–4.

[9] G.A. Res. 48/96, U.N. GAOR, 48th Sess., Supp. No. 49, Annex at 202011, U.N. Doc. A/Res/48/49 (1994).

people with disabilities in the voting process. The International Foundation for Electoral Systems has drafted a *Bill of Electoral Rights for Citizens with Disabilities,*[10] which, amongst other things, provides that citizens with disabilities have the right to participate on general terms of equality in the conduct of elections, including the right to vote by secret ballot. The International Foundation for Electoral Systems takes the position that these rights are guaranteed by Article 25 of the *International Covenant on Civil and Political Rights*. It has also drafted global standards making clear that it believes states are obligated to conduct voting at sites which are accessible for citizens with physical or other disabilities and to protect the right wherever possible to a secret ballot, without assistance, at public polling places.

As a culmination of a human rights approach to disability issues, the United Nations has adopted a comprehensive treaty on the rights of people with disabilities. The *Convention on the Rights of People with Disabilities* entered into force on 3 May 2008. The Convention is broad in scope, covering a bevy of issues impacting the lives of people with disabilities. The provisions of this Convention that deal with voting will likely become the preeminent international standard on the voting rights of people with disabilities. Article 29, Participation in Political and Public Life, provides, *inter alia*:

> States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake:
> a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:

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[10] This document was drafted and endorsed by participants attending a four-day workshop held in September of 2002 in Sweden. Participants from twenty-four nations participated, as did representatives of the Inter Parliamentary Union, the Council of Europe, and the Organization for Security and Cooperation in Europe. The Workshop was jointly convened by the International Foundation for Electoral Systems and the International Institute on Democracy and Electoral Assistance, with funding from the Swedish International Development Cooperation Agency. See: *Global Initiative to Enfranchise People with Disabilities – Rights and Standards*, available at http://www.electionaccess.org/subpages/Rights_Standards.htm. (last visited March 10, 2004).

> Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;
>
> Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;
>
> Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;
>
> b) To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:
>
> Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
>
> Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

The basic conceptual approach of Article 29 is consistent with the overall approach of the draft UN treaty – a nondiscrimination framework grounded on the idea of equal protection. People with disabilities should be able to exercise their political rights "without discrimination," essentially meaning on the same terms as their fellow citizens. The range of tasks that Article 29 commits states to undertake – promoting an environment in which people with disabilities can effectively and fully participate in political life; accessible and appropriate facilities; and secret ballots – seem largely justified on the basis that these are features of voting systems available to voters without disabilities.

THE HUMAN RIGHT OF POLITICAL PARTICIPATION FOR PEOPLE WITH DISABILITIES

People with disabilities should be explicitly guaranteed the same voting experience as the general population, to the greatest extent possible. This approach is both desirable as a policy matter, and is consistent with international human rights norms. This is reflective of the third understanding of equality set forth by Degener and Quinn. The first – formal equality – would be met if people with disabilities were not overtly excluded from the political process. As set forth below, this could leave people with disabilities with diminished political power. Similarly, the second understanding of equality – equality of results – is also inappropriate for political participation. The whole political process hinges on various groups being able to influence the political process. People with disabilities, who will likely be members of other political constituencies as well, deserve an equal place at the table, but no more. It is only through the third conception of equality – equality of opportunity – that this can happen. This provides equal access to voting opportunities for people with disabilities, and thus creates a level playing field for their political participation.

As set forth above, all people have the internationally recognised human right to participate in the political process, often expressed through voting in free and open elections. Most states (or at least democratic ones) have laws and norms protecting these "big picture" values. Broadly speaking, these norms provide that the franchise should be extended on equal terms and in a non-discriminatory manner. Individuals should be able to freely participate in elections, without fear of reprisal. There should be a reasonable level of certainty that votes will be counted. Elections should be governed by the rule of law, and voting institutions should be transparent to the greatest extent possible.

Under a model of formal equality, this should be sufficient to protect the human right of political participation for people with disabilities, who should fall within "all people." Yet in voting, the minutia matters. The way that elections are administered plays a vital role in determining whether people with disabilities get to participate in the political process in an equal and meaningful way. All too often, however, democratic states have administered elections in a way that compromises the voting equality of people with disabilities. Although states administer elections differently, there are often two ways that people with disabilities have fundamentally different voting experiences: by not being able to vote by secret ballot, and by not being able to vote at a polling place.

In the United States, for example, people with disabilities have generally not been able to vote secretly and independently, despite the fact that the secret ballot is a much valued feature of the American voting system. Its historical basis was to avoid the fraud and intimidation that occurred during voting early in America's history. But people with visual disabilities are typically directed to vote with the assistance of a friend or co-worker, or by absentee ballot. Several advocates have forcefully argued that this creates opportunities for third-parties to pressure them to change their votes, and otherwise cheapens the voting experience.[11] People with physical disabilities who are not able to access voting systems that have been designed without their interests in mind are typically offered "curbside voting," whereby voting machines are brought out to their vehicles. This form of voting does not include the traditional protections offered by voting in the voting booth.

People with disabilities in the United States have also been restricted from voting in polling places because of accessibility issues. Studies have shown that American polling places have significant barriers to accessibility for people with physical disabilities.[12] The traditional answer has been to allow people with disabilities an almost unqualified ability to vote by absentee ballot. But this curtails the expressive element that accompanies voting in the actual polling place on Election Day. Voting should properly be viewed as more than a strictly instrumental choice in electing a candidate.[13] Voting in a polling place is a way that a citizen asserts his or her place in the community. In the case of people with disabilities, a group that has traditionally been isolated and marginalised, this is particularly important. Absentee ballots also create an enhanced risk of fraud, and often have to be filed in advance

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[11] See Dickson, J.C. (22 July 2002). N.Y. city council committees on mental health, mental retardation, alcoholism, drug abuse and disability services. *N.Y. City Council Committees*; *see also* Disabled hail e-voting despite doubts, *CNN.com,* October 4, 2004 ("Blind, Rivera Ley had to rely on someone else to read the ballot aloud, then vote for her. That meant as many as four people – Rivera Ley, the person who pulled the levers and the election judges from both major parties as witnesses – huddled in the voting booth. "It's like a party in there," Rivera Ley said. "You lose any kind of privacy when you have to speak how you want to vote").

[12] U.S. Gen. Acct. Off. (2001) *Voters With Disabilities – Access To Polling Places and Alternative Voting Methods* (Oct. 2001) (hereinafter GAO Report) (finding that 84% of polling places had one or more features that could present challenges to physical access for voters with disabilities).

[13] See Winkler, A. (1993). Expressive voting. *New York University Law Review, 68*, 330–388, at 330, 331 ("By voting, the individual says essentially, 'I am a member of the American community.' Through participation itself, the voter expresses an identification with the greater community and reveals her attachments to and associations with it. In this way the act of voting is the individual's alignment to the greater society; it is the method by which the individual 'signs' her name to the social contract and becomes herself part of the collective self-consciousness."); see also Tokaji, D. (2003). First amendment equal protection: On equality, discretion and participation. *Michigan Law Review, 101*, 2409–2524.

of Election Day. This can cause voters to miss out on late-breaking election developments or polling place politicking in places where it is allowed. When the community of people with disabilities is systematically steered toward absentee voting, their cumulative voting power is therefore disproportionately diminished.

These issues of inequality in the administration of elections are not confined to the United States. In 2004, I conducted a study of democratic states' election laws. I found that of democratic states that provided for a secret and independent ballot for all citizens (61% of total democratic states) only 10% specifically provided for a secret and independent ballot for voters with disabilities.[14] Only 11.7% of democratic states had election laws that contained some type of provision regarding polling place access for people with disabilities.[15]

In the United States, these election administration issues had an adverse effect on the access to, and participation in, the democratic system for people with disabilities. In the United States, a 2000 National Organization on Disability/Harris Survey found that voter registration is lower for people with disabilities than for people without disabilities (62% vs 78% respectively).[16] A different survey in 1999 found that people with disabilities were on average about 20 percentage points less likely than those without disabilities to vote, and 10 points less likely to be registered to vote, even after adjusting for differences in demographic characteristics (age, sex, race, education, and marital status).[17] People with disabilities were less likely to be contacted by political parties. They were less likely to view the political system as responsive "to people like me." They were less likely to have contributed money to a political party or candidate, written or spoken to an elected representative/official, attended a political meeting, written a letter to a newspaper, contributed money to an organisation trying to influence governmental policy or legislation, or worked with others on a community problem.[18]

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[14] See Waterstone, M. (2004). Civil rights & the administration of elections – toward secret ballots and polling place access. *Journal of Gender, Race & Justice, 101*, 119.

[15] Ibid., at 121.

[16] See 2000 National Organization on Disability/Harris Survey of Americans with Disabilities (2000), 83.

[17] See Kruse, D., et al. (1999). *2000 NOD/Harris survey of Americans with disabilities*. (Executive Summary at 5). Final Report to the Disability Research Consortium and New Jersey Developmental Disabilities Council, Piscataway, NJ: Rutgers University.

[18] Ibid.

This is also true of other nations. International non-governmental actors have recognised that people with disabilities have frequently been denied the fundamental right to vote.[19] The International Foundation for Electoral Systems has started "electionaccess.org," a clearinghouse for information on the participation of people with disabilities in the electoral process and gathered numerous publications documenting the historically uneven treatment of people with disabilities in voting.[20]

Progress is being made at both the individual state and international levels. My 2004 study of all democratic states' election laws showed that that the voting rights of people with disabilities are on most states' agendas, and that states are legislating on this topic in different ways.[21] Different international organisations, and most actively the International Foundation for Electoral Systems, have keyed into the importance of the administration of elections to achieving equivalent participation for people with disabilities. These actors are working to make voting equality for people with disabilities an international norm.

These reforms acknowledge that in realizing the international human right of political participation, broad principles of formal equality may not be specific enough to guarantee true equal access for people with disabilities. Rather, to create a world where "every citizen" has the right and opportunity to vote, additional and specific steps need to be considered for citizens with disabilities. This is consistent with the evolving human rights approach to disability, which teaches that the needs of people with disabilities must "be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation."[22] An equal opportunity to participate means participation on

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[19] See Landmine Survivors Network. (2004). *Convention document legal analysis: A legal commentary on the draft convention text produced by the working group for the UN ad hoc committee on a comprehensive and integral international convention on the protection and promotion of the rights and dignity of persons with disabilities*. Washington: Landmine Survivors Network, (distributed by Land Mine Survivors Network at UN Working Group Meeting, on file with author).

[20] See, for example, BBC News. (22 March 2001). Blind voters get secret ballot. *BBC News Online* (more than 50% of blind voters in the UK found voting too difficult); Morris, G., et al. (2002). *Electoral commission, polls apart: A future for accessible democracy* No. 24). London: Scope.; see also www.electionaccess.org.

[21] See Waterstone, *supra* note 14, at 122–125.

[22] See Standard Rules, *supra* note 9.

equal terms. In the case of voting, this should mean secret ballots and polling place access in a manner commensurate with other citizens.

As suggested above the trend in international human rights law (as well as state domestic laws) has been a move from a general statement of voting equality to more specific protections for people with disabilities. This has been a slow process, but seems to be moving in the right direction. The following section explains one state's journey toward equality of voting opportunity for people with disabilities in its domestic laws.

United States Law and Policy Relating to Voting For People with Disabilities

The United States has some legal and policy experience in reconciling larger voting equality norms with the "nuts and bolts" issues of administering elections. Early American legal and policy statements could be characterised as providing "formal equality," but not guaranteeing true equality of access. Courts and legislatures were content with allowing human variation to create different and inferior voting experiences for people with disabilities, as long as this group was not formally denied the right to vote. Recent statutory developments, however, have moved toward guaranteeing specific enumerated rights; in particular, the ability to vote by secret ballot. This constitutes a move toward acknowledging difference to provide equality of opportunity.

The first American statutes dealing with voting and disability were the *Voting Rights Act*[23] providing, *inter alia*, that a voter who requires assistance to vote by reason of blindness or disability may be given assistance by a person of the voter's choice, and the *Voting Accessibility for the Elderly and Handicapped Act*, providing that state political subdivisions must assure that polling places used in federal elections are "accessible."[24] What accessibility means, and the manner by which it should be achieved, is left entirely to the states. This lack of federal guidance has led to inconsistent and incomplete conceptions of accessibility. Both of these laws only apply to federal elections. This has left state level elections – where the bulk of political participation occurs – solely within the jurisdiction of the states who, by and large, have not

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[23] 42 U.S.C. § 1973aa-6. (as amended in 1982).

[24] 42 U.S.C. § 1973ee.

responded by enacting laws protecting the voting equality of people with disabilities.[25]

The *Americans with Disabilities Act*[26] [ADA] and Section 504 of the *Rehabilitation Act*[27] are the two main statutes protecting people with disabilities from discrimination in all areas of life. The *Rehabilitation Act* passed in 1973 provides that, "no otherwise qualified individual with a disability in the United States…shall, by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." The ADA was passed in 1990. Title II of the ADA protects against discrimination in public services, providing that, "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."[28] Title III of the ADA protects against discrimination in public accommodations, providing that, "no individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodations."[29]

Congress certainly considered voting when it passed the ADA, and courts have uniformly held that voting is covered by its program accessibility standard.[30] This means that the voting "programs, services, and activities" offered by states, when viewed in their entirety, must be readily accessible and usable by people with disabilities, unless to do so would result in a fundamental alteration (meaning change would transform the program into something completely different) or cause an undue burden (meaning it would create a large and detrimental

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[25] See Waterstone, M. (2003). Constitutional and statutory voting rights for people with disabilities. *Stanford Law and Policy Review, 14*, 353.

[26] 42 U.S.C. § 12101 *et. seq.*

[27] 29 U.S.C. § 794.

[28] 42 U.S.C. § 12132.

[29] 42 U.S.C. § 12182(a).

[30] See 42 U.S.C. § 12101(a)(3) ("[D]iscrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, *voting*, and access to public services.") (emphasis added); see *New York v County of Schoharie*, 82 F.Supp.2d 19, 25 (N.D.N.Y. 2000) (holding that accessibility to polling places qualifies as a "service, program, or activity"); *AAPD v Hood*, 310 F. Supp.2d 1226, 1234 (M.D. Fla. 2004) (same).

financial impact). Although not clear from the statutory text, lawyers and commentators have argued that the ADA requires secret and independent voting and polling place access. A different (and worse) voting experience on the basis of disability violates Title II (with voting as a program, service, or activity) or Title III (with voting taking place in places of public accommodation). The ADA Title II regulations draw a connection between "different" and "discrimination." Further, the Title III statutory text also equates discrimination with separate and unequal benefits. Under this argument, to the extent that difference in voting is necessary, it would need to be justified under the undue burden or fundamental alterations standard.[31]

This argument fits well into the overall structure and purpose of the ADA. When Congress passed the ADA, it intended to remedy the "political powerlessness" of people with disabilities.[32] Its goals were to ensure, "equality of opportunity, full participation…[and] independent living."[33] Congress expressly recognised that there was discrimination against people with disability in voting.[34] This also would have been the preferred interpretation under a rights-based approach that emphasises equality of opportunity, accepting difference over formal equality.

Although the case law has been fairly sparse, a limited number of courts have embraced a vision of the ADA as requiring equality of access in elections. In *American Association of People with Disabilities v Hood,*[35] a group of manually and visually impaired voters sued the Secretary of State of Florida, arguing that Title II entitled them to accessible voting machines. The Court held that Duval County, Florida violated Title II of the ADA by purchasing machines that only allowed the plaintiffs to vote with third-party assistance.[36] Similarly, in *New York v County of Scoharie,*[37] a federal district court in New York held that the defendants had violated the ADA by having all twenty-five polling places in Scoharie County inaccessible to people with disabilities.

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[31] See 28 C.F.R. § 35.130(b)(7); see also 42 U.S.C. § 12182(b)(2)(A)(i)–(v).

[32] See 42 U.S.C. § 12101(A)(7).

[33] Ibid., at § 12101(A)(8).

[34] Ibid., at § 12101(A)(3).

[35] 310 F.Supp.2d 1226 (M.D. Fla. 2004).

[36] The Court held that at the time the City purchased its optical scan system, it was technologically and financially feasible to employ a voting system readily accessible to visually impaired voters. Ibid., at 1234.

[37] 82 F.Supp.2d 19, 25 (N.D.N.Y. 2000).

Although the Supreme Court has not yet addressed this issue, most lower courts and administrative agencies have not interpreted the ADA in this way. Rather, they have held that these statutes only require formal equality in voting (meaning that people with disabilities cannot be excluded from voting) as opposed to equality of voting experience. Various administrative agencies have rejected the idea that the ADA requires secret and independent voting, and polling place access. The Department of Justice has issued non-binding "letters of finding," taking the position that curbside and absentee voting are consistent with the ADA. The Title II Assistance Manual, promulgated by the Attorney General, opines that blind voters are not entitled to cast ballots in Braille, even though this method would allow them to vote in private.[38] And the Federal Election Commission's statement of voting requirements under the ADA takes the position that states are not required to furnish Braille or tape-recorded ballots for blind voters.[39]

Similarly, most case law involving voting and the ADA has been inhospitable to the idea that these laws require polling place access and secret and independent voting. To date, two cases have reached the federal Court of Appeals, both with negative results. In *Lightbourn v County of El Paso,*[40] a class of mobility and vision impaired Texas voters brought an action under the *Rehabilitation Act* and Title II of the ADA, alleging that El Paso County discriminated against them by providing inaccessible polling places and voting apparatus that only allowed blind individuals to vote with third-party assistance. The court held that the *Rehabilitation Ac*t did not apply because the Texas Secretary of Elections did not receive federal funds. The court further held that the plaintiffs could not make out an ADA claim because the Secretary did not have a duty or responsibility to prevent the claimed violations. Although the Secretary was charged under a Texas law with assisting election authorities in interpreting "election laws," the court held that the ADA was not an "election law."[41] So in this case, relying on dubious formalities, the court completely avoided the real rights issue of whether different voting experiences for people with disabilities compromised equality of opportunity.

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[38] See Title II Assistance Manual, § 7.1100.

[39] See Federal Election Commission, (1996) *Innovations in Election Administration 15: Ensuring the Accessibility of the Election Process,* at 3–4.

[40] 118 F.3d 421 (5th Cir. 1997).

[41] Ibid., at 428–31.

In another case, *Nelson v Miller,*[42] a class of blind voters brought suit against the Michigan Secretary of State, alleging that the Secretary violated the *Rehabilitation Act* and the ADA by not providing machines through which blind voters could mark ballots without third-party assistance. The district court rejected these claims, holding that the *Rehabilitation Act* and the ADA did not intend to displace the *Voting Accessibility for the Elderly and Handicapped Act* and the *Voting Rights Act*, which the court construed to provide that third-party assistance for blind voters is sufficient.[43] The Sixth Circuit affirmed, holding that the Michigan Constitution did not guarantee a secret vote, and therefore the state of Michigan had not denied its visually impaired citizens a right that it had given to its other citizens.[44] Again, the focus was incorrectly on formal equality (that is, are people with disabilities being denied the right to vote?) instead of what the actual voting experiences of people with disabilities were, and how those experiences were different from other citizens' experiences.

At least one lower court has recently come to a similar conclusion. In *American Association of People with Disabilities*, a group of visually and physically impaired voters challenged the decision by the California Secretary of State to decertify certain direct recording electric machines.[45] The Secretary had concerns about the reliability, accuracy and security of these machines. The plaintiffs argued that these machines allowed them to vote secretly and independently and were therefore required under Title II of the ADA. The court, while conceding the importance of a secret and independent vote, nevertheless held that Title II did not require it.

Besides federal statutory law, the other body of American law that governs voting on the federal level is constitutional law. Constitutional law sets certain parameters that states and localities must meet when they administer federal and state elections. For example, any state or local regulation or practice that discriminates in elections on the basis

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[42] 170 F.3d 641 (6th Cir. 1999).

[43] 950 F.Supp. 201, 204–05 (W.D. Mich. 1996).

[44] 170 F.3d 641, 649–53 (6th Cir. 1999).

[45] See *American Association of People with Disabilities v Shelley,* 324 F.Supp.2d 1120, 1126 (C.D. Cal. 2004) ("It cannot be disputed that casting a vote independently and secretly would be preferred over casting a vote with the assistance of a family member or other aide. However, the ADA does not require accommodation that would enable disabled persons to vote in a manner that is comparable in every way with the voting rights enjoyed by persons without disabilities. Rather, it mandates that voting programs be made accessible, giving a disabled person the opportunity to vote."

of race is invalid under the *Equal Protection Clause*.[46] But for several reasons, constitutional law has not protected the ability of people with disabilities to vote in the same way as their fellow citizens; that is, secretly and independently, and in polling places. Instead, like statutory law, the focus has been on formal exclusion instead of actual voting experience.

Courts use heightened scrutiny to review actions by states that draw lines on the basis of race or gender. This makes it more likely that these types of laws will be struck down. In contrast, state laws or policies that draw lines on the basis of disability are not reviewed under heightened scrutiny. In *City of Cleburne v Cleburne Living Center,*[47] the Supreme Court held that state laws that discriminate on the basis of disability only receive rational basis review. Subsequent Court decisions have reinforced this rule.[48] This doctrine has limited the ability of people with disabilities to bring constitutional challenges to voting practices that provide different voting experiences for people with disabilities. As stated by one Court (in dicta): "it is not necessarily irrational for a state to require disabled voters to submit absentee ballots rather than going to the expense of retrofitting or relocating an established polling place."[49] This misses the importance, as set forth in the rights-based approach of equalizing voting experiences, of allowing for equal opportunity to influence the political process.

Second, although voting is a "fundamental right," which means that state actions impairing the right of people to vote generally receive strict scrutiny,[50] the Court has not applied strict scrutiny to claims involving the administration of elections.[51] While state laws or practices that completely deny the right to vote receive strict scrutiny,

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[46] See, e.g., *Reynolds v Sims*, 377 U.S. 533 (1964) (striking down apportionment scheme as violative of the Equal Protection Clause).

[47] 473 U.S. 432, 446–47 (1985).

[48] See, for example: *Board of Trustees of the University of Alabama v Garrett*, 531 U.S. 356 (2001).

[49] *Wessel v Glendening*, 306 F.3d 203, 212 (4th Cir. 2002).

[50] See, for example, *Reynolds v Sims*, 377 U.S. 533, 562 (1964) ("any alleged violation of the right of citizens to vote must be carefully and meticulously scrutinized."); see also *Dunn v Bumstien*, 405 U.S. 330, 337 (1972); *Harper v Va. Board of Elections*, 383 U.S. 663, 670 (1966).

[51] See *Burdick v Takushi*, 504 U.S. 428, 436 (1992) (applying "flexible" scrutiny to challenge on Hawaii's prohibition on write-in voting, which the court characterized as regulating the "mechanism by which a candidate may appear on the ballot."); see also *McDonald v Board of Election Commissioners*, 394 U.S. 802, 807 (1969).

state action that provides different voting experiences for different groups of people do not.[52] This demonstrates an application of the first type of equality rights (formal equality) but not the third (acknowledging difference).

The final element of the American legal landscape regulating voting and disability is state law. Except for federal constitutional and statutory "baselines," states and localities are free to administer federal and state elections as they see fit. Practically speaking, this is where the bulk of election law relating to the administration of elections exists. With some exceptions, state laws have not guaranteed people with disabilities (either textually or in practice) the ability to vote secretly and independently, or in polling places.[53] Commentators have speculated on several reasons for state law's failures.[54] The first is lack of funding: voting machines and polling place accessibility modifications are expensive and often states and localities are working with limited funds as they seek to administer their elections. There is also a lack of political will at the local level to spend the funds to make necessary changes. Even when accessible machines exist, they require poll workers with the training and expertise to make them work. State officials also cite frustrations in procuring accessible buildings, showing the extent to which disability discrimination is literally built into the environment.[55]

These issues helped American advocates develop arguments that more explicit statutory protection for the voting rights of people with disabilities was needed. Yet another (unforeseen) series of events focused popular attention on the administration of elections. The United States presidential elections of 2000 and 2004 placed many hard questions regarding the ways people vote squarely in the public view. The 2000 election was closer than any in history, with the outcome of

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[52] Although the historic decision of the United States Supreme Court in the 2004 election, *Bush v Gore,* 531 U.S. 98 (2001), may ultimately call this principle into doubt, for now it seems relatively safe. For a more detailed explanation of these concepts, see Waterstone, *Constitutional and Statutory Voting Rights for People with Disabilities*, *supra* note 25, at 371–74.

[53] See GAO Report, *supra* note 12, at 26–32 (showing that although nearly every state has some type of provision that explicitly addresses voting for people with disabilities, not all counties allow for curbside voting on Election Day to combat inaccessible polling places, and no counties have special ballots or voting equipment adapted for blind voters to vote independently and in secret.").

[54] Ibid., at 30–36.

[55] Ibid., at 33–35.

the election hinging on a small number of highly contested ballots.[56] After this election, the curtain traditionally shrouding the machinery of elections was lifted. Far from being a national, centralised process, the United States election system was revealed to be a patchwork of largely locally-run enterprises. Different machines in different systems counted votes in different – and at times outdated and flawed – ways.

In the aftermath of the 2000 election, the United States Congress passed the *Help America Vote Act*[57] in reaction to many of these problems. This statute attempted to set very general baseline voting standards, and with a combination of sticks and carrots, worked to phase out certain types of voting machines (most notably, the infamous "punch card" ballots). In response to claims of individuals who were unjustly turned away from polling places in the 2000 election, the *Help America Vote Act* also created the right to a provisional ballot, in which the propriety of the individual's voting status could be assessed at a later point.

Some, but not all, of the changes created by the *Help America Vote Act* were first tested in the 2004 presidential election. The results were mixed. There were real concerns that the electronic voting machines preferred under the *Help America Vote Act* compromised voting security. Computer scientists, legal scholars, and the media contended that the code protecting these systems could be hacked into, thus calling the legitimacy of elections into account.[58] And the parts of *Help America Vote Act* requiring a provisional ballot proved to be vague indeed, allowing states to set the standards for how and when those ballots should be counted. This led some to argue that states could essentially define away this requirement.[59] Even two years after the election, doubts remain about voting in certain geographic areas (in perception, if not reality).[60]

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[56] For an excellent collection of essays concerning the 2000 United States' presidential election, see Raskove, J. (2001). *The unfinished election of 2000*. New York: Basic Books Publishers.

[57] 42 U.S.C. § 15301, *et. seq*.

[58] See, for example, Levy, S. (3 November 2003). Black box voting rules. *Newsweek*, at 69.

[59] See *Sandusky County Democratic Party v Blackwell*, 387 F.3d 565 (6th Cir. 2004).

[60] See Hasen, R. (4 November 2004). Time to fix election system. *Law.Com*; see also Editorial. (7 November 2004). New standards for elections. *New York Times*; Tokaji, D. (20 November 2004). The 2008 election: Could it be a repeat of 2000? The legal problems that still persist. *Findlaw Legal Commentary*.

Congress certainly had the voting rights of citizens with disabilities in mind when it passed the *Help America Vote Act*. Unlike previous statutes, legislators got fairly specific in discussing the Act's guarantees of equality of access. In discussing proposed minimum standards, the legislative history provides that:

> the State requires new voting systems to provide a practical and effective means for voters with physical disabilities to cast a secret ballot. Advancements in technology make it possible for voters with physical disabilities to cast a secret ballot. New systems should strive to make it possible for voters with physical disabilities to cast secret ballots.[61]

And Steny Hoyer, a Democratic Representative from Maryland, stated:

> Voting is one of the fundamental rights of citizens in a Republic. As such, the right should not depend on the vagaries of local budgets – certainly not in an affluent society like ours. Physical access to the ballot box should be unconditional. Every polling place in America should be accessible to persons with the full range of disabilities.[62]

He also stated:

> Most of the ongoing discrimination against persons with disabilities concerning voting is no longer motivated by deliberate efforts to exclude. However…the choice, design and administration of polling places, voting methods and machines continues in many instances to be driven by a careless assumption on the part of election administrators that all voters are able-bodied.[63]

With sentiments like these in mind, there are several parts of the *Help America Vote Act* that are relevant to people with disabilities. Regarding polling place access, the Act provides funds to states and units of local governments to:

> mak[e] polling places, including the path of travel, entrances, exits, and voting areas of each polling facility, accessible to individuals with disabilities, including the blind and visually impaired, in a manner that provides the same opportunities for access and participation (including privacy and independence) as for other voters.[64]

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[61] See H.R. Rep. No. 107–329, pt. 1, at 50 (51).

[62] Ibid., at 86 (additional views of Hon. Steny H. Hoyer).

[63] Ibid.

[64] 42 U.S.C. § 15421.

While the Act gives money to achieve accessibility and offers more guidance on the meaning of accessibility than previous federal statutes, it still does not guarantee to people with disabilities that their polling places will be fully accessible.

The provisions of the *Help America Vote Act* regarding secret and independent voting are more absolute. It states that voting systems shall, "be accessible for individuals with disabilities, including non-visual accessibility for the blind and visually impaired, in a manner that provides the same opportunity for access and participation (including privacy and independence) as for other voters."[65] The Act does not create a private cause of action to enforce this right. The Attorney General is authorized to bring civil actions:

> against any State or jurisdiction in an appropriate United States District Court for such declaratory and injunctive relief as may be necessary to carry out the uniform and nondiscriminatory election technology and administration requirements.[66]

A second enforcement scheme rests on state-based administrative grievance proceedings.[67]

The American journey, then, started with first-level equality, which protects against formal exclusion. Institutional actors, in particular courts, have been reluctant to move it past that stage. With the *Help America Vote Act*, the United States Congress has insisted on third-level equality, which recognises and accommodates difference in the voting process. This is more consistent with a rights-based approach.

MOVING FORWARD – PROTECTING EQUALITY OF OPPORTUNITY IN INTERNATIONAL HUMAN RIGHTS LAW AND DOMESTIC LAW

Thus far, I have argued that to protect the human right of political participation for people with disabilities, domestic and international human rights law needs to do more than provide formal equality. Rather, it needs to provide equality of opportunity, and do so fairly specifically in a way that acknowledges difference. Article 29 of the United Nations *Convention on the Rights of Persons with Disabilities* is the most recent international human rights statement on these issues.

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[65] Ibid., § 15481.
[66] Ibid., § 15511.
[67] Ibid., § 15512.

The text, described above, goes far toward protecting equality of opportunity for people with disabilities in the political process. How does the *Help America Vote Act*, the primary policy and legal statement in the United States relating to the voting rights of people with disabilities, match up to this international human rights standard? Both in taking an anti-discrimination approach and its specific steps to create equal access, the *Help America Vote Act* is completely consistent with Article 29 and should satisfy the United States' treaty commitments should the U.S. decide to become a state party. Regarding secret and independent ballots, the *Help America Vote Act* requires that voting systems shall be accessible for individuals with disabilities in a manner that provides the same opportunity for access and participation (including privacy and independence) as other voters. The *Help America Vote Act* also establishes several grant programs that dedicate significant funds to states and units of local governments (the entities that actually administer elections) to ensure access for people with disabilities. Under the *Help America Vote Act*, these funds are to be used to make polling places, including the path of travel, entrances, exits and voting areas of each polling facility, accessible to individuals with disabilities in the same way as for other voters. These funds are allocated for providing individuals with disabilities with information about the accessibility of polling places, including outreach programs to inform individuals about the availability of accessible polling places and training for polling place workers and election officials. These steps square perfectly with Article 29's commitment to promote an inclusive environment and provide appropriate and accessible voting systems.

Turning away from secret and independent voting, the other issue area that has traditionally created barriers to the political participation of people with disabilities is polling place access. Voting machines designed for people with disabilities do not serve their purpose if there is no access to the actual voting area. Article 29 provides for "appropriate and accessible" voting facilities, which presumably – although not explicitly – commits state parties to polling place access. Regrettably, the *Help America Vote Act* is somewhat less explicit on this point. It does provide for payments to ensure accessibility, but the provisions of the *Help America Vote Act* that provide positive rights only deal with "voting systems," which are not specifically defined to include the actual polling facility. Although Title II of the ADA provides that "public services" need to be accessible, and the overall voting process has been accepted by courts to be a public service, this requirement is tempered by an undue hardship exemption, and practical experience has shown that the letter of the law is not necessarily being carried out by all government units that offer public services.

Domestic-level reform like the *Help America Vote Act* and international human rights law like Article 29 should greatly improve the climate of political participation for people with disabilities in the United States. But American history offers important lessons for the emerging international standards (and for individual states as they craft their own legal and policy initiatives). Article 29, for example, contains one significant ambiguity: it provides for secret and independent voting, but also allows, when appropriate, voting with assistance. As the United States' voting experience demonstrates, voting with assistance is, by definition, not secret. The *Help America Vote Act* more firmly comes down on the side of secret voting in nearly every circumstance by not leaving a similar "with assistance" escape valve. The draft article provision for assisted voting may be an acknowledgement that there may always be a small universe of cases where voting with assistance will be necessary (or actually preferred by the voter with a disability). If so, this seems reasonable. But if it becomes a substitute for secret and independent voting – which it was for many years in the American experience – the political participation rights of people with disabilities will suffer.

Past experience in the enforcement of American federal civil rights laws relating to voting and disability also cautions restraint. As discussed above, for many years the *Voting Accessibility for the Elderly and Handicapped Act* has provided for "accessible" polling places. Similarly, the ADA takes some steps toward ensuring accessible public buildings and government services, like voting. Yet recent studies (albeit pre-dating the *Help America Vote Act*) have shown significant accessibility barriers for mobility and sight-impaired voters.[68] This experience teaches that these laws are not self-executing. The administration of elections is a sprawling, diffuse enterprise in which innumerable actors will be responsible for ensuring accessibility and secret and independent voting. As in other areas of civil rights, the vigorous enforcement of these laws depends upon a private attorney general scheme. This means that individual actors who are denied guaranteed rights can bring private enforcement actions to vindicate these rights and force compliance.

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[68] See, for example, *GAO Report, supra* note 12.

The *Help America Vote Act* itself contains significant weaknesses in this regard. It does not provide for a private right of action. Its enforcement is limited to suits brought by the Department of Justice, and a state-based administrative grievance procedure. At least one case brought during the 2004 election, however, allows a private right of action under the *Help America Vote Act* (albeit in a different section of the statute not dealing with disability rights).[69] So it is possible that future courts will hold that lack of an explicit private right of action in the *Help America Vote Act* does not bar individuals bringing suit to enforce its guarantees.

This does not tell the complete story, however. Historically, the private attorney general method of enforcement has proven most effective when harmed individuals can sue for damages.[70] This raises one of the most contested, contentious, and complicated features of American law. The principle of sovereign immunity generally prevents the United States Congress from passing laws that provide for private individuals to sue state actors in federal court, particularly if the statute provides for damages against states. There is an exception to this principle when Congress legislates, in a, "proportional and congruent manner," pursuant to Section 5 of the *Fourteenth Amendment* which, amongst other things, guarantees due process and equal protection of the laws. Congress explicitly passed the ADA pursuant to this power, whereas the *Help America Vote Act* is silent as to its constitutional basis. The current United States Supreme Court has taken an increasingly narrow view of when this has occurred. Several federal civil rights laws have been struck down, in whole or in part, on the basis that Congress has exceeded its powers under Section 5 of the *Fourteenth Amendment* and unconstitutionally encroached upon sovereign immunity.[71]

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[69] See *Sandusky County Democratic Party v Blackwell*, 387 F.3d 565 (6th Cir. 2004).

[70] See Colker, R. (2000). The section 5 quagmire. *UCLA Law Review, 47*, 653, commenting on importance of damage remedy in enforcing civil rights; *see also* Paradis, L. (2003). Title II of the Americans with Disabilities Act and section 504 of the Rehabilitation Act: Making programs, services and activities accessible to all. *Stanford Law and Policy Review, 14*, 389 (same).

[71] See *City of Boerne v Flores,* 521 U.S. 507 (1997) (*Religious Freedom Restoration Act* unconstitutional); *Florida Prepaid Postsecondary Education Expense Board v College Savings Bank,* 527 U.S. 666 (1999) (*Patent and Plant Variety Protection Remedy Clarification Act* unconstitutional in part); *Kimel v Florida Board of Regents,* 528 U.S. 62 (2000) (provision of *Age Discrimination in Employment Act* allowing private individuals to sue states for damages unconstitutional); and *University of Alabama v Garrett,* 531 U.S. 356 (2001) (ADA Title I's private damage remedy against states unconstitutional).

It is from the depths of this thicket that the *Help America Vote Act* was passed, and its weak enforcement scheme is likely testament to Congressional skittishness in the rapidly developing reworking of federal-state relations. As written, the *Help America Vote Act* provides no private damage remedy against states. But even since the *Help America Vote Act* was passed, there have been some significant developments in federalism and sovereign immunity that might allow for subsequent amendments to the *Help America Vote Act* to include a private enforcement mechanism with a damage remedy. In *Tennessee v Lane,*[72] the U.S. Supreme Court held that the ADA Title II's damage remedy was constitutional insofar as it related to the fundamental right of access to courts. *Lane's* scope is still an open issue.

Voting, like access to courts, is a "fundamental right." It is a reasonable interpretation of *Lane* that when courts are legislating to protect fundamental rights, their ability to abrogate sovereign immunity and pass statutes with damage remedies expands.[73] The difficulty will be in convincing the Court that with the *Help America Vote Act* (or at least the provisions of the Act relating to voting for people with disabilities) Congress was looking at a *constitutional* problem. The Court's constitutional jurisprudence regarding voting, discussed above, presents a significant – though perhaps not insurmountable – barrier.

This concern with the enforcement of laws as written is not a strong suit of international law, where state-level compliance with human rights treaties is always a matter of concern.[74] Groups like *International Foundation for Electoral Systems* are developing trained election monitoring apparatus, which should be helpful, but this is no substitute for states rigorously enforcing their own laws.

In conclusion, the movement toward treating disability issues under a human rights framework (like domestic law) has been a history of how to deal with equality and difference. Nowhere has this been more true than in political participation, itself a recognised international human right. This essay has argued that the right to political participation for people with disabilities needs to be defined and enforced in a way that moves past formal equality. Broad statements under

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[72] 124 S.Ct. 1978 (2004).

[73] I have previously made this argument in the ADA Title II context. See Waterstone, M. (2005). Lane, fundamental rights & voting. *Alabama Law Review, 56*(3), 793–850.

[74] For an excellent discussion of this, *see* Hathaway, O. (2002). Do human rights treaties make a difference? *Yale Law Journal, 111*, 1935–2042.

international human rights and domestic law that all individuals have the right to participate in the political process are insufficient. What is needed are specific statements, like those encapsulated in *Help America Vote Act* and Article 29, that people with disabilities should be afforded the ability to vote, to the maximum extent possible, in the same way as their fellow citizens. This should include the ability to vote secretly and in a polling place when these opportunities are provided to other citizens. Only in this way will the human rights of people with disabilities be protected.

THE RIGHT TO LIVE A LIFE FREE OF VIOLENCE FOR PEOPLE WITH DISABILITIES

Rodrigo Jiménez

International Human Rights Law and non-violence against people with disabilities

The battle for recognition of the right to live a life free of violence is closely tied into the women's movement. It is women who, along with States, have established the importance of eradicating gender violence and have expended a great deal of effort to prevent, condemn, assist and eradicate the different manifestations of violence in various areas which in one way or another contribute to perpetuate social inequalities among men and women.[1]

These actions began with the three *World Conferences on Women* – México City (1975), Copenhagen (1980) and Nairobi (1985) – and in the parallel forums organised by non-government organisations. The women's movement brought forward the discussion of the subject of violence against women and gave special attention to the restrictions that violence imposes on the full participation of women in society. The Nairobi strategies "[o]rientated towards the future for the advancement of women," established the concern of the international community and recognised State responsibility for the eradication of violence. These actions had impact in other areas as, for example, in 1990, the Inter-American Commission for Women (CIM) published the *Conclusions and Recommendations of the Inter-American Consultancy on Women and Violence*.

In 1992 the Committee for the Elimination of All Forms of Discrimination against Women (CEDAW Committee), which was established under the *Convention on the Elimination of All Forms of Discrimination against Women* (CEDAW), adopted *Recommendation No. 19: Violence against Women*.[2] This Recommendation states that

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[1] Arroyo, Roxana & Rodrigo Jiménez. (2005). El Estado de los Derechos de las Mujeres. INAMU, San José.

[2] Office of the High Commissioner for Human Rights, *Violence against Women*: 29/01/92 CEDAW General Recommendation 19, A/47/38 11th Session 1992.

violence against women is a form of discrimination against them which reflects and perpetuates their subordination and requires States to eliminate violence in all spheres. In relation to this *Recommendation No.18: Disabled Women* proposes:

> that all State Parties include in their periodical reports information on women with disabilities and on measures adopted to face their particular situation, including special measures in relation to equal opportunities in the area of education, work, health services and social security, and guarantee that they can participate in all aspects of social and cultural life.[3]

Thus, countries that have ratified CEDAW shall, in reports prepared every four years, include information on laws and incidence of violence against women, including women with disabilities, as well as measures adopted to confront it.

The World Human Rights Conference held in Vienna in 1993 recognised that violence against women is a human rights problem, and called for gender mainstreaming[4] in the mechanisms developed in the international, regional and national arenas in order to eliminate violence against women. In 1993, the United Nations General Assembly adopted the *Declaration on the Elimination of Violence against Women*[5] which is addressed to all member States of the United Nations and which must be implemented internationally by the different treaty-committees, including the CEDAW Committee.

In 1994, the United Nations Human Rights Commission appointed Radhika Coomaraswamy as the first *Special Rapporteur on Violence against Women, its Causes and Consequences*. The Special Rapporteur's mandate allows her to receive petitions and initiate investigations on violence against women in all the member States of the United Nations.

During that same year, the Organization of American States (OAS), adopted the *Inter-American Convention for the Prevention, Sanctioning and Eradication of Violence Against Women* (Belem do Pará

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[3] Office of the High Commissioner for Human Rights, *Disabled Women*: 04/01/91 CEDAW General Recommendation 18, A/46/38 10th Session 1992.

[4] Understood as the incorporation of the multiple forms of subordination and discrimination suffered by women of all ages, ethnic groups or races, socio-economic conditions, disabilities, sexual preferences, geographical location, etc., in regards to men, which gives rise to a great diversity among women, that influences the way in which they experiment the abovementioned subordination and discrimination.

[5] United Nations General Assembly Resolution A/RES/48/104 23 February 1994.

Convention).[6] According to this Convention, CIM has the responsibility to implement positive measures for the advancement of this Convention, and the Inter-American Human Rights Commission (IHRC), is empowered to receive petitions against States that have ratified the Convention. In response to the *World Human Rights Conference*, the IHRC created the position of a *Special Rapporteur on Women's Human Rights* in 1994, which has taken important actions with respect to social violence against women in Ciudad Juarez and other parts of the American continent.

Moreover, in 1994, the *Program of Action* of the *International Conference on Population and Development*, held in Cairo, recognised that gender violence is an obstacle for the health and sexual and reproductive rights of women, for their education and participation in development, and thus exhorted States to implement the *Declaration for the Elimination of Violence Against Women* and the CEDAW Convention.

Similarly, in that year, the *Regional Action Program for Women of Latin America and the Caribbean*, 1995–2000, adopted by the governments during the *Preparatory Conference* in Mar del Plata, Argentina, within its Area V, *Human Rights, Peace and Violence*, included three objectives:

1. Consolidate the full respect of human rights (civil, political, economic, social and cultural) of women in the region, within a framework which gives priority to the elimination of violence and discrimination due to sex, as well as the rights of the poorest and displaced women, taking into consideration their ethnic and racial differences.
2. Promote actions that make visible all forms of violence against women and that aim towards its elimination.
3. Create awareness among mass media on the impact of diffusion of a culture of violence, with the objective of eradication the image of women there presented, which is a product of discrimination.

The Inter-American Commission of Human Rights devoted, for the first time in 1995, a section of its *Report on the Human Rights Situation in Haiti* to the topic of sexual violence against women during the illegal regime in Haiti, and declared that rape is a form of torture according to the *Inter-American Convention of Human Rights*.

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[6] The Convention was drafted by the delegates of the Inter-American Commission on Women, and adopted by acclamation in the 24th ordinary session of the OAS General Assembly on the 9th of June, 1994, in Belem do Pará.

The Declaration and Platform of Action of the World Conference on Women,[7] held in Beijing in 1995, dedicated an entire section to the issue of violence against women, recognising that its elimination is essential for achieving world equality, development and peace. The Platform recognises the right of women to freely and responsibly control and decide on matters related to their sexuality, including reproductive and sexual health, free of coercion, discrimination and violence (Paragraphs 8,44,46 and 58 of the Platform).

In December 1997, the United Nations General Assembly adopted *Resolution 52/86*,[8] calling upon Member States to revise and evaluate their legislation, legal principles, procedures, practices and policies related to criminal matters, in order to guarantee that women are treated justly by the criminal justice system, and that this system be guided by the *Model of Practical Strategies and Measures on the Elimination of Violence Against Women in Matters of Crime Prevention and Criminal Justice*, annexed to the resolution. The *Model of Practical Strategies and Measures* is based upon the measures included in the *Beijing Platform of Action*. The document contains eleven articles related to criminal law, criminal procedure, police, sentencing and correction, assistance and support to victims, social and health services, training, investigation and evaluation, as well as monitoring activities. The *Model of Practical Strategies and Measures* also provides instructions for the effective implementation of the Belem do Pará Convention.

The Belem do Pará Convention is the specific legal context to consider the topic of violence against women among Member States of the Organization of American States. The Convention is an obligatory treaty inspired by the United Nations *Declaration for the Elimination of Violence against Women*. As of 2005, twenty-seven of the thirty-four Member States to the OAS have ratified the Convention.

In the framework of the regional system the elaboration and entry into force of the Belem do Pará Convention constitutes a true redefinition of Inter-American human rights law, as it is applied with a gender perspective. It is possible to affirm that there exists political will among those that have ratified the Convention, as well as among the non-governmental actors, to eradicate gender violence through specific

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[7] *Beijing Declaration and Platform for Action, Fourth World Conference on Women*, 15 September 1995, A/CONF.177/20 (1995) and A/CONF.177/20/Add.1.

[8] UN General Assembly 52/86 *Crime Prevention and Criminal Justice Measures to Eliminate Violence against Women* Report A/52/635 12th December 1997.

policies and measures.[9] The Convention takes a fundamental step in the theory and practice of human rights, as it recognises that violence against women is a manifestation of historical unequal power relations between men and women.

The concept of violence against women expressed in the Convention is firmly founded in the basic rights already recognised in the Inter-American human rights system, including the right to life, physical and psychic integrity, personal liberty and the right to equal protection under the law and of the law. This concept challenges the division between what is public and private, making clear that violence against women generally, and women with disabilities in particular, breaches already accepted human rights, and defines the responsibility of States in regards to the adoption of specific measures and actions to eliminate violence against women. The Convention also develops the interrelation between gender violence and discrimination, establishing in Article 6 that the right of women to live a life free of violence includes, among others, the right to live free from all forms of discrimination, as well as the right to be valued and educated free of all stereotyping and of social and cultural practices based on concepts of inferiority and subordination.[10]

To give effect to the right of women to a life free of violence, it is necessary to determine when violence against women generates State responsibility. Articles 7 and 8 enumerate the principal policies and measures that must be adopted by States in order to prevent, punish and eradicate violence. It is from this point of departure that the progress and obstacles in implementing of the Convention must be measured.

Articles 10, 11 and 12 deal with petitions about violations of rights. The petitions may be communicated to the Inter-American Commission on Human Rights by individuals, state parties or CIM. The Commission informs the state named in the petition and delivers advisory opinions on the application of the Convention. In accordance with the Convention, State Parties must report to CIM on adopted measures and confronted obstacles when responding to gender violence. In turn, CIM must inform the OAS General Assembly on the progress made in

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[9] Organization of American Status, OAS, Report of the Inter-American Commission on Human Rights on the Condition of Women in the Americas, General Secretariat, OEA/Ser.L/V/II.100, Washington, D.C., 1998.

[10] Jiménez, Rodrigo. (1996). Los Derechos Humanos de las Personas con Discapacidad Instituto Interamericano de Derechos Humanos. San José.

the application of the Convention[11] and the results achieved from initiatives and programs of Member States to prevent violence against women every two years. CIM presented its first biannual report in November 1998.

I. *Violence: The Situation of People with Disabilities*

Parallel to the struggles of women against violence, the movement of people with disabilities struggles for the recognition of their human rights from a perspective of people with disabilities.[12]

Violence against people with disabilities includes physical, sexual, psychological, proprietary and negligent violence, which occurs in the public as well as in the private spheres, and constitutes one of the most complex social problems faced by societies around the world.[13] It is important to differentiate between structural violence that arises from social, political and economical systems, thus denying opportunities, benefits and access on grounds of inequalities and direct violence that is enhanced by the structural violence and is a reflection of the unequal power relationships between these two groups.[14] It is in relation to these kinds of violence that the disability of victims is portrayed and that the role of power and domination in the use of force is highlighted.

According to social, political, economic and historical reality, the manifestations of violence against people with disabilities varies, from physical abuse to sexual, psychological and/or economic abuse or abandonment, with the possibility of all the dimensions of harm being directed towards individuals.[15]

Some of the forms of structural violence relate to the attitude towards and the perceived value of people with disabilities. These include:

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[11] Consistent with AG/RES 1456 (XXVII-O/97)(Appendix IX).

[12] "Understood as the incorporation of the multiple forms of subordination and discrimination suffered by persons with disabilities in their context, regardless of age, ethnic groups or races, socio-economic conditions, disabilities, sexual preferences, geographical location, etc., which gives rise to a great diversity among persons with disabilities, that influences the way in which they experiment the abovementioned subordination and discrimination." Jiménez Rodrigo, Conference presented at Natal RICOTEC "Genero y Discapacidad", 2005.

[13] Jiménez, Rodrigo & Catalina Montero. (2001). Conociendo Nuestros Prejuicios, lo que Hemos Aprendido de las Personas con Discapacidad y Conociendo las Barreras y sus Consecuencias Defensoría del Pueblo de Perú, Lima.

[14] Arroyo, Roxana. (2004). La Violencia Contra la Mujer como Producto de una Violencia Estructural de Género ILANUD. San José.

[15] Jiménez, Rodrigo. (2003). Conocer y Prevenir la Violencia Intrafamiliar contra las Personas con Discapacidad Consejo Nacional de Rehabilitación y Educación Especial. San José, Costa Rica.

people with disabilities being ridiculed; being socially excluded; being devalued or made invisible; being denied legitimacy as sexual actors; being forced to be dependent; and being segregated. This response to disability is reflected in the media and in other social action. Further, people with disabilities are exploited in a number of ways, including being used as beggars and being trafficked.[16]

Society has built a relationship between disabilities and begging. Many of the people with disabilities that walk in the streets face people who offer them charity. Currently a new network of trafficking in people with disabilities has been discovered. People with disabilities are sold to countries in order to be economically exploited, either in forced labour or as beggars. Another example is the use of people with disabilities as objects of pity for fundraising purposes. People with disabilities have been used by different social institutions, such as religious organisations, and social programs, to create a sense of pity and thus obtain benefits for those people heading the programs.

Disabilities have been the focus of mockery and laughter, regardless of the feelings of those subject to ridicule. People with disabilities are socially disqualified, categorized as useless, dependent and incapable. People with disabilities are not socially valued, and thus their needs are not satisfied. As they are ignored, their human rights are constantly breached. In accordance with the socialisation process, it is considered that people with disabilities ought to hide their erotic and sexual feelings, since they are considered as asexual persons. Additionally, society makes fun of the sexuality of people with disabilities by means of jokes, myths and beliefs.[17] A further problem confronting people with disabilities is the belief that all people with disabilities are the same, preventing the awareness of their diversity and their specific life conditions, as well as the different needs of different people with disabilities.

Historically, people with disabilities have been segregated in ghettos, either in hospitals (psychiatric hospitals), educational centres (special education schools), labour centres (protected workshops), or similar

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[16] Jiménez, Rodrigo. (1997). Eliminando Barreras Construyendo Oportunidades Instituto Latinoamericano de Naciones Unidas para la Prevención del Delito y Tratamiento del Delincuente y la Organización Mundial de Personas con Discapacidad DPI. San José, Costa Rica.

[17] Ibid.

institutions. Society has created an image of the dependency of people with disabilities, which prevents them from developing their own potential. This is reinforced by the portrayal of people with disabilities in literature, movies, and television.[18] The mass media, as well as institutions participating in socialisation, create a series of roles and stereotypes about people with disabilities that undervalue and discriminate against them. A further reflection of the devaluing of people with disabilities can be seen in the pre-selection for the abortion of foetuses on the grounds of disability: This refers to the legal defence to abortion where the foetus has a probability of possessing a disability. Moreover, health systems devote little attention and budget (compared to other services) to research on disabilities, highlighting an insensitivity to the health care needs of people with disabilities.

The ways in which people with disabilities experience violence is not only made invisible, but is also publicly tolerated by laws, mass media, the church, education and other institutions that justify and confer legitimacy on it. One effect of this is that a number of people with disabilities are not conscious of the violence directed at them. Socialisation of people with disabilities leads them to accept violent actions as something natural arising out of their position *as* people with disabilities. Consequently, they are rendered unconscious of this violence that influences their development as human beings. In fear of being the victim of some kind of aggression, subsequent to personal experience, the low self-esteem of people with disabilities is maintained by this violence, giving rise to reliant, dependent, less-assertive persons.[19] Most of the violence is much more serious, intense and frequent than we know. This is due to the existing social silence and the myths and beliefs about people with disabilities. It is thought that these forms of violence are appropriate forms of relating and that people with disabilities feel comfortable about them. Because of the existing myths about people with disabilities and violence, many victims do not report or denounce it, adding to low self-esteem generally caused by suffering constant aggressions. Further, the State and its institutions do not take these forms of violence seriously. State and community response to violence against people with disabilities is insufficient. State services discriminate

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[18] Jiménez, Rodrigo & Catalina, Montero. (2001). Conociendo Nuestros Prejuicios, lo que Hemos Aprendido de las Personas con Discapacidad y Conociendo las Barreras y sus Consecuencias Defensoría del Pueblo de Perú. Lima.

[19] Jiménez, Rodrigo. (2005). Gender Disability and Violence Conference Universidad Diego Portales Santiago de Chile.

against the population with disabilities, denying equality of conditions in the services provided for them. These forms of violence prevent people with disabilities from enjoying equal opportunities and participation in the resources of society. Further, these forms of violence take place between a person with more power (social, cultural, economic, family, age, etc.) and someone with less power.

Criminal and discriminatory practices that constitute violence on grounds of disability not only cause harm, suffering or death for each person that experiences them, but also have an un-estimated social cost as they deprive society of the full participation of this population group in all the areas of development.

Violence and the Public Sphere

The assumption that States are not responsible for human rights violations committed in the private sphere ignores the fact that many of the forms of violence against people with disabilities occur in that sphere. It is important to recognise that the denial of human rights of people with disabilities in the private sphere could be considered a violation of human rights in the public sphere, since what occurs privately determines the capacity of people with disabilities to participate in the public sphere. Violence in the private sphere against people with disabilities must be socially acknowledged. Many of the existing manifestations of violence are socially accepted.

The distinction between public and private violence has been questioned by the movement of people with disabilities, in the course of its participation in the different United Nations conferences, and by the non-governmental and governmental organisations that work for the rights of people with disabilities. The dichotomy between the public and the private has served the purpose of justifying the lack of State responsibility for a serious social problem and provided the justification for the subordination of and discrimination against people with disabilities in our societies.

The recognition of disabled rights as human rights requires that the experiences and needs of all people with disabilities are taken into account as this helps to define and determine what it means to be human.[20]

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[20] Jiménez, Rodrigo. (1999). Conociendo Derechos y Cumpliendo con Obligaciones Instituto Latinoamericano de Naciones Unidas para la Prevención del Delito y

This type of observation has brought about a conceptual change in the understanding of human rights which is apparent in the United Nations *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (Standard Rules). The experience of violence in the lives of people with disabilities brings to the surface questions about the division between what is public and private, and results in the recognition of all forms of violence against people with disabilities as human rights violations.

The elaboration and entry into force of the Belem Do Pará Convention and the Inter-American Disability Convention constitute the framework of the regional system. This is a true redefinition of Inter-American human rights law which is implemented from a gender and disability perspective. It is possible to affirm that there is political will, among those that have ratified the Convention as well as the non-governmental actors, to eradicate violence and discrimination on grounds of disability by means of specific policies and measures.[21]

Protecting the Rights of People with Disabilities

Movement towards the recognition of the human rights of people with disabilities began with a process in which valuation of differences is initiated, abandoning the traditional concept of formal equality, where all of us are equal, and moving to a concept in which all of us are equally different. This estimation of differences affects the concept of equality used by people with disabilities, which is enhanced with the principle of an independent life, thus achieving a reformulation of the concept which is reflected in the Standard Rules.[22]

Rule 9 refers to family life and personal integrity. It promotes the full participation of people with disabilities in family life, eliminating any discrimination in relation to sexual relations, marriage and parenthood:

> States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities

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Tratamiento del Delincuente y la Organización Mundial de Personas con Discapacidad DPI. San José, Costa Rica.

[21] Organization of American Status, OAS, Report of the Inter-American Commission on Human Rights on the Condition of Women in the Americas, General Secretariat OAS, OEA/Ser.L/V/II.100, Washington, D.C., 1998.

[22] A/RES/48/96 adopted by the United Nations General Assembly at the 48th Session 20th December 1993.

> with respect to sexual relationships, marriage and parenthood. It refers to the importance of eliminating and punishing sexual abuse and all forms of abuse.

On the other hand, the United Nations *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care* (Mental Health Principles) establishes a series of rules for the prevention and punishment of violence.[23] Principle 1(3) establishes the importance of protecting victims from economic, sexual and physical exploitation and any other form of humiliating treatment. In respect to the treatment given in a psychiatric institution, the person has the right to be near his or her community and family. Treatment should be aimed at the preservation and enhancement of personal independence and sterilization is absolutely prohibited as a treatment for a mental illness (Mental Health Principle 11(12)).

Because the Standard Rules and the Mental Health Principles are recommendatory in nature much effort has been expended at the international level to create a binding convention on the rights of people with disabilities. In 1994 after various failed attempts within the United Nations system, Disabled People International, with the support of the Costa Rican Federation of Persons with Disabilities, commenced with the elaboration of the first draft Convention in the Organization of American States. The draft aimed for:

1. A symbolic two-way effect in which society would recognise discrimination due to disabilities, as well as the awareness of the population with disabilities about disability discrimination.
2. A guarantee that, in those States in which international treaties have the same or a superior value to the law, legal achievements were not reversed.
3. The promotion of legislative development in the region.
4. The inclusion of the issue of non-discrimination due to disabilities in international organisations, thus taking advantage of the international mechanisms in regards to the acquired obligations.
5. The creation of a new concept of human rights from the perspective of people with disabilities which values differences.

The elaboration of the first draft of the treaty was time-consuming, since the objective was to include diversity within disabilities, which

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[23] A/RES/46/119 adopted by the United Nations General Assembly at the 46th Session 17th December 1991.

meant a redefinition of the rights from the perspective of the population with disabilities. In order to achieve the desired goal, different sectors had to be invited to participate in the activation of human rights of people with disabilities. In order to achieve this, Disabled People International organised several workshops with heads of non-governmental organisations of people with disabilities, thus attaining a final document in Tegucigalpa, Honduras in 1995. This document was the basis that later was enhanced with the contributions of experts from the World Union of Blind People, Mental Disability Rights, the Inter-American Institute of Human Rights, the United Nations Latin American Institute from Crime Prevention and Treatment of Offenders and Human Rights Watch.[24]

This preliminary document was presented to various delegations in order to create awareness of its importance and thus achieve its support. The delegation of Costa Rica, with the strong support of the Panama delegation, gave the first initial momentum, attaining the creation of a commission to draft a disability convention. The advances were slow and the movement of people with disabilities had to participate in several General Assemblies of the Organization of American Status in Lima, Caracas, Panama, Port-au-Prince and Guatemala City. Likewise, when possible, participation was fundamental in the constant assessment to the drafting commission. Moreover, an expert meeting was convened with the participation of representatives principally from non-governmental organisations of Canada and the United States.

The standpoint of States was clear. A sector, headed mainly by Canada, and followed by some Latin-American countries such as Chile and Costa Rica, considered that the discussed text was weak and needed to be reinforced. Another more moderate sector promoted the approval of a text with progressive fulfilment of obligations in accordance with the socio-economic realities of the region. Brazil, Colombia, Mexico and Argentina were included in this group. A third group, headed by the United States and some countries of the English-speaking Caribbean, wanted a less compulsory document, where the discriminatory acts could be justified by economic cost under the legal provision of "reasonable accommodations." However, as resolutions of the Organization of American States are taken by consensus, all parties

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[24] *Inter-American Convention for the Elimination of All Types of Discrimination Against Persons with Disabilities. Inter-American Institute of Human Rights.* San Jose, 2002.

had to renounce certain aspects of their positions. Neither the weak text proposed by the United States, Haiti, Dominica, etc., nor the strong text proposed by Canada, Chile and Costa Rica, was adopted.

The *Inter-American Convention for the Elimination of All Types of Discrimination Against Persons with Disabilities* (Inter-American Disability Convention) was adopted on June 7th 1999 by the General Assembly of the Organization of American States that took place in Guatemala City and was signed by twenty States.[25] The Convention is an international instrument that combats discrimination and appeals for equality. As such the text must be analysed from an equality perspective.

Article 1 defines discrimination against people with disabilities in paragraph 2:

> The term 'discrimination against persons with disabilities' means any distinction, exclusion, or restriction based on a disability, record of disability, condition resulting from a previous disability, or perception of disability, whether present or past, which has the effect or objective of impairing or nullifying the recognition, enjoyment, or exercise by a person with a disability of his or her human rights and fundamental freedoms.

This Article broadens the concept of the right to non-discrimination, which was limited to people with disabilities throughout domestic laws in the region. Another important aspect in regards to the distinction, exclusion or restriction caused by discrimination is that its objective or result must be to impair or nullify the recognition, enjoyment, or exercise, by a person with a disability, of his or her human rights and fundamental freedoms. As a consequence an act or omission not intended to be discriminatory may be declared discriminatory due to its discriminatory result. Finally, it is significant that a State Party may intervene in the public and private spheres if there is discrimination and a human rights violation.

Article 1(b) of the Convention refers to affirmative or corrective measures that shall not be considered discriminatory. This provision corrects the situation of disadvantage resulting from the non-evaluation of distinctions made in society. It is worth noting that people with disabilities are not required to accept the intended distinctions.

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[25] Argentina, Bolivia, Brazil, Colombia, Costa Rica, Chile, Dominica, Ecuador, El Salvador, Guatemala, Haiti, Jamaica, Mexico, Nicaragua, Panama, Paraguay, Peru, Dominican Republic, Uruguay and Venezuela.

In order to achieve equality, a series of actions must be taken by States. These include the adoption of legislative, social, educational, labour-related, or any other measures needed to eliminate discrimination. These activities are very diverse, covering labour, transportation, communication, housing, recreation, education, sports, justice, law enforcement, accessibility to urban places, etc. This obligation applies to public and private entities, limiting the actions in private entities to the fulfilment of the principle of equality. However, the achievement of this objective is to be progressively accomplished. While people from developed countries find the progressiveness difficult to understand, for developing countries, this is the only genuine option for a true application of the provisions. For example, there are millions of people with disabilities throughout the region who do not have wheelchairs, hearing aids, materials for blind persons, and other adaptive equipment.[26]

The Convention applies the perspective of people with disabilities and increases awareness of rights in its application. This not only creates awareness throughout society in general of the existence of the rights of people with disabilities, but also creates awareness in all the millions of persons who have a disability and still believe that they don't have rights and thus must be treated unjustly and unequally.

The Convention also facilitates and promotes independence in order to achieve full integration and equal conditions. This is a further step towards the sought equality. Since, throughout the region, the concept of independent life is unknown, being aware of its principles is an advancement towards true equality. Further, active participation of non-governmental organisations of people with disabilities in the decision-making process opens opportunities for the political equality for which the movement of people with disabilities has extensively worked.

Under the Convention States must also undertake scientific and technological research related to the prevention, treatment, rehabilitation or integration into society of people with disabilities. It is necessary that science and technology work for people with disabilities in order to guarantee the equalisation of opportunities. An example is the impact of talking-computers, which have created opportunities for the

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[26] Jiménez, Rodrigo. (2002). Convention contre la discrimination des personnes handicapées 6e Assemblepe mondiale OMPH. Sapporo.

population of people with visual impairments. Currently, it is important to improve the technology and formulate inexpensive options that can be accessible to all the population.

The principle of equality in the Convention is to be read in accordance with article VII, that is, in relation to all recognised customary international law that protects the rights of people with disabilities. This means that, for example, the Standard Rules or the United Nations Mental Health Principles, as well as other international instruments already developed or adopted in the future, are to enhance the application of the text of the Convention.[27] The effect of Article VII is that the Convention incorporates within its text a series of advanced provisions that would come to fill existing legal omissions.

The Convention will be enforced and monitored both in the domestic as well as international spheres, with the participation of disability rights activists. The commitments may be undertaken through two channels. First, States are required to submit reports to the Inter-American Committee of the Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities, establishing the advances made in regards to the implementation of the Convention. These reports shall be reinforced with parallel reports submitted by civil society. Secondly, petitions may be presented to the Inter-American Commission on Human Rights in regards to the overall interpretation of the American Convention on Human Rights, the El Salvador Protocol and other inter-American instruments of human rights.

The Inter-American Disability Convention set the foundation for the presentation of an initiative by the government of Mexico at the United Nations *World Conference against Racism*, held in Durban, South Africa. The Mexican government organised to draft an international convention promoting and protecting of the rights and dignity of people with disabilities. The Mexican draft gave emphasis to the prohibition of segregation as well as forced interventions or obligatory internment, on the ground that they are serious forms of violence. It further emphasised the obligation of States to give special attention to the victims of violence who have a disability.

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[27] Gonzalez René, et al. (1997). Derechos Humanos de las Personas con Enfermedad Mental en el sistema de Salud Organización Mundial de la Salud.

On the 13th of December 2008, the General Assembly of the United Nation adopted the *Convention on the Rights of Persons with Disabilities*. This Convention has established a series of rights and directions relevant to violence against persons with disabilities. It has been determined that the interpretation of the Convention had to take into consideration the gender perspective and CEDAW and the recommendations of the CEDAW Committee.

Article 16 regulates the freedom from exploitation, violence and abuse determinate on the obligation of the States Parties to promulgate legislation and other measures such as administrative, social, educational regulations to protect and to prevent all forms of exploitation, violence and abuse against person with disabilities.

On the other hand States Parties have to ensure that all facilities and programmes are designed to serve persons with disabilities who face violence, exploitation and abuse and promote programs of rehabilitation and social reintegration for victims with disabilities.

The concurrent development of international law relating to the rights of people with disabilities, on the one hand, and violence against women, on the other, enhance the commitment of the American countries to respond to violence both against women and people with disabilities.

II. *National Response to Guarantee the Right of People with Disabilities to Live a Life Free of Violence*

Actions may be categorized as legislative, administrative and judicial. In the legislative sphere throughout the region, legal development has been noteworthy where laws related to domestic violence and sexual harassment have been adopted, as well as reforms in criminal codes.[28] However, these have not yet been integrated and legal omissions remain such that victims of violence with disabilities continue to be neglected. Despite the fact that the laws of Argentina,[29] Costa Rica,[30] El Salvador[31] and Guatemala[32] expressly mention people with disabilities

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[28] For example, Panama and Uruguay have adopted reforms.

[29] Law 24417 article 2 "When the victim is a child or an incapable person, elderly or disabled, the conducts shall be denounced by the legal representative…".

[30] Law 7586.

[31] Decree 902, article 15 "When the victim is a child, an incapable or disabled person, the conducts may be denounced by the legal representative, by the victim and by assisting institutions…".

[32] Law 97–96 provides in article 2: "…such as providing special protection to women, children, young, elderly persons and persons with disabilities, taking in consideration the specific situations case by base".

as beneficiaries of rights, in many cases this is under a biological paradigm and thus diminishes the potential of people with disabilities to act.[33] The need to act through a legal representative places barriers of access and equity between a disabled victim and legal action.

Legal omissions take a number of forms. Traditional forms of domestic violence suffered by people with disabilities, such as negligect or abandonment, are not recognised. Precautionary or protective measures are aimed at the protection of the integrity of women in a partner relationship. This ignores the specific needs of people with disabilities who are not in a partner relationship. Further, procedures for responding to violence do not recognise the situations of people with disabilities. People with disabilities are not granted full legal capacity and do not have legal standing to bring actions to denounce violence. A particular issue that arises is the dependency relationship that a person with disabilities may have with their aggressor. This is exacerbated by the reality that there may be no alternative but to continue to depend upon the aggressor. This problem is further highlighted where mediation is performed without taking into consideration power relations. These are some of the weaknesses of the legislation in the region.

Laws on equality of opportunities may be categorised according to their philosophical paradigm. First there are those that are strongly influenced by the biological paradigm, for example, the *Law for the Prevention, Rehabilitation and Equalization of Opportunities for Persons with Disabilities* of Nicaragua. This law treats disability medically and focuses on the person, not his or her surroundings. Due to this same characteristic, the topic of structural violence against people with disabilities and domestic violence are not considered.[34] Secondly, there is legislation within the biological paradigm, that contains human rights elements. An example is the *Law 19284* from Chile[35] and *Integral Protection Law for Persons with Disabilities* of Uruguay. These laws

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[33] Article 7 of the Domestic Violence Law of Costa Rica: "Persons younger than twelve years of age who are affected by a situation of domestic violence. When the person concerned are younger than twelve years of age, or persons with physical or mental disability, the measure must be requested by his or her legal representative…".

[34] Article 1, Law 202: "This law establishes a system of prevention, rehabilitation and equalization of opportunities for persons with disabilities in order to improve their quality of life and guarantee their full integration into society".

[35] Article 37: "The State, through its competent organisations, shall create the conditions and monitor the employment of persons with disabilities in order to guarantee their independence, personal development, exercise of their right to have a family and enjoy a dignified life".

affirm the importance of prevention, measuring and certifying disabilities, but they introduce aspects related to the equalization of opportunities and thus, structural violence. Moreover, these laws recognise the right of people with disabilities to live with their family or in substitute homes, with a clear tendency towards community living.[36] Thirdly, there is legislation that adopts the human rights paradigm, but has biological elements. For example, the *Law on Equal Opportunities for Persons with Disabilities* of Costa Rica and the *Law on the Attention of Persons with Disabilities* of Guatemala. While the influence of the previous paradigm remains,[37] these laws constitute a fundamental move towards the eradication of structural violence against people with disabilities, introducing provisions to combat domestic violence.[38]

Despite existing legislation, there remains a need to develop rules to prevent, punish and eradicate violence against people with disabilities. In particular, laws are needed which specifically address the experience of people with disabilities.

A series of administrative actions, such as plans, programs, policies, services, and monitoring actions, have been undertaken by women's institutes and ministries in regard to violence against women. Unfortunately, though, they do not incorporate the perspective of people with disabilities.[39] Thus women with disabilities are excluded from the services and their needs are made invisible.[40] With regard to disabilities, Councils relating to disabilities have been created or strengthened. Nevertheless, their work has had little impact in matters of prevention, punishment and eradication of violence against people with disabilities.[41] The Ombudsman's offices in the region have specialised units on the

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[36] Article 5, paragraph f): "To live with their family or a substitute home".

[37] Article 2, Law on Equal Opportunities of Costa Rica: "Disability: any physical, mental or sensorial deficiency that substantially limits one or more principle activities of a person".

[38] Article 21, Law for the Attention of Persons with Disabilities: "The parents shall take adequate care of their children with disabilities, in order to facilitate their physical, mental, moral and social development; likewise, they shall participate in the social and legal protection programs that they shall require".

[39] Arroyo, Roxana & Rodrigo Jiménez. (2005). Eficacia y Eficiencia en la Aplicación de la Ley contra la Violencia Doméstica. Instituto Nacional de la Mujer de Honduras Tegucigalpa.

[40] Modelos de leyes y políticas sobre violencia intrafamiliar contra las mujeres Organización Panamericana de la Salud Washington. (2004).

[41] Recently, the National Rehabilitation and Special Education Council created a manual on the prevention of domestic violence and has carried out training and diffusion activities on the subject.

topic of disabilities and have developed interesting actions to combat structural violence.[42] However, they have not acted in respect to domestic violence. It is therefore urgent to mainstream disabilities in all areas of institutions related to violence, and thus provide people with disabilities with the means to prevent, punish and eradicate violence.

With the exception of some cases in Argentina and Costa Rica, relatively little judicial action has been taken in the region to promote the rights of people with disabilities. It is necessary to promote the demand of rights before judicial entities.[43] In Costa Rica there have been interesting jurisprudential developments in recent years. Many of the cases have been related to discrimination or structural violence. These have included cases dealing with the right to access justice, the right to information, to social security, and to education. In some cases, the Constitutional Chamber of Costa Rica has affirmed the application of international human rights law:

> First of all, it is important to state that the Political Constitution of Costa Rica and the American Convention on Human Rights (international instrument with superior hierarchy to the law, in accordance with constitutional article 7) consecrate the principle of equality among persons and the prohibition to make distinctions contrary to dignity – articles 33 and 24 respectively. Additionally, the rights of people with disabilities are recognized in other international instruments, such as the "Inter-American Convention on the Elimination of all Forms of Discrimination for Persons with Disabilities" …This latter Convention defines in its article 1, discrimination, as following:
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> > The term "discrimination against persons with disabilities" means any distinction, exclusion, or restriction based on a disability, record of disability, condition resulting from a previous disability, or perception of disability, whether present or past, which has the effect or objective of impairing or nullifying the recognition, enjoyment, or exercise by a person with a disability of his or her human rights and fundamental freedoms.
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> Likewise, it consecrates the obligation of States that have ratified it to adopt:
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> > Measures to eliminate discrimination gradually and to promote integration by government authorities and/or private entities in providing

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[42] Cases of Guatemala, Costa Rica and Peru.

[43] Facio, Alda & Rodrigo Jiménez. (2005). Gender Equality and Internacional Human Rights In Costa Rican Constitucional Jurisprudente. Cambridge University Press.

> or making available goods, services, facilities, programs, and activities such as employment, transportation, communications, housing, recreation, education, sports, law enforcement and administration of justice, and political and administrative activities.[44]

Another example is vote 09650 of the year 2002, in which the same Constitutional Chamber stated:

> The Law on Equal Opportunities for Persons with Disabilities, in accordance with the principles of equality and human dignity consecrated in the Universal Declaration on Human Rights, the Inter-American Convention on Human Rights, The International Covenant on Economic, Social and Cultural Rights, The International Covenant on Civil and Political Rights, the Convention on the Rights of the Child, the Inter-American Convention on the Elimination of All forms of Discrimination Against Persons with Disabilities, the International Labour Organization Convention 169, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities; among other international human rights instruments, create the material and legal conditions to eliminate discrimination against people with disabilities. It compels the Costa Rican public powers and society in general, to implement the measures in order to achieve the equalization of opportunities for people with disabilities.

Another example is resolution 7275 of 2003 which, referring to the right to information, states that:

> This right, in relation to the particular case of those who experience any form of disability is recognized by international law in the *United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (Resolution 48/96, of 20th December, 1993), which refers in its rule 5 to the possibilities of access to different services, including, in paragraph b, the access to information and communication. Paragraph 6 of this rule states that:
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> > States should develop strategies to make information services and documentation accessible for different groups of persons with disabilities…appropriate technologies should be used to provide access to spoken information for persons with auditory impairments or comprehension difficulties.
>
> Moreover, paragraph 9 affirms that: "States should encourage the media, especially television, radio and newspapers, to make their services accessible."

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[44] Resolution *number 2001–08559, of 15: 36 hours of 28 August, 2001.*

> These rules pretend to specify the right that, in a more general manner is provided for in the *Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities* (articles I.2, II, III), which pursues the eradication of distinctions, exclusions or restrictions against this population, promoting their full integration into society.

Many judges have tried to incorporate the perspective of people with disabilities by imposing atypical precautionary measures in response to the specific needs of the victims of violence who have some kind of disability[45] in the spirit of the Inter-American Disability Convention. However, these have been specific actions taken by judges who are sensitive to the subject matter. On the whole judicial structures still ignore and neglect the need of this population in regards to violence.

Conclusion

The experience of the Inter-American Convention recommends the importance of strengthening international legislation on human rights of people with disabilities. In particular, it is crucial that United Nations *Convention on the Rights of Persons with Disabilities* be vigorously implemented.[46] This would enhance the legal framework needed to counter violence against people with disabilities. At a domestic level, specific legislation is needed that in practice protects victims of violence with disabilities. Current laws do not satisfy the requirements nor sufficiently respond to the particularities of this population.

Access to justice is still very distant for people with disabilities. This renders difficult the demand for their rights. Judicial branches must implement programs aimed towards the appropriate interpretation of laws regulating the human rights of people with disabilities, as well as to offer the necessary services to guarantee equal opportunities in the judicial sphere. It is crucial that judges appropriately interpret laws regulating the human rights of people with disabilities and that action is taken to guarantee equal access to justice. The success of law ultimately depends on the diffusion of information about these rights among people with disabilities, their relatives and society in general.

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[45] Family Court, decision 267–05.

[46] Editors' Note – The Convention on the Rights of People with disabilities was adopted by the UN General Assembly in 2006 and came into force in May, 2008.

STANDARD RULES ON EQUALITY OF OPPORTUNITIES FOR PERSONS WITH DISABILITIES: LEGAL VIEW OF PROVISIONS ON SUPPORT SERVICES, AUXILIARY RESOURCES AND TRAINING / VIEW FROM LATIN AMERICA[1]

María Soledad Cisternas Reyes

Introduction

The *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (*Standard Rules*) constitute an important change in paradigm, moving away from a medical-assistance perspective towards an approach focusing on rights with an interdisciplinary focus, emphasizing the psychosocial, environmental and contextual perspective in its broadest sense.

Within the hierarchy of regulations, a resolution by an international entity is not binding on States, unlike Conventions and International Conventions that are binding because States are subjects of public international law and actors in international relations.[2] Even though the *Standard Rules* are non-binding, there is no doubt about the effectiveness they have had in terms of orientation within national legislation and of public policy in the subject of disability.

This was recognized by the former United Nations Special Rapporteur on Disability in his Final Report where he stated that *Standard Rules* "have clearly defined the functions of the State in planning of measures aimed at achieving full participation and equality of opportunity, have

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[1] Editors' Note: This paper is based on a presentation that the author gave before the "Observatorio inter-paises" (International Observatory) on the Standard Rules of the United Nations for the equal opportunity of persons with disability, presented by the "Panamerican Health Organization", PAHO/WHO, in the year 2005. Some adjustments have been incorporated in accordance to the time elapsed. The original version of this paper is in Spanish. Since the time of this presentation The Convention on the Rights of People with Disabilities was adopted by the UN General Assembly in 2006 and came into force in May, 2008.

[2] Santiago Benadava Cattan. (1997). *Derecho Internacional Público,* Editorial Conosur, 5th Edition, Santiago de Chile.

strengthened aspects related to human rights and have provided a mechanism for active supervision."[3]

Rules 4 and 19 of the *Standard Rules*, will be analyzed from the perspective of law, with political science and bioethical aspects in the application of these precepts, taking into account the challenges and answers that we find in the United Nations reports on human development. Subsequently, this chapter surveys local experiences regarding training and legal proceedings resulting from the nonexistence or insufficiency of support services and auxiliary resources (also touching upon aspects of training), and shows the concrete achievements that have been made in this area.

There has been no specific investigative works that take into account a regional overview of the advances in the application of *Standard Rules* 4 and 19 in terms of achieving the full participation and equality of opportunity of persons with disability in Latin America and the Caribbean. Indeed, the result of the present inter-country study in which the local experiences of participants is collated, draws conclusions of vital importance in terms of identifying best practice. It also points to the practices that can be improved; promotes the exchange of successful experiences through networking between institutions, countries and sub-regions; and promotes the transfer and dissemination of innovative initiatives in the field of community-based rehabilitation.

Part One: General Overview

1. *Legal Perspective of the Standard Rules*

Of Rules 4 and 19: Support Services, Auxiliary Resources and Training

Support services, explained in Rule 4, can be understood as the material resources, human resources and available strategies to facilitate performance of a person with disability, in terms of activity and

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[3] Bengt Lindqvist. (2000–2002). Final Report of the Special Rapporteur of the UN Commission on Social Development on the application and oversight activities of the Standard Rules on the Equalisation of Opportunities for Persons with Disability, 27–28.

participation.[4] Thus, support services are diverse in relation to the type of disability, the specific person receiving the service and the social context, also taking into account the nature of the provider (institutions, family, community). The objective of these support services, in light of Rule 4, is to augment personal autonomy in daily life and in the exercise of rights. In essence, support services should support independence and be withdrawn as recipients develop their own capabilities.

The concept of support services is broad and it could be understood that auxiliary resources are included in the notion. However, if we wish to conceptualize them separately, they can be understood as resources that complement the original intervention; for example, those that facilitate access to special learning opportunities in community or in cultural contexts or that improve individual willingness to respond to that intervention.[5] There is conceptual overlap as, for example, a certain technology can be considered a material resource or part of a support service. For others in certain cases the technology could be an auxiliary resource. This depends on the point of view of the service provider.

The aims described in the *Standard Rules* in terms of autonomy and rights clearly indicate that their field of application is not just medical, but also apply to all fields that affect human integrity. Therefore, support services and auxiliary resources are steps that directly or indirectly represent a means to achieve the human development to which the global community aspires. Support services and auxiliary resources are called upon to cover a spectrum that includes economic rights, social and cultural rights, but also civil and political rights.

Several questions arise about the application of Rule 4 which covers support services. First, do States provide the equipment and auxiliary resources, personal assistance and interpretation services according to the needs of those with disability, and particularly those with severe or multiple disabilities (Rule 4.1 and 4.6)? Secondly, do States undertake the development and subsequent processes caused by the production and repair of equipment and auxiliary resources (Rule 4.2)? Thirdly, do

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[4] Information provided by the presidency of Fundación Pro-Ayuda al Niño Limitado/COANIL that caters for persons in social risk suffering from intellectual disability. Such information is supplemented with background data from various institutions working on the issue of disability.

[5] Ibid.

States disseminate knowledge about assistive devices and equipment (Rule 4.2)? Fourthly, is there the necessary consideration of special needs of children with respect to support and equipment (Rule 5)? Fifth, are persons with disabilities involved in the manufacturing of equipment and auxiliary resources (Rule 4.3)? Sixth, are personal assistance programmes conceived in such a way that persons with disabilities that use them exercise decisive influence in their execution (Rule 4.7)?

The answer to the questions raised, in relation to several States, would probably be average, less than average or non-fulfillment. Despite the fact that the *Standard Rules* prescribes that States should recognize that all persons with disabilities who need equipment or auxiliary resources should have access to them, including the financial capacity to procure them, the language is tenuous and does not constitute a binding obligation. This gives rise to a final question: is access to equipment and support provided free of charge or at low cost for persons with disabilities and their families (Rule 4.4)?

Training, described in Rule 19, is understood as the sum of actions supportive of a programme, that tends towards "qualifying or enabling a person or group of persons for their fulfillment"[6] in the areas or tasks and understanding in the objective of the training or instruction proposed. This Rule should not be left limited to those that participate in the planning and in the provision of services and programmes related to persons with disability. It applies wherever public and private functionaries sell services to the public: it should be recognized that the real inclusion of persons with disabilities results in individuals circulating in different spheres and not being seen as existing in real "ghettos" or segregated groups that are allegedly monothematic in relation to their own situation. Therefore, the prescription of Rule 19.1, which obliges the authorities that provide services in the sphere of disability to train their staff adequately, should be extended to all sectors.

In the application of Rule 19, the following questions arise: do states develop training programmes in consultation with organizations of persons with disabilities; do persons with disabilities participate in training programmes as teachers, instructors or advisors; and is it state policy to train persons with disabilities as workers in the community?

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[6] Ibid. Definition made with facts derived from various institutions dedicated to the subject of disability.

The last question becomes more complex when we link it with the issue of employment of persons with disabilities in the public sector, especially given the low employability in this sector and the insufficiency of public policy in this direction. National Councils on Disability and the organization in civil society of people with disability play an important role in the fulfillment of these goals.

Bioethical and Biolegal Perspective of the Rules on Support Services, Auxiliary Resources and Personnel Training

> The meaning of the term bioethics is determined by the two Greek words that make up its composition: *bios* –life, and *ethos* –custom. Etymologically the term bioethics serves to designate customs that are to do with life or care of life. The term can be understood in a second manner, giving rise to its more scientific meaning. Thus, the root *bios* designates the life sciences and the root *ethos*, the science of customs, or rather ethics.[7]

Rules 4 and 19 are clearly designed to give effect to bioethical principles such as justice. What do we mean when we refer to justice as a bioethical principle, with its links to support services and training for people with disabilities? "What is at stake is not that all should receive the same but rather that one should receive proportionately to what one is, what one deserves and to that which one has a right."[8] In this sense, granting support services to an individual in order for them to achieve a functional level in accordance to their needs, realizes the principle mentioned. It is best when training occurs in the triangulated application of the principle (in the sense of training third parties – functionaries who serve those with disabilities and public servants in general with the objective of being facilitating agents in the development of persons who live with various limitations. It is important to note that we use the words *possibility* and *their needs*, whilst it is incumbent upon the potential recipient of rehabilitation to make the option effective and relevant to their lives, in the exercise of the bioethical principle of autonomy of will.

Furthermore, "if we extend the concept to the rest of society, we find that the concept of distributive justice which refers to the measured,

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[7] Gracia Guiññén Diego. (2002). De la Bioética Clínica a la Bioética Global: Treinta años de Evolución, en *Revista Acta Bioethica: Debate Etica y Ciencias Sociales, Programa Regional de Bioética OPS/OMS*, Editorial Maval Ltda, Santiago, 28.

[8] Lolas Fernando. (2001). *Bioética. El Dialogo Moral en las Ciencias de la Vida*, Segunda Edición, Editorial Mediterráneo, Santiago, 68.

equal and appropriate distribution of goods and social responsibilities based upon norms that detail the meaning and the aims of social cooperation."[9] What is more, authors such as Norman Daniels suggest that the "idea of healthcare should give way to social justice as the best way of creating a just society and improving health in general."[10] But to whom does it fall to provide the necessary conditions for this social justice, taking as given the personal effort of the individual who decides to resort to support services and training for themselves, or for others as facilitating agents? Evidently, one of the most involved would be the state, as we have seen in the pledges that they are called to honour as part of international norms.

Justice requires that everyone has the opportunity to receive a similar value of services, with the absolute need determined by each individual:

> This value of services needs to be fairly robust in order to cover most measures[11]…[t]he real theme of justice is that the basic system – the one for all – be adequate in such a way that most people do not feel compelled to buy into a more expensive system, in other words the basic level cannot be the level for the poorest.[12]

Finally, it should be underlined that it is incumbent upon the state – as the creator of the conditions of the common good and guarantor of life and the physical and psychological integrity of individuals – to take upon itself the rehabilitation of persons with disabilities, which implies its intervention in various aspects "in order to approve insurance plans, offers of managed health etc and fundamentally, the government will be necessary in order to evaluate the quality of care."[13] Therefore it is worrying that the United Nations states that "98% of persons with disability living in developing countries do not have access to rehabilitation services."[14] As can be understood this statement includes

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[9] Ibid., 68.

[10] Emanuel Exequiel. (2000). Inequidades, bioética y sistemas de salud. Bioética y Cuidado de la Salud: Equidad, Calidad y Derechos, Programa Regional de Bioética OPS/OMS, LOM Ediciones, Santiago, 104.

[11] Ibid., 105.

[12] Ibid., 106.

[13] Ibid., 106.

[14] Rueda C. Laura & Miranda Z. Orquídea. (2002). Main bio-ethical dilemmas in persons with prolonged disability *Revista Acta Bioethica: Debate Etica y Ciencias Sociales, Programa Regional de Bioética OPS/OMS*, Editorial Maval Ltda, Santiago 128.

support services and auxiliary resources, and can be extended to specific training.

Given the difficulties of the state as an entity we should highlight the importance of society acting in conjunction with it, as a facilitating agent and executor of procedures applicable to persons of disability, inaugurating a new form of social justice in the bioethical field through Community Based Rehabilitation (CBR).[15] The CBRs aims can be achieved through various actions (The invention of which is virtually endless), which would be confirmation of the indicated principle – in auxiliary form – given the state has the main responsibility in this. Although the indicated intervention model was conceived of to answer the needs of persons with disabilities inhabiting places far removed from the urban centres, and for the sectors in need of healthcare and support services, it is no less true that the same limitation of state resources results in a progressive application of these ideas of CBR for all those that require it, independently of their place of residence in order to apply the bioethical principles implicit in the norms.

Human Rights Perspectives on Support Services, Auxiliary Resources and Training

The great advance that the *Standard Rules* outline is to consolidate the specificity of disabled human rights. Rules 4 and 19 constitute a good example of this. In effect, the *first generation* of human rights enshrined in the International Covenant on Civil and Political Rights and the *second generation* of human rights enshrined in the International Covenant of Economic, Social and Cultural Rights, are of course applicable in full to people with disability. However, the exercise of these rights has historically been complicated for this group. Therefore, their specific rights can be inserted within the development of the theory of *third generation* human rights, recognizing within these rights, those *everyday rights*, those that make human rights of first and second generation operative when dealing with specific groups.[16] In this way a process can be identified in the codification of particular rights for under-protected groups. In turn, the *Standard Rules* have served as an inspiration for

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[15] The conception of CBR has its origin in the works conducted by the World Health Organization (WHO).

[16] Ara Pinilla, Ignacio. (1990). *The Foundations of Human Rights*, Editorial Tecno, Spain, & López Calera Nicolás. (2002). *Are there Collective Rights*?, Editorial Ariel S.A., Barcelona, 174.

national legislatures in this field. The following examples demonstrate the link between human rights of first and second generation (mother rights or rights bodies) with those third generation rights which make the former a reality when dealing with the disabled in terms of support services and training.

With respect to the first generation of human rights, the right to freedom of movement is one key aspect. In order for a person with a physical disability in their lower limbs to exercise their right to freedom of movement, recognition of other rights are necessary: the right to basic equipment (such as a wheelchair to provide mobility); the right to accessibility (to enable the use of the wheelchair); and a trained personnel. These last examples are third generation human rights or the basic right of persons with disabilities. Similarly, blind people have the right of suffrage in common with all citizens. In order to exercise this right they require that the electoral system use support services and auxiliary resources to provide equipment (special stencils, personal assistants, etc), and also train the personnel in charge of the voting stations and voting tables to understand these special needs. These last are human rights of the third generation, or basic rights of persons with disability.

An example of second generation human rights is the right to education. The support services and auxiliary resources would vary according to each disability. In this way, a deaf person requires a sign language interpreter, curricular adjustments and personnel prepared for this challenge in order to make their education effective. As is understood, these specifications are operative third generation rights. The same is applicable in the exercise of the right to work, the right to health, sport and recreation among others.

In consequence, it is clear that the right to support services and the right to training are human rights, within the expressed legal logic. From this point of view, it is important to enshrine the right to support services and training as human rights in positive human rights norms.[17] As such, a consideration of the following instruments is helpful.

In the *Convention for the Elimination of All Forms of Discrimination Against Persons with Disability* ("Inter-American Disability Convention"),[18] ratified by the states of the region, articles are enshrined whose

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[17] The expression "positive norms" should be understood in the sense of laws set down in legal documents.

[18] Convention approved by the General Assembly of the OAS in June 1999.

reading should be concordant with Rules 4 and 19. The virtue of these is that they are binding on the states which have signed said convention. Article 3 signals that "in order to achieve the objectives of this Convention, the signatory states commit to1 a) adopt measures to progressively eliminate discrimination and promote integration on behalf of state authorities and/or private entities in the lending or supply of goods, services, installations, programmes and activities such as employment, transport, communications, housing, recreation, education, sport, access to the law, police services and the political activities of the administration;" 2 To assign priority to the following areas: b) early detection and intervention, treatment and rehabilitation…and the supply *overall services* to assure an optimal level of independence and quality of life for disabled persons."[19]

On the other hand, Article 4 prescribes that "In order to achieve the objectives of this convention the signatory states commit to: 2 collaborate effectively in b) the development of…resources designed to facilitate or promote an independent life, self sufficiency and total integration under conditions of equality…for disabled persons."[20]

The legal formulation of Rule 4 of the *Standard Rules* allows for a focus towards a specific right of persons with disability, which is the right to accessible technology, in view of such assistance that allows for a higher efficency and thus a better effectiveness in terms of activity and participation following the indicators of the World Health Organization in such matters.[21]

Therefore, the challenge is to place this right in the public eye and among the political priorities of States. *This should not be understood as a search for luxury, but rather for a basic necessity for millions of human beings*, insofar as placing at their disposal technology that already exists and is available which gives meaning and function to other rights. The invocation of this new right is nothing more than the logical conclusion of the advancement of our human family towards solidarity with strong elements of human cooperation and within the framework of third generation human rights, that take the shape of collective rights of an everyday nature.

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[19] Ibid., article 3, N°1, N°2.

[20] Ibid., article 4, N°2.

[21] International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organisation.

In turn, the *Standard Rules* analyzed within the concepts of our interest, have allowed the disability community to advance towards proposals that would have been unthinkable before. It is thus that in the Ad Hoc Committee that elaborated the *Convention on the Rights of Persons with Disabilities* (CRPD)[22] discussed the existence of support services to guide certain basic decision-making processes dealing with persons whose legal capacity has been suppressed or legally limited through prohibitions.[23] Finally, this proposal achieved normative consagration in Article 12 of the CRPD giving support to a change in the paradigm, in which all persons with disability have a right to legal capacity in equal condition with the rest in all aspects of life.

In the same manner articles 4 and 19 of the *Standard Rules* were a valuable contribution to other articles of the CRPD. Some examples are:

Article 4: The General Obligations of States. To undertake or promote research and development of universally designed goods, services, equipment and facilities, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;

To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;

To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities; To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights.

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[22] By resolution N°56/168 of the General Assembly of the UN, a Special Committee was created charged with developing an International Convention to Promote and Protect the Rights and the Dignity of Persons with Disability. 2001.

[23] By interdiction we understand the result of a legal process that restricts the legal capacity of persons with mental illnesses or disabilities.

Article 19: Living independently and being included in the community: Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.

Article 21: Personal mobility: Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;

Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities.

Article 21: Freedom of expression and opinion, and access to information: Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;

Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;

Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;…"

Article 24: Education: Reasonable accommodation of the individual's requirements is provided;

Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion;

Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;

Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;

Ensuring that the education of persons, and in particular children, who are blind, deaf or deaf blind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development;

Take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

Article 26: Habilitation and rehabilitation: States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services;

States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Article 29: Participation in political and public life: Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;

Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;

Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice.

Undoubtedly, Article 9 of the CRPD, contains broad details of the diverse ways that the principle of accessibility must be a reality, in turn a synthesis of the central axis in the issues at hand in this paper.

Challenges:

1. That the judicial guidelines of positive national rights, consagrate the support services and training in the rank of rights with persons with disability.

Safeguard the usage of more imperative verbs when addressing States. In other words, instead of using *promote, watch over, foster or support,* use the verbs *ensure* or *guarantee.*

2. That national communities take an in-depth look at the development of the theory of human rights of persons with disability, in such a way that the right of counting on support systems and the right to training and have effective guardians through each internal individual State mechanisims. There should be a tendency towards language and content within international and national areas.

2. National Disability Councils: Their Role in Public Policy

It is true that in most countries there exist constitutions that indicate that the state is at the service of the human being and that its function is to promote the common good, together with assuring equality before the law and equality of opportunity. Most countries also have legislation on the social inclusion of persons with disabilities and, although International Treaties such as the Covenant of Civil and Political Rights, the Covenant of Economic, Social and Cultural Rights, the American Convention on Human Rights and the Additional Protocol of San Salvador have been ratified. However, in many cases, global and transversal public policies regarding persons with disability did not materialize, only sectoral efforts that, many times, were not sufficiently coordinated or systematic. The challenge will be to see what happens now, after the ratification of the CRPD in the different national realities.

Efforts made by the Ministries of Education, of Labour and Social Provision, of Health, of Women and the Family, of Housing, Transport and Planning, must include a correlation with other secretariats of the state such as Finance and Economics (given the distribution of economic resources that should be assigned in the adequate execution of the policies and programmes of disability action), one of whose principal aspects for disabled persons is constituted by support services and auxiliary resources. This connection should also include Ministries of Foreign Relations whilst important transformations are being experienced in the multidisciplinary focus on this subject at international level, at the level of the UN and the OAS.

The creation of the National Councils on Disability as multi-sectoral organizations in which we find represented not just the governmental sector, but also the disabled, who are actors and recipients of these processes and rules, has been a significant advance since the 1990s in the countries of Latin America and the Caribbean.

Any Ministry that forms a link with the Executive,[24] with greater or lesser legal independence, normatively or *de facto*, has been transformed into an entity with a recognized voice on the subject of disability, called on to effect the necessary intersectoral coordination. However, their work is limited by a budgetary allocation that must cover all the angles referring to prevention, rehabilitation and equalization of opportunities in their most varied expressions. These limitations effect their operative capacity as well as the support capacity, (which is often not present in the different regions of a country), as well as the insufficient provision of direct and indirect subsidies for the acquisition of technical help. These difficulties produce a complex knot which means that many disabled persons cannot count on that which they need depending on their disability and the their location. In this last case, the administrative procedures establish priority criteria among the persons with disability themselves, *occasionally* causing waiting lists in order to receive the above mentioned technical help. The difficulties that this selection process implies are significant whilst the great majority of the disabled live in very complex economic situations, not just because of the costs that they must incur to sustain their existence but also due to lack of employment and precarious incomes (which sometimes consist only of a scant pension).

The insufficient budgetary allocation also limits the training of functionaries and of persons with disabilities with regard to their inclusion in the labour market. These shortcomings are a link in the chain which keeps societies without profound education in matters of equality and discrimination uneducated, which makes it more difficult to break the stereotypes that lead to segregation. A critical view of these National Councils is often generated among persons with disabilities, seeing them as ineffective. It should be noted that the Councils do not always have authority in the arena of public policy. This should be rectified.

Challenges:

1. Paths should be defined in order to achieve a greater share of state resources for the total satisfaction of Rules 4 and 19. The strengthening

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[24] Each country generates their own formula to annex their national councils on disability. Following this statement, we can find experiences that have this councils within the Health ministry, Family Ministry, Women Ministry or Planning and Social Affairs Ministry.

of the National Councils should be considered in view of this objective, given their intersectoral character.
2. National Councils influence the design of public policies on disability.
3. In order to make the most of existing resources, National Councils on Disability must play an active and effective role in the coordination of sectoral efforts on the subject of disability.
4. Councils should act as catalysts in the adoption of legislation according to legislation in accordance to the CRPD, the *Standard Rules*, and the OAS Convention.

In the developing countries, persons with disabilities are generally the poorest of the poor. Latin America and the Caribbean are no exception. In effect a disabled person is trapped in a cycle, which on the one hand makes their employment difficult and therefore affects their income (made up of only a pension in some cases); and, on the other hand, their living costs tend to be higher than for most people, in terms of treatments, transport, and often the self-provision of support services, auxiliary resources and training.

From another angle, with the condition of disability being a circumstance that involves a person's individual integrity in their various activities, the analysis of their situation should not be made from a perspective isolated from the rest of society. Along this line of thought, when we refer to persons with disabilities we are also talking of access and accessibility to the different areas in which a person and a citizen are expected to operate. Finally, the support services, auxiliary resources and training constitute the connection necessary for the fulfillment of these principles and the enjoyment and exercise of rights.

For this reason the UN *Report on Human Development*, together with the Millennium Goals, should be analysed from the perspective of persons with disability. The Millennium Goals "…should be parameters that serve to measure the advances made in development, peace, and human rights measured according to certain fundamental values…".[25] Without doubt this includes persons with disabilites in the terms previously indicated.

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[25] UN Programme on Development. (2004). Los objetivos de Desarrollo del Milenio: un pacto entre las naciones para eliminar la pobreza. *Report on Human Development (2003)* 28.

Global statistics show that "more than a billion people fight every day to survive the scourge of hunger and uncertain health."[26] In the developing countries 799 million people suffer from hunger, that is to say approximately 18% of the world population.[27] Within this segment, many people with disability are found far from the possibility of counting on support services, auxiliary resources and different types of training.

Faced with these facts, the Report on Human Development forces us to look at certain elements that should be considered when looking seriously at eradicating poverty. In this way, the perspectives of the Report that together with analyzing the internal variables of the countries to achieve this objective – in terms of respect for rights, economic growth, social development, social participation, technology and governance – reveal international cooperation as a vital axis in this commitment.

Respect for Rights:

The programmes to reduce poverty and its effects "should respect human rights, defend legal precepts and commit to apply them honourably and effectively."[28] One of the political measures of the Human Development Index to avoid the poverty trap is: "The promotion of human rights, social equality and the well-being of all, guaranteeing that the poor and the marginalized, including girls and women, have the freedom and the voice to speak and be able to influence in the decisions that affect their lives."[29] In the same way, "If these conditions are fulfilled the poor countries should be able to count on a notable increase in assistance on the part of the rich countries, in financial terms and in the application of the fairest rules of the game in the commercial, financial, scientific and technological spheres."[30]

Economic Growth and Social Development:

It is stated that, "To escape the poverty trap, countries should attain a series of critical benchmarks in the areas of sanitation, education, infrastructure and governance, which will permit them to break away towards sustained economic growth.[31] Moreover, "The synergy between

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[26] Ibid., 16.
[27] Ibid., 87.
[28] Ibid., 15.
[29] Ibid., 19.
[30] Ibid., 15.
[31] Ibid., 18.

social investments, understood as the interrelation of these, is fundamental in the reduction of poverty."[32] The achievements in this area are not automatic, "they can vanish if income inequality increases and the poor do not participate adequately in growth, a phenomenon found in many countries in the last few years."[33]

It is emphasized that "Although economic growth is not an automatic cure for non-economic poverty, without a doubt it contributes to reducing it, only when public policy guarantees that its dividends reach the poor."[34] Non-economic poverty is related to other shortcomings that are not directly those of economic income. Thus, for a person with a disability there exists non-economic poverty when they do not have access to public transport, housing, education, work, and also to support services, auxiliary resources and training for themselves or for third parties with whom they interrelate.

From the early 1990s, the defenders of human development have fought for an increase in social spending until it reaches, at a minimum, 20% of the national budget and aid.[35] It is important to note that "The medium income countries should incorporate themselves to the regular process of budgetary planning and to longer term development strategies."[36]

The United Nations *Millennium Declaration* calls for all developing countries to include the Millennium Development Goals into their development strategies, taking into account their national priorities and necessities.[37] It is noted that, "The Index for Human Development and the Gross Domestic Product per capita can also differ, showing that it is possible to reach high levels of human development without high incomes and that high incomes are not a guarantee of high levels of human development."[38] A dozen developing countries exist that have evolved with great speed reaching social indicators comparable to those of the rich countries.[39] The countries with good results allow us to state

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[32] Ibid., 85.

[33] Ibid., 17.

[34] Ibid., 18.

[35] Ibid., 146.

[36] Ibid., IV.

[37] Ibid., 21.

[38] Ibid., 60.

[39] Ibid., 86. Example: In Sri Lanka in only 7 years (1945–1952) life expectancy rose 12 years. In China in 9 years (1953–1962) the increase was 13 years. No Latin American countries were found on the list that have achieved similar results.

that, by choosing the right priorities and policies, it is possible to reach a level of social development, even when the economy is not flourishing.[40]

Social Participation:
These approaches reflect the triple function of civil society: participation in strategy design, lending services through community organizations and national NGOs and acting as a guardian that ensures the fulfillment of commitments made by the government.[41]

This is how "The Millennium development objectives represent national political commitments with the potential to be a powerful implement for the population to make their leaders responsible for results."[42] It will be very important for disabled persons and their organizations to know these objectives well, with the corresponding exigencies towards the authorities.

Following this line, "In order to realize the potential of the objectives it requires that the poor organize and adopt measures collectively and this is not easy."[43] The report considers that "these people tend to be less organized, less capable of articulating their concerns, less capable of obtaining public services and legal protection, less linked to influential people and more vulnerable to economic impacts."[44] In any case people with disabilities and their organizations have slowly been generating a certain capacity for action, although the results achieved have been small, achieved through micro-initiatives.

In these terms, "As part of these political changes steps have been taken towards decentralization and new social movements have sprung up, which provide citizens with new avenues of collective action."[45] For its part, the "Collective direct action is another path that allows people, especially the poor to exercise influence on decision-making and to demand responsibilities from the authorities. The social movements have placed exclusion and penury at the centre of the political stage."[46]

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[40] Ibid., 87.
[41] Ibid., 24.
[42] Ibid., 134.
[43] Ibid., 134.
[44] Ibid., 134.
[45] Ibid., 134.
[46] Ibid., 140.

Technology:
It is important to underline that "The technological innovations advance human development in two ways: they improve productivity which raises family incomes and they provide solutions to the problems of ill health, transport, energy, water provision, sanitation and they provide information and communication technology for education all of these very important to achieve objectives."[47] It is also important to mention that "The subject of technology and its mass distribution constitute the central feature of the Report on Human Development 2001[48] whereas the reflection should be on the necessity for the mass distribution of technology to reach persons with disabilities."

Governability:
One of the main conclusions of this report is that it is not enough to rely on measures such as the reassignment and greater mobilization of national resources. Overcoming poverty also requires the strengthening of governance of institutions and the adoption of solid social and economic policies.[49] Thus "Without solid governance, it is probable that the great financial injections are misspent and without democratic governance which gives voice to the people, development efforts will not give power to the poor."[50]

International Cooperation

In practice, governments "should specify the budgetary commitments that can be covered by the national resources and those that require an increase in aid in order to develop."[51]

The attainment of objectives demands close attention to the Millennium Development Goals. The low income countries should resort to external sources in order to obtain a significant part of the additional resources needed for social investment.[52]

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[47] Ibid., 157.

[48] Report on Human Development. (2001). Poner el Adelanto Tecnológico al Servicio del Desarrollo Humano elaborado por el Programa de Naciones Unidas para el Desarrollo/PNUD, año 2002.

[49] Report on Human Development. (2003). Los objetivos de Desarrollo del Milenio: un pacto entre las naciones para eliminar la pobreza.

[50] Ibid., 149.

[51] Ibid., 21.

[52] Ibid., 108.

It should be remembered that the multilateral contribution has represented a third part of official aid for development, including United Nations entities, the World Bank and regional banks."[53] The Millennium objectives, as regards the eradication of poverty, are based on sustaining the global commitment with regard to the growth of mutual responsibilities between rich countries and poor countries.[54] In order "To reach these objectives, far more ambitious cooperation programs will be required to cater for political, institutional and resource limitations."[55]

Within these limitations, international cooperation must bear in mind that in developing countries the most difficult areas to finance are operational expenditure and the salaries of the human capital that devotes its knowledge, time and conviction to social issues. Therefore "Bilateral donors must definitely do away with the erroneous distinction between aid by means of capital costs and current costs since both items require great support."[56]

In consequence, consistent international cooperation should reach those areas which the state cannot afford in terms of policy for persons with disabilities, particularly on subjects like accessibility, the provision of support services, auxiliary resources and training.

The Millennium Goals aspire to lift the restrictions that impede people's freedom of choice. However, they do not cover all the fundamental dimensions of human development.[57] Do persons with disability not find themselves limited in the ability to choose freely when they find themselves lacking in basic elements of autonomy and the exercise of rights? The Human Development Index (HDI) is a synoptic vision of three dimensions of the concept of human development: to enjoy a long and healthy life, to have a dignified standard of living[58] and to have access to education. In consequence, the objectives of persons with disability to enjoy autonomy and be able to exercise their rights for which they count on support services, auxiliary resources and also training,

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[53] Ibid., 108.
[54] Ibid., 145.
[55] Ibid., 148.
[56] Ibid., 23.
[57] Ibid., 27.
[58] Ibid., 60.

are, without doubt, central aspects of a dignified life for this community and therefore a dimension that should be considered.

From the creation of the HDI in 1990, three complementary indices have been developed to highlight the specific aspects of human development: the Index of Human Poverty (IHP), the Gender-related Development Index (GDI) and the Gender Empowerment Measure (GEM).[59] The Index of Human Poverty (IHP) reflects the distribution of advances and measures the delays in the privations that yet exist.[60] However, the question is: why does this Index not take into account the variable of disability in aspects such as access and accessibility, where support services, auxiliary resources and training are the measurable aspects within States?

We should consider that both malnutrition and events such as occupations, armed conflicts, wars and natural disasters, increase the numbers of persons with disabilities. The application of the World Health Organization's International Classification of Functioning, Disability and Health (ICF) indicates that the universe of persons with disabilities is larger than other measures had allowed for.[61] Evidently the progressive application of the ICF to different countries should not only result in a statistical fact, but will also be an important support to the claims for larger national budgetary allocations, aimed at the different aspects of disability such as support services, auxiliary resources and training among others.

At the same time IHP breaks this down:

1. IHP 1 measures poverty in developing countries focusing on privations in three areas: longevity, knowledge and economic provision in general, both public and private.[62] Would it not be appropriate to incorporate here access to support services and auxiliary resources for people with disabilities?
2. IHP 2 applied to certain developed countries it also measures deprivation using the same parameters as IHP 1, but adding one more:

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[59] Ibid., 60.

[60] Ibid., 61.

[61] Chilean experience according to the last 2002 Census indicates that 2.21% of the population has some disability. The Inquest of Socioeconomic Characterisation Casen 2000 puts it at 5.3% and the ICF in 2004 registered 12.9% Editors' Note Australian statistics recognise that close to 20% of the population are people with disabilities. It is highly unlikely that a developing country would have a lower disability population.

[62] Report on Human Development 2003 "Los objetivos de Desarrollo del Milenio: un pacto entre las naciones para eliminar la pobreza."

social exclusion, in terms of recording the percentage of people living under the threshold of income poverty and long term unemployment.[63] Could it be that variables such as these could be diversified and broken down for persons with disability?

We could even envisage the creation of a separate index for disability, as exists for IDG and IPG.

Although it is true that there is no specific Millennium Goal relating to persons with disabilities, the link between disability and poverty is relevant. For example, it is conceivable that international cooperation channeled through the United Nations, could operate through a Global Fund for persons with disabilities in the same way that the Global Fund for Aids has been of such importance in the developing countries. Such a fund could complement the resources of the developing countries were it directed at support services, auxiliary resources and training.

Challenges:

1. Link the disability variable with the Millennium Development Goals in terms of the eradication of poverty.
2. Introduce the disability variable in one of the approaches of the Human Development Index, either incorporating it into IPH or creating a new indicator on disability as a multifocal concept.
3. Explore the creation of a Global Fund or similar initiative around the issue of disability, in order to funnel international cooperation towards developing countries.

To promote this idea, an important strategy shall be the application of CIF with the objective of producing quantifying and quality elements in order to compare data with a vision towards the development of action plans to cause a real positive impact in the life of persons with disability in the world.

3. *Conclusions*

1. Challenges posed in terms of the legal vision and the prospects of the regulations analyzed (Rules 4 and 19) in terms of being enshrined in both international and local legal systems, are closely linked to the positioning of National Councils on disability and

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[63] Ibid., ID, 61.

organizations of persons with disability, acting in the manner that has been described. Their importance is a reflection of the mandatory nature that support, auxiliary and training services must have as rights.

2. National Councils on Disability are called upon to play an important role in coordinating efforts on disability in each State, thus making the best possible use of resources allocated. Their strength as inter-sector entities must be taken into consideration.
3. Organizations that bring together persons with disabilities are called upon to play a role in demanding and exerting social control of authorities and public policies. Their role in contributing to State efforts in the field of support, auxiliary and training resources must be recognized.
4. The application of CIF in different countries will lead to a further strengthening of the role of persons with disability because it is felt that this measurement will provide quantifiable and quality data for the elaboration of solid action plans.
5. The figures obtained, together with respect for human rights, economic growth and social development, technology, social participation and governance are all highly significant to attract international cooperation that translates in developing countries into support services, auxiliary resources and training in the area of disability, among others.
6. From the perspective of the United Nations, it is interesting to insist on the inclusion of the variable of disability in the Human Development Reports, either integrating it in the Human Poverty Index (HPI) or creating a separate indicator for disability. That would contribute to the visibility of a situation that is lived by millions of persons with disability in the world and the eventual creation of a Global Fund dedicated to this matter.

Part Two: Local Experience

The Work of the Legal Programme on Disability of the Diego Portales University, on the Promotion of Rights, Advice and Legal Defense

Following on from the macro analysis that gives us global answers to the challenges identified, it is useful to bring into the equation local experience gained by the Legal Programme on Disability of the Faculty of Laws – Diego Portales University of Chile (project from the years 2000–2008).

Starting from the disciplines of law and political science allows us to visualize disability in the context of the law of a democratic state, with a political system that is called upon to be truly inclusive in order to improve the governance of the nation. Tools and mechanisms have been identified that are legitimate and viable within a democratic state. The two priority areas relate to, first the promotion of the rights of the persons with disabilities to civil society, public functionaries and to judges and, secondly, with respect to legal experience in human rights of persons with disability and outcomes.

The Promotion of Disability Rights: To Civil Society, Public Functionaries and Judges has involved training of persons with disabilities and public functionaries. Special care was taken with the physical spaces where these activities take place, so that they were accessible (starting from the adjustments made), with adequate materials in appropriate language and formats in accordance to respective disabilities (Braille and cassettes for blind persons and always having sign language interpreters for deaf people). Working groups, in which persons with disabilities have played an important role, produced documents which analyze legal and legislative actions. These documents were submitted to the Commission on Disability of the Chamber of Deputies.

Training of public sector functionaries has also been carried out, utilizing disabled civil society leaders as trainers, and including the participation of women with disabilities to incorporate gender perspectives.

An important experience has been the training of judges who, according to the *Law on the Social Integration of Disabled Persons,*[64] have the ability to try rights violations. In this respect a pilot programme was begun at the level of Local Magistrates in the Metropolitan Region. When this initiative was successful, the participation of the National Institute of Local Magistrates was coordinated and they brought magistrates from all over the nation to the Second Bi-annual Congress of the Legal Programme on Disability. The third step was the execution of the project *Judges and the Citizenry of the Native Peoples as Concerns the Disability Variable in Connection to Indigenous Rights.*

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[64] *Law 19.284 on Social Integration of Persons with Disability*, Published in the Official Newspaper in Chile on 14 January 1994.

The previous activities had been extremely successful, which justified the seriousness and the size of the initiative, and at the same time, allowed us to obtain the support of a foreign diplomatic mission.

As a consequence of external support we were able to carry out training in the north of the country, where the Aymara people are found; in the south where the Mapuche people are found; and on Easter Island, where the Rapa Nui people live. In this last case, together with the arrival to the legal community that works on the island, we were able to support the disabled persons that are found there, in the training of the first and only organization that groups them together. All this meant a second trip to the island was needed in order to train them in the formulation of projects towards certain community ends. A visit to the island of Chiloe was then made as a result of an invitation from the local judge.

This demonstrates that universities can play a valuable role in assisting the state in terms of training. There were four significant aspects to the project carried out in Chile. First, the program was interdisciplinary and had a strong academic base. Second, it involved persons with disabilities in its design, execution and evaluation. Third, it reached into the citizenship spaces of the different places where the Project was carried out, with the participation of Indigenous Peoples. Finally, the training on the subject of disability covered all areas, including those not traditionally covered, such as the judiciary. This training reached 200 Local Magistrates and their respective functionaries.

Legal Advice and Legal Defense in Emblematic Cases Involving Discrimination Due to Disability

This aspect of the project was directed at demanding the fulfillment of the Constitution and the letter of the law on disability, invoking the *Inter-American Convention for the Elimination of all Forms of Discrimination*. Much of this work has been carried out by the Legal Clinics of Public Interest and Human Rights of the Faculty of Law of the Diego Portales University of Chile, which consisted of avid participation of the students. This was an innovative experience which, while not always successful, has left an important legacy of results for change. Some examples are:

a) *Television Show:*

One example was the case brought against a national television station which travelled to various regions of the country organizing competitions for local artists. The prize for the winners was a promotional appearance in a star studded spectacular. The winner of the show was an adolescent boy with a visual disability. On the day of the show, he was not permitted to enter the building or appear on the show, as management felt that his disability would lower the ratings. He brought a case of discrimination before the Local Magistrates, under Law 19.284 on *The Social Integration of Disabled Persons*. The station was forced to allow the claimant to receive his prize of performing on primetime television. As the production was in Santiago, the station was also required to pay the royalties for the performance, the hotel for the artist and his mother, his travel expenses and the court costs of the case.

b) *Public Library:*
In an action relating to physical access, a disabled person presented a discrimination case under the *Law on Social Integration of Persons with Disability*, against the Municipal Library. This new building had inadequate access to the public computer rooms. As a result, the municipality recognized that its facilities had inadequate access, and committed to make the changes necessary. This has now been done.[65]

c) *Access to Public Transport:*
Persons with physical disabilities brought a Constitutional Protection Claim against the Ministry of Transport and Telecommunications before the Appeals Court in Santiago.[66] The action was brought as a result of the lack of accessibility to public transport and the failure of the ministry to publish regulations about accessibility. The claim was rejected by the Court, on the grounds that there was some relevant regulation. The said regulation requires the placement of a sticker indicating seats reserved for the disabled, however wheelchair users cannot get up the three steps nor pass through the narrow entrance of the buses. Moreover, there where no spaces reserved to place a wheelchair inside the buses.

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[65] Querella infraccional caratulado "Espinoza Jazmín contra Municipalidad de Vitacura" presentado ante el 4° Juzgado de Policía Local de Santiago, año 2003, Rol N°14.123–03/ Clínica de Acciones de Interés Público y Derechos Humanos – Programa Jurídico sobre Discapacidad – Facultad de Derecho, Universidad Diego Portales.

[66] Constitutional Protection Claim "Muñoz Noemí con Ministerio de Transportes y Telecomunicaciones", presented to the Appeals Court in Santiago, 2001, Rol N°4427–01/ Clínica de Acciones de Interés Público y Derechos Humanos-Programa Jurídico sobre Discapacidad - Facultad de Derecho, Universidad Diego Portales.

The legal action had the merit of making visible the issue, which was then considered by the public authority. Thus, the new Plan for Urban Transport (*Transantiago*) included norms for accessibility, support services, auxiliary resources and also the training of functionaries who work in the sphere.

d) *Right to Vote:*
When a person with a visual disability attempted to enter a voting booth accompanied by a trusted assistant, the polling station manager denied them entry. Despite the fact that the person with a disability told him it is impossible for her to know what is on the ballot without the help of a trusted sighted person, the polling station manager denied the right to suffrage believing that equality of opportunity requires independent voting.

An action was brought under the *Law on the Social Integration of Persons with Disability*. However, the Tribunal declared itself unable to pass judgement, even though it was meant to do so under the Social Inclusion Law and under the *Law on Popular Votes and Scrutiny*. Nonetheless, this event generated a legal investigation which found that there was a need to modify the laws related to voting for persons with disabilities. The proposals where accepted and from the year 2008, we now have the *"Law of Assisted Voting."*[67]

e) *Air Traffic*: Another inquiry was established in response to a case brought before the Appeals Court in Santiago by a passenger with a visual impairment.[68] In this case the passenger was denied the right to travel with a helper or with a guide dog, unless a separate ticket was purchased. The Appeals Court accepted the Airline's argument that the restriction was established for security reasons and rejected the claimant's petition. The case was seen as a private dispute between individuals and not as a violation of constitutional guarantees (equality and freedom of movement). Wanting to achieve an amicable solution, an agreement was signed between the Chilean state and the claimant. This required the the consultation of an expert on disability to the

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[67] Querella infraccional caratulado "Espinoza Jazmín contra Municipalidad de Vitacura" presentado ante el 4° Juzgado de Policía Local de Santiago, año 2003, Rol N°14.123–03/ Clínica de Acciones de Interés Público y Derechos Humanos – Programa Jurídico sobre Discapacidad – Facultad de Derecho, Universidad Diego Portales.

[68] Constitutional Protection Order presented to the Appeals Court in Santiago, en contra de Lan Chile S.A., 1998.

Commission, to study the Air travel regulations regarding the persons with disabilities and special needs passengers.[69]

f) *Deaf Persons versus Television Stations:*
In another case involving domestic television stations, persons with hearing disabilities presented a Constitutional Protection Claim to the Appeals Court in Santiago regarding the right to information being provided by news programs.[70] The Court supported the claim for sign language interpretation in news broadcasts. The Court commented that:

> It is true that until now, the only language that is proven to allow this part of the population to communicate, is that when another person expresses it in signs, a language that is used by 90% of the deaf population and that constitutes their real method of communication…

It added:

> That the TV Channels were guilty of an illegal or arbitrary act by not using sign language in some of the news shows, which meant that they had violated guarantee number 12 of article 19 of the Political Constitution of the Republic of Chile, relating to freedom of information a part of which is the right to receive information…

This verdict was so powerful that it placed the subject of information access for the Deaf persons in news programmes on the public agenda. As a result, the National Television Council, the National Television Association and other political actors made an agreement with the deaf persons community of Chile to the effect that sign language interpretation is provided in at least one television news programme each day.

g) *Isapre/Health Insurance Case:*
When a person with a visual disability attempted to join the Institute of Social Health (ISAPRE), which had made a collective arrangement with the Bank where he worked, his application for membership was rejected. He presented a Constitutional Protection Claim to the Appeals

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[69] Commission depending of Chilean Aeronautic Civil General Direction.

[70] Constitutional Protection Claim "Molina contra Canales de Televisión" presented to the Appeals Court of Santiago, 2001, Rol N°5527–2001/ Clínica de Acciones de Interés Público y Derechos Humanos- Programa Jurídico sobre Discapacidad- Facultad de Derecho, Universidad Diego Portales.

Court in Santiago.[71] The claim was unanimously upheld by the Appeals Court and by the Supreme Court on appeal.

The Court of Appeals stated:

> As is known, discretional institutions cannot become arbitrary and therefore the doctrine states that their liberty to choose is limited by reasonableness and good faith and the correct technical foundations for the decision…
>
> That a procedure such as that described lacks reasonableness, lacks the minimum of respect and consideration of the person, who, in good faith responded to the offer which he deserves especially given the nature of the institution referred to – it being charged with the protection of peoples health. Thus, its decision, unfounded and unfortunate-eroded a central value of the Constitutional Order: that of Human Dignity.
>
> That dignity and equality are values inherent in all human beings, and of such importance that the Parliament has proclaimed it to be so as the basis of institutionalism….precisely in order that any body, person, institution or group is required to guard and protects them effectively. Consequently, the negative response [to the application], its inopportune nature and its lack of reasonability, caused the arbitrary violation of dignity, which becomes more grave when regarding a person whose disabled condition makes them more sensitive to perceiving discrimination.
>
> That the ISAPRE, as a provider of goods and services is not exempt from the constitutional prohibition that flows from article 19, No2 of the Political Constitution and that specifically they impose articles 3 and 13 of Law no.19.496…
>
> Which makes this a discriminatory exclusion which impedes, annuls the enjoyment or exercise of the right to join an institution of his choice which assures him the final clause of point 9 of article 19 of the Political Constitution
>
> …this constitutional action will be supported, being in favour of the claimant the measure of protection that is indicated in the resolution with the aim of re-establishing his dignity, his equal treatment and his right to choose a private health provider.

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[71] Protection claim "Palma contra Isapre Colmena Golden Cross", presented to the Appeals Court in Santiago 2003, Rol N°4594–03/ Clínica de Acciones de Interés Público y Derechos Humanos – Programa Jurídico sobre Discapacidad – Facultad de Derecho, Universidad Diego Portales.

The Supreme Court reinforced the sentiments of the Court of Appeals, stating:

> that the actions of the ISAPRE mentioned and being punished, are clearly discriminatory, for it denied membership to the claimant, excluding him from a collective contract. This discriminatory conduct was totally arbitrary as the exclusion was based on examinations that were tampered with…[cholesterol and amino acids],
>
> the cited conduct is evidence of the fact that the accused tried to allow the affiliation of only those that enjoy good health…
>
> Which in addition to the arbitrary and discriminatory actions of the accused ISAPRE, goes against the constitutional guarantee laid down in No. 2 of article 19 of the Constitution and that evidences behaviour that does not conform to the assistential nature of Social Health.

As a consequence of this case a similar claim for constitutional protection was supported by the Appeals Court of Santiago and another is being prepared for its consideration.[72] Further, action was taken to ensure that the Superintendent of ISAPRE publish a circular to prevent a situation such as this from occurring in the future.

Conclusions

1. These cases demonstrate the value of using existing legal channels to protect constitutional and legal rights, with the invocation of international norms. These actions constitute a viable and effective tool for demanding support services, auxiliary resources and training in a democratic society.
2. Even where emblematic cases fail, the bringing of legal action can have a significant effect. Legal actions generate public and political opinion that translate into effective rulings in the legal and regulation spheres of public policy and result in specific actions independent of the verdicts.
3. Moreover, the bringing of legal action allows for the participation of persons with disabilities as active citizens in the exercise and reclamation of their rights.

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[72] Constitutional Protection Claim "Camus contra Isapre ING", presented to the Appeals Court of Santiago. 2004, Rol N° / Clínica de Acciones de Interés Público y Derechos Humanos – Programa Jurídico sobre Discapacidad – Facultad de Derecho, Universidad Diego Portales.

General Conclusions

The *Standard Rules* of the United Nations which pertain to support services and auxiliary resources and training constitute valuable guidance for states for the legislative improvement and definition of public policy. However, if these rules are translated into questions in order to determine the level of compliance or non-compliance with them in national realities, it is concluded that there may be insufficiencies or shortages, particularly in terms of provision, costs and participation of persons with disabilities themselves.

The Rules in question include significant bioethical content based primarily on the principle of social justice and community-based rehabilitation is an expression of this axiological dimension. Rules 4 and 19 shaped human rights specific to persons with disabilities. In regards to this study, support systems, auxiliary systems, and training all support delivering supplies the elaboration of the CRPD. However, measures need to be taken to ensure the effective protection of these rights and demand their enforcement.

The National Councils on Disability and the Organizations of Civil Society are called on to play an important role in the harmony in which this legal objective is reached, as well as in the homogenization of national legislation on this matter in line with international standards. These entities should have decisive participation in the design, execution and evaluation of public policy and – in so far as National Councils are concerned – become the main entity in the coordination of sector efforts in this arena.

The insufficient budget in the area of disability has meant an incomplete solution with regards to support services, auxiliary resources and training for persons with disabilities, many times leading to the dissatisfaction of persons with disabilities. In this sense, the prospect of the application of ICF implies an appropriate strategy for obtaining data for the elaboration of action plans to positively impact the lives of people with disabilities.

However, given that persons with disabilities are the poorest among the poor, we should link the challenges mentioned to the achievement of the Millennium Development Goals, with regard the eradication of poverty. Undoubtedly, insufficiencies in support services, auxiliary resources and training limit the freedom of choice of these persons with disability, which is a goal of human development. As such, recommendations regarding respect for human rights, economic growth, social development, technology, social participation and governance contained in the *Report on Human Development* 2003, should be linked to the achievement of standards and good practice in the field of disability. In developing countries, international cooperation will be of fundamental importance for achievement of this objective.

Moreover, it is also important to explore the possibility of creating a Global Fund for Disability, under the auspices of the United Nations, to channel international cooperation in this area. This is not far from reality now that there is a Global Fund for AIDS dealing with this pandemic.

On another level, local experience shows the significant influence that universities can have in terms of interdisciplinary training in the field of disability, directed at both law students and public servants. It is important to develop and run training programmes aimed at sectors rarely targeted, such as magistrates and judges who try discrimination cases or cases affecting the rights of people with disabilities.

Finally in a democratic society, constitutional and legal mechanisms should be used, invoking international standards, to bring claims involving shortages or errors in support services, auxiliary resources and training. The examples shown the important influence that judicial actions can come to have in the improvement of legislation and public policy. Moreover, these actions empower the participation of persons with disability as active citizens in the exercise of their rights.

MONITORING HUMAN RIGHTS: A HOLISTIC APPROACH

Paula C. Pinto

Introduction

Human rights are commonly understood as being those rights which are inherent to all human beings. Human rights apply equally to all peoples around the world, regardless of whom they are and where they live. They set up common minimum standards protected by international law. The modern concept of human rights, as recognized in the *Vienna Declaration and Programme of Action*[1] further acknowledges that human rights are "indivisible and interdependent and interrelated." Indeed, all human rights are of equal importance and all are equally essential for the dignity and worth of the person. In other words, no right can be really achieved if all the others are not similarly guaranteed.

Under international law, governments are obliged to provide human rights protection to all, but particularly to those who are the most vulnerable: women, children and minorities, including persons with disabilities. The international community, consisting not only of governments but also intergovernmental organizations, transnational corporations and the global civil society, is also called upon in its responsibility to promote and protect human rights and fundamental freedoms all over the world.

While it is important to formally establish "all rights to all peoples," it is critical to ensure that every person is actually able to enjoy fundamental human rights. Some individuals in contemporary societies are less likely to be afforded ways to enjoy rights equally. Persons with disabilities, in particular, have historically been a disadvantaged group. In their daily lives many disabled people have faced (and continue to experience) marginalization, powerlessness, violence and harassment, and other forms of social oppression.[2] Their bodily differences,

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[1] World Conference on Human Rights, 1993 *Vienna Declaration and Programme of Action* A/CONF.157/24, 25 June 1993, Para 5.

[2] Young, I.M. (1990). *Justice and the politics of difference*. Princeton, New Jersey: Princeton University Press.

perceived as abnormalities and deficiencies, have set them apart as a distinct group in society, justifying and legitimizing their exclusionary and oppressive treatment.[3] Despite being included in theory in the dispositions of existing human rights instruments, in practice people with disabilities have been denied the rights and fundamental freedoms enjoyed by all others. However, evidence on rights abuses and violations against disabled people has not been systematically gathered. Indeed, most approaches to document the lives of disabled people continue to rely on traditional, medically informed views of disability, and therefore emphasize their *needs* rather than *rights*. We need new methodologies of research, analysis, and reporting that are consistent with a human rights framework in the field of disability. Such methodologies are found in disability rights monitoring models.

In this chapter, I outline what is involved in disability rights monitoring and argue that this approach is crucial to advance the human rights of people with disabilities. I describe the monitoring system that has been developed by Disability Rights Promotion International (D.R.P.I.), an international project dedicated to monitoring disability rights worldwide, and provide examples from country pilot projects to illustrate the strands and outcomes of this initiative. First, however, I discuss how shifting understandings of disability have provided the fundamental basis for the emergence and development of disability rights monitoring models. In the context of the recently adopted UN *Convention on the Rights of Persons with Disabilities* (CRPD or Disability Convention), the chapter concludes with remarks about the potential uses and impacts of rights monitoring approaches.

From Welfare to Rights – A "Paradigm" Shift in Approaches to Disability

The subordination and social oppression of disabled people briefly characterized above is better described by the *individual model of disability,* which until recently has dominated society and state responses to those with disabilities. Focusing solely on the individual deficits and "abnormalities" this approach has contributed to problematize the disabled person and turned disability into a private, personal issue.[4]

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[3] Barnes, C. & G. Mercer. (2003). *Disability*. Cambridge: Polity Press.

[4] Rioux, M.H. & F. Valentine. (2006). Does theory matter? Exploring the nexus between disability, human rights and public policy. In D. Pothier & R. Devlin (Eds.),

The role of the state has thus been centered on either eliminating and curing disability, or supporting and compensating if the former where not possible to achieve. And so, disabled persons have been construed as "objects" of medical treatment and public assistance. Disability has been dealt with by governments as a welfare issue competing with other social issues for increasingly scarce public resources.

This strategy has been facilitated by the pervasive "invisibility" of disabled persons in the public sphere.[5] The marginalization and exclusion of disabled persons is in fact caused by lack of access to educational opportunities, meaningful jobs and public spaces, since all these have been built with only non-disabled people in mind. Nevertheless, this invisibility is often understood and accepted as "natural" and viewed as intrinsic to the status of being disabled. Thus a double standard in law and policy has been created and even though the human rights framework has always been available to all, existing protections have not been applied, or have been differently applied in the case of disabled persons.[6] Excluded and marginalized, the lives of disabled people have traditionally invoked pity and perhaps charitable action on the part of governments, but seldom the respect owed to equal citizens.

During the nineteen seventies disability scholars and advocates in both sides of the Atlantic begun to advance a very different conception of disability. In what became known as the *social model*, disability was recast as a consequence of "social" rather than "individual pathology,"[7] rooted in society's barriers that impose restrictions on what disabled people can *do* and *be*. In other words, disablement became viewed as the result of social, economic and physical environments that are unable to accommodate "difference." In this new perspective, the problem of disability is no longer located in the individual but outside the person and in society. Since it is society, not individuals that need to be "fixed" this approach emphasizes states' responsibility in bringing about systemic and structural change aimed at eliminating barriers and obstacles and creating genuinely inclusive societies. The social model has

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Critical disability theory: Essays in philosophy, politics and law (pp. 47–69). Vancouver: UBC Press.

[5] Quinn, G. & T. Degener (with Anna Bruce, Christine Burke, Joshua Castellino, Padraic Kenna, Ursula Kilkeilly, Shivaun Quinlivan). (2002). *The current use and future potential use of United Nations human rights instruments in the context of disability.* New York & Geneva: United Nations.

[6] Quinn and Degener (2002).

[7] Rioux and Valentine (2006), 49.

been determinant in shifting the focus of disability from *welfare* to a *rights* issue. If society is responsible for creating disablement then it seems logical that those construed as disabled demand being treated as equals and having their needs addressed as a matter of rights, not charity.[8] The social model and the rights approach are, in this sense, mutually reinforcing.

A fundamental tenet of the rights perspective is that individuals possess rights simply because of their humanity, not because of government beneficence. As it has been noted[9] this is a particularly important claim for people with disabilities, who historically have had to confront negative stereotypes and have been denied access to opportunities and resources on the grounds of their "natural" differences. Rights are legal entitlements, grounded in international human rights instruments and domestic legislations, which set up legitimate expectations to all citizens – not simply privileges granted as a matter of charity or goodwill. In this sense, the shift to a rights approach fundamentally implied a re-conceptualization of persons with disability. No longer viewed as problems or "objects" of public policy and charitable efforts, disabled persons become legal "subjects" and "holders" of rights. This is a substantial difference with real impact on the lives of people. As *subjects* and *holders* of rights persons with disabilities can now claim from governments that action is taken and obstacles removed to grant them the resources and opportunities needed to live meaningful and independent lives on an equal basis with all other citizens. And governments may be legally bound to fulfill these obligations which no longer are contingent on states' politics and discretionary power.[10]

Enshrining disabled people's rights in both international human rights covenants and national legislation is certainly a significant step in affirming their human worth and dignity. The adoption on 13 December 2006 by the United Nations General Assembly of the *Convention on the Rights of Persons with Disabilities* was therefore an important hallmark culminating a long struggle of the disability community and human rights advocates. But the challenge remains in assessing the extent to which signatory governments comply with their

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[8] Quinn and Degener (2002).

[9] See for instance Barton, L. (1993). The struggle for citizenship: The case of disabled people. *Disability, Handicap and Society, 8*(3), 235–248 and Gostin, L. (2001). Beyond moral claims: A human rights approach in mental health. *Cambridge Quarterly of Healthcare Ethics, 10*(3), 264–274.

[10] Governments are legally bound if they are signatories to the UN Convention on the Rights of Persons with Disabilities or regional international instruments.

obligations and translate these rights into practice to affect in a positive way the lives of disabled citizens. *Human rights monitoring* is the activity that enables us to evaluate whether progress in securing rights for people with disabilities has taken place, and the work that remains to be done. This approach differs from traditional methodologies which consisted of surveying services and access to services in line with a perspective of disability as a welfare issue. In fact, where a view of disability as a matter of medical treatment and social protection prevails, the approach favoured relies on detailed classifications and counts of persons with disabilities according to perceived medical conditions to then determine their needs for services. Human rights monitoring, in contrast, focuses on the inherent dignity of the person with disability and thus places access to rights (including rights to services) within a broad range of indivisible, interrelated and interconnected spheres of human life that span civil, political, social, economic and cultural dimensions. Furthermore, human rights monitoring scrutinizes states' responsibilities and practices in protecting and promoting those rights for all citizens, without any exclusions or discrimination.

What is Disability Rights Monitoring?

Monitoring has been defined as the "collection, verification and use of information to address human rights problems."[11] It involves researching, gathering, analysing, and reporting information with the purpose of identifying human rights abuses and violations and support efforts to remedy them.[12] Monitoring activities are planned and systematic, and generally take place over an extended period of time, either in a constant or intermittent way.[13]

The critical goal of disability rights monitoring is contributing to improve the human rights protection of disabled people in a particular country or region. In this sense, monitoring is not just about describing

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[11] Maelhum, M. (2002). Monitoring human rights. In I.K.E. Hogdhal & L. Sadiwa (Eds.), *NORDEM manual on human rights monitoring*. Oslo: Norwegian Institute of Human Rights, online, http://www.humanrights.uio.no/english/research/programmes/nordem/manual.html (visited February 20, 2008).

[12] Guzman, M. & B. Verstappen. (2003). *What is monitoring?*. Versoix: HURIDOCS, online, http://www.huridocs.org/tools/violations (visited February 12, 2008).

[13] Nowicki, M. & Z. Fialova. (2001). *Human rights monitoring*. Warsaw: Helsinki Foundation for Human Rights, online, http://www.humanrightshouse.org/assets/1003Monitoring_eng.pdf (visited February 24, 2008).

and diagnosing a situation of abuse or violation, but rather is intended to bring about social change.[14] By documenting and illustrating incidences of abuse against persons with disabilities, monitoring projects will enable us to gather arguments and issue recommendations about what should be changed in the law, its application, and the workings of state institutions to eliminate discrimination and prevent rights violations from occurring. Monitoring is therefore a fundamental tool to encourage and pressure governments into adopting and implementing human rights standards when dealing with their disabled citizens.

The principles and norms established in UN international conventions, covenants and declarations are generally the standards used as references in assessing situations of human rights violations and abuse. These standards are relevant to persons with disabilities in the same way they are to all other human beings although in addition, as former UN High Commissioner for Human Rights Mary Robinson has pointed out, disabled people may require "support and protection unique to the issues they face".[15] The recent CRPD and its *Optional Protocol*[16] are precisely intended to grant that protection by identifying areas where adaptations are necessary to ensure the effective enjoyment of all human rights by persons with disabilities. With the 20th ratification presented by Ecuador on 3 April 2008, the CRPD and Protocol entered into force on 3 May 2008, providing an additional impetus to the important role of monitoring in persuading governments to take steps in order to implement the Convention and realize the rights of persons with disabilities.

As a methodology, monitoring relies on a set of instruments (e.g. surveys, questionnaires, and other recording tools) to systematically collect and analyse data on a specific geo-political context, and evaluate this data against existing human rights standards to identify

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[14] Nowicki and Fialova (2001).

[15] Robinson, M. (2003). Foreword. In S. Herr, L. Gostin & H. Koh (Eds.), *The human rights of persons with intellectual disabilities: Different but equal* (pp. iv–viii). Oxford: Oxford University Press.

[16] While the Convention elaborates a comprehensive list of rights of persons with disabilities, the Optional Protocol establishes procedures for strengthening and monitoring the implementation of the Convention, notably through individual communications procedures allowing individuals or groups of individuals to make claims as victims of violations of rights, and an inquiry procedure giving the Committee on the Rights of Persons with Disabilities (a new body established by the Convention) authority to conduct inquires on disability rights violations.

existing gaps and contradictions.[17] This activity can be very empowering for disabled people and their organizations, and remains a vital instrument to enhance public awareness about the situation of persons with disabilities. Listening to people's stories can "restore dignity" by providing a voice to otherwise silenced and marginalized groups.[18] Moreover, monitoring processes place analysis of individual stories in the context of prevailing structural and systemic barriers. This has the potential of reinforcing a collective identity among disabled persons while supporting their efforts to achieve social justice. Finally, systematic monitoring provides clear, accessible and detailed information about the human rights abuses experienced by people with disabilities which can serve to raise public awareness around disability issues. The stories of particular individuals (case studies) as well as statistical data collected through monitoring projects can be used in public ads and campaigns to educate people and mobilize public support for necessary political change.[19]

Disability Rights Promotion International – A System for Disability Rights Monitoring in Action

In the increasingly populated field of human rights operations, monitoring the rights of persons with disabilities has been, until quite recently, a relatively neglected area of work. Disability Rights Promotion International (D.R.P.I.) is a singular example of a pioneering project dedicated to establishing a comprehensive global monitoring system for disability rights. The project was initiated in response to the recommendations of an international seminar held at Almåsa Sweden in 2000 and hosted by Bengt Lindqvist, the UN Special Rapporteur on Disability at the time. In their final report, "Let the World Know," experts participating in the Almåsa Seminar, many of them representatives of all the major international disability organizations, called for the establishment of an international disability rights monitoring system and elaborated guidelines for identifying and reporting human rights abuses against

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[17] Guzman and Verstappen (2003).

[18] Devine, C. & V. Coakley. (2001). Human rights monitoring. *Human rights defender manual: Diplomacy training programme* (pp. Chapter 15). Australia: Human Rights Law Resources, online, http://beta.austlii.edu.au/au/other/HRLRes/2001/16/ (visited February 20, 2008).

[19] Nowicki and Fialova (2001).

people with disabilities. With its coordination centre established at York University in Toronto, Canada,[20] D.R.P.I. was launched in 2002.

As recommended by participants at the Almåsa Seminar, D.R.P.I. adopted from its inception a holistic approach to disability rights monitoring, which encompasses three broad areas: monitoring *individual experiences*, monitoring *systems* (including law, policy and programs), and monitoring *media*. Traditional rights monitoring tends to privilege one or the other of these three dimensions; by contrast, this inclusive framework enables us to conduct a comprehensive assessment. Combining information collected at the micro, meso, and macro levels, the approach allows a more complete profile of the human rights situation of disabled persons in a particular society. Using human rights standards as benchmarks, attention is focused on the ways that systemic discrimination and social exclusion increase vulnerability to abuse, chronic poverty, unemployment, and inequitable social conditions for people with disabilities.

To accomplish this work D.R.P.I. is guided by five general principles.[21] The first principle demands the "*involvement of people with disabilities and their organizations.*" Recognizing the expertise that emerges from the experience of living with a disability D.R.P.I is committed to having disabled people involved in all aspects of the monitoring process (as members of the Advisory Committee, researchers, trainers, local coordinators, monitors, etc), as well as to have disability organizations (of local regional, national and/or international scope) implicated in the pilot projects in the countries where these have taken place. D.R.P.I. also seeks to ensure that disabled people take ownership of monitoring activities – in this sense a great effort has been placed in the development and dissemination of accessible training tools. The ultimate goal is that organizations of people with disabilities all over the world can learn to conduct disability rights monitoring, and that they can systematically rely on this methodology to document rights

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[20] DRPI is co-directed by Marcia Rioux and Bengt Lindqvist. During Phase I the project coordinator was Fiona Sampson, but since 2004 the coordination has been undertaken by Rita Samson. D.R.P.I. was initially funded through the Swedish International Development Coordination Agency (SIDA). For more information on the project and access to the documents issued visit the D.R.P.I. website at: http://www.yorku.ca/drpi/.

[21] See D.R.P.I. (2007). *Moving forward: Progress in global disability rights monitoring.* Toronto: Disability Rights Promotion International, 9–10. (also available electronically in PDF and HTML formats at http://www.yorku.ca/drpi/).

abuses and press for legal and social change. These goals are encapsulated in D.R.P.I. second fundamental principle, which calls for *"sustainability and capacity building in the field of monitoring."* D.R.P.I. is further oriented by the notion of "*cross-disability involvement*." This tenet acknowledges the fact that all persons with disability are equally entitled to the protection and promotion of their human rights and in this sense all should be involved in the monitoring process. The fourth principle concerns the "*integration of the three broad areas for monitoring*." The D.R.P.I. approach is *comprehensive* and *holistic*, not only for its multi-dimensionality, but also because it aims at integrating these various dimensions to both tease out their mutual intersections and underline the tensions and contradictions that they may conceal. Individually, each of the areas assessed (individual experiences, legal and policy systems and media) provide valuable information that exposes factual data on the extent of discrimination and abuse perpetrated on persons with disabilities. Together they offer a more complete perspective that also often highlights prevailing inconsistencies. For example it is not uncommon that the actual practice or daily life experiences of individuals with disabilities contradict popular media images of disability. To reveal these tensions is an important part of advocacy efforts that aspire at improving the human rights situation of persons with disabilities.[22] Naturally, all these complex tasks could not be achieved by a sole person or individual project. The last principle recognizes just this when it acknowledges D.R.P.I.'s "*engagement with multi-sectoral organizations.*"[23] Typically D.R.P.I monitoring projects are undertaken in partnership with a diversity of local, regional and international partners, including universities and research centres, organizations working in the field of human rights monitoring, the community and government. The synergies created by these kinds of partnerships also remain significant in bringing about positive changes in the lives of disabled people throughout the world.

D.R.P.I. is currently initiating Phase Three of its broad program of action. During Phase One (2002 – 2004) the project focused on surveying existing international human rights instruments to assess their potential use for monitoring disability rights. It also reviewed monitoring tools and training resources to determine their applicability in the

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[22] See D.R.P.I. (2007). *Moving forward, 9–10.*

[23] See D.R.P.I. (2007). *Moving forward, 9–10.*

disability field. As stated in the Phase One Report this research signalled some opportunities for disability rights advocacy within the framework of the international human rights system, but most fundamentally it confirmed "…the need to raise awareness and build capacity related to disability rights." In particular, it was observed that few monitoring tools referred to disability rights and very few training resources "adequately cover disability issues."[24] This then became the task for D.R.P.I. during Phase Two – to develop and test "a comprehensive set of tools and mechanisms that can be used by people with disabilities and their organizations around the world to monitor disability rights in all three focus areas (systems, individual experiences and media)."[25] The adoption of the CRPD brought renewed international attention to the rights of persons with disabilities and provided sound human rights standards against which to assess the status of disabled people in countries worldwide. In its monitoring work D.R.P.I. follows a "twin-track approach" that recognizes the protection and promotion of disability rights, not only in the disability-specific Convention, but within all existing international human rights instruments. Following a twin-track approach is indeed important for more than one reason. First, it serves to stress the fact that as human beings equal in dignity and rights people with disabilities are protected under the international human rights system as all other citizens. There is yet another motivation for insisting on mainstreaming disability rights in all human rights treaties and respective monitoring efforts. Undeniably the adoption of a disability-specific convention represents a major achievement for the disability community. But the CRPD is the outcome of a complex process of political negotiation, involving multiple players. Therefore, the text which was adopted is less demanding to State parties than were progress-drafts, certainly reflecting the need to build consensus among the largest number of states and the urge to speed up the process of adoption of this instrument in the UN Assembly. In light of this, insisting on all human rights for all becomes also a guarantee that concerns with the human rights of disabled people are not only taken into consideration in the work of disability-specific monitoring bodies but

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[24] D.R.P.I. (2003). *Phase I Report: Opportunities, methodologies and training resources for disability right monitoring*. Toronto: Disability Rights Promotion International. (also available electronically in PDF and HTML formats at http://www.yorku.ca/drpi/).

[25] D.R.P.I. (2007). *Moving forward, 18.*

all human rights monitoring systems at both national and international levels.

With the active involvement of disabled people and their organizations D.R.P.I. launched pilot projects in Kenya, Cameroon, India, Bolivia, the Philippines and Canada, and collaborated with projects in Sweden and Australia. As the project now enters Phase Three of worldwide dissemination and implementation, the data collected and analyzed in some of these pilot sites will provide real examples to illustrate the discussion that follows.

Strategies and Tools for Disability Rights Monitoring

As stated earlier in this chapter, monitoring requires a set of instruments to systematically gather and analyse data on a specific context, and evaluate this data against existing human rights standards in order to identify persisting gaps, violations, abuses and discrimination. For the longest time, the issues confronting disabled persons have remained outside the concerns of those engaged in promoting and monitoring human rights. This absence is related to what Richard Devlin and Dianne Pothier have termed the "de-citizen" status assigned to persons with disability in our societies – their unequal, inferior position, their lack of opportunities to participate, to contribute and be recognized as valuable members of the human family.[26] D.R.P.I. is working to counter this neglect by focusing specifically on monitoring disability rights. Since disability has implications in all areas of people's lives, this is an enormous task which requires a multidimensional framework. Therefore D.R.P.I. has developed a holistic approach to monitoring the human rights of disabled people which involves looking at the media, the law and policy systems, and the everyday lives of persons with disabilities.

In each of these areas specific instruments were created to guide the process of data collection. Adjusted to the specific goal each seeks to attain, these tools are all structured around an underlying set of human rights values which include the five following principles: *Dignity*; *Autonomy*; *Non-discrimination and Equality*; *Participation*, *Inclusion*

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[26] Devlin, R. & D. Pothier. (2006). Introduction: Toward a critical theory of dis-citizenship. In D. Pothier & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy and law* (pp. 1–22). Vancouver: UBC Press.

and Accessibility; and *Respect for Difference*. These are the key standards on which a rights approach to disability stands. Most of these principles have been defined and their relevance discussed in earlier chapters of this book,[27] so I abstain from debating them here again. Suffice it to say for now that they frame our analysis and provide a common ground for an integrated reading of data collected at the multiple levels. Let us now look in greater detail to the dimensions of monitoring pursued by D.R.P.I., the specific tools developed for this purpose, and the information which they have enable to gather so far.

Monitoring at the Individual Level

Monitoring at the *individual* level is intended to document individual experiences of exercise and denial of human rights. Through personal interviews valuable information is collected about the facts and the contexts in which the human rights of disabled individuals have been realized, violated, or ignored. The interviews allow monitors to examine situations of inclusion and discrimination faced by persons with disability in the private and the public sphere and across multiple domains (social, economic, legal, etc). While these analyses grant important knowledge about individual cases, the aggregate outcome of individual monitoring often reveal more general patterns of discrimination. In this sense, monitoring at the individual level also provides important indicators of systemic breaches in the state's compliance with its human rights obligations regarding disabled citizens.[28]

To guide the personal interview, an individual questionnaire was developed and revised during D.R.P.I. pilot phase. The questionnaire is applied to a purposeful sample[29] of persons with disabilities recruited through the snowball technique.[30] In line with the principle of involving disabled people in all phases of the monitoring process interviews are conducted by monitors who are themselves persons with disability.

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[27] See in particular above chapters of this text: on "Dignity and Difference," Basser; on "Equality," Rioux and Riddle; on "Inclusion and Participation," Jones.

[28] See D.R.P.I. (2003). *Phase I Report and* D.R.P.I. (2007). *Moving forward*.

[29] A purposeful sample is a sample that fits the purposes of the study, the questions asked, the resources available and the constraints being faced. It does not aim at mirroring the population from which is drawn, although it seeks to represent at the best possible level, its diversity and richness.

[30] Snowball sampling is the technique that allows us to identify respondents who are then used to refer researchers on to other respondents. It is the most common sampling strategy used to reach difficult to access, marginalized groups such as persons with disability.

Before initiating the fieldwork, monitors receive an intensive training provided by D.R.P.I. The training offers an opportunity to discuss the human rights approach to disability and practice interview techniques. Interviews are tape-recorded, after a free written consent has been obtained from participants.

The questionnaire covers several aspects related to the sociodemographics of participants including age, sex, and type of disability, but also comprises issues less frequently addressed in other surveys as for instance the type of household and the proximity of infrastructures in the community such as a healthcare center and a police station. Answers to these questions provide an important measure of the background and socioeconomic status of the sample. In addition to these issues, the questionnaire is oriented to gather information about experiences of access to, or denial of, human rights basic principles, and how participants have dealt with those situations. Interviewees are asked to provide concrete examples and indicate names of other persons that may have witnessed the events they described. Box 1 presents an example of questions that probe the impact of discriminatory events on participants' sense of dignity and self-worth.

Since the large majority of questions used are open-ended, data collected through the interviews is mostly of a qualitative nature. A coding scheme has thus been developed to assist with and provide a common standard to data analysis across all sites. The scheme encompasses 112 codes, distributed along 5 main areas or themes: "human rights implications" (covering life experiences reported by interviewees as they relate to key human rights principles); "responses to discrimination" (referring to the ways that interviewees have dealt with or responded to situations of abuse and discrimination); "reasons for not reporting" (encompassing the reasons interviewees provide for not reporting the

Box 1

Excerpt from the D.R.P.I. Individual Questionnaire

[Dignity]

2.5 HOW did this situation make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/unworthy?)
2.6 WHAT made you feel that way?
2.7 WHY do you think people treated you that way?

situations of abuse and discrimination they have endured); "systemic roots of discrimination" (comprising interviewees' ideas about the social, economic and political factors that create or reinforce in their society the discrimination they have experienced on the grounds of disability); and "recommendations" (involving the ideas put forward by participants for future social and political action to prevent discrimination and abuse of people with disabilities). Data analysis relies on NVIVO as the support software and is conducted by local research teams involving representatives of disabled people's organizations. To ensure the goal of capacity building and sustainability of the project, D.R.P.I. has created detailed manuals to assist local teams with all of these tasks.

The outcome of the individual data analysis process is a report which integrates the final country report resulting from the holistic rights monitoring process advanced by D.R.P.I. The report combines qualitative and quantitative information to highlight and illustrate the human rights situation of disabled people in the particular jurisdiction under review. Box 2 offers an excerpt of the D.R.P.I. Kenya report where this mixed approach to data analysis is exemplified.

Box 2

Excerpt from the D.R.P.I. Kenya Report

Dignity

As a human right, *dignity* relates to the impact of particular life experiences on the individuals' perceptions of self-worth. Results are presented in table 6.

Table 6

Dignity

Variable	Sources Coded	%
Interviewee reports feeling *disrespected and devalued*	90	94.7%
Interviewee reports of *other persons* feeling disrespected and devalued	2	2.1%
Interviewee reports being *respected and valued*	24	25.3%

Examples of discrimination, abuse and violence that led to the violation of rights of people with disability are found in virtually every single interview. Results indicate that approximately 95% of the interviewees reported feeling disrespected and devalued in their experiences and opinions or were not able to form opinions without fear of physical, psychological and/or emotional harm. Locked in the house permanently or forced to spent sleepless nights in the open seem to be common experiences for many disabled people. Some disabled women reported having been sexually abused and even raped. When they saw their rights violated the majority of the respondents reported feeling disrespected, not cared for, neglected and oppressed, less valued than others, unwanted, unworthy, and most of all felt that their needs were not taken into account. For instance, a woman who is blind and used to sell on the street with the help of her children reported:

> *…On this day I was selling kerosene but my children were not around. I called on a woman to help me pour kerosene into a customer's container. She however brought an extra container and took some for herself and left without paying. Someone (I do not remember who) told me what had transpired and I felt so bad that I decided to discontinue with the business. I also tried to sell charcoal and open a shop but people would steal from me and I had to leave. Some people would pretend to give me a high denomination currency so that I gave them greater change. Someone even used Tanzanian [neighbouring country] currency to buy merchandise from me. These people despised me a lot. If they did not despise me, then they would never have done to me what they had. They looked on me as an incomplete person. I think the reason was my lack of sight.*

Source: State of Disabled Peoples' Rights in Kenya. 2007. Final Report. http://www.yorku.ca/drpi/index.html.

In the countries where reports are already concluded the data gathered from personal interviews has been crucial to obtain a more detailed picture of the rights violations and abuses facing disabled people. In most of these sites, the D.R.P.I. study represented the first attempt to holistically monitor disabled people's access and exercise of human rights, give them voice in articulating their experiences of discrimination and in expressing their concerns, aspirations and needs. In addition to documenting individual stories of abuse and violation, data collected through personal interviews has been critical to identifying systemic patterns of exclusion and discrimination that characterize the treatment of disabled people in these societies. Hence, for instance, Kenyan researchers were able to conclude:

> [the research] clearly indicates that experiences of *oppression, discrimination and violation of basic human rights* pervade the lives of many disabled people in Kenya. As it emerged from the stories gathered, most people with disabilities, regardless of their age, gender, where they live or their disability type, are prevented from making decisions on issues that affect their lives. They are treated unequally and with disrespect by their families, communities, and even public authorities. They face prejudice and negative stereotypes, and are excluded in a multitude of ways from their communities and mainstream society. Viewed as a burden and a curse to their families, they are regarded as second class citizens. Their dignity, as members of the human family, is seriously affected.[31]

Similarly, the team that worked in Cameroon noted:

> The results indicate that a distinct pattern of barriers exists for males and females: …incidences of abuse are almost twice as much reported by women than by men, suggesting that gender intersects with disability to produce an increased vulnerability of women to this particular form of discrimination.[32]

In sum, personal interviews provide a critical source of information in monitoring the human rights of disabled people. Data collected through individual questionnaires is useful to documenting specific events of abuse and violations, and also may indicate more general patterns of discrimination prevailing in a given society. This data then serves to cross-examine existing law and policy and distinguish between the *de jure* and the *de facto* disability rights situation in a particular context. We turn now to the strategies and tools used by D.R.P.I. to gather and examine information at the systemic level.

Monitoring at the System's Level

Analyses of individual stories of discrimination and denial of human rights provide detailed accounts of the actual lives of persons with

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[31] D.R.P.I. (2007). *State of disabled peoples' rights in Kenya*. Toronto: Disability Rights Promotion International, online, http://www.yorku.ca/drpi/index.html.

[32] D.R.P.I. (2007). *Human rights of persons with disability in Cameroon*. Toronto: Disability Rights Promotion International, online, http://www.yorku.ca/drpi/index.html.

disabilities. To get a more complete picture, however, these stories need to be placed in context. Monitoring at the *systems' level* enables us to do that by moving the analysis to a more general level of assessment.

Specifically, monitoring at the *systems' level* involves the investigation of the laws, policies and programs carried out for people with disabilities in a particular jurisdiction. This exploration serves to determine whether legislative frameworks in place fail to respect and protect the human rights of disabled people, or even violate them by containing discriminatory dispositions. A thorough review of law and policy is thus a necessary stage of the holistic monitoring process, and a critical one to potentiate social and legal change. In addition to law and policy assessments, the D.R.P.I. framework proposes, at the system's level, to compile and analyze disability cases, brought before the court and other statutory human rights bodies, in order to gain knowledge about the ways that legal institutions interpret and enforce disability rights. This is a significant dimension with direct impact on the lives of disabled people and one whose effects often propagate across society. Finally, monitoring at the systems' level involves scrutinizing governmental services and programs to inquire about their impact on the human rights status and freedoms of people with disabilities. Documenting the gaps and violations embedded in legislative frameworks is a powerful way to point out what governments still need to do in order to improve the protection, promotion and fulfilment of human rights of disabled citizens.[33]

Monitoring processes conducted under the auspices of D.R.P.I. included a systemic focus. Through this strand of the study, the human rights protections available to persons with disabilities in these two countries both at international and domestic level were identified and critically assessed. The two final reports highlight prevailing problems with the application of existing legislation and point to the areas where insufficient or inadequate protection is granted. For instance, the Kenya report states:

> The study findings show that Kenya is a party to most of the major international human rights instruments and has signed but not yet ratified the international *Convention on the Rights of Persons with Disabilities*. At the national level, the government of Kenya has enacted the *Persons with Disabilities Act* (PDA) 2003 which creates the National Council of Persons

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[33] D.R.P.I. (2003). *Phase I Report* and D.R.P.I. (2007). *Moving forward*.

> with Disabilities as a statutory organ to oversee the welfare of disabled persons.....[Yet] the study also found that the [Kenyan] law itself is discriminatory to persons with disabilities in certain cases. For example, when prescribing principles of criminal liability, the *Penal Code* provides for the protection of "idiots" and "imbeciles". This language is highly derogatory and does not even clearly identify the persons it seeks to protect, that is, persons with mental disabilities.[34]

Similarly, researchers in Cameroon concluded:

> .... article 3 (1 and 2) of the 1983 [Cameroonian disability] law, forbids all forms of discrimination towards persons with disabilities. This measure has been criticised for its ambiguity because its practice is uncertain; for example families and sometimes the society in general, show little concern towards persons with disabilities.[35] (...) In the Cameroonian society, persons with disabilities are the most vulnerable and poorest because most of them are uneducated and unemployed. Many live in the streets and begging has become their major occupation.[36]

To support monitoring activities at the systemic level the D.R.P.I. Law and Policy Assessment Template was created.[37] The template has been applied by a team of Canadian researchers and disability activists[38] and by researchers in Kenya and India.

As shown in Table 1, this assessment tool has several components. The first column (column 1) identifies the articles of the most important international human rights instruments which relate to each of the questions included in the template. This serves to stress D.R.P.I.'s view that disability rights are not a separate category of rights but rather "refer to the full range of human rights available to all, applied effectively to respond to the specific situation of people with disabilities."[39] In this sense, information contained in this section is intended to provide background references that may be useful for a full understanding of the content of each question, as well for the advocacy work that may

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[34] State of Disabled Peoples' Rights in Kenya (2007), 9–10.

[35] Study on the Human Rights of Persons with Disability in Cameroon (2007), 33.

[36] Study on the Human Rights of Persons with Disability in Cameroon (2007), 35.

[37] The template was initially created by Paula C. Pinto and a sample of questions from the template was pre-tested in Portugal by the author: see Pinto, P. "At crossroads: Disability policy and human rights in Portugal and the EU", presented at the 2006 Canadian Congress of the Humanities and Social Sciences.

[38] The team includes Roxanne Mykitiuk, Yvonne Peters, Michael Prince and Mihaela Dinca-Panaitescu, the project coordinator for D.R.P.I. Canada.

[39] D.R.P.I. (2003). *Phase I Report,* 3.

Table 1. Excerpt from the D.R.P.I. Law and Policy Template

Convention/ Art. (1)	Question (2)	Definitions and Requirements of the Question (3)	Description & Citation of Relevant Laws/ Policies Relied Upon in Analysis (4)	Gap Analysis of Laws/ Policies identified (in relation to the standards of relevant Conventions) (5)	Other Sources Relied Upon in Analysis (e.g., statistics, national budget and accounts, key informants interviewed, etc) (6)	Integrated Analysis (7)
Inclusion in Society CRPD, art 19 SR 4, 5 & 9 IACEDPD, art 13.1b & 1c ACHR-PSS, art 18c (ECHR-P4, art2) (CERD, art 5f) (CCPR, art 25c)	26. Does any law or government policy ensure that persons with disabilities can live independently and be included in the community? Yes No	In relation to this right, the UN Disability Convention requires States to take appropriate measures to: [check requirements considered in analysis] • protect the right of persons with disabilities to determine how, where, and with whom they live, on an equal basis with others, and ensure that they are not forced to live in a particular living arrangement; • ensure access for persons with disabilities to a range of in-home and other community support services, including personal assistance, necessary to support living and inclusion in the community; • ensure that community services and the facilities for the general population are made available on an equal basis to persons with disabilities and are responsive to their needs.				a.Inconsistencies between laws/ policies in paper and in practice b. How these inconsistencies impact the five general human rights principles: • Dignity • Autonomy • Participation, Inclusion & Accessibility • Non-discrimination & Equality • Respect for Difference

result from the completion of a country's assessment. Sequentially, the next column (column 2) provides specific questions about laws and policies that relate to the articles specified in column 1, while column 3 offers further specifications to clarify the meaning of those questions.

The template is further divided into two sections – the *de jure* and the *de facto* assessment sections. The *de jure* assessment involves completing columns 4 and 5. It requires a thorough review of the laws and policies of the state to verify their compliance with human rights principles and law. Quotations and references to the laws relied upon in analyzing a country's compliance with each individual right will be inserted in column 4.

The *de facto* analysis (columns 6 and 7) seeks to determine the extent to which people with disabilities, in practice, are able to realize their rights, and what obstacles may impede equality for them. This requires selecting, compiling and analysing data from diverse sources including national and local statistics, national budgets, and policy or research reports (column 6). It is also in this section that the integration with the data collected through personal interviews must occur.

Finally, the template comprises an evaluation section, involving column 7. Based on the information collected through both the *de jure* and the *de facto* analysis, the assessment team will provide an integrated summary analysis of the situation and status of people with disabilities in the country in regards to each right. The summary should highlight both the gaps and contradictions between laws in paper and in practice and how these impact the five human rights principles that anchor the entire D.R.P.I. project: dignity, non-discrimination and equality, accessibility, participation and inclusion and respect for difference. Table 2 provides an example of how the Canadian team is currently tackling this task, which is at this point still a work-in-progress. A similar procedure is being developed to create a disability case law database.

In parallel to field testing this template, D.R.P.I. is collaborating with several international human rights organizations including the Asia Pacific Forum of National Human Rights Institutions (APF) to raise awareness and interest on disability rights and develop new tools that will assist in bringing forward and/or tracking disability case law.[40] In collaboration with the International Coordinating Committee of

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[40] See D.R.P.I. (2007). *Moving forward.*

National Human Rights Institutions (ICC) and APF, work is progressing on developing Disability Rights Database and software program that will facilitate the collection, analysis and reporting of internationally comparable information by National Human Rights Institutions. This data set will help provide greater visibility to disability rights issues at both the international and domestic level in the four regions of the world where ICC is represented: Africa, Americas, Asia-Pacific and Europe. The database is envisioned to provide an evidence-base to support international comparative research about important issues such as the human rights violations experienced by people with disabilities, complaints and best practices in handling them, and other initiatives in relation to disability rights. It is expected that the project will assist in capacity building within National Human Rights Institutions to enhance their ability to address the human rights of persons with disabilities, while also facilitating innovation and greater awareness and commitment to promote and protect disability rights among human rights organizations, governments, intergovernmental bodies, and the civil society.

Monitoring at the Societal level – The Depiction and Coverage of Disability in the Media

Media monitoring constitutes a further important dimension of assessment in the D.R.P.I. holistic approach. How people with disabilities are perceived in society (and often how they perceive themselves) is highly influenced by the ways in which they are portrayed in the media. Social attitudes, myths and stereotypes around disability and its meanings emerge, are reinforced and circulate through images and texts that constantly surround us in multiple media forms. To include this level of monitoring thus represents an attempt to get at the ways that in a particular society disability is, using Tanya Titchosky's expression, "read and written"[41] at the most general societal level. Media coverage and depiction of disability is an important component of the daily life experiences of disabled persons for in decisive ways these representations create (and constrain) the very possibilities available to those with disabilities to assert and realize their rights.[42]

The D.R.P.I. approach to monitoring disability rights through media stories involves both qualitative and quantitative methodologies.

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[41] Titchkosky, T. (2007). *Reading and writing disability differently*. Toronto: University Press.

[42] D.R.P.I. (2003). *Phase I Report* and D.R.P.I. (2007). *Moving forward*.

Table 2. Excerpt from D.R.P.I. Canada Law and Policy Template

Convention/ Art. (1)	Question (2)	Definitions and Requirements of the Question (3)	Description & Citation of Relevant Laws/Policies Relied Upon in Analysis (4)	Gap Analysis of Laws/Policies identified (in relation to the standards of relevant Conventions) (5)	Other Sources Relied Upon in Analysis (e.g., statistics, national budget and accounts, key informants interviewed, etc) (6)	Integrated Analysis (7)
Inclusion in Society CRPD, art19 SR 4, 5 & 9 IACEDPD, art 13.1b & 1c	25. Does any law or policy of the State protect the right of persons with disabilities to *live independently* and be *included in the community?*	✓ protect the right of persons with disabilities to determine how, where, and with whom they live, on an equal basis with others, and ensure	CONSTITUTION: *Canadian Charter of Human Rights and Freedoms,* s.7 right to life, liberty, security of the person → liberty includes the right to choose one's own living arrangement.	In Canada there are laws and regulations protecting people with disabilities' rights to personal mobility and transportation, both at federal and provincial levels (e.g. the Intercity Bus Code of	D.R.P.I. INDIVIDUAL MONITORING Users of Wheel-trans, interviewed in Toronto, voiced a number of complaints about the ways in which the service operates, e.g.:	Despite the legislation in place, in the city of Toronto (Ontario) the mainstream transportation systems (buses, streetcars and the subway) are still inaccessible to many users with disabilities. To deal with that, the city runs a special transportation service for people with disabilities (Wheel-trans) that provides door-to-door transportation on

ACHR-PSS, art 18c (ECHR-P4, art2) (CERD, art 5f) (CCPR, art 25c)	Yes	No	that they are not forced to live in a particular living arrangement;	LEGISLATION: *Canadian Human Rights Act*, (R.S.1985, c. H-6) (current as of [DATE]), s.6 denial of commercial premises or residential accommodations on grounds of disability is prohibited → this permits persons with disabilities to choose to occupy commercial or residential spaces freely	Practice, issued in 1998 by the Canada Transportation Agency and the Accessibility Standards for Costumer Services, Ontario).	*"With wheel-trans you can't control. Today my return ride is almost at 5:30. I didn't really need to leave at 5:30 but I have to stick around and wait. I don't have a choice" (18-06-2008-interview 16)*	an individualized basis to persons with disabilities. Although Wheel-Trans provides some access to transportation for persons with disabilities, it operates on grounds that are inconsistent with human rights principles of inclusion, autonomy, dignity and non-discrimination: it is a segregated service, overs which users have little or no control at all, and because of limitations in the number of buses available and the long rides offered, it creates for users barriers to social participation on equal terms with others.

Quantitative analyses require collecting information relative to the number of publications and format of publications per day, their placement (which section, where in that section), the types of disability covered, and sources of disability information relied upon, paying particularly to the role people with disabilities themselves take in the story (that is, whether they figure as sources or just subjects). Qualitative assessments, in turn, focus on content and therefore involve the examination of features such as language and presence of stereotypes, the ways sources are used (whose voice is authoritative, and why), the visual images which are made available, the angle/perspective deployed (including attention to missing voices, implicit judgments, model being used to portray disability) and the context (what stories or items are before/after/around a particular piece). Since analyses are developed from a human rights perspective, this framework is grounded on the above stated key human rights principles of *dignity, autonomy, non-discrimination, inclusion, respect for difference, and equality*.

To develop this work D.R.P.I. is partnering with a team of researchers from State University at Buffalo (USA) who have developed neuronetwork software to collect and analyse media stories in multiple formats and languages, and a researcher from the University of Umea in Sweden for the critical discourse analysis component of the study. A Panel of Experts including media representatives and persons with disabilities, both from the community and the academy, is also assisting with this task. The media monitoring research is guided by a set of questions (see Box 3) which seek to capture the representations of disability in the media and attempts to determine whether there is a movement towards a positive expression of rights for people with disabilities internationally.

The tools developed are now being tested by this group. As a critical component of D.R.P.I. monitoring system, information collected through media monitoring will add to data that comes from the monitoring of individual situations and systemic monitoring to provide a broad and robust picture of the human rights situation of disabled people.

Disability Rights Monitoring: The Way Forward

Rather than an end in and of itself, monitoring is a social tool that serves the purpose of helping us understand a particular situation and

Box 3

D.R.P.I. Media Monitoring Substantive Research Questions

1. The last twenty years have marked a paradigm shift in the way that society understands disability.
   To what extent does media coverage of disability issues reflect this paradigm shift?
   (a) To what extent are disability issues and people with disabilities portrayed in major print and broadcast media coverage?
   (b) Are disability rights recognized/affirmed/denied by this coverage?
   (c) Do media stories acknowledge newly recognized rights?
   (d) Is there a significant divergence in the depiction of disability and the nature and extent of disability coverage between mainstream and disability media?

2. What is the media transmitting to us about disability?
   (a) How is disability defined by media?
   (b) What are the perspectives from which the media addresses disability? (e.g. charity, medical, service delivery, others?)
   (c) How is public opinion influenced by media?
   (d) Does the press lead or follow public opinion?

what it means for the persons involved. The outcome of D.R.P.I. national monitoring projects is a report that holistically integrates data gathered at the individual, systemic and media levels. A good report links all these levels of information offering a broad picture in ways that are accurate, objective and reliable.

An important step after the report is completed is to ensure its wide dissemination so that the abuses and violations of rights highlighted and the recommendations put forward reach the political powers and strengthen the disability community advocacy efforts. D.R.P.I. country reports issued to date draw attention to prevailing violations of human rights and suggest actions to be taken in the future to tackle these issues and improve the rights protection of disabled people in these countries. Country reports are presented to the media, the disability community and local authorities in public sessions but they are also posted in the D.R.P.I. website to warrant continuing circulation in the future.

What does then the future hold for D.R.P.I.? Certainly the passage of the CRPD has signalled an important moment that fundamentally reframed disability as a human rights issue. Now that an international legally binding document provides a comprehensive protection of the human rights of persons with disabilities, governments all over the world are under greater pressure to put an end to discrimination and provide a political and legal environment that ensures the rights of disabled people on equal grounds to all other citizens. Article 33 of the new Convention explicitly asks for the development of monitoring mechanisms to assess the status and function of national institutions in protecting and promoting the human rights of persons with disability. Monitoring has become crucial to assess persisting gaps in the field and encourage change, while measuring the progress made towards the goal of full participation and substantive equality.

D.R.P.I.'s holistic system of rights monitoring offers disabled people and their organizations a comprehensive approach to this complex task, supported by a range of assessment tools, instruments and strategies specifically designed and refined to address human rights issues relevant for persons with disability all over the world. With monitoring projects already concluded in a number of countries including Kenya, Cameroon, India, Bolivia and the Philippines, and under way in Canada and various other countries, D.R.P.I. is about to enter the third stage of its program. Building on previous experience and expertise, the third phase will expand the initiative to involve as many countries in all regions of the world as possible in monitoring the human rights of people with disabilities. Two building blocks of the project will continue to strengthen the participation of disabled persons and their organizations in all steps of the monitoring process, and fostering the sustainability of the initiative through the establishment of multi-actor partnerships and the production and dissemination of training tools. The D.R.P.I. office in Toronto will continue to provide technical support and coordination to these actions, but the creation of the figure of Regional Managers (one per region of the globe) along with the ongoing involvement of the International Advisory Committee[43] (where disabled

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[43] Currently the International Advisory Committee integrates 16 experts in disability and human rights, from all regions of the world, most of whom are also themselves persons with disabilities.

people will continue to have a majority of seats), and the collaborative efforts of various international, regional and national partner organizations will amplify this work by ensuring local support to several country monitoring teams that will integrate the large D.R.P.I. Disability Rights Network.

Even though a legally binding treaty is now available to promote and protect the rights of people with disabilities, the struggle for the human rights of disabled people all over the world is far from being complete. Everywhere persons with disability are still victims of social and economic injustice, discrimination and violation of basic human rights. Monitoring initiatives are required to document and expose these abuses and thus contribute to raising public awareness of disability as a human rights issue. More than ever, we need strong mechanisms to highlight persisting discrimination, draw attention to gaps between legal and policy frameworks and the lived experiences of disabled people, and ensure compliance with the standards of the new Convention. Whether monitoring results in shadow reports for national or international human rights bodies, public campaigns, political lobby or legal advocacy, it is crucial that these efforts engage the active participation of people with disabilities, who are those directly affected by these actions. Their active involvement will ensure that as rights monitoring advances and more evidence becomes available to challenge governments and the international community, the lives of people with disabilities, their interests and concerns are accepted, respected and reflected in the changes that will end disability discrimination one day.

CONCLUSION

WORKING WITHIN A NEW HUMAN RIGHTS PARADIGM – THE WAY FORWARD

The objective of this collection has been to consider ideas about human rights as they affect legal decision-making and state action relating to disability. The book begins with recognition of some key principles of human rights – the values at the essence of a just society. These principles are: first, that all people are treated with dignity and respect; second, that all groups of people and all individuals within those groups are recognised as equal; and finally, that all people are actively included into the communities in which they live. For law to be consistent with human rights the state has to ensure that legal decision-making and social action is consistent with these principles and that agents of the state are required to promote dignity, demand equality and enhance inclusion. The articles that follow take on particular legal circumstances in a number of countries and show the way in which law has addressed those principles.

A human rights approach to law and disability leads to fundamentally different assumptions about disability and the legal and social construction of the status of people with disabilities.[1] Translating human rights principles into legal decision-making provides a different perspective on disability in the field of law. This has the potential to lead to different outcomes for people with disabilities and to conclusions which allow us to reconsider the place and power of human rights for people with disabilities.

When we started this book, the *Convention on the Rights of Persons with Disabilities* was still an unrealised proposal. Never before has the international human rights community moved so quickly through the drafting process to the adoption and ratification of a treaty. With an

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[1] Rioux, Marcia H. (2003). On second thought: Constructing knowledge, law, disability and inequality. In Stanley S. Herr, Harold Hongju Koh & Larry O. Gostin (Eds.) *The human rights of persons with intellectual disabilities: Different but equal.* Oxford: Oxford University Press, 287–318. See also Jones, M. & L. Basser Marks. (1999). Law and the social construction of disability. In M. Jones & L. Basser Marks (Eds.) *Disability divers-ability and legal change*. The Hague: Martinus Nijhoff, 1–24.

unprecedented level of involvement of the international disability community, the terms of the *Convention on the Rights of Persons with Disabilities* (CRPD) reflect what human rights mean for people with disabilities. The CRPD opened for signature on 30th March 2007 and came into effect on 3rd May 2008. The significant number of signatures and ratifications in such a short time reflects the high level of international consensus of the need for this Convention.

The significance of this Convention is that it represents an articulation of a paradigm shift, which has been emerging over the last 30 years. While earlier international instruments also applied to persons with disabilities, there was no concrete recognition of how they were included and few legal applications of those human rights. Throughout this volume contributors ask about the way in which a human rights perspective on disability can bring about different outcomes for people with disabilities in law and what this means in the day-by-day lives of people with disabilities. While the Convention is important and an outstanding achievement, the distance between a declaration or an international agreement about human rights and its application for people with disabilities needs to be explicitly recognized. The scope of the CRPD is itself an indication of the many areas of life in which people with disabilities may experience human rights abuses and the very detail of the Convention suggests the complexity of ensuring human rights for people with disabilities.

This book represents a step towards more detailed focus on the intersection of human rights, disability and law. This analysis is important for an understanding of CRPD and will aid in the interpretation of the CRPD. The contributors examine discrete areas of law and bring human rights to bear in the specific circumstances explored. A breakdown of the reasons why people with disabilities continue to be the subject of rights infringements and the ways in which these rights are disregarded is highlighted. The authors demonstrate the difficulty of dealing with this subject as they consider the ways in which the legal construction of disability has traditionally reflected a disabilist perspective. What is needed is a move from a charitable status to a rights status; a move from a second rate status to a favoured status; from disabled people as second-rate citizens to disabled people as rights holders. Given the complexity of this subject, we recognize that an enormous amount of work is yet to be done to make the human rights of people with disabilities meaningful. The law is an important instrument in this shift and the authors in this volume unpack issues that block the legal construction of people with disabilities as rights holders.

THE PARADIGM SHIFT TO A RIGHTS BASED APPROACH

The paradigm shift referred to in the title to this chapter is the shift from thinking of disability as a matter of individual pathology, of welfare, charity and services, to conceptualising disability as a human rights issue.[2] In the words of the former High Commissioner for Human Rights Madame Louise Arbour:

> [T]he Convention represents a paradigm shift in attitudes that moves from a perception of persons with disabilities as objects of charity, medical treatment and social protection to subjects of rights, able to claim those rights as active members of society. The Convention achieves this paradigm shift by affirming that persons with disabilities hold civil, cultural, economic, political and social rights, are entitled to full protection against discrimination and by establishing monitoring mechanisms at the national and international levels to ensure that persons with disabilities are able to enforce those rights.[3]

Taking this human rights approach to disability is important because, as Quinn and Degener argued in their 2002 report:

> …the human rights perspective on disability means viewing people with disabilities as subjects and not objects. It entails moving away from viewing people with disabilities as problems towards viewing them as holders of rights. Importantly, it means locating problems outside the disabled person and addressing the manner in which various economic and social processes accommodate the difference of disability…[4]

The push for a disability convention came from the international disability community. It started with the Swedish proposal in the 1980's

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[2] There is now a significant literature on the various approaches to disability see for example: Barnes, C. (1996). Theories of disability and the origins of the oppression of disabled people in western society. In L. Barton (Ed.). *Disability and society: Emerging issues and insights.* Disability and Society: Emerging Issues and Insights. London & NY: Longman; Oliver, M. (1996). *Understanding disability: From theory to practice.* London: MacMillan; Shakespeare, T. (1999). What is a disabled person? In M. Jones & L. Basser Marks (Eds.), *supra.* With respect to the human rights approach to disability see: L. Basser & M. Jones. (2001). Law and people with disabilities. In N. Smesler & P. Baltes (Eds). *International encyclopaedia of social and behavioral sciences.* Elsevier; Rioux, M. (2003), *supra* note 1.

[3] U.N. Human Rights Council, *Report of the United Nations High Commissioner for Human Rights on Progress in the Implementation of the Recommendations Contained in the Study on the Human Rights of Persons with Disabilities,* 31, U.N. Doc. A/HRC/4/75, *available at* http://www.un.org/disabilities/default.asp?id=135.

[4] G. Quinn & T. Degener (Eds.). (2002). *Human rights and disability: The current use and future potential of the United Nations human rights instruments in the context of disability.* Geneva: Office of the High Commission for Human Rights.

when the international community was not yet ready for a Convention and, in the place of a Convention, instead adopted the *Standard Rules on the Equalisation of Persons with Disabilities*.[5] That was followed by a series of international meetings sponsored by the United Nations in Berkeley,[6] Hong Kong,[7] Almosa, Sweden[8] and Mexico[9] where people with disabilities called for a distinct convention on disability rights.

The Convention does not intentionally create new rights.[10] Rather it restates and clarifies existing rights and what those rights encompass from a disability perspective. With respect to these rights, the Convention seeks to identify those areas where adaptations are required to ensure that people with disabilities can effectively exercise their rights, those areas where the rights of people with disabilities have been violated and where protection of rights must be enforced.

There was already significant evidence that disability rights had been sidelined in international instruments and reporting, even while it was recognized that people with disabilities were included within their scope. In Mr. Despouy's 1993 report, Human Rights and Disabled Persons, the UN Special Rapporteur made it clear that disability was a human rights concern, in which the United Nations treaty monitoring bodies should be involved. Included among his recommendations was the following:

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[5] *Standard Rules on the Equalization of Opportunities for Persons with Disabilities,* A/RES/48/96, 20 December 1993Cong. (1993).

[6] *Report of the United Nations consultative expert group meeting on international norms and standards relating to disability*. (1998). Berkeley, California, United States of America, 8–12 December 1998, online: http://www.un.org/esa/socdev/enable/disberk0.htm.

[7] *Report of the interregional seminar and symposium on international norms and standards relating to disability*. (1999). Hong Kong, China 13–17 December 1999, online: http://www.worldenable.net/hongkong99/.

[8] *Let the world know: Report of a seminar on human rights and disability*. (2000). (Stockholm, November 5–9, 2000), organized by the UN Special Rapporteur on Disability, Mr. Bengt Lindqvist, online: http://www.un.org/esa/socdev/enable/stockholmnov2000.htm; See also Disability Rights Promotion International (D.R.P.I.) website for report http://www.yorku.ca/drpi.

[9] *Interregional expert meeting on international norms and standards relating to disability*. (2002). Mexico City, Mexico, 11–14 June 2002.

[10] Byrnes argues that because it is a comprehensive and integral treaty the CRPD does in fact create new hybrid rights. See: A. Byrnes (2008). Monitoring the fulfilment of CRPD Rights in Australia: Issues and challenges. Transcript from the Queensland Advocacy Inc Human Rights Seminar 20th August 2008, online: http://www.qai.org.au/content/online_library_documents.cfm?ID=69.

> After the Decade has ended, the question of human rights and disability should be kept on the agendas of the General Assembly, the Economic and Social Council, the Commission on Human Rights and the Sub-Commission as an item of constant concern and on-going attention.[11]

The Committee on Economic, Social and Cultural Rights in 1994 assumed the responsibility for disability rights by issuing General Comment No. 5 in which the Committee analyses disability as a human rights issue. The General Comment states:

> The Covenant does not refer explicitly to persons with disabilities. Nevertheless, the Universal Declaration of Human Rights recognizes that all human beings are born free and equal in dignity and rights and, since the Covenant´s provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognized in the Covenant.[12]

At the 54th session of the United Nations Commission on Human Rights, the United Nations assumed responsibility for the human rights of persons with disabilities. This was followed at its 56th session in April 2000 in which the Commission[13] recognized the United Nations *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (General Assembly resolution 48/96, annex) as an evaluative instrument to be used to assess the degree of compliance with human rights standards concerning persons with disabilities:

> [The Commission] *recognizes* that any violation of the fundamental principle of equality or any discrimination or other negative differential treatment of persons with disabilities inconsistent with the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities is an infringement of the human rights of persons with disabilities.[14]

Further, the Commission encouraged all the treaty bodies to monitor the compliance of States' commitments in order to ensure full enjoyment of rights by persons with disabilities. Governments were urged to cover fully the question of human rights of persons with disabilities, when reporting under the relevant United Nations human rights instruments.

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[11] Human Rights and Disabled Persons, para 274.

[12] General Comment no. 5: Persons with Disabilities, 5, 09/12/94Cong. (1994).

[13] UN resolution 2000/51 General Assembly resolution 48/96, annex.

[14] CHR resolution 2000/51, para 1.

> [The Commission] *invites* all the human rights treaty monitoring bodies to respond positively to its invitation to monitor the compliance of States with their commitments under the relevant human rights instruments in order to ensure full enjoyment of those rights by persons with disabilities, and urges Governments to cover fully the question of the human rights of persons with disabilities in complying with reporting obligations under the relevant United Nations human rights.[15]

This framework provided the impetus for the Special Rapporteur on Disability, Mr. Bengt Lindqvist to hold the *Stockholm Seminar on Human Rights and Disability* titled *"Let the World Know."*[16] In a statement to the Seminar, Mary Robinson, UN High Commissioner on Human Rights at the time said:

> This seminar is a vital step towards the full recognition and realization of the human rights of all persons with disabilities...We know that persons with disabilities frequently live in deplorable conditions, and face physical and social barriers, which prevent their integration and full participation in the community. As a result, millions of adults and children throughout the world are segregated, deprived of virtually all their rights, and, sometimes, lead wretched and marginalized lives. This is completely unacceptable.
>
> The Universal Declaration of Human Rights refers specifically to the rights of persons with disabilities. Article 1 declares that all human beings are born free and equal in dignity and rights. There is a joint responsibility at the national and international level to ensure these rights are translated into concrete action.[17]

When the Convention process itself began,[18] people with disabilities were involved through their representative organizations and as part of the government contingents on the Ad Hoc Committee[19] and the

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[15] Ibid., para 11.

[16] *Supra*, note 7.

[17] Mary Robinson, United Nations High Commissioner for Human Rights, Video Message to the International Seminar on Human Rights and Disability, Almåsa Conference Centre, Stockholm Sweden, 5 November 2000.

[18] The process of development of the CRPD began in December 2001 with the Mexican proposal in the General Assembly to establish an Ad Hoc Committee to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, online: http://www.un.org/disabilities/default.asp?navid=22&pid=153.

[19] The General Assembly established an Ad Hoc Committee in 2001 "to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination and taking into account the recommendations of the Commission on Human Rights and the Commission for Social Development."

Working Group.[20] Through this process not only has the discourse of disability changed and disability been made more visible, it has continued and accelerated the process begun earlier in many countries, to put disability on the international and domestic law and policy agenda. Just as importantly, the process of developing the Convention provides a model for the development of law, policy and programs at the national and local level, involving people with disabilities in that development. This is formally mandated in Article 4.3 of the Convention:

> In the development and implementation of legislation and policies to implement the present Convention and in other decision making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

The significance of this paradigm shift cannot be understated. More often than not people with disabilities have been seen as individuals with tragic lives, in need of fixing. The assumption of what has become known as the bio-medical or individual pathology model of disability is that the individual is conflated with their "condition" or "impairment" and their personhood subsumed into their disability. The alternate model of disability, put forward by critical disability scholars and advocates, is known as the social pathology model of disability. This model locates the pathology or the problem of disability outside the person, attributing responsibility to the disabling effect of social, legal and political structures.[21] The human rights framework of disability takes us one step further in its recognition that responsibility for disability lies both in the individual experience and in social structures.[22] While putting the person first, the principle of dignity requires that an individual's disability is acknowledged and the impact of the "condition" on a person's life is recognized. Adherence to the principle of equality

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On 5 December 2006, the draft final report and the optional protocol were presented to the General Assembly for adoption, online: http://www.un.org/esa/socdev/enable/rights/adhoccom.htm.

[20] The Working Group is composed of representatives of Member States, non-governmental organizations and a national human rights institution who prepared and submitted a draft of the text in 2006.

[21] Rioux, M. (2003), *supra* note 1.

[22] Rioux, M. (1997). Disability: The place of judgement a world of fact. *Journal of Intellectual Disability Research*, 41(2); L. Basser & M. Jones. (2001). Law and people with disabilities. In N. Smesler & P. Baltes (Eds). *International Encycopledia of Social and Behavioral Sciences* Elsevier.

requires an examination of the differential impact of social structures on the disabled and non-disabled populations. Often inequality is invisible, operating at both at a systemic level and encapsulated in "common sense."

Throughout this volume we have seen authors come to terms with ways in which the law can be viewed from this rights perspective, challenging both understandings of the disabled person in law and ideological assumptions surrounding disability. These essays provide a starting point for the initiation of movement towards the re-conceptualization of the meaning of law for disability as a rights issue. Using human rights principles as a foundation, these analyses of legal action, in light of the recent ratification of the CRPD, show genuine commitment to the re-evaluation of people with disabilities as valued members of society and as rights bearers.

Including the full range of people with disabilities is sometimes construed as overly complex. People with disabilities are heterogeneous and they are at the same time members of other rights-seeking groups as well. That intersection of disability and other statuses cannot be downplayed or masked. Different impairments also intersect differently with different environmental and attitudinal barriers. What constitutes a barrier to one group may not be disabling in the same way or have the same impact to another. In addition, as the preamble to the CRPD recognizes, disability is an evolving concept and an unstable category, which is determined by the interrelationship between bodies, impairments, concepts of normalcy, attitudes to disability, social and structural institutions and political ideology. Even recognizing all these issues, providing human rights for people with disabilities is not necessarily as complicated as it is sometimes presumed.

Proceeding from commitments to treating people with dignity and respect; ensuring equal outcomes among people; and making changes where required to facilitate the inclusion of people with disabilities, ways of moving forward will be clearer. The outcomes result in casting aside intuitive or emotional reactions of people with disabilities and eliminating the equation of services with rights. The task will be locating entitlements arising from law by taking a human rights approach. Outcomes must ensure, first, that the dignity of the person is maintained and promoted. Second, accommodations need to be made to ensure equal outcomes between disabled and non-disabled persons. Third, inclusion must be facilitated such that participation is on equal terms to those of the non-disabled population. In other words, what is needed is a principled approach to the interpretation and practice of law.

The CRPD as a Catalyst for Change

The success of the CRPD, and of law generally, will be measured by the extent to which the underlying principles are reflected in the development and administration of laws, policies and programs, in the rulings of domestic courts and tribunals and in the changes experienced at the grass roots. Overall, the achievements of the Convention support the understanding of the entitlements of people with disabilities as rights bearers. The Convention affects a paradigm shift in the approach to disability. Disability is more than a thematic issue for the United Nations and other world bodies, for example, in development. The Convention requires that disability be seen as more than simply a matter of charity – disability is centre stage as a rights issue. The Convention makes it clear that disability rights are human rights and people with disabilities, in common with all members of the human family, are entitled to be treated with dignity and respect and to exercise the full range of human rights.

However, the Convention, like much current domestic law, does not tell us what to do in the specific application of the rights guaranteed by its terms. The dilemma, as demonstrated throughout the chapters of this book, is in the application of principles to particular cases, involving particular individuals, in particular circumstances. Traditional failure to translate rights as requiring facilitation has resulted in hollow promises. People with disabilities, unlike people from historically disadvantaged groups, cannot be granted rights-bearing status by simply addressing previous discriminatory practices.[23] For rights to be meaningful for people with disabilities the rights must be inclusive and facilitative. We can identify the application of disability rights by looking to legal decisions in which the Courts have clearly recognized that people with disabilities must be provided the same rights as others.[24] Unless

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[23] Rioux, M. (1994). Towards a concept of equality of well being: Overcoming the social and legal construction of inequality. *Canadian Journal of Law and Jurisprudence*, 7(1): 127–148.

[24] See for example *Eve (Mrs.) v Eve* 2 S.C.R. 388 (1986), *PGA Tour Inc. v Martin* 532 US 661 (2001), *Hornstine v Township of Moorestown,* 263 F.Supp.2d 887 (2003), *Victor Rosario Congo v Ecuador* 11.427 (1997).

the lives of individuals with disabilities are improved, unless it can truly be said that people with disabilities are active participants in the societies in which they live and unless there are processes available to people with disabilities that translate their rights into lived experience, rights are not being translated from their rhetorical base.

Beyond the *Convention:* Living the Paradigm

In many jurisdictions the interests of people with disabilities have been translated into anti-discrimination law, which have often been the first state declaration of the human rights of people with disability. The introduction of these laws has been enormously progressive and, while not a panacea, this is an essential step. The potential achievement of anti-discrimination law could be the transformation of society as a whole. For example, when the Australian *Disability Discrimination Act* 1992 (Cth) was introduced into the Australian Parliament, it was inspired by the idea of:

> …a fairer Australia where people with disabilities are regarded as equals, with the same rights as all other citizens, with recourse to systems that redress any infringement of their rights…where difference is accepted, and where public instrumentalities, communities and individuals act to ensure that society accommodate difference.[25]

The operation of the Australian Act, however, has rarely encapsulated this vision. This is in part because of the very complexity of the subject with which we are dealing.

In some cases the failure to accord applicants with human rights outcomes is more a reflection of the failure to understand the nature of disability than it is a resistance to human rights.

Even where the commitment to equality of people with disabilities is found in a country's constitution or a legislative bill of rights, the human rights framework of the law has again offered no guarantee to people with disabilities that their human rights will be protected. For example, the equality guarantee in section 15 of the Canadian *Charter of Rights and Freedoms*, embedded in the Canadian Constitution, while clearly intended to extend equality to people with disabilities, has not yet seen

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[25] The Hon Brian Howe, Minister for Health, Housing and Community Services, Second Reading Speech *Parliamentary Debates* 26th May 1992, 2755.

its full potential realized,[26] although there are cases which have been exemplar.[27]

While there have been glimpses of hope in national law, in many cases people with disabilities have gained access to services rather than having their rights entrenched. The accounts of the authors of this volume tell that story. Though officially found in law, the meaningful application of rights protections for people with disabilities are frequently inadequate and the realization of disability rights long overdue.

Given the number of people with disabilities in every society, it is important to recognize that any law, or any regulation, by-law or policy will have an impact on people with disabilities and, therefore, ought to be read in a way consistent with the principles of dignity, equality and inclusion. To achieve this a nuanced understanding of the operation of law is required:

> If we take law to have as its essential feature the exercise of state power which has the effect of regulating and controlling behaviour, we can also come to see that the success of law depends on its ability to discipline behaviour…In other words, law works by categorising, isolating, ostracising, dehumanising, rather than by just punishing identifiable acts of wrong doing…[T]he formal proclamations of law are far less significant in the lives of people with disabilities than in its capillary effect.[28]

To bring real change through law, and to bring human rights into daily operation, what is needed is political will coupled with a sophisticated understanding of disability. What is being asked is no easy task, for this involves a radical disruption of the status quo. For this shift to human rights to filter through to every aspect of society, change must happen at every level of society. What is required is that people with disabilities know and understand that they can demand their rights along side others and that there is recognition by others that people with disabilities have rights. Many people will need to understand the depth and significance of this – from disability workers, through to judges and lawyers; from teachers and parents through butchers and corner store

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[26] See for example *Eaton v Brant County Board of Education* [1997] 1 S.C.R. 241.

[27] See for example *Eldridge v British Columbia (Attorney General)* [1997] 3 SCR 624.

[28] Jones, M. and L. Basser Marks. (1999). Law and the social construction of disability. In M. Jones & L. Basser Marks (Eds.). *Disability, divers-ability and legal change.* The Hague: Martinus Nijhoff, 1–24, at 1–2.

operators; to policy drafters and administrators, police forces and politicians. More fundamentally, both public and private institutions, which structure social relations such as schools, businesses and service providers, will need to alter existing practices to become inclusive of those with disabilities.

The denial or achievement of disability rights is a public responsibility. It is time to think critically about the extent of the barriers for people with a disability living in societies that are inaccessible – barriers that are physical, environmental, organizational and attitudinal. Concurrently, laws and policies have to be scrutinized so that their effect, even at the margins, become consistent with ensuring that people with disabilities are accorded dignity and accommodated in such a way that there is true equality between people. Furthermore, laws, policies, and programs will need to be examined through a disability rights lens. This is demonstrated by the contributors to this book who have scrutinised specific areas of law for its consistency with the human rights of people with disabilities, in such a way as to encourage social change and to promote the rights of people with disabilities internationally.

While there have been widespread efforts by international and national organizations to promote the rights of people with disabilities at both grassroots and governmental levels, the promotion of these rights has neither been respected nor enforced to its full capability. Information that becomes available about disability through monitoring processes sheds light on what needs to be done. Recent research from Disability Rights Promotion International,[29] for example, has shown a consistent denial and violation of human rights for people with disabilities across all domains of life examined – education, work, income security and supports, privacy and family life, social participation, information and communication, health, habilitation and rehabilitation, access to justice.[30] Similarly, the International Disability Rights Monitor[31] has demonstrated through the production of regional reports of the Americas (2004),[32] Asia (2005),[33]

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[29] More information on the D.R.P.I. project, including copies of research reports can be found on the D.R.P.I. web site: http://www.yorku.ca/drpi See also, Pinto chapter 16.

[30] Pinto, P. (2010). Monitoring of human rights of people with disabilities: Toronto Site Individual Experiences Fact Sheet, online http://www.yorku.ca/drpi.

[31] International Disability Rights Monitor, online http://www.idrmnet.org/.

[32] International Disability Rights Monitor. Regional Report of the Americas 2004, online http://www.ideanet.org/cir/uploads/File/IDRM_Americas_2004.pdf.

[33] International Disability Rights Monitor. Regional Report of Asia 2005, online http://www.ideanet.org/cir/uploads/File/CIR_IDRM_Asia_05.pdf.

and Europe (2007)[34] that though countries provide "adequate basic legal protections" for the most part, many challenges remain for the implementation of these rights including ensuring access to inclusive education and employment practices, health, housing, accessibility and inclusive communication practices.[35]

Our hope is that this book is the beginning of a process whereby there is a clearer understanding of the legal interpretation of disability rights and the way in which disability rights can be argued in law. In this way, there can be a clear recognition that disability is an overlay on every interaction between the state and society.

This book focuses on everyday situations for people with disabilities in which law is implicated. Without a commitment to valuing people with disabilities, we cannot begin to see what is required of law to demonstrate that valuing. By modifying the gaze to include a disability filter we can begin the process of making real change. After all, the grand design of international law has the objective of reaching ordinary people in "small places."[36]

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[34] International Disability Rights Monitor. Regional Report of Europe 2007, online http://www.idrmnet.org/pdfs/IDRM_Europe_2007.pdf.

[35] Ibid.

[36] Eleanor Roosevelt on the development of the *Universal Declaration of Human Rights*.

APPENDICES

Appendix A: Case List

American Association of People with Disabilities et al v Hood [2004] 310 F. Supp. 2d 1226

American Association of People with Disabilities v Shelley [2004] 324 F. Supp. 2d 1120

Andrews v Law Society of British Columbia [1989] 1 S.C.R. 143

Attis v Canada (Minister of Health) [2003] O.J. No. 3766

Autism Europe v France [2002] Complaint No. 13

Auton (Guardian ad litem of) v British Columbia (Attorney General) [2004] 3 S.C.R. 657

Baker v Canada (Minister of Citizenship and Immigration) [1999] 2 R.C.S. 817

Bear v Canada (Attorney General)(C.A.) [2003] 3 F.C. 456

Board of Trustees of the University of Alabama v Garrett [2001] 531 U.S. 356

Botta v Italy [1998] 26 E.H.R.R. 241

British Columbia (Public Service Employee Relations Commission) v British Columbia Government Service Employees' Union [1999] 3 S.C.R. 3

British Columbia (Superintendent of Motor Vehicles) v British Columbia (Council of Human Rights) [1999] 3 S.C.R. 868

Brown v Board of Education [1954] 347 U.S. 483

Buck v Bell [1927] 274 U.S. 200

Burdick v Takushi [1992] 504 U.S. 428, 436

Bush v Gore [2001] 531 U.S. 98

Cameron v Nova Scotia (Attorney General) [1999] 204 N.S.R. (2d) 1

CES v Superclinics (Australia) Pty Ltd [1994] 38 NSWLR 47

Chaoulli v Quebec (Attorney General) [2005]1 S.C.R. 791

Children's Aid Society of Ottawa-Carleton v A [2001] O.J. No. 2887 S.C.J.

Children's Aid Society of Owen Sound and the County of Grey v B.H. [2000] O.J. No. 5308 O.C.J.

Children's Aid Society of Simcoe v L.A.M. [2000] O.J. No. 389 S.C.J.

Children's Aid Society of the Niagara Region v M.C. [2000] O.J. No. 3268 O.C.J.

City of Boerne v Flores [1997] 521 U.S. 507

Council of Canadians with Disabilities v VIA Rail Canada Inc. [2007] 1 S.C.R. 650, 2007 SCC 15

Curlender v Bio-Science Laboratories [1980]165 Cal Rptr 477

Dawood & Anor v Minister of Home Affairs & ors; Shalabi & Anor v Minister of Home Affairs & Ors; Thomas & Anor v Minister of Home Affairs & Ors [2000] ZACC 8; (2000) (8) BCLR 837 Butterworths Constitutional Law Reports SA

Dawson v Canada Post Corporation [1] [2008] CHRT 412008/10/03

Dunn v Bumstien [1972] 405 U.S. 330

Dybeku v Albania [2007] 41153/06

Eaton v Brant County Board of Education [1997] 1 S.C.R. 241

Eldridge v British Columbia (Attorney General) [1997] 3 S.C.R. 624

Estate of C.W. (1994) 640 A. 2d 427

Eve (Mrs.) v Eve [1986] 2 S.C.R. 388

Florida Prepaid Postsecondary Education Expense Board v College Savings Bank [1999] 527 U.S. 666

Gelfmann v France [2003] Application No. 25875/03

Gillick v West Norfolk and Wisbech AHA [1986] AC 112

Glass v United Kingdom [2004] 1 FLR 1019

Glor v Switzerland, [2009] European Court of Human Rights. Application No. 13444/04

Gorshkov v Ukraine [2005] 67531/01

Gosselin v Québec (Attorney General) [2002] 4 S.C.R. 429

Granovsky v Canada [2000] 1 S.C.R. 703

Hamilton v Jamaica [1995] Communication No 616

Harper v Virginia Board of Elections (1966) 383 U.S. 663

Harriton v Stephens (2006) 226 CLR 52; 226 ALR 391; [2006] HCA

HE v A Hospital NHS Trust [2003] 2 FLR 408

Herczegfalvy v Austria [1993] 15 EHRR 437

Hornstine v Township of Moorestown [2003] 263 F. Supp. 2d 887

Hutchinson v British Columbia (Ministry of Health) [2004] B.C.H.R.T.D. No. 55

International Association Autism-Europe v France [2004] 3 CoE. 12

In Re Merck & Co. Inc. Derivative & ERISA Litigation (5 May 2006), New Jersey 3: 05cv02368 (D.N.J), 2006 WL 1228595 (WL)

Johnson v Superior Court of Los Angeles County [2002]124 Cal. Rptr. 2d 650

K v Minister for Youth & Community Services [1982] 1NSWLR 311

Keenan v UK [1998] EHRLR 648

Kimel v Florida Board of Regents [2000] 528 U.S. 62

Korn v Potter [1996] 134 D.L.R. (4th) 437

Kotsaftis v Greece [2008] no. 39780/06

Kucherek/Koutchereouk v Ukraine [2007] 2570/04

Law v Canada (Minister of Employment and Immigration) [1999] 1 S.C.R. 497

McKeigan v Department of Community Services Province of Nova Scotia (18th August 2004) Halifax File NO SH 205270 (NSSC)

Mathew v The Netherlands (24919/03) (2006) 43 EHRR 23

McDonald v Board of Election Commissioners (1969) 394 U.S. 802

McGlinchey & Others v UK (50390/99) (2003) 37 EHRR 41

McKay v Essex Area Health Authority [1982] 1 Q.B. 1166

MDAC v Bulgaria [2008] Complaint No. 41/2007, European Committee of Social Rights

Merck Frosst Canada & Co. v Canada (Minister of Health) [2004] F.C.J. No. 1178 (FCTD)

Mouisel v France [2002] Application No. 7263/01

Muir v Alberta [1996] 132 D.L.R. (4th) 695

N v Dr M [2002] EWCA Civ 1789

Napier v Scottish Ministers [2005] S.C. 229

National Coalition for Gay & Lesbian Equality v Minister of Justice [2000] (2) SA 1 (CC)

New York v County of Schoharie [2000] 82 F. Supp. 2d 19

Newfoundland (Treasury Board) v N.A.P.E. [2004] 3 S.C.R. 381, 2004 SCC 6

Nova Scotia (Minister of Community Services) v F(B) [2003] 219 N.S.R. (2d) 67

Nova Scotia (Workers' Compensation Board) v Martin [2003] 2 S.C.R. 504

Okunda v Republic (1970) EA 453

Olmstead v L.C. [1999] 527 U.S. 581

Ostrovar v Moldova (2007) 44 EHRR 19, 35207/03

Paretta v Medical Offices for Human Reproduction [2003]760 N.Y.S. 2d 639

Parkinson v St James' & Seacroft University Hospital N.H.S. Trust [2001] 3 All E.R. 97

Peers v Greece (28524/95) (2001) 33 EHRR 51

People of the State of New York v GlaxoSmithKline [2004] CIV-5304 (MGC) (S.D. N.Y.)

Perruche (Cass. ass. plén.) [2000] no 99–13.701, no 457P

PGA Tour Inc. v Martin [2001] 532 U.S. 661
Portsmouth NHS Trust v Wyatt and Wyatt [2005] 1 F.L.R. 21
Pretty v UK [2002] 35 E.H.R.R. 1
Price v UK (33394/96) (2002) 34 E.H.R.R. 53
Purohit and Another v The Gambia [2003] AHRLR 96
Quebec (Commission des droits de la personne et des droits de la jeunesse) v Montréal (City)[2000] 1 S.C.R. 665
Quesnel v London Educational Health Centre [1995] 28 C.H.R.R. D/474 (Ont. Bd. of Inq.)
R (Burke) v General Medical Council [2004] 2 F.L.R. 1121
R (PS) v G and W [2003] E.W.H.C. Admin 2335
R (Wilkinson) v Broadmoor Special Hospital Authority [2001] E.W.C.A. Civ 1545
R (Wooder) v Feggetter [2002] E.W.C.A. Civ 554
R v Anthony James Drew [2003] U.K.H.L. 25, HL
R v Arthur [1981] 12 B.M.C.R. 1
R v Ashworth Hospital Authority ex parte Munjaz [2005] U.K.H.L. 58
R v Kapp [2008] S.C.C. 41
R v Oakes [1986] S.C.R. 103
R(A B X & Y) v East Sussex CC and the Disability Rights Commission (No2) [2003] E.W.H.C. 167 (Admin)
Re Angela (Special Medical Procedure) [2010] FamCA 98
Re B [1981] 1 W.L.R. 1421
Re B [1987] H.L.J. 21
Re B v NHS Hospital Trust [2002] 2 All E.R. 449
Re C [1989] 2 All E.R. 782
Re C [1994] 1 W.L.R. 290
Re C [1997] 2 F.L.R. 180
Re C [1998] 1 F.L.R. 384
Re C.M.L. [2001] A.J. No. 331
Re D (1997) 38 B.M.L.R.
Re D (A Minor) [1976] 1 All E.R. 326
Re Estate of K.E.J. 382 Ill.App. 3d. 401
Re G (2001) 65 B.M.L.R. 6
Re Grady [1981] 426 A. 2d 467
Re Hayes [1980] 93 Wash. 2d 228
Re J [1990] 3 All E.R. 930
Re J [1991] 1 F.L.R. 366
Re J [1992] 2 F.L.R. 165

Re K and Public Trustee [1985] 19 D.L.R. (4th)
Re R [1992] Fam 11
Re S (adult patient: sterilisation) [2001] Fam 15
Re S [1994] 2 F.L.R. 1065
Re W [1993] Fam 64
Rees v Darlington Memorial Hospital N.H.S. Trust [2002] 2 All E.R. 177 (C.A.)
Renolde v France [2009] Application No. 5608/05
Reynolds v Sims [1964] 377 U.S. 533
Riviere v France [2006] Application No. 33834/03
Rojas v British Columbia (Ministry for Children and Families) [2001] B.C.H.R.T.D. No. 17
S v Makwanyane [1995] 3 SA 391 (CC)
S v Makawanyane [1995] 6 BCLR 778 (CC)
Sandusky County Democratic Party v Blackwell [2004] 387 F. 3d 565 (6th Cir.)
Schloendorff v Society of New York Hospital [1914] 105 N.E. 92
Secretary, Department of Health and Community Services v JWB and SMB [1992] 106 A.L.R. 385 (QL)
Skinner v Oklahoma [1942] 316 U.S. 535
Soobramoney v Minister of Health, KwaZulu Natal [1998] 1 S.A. 765 (CC); (1997) 12 B.C.L.R. 1696 (CC)
Starson v Swayze [2003] S.C.C. 32
Symes v Canada [1993] 4 S.C.R. 695
The Matter of Terwilliger [1982] 450 A. 2d 1376
Thlimmenos v Greece [2000] Application No. 34369/97
University of Alabama v Garrett [2001] 531 U.S. 356
Victor Rosario Congo v Ecuador [1997] Inter-Am.C.H.R. 11.427
Vincent v France [2007] Application No. 6253/03
Viviers v Connolly [1995] 2 Qd R 326
Vriend v Alberta [1998] 1 S.C.R. 493
Wandsworth LBC v Michalak [2003] 1 W.L.R. 617
Wessel v Glendening [2002] 306 F. 3d 203 (4th Cir.)
Wyatt v Portsmouth Hospital NHS and Wyatt (by her Guardian) (No 3) [2005] 2 F.L.R. 480
X and Y v The Netherlands [1985] 8 E.H.R.R. 235
Yakonvenko v Ukraine [2008] Application No. 15825/06
Zeitzoff v Katz [1986] 40(2) P.D. 85

Appendix B: Cited Significant Human Rights Instruments

UN Instruments

Universal Declaration of Human Rights (Universal Declaration) (1948)

The Universal Declaration of Human Rights (UDHR) was adopted by the General Assembly of the United Nations in 1948. It was the first listing of universal human rights ever agreed to by states. The UDHR declares that everyone has equal and undeniable entitlement to all types of rights – economic, social, cultural, civil and political. While not legally binding, the UDHR holds significant moral weight. Some experts consider that it is now part of customary international law. Many laws and legal documents in countries around the world are based on the principles set forth in the UDHR.

International Covenant on Civil and Political Rights (ICCPR) (1976)

The International Covenant on Civil and Political Rights (ICCPR) was adopted by the UN General assembly in 1966 and entered into force in 1976. The ICCPR is legally binding on all states that have ratified it. The ICCPR further develops the civil and political rights set out in the UDHR.

International Covenant on Economic, Social and Cultural Rights (ICESCR) (1976)

The International Covenant on Economic, Social and Cultural Rights (ICESCR) was adopted by the UN General Assembly in 1966 and entered into force in 1976. The ICESCR is legally binding on all states that have ratified it. The Covenant further develops the economic, social and cultural rights set out in the UDHR.

> *General Comment No. 5 (1994)*
> The body that is responsible for monitoring compliance with the ICESCR is the Committee on Economic, Social and Cultural Rights. In 1994, the Committee issued its General Comment No. 5 which reviews and emphasizes some of the ways in which issues concerning persons with disabilities arise in connection with the obligations contained in the ICESCR.

Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) (1981)

The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) was adopted by the UN General Assembly in 1979 and came into force in1981. It applies to all women and girls, including women and girls with disabilities and covers all categories of rights – economic, social, cultural, civil and political. The CEDAW is legally binding on all states that have ratified it.

Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) I (1984)

The CAT was adopted by the UN General Assembly and entered into force in 1984. It is legally binding on all states that have ratified it. People with disabilities and especially those who live in institutionalized settings, are particularly vulnerable to torture and other forms of cruel, inhuman or degrading treatment.

Convention on the Rights of the Child (CRC) (1990)

The Convention on the Rights of the Child (CRC) was adopted by the UN General Assembly in 1989 and entered into force in 1990. The CRC is legally binding on all states that have ratified it.

Children with disabilities are entitled to equal enjoyment of all rights found in the CRC. The convention covers all categories of rights – economic, social, cultural, civil and political. The equal application of CRC rights without discrimination is guaranteed in Article 2 and includes an explicit prohibition of discrimination on the basis of disability. In Article 23, the CRC explicitly refers to children with disabilities stating that States must ensure each child with a disability has "effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities." Children with disabilities are frequently denied these rights because of physical barriers and lack of supports.

Convention on the Rights of People with Disabilities (CRPD) (2008)

The Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the UN General Assembly in 2006 and came into force in May 2008. The CRPD is legally binding on all states that have ratified it. People with disabilities, disability organizations and their allies played an active role in drafting the CRPD.

The CRPD does not create new rights for persons with disabilities. Instead, it explains what existing civil, cultural, economic, political and social rights mean in the context of disability. The CRPD calls for more attention to be paid to people with disabilities within the international human rights system, by governments and by society.

Declaration on the Rights of Disabled Persons (1975)

The Declaration on the Rights of Disabled Persons was made by the United Nations General Assembly in 1975. A precursor to the CRPD, this resolution though not binding, has been used in the past as a framework for national and international law.

Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care, Promotion of Mental Health and Prevention of Mental Disorders (1991)

The Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care was adopted by the UN General Assembly in 1991. The instrument refers to choices related to living independently and participating in the community. Rights to live and work in the community, rights to treatment in the least restrictive environment, and other principles related to consent to treatment are addressed. Principles set out clear criteria for involuntary admission to a mental health facility to ensure that the rights of persons with mental disabilities are respected.

Standard Rules on the Equalization of Opportunities for People with Disabilities (1993)

In 1993, the UN General Assembly adopted the Standard Rules. There are 22 main rules and additional subrules and guidelines outlining a policy of integration and participation. Coming before the CRPD, the Standard Rules played an important role in shifting the understanding of disability from a problem of the individual to something created by society and an issue of human rights.

The Standard Rules provide direction to governments and address government responsibility. While not legally binding, they hold moral weight.

Vienna Declaration and Programme of Action (1993)

The Vienna Declaration and Program of Action reaffirms the promotion and protection of human rights as an international priority. Providing a comprehensive analysis of international human rights instruments and implementations. This recognition of a minimum standard of human rights, which is of particular importance to people with disabilities recognizes that all human rights are of equal importance and all are equally essential for the dignity and worth of the person.

Beijing Declaration and Platform for Action (1995)

This declaration and platform for action was a result of the Beijing fourth World Conference on Women in 1995 which focused on issues of equality, development and peace. This instrument aims at the empowerment of women through the removal of barriers, and obstacles to women's public participation in public and private spheres and full participation in economic, social, cultural and political decision making.

Regional Instruments

African Charter on Human and Peoples' Rights (1986)

The African Charter on Human and People's Rights came into force in 1986. The charter recognizes civil and political rights including rights such as the right to freedom from discrimination, equality, life and personal integrity, dignity, freedom from cruel, inhuman or degrading treatment, freedom of association and movement, political participation and the right to property.

The African Charter stipulates rights such as equality and non-discrimination, critical to the protection of persons with disabilities. The African Charter has a specific provision addressing disability at article 18(4).

Charter of Fundamental Rights of the European Union (2000)

The Charter of Fundamental Rights of the European Union was proclaimed in 2000, and entered into force in 2009. It upholds political, social and economic rights in European Union law and provides that countries of the European Union must act and legislate consistently with the charter. Courts of member states in accordance with this must strike down legislation which breaches the charter.

European Social Charter (1961)

The European Social charter was adopted in 1961 and amended in 1996. This charter outlines rights and freedoms as they apply to the daily living of individuals as protected by State parties. Rights that are of particular importance to people with disabilities include the right to housing, health, education, employment, social and legal protection, free movement of persons and non discrimination.

Inter-American Convention for the Elimination of All Types of Discrimination Against Persons with Disabilities (1999)

The IACEDPD was adopted in 1999. This Convention aims to prevent and eliminate discrimination against people with disabilities and to promote their full inclusion in society. This includes legislation, educational, social and employment policy.

National Instruments

Americans with Disabilities Act (1990)

The ADA was signed into law in 1990, and was amended in 2009. This civil rights law prohibits discrimination on the ground of disability in the areas of employment, public services, including public transportation, operated either by government or by private entities (e.g. restaurant, hotel, theatre, store, etc.).

Canadian Charter of Rights and Freedoms (1982)

The Charter forms part of Canada's constitution and guarantees certain civil and political rights to all people in Canada, including people with disabilities, restricting the policies and actions of all levels of government. The Charter extends to people with disabilities through its Article 15 equality rights provision which states:

> 15. (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

Charter of Human Rights and Responsibilities Act (2006)

The Victorian Charter of Human Rights and Responsibilities Act serves to protect and promote human rights based on the ICCPR. The charter centers on civil and political rights, as well as protection from forced work, the right to privacy, a fair trial and cultural rights.

Constitution of the Republic of South Africa (1996)

The existing Constitution of South Africa, know also as ("An Act to introduce a new Constitution for the Republic of South Africa and to provide for matters incidental thereto") was adopted in 1996 and came into effect in 1997. This Constitution replaced the Interim Constitution of 1993. This supreme law outlines the rights and duties of citizens and the structure of government of South Africa.

Disability Discrimination Act – Australia (1992)

Australia's Disability Discrimination Act was passed in 1992 in order to standardize disability rights across the country, and to regulate discriminatory practices against people with disabilities. This Act promotes the rights of people with disabilities and prevents discrimination in areas of housing, education and the provision of goods and services.

Disability Discrimination Act – UK (1995)

The Disability Discrimination Act in the UK was enacted in 1995, and has been amended by the Disability Rights Commission Act in 1999, The Special Educational Needs and Disability Act in 2001, the Disability Discrimination Act 1995 (Amendment) Regulations 2003 and the Disability Discrimination Act 2005.

This act protects people with disabilities from discrimination in the areas of education, employment, access to goods, facilities and services, buying and renting property and public transportation.

Declaration of the Rights of Man and of the Citizen (1793) *(Déclaration des droits de l'Homme et du citoyen)*

This Declaration is a fundamental document of the French Revolution, which defines individual and collective rights. Confirming rights as universal and perpetually valid, this declaration established the fundamental rights of all French citizens.

Human Rights Act (2004)

The first Act of its kind in Australia, the Human Rights Act, amended in 2005, identifies the human rights of individuals. This act preceded the Victorian Charter of Human Rights and Responsibilities.

The Mental Capacity Act (2005)

The Mental Capacity Act of the United Kingdom came into force in 2007 providing a legal framework for decision making for those who are deemed to lack the capacity to make decisions themselves. This Act, aimed at protection and maximizing an individual's ability to participate in and make their own decisions highlights the importance of support in decision making, the need for provisions allowing individuals to plan ahead for a time when they may need support. It also deals with decision specific difficulties, upholds the principle of "best interest", provides advocacy and makes it a criminal offence to willfully neglect a person who lacks capacity.

SFS nr: 2003:307 Act prohibiting discrimination – Sweden (2003)

This Act adopted in 2003 serves to counteract discrimination connected with ethnicity, religion, sexual orientation or disability.

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