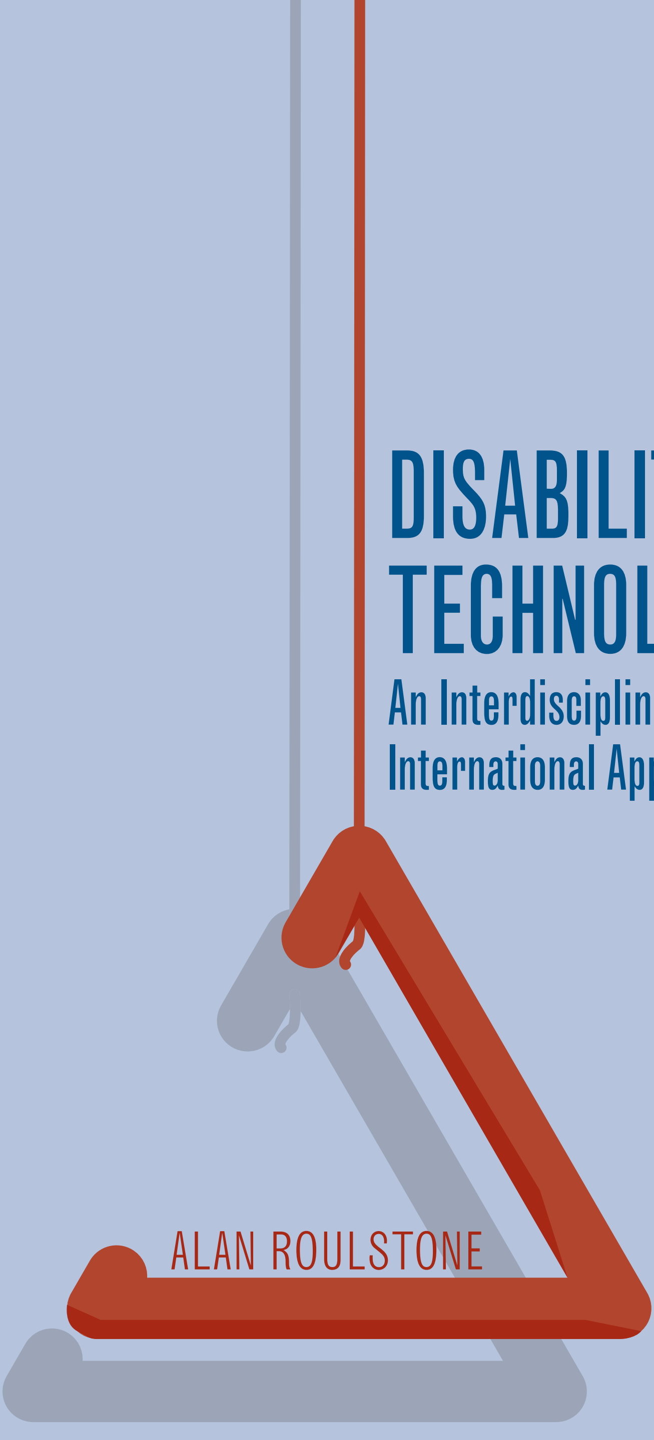
# DISABILITY & TECHNOLOGY

## An Interdisciplinary and International Approach



ALAN ROULSTONE

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## An Interdisciplinary and International Approach

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*Sapientia Sola Libertas Est.*

# Contents

# Abbreviations

| | |
|---|---|
| ADA | Americans with Disabilities Act 1990 |
| ADL | Anti Discrimination Legislation |
| ANT | Actor Network Theory |
| ASL | American Sign Language |
| AT | Assistive Technology |
| CCTV | Closed-Circuit Television |
| CI | Cochlear Implant |
| CRPD | Convention on the Rights of People with Disabilities |
| DDA | Disability Discrimination Act 1995 |
| DDAA | Disability Discrimination Amendment Act 2005 |
| DRC | Disability Rights Commission |
| EA | Equality Act 2010 |
| EC | European Commission |
| EPIOC | Electrically Powered Hybrid Indoor–Outdoor Wheelchairs |
| DH | Department of Health |
| DO-IT | Disabilities, Opportunities, Internetworking and Technology |
| DRC | Disability Rights Commission |
| DTI | Department of Trade and Industry |
| EPW | Electric Powered Wheelchairs |
| FDRA | Federal Deficit Reduction Act 2005 |
| GPS | Global Positioning System |
| GSM | Global System Mobile |
| HTC | Health Technology Cooperative |

| | |
|---|---|
| ICSC | International Conference on Spatial Cognition |
| ICT | Information and Communication Technology |
| IT | Information Technology |
| IVF | In Vitro Fertilisation |
| JRRD | Journal of Rehabilitation Research and Development |
| MCS | Minimally Conscious State |
| NAD | National Association of the Deaf |
| NHS | National Health Service |
| ODPM | Office of the Deputy Prime Minister |
| PVS | Persistent Vegetative State |
| PWD | People with Disabilities |
| RfID | Radio frequency Identification Devices |
| STS | Science and Technology Studies |
| TD | Technological Determinism |
| W3C | World Wide Web Consortium |
| WCAG | Web Content Accessibility Guidance |
| WHO | World Health Organization |
| WSDAN | Whole System Demonstrators Action Network |

# 1

# An Introduction and Overview

The question of technology and disability has provoked an array of academic and clinical work which, although disparate, shares the objective of enhancing social or bodily function. Although diverse models of disability attempt to locate the role technology plays in disabled people's lives, historically concern has been directed towards enhancing the human condition or to be more precise to address the function of technology in relation to facilitating what Nussbaum calls capabilities (Nussbaum 2011). Of course, extreme technocentric constructions can both misread the benefits of technology and also offer misplaced hope as to the potential of technology. This is evident in recent discussions of 'cure' in spinal injury via stem cell therapy, exoskeletal shells and thought-activated prostheses (Breen 2015; Marchal-Crespo and Reinkensmeyer 2009). These approaches, in say clinical rehabilitation or engineering, focus on 'high-tech' interventions, often for those with the most significant impairments. At the opposite extreme are social-determinist views, which assert that technology can play only a small part in helping to produce an enabling society (Oliver 1990; Zola 1989). Both views distract attention from the myriad ways in which technology (low/high, cheap/expensive, tangible/virtual) can aid choices in daily living and independence for disabled people. It is clear

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that technological ‘gold standards’, both of technologies themselves and their wider techno-social support systems, may simply miscomprehend the gains technology affords for many disabled people. However, we do need to be cautious about the claims made of technology, of its ability to improve the lives of disabled people. Industry, professional and early adopter enthusiasm may detract from the limits of a given technology (Hannukainen and Hölttä-Otto 2006). Why else is so much technology not used or under-used?

Ergonomically designed aids to daily living such as well-designed cutlery, door furniture and screw tops may have as much impact on independence and control for some (Renda and Kuys 2013) as sophisticated global positioning systems (GPS) or infra-red tracking systems do in aiding others (Helal et al. 2001). Much social science writing on disability and technology is theoretically intense but is often lacking in empirical support: it is unusual for much of the research to be upfront about the research methods used in the studies they are evaluating. Meanwhile, clinical and rehabilitation studies may provide rich detail of the methods adopted but are often unaware of or fail to mention their epistemological standpoint and whether their research question can be viewed in a different way. Many theories and writings assume that the only requisite focus is on studies of the same type; so that sociological studies tend to cite other such studies, while clinical studies may draw down only those studies in their own image, even if they come to very different conclusions. When I began the book *Enabling Technology* back in the mid-1990s, the key reference points were the UK; looking back, insufficient attention was given to the diversity of models and narratives available in the literature (Roulstone 1998). Many studies are context blind and do not aim to account for international or country-specific factors, such as the mix of market and state, demographic specificities and cultural responses to technology and disability. For example, attitudes to disability in Malta, a small-sized but largely Catholic country with close-knit socio-cultural systems, may be very different from say a large, universalistic and technologically advanced nation like Germany. In these very different contexts, how might attitudes to say exoskeletons, texting and telecare vary?

The only way then to understand and provide a complex model of disability and technology is to seek international evidence, to acknowledge diverse social and cultural contexts, to register disabled people's perceptions and experience (Chaves et al. 2004) and to factor in age, generation, gender, impairment and locality wherever possible. The increasing marketisation of technology, aids and equipment also requires a greater understanding of the interplay between 'need', market-imperative and the just allocation of technologies to provide assistance (Stone 1984). Markets have the potential to foster false needs (Herbert 1964) of course, but also to be more responsive than say centralised state bureaucracies: much of the available literature points to insufficient access and supply in both market and state welfare contexts of say power chairs but for very different reasons. The recent retraction of welfare settlements across the northern hemisphere and the advent of a recommodified state (Morel et al. 2012) require renewed attention in terms of what these produce and how they match social need (Doyal and Gough 1991). Only by comprehending the above mix of variables can technology, enablement and the social gains and disbenefits of technology be fully understood.

One thing that is a leitmotif in this book is the paradoxical nature of technology: its simultaneous ability to open up but also to limit opportunities, access and inclusion. The fragmentary nature of the study of disability and technology to date has arguably not synthesised the fullest implications of this paradox. Somewhere between technological determinism (Ellul 1954a,b) and a full-blown theory of personal agency (Lasén and Casado 2012) to shape technology is the critical realisation that technologies and disabled people intersect in often unpredictable ways. Planned activity-design, implementation, procurement and use may easily produce negative unintended consequences (Hughes et al. 2001), while the benefits of technology in opening up environments, access and inclusion may be the 'result' of unplanned or even remote technological developments, for example with texting for d/Deaf people (Okuyama and Iwai 2011; Power and Power 2004). Serendipity and its obverse have been important factors in shaping the benefits and limits of technology for disabled people (O'Donoghue 2013) which clearly need unpacking further. We need to understand the direct benefits of technology for disabled people, for example those that come with many handheld technologies, as well as the indirect benefits, as a 'means to an end' in helping them achieve social goals. Although engendering frustration in some writers, it is this unpredictability of technology, disability and society, and their intersection, that makes this a rich and nuanced field of study. Technologies do not emerge without human preconceptions of need and functional benefit. In this sense, technologies represent the wider constructions, zeitgeist and social imagination as much as they represent tangible artefacts (Mackenzie 1999; Roulstone 1998; Williams and Edge 1992; Winner 1986). Technologies have the power to enable, yet also disable, to foster greater control and surveillance, and conceivably to embody the very symbol of alienation for disabled people. Technology, although aimed at aiding disabled people, has often been designed and procured by non-disabled people.

The question of the scope and role of technologies, their enabling potential for disabled people's access and inclusion, is now well recognised (Harris 2010a,b; Woods and Watson 2003). Writers and researchers also point to the limits or misuse of such technologies, that they can be disabling and close off options for disabled people. A good example of this tension between enabling and disabling surrounds new complex technological interventions that make possible more precise pre-birth diagnoses of disabled babies (Asch 1999; Saxton 2000) yet also present new moral and ethical dilemmas that did not previously exist. Further, even relatively straightforward technologies, ones often overlooked in technology studies, such as wheelchair design and access, afford new possibilities, but which at the same time also present new avenues for exclusion, especially if those technologies become over-engineered and too costly (Harris 2010a,b). While the design of wheelchairs, for example, becomes more user-centred, their availability, especially of power chairs, is increasingly problematic in the context of austerity, even in the historically better resourced northern hemisphere (Eggers et al. 2009; Staincliffe 2003). Some disabled people are refused access to wheelchairs due to medical conceptions which connect certain impairments with 'wheelchair need' and not others, while the 'need' for technology is often conceived as either total or absent. This is especially true in biomedical systems that often fail to, or are not allowed to, understand the complex relationship between technology and disabled lives. A good example of this is that non-disabled thinking on cars, bikes and public transport technologies would not conceive these needs in a binary need/does not need manner.

Location, distance, subjective conceptions of need and the complex interplay of say 'need' for mobility options may be in tension with the 'need' to take exercise. These nuances are often absent in need and eligibility conceptions that are regularly imposed on disabled people regarding technology systems. Disability is often viewed as a static and unchanging entity, but the evidence suggests that impairment is changeable for many (Boyd 2012; Vick 2013), while environmental challenges and options are massively diverse. This book makes it clear that both clinical studies and social science thinking often homogenises disability. Even post-structural accounts that are inherently authored to trouble categorical theorising may fail to interrogate disability diversity (Haraway 1991a).

The premise in this book is that a complex interplay between technology and disability exists, one which can best be understood by recourse to interdisciplinary and international evidence. Drawing on sociology, philosophy, ethics, rehabilitation engineering, medical, para-medical, computer science and technology studies (e.g. Science and Technology Studies or STS) (Hackett et al. 2008; Hoppe 2005; Sismondo 2011) I aim to comprehend disability and technology in a holistic way and explore the intersection of self, identity, corporeality and technology. It will be argued that some social science studies of disability pay too little attention to the nature of a technology and its proximate character, benefits and risks to end users. A corresponding dismissing of the benefits of a technology can be seen in the absence of the widest examination of evidence. A good example is the bandwagon of criticism of cochlear implants in the absence of any real attempt to look at what such implants might offer or indeed those deriving benefits from them. This is not to diminish the Deaf cultural backlash against implants, but to note that the population of users, the impairments, risks and benefits are often not engaged with. High theory is seen to posit cyborg or prosthetic identities, but the authors at no point define or engage with examples of either cyborg science or prosthetics as real entities as opposed to imagined futures. The corrective I put forward is to argue that both social science and clinical science has to offer greater coordinates, reflexivity and proximity to end users in its research. This distance partly explains why so much has been written about determinist forces at the expense of everyday lives where disability and technology meet. In concrete, a greater proximity of focus might throw out more interesting questions such as does a person connect with technology as an identity before he or she connects with it as a disabled person? In other words when we talk of disability and technology converging, we risk losing the person from our analysis and argue a priori for the meaningful use of the term 'disabled person' as our unit of analysis. Meanwhile technologies viewed in a more proximate vein may well be constructed very differently by two people either as central to their independence and identity or as another irksome gadget that an official has told you is good for you.

Many accounts of disability and technology are culture or jurisdiction-bound, often without this being acknowledged. The culture, the resource environment, the entitlement systems, the degree of development of disabled people's organisations and disabled identity can each shape the understanding of, the relationship to, the access to and the use and disuse of technologies. Following and adapting Lane (2006), 'technology' is taken to mean the array of tools, machines, artefacts and assistive devices that aid human functioning and autonomy: wheelchairs (powered and manual), lifts, hoists, crutches, room/building sensors, remote switching, microchip-based hand-held aids, desk-top technology, GPS tracking systems, implantation devices, biotechnologies and social practices and their intersection. The benefits and barriers of technology are taken to apply to people with a range of impairments, conditions and long-term illnesses that inter alia include sensory impairment, stamina impairment, mobility impairment, mental health issues and learning and social learning difficulties (e.g. Aspergers and Autism).

International evidence points to technologies having the potential to reduce barriers in environmental, interpersonal, virtual and psychosocial spaces (Burgstahler 2003; Eng et al. 1998; Fichten et al. 2000; McNaughton and Bryen 2007; Roulstone 2003). Technologies have the scope to impinge diversely on almost every aspect of our life, from birth, through our identity-forming childhood, early adulthood, working life and when our bodies become old and decline (Marshall 2001). New biomedical and rehabilitation technologies enhance the survival rates and recovery for disabled people who would have died as recently as only 30 years ago (Seelman 2000). Technology has the power to open new social horizons and to recognise new social and political identities, but it also holds the potential to alienate and technologise previously expressive human life (Edwards et al. 2010; Lupton and Seymour 2000; Zola 1989). Technologies, their design (Dym et al. 2004) and use, have both intended and unintended consequences that have indirect but powerful implications for disabled people (Miller and Rose 1990). Seelman's classic review of technology and equity in the USA also highlights the stereotyped availability and social distribution of assistive technologies. The market response to disabled people's technological preferences seems to be sluggish, whether we are talking about everyday low-tech equipment such as ergonomically designed cutlery, or whole system telecare packages (Harris 2010). Unlike adult social care and support more generally, personalised choice has not permeated technology design, commissioning or procurement. This is evident in the fact that mobility aids, although categorically similar to most human tools and aids, are not ordinarily available 'off-the-shelf' from local hardware or motor vehicle outlets, but are somehow culturally separate and 'specialist', despite the growing number of users. There are few direct payment (direct cash transfers to disabled people) approaches, for example, in the technology area in Europe. This is important as disabled people are more likely to be reliant on state benefits and/or a low income, even in higher and middle-income economies, and to find assistive technologies too costly (Harris 2010; World Health Organisation and World Bank 2011). However, more positively, disability has been reframed by key observers so as to problematise the relationship between impairment and the social environment. Technology has a key role in both this redefinition and in rehabilitating formerly exclusive environments (Roulstone 1993; 1998; Seelman 2000; Sheldon 2004). Although debates as to the role of technology continue, it is clear that personalised approaches are now more likely to merge with social barrier constructions of disability than say 30 years ago.

One of the main challenges in a book of this kind is the disparate nature of the field. The writing to date on technology and disability has, arguably, been rather compartmentalised and linked to institutional/professional narratives or social science sub-disciples such as education studies (Seale and Cann 2000), employment studies (Pell et al. 1997; Roulstone 1998), STS (Asdal et al. 2007; Woods and Watson 2004) and more recently technologies of augmentation and enhanced performance in sports studies (Burkett et al. 2011). This valuing and comprehension of technology may inadvertently overlook key issues such as societal and political challenges and disabled people's life courses and transitions. Recent theoretical writings around technology and disability are very varied and range from philosophical and ontological explorations of disability and online identity (Bowker and Tuffin 2002; Saltes 2013a), technology as prosthesis, cyborg identities (Swartz and Watermeyer 2008), the intersection of telecare technology, and independence and identity (Lopez and Domenech 2008a,b). These new writings, however, often sit alongside rather than engage with earlier writings. Much work continues to be premised on a 'care' construction of disablement and impairment and takes little account of new models of disability and the impact of the disabled people's movement and its relationship to technology (Schillmeier and Domenech 2010).

A recent development in the field of assistive technology has been the focus on the 'aesthetics of design'. This work is perhaps best illustrated in Graham Pullin's book *Design Meets Disability* (2009). Pullin asks important and interesting questions about the intersection between disability and design, such as why is it that glasses, an aid which corrects bodily change and function, can be seen as a fashion statement but not hearing aids? Pullin also questions the extent to which our preconceptions concerning assistive technology functions blind us to their aesthetic possibilities (see also Gitlin 1998; Giusti and Marti 2011). This is much more than offering young deaf people the chance to have styled and brightly coloured hearing aids that they can individually tailor to suit their personal requirements, important though that development is. Designers of assistive devices have historically paid very little or no attention to individual aesthetic wishes and requirements (Bichard et al. 2008). This absence of personalisation in technology design is arguably now changing. The 'Blade Runner' images from the Paralympics appear to be altering traditional non-disabled people's views of disability and disabled people, especially in the UK, but it is not yet known whether this will be a lasting effect or will be confined to 2012. What is exciting and interesting currently is that designers are at last recognising that they have a role in facilitating individual aesthetic preferences. Matters of functionality and ergonomics have also perhaps surprisingly been overlooked in some impairment groups (Herrera-Saray et al. 2013).

It is now widely accepted that each disabled person is affected differently and uniquely by his or her impairment and social barriers (Cheyne 2009). This makes designing for disabled people as a group very challenging. In general, the more a device incorporates flexibility and adaptability, the more likely it is to be of use to disabled people (Harris et al. 2006). Designers and engineers in the assistive technology field have attempted to tackle this situation in many ways, but in general the field still suffers from too much 'top-down thinking' of designing a device and then searching for an impairment group that can use it, rather than 'bottom-up design' (ibid.). A related issue here is that sometimes designing for one impairment group can exclude another (Scherer 2006). Full accessibility of all devices and environments is almost impossible to achieve. For example, raised markers in pavements are useful for visually impaired people who use canes, but are a source of annoyance to those who do not and often provide a trip hazard (French 2003). The intricacies of these debates and interactions will be examined, for example how far can accessibility be extended, both in the physical environment and in assistive technological devices, given the diversity of impairment?

The Universal Design movement, fashionable since the late 1990s (Meyer and Rose 2000; Preiser and Ostroff 2001; Story et al. 1998), sought wherever possible to incorporate as many accessibility features as possible into every environment and designed device. The intention behind Universal Design is laudable and aspirational. The idea of a barrier-free environment is arguably the Holy Grail for many disabled people. It is therefore important to examine the many facets of these debates and provide some answers to these truly interdisciplinary issues, for example Seelman's important discussion as to the relationship and tension between universal mass technologies and targeted 'orphan' devices which may be philosophically at odds with mass universality as they are designed with a particular impairment or condition in mind (Seelman 2005). Can the functionality, universality, aesthetics and the increased personalisation of responses to disability and impairment in Universal Design be reconciled? Do they need to be reconciled? The rapid growth, dissemination and power of the World Wide Web makes reflection on accessibility paramount if its potential is to be enjoyed by disabled people. Alongside everyday access to the internet, the scope presented for new forms of solidarity, identity and social protest is clearly huge (Pearson and Trevisan 2015). However, the issue of web accessibility has been a major challenge from the outset, as a former US president makes clear:

> New information and communications technologies can improve the quality of life for people with disabilities (PWD), but only if such technologies are designed from the beginning so that everyone can use them. Given the explosive growth in the use of the World Wide Web for publishing, electronic commerce, lifelong learning and the delivery of government services, it is vital that the Web be accessible to everyone. The Web Accessibility Initiative will develop the tools, technology and guidelines to make it possible to display information in ways that are available to all users. (Clinton 1997: White House Speech)

It is important to state the limitations of this book. Firstly, although consciously crossing international boundaries, the book is largely based on the northern hemisphere. The reasons for this are manifold: technology in the southern hemisphere is scarce and mediated by very different social and economic processes in low and middle-income countries. The inclusion of the few comprehensive studies on the Majority World would feel more like a contribution to a development studies piece with a sub-focus on technology. Specific chapters focusing on say employment would also be mismatched with the global South, where much economic activity is outside of formal contractual relations (Roulstone in Watson et al. 2013). An initial search for articles in English also highlighted a methodological challenge in sourcing materials in that language, while a number of studies funded by NGOs were found to contain a quality of research design that is very variable. Very few people in the global South have access to rehabilitation services (Parnes et al. 2009). Technology often means different things in the Majority World; wheelchair access politics relate to the Minority World; and telecare, robots and electronic devices would be very limited issues in the global South. Thus while it is unfortunate that 'international' is taken to mean the Minority World, a focus on the global South is another book as they say, and others are better placed to claim authority on these matters (Coleridge 2006).

In this book I aim to provide an in-depth exploration of key technologies, especially where academic and clinical attention has perhaps been less intense (wheelchairs, exoskeletons, telecare, desk-top technologies) or where a fuller reflection was felt to be justified (cochlear implants). Areas that are already very well surveyed in the literature, such as disability, technology and education (Blamires 2000; Florian and Hegarty 2004; Konur 2007; Lanyi et al. 2012; Seale and Cann 2000; Seale 2013) and disability and the internet, are mentioned in passing, but again I defer to those scholars and professionals who have devoted their time to these endeavours (Bowker and Tuffin 2002, 2003). I will fight shy of detailed engagement with bioethical issues as again these are well trodden and are domains that have been expertly handled by others (Asch 2001; Kitzinger and Kitzinger 2015a; McLaughlin and Clavering 2011; Scully 2008). However, ethics attaches to many of the issues explored in the book, especially notions of acceptance, rejection and the implications of a rejectionist stance to technology in preservation of social rights.

## The Structure of the Book

What then are the books aims and structure? The book is divided into two parts. Part I, 'Disability and Technology in Context', aims to provide what is essentially a theoretical primer to ensure that the detailed chapters in Part II can be framed and understood. Without this primer, the detailed areas in disability studies and the related academic endeavour would be more difficult to locate. Part II then aims to provide detailed assessments of theories, narratives and evidence on the specific topics of (1) disability and employment, (2) ageing with a disability and telecare, (3) disability and 'health' technology and (4) the question of whether to augment or not to augment in the context of cochlear implants and prosthetics.

### Part I: Disability and Technology in Context

Chapter 2 provides a primer which theorises and contextualises disability and technology studies to date. In aiming to attract a broader audience well beyond disability studies, the chapter makes no assumptions about previous knowledge of disability or technology theory. The first part of the chapter explores disability theories and models in a way that helps place later discussion of disability and technology in context. The chapter will explore, within a broad chronological framework, the development of new ways of thinking about disability that challenge what went before. It will explore the pervasive, powerful, yet often implicit construction of disability as a body deficit within much biomedical and therapeutic research concerned with technology and disability. It is important, however, to respond to the assumption that all this literature is somehow trapped within a deficit model of disability: indeed the last 30 years has witnessed a growing diversity of constructions of disability in biomedical, rehabilitation and occupational therapy research.

I will make it clear that the term 'medical model' of disability is problematical if we are to understand the framing and provision of technology in a biomedical setting. However, it remains reasonable to assert that the epistemological foundations of these works were clearly in the individual deficit understanding of disability, impairment and difference. I will question the use of the term 'model' in much disability research and the status of models as heuristic devices compared to theories of disability. In terms of disability theories and models, the chapter explores the development of a 'first wave' of disability studies in the UK and the USA, beginning in the 1960s, but more meaningfully from the 1980s, and which reframed the 'disability problem' away from a theory of the failed body to a study of social barriers: what some writers dubbed a social model of disability (Barnes 1990; Finkelstein 1980; Hunt 1966; Oliver 1990). This model, largely rooted in an economic analysis, was principally a UK phenomenon, with US writers more wedded to a legally based minority rights approach (Charlton 1998; Hahn 2002). However, both UK and US writers of the first wave blended activism and academic endeavours. The implications of a social or minority rights model for this book are that the focus of the benefits of technology shift from technical fixes of the body to notions that some technology may rehabilitate environments (Roulstone 1993, 1998). Critiques of this interpretation of a social model of disability have pointed to the loss of the body in first wave theory, arguing that a progressive model need not deny impairment (Crow 1996). Post-structuralist writings have entered the theoretical fray, arguing that disability is not ontologically separable into body and barriers in the way first wave disability studies suggest and that impairment needs to be taken seriously as a theoretical focus, otherwise theory risks representing the 'disability problem' (Corker 2002; Davis 1995; Hughes 2005; Shakespeare 2006; Shildrick 2009). Other writers have sailed a course between more structural and post-structural concerns in emphasising the importance of the relationship between disabling barriers and impairment (Thomas 2007). Recent theoretical divisions have revolved around North American disability studies, its focus on ableism and normalcy, which at its extremes may suggest that disability is simply what is labelled as such (Goodley 2010). This would reflect the labelling theory of the 1960s, which reached its logical conclusion in the forging of systems of exclusion. Critiques of Goodley revolve around concerns that such a linguistic turn moves the focus away from the very real barriers in disabled people's day-to-day lives (Vehmas and Watson 2014). In reality each of these theoretical traditions is concerned with social barriers, but the explanations for these barriers often differ fundamentally. These differences have implications for how the interaction of technology and disability are understood: as the end product of exclusive material systems, as extensions of ableist language constructions, or as relational entities where technology, provider systems and impairment must all be comprehended.

The second part of the chapter will then apply the same approach to exploring the broader theorisations of technology by providing an overview of developments in technology studies more generally. Approaches to comprehending technology are varied, but broadly follow the contours of wider models or theories of disability with a shift from more structural to post-structuralist analyses, from macro-determinist or technological systems approaches (Castells 2010; Ellul 1954a,b; Habermas 1970; Postman 1992; Toffler 1970, 1980) to more fluid, localised, porous and problematised constructions of technologies. Here I will explore the variety of theories of technology beyond determinist ideas, working through the social construction of technology (Robins and Webster 1989; Mackenzie 1999; Cowan 1997; Wajcman 1991, 2004) and STS. A key theoretical development in STS has been 'actor network theory' (ANT) which has posited that technology can shape human behaviour as much as human behaviour can shape technology (Bijker and Law 1992; Latour 1987). Whereas the social constructionist approach assumes a complex but knowable social context, through to understanding technology, technological artefacts are not accorded the same attention. Both materials and semiotics (the study of cultural signs and symbols) are important, while technology and social context are both 'active' within actor network theory. The notion of an 'actant' conveys this new way of thinking about the influence of technology (Bengtsson and Ågerfalk 2011). This multi-directional theoretical stance seems to be a key development in technology studies. Haraway's notion of the 'cyborg' (part-human, part-science) product seems to draw down these post-structural themes (Haraway 1991). Rather like the post-structural turn in disability studies, however, the critique that structural factors that underpin the design, marketing, procurement and apparent convergence of the health system may all be important challenges to ANT.

Chapter 3 explores the intersection of thinking on disability *and* technology. The chapter begins with an exploration of early constructions of microchip technology as offering fixes for disabled people's deficits (Church and Glennen 1986; Cornes 1991; Tanenbaum 1986). The biomedical roots of this approach will be examined along with their impact on shaping later debates. The birth of a social model of disability in turn provided the vocabulary for applying a social-barriers interpretation of the role and potential of technology, even if this potential was not fully realised or negated by wider influences (Finkelstein 1980; Gleeson 1999; Hakken 1995; Roulstone 1998). In time, and reflecting the major shifts towards post-foundational theories of disability, writings on technology within disability studies became more pluralistic and contested (Corker and French 1999; Watson and Woods 2004). It is worth mentioning that opposition to an enabling construction of technology sat alongside the development of foundational views of enabling technology, and not all writing invested the promise or potential in such technological developments (Oliver 1991; Zola 1989). The changing construction of social and legal rights to accessible social environments do of course support and also delimit technology's potential for disabled people, even where they are favourable to its use (Borg et al. 2011; Mendelsohn and Fox in Scherer

2002). While acknowledging the potential for enabling technology, some work also places disabling potential, stigma amplification and the reduction of social inclusion in technology in a wider social context (Gibson et al. 2007; Goggin and Newell 2007; Illich and Lang 1973; LaPlante et al. 1997; Moser 2006; Seelman 2000; Soderstrom and Ytterhus 2010; Thornton 1993; Wessels et al. 2003). Others refer to the inadvertent role of technologies in furthering a digital divide (Dobransky and Hargittai 2006; Ellis and Kent 2011; MacDonald and Clayton 2013; Goggin and Newell 2007; Seelman 1993).

More recent post-structuralist ideas underpin the growing literature which challenges blanket assumptions on the widespread benefits of enabling technology while foregrounding a critical construction of technology, meaning and ontology (Pape et al. 2002; Lopez and Domenech 2008a,b; Rizzo et al. 2002; Seymour 2005). Notions of surveillance, identity, risk and resilience (Lopez and Domenech 2008a,b; Niemeijer et al. 2010, 2011) are all being seen to add new dimensions in appraising the complex interplay between disabled individuals and technologies. Ideas from computing, philosophy and sociology posit notions of cyborg identities, a phenomenology of technology and disability, prosthetic selfhood and online identity (Bowker and and Tuffin 2002; Burkett et al. 2011; Coronel 2008; Goggin and Newell 2006; Johnson and Moxon 1998; Saltes 2013; Swartz and Watermeyer 2008). Haraway's (1985) use of the cyborg as a metaphor questions the assumed Cartesian dualism between mind and body, 'representation' and 'reality', and culture and nature (Gordo López and Parker 1999). The complexity of relations between technology and disability is evident in, for example, the development of the ultra-lightweight wheelchair, which although allowing greater speed and manoeuvrability overall may be less suited to certain environments than would previously have been the case. The relationship between specified design trends, for example as fostered by wheelchair sport, may inadvertently pull attention away from the everyday needs of the majority of chair users. In this sense elite disability design may reflect the shift to elite disability sports (Howe 2008, 2011). These insights will provide a better sense of how constructions of disability and technology intersect, as do the more nuanced micro-level insights provided by more recent debates. It will argued that, while of great importance, given the continued exclusion of disabled people from many areas of life, earlier debates around social barriers remain important in the theoretical toolkit with which to examine disability and technology.

## Part II: Understanding Disability, Understanding Technology

These technologies and contexts provide very different social spaces in which social capital, age, health status, dependence and independence are uniquely lived out.

Chapter 4 explores the important arena of the role of technology in aiding disabled people to get closer to, sustain or retain paid work. There are good examples of technology supporting workplace access and job retention internationally (Roulstone 1993, 1998; Roulstone et al. 2003; Scherer 2006; Thornton 1993); and employment might be seen to symbolise greater degrees of control over the use and access to technology (Nijboer et al. 1993). Applications of Universal Design principles may also avert the need for retroactive interventions (Mueller 1998). However, evidence also points to conditionality, disclosure risks and organisational funding conflicts (Roulstone and Williams 2014) which can detract from enabling workplaces. Technology is increasingly seen to play a part in the jeopardies involved in workplace change. Drawing on international evidence, the chapter explores the contributory role of technologies, both within and outside the workplace, that make paid employment possible for some disabled people (Bruyère et al. 2006; Cornes 1991; Galvin 1986; Nochajski et al. 1999; Roulstone 1998; Roulstone et al. 2003; Scherer 202; Scherer et al. 2005). The extent to which technologies assist disabled workers and job seekers (Burgstahler 2003; Kruse et al. 1996; Sauer et al. 2010) will be appraised, alongside considerations of the wider complex of factors, including intersectional variables such as gender dynamics, education, technology design, benefits systems, accessibility of workplace online systems, veterans' lobbies (in the USA) and personal assistant (PA) support (Bruyère et al. 2006; Fifield et al. 1989; Fitzgerald 1998; Gamble et al. 2006; Hedrick et al. 2006; McNaughton et al. 2002; Strobel and McDonough 2003). A key question attaches to those factors that shape technology: the extent to which it is enabling or disabling in pathways to and experiences within paid work. Certainly we know that technologies can, following Stonier, extend the musculature and neurology of human bodies, and may be used as alternatives to physical prowess previously assumed in a more physical workplace environment (Stonier 1983). Mueller provided the blueprint for Universal Design features that can be used in the workplace to avert the need for retrofitted options. Core design features from iWatch speech output and zoom features to mainstream design access features in everyday software have led to the partial mainstreaming of key environmental access features. We know that technological change may happen for a variety of reasons: that new technologies become available and cheaply—as is the case of more powerful personal computers, larger screen technology, portable but expansive data storage, web-based and email communication—such that it has over-ridden the use of paper communications in many contexts (Åborg and Billing 2003). We also know that globalised employment practices expose workers to new uses of technology which benchmark them against other branches of the organisation's operation. Technology makes possible a metrics-based environment, one which is used in even the relatively protected professions of medicine, academia and education (Hazelkorn 2015).

In this sense, do technologies and the systems that shape its use enhance or reduce disabled people's employability in the contemporary workplace (Pell et al. 1997)? As this is an arena in which centralised policy underpins many country approaches to technological support (Butterfield and Ramseur 2004; Langton and Ramseur 2001; McKinley et al. 2004; Mueller 1998), for example the UK Access to Work scheme, the chapter will look at the efficacy and impact (planned and unplanned) of policy on disabled workers. There will then be an exploration of the links between Information Technology (IT)-based employment and disabled employees/jobseekers (Schartz et al. 2002). Has new technology afforded greater permeability between home and work, and is this beneficial for disabled workers (Towers et al. 2006)? The degree of the potential of technologies for making paid work possible, any barriers in current technology use (Schneider 1999; Wehmeyer et al. 2006; Yeager et al. 2006) and assumptions about disability that may reduce the potential of such technologies will all be examined. Technology then might easily be presented as a panacea for reducing barriers to, and presenting opportunities for, getting and staying within paid work. Paid employment, however, remains a domain of hierarchies, exclusion and at times is the apotheosis of the competitive spirit, all of which may shape access to technology and its enabling potential. Indeed one way to gauge an office complex is to judge its technology use and access by grade and seniority of each employee. This is not to deny the importance of technology, especially assistive technology such as screen readers, speaking devices for blind employees and text-based communication for d/Deaf employees.

Chapter 5 examines the benefits, drawbacks and ethical considerations in the use of telecare in later life. In the context of care and support, there is now a very large international evidence base on the benefits and problems with assistive technology. Questions of ageing in place, home-based choices and reduced residential care sit alongside critiques of telecare as new and dehumanising 'options' that further degrade social networks. The evidence suggests that, where freely embraced, well designed and where not substituting wider social supports and entitlements, telecare is a major aid to independence. A good case in point is GPS tracking systems: these could easily be misused to offer unconsented panopticism. However, international evidence suggests that they were consented to offer freedom for people with early stage dementia and their families if route-finding/retracing becomes difficult (Landau et al. 2009; Miskelly 2005; Rasquin et al. 2007). Care and support intersect with technologies in low-tech ways which risk being overlooked in newer narratives. Access to long-established technologies, such as ramps, wheelchairs, hoists and remote access switching, provides important, but increasingly means-tested, technologies in advanced societies (Heywood 2005).

A number of drivers for the increased use of telecare can be identified in internationally demographic and technological changes, pressure on social care systems, the disabled peoples' movement and the independence and personalisation agenda that converge around notions of ageing in place (Wiles 2011). Older disabled people have tended to attract less attention from disabled people's organisations and disability studies (Roulstone 2012, 2013; Zarb and Oliver 1993). However, ageing with an impairment, and the choices agenda in later life, will not likely subside (Webber et al. 2010). The role of new domestic technologies is already central to these debates (Barlow et al. 2005; Curry et al. 2002; Doughty and Williams 2001). Governments internationally are investing in telecare to aid ageing in place and later life independence. For example the UK government introduced the Preventative Technologies Grant (2006–08) which provided £80 million to support local authorities in developing telecare initiatives, in partnership with housing, health and the voluntary and independent sectors (National Audit Office 2002). The ethical implications of telecare, particularly issues around privacy and surveillance, do however need to be considered; and telecare risks being seen as a way of making savings in adult support and reinforcing social isolation (Abascal 1997; Rauhala and Topo 2003; Sorell 2011). Psycho-social barriers such as whether telecare conflicts or preserves a person's self-image (Bayer et al. 2007), and whether there is a 'felt need' for telecare, are both important considerations (McCreadie et al. 2002). The home context is important here. Those whose sense of self is linked to their home may be more willing to use telecare to prevent admission into residential care. The nature of a person's impairment may affect usage, for example cognitive decline, as well as the provision of appropriate training (Cowan and Turner-Smith 1999). Generations more accustomed to technology may find telecare easier to use (Tinker and Lansley 2005). Commissioning and funding issues can also impede uptake, such as if resources are not available or telecare providers and paid care workers are not fully engaged in the telecare agenda (Tinker and Lansley 2005; Dunk and Doughty 2006). Poor design and a lack of regular maintenance is also a recurrent challenge (Wielandt and Strong 2000; Lansley et al. 2005). Some technologies may be feared as symbolising the need for institutional care (Lopez and Domenech 2008a,b). Perhaps more than in any point in the life course, ageing, disability and enabling/disabling technology is bounded by the wider matrix of personal, social attitudes and dynamics and the growing sense that, despite its potential, telecare is seen as integrally linked to austerity and the retraction of public spending on other forms of social support.

Chapter 6 explores perhaps the most iconic of all technologies: the wheelchair. Originally designed as a recuperative device similar to a semi-recumbent stretcher and then the bath chair (Kamenetz 1969), the wheelchair has developed to the very apotheosis of independence, especially in the Disabled People's Movement's construction of independence as having greater choices and rights (Charlton 1999). It is easy to forget that the rapid development of wheelchair redesign and procurement was driven largely by combat injuries (Brubaker 1986; Gutman and Gutman 1968). The integration of wheelchair services into the wider health service and away from military services has been a relatively recent event (DH 1986). The continued irony is that it continues to be treated in statutory and insurance-based systems as a health technology, one that can only be accessed in many countries where an impairment has been accredited by a physician or para-professional. This binary construction then places the object of a wheeled-chair somewhere between a health-rehabilitation technology and an independence technology. It is still unusual for someone to make a unilateral decision as a disabled person to simply go out and acquire a wheelchair. A visit to a clinician, social worker, occupational therapist continues to precede the question of affordable access and suitability of a wheelchair for a given impairment (US Government 2015). This is important, therefore, as wheelchair use is rarely freely chosen as diagnoses and treatment tend to drive technological interventions. Whatever the issues of consent, alternative life options intersect with health-driven imperatives in a way that requires further exploration. The perception of many disabled people increasingly is that a wheelchair is a tool rather like a car in that it offers another mobility alternative. Disabled people may also wish to use such a device intermittently which also cuts across biomedical assumptions that a person either needs a wheelchair or does not need one.

The form and function of medical and rehabilitative technologies have changed dramatically through the course of the twentieth century. They have developed in the case of the power chair into powerful tools enabling ever greater inclusion and function for their users and they have played a significant role in the liberation of disabled people, a role that has, to a large extent, been both underplayed and unexplored in official research (Audit Commission 2000; DH 1986; Gerber 2001, 2003). Objects, such as wheelchairs, are individualised technologies in that the principal concern is not to affect the wider environment, but to improve the function and reach of the individual user and by so doing to aid environmental and social opportunities: 'wheelchairs remain distant from the status of everyday objects—sitting uneasily between the mundane and the exotic: simultaneously recognisable and yet alien' (Parr et al. in Webster 2006: 161).

Thus, the primary focus in wheelchair assessment is of necessity one of eligibility and fit, which makes say a social model analysis of the wheelchair both important and problematical. This can create a tension within disability studies, and to a certain extent is an area that the discipline has failed to either acknowledge or explore. The tension between the evolution of technological design and disability politics is important. The emphasis in the social model of disability on wider (supra-individual) access and barrier reduction, may have inadvertently left micro-level influence over wheelchair research and design the principal domain of non-disabled experts (Bailey et al. 2007; Desmet and Dijkhuis 2003; Di Gironimo et al. 2013; Hüttenrauch et al. 2004; Pineau et al. 2011; Yoder et al. 1996). As Parr et al. note, although these technologies are, to a large extent, controlled by health and medical professions, as is their use and their prescription, the same professionals have had little interest in what are seen as largely low-tech and dull artefacts, ones that symbolise the failure of allopathic cure (Parr et al. in Webster 2006: 163). It is perhaps not surprising that, given the administered nature of this technology (by veterans and health gatekeepers) and the low priority afforded to the wheelchair in state policy, much wheelchair design, pricing and procurement is not especially responsive or enabling. The question of accessing a suitable and affordable wheelchair remains a major challenge even in advanced economies (Audit Commission 2000; LaPlante and US Access Board 2003; LaPlante and Kaye 2010; Neri and Kroll 2003).

The hegemonic meaning that has historically tied technologies for disabled people to injury, loss or illness, and has often re-created their users as passive and dependent, has not only misconstrued the technologies as simply medical devices, but has also had wider consequences that serve disabled users in a myriad of different ways. Both the agencies who provide the technologies and the designers and the companies that manufacture them seem to have little understanding of how they are actually used (Woods and Watson 2003). This has led not only to their poor development but also to their neglect and their failure to be included in the design of wider technologies in many studies, which has in its turn contributed to the structural exclusion of disabled people. This is not universally the case, however, and there are a growing number of user-led studies in wheelchair design. Clarke et al.'s UK development of a Health Technology Cooperative (HTC) successfully established end-user, health professional, industry and academic partners to review a range of methodologies and substantive 'healthcare' technology challenges (including wheelchair design) for the cooperative to respond to (Clarke et al. 2011). Despite islands of co-produced research, wheelchair technologies continue to be constructed across a binary: one with very different constructions of the meaning of the term 'wheelchair'. Wheelchairs as tools of independence challenge the biomedically hegemonic representation of this important technology.

Chapter 7 explores the developments in augmented selfhood and the marriage of human and technological entities. Technology is becoming increasingly ubiquitous in all our lives: microchip technologies are with us daily. Who does not navigate the tasks of working, shopping, social engagement and managing their personal lives without recourse to such technologies? For some disabled people, technology has been seen to take on added meaning, for example in offering alternative modes of communication, new prosthetic identities and the growth of virtual lives which can at times seem to be as important as traditional face-to-face and community interactions. This extension of self, community and identity provides opportunities and new challenges/divisions. The chapter begins with perhaps the most controversial issue in augmentation by looking at the debates around the promise, risks and cultural issues thrown out by cochlear implants. The wider question of technological alternatives to normative communication has received generally much less attention in disability studies (Law et al. 2005) and technology studies. Insights tend to emanate from more specialist impairment-specific work which is often located in a therapeutic 'aids and equipment' or technical-engineering domain. Writers are often occupational, speech and language, or hearing/audiology therapists or those working in visual reablement (Bingham et al. 2007; Lazar et al. 2007). The area of communication options also has to account for the often very varied constructions of say blindness and speech impairment cross-nationally (Vaughan 1998). There is a need to acknowledge this work, some of which is based on holistic, socially located ideas. However, much of the literature is replete with depictions of very obtrusive and potentially stigmatising technology which is arguably driven by technological imperatives and over-engineered. One good example of this is a body-worn infra-red device for wayfinding in complex environments that aims to support blind people in unfamiliar contexts (Velázquez 2010; Wasson et al. 2001). Some field testing has begged the questions as to why the technologies need to be so visible and why they cannot be in a mobile phone or ear piece (Willis and Helal 2005). A search of the journal *Science and Technology Studies* yielded, for example, no references to speech augmentation or speech boards, despite the latter being iconic in the life of Stephen Hawking, perhaps the most famous marriage of technology and disability.

In the case of D/deafness, technologies such as text-based telephony have had a significant unplanned impact in affording alternatives to speech and signing (Bakken 2005; Pilling and Barrett 2008). Such has been the importance of text use, Power and Powert, paraphrasing Groce's classic formulation (Groce 1985), have adopted the term 'everyone here speaks text' (Power and Power 2004). This seems to transcend cultural and geographical boundaries (Okuyama and Iwai 2011). This has led to greater amounts of academic work within a barriers approach, despite many Deaf people distancing themselves from a disabled identity. The question of non-verbal alternatives is very important for many D/deaf people. Computer-mediated options for signing are also providing key alternatives to face-to-face communication (Keating and Mirus 2003).

However, despite this dearth of attention in communication-enhancing technologies, cochlear implants, the devices to aid restoration of sensori-neural related hearing, have attracted a great deal of attention from Deaf studies, audiology, philosophy, and science and technology studies. Cochlear implant technologies have arguably sparked so much debate as what might sound like a purely technical intervention is in fact highly charged as implantation sits at the convergence of technological, cultural, identity and ethical politics (Blume 2009; Cherney 1999; Lane 1992; Swanson 1997). Cochlear implants have made possible the solution to a problem that not everyone wants fixed. While some, especially post-lingually deaf people may embrace the technology, those who see themselves as a cultural or linguistic minority and refuse to see their worlds as tragically silent have reauthored biomedical narratives in a way that depicts a colonial force or, as one author put it, a form of ethnocide (Sparrow 2010). Other writers make plain the limitations of the technology as not guaranteeing normal speech and risking placing d/Deaf implantees in a liminal state between being culturally Deaf and appearing 'normal' (Goggin and Newell 2003; Lichtert and Loncke 2006). As the literature is replete with critiques of the risks involved in cochlear implantation it was felt important to survey the clinical literature to gauge better the validity of the claims and counterclaims being made. Diverse sources of evidence need to be accounted for in this area.

In the cultural studies and philosophy literature, writers are beginning to question whether non-human body parts add to the sense of disabled people as not being quite or fully human, or whether it might itself be challenging the fundamental conception of just what is considered human, say when compared to artefacts. Haraway's famous discussion of cyborgs helps formulate these ideas: 'A cyborg is a cybernetic organism, a hybrid machine and organism, a creature of social reality as well as a creature of fiction' (Haraway, 1991b:149). Haraway believed cyborg selves (she was most occupied with gender studies of post-biological selfhood) can provide a challenge to gendered or in our case ableist normativity. Manderson's work (2011) raises similar issues or what she calls 'surface tensions' in negotiating bodily boundaries post-implant. Dery (1995, p. 231) makes clear that 'cyborg' can mean not simply physical prostheses, but also cyber-cyborgs and notes that 'in cyberculture the body is a permeable membrane, its integrity violated and its sanctity challenged by titanium alloy knee joints, myoelectric arms, synthetic bones and blood vessels, breast and penile prostheses, cochlear implants and artificial hips' (see also Clausen's notion of man, machine and 'in between', 2009). Howe, as with many writers in this area, has questioned the assumption that prosthetic and cyborg technologies are a good thing in paralympic sport, noting that 'technocentric ideology within the Paralympic Movement has led to the cyborgification of some Paralympic bodies' (Howe 2011). This raises complex issues around disability, impairment and identity. Heated debates about the tensions between cochlear implant use and Deaf rights also share this diametrically opposed view of the benefits of prostheses. Clearly technologies are far from socially neutral (Brusky 1995; Preisler et al. 2005; Sparrow 2005). Beadle et al. (2005) make clear the employment and wider social inclusion benefits of cochlear implants from their longitudinal studies. However, strong rights-based arguments call for an acknowledgement of the citizenship rights of those who identify as politically Deaf. Guillemin et al. (2005) talk of a 'critical engagement and pragmatic reconciliation with these technologies' that takes us beyond any simplistic binary, as they see it.

The chapter then looks at the slightly less contentious issue of prosthetics. Although the sports-related controversy of the South African athlete Oscar Pistorius has sparked debate within sports and disability studies in seeming to have troubled normative notions of mainstream versus para-sports, there has actually been very little attention to prosthetics given their importance in rehabilitation and independence for a large section of often younger disabled people (Camporesi 2008; Chappell 2008; Jones and Wilson 2009; Swartz and Watermeyer 2008). The absence of social science attention to prosthetics is important, given that Haraway refers to the mediating role of technology as prosthesis, which is clearly derived from actual body prostheses even though, once fitted, the line between it and humanness is immediately blurred. Critiques of Haraway and other cyborg-manifesto adherents take many forms. My own personal critique is that it might have been useful to talk to people who had undergone major prosthetic surgery to talk through just what cyborg identity might mean in reality.

The chapter also explores the history of prosthetics (Norton 2007), and one can see similarities with the history and development of the wheelchair and how technical developments afforded social opportunities and vice versa in line with ANT. Ott's influential *Artificial Parts, Practical Lives* (2002) provides a rare social science analyses which is clear that antisepsis, anaesthetics and later plastic surgery were central to the successful development of prosthetics as substantial remedial work was required at the point of amputation before a prosthesis could even be considered suitable. As with the history of the wheelchair and military rehabilitation, the role of prosthetics as a sub-discipline of medicine was to return function as a means to the end of restoring the injured person to gainful economic contribution (Anderson 2003; Gutman and Gutman

1968). Beyond war injured populations, later users of prostheses have more diverse antecedents to prosthesis use, for example from accidents, illness and congenital malformation. As Smith and Morra (2006) point out, many of these recipients were keen to have a suitable prosthesis, which points up a clear difference with say cochlear implantation, there being no equivalent of Deaf culture in limb prostheses. Of note, it has become fashionable to wear shorts in the UK and display one's prosthetic leg, reflecting the complexity of stigma as the militarily injured may be valorised in some contexts. Debates around full body prostheses are more contested, albeit the recent nature of these debates makes the identification of evidence difficult at this stage. This leaves most of the literature a site for engineers and robotics experts, certainly the technical and cost limits of these devices will limit their effectiveness in say the lives of people with spinal injuries. Breen's recent work makes clear, however, future ethical dilemmas which may emerge where exoskeletons or electrical stimulation devices become cheaper and spinal injured people may fear loss of social and legal protection if they do not avail themselves of a 'cure' (Breen 2015).

In the Final Reflection an attempt is made to extrapolate from current trends to look at the future role and potential of newly developed technology, policy and procurement. Are developments likely to lead to more enabling societies, and how might generational factors open up new horizons for the 'young old' in say 2025 who will have grown up with computer hard/software as an integral part of their lives? Which factors may lead to greater barriers to the enabling use of technology? Might new developments inadvertently exclude disabled people into the twenty-first century?

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# Part I

## Disability and Technology in Context

# 2

# Between Bodies, Artefacts and Theories: Theorising Disability, Theorising Technology

In order to help navigate the more in-depth context and interconnections of the book's wider insights on disability and technology, it is important to provide a good working knowledge of the theories of disability and the theories of technology. Given the interdisciplinary ambitions of this book, no assumptions are made as to readers' familiarity with disability studies and technology studies. Indeed, a section of the potential readership may be rooted in medicine, paramedical studies, occupational therapy and psycho-therapeutic domains and be schooled in very distinct literatures. This requires an overview of the key debates, therefore, one which assumes little prior knowledge. In that sense, the following does not aim to be a definitive version of disability models and theories, nor indeed of social theories of technology. These are available elsewhere and with more depth and acuity (Albrecht et al. 2001; Barnes et al. 1999; Ellul and Merton 1964; Goodley 2010; Heidegger 1977; Thomas 2007; Verbeek 2011; Wajcman 2010; Watson et al. 2013). However, the key debates and implications for understanding the intersections of disability and technology are required. There are, however, some new insights here even for readers rather more familiar with these debates, given the lens through which we will view technology, which will be much

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wider than simply microchip technology (Lane 2006) and will be in an interdisciplinary context (Repko 2008).

One of the challenges of beginning to locate models of disability from certain biomedical writers and researchers is that their epistemological premises are often assumed and implicit. While methodology and method may be very clearly explicated, the nature of the 'disability problem' may not be. Indeed there are no books, in even the most comprehensive libraries, entitled 'In Praise of a Medical Model of Disability' or 'Technology and Disability: Towards a Deficit Approach'. This is explicable in at least two key ways. Firstly it is axiomatic that embedded power has not to justify itself. Thus although there are no books praising patriarchy and very few overtly lionising racism, these phenomena are very real, socially divisive and at times harmful (Walby 1990; Ware 2015). A more benign interpretation is that say a rehabilitation technologist, an occupational therapist and an orthotics practitioner are of necessity concerned with body deficits or at least differences. Why else would their services be called upon to intervene in disabled people's lives? This latter point has to be taken seriously and not be viewed as a mere footnote in theorising disability. Many professionals that connect with disabled people in their work do so not in conditions of what might be called practice utopias, but to promote the most efficient use of scarce resources and often with a specific intervention (Lusardi et al. 2012; Palmer and Director 2007; Sundström and Tortosa 1999). Critiques of professionals by some first wave disability writers arguably homogenise and reify much practice (Ulich et al. 1977). While individual professionals may construct disability in a given way, cultures of practice, training protocols and 'evidence-based' governance bodies often closely frame professional activity. This is not of course to argue that street-level bureaucracy does not take place, it clearly does; however, the latter may be more or less enabling for disabled people (Wray 2015). The limitation of economic resources, whether via state funding cuts or marketised principles, has been seen to shape professional practice for some decades and is unlikely to diminish in an era of welfare retraction and competitive health and disability markets (Eisenberg 1985; Mechanic 1985; Roulstone 2015; Sapey and Hewitt in Oliver 1991). These issues and dynamics often get ignored in debates about disabling professions.

The question of the aims, constructions and impact of professionals in the lives of disabled people is then a complex and indeed thorny issue. Evidence suggests the reality is somewhere between these theoretical coordinates of disabling and enabling professions (Finkelstein 1980). Firstly, disabled people do at times need biomedical professions, a point acknowledged but rather played down in social models of disability. Secondly, the narrowly defined intervention of professionals has sometimes generalised into a powerful and broader defining role of what disability is and how eligible disabled people are for a given social good. This is no more evident than the fact that in many 'advanced' countries, medical professionals define who is eligible for wheelchair services, which, given the knowledge held by many disabled people on their needs, is arguably clear evidence of medicalisation and an absence of user voice (Chamberlain 2012). Similarly, it could be argued that the very language used to conceive disabled people, service users, patients and so on points to an incommensurability of life worlds depending on one's standpoint (McLaughlin 2009). Perhaps more common however are implicit, hybrid or 'atheoretical' assumptions about disability in many biomedical and technological journals. Implicit theory is evident in those articles on disability, rehabilitation, assistive and prosthetic support where they seem to exhibit scientific objectivity, but on closer inspection make a good deal of assumptions about just what disability is and thus how it should be dealt with. The absence of disabled end user voice in some research also speaks volumes about research expertise and who knows best. This is true of Donaldson et al.'s (2015) study of the use of limb-lengthening in achondroplasia, a form of dwarfism. The study's construction of moral and psycho-social dilemmas in the research relates to the production of other impairments in the lengthening process. A very different interpretation might be placed on the study as one positioning normalisation ahead of both the physical risk of the procedure and the social risk of being viewed as outside the parameters of both normal bodies and dwarfism.

Odman and Öberg's (2005) study of different 'intensive training' regimes to reduce the effects of cerebral palsy is also typical of biomedical assumptions in presenting technical data but without a reflection on the normalising thrust that critiques see as sitting behind such schemes

(Oliver 1989). This sort of critique often highlights the need for attitudes to change towards disabled people rather than making them equate to non-disabled social norms. The critique of biomedical research of this kind is that such choices are often assumed to be based on false need (Marcuse 1964) or professional pressure to choose normalised solutions. While there is much evidence for this, there is also growing evidence to the contrary where clinicians have placed the views of disabled people and parents (where a disabled child is concerned) at the forefront of decision-making. Read, a disability and childhood writer, also notes that these options might be freely chosen and be more beneficial in social terms than some writers acknowledge (Read 1992). Clearly it would be misplaced to continue to talk of biomedical research as epistemologically clichéd. Indeed heroic medicine has always arguably sat alongside a spectrum of evolving practice since the late twentieth century at least. To provide specific examples, there have been a number of important user-led or user-aware research projects within what might be described as clinical or biotechnological research, which is reflexive and sees biomedicine in its wider social context. This is the case in Moody's recent study of enhancing the stability of wheelchair users from the outset of the design (Moody et al. 2015). Audiology and otolaryngology research over the last 20 years has grown increasingly cognisant of the politics of Deafness as a linguistic and cultural identity and not simply as a clinical intervention (Christiansen and Leigh 2004; Tyler 1993). It would still be correct, however, following Marcuse, to state that in many contexts a technological means-analysis of how technologies can aid, cure and augment disabled people is more pervasive than an ends-analysis, which concerns why an intervention or provision is taking place. The sheer speed and ubiquity of technology arguably accelerates this process, and one might say the very advancement of technology forms its own narrative that technology justifies its own use and appetites for its use (Marcuse 1964). Certainly, while challenging the tendency of disability studies to conceive of professionals as the villain of the piece, it would be inaccurate to suggest that an evolutionary shift in biomedicine towards a better widespread comprehension of disablism and the wider social consequences of technological intervention and provision is taking place.

## Is There a Medical 'Model' of Disability?

While there are many negative constructions and examples of equating disability and difference with socially stigmatised symbols, this may not in itself justify the use of a term such as 'a medical model'. 'Model' suggests the result of an active and concerted process of idea building. While models are not theories or paradigms in the Kuhnian (Kuhn 1962) sense they clearly assume a system, clarity and meaning system, which may well be absent. Certainly even a detailed archival study of medical language to describe and situate disability would likely fall somewhere short of a model or, as Weber phrased it, 'ideal' types or 'conceptual utopias' (Weber 2009). McBurney (2012) states that models are attempts to build constructs that aid more generalised systems of comprehending and coordinating phenomena, and that they are tested by references to and from the phenomena they claim to model. This is helpful, and the extent to which a 'medical model' has existed is debatable. Finkelstein makes clear that, although medicine has had a key defining role historically in shaping understandings and responses to disability, the notion of an 'administrative model' better captures the broader construction and array of professionals impinging upon disabled people's lives:

> In this respect experts are often encouraged to see the lives of disabled people in terms of problems to be solved and their role as providing solutions. Nationally, then, the existence of large and expensive social and welfare services provides ample evidence that a characteristic of all disabled groups is that they face a series of problems which they cannot solve on their own and which the state has had to administer through the provision of specialised services. (Finkelstein, in Swain et al. 1993)

However, there is much historical and some contemporary evidence from studies of medical and wider professional interactions with disabled people which display assumptions that disabled people are defined by their condition, that their deficits translate to helplessness and assumed dependency. Finkelstein is perhaps the best starting point here once again. As a clinical psychologist turned academic, and as a person with a spinal injury, he was able to see both sides of the professional fence.

He was not, as some suggest, anti-professional, and much of his work was an attempt to foster enabling professions; however, he did get to the nub of the problem about the deficit approach to disability when he captured the growth and development of professions who ministered to disabled people:

> Traditionally, disabled people have been viewed as passive, unable to cope with normal social relations and dependent upon others. The professions came into being with this assumption as the key to the relationship that developed over the centuries between the active able-bodied helper and passive disabled object of attention. The refinement of professional education and training programmes over the years has not only entailed acquisition of specialised skills in 'treatment' but formalised ways of behaving towards patients and clients. (Finkelstein 1991: 1)

For Finkelstein the recognition of need and the response to that need came with negative consequences. The formalisation of support carried with it a set of assumptions that, since informal or self-responses to the 'disability problem' had failed, required the intervention of professionals, which in turn signalled the helplessness of the disabled person. This of course conflates need with the consequences of social change beyond an individual's control. It also 'imagines' an independent citizen, arguably the creation of a certain species of Enlightenment philosophy. However, the evidence suggests that complex social interdependencies are central to all our lives (Morris 1995; Reindal 2010). For some writers the very phrase 'dis-abled' was born out of the professionalisation of support and formalised services (Foucault 1980). To qualify, one had to enter a social category which essentially took one into the gaze of biomedicine. In essence a price had to be paid for receiving support, whether in terms of the professional gaze or wider stigma. Cabrera, writing in the era of nanotechnology, maintains that such associations are still powerfully operative:

> Unfortunately, the term disabled is predominantly used to describe a person who is perceived as having an impairment, intrinsic defect, chronic illness, or disease leading to subnormal functioning and expectation. (Cabrera 2009: 1)

Although now very rare in published academic form, even as recently as the 1980s some clinical writers were equating disability categorically as a tragedy. Peggy Jay writing in the seminal book *Handicap in the Social World* (in Brechin et al. 1981) equated disability to other tragedies and loss such as death, divorce and unemployment. A slightly less cataclysmic construction has been to see disability as an individual loss, but not necessarily as a tragedy, as Borsay notes:

> When disability is interpreted as a 'personal trouble', sharp distinctions are drawn between different types of impairment and their causes are sought exclusively within the individual: thus, mental and physical handicaps are construed as mere biological deficiencies; mental illness is explained with reference to personal genetics, biochemistry or psychology; and ageing is viewed as an unavoidable physiological process. (Borsay 1986: 180)

Taken together, notions of deficit, individual failure, lack and at worst personal tragedy have been seen to underpin assumptions about the nature of disability and the disability problem. However, professionals will have been influenced by issues of causation and the history of a given impairment in coming to a view on it. Not only have professions not been immune to these views but arguably have until recently based their unspoken professional narratives on these. These are nowhere more powerfully expressed than in the work of Sally French, a visually impaired physiotherapist turned academic whose studies of disabled professionals makes plain the awkwardness many health professionals admit to when working with disabled colleagues, stating that their training and cultures prepared them for working on not working with impairment (French 1994).

Whether or not the term 'medical model of disability' is viewed as helpful depends upon the detail of one's historical readings. The interdisciplinary focus of this book makes the adoption of a medical model problematical where specific professional dynamics need to be better understood and where nuance is foregrounded. For example, occupational therapists and orthotists do not share the power, professional resource or histories of say medical clinicians (Freidson 1988; Yerxa 1992). Of course, the application of medical, paramedical and user-led constructions of disability also often intersect in interdisciplinary clinical, research and design activity. Thus the monolithic image of a distant and dominant professional with clearly defined role boundaries and views of disability is not that helpful in viewing technology and disability. As the above suggests it was disabled former clinicians who in part brokered new ways of researching, writing about and influencing professional practice, often against the grain of professional opinion. Another difficulty in pinning down analyses of medical models is the tendency of their architects to reject their status as theories of disability while using the terms 'models' and 'theories' interchangeably (Oliver 1996, 1998). Both models and theories are conceptual utopias and broad coordinates which, although in search of generalisations, invariably limit their claims to being able to comprehend all given phenomena within a single conceptual framework. The distinction between a model and a theory applies more fully in mathematical or philosophical domains as models are smaller, carefully delineated examples of comprehending highly specific phenomena (Cundy and Rollet 1961). This cannot be said of say a medical or social model of disability given the breadth and depth of the phenomena in question and the use to which they are being put. Thus and rather provocatively, the distinction is not embraced in this book. It is also important to locate professional assumptions and practices in a specific time period given the historical specificity of certain of the views explored above. This is not to argue that everything in the garden is beautiful, far from it; however, as Shakespeare makes clear, professional practice is improving, the voices of disabled people are increasingly being heard, while we need to collaborate rather than bunker down regarding sharing our understandings of disability (Shakespeare 2007, 2013). What then of the development of alternatives to deficit constructions of disability?

## Social Approaches to Disability

Not surprisingly changing social sentiment about disability, the very damaging legacy of institutions and growing civil rights agendas across the 'developed' world, led to reappraisals of the disability problem. These responses have varied by context. For example, in the USA market principles have fostered a legal and minority rights approach based on disabled people's claims to equality before the law. This movement and reframing of disability emanated from the broader civil rights struggles of the 1960s and was initially focused around campus access and protest (Charlton 1998; Hahn 2002). In Scandinavia, where arguably the first disabled people's movement was established, a relational model of disability has prevailed which has responded to the fallacy of disability as a purely body-centric idea with weight being given to both the disabled individual *and* society in influencing social opportunity (Reindal 2008; Thomas 2004). Academic researchers have seemingly played a greater role in this redefinition of disability in the UK or USA, while strong special education and social work cultures have ensured a continued status for professions working in these fields. However, it should be noted that such professional histories have not diminished or been absent from the forcefulness of societal critique of institutionalisation, sterilisation and eugenics, that professions remain intact and a pervasive relational model reflects the cultural and welfare histories of these countries and the more consensual approach to investment welfare states where professionals are afforded a key role (Roulstone 2013a; Simonsen 2005).

Globally, the spread of a rights agenda for disabled people has been largely via legal channels. Anti-discrimination legislation (ADL) and convention rights, most notably the Convention on the Rights of People with Disabilities (CRPD), have been the key tools with which disabled people's exclusions have been addressed (Harpur 2012; Kanter 2003). Here the banning of unfair, inhumane treatment and the right to a normal family life are the tangible legal supports to counter gross exclusion. Often, however, these instruments reflect formal legal rights which are difficult to substantiate in practice and are only as effective as their host country's policy response to disability and their legal systems accessibility (Lord and Stein 2008). Such measures, although important, do not have a great deal to say about technological interventions and the processes which surround them: where problems relate to attitude constructions, imposed interventions and professional dominance, but fall well short of thresholds for say inhumane treatment and the denial of a family life. A good example of this is the CRPD which does not mandate a right to inclusive education nor does it halt the growth in segregated schooling. Such legal approaches are concerned jurisprudentially with individual events and acts rather than the evaluation of disablist systems (Mladenov 2013).

In the UK, the disillusionment felt around previous 'expert' constructions of disability led to what might be viewed as the most direct and active counter-efforts against professional dominance and wider assumptions of disability as loss or deficit. A small but influential group of disabled people made efforts from the mid-1960s to redefine the 'disability problem'. This was an activist movement prompted by survivors of long-stay institutions, such as the experiences detailed in the work of Paul Hunt (1966). Alongside system survivors were clinician-academics, most notably Vic Finkelstein, and cultural activists, including Elspeth Morrison (Morrison and Finkelstein 1993) and Sian Vasey (Vasey 1989), who identify the arts and disability culture as a means to develop a bottom-up vision of defining disability. This change involved not simply direct action but also what Freire called a 'reconscientization' of the way we think about and respond to an issue (Freire 1970). Disability was both redefined and contested in day-to-day terms. Each element was interdependent in this sense. In language terms, Oliver, drawing on the Disabled People's International's earlier formulation, was instrumental in translating activist ideas into an academic context (DPI 1982; Oliver 1990). In terms of reconstructing relations with professionals, Finkelstein's early writings and activism required professionals to be allied to the 'community' as opposed to their own 'profession' (Finkelstein 1999). It was felt that professionals needed their clients as much as clients needed their professional and that disabled people often came second in these formulations (McKnight 1977). Disabled people thus had to be at the centre of the support relationship and be afforded a greater voice in how their problems were constructed and responded to. Of note, this approach, a sort of rapprochement, rather than a fundamental rejection of professionals, was not shared by all critics, some viewing professionals as inherently rooted in an oppressive cultural location and as a form of parasitism (Davis 1993; Hunt 1966). How though was disability reframed within a social model of disability? Thomas suggests that 'the social model asserts that disability is not caused by impairment but results from the social restrictions imposed upon people with impairments' (Thomas 2007: 57).

This reframing, most notably following the publication of the Union of Physically Impaired Against Segregation's landmark report (UPIAS 1976) of the disability problem away from the body to the social environment, was important, and Oliver's academic work points out that disabled people face major external barriers, 'ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements' (Oliver 1996: 31).

The social model of disability, although increasingly critiqued since the mid-1990s, remains a major paradigm shift in which disability is not simply reframed, but is reconstructed in a way that begs questions of the systems that appear to respond to, but in reality might limit, the lives of disabled people. Transport, workplace design, technology procurement, attitudes and social policies have all been challenged to respond to the new way of thinking about the disability problem. Given the stridency of the social model of disability, it is perhaps not surprising that it has spawned criticism even from those with some indebtedness to the model. The shift towards post-structuralism in the social sciences in the 1990s led to the observation that medicine, first wave medical sociology and the social model had much in common epistemologically, as all assumed an essentialised view of the disabled body. Critics note that in each analysis the body simply existed unproblematically and that there was little room for agency, messiness and self-reconstructions (Shakespeare and Watson 2001). The very malleable nature of disability meant that two people with the same impairment might have very different self-perceptions, even to the point of one person not seeing themselves as disabled (Watson 2002). The making of disability into a political entity within the social model arguably added to the complexity of self-constructions: some people might say 'I am disabled but not oppressed'. Also the very boundaries of disability have been and remain very blurry: whereas spinal injury might be unambiguously described as a disability, multiple sclerosis and arthritis might more nearly be seen to be illness; cancer might straightforwardly be dubbed an illness by most first wave disability writers (Bury 1996). This is important for the wider analyses in this book as such distinctions do not ordinarily attach to illness versus disability in technology research and writing (Lupton and Seymour 2000; Roulstone 1998) and make it perhaps a less defined but more inclusive space in other ways.

Other criticisms of the social model of disability point to its downplaying of impairment effects as a number of disabled writers noted the reality and biographical significance of pain, fatigue and uncertainty (Crow 1996). Marks' work (1999) notes how even when equating to clear-cut disablement such as organic brain injury, we need to be clear that impairment effects are for many very real and that by playing down difference in a social model of disability, the specific needs and interactions with wider society might be overlooked. In a similar but more theoretical vein, Hughes notes the inherent problem of falsely separating impairment from disablement:

> The social model focuses on 'the various barriers, economic, political and social, constructed on top of impairment' (Barnes et al. 2002). The metaphor 'on top of' is of vital significance because it is designed to delimit the field or domain of disability studies to exclude, for the most part, those matters of biology that lie 'below' and had been prioritised as the categorical and ontological core of disability prior to emergence of the social model. (Hughes 2007)

Another important response to first wave social model ideas is the notion of psycho-emotional disablism. This argues that disablism rather than being the result of solely external barriers can be the product of social interaction and oppression which leaves disabled people limited in terms of psycho-social confidence and therefore of social horizons (Reeve 2002). This is an idea closely linked to internalised oppression, but it makes clear that such psycho-social barriers are of more than subsidiary importance to external barriers as implied in the latter term. Goodley takes a more sympathetic view of the need to comprehend disability and impairment as discrete and interacting entities. He posits the need additionally for a social model of impairment:

> Thus, rather than viewing a turn to impairment as de-politicising, re-medicalising and 'watering down' the social model, more and more writers

> are arguing that a focus on impairment, alongside an alliance with the social model and disability movement, re-socialises impairment. (Goodley 2001: 208)

By this point some writers of disability and related studies were critiquing the once assumed solidity of 'disability' and were even questioning whether anyone was disabled or just the product of systems of othering, labels and normalcy (Dudley-Marling 2004; Goodley 2001). These perspectives, dubbed 'Critical Disability Studies', were largely derived from North America and were concerned with cultural and linguistic analyses that, in essence, claimed disability is not an embodied entity but what language deems it to be. These ideas quickly spread, with one important strand of disability theory suggesting that, rather than talk of disablism, the term 'ableism' was more appropriate. Criticised by opponents as theories of everything (see Kumari-Campbell for the best overview, 2014), ableism aims to go beyond a focus on material barriers to look at the way in which binaries of normality (often termed 'normalcy' as these debates are largely North American in origin) and difference sit in the very language we use and in the social language of our interactions (Linton 1998). This development, one reflecting the linguistic turn in the social sciences, mirrors feminist discussions of the way power relations are embedded in everyday language and social relations. Wolbring provides an overview of ableism:

> Ableism is a set of beliefs, processes and practices that produce, based on abilities one exhibits or values, a particular understanding of oneself, one's body and one's relationship to others of humanity, other species and the environment, and includes how one is judged by others. (Wolbring 2008: 252)

This linguistic and constructivist turn, arguably a more extreme interpretation of the labelling theories of the 1960s, has not gone without criticism. Watson and Vehmas have mounted a sharp counter-attack in arguing that to state disability is whatever we say it is ignores, and dangerously so, the very real troubles disabled people face in their daily lives (Vehmas and Watson 2014). This point is a very valid one; however, Watson and Vehmas are elsewhere criticised for their wholesale rejection of a social model and could be accused of wanting their theoretical cake and eating it in their critiquing of Goodley and others for their apparent drift from material realities. However, in their defence they are offering a clear alternative in the form of what they see as a critical realist alternative to structural and ultra-relativist stances (Archer et al. 2013). In reality the above debates and skirmishes, while premised on key differences, hide the similarities of the concerns of social model, critical disability studies and critical realists as all are in reality concerned with the barriers faced by disabled people. Perhaps the best measure of such theories and models is not simply their ability to grasp the complex realities of disabled people's lives but also what they are doing to effect change.

## Summing Up Social Approaches to Disability

It would be rather tempting in social theory terms to take the latest critique and iteration of theory to be the one best way of framing the benefits of technologies for disabled people. This would not be helpful even with a theory as all-embracing as say that of ableism or critical realism. Whether as theories or models, each has value in framing our understanding of the role and interaction between technology and disability-impairment. One thing that becomes clear if we take even a cursory glimpse at the available research, is that the body and society have to be accounted for in such an analysis. This was made clear in my earlier work on the enabling and disabling potential of technology for disabled people (Roulstone 1998) when I stated that we could not understand the interaction of impairment, disablism and technology without accounting for all three. The social model of disability does risk playing down both difference and bodily limitations; however, its epistemological shifting of analyses towards external barriers has arguably done more to aid our study of technology than any other single social approach. Even so the social model does shift the focus away from the individual and his or her interaction with technology. In reality structural, institutional, individual and technological issues all need to be accounted for, including the role and value of technology in reducing impairment effects and refining bodies and environments. To fail to account for these facets would produce a very partial picture of technology and disability.

A modified model would bring the body back in terms of impairment effects and needs. However, it can be argued that unless one sees the social model as largely about the external environment (Barnes 1991) then it seems reasonable to speak of social *models* which can modify the first wave of thinking about disability in a less reductionist way (Thomas 2007). On the question of being fair-minded towards social practices, it is also conceivable that technology research in a clinical context might be entirely focused on a specific body–brain intervention which may superficially sound as though it is epistemologically a medical model in its assumptions. This seems misplaced if the work is narrowly therapeutic and does not involve or impinge on wider social decisions, constructions and barriers. For example, many procedures that are technological in nature may be simply correcting a malfunction which is 'silent' and in no way affects an individual functioning and is unlikely to affect the perceptions of others. Much general surgery such as the fitting of 'stents and shunts' would fit with this narrow clinical activity and thus sits outside of the analysis that follows. Surgery which is aimed at correcting mobility, appearance, grip, dexterity, consciousness and mental comprehension, and involving technological intervention, would however fit fairly well into the focus of this book.

What the above suggests is that alongside an inclusion of body, technology and environment the following are also of importance:

1. A grasp of the policy, social, community, professional and cultural context (including the presence of disabled peoples and disability organisations in a locality) in which technology is designed, procured, accessed, used and reviewed. An acceptance that there is a politics of technology and that technology, due to its sophistication, may detract attention away from wider social dynamics and that technology be seen to embody its own dynamic force.
2. That the psycho-social as well as external social impact on the body are both important.
3. That practice in design, fitting and matching technology is on a spectrum from user-led, through user-aware, to designer or professionally/administratively led.
4. That even where impairment is significant, default assumptions that technology is fixing the problem of deficits in an individual may be

misplaced, depending on the circumstances. Analysis has also to discern where impairment effects are not being fully accounted for in technology interventions.

To return to the core message from the above, however diverse, the professional relationships to disability and technology have to be comprehended, as the following suggests:

> Services of the future, then, must ensure that users and their organisations play a central and decisive role in any assessment and goal-setting process. The role of the service provider should be just that—to provide services and allocate resources which would enable the attainment of lifestyle goals which the user has identified as most appropriate to his/her personal circumstances. (Hales 1996: 173)

## Theorising Technology

What then of the nature of technology and its relationship to the social world? As stated earlier, the following is not an attempt to provide a comprehensive picture of technology theories—these are available elsewhere (Hackett et al. 2008)—but to frame the focus of the book in a way that provides the reader with a connection between specific examples of the role and function of technology with the wider debates. The following will explore what might be viewed as the key theories or perspectives on technology:

- Technological Determinism;
- Economic and Social Determinism;
- Social Shaping of Technology Theories;
- Social Constructivist Theories;
- Actor Network Theory.

As with the study of disability, technology studies have followed a similar path from modernist to post-modernist theories, a shift from grand meta-narratives to more localised, fluid and reflexive accounts. These summations of theory are never straightforward and many theories are part analysis and part normative attempts to create new paradigms. For example, one could posit, as Boyne and Rattansi suggest, that post-modernism's announcement of the death of meta-narratives is itself a meta-narrative (Boyne and Rattansi 1990). That said, the shift has been evident, although like all shifts it has carried with it a plurality of perspectives and no clear linear shift to post-structural views is present. The earliest theories of technology, those enshrined in technological determinist views, draw on 'march of progress' or Enlightenment narratives, despite increased scepticism about such thinking (Habermas and Levin 1982; Hård and Jamison 2013). Technology for such determinists is made possible by a wider civilising and adaptive progress of humans (thus not entirely without a sort of developmental determinism) but is seen as a key driver of social possibilities and change. The discovery of time-keeping, explosives, mineral use, combustion and new construction techniques are themselves made possible by the much earlier self-discovery made possible by the opposable thumb (Littler 1973) and the use of bone, flint and stone to afford mastery of one's environment (Oakley 1961). Although an interaction of technology and human action, technology—its discovery, use and development—makes possible an array of wider social possibilities not previously evident. Modernist 'Enlightenment' type histories of social development often begin with the constructions and material achievements of a given historical and social context—for example the pyramids in Egypt, the Neolithic structures of Western Europe and the aqueducts of the Roman Empire. There are perhaps, not surprisingly, affinities between theorists concerned with the rise of modernity and the role of technology, given the importance of both in recent human history, as Brey suggests:

> Technology made modernity possible. It has been the engine of modernity, shaping it and propelling it forward. The renaissance was made possible by major 14th and 15th-century inventions like the mechanical clock, the full-rigged ship, fixed-viewpoint perspective and global maps, and the printing press. The emergence of industrial society in the 18th century was the result of an industrial revolution that was made possible by technological innovations

> in metallurgy, chemical technology and mechanical engineering. The recent emergence of an information society is also the product of a largely technological revolution, in information technology. Technology has catalysed the transition to modernity and catalysed major transitions within it. More than that, technologies are and continue to be an integral part of the infrastructure of modernity, being deeply implicated in its institutions, organising and reorganising the industrial system of production, the capitalist economic system, surveillance and military power, and shaping cultural symbols, categories and practices. (Brey 2003: 1)

Even the above summary of modernity and technology can be seen as ambiguous in the sense that technology, its materiality, is the result of social choices and that objects are saturated with social meaning and are the end result of choice-making. This may not of course be true in the sense that a wheel can be anything other than round to be efficient; however, many less foundational technologies such as factory machinery embody values as well as the best interpretation of abstract laws of physics, electronics and thermodynamics. The closest approximation to a technological determinist stance was taken by the French sociologist Jacques Ellul. His book *The Technological Society* (1964) makes plain that technology, both the core entity and the processes that surround it, have become the motive force that shapes social and economic dynamics: 'technique has become autonomous; it has fashioned an omnivorous world which obeys its own laws and which has renounced all tradition' (Ellul: 1964: 14). He posits that technology has not only usurped human autonomy in certain contexts but is actually the bearer of autonomy: 'technological autonomy reduces the human being to "a slug inserted into a slot machine"' (1964: 135); 'there can be no human autonomy in the face of technical autonomy' (1964: 138).

A close reading of Ellul does prompt a questioning of even his interpretation of technological determinism (TD). His work nowhere seems to suggest that technology has always been the motor of history or human actions. His philosophical worldview is akin to that of Marx and the later Marcuse on alienation and with Weber on liberal pessimism with the decline of traditional charismatic systems yielding to legal-rational technical systems. Indeed Ellul is really studying systems of productive efficiency rather than say 'machines': 'modern technology has become a total phenomenon for civilization, the defining force of a new social order in which efficiency is no longer an option but a necessity imposed on all human activity' (Ellul cited in Fasching 1981: 17).

The notion of a determinist interpretation of history has helped shape key economic and philosophical writings. Marx has at various points been credited with economic and TD. The following seems to meld together both the economic logic and productive niceties of advanced capitalism. As with Ellul, this is a pessimistic appraisal with little space for agency and struggle, at least within capitalism:

> Owing to the extensive use of machinery and to division of labour, the work of the proletarians has lost all individual character, and, consequently, all charm for the workman. He becomes an appendage of the machine, and it is only the most simple, most monotonous, and most easily acquired knack, that is required of him. Hence, the cost of production of a workman is restricted, almost entirely, to the means of subsistence that he requires for his maintenance, and for the propagation of his race. (Marx and Engels 1848: 18)

As with any prolific commentator there are writings which get close to sounding technologically determinist:

> In acquiring new productive forces men change their mode of production, and in changing their mode of production they change their way of living—they change all their social relations. The hand-mill gives you the society of the feudal lord; the steam-mill, society with the industrial capitalist. (Marx 1847)

Here then are clear causal-sounding links between a given technological system and a given era of social-economic organisation. Now, whether technology determines or has an elective affinity with say feudal or capitalist systems can be debated. A more different appraisal is offered by Roth's analysis of Marx's writings on technology: 'the development of machinery creates the material conditions necessary for the superseding of the wages system by a truly social system of production' (Marx cited in Roth 2010: 1223).

This seems to suggest an affinity rather than causal determinism, one where economic and technological developments appear to coalesce and causality is hard to discern. Marx of course is often criticised for having rather limited analytical purchase on those societies that did not conform to the developmental path of Western capitalism (Ashley 2015). Another careful exposition of Marx is offered by Bimber (1990). Here he seems to be suggesting a dialectical relationship between human need and the technological potential of economic systems to support ever greater exploitative systems:

> The literature on Marx reveals conflicting claims about the role of technology in social change. Much of the debate is attributable to confusion over what is meant by 'TD'. There are several approaches to this concept: 'Norm-Based Accounts' interpret TD as a chiefly cultural phenomenon; 'Unintended Consequences Accounts' view it in terms of unexpected social outcomes of technological enterprise. Neither of these two approaches makes claims which are strictly deterministic, and which rely upon features of technology itself; they should not be considered to be TD. 'Logical Sequence Accounts', on the other hand, make an ontological claim, viewing TD in terms of universal laws of nature; these deserve the 'TD' label, and suggest criteria for assessing Marx's views about technology. Marx's arguments about the forces of production do not represent a Logical Sequence Account. The primary factors in the development of the forces of production are human, involving drives for self-expression, resistance to alienation, and expanding needs. Technology plays only a facilitating role in this process, which is essentially non-technological in character. (Bimber 1990: 333)

Llobera gets the last word and concurs broadly with Bimber in alighting on a view that claims that factors intersect to integrate economy, technology and social dynamics: 'accounts often assume economic and technological drivers in concert drive social change—but they interact in Marx's writing and should not be seen as determinist singly or together' (Llobera 1979). Certainly we can state with some authority that technological change rarely if ever determines in a meaningful and straightforward way. Events and changes in the material world do afford new social and economic opportunities. The exact use and interpretation of technology is highly variable cross-culturally, historically and even intra-socially. Why for example did pre-communist China develop so late industrially given its early development of key material technologies? Why did industrial capitalism develop in certain jurisdictions rather than others (Weber 1904)? For Weber, socio-cultural, religious and economic factors all helped shape the technical infrastructure and ambitions of a given country, helping to explain the affinity between Protestantism and industrial capitalism, that is, respectively, their basis in doubt and the need to reinvest to gain a surplus of God's grace. What then of more recent interpretations of technology as determinist? Peter Conrad writing in 1979 laid out a very stark image of medical technology being used as forms of behavioural control. There is little space for agency and street-level interpretation of these technologies according to him. Writing in the first ever issue of the journal *Sociology of Health and Illness*, he explores this technological control in the fields of psychiatry and public health, noting:

> The growth of specialised and technological medicine and the concomitant development of medical technology have produced an armamentarium of medical controls. Psychotechnologies, which include various forms of medical and behavioral technologies, are the most common types of medical control of deviance. Since the emergence of phenothiazine medications in the early 1950s for the treatment and control of mental disorder, there has been a virtual explosion in the development and use of psychoactive medications that control behavioral deviance: tranquillisers like Librium and Valium for anxiety. (Conrad 1979: 3)

Technologies, for Conrad, have an affinity with the wider narratives of professional and medical control. This may be shifting the definitional goalposts in merging medical imperatives with technologies and it is unclear which comes first: the desire to make the patients conform or the technologies. However, these writings come close to TD in a meso-institutional context as they afford little professional, patient or managerial subversion of medical meta-narratives. In the field of reproductive medicine, Denny (1994) adopts similar deterministic language to convey the patriarchal thrust of this branch of medicine in controlling women's reproductive choices:

> One of the main themes of radical feminism is that of power and control. In Vitro Fertilization (IVF) is part of a male attempt to control female sexuality and fertility, and needs to be placed within this wider context. Although IVF is promoted as a treatment for infertility, the emphasis on technology is about control of reproductive capacity. … In radical feminist ideology women's desire for children is fuelled by pro-natalist ideology and exploited by men eager to master nature. (Denny 1994: 70)

Such latter-day determinism is hard to sustain, whether in a general or specific sense. These representations offer an image of technology as erasing or pre-emptively denying agency. The wider evidence points to street-level interpretations and counter-narratives being a feature of social life even where strong and rapid social, economic or institutional narratives are evident (Dent 1996).

## Dilute Determinism?

There is a tendency with some writers and researchers to avoid direct reference to technology determining social phenomena, but for it to be framed as part of a broader analyses of macro-level social systems (e.g. autocracy versus liberal democracy) which sound to all intents and purposes determinist. Perhaps inadvertently then the framing of societal-wide technological change often sounds superficially like determinist thinking. More contemporary analysts of social systems, such as Fukuyama, makes clear the importance of political and social dynamics in shaping autocracy and liberal democracy at the same time as technology, and the speed and ubiquity of its development, may, he argues, be outstripping our ability to control its own longer-term effects (Fukuyama 2003, 2006, 2011). For example, Fukuyama makes plain that not all technologies shape social systems and human behaviour in the same way, exploring for example what he sees as the beneficial nature of information technology as a sort of democratic technology, but he presents a very bleak view of the pace of developments in biotechnology which threaten to erode debate in what we might call an autocratic pace of technological change. Thus the type of technology is important here given the reach and power of certain technologies and the more localised and open impact of other forms of technology. What is clear from his wider works is that technology has a major role in influencing the future, not just of a given society but of the future sustainability of humankind globally. This might be dubbed a form of 'dilute determinism' or 'selective technological determinism'. Another systems-level writer with a dilute sense of determinism is Castells, who, despite the uneven spread and impact of digital technology, asserts that the impact on the global economy and human behaviour is profound:

> The global economy is now characterised by the almost instantaneous flow and exchange of information, capital, and cultural communication. These flows order and condition both consumption and production. The networks themselves reflect and create distinctive cultures. Both they and the traffic they carry are largely outside national regulation. Our dependence on the new modes of informational flow gives to those in a position to control them enormous power to control us. The main political arena is now the media, and the media are not politically answerable. (Castells 2011: 3)

We can discern in Castells both the plurality of social formations and the influence of technology in his reference to 'distinctive cultures'. However, it is also possible to see evidence of technology substantially 'conditioning' behaviours. Agency is not absent in this formulation, but systems-level globalised communications and technological diffusion might be seen to suggest a convergence of controlling technology, surveillance being the most obvious example of where Castells' work might be most analytically powerful. Thus in the realm of media and surveillance, the tone of Castells is arguably pessimistic, with networks being ubiquitous, though the key nodes of control characterising those networks is highly concentrated. On the other hand, on say national-level work production systems, the tone is more optimistic and pluralistic:

> **On Media**
> The sense of disorientation is compounded by radical changes in the realm of communication, derived from the revolution in communication technologies. The shift from traditional mass media to a system of horizontal communication networks organised around the Internet and wireless

> communication has introduced a multiplicity of communication patterns at the source of a fundamental cultural transformation, as virtuality becomes an essential dimension of our reality. The constitution of a new culture based on multimodal communication and digital information processing creates a generational divide between those born before the Internet Age (1969) and those who grew up being digital. (Castells 2011: 18)
>
> **On Work Systems**
>
> Information and communication technologies have had a powerful effect on the transformation of labour markets and of the work process. However, their effects have been substantially mediated by the strategies of firms and the policies of governments. Thus, when public support of labour unions provokes businesses to agree on job security in exchange for moderate wage increases, stable jobs are protected, but labour creation dwindles because technology is used to substitute automation for labour. On the other hand, when companies have free rein in labour-hiring practices, they tend to achieve their ideal labour force pattern: talent attracted with high salaries, perks, and a degree of autonomy, in exchange for commitment to the company; automation and off-shoring of the core labour force; and subcontracting of low-level service activities (such as cleaning or maintenance) to suppliers specialising in a lowly paid labour force. Thus, there is a wide range of variation of the transformation of labour in the new economy, depending on the level of development, and the institutional environment. (Castells 2011: 24)

David Lyon's updating of his classic text *Surveillance Society* (Lyon 2001, 2013) makes clear that, although not TD, the ubiquity of and affinity between information technology, market research and trackin g technology each provide the context for societal-wide changes. These changes are made possible by and then cemented into social practices by cookies, closed-circuit television (CCTV), radio frequency identification devices and shared database screening, which afford new levels of surveillance, especially of the consuming citizen. So although perhaps less sinister than state sponsored surveillance, such market and movement tracking seem to represent a new layer of technological shaping of human behaviour. A related concern in the literature on the role of power in mediating technology is that of the sub-literature on 'disappearing technology'. Although the opposite of the visibly controlling technology of surveillance, disappeared technology is concerned with the power of technology discourses to hide the overt functions and constrained uses of technology. As with the discussion of the medical model of disability—its unseen and uncodified power—writers argue that the discourses that surround technology serve to limit critique and the shaping of the uses of technology. Bruce and Hogan, writers on critical pedagogy, note the processes of disappearance in the classroom:

> This process is one of the crucial ways in which all literacy technologies—slate tablets, typewriters, word processors, networks, computer interfaces, databases, the Web—are ideologically embedded. Effective use of the dominant reading and writing technologies then becomes the defining characteristic for new forms of literacy (Bruce 1995). Lack of such ability can be conceived as an inherent disability, located in the individual, which might or might not be alleviated through various measures, such as providing more time, easier texts, skill training, tutoring, help features, donations of equipment, and so forth. (Bruce and Hogan 1998: 270–271)

Rather in the spirit of McLuhan and Marcuse, there is a risk that technology appears to be the marker of ideology and social power rather than being seen to be the dependent variable in modern society (McLuhan and Fiore 1967; Marcuse 1968). Timmermans and Berg (2003), writing about academic work on sentiment in a technologised hospital context, also point to assumptions made by researchers that technologies speak for themselves and that much work fails adequately to problematise and foreground technology in studies of clinical systems. Clearly as symbolic spaces, the clinic and pervasive technology convey their own sentiment, or at least meaning systems:

> Anselm Strauss and collaborators (Strauss et al. 1982) conducted an ethnography of technology use in six hospitals. Yet, their study contains surprisingly little about the technologies themselves. While they discuss in one page how the 'biography' of fetal monitoring went through research, development, refinement, to controversy … the bulk of their analysis is on how technologies lift patients' spirits and courage, help staff maintain professional composure, allow correction of 'interactional errors', or contribute to the broad category of 'sentimental work'. (Timmermans and Berg 2003: 99)

Thus any analyses of technology in-use have to be clear as to how its use is being constructed. What looks like an innocent extension of technology use may be a technologising of a problem, one constructed by a broader discursive construct of technological competence.

The above has presented a picture of technology happening to social actors, whether in a concentrated or diffuse sense. The section began with some of the more extreme versions of determinism and moved on to more dilute or merged constructions of determinism. We can now move on towards a more socially mediated image of technology as outlined in the notion of affordances. Affordances as a concept emanates from Science and Technology Studies (STS), a broad academic tradition founded to comprehend, in diverse and critical ways, the interaction of science and technology and to link social and political theory to technology. The 'Social Construction of Technology' and 'Social Shaping' of technology are two key and more immediate interpretations of STS's concerns (Wajcman and MacKenzie 1985; Bijker et al. 1987, 2012). By so doing it aimed to break down assumptions that led to a perceived hierarchy of credibility that placed science over social science and hence to the need to bring science and social science insights together. For STS writers, both technology and society have to be understood at their intersection.

## Affordances and Technology Theory

Somewhere between technological/economic determinism and social constructionism is the notion of 'affordances'. Although a complex formulation in some of its iterations, the approach situates technology in the environmental context of its use, as a sort of naturalistic picture of technology 'in-use'. Technology and environment together afford certain uses and benefits, ones that can be ignored in more systems-driven or hyper-constructivist formulations. The following provides a really helpful impression of affordances and the attempt to steer between the Scylla and Charybdis of over and under-socialised constructions of technology:

> Sociological studies of technological objects, it is claimed, are faced with an unpalatable choice between under socialised and over socialized conceptions

> of technology—represented by technological determinism and social constructivism respectively. This framing of the problem inevitably leads to a quest for a 'third way', a conception of technology that is neither over nor under socialized … For seekers of this third way, Gibson's (1979) concept of 'affordances' has obvious attractions. As is well known, Gibson coined this neologism as a description for the 'action possibilities' which a given environment presents an animal. For instance, for an object to be graspable, that 'object must have opposite surfaces separated by less than the span of the hand' (1979: 133). 'Affordances' reflect the co-evolution of (human and non-human) animals and environments. They are understood as products of the animal–environment system: … an affordance is neither an objective property nor a subjective property; or it is both if you like … [It] points both ways, to the environment and to the observer. (Bloomfield et al. 2010: 416)

This formulation begins to connect technology within an environment, which in turn makes or limits the opportunity to exploit a given technology. This is therefore a good starting point for a truly interactive and interdependent framework for understanding technology, but which does not bury the very tangible nature of technology in a strong constructivist framework. In emphasising interdependence this approach also mirrors the helpful shift in disability studies away from independence models to interdependence models.

## Social Construction and Social Shaping of Technology

It is perhaps stating the obvious that social norms, preferences and imperatives may shape technology. We know that technologies are constructed in their social and political context. Built-in obsolescence is a feature of many technologies, despite their being sold as the ultimate response to a human need. Capitalism and communist value systems, whatever one makes of each, would approach the end product and user differently in a way that reflected valorised ideological structures as much as it would be conscious of technology itself (Scanlan 1992;

Singh et al. 2004). In addition to macro-level factors shaping technology, meso-level production cultures ensure that the process of manufacture, itself a 'technology producing other technologies', is heavily shaped by political, managerial and increasingly safety concerns. From the highly automated car factories of Northern Italy through to high-end bespoke fashion, jewellery and furniture, very different relationship between humans and technologies are evident. Even the broader shifts from Taylorist to Fordist and Post-Fordist production systems does not encapsulate the diversity of such relations in their diverse forms (Grint and Woolgar 2013; Orlikowski 2007). At a micro-level, the cultural intersections of age, generation and social milieu will determine whether or not a technology is sought, used or discarded (Stowe and Harding 2010). Social constructionism then offers a more fluid and complex picture, not simply of the relationship between society and technology but also of social life itself. The social shaping of technology as a concept is clearly a 'no brainer' in a general sense, as the social obviously does shape technology—its design, procurement, use and review. However, this may not be inimical to arguments like Castells' which are systems-level analyses of ubiquity, diffusion and felt (or false) needs for certain technologies. Certainly at the meso and micro-levels we can say with some certainty that technology is not determined in any profound sense. Even at a macro-level we can say that it is contested. As Mackenzie and Wajcman, two of the progenitors of the term 'social shaping of technology' make clear in their historical assessment of activism as a means of shifting previous system-bound understandings of technology on to another analytical plane:

> Members of the radical counterculture of the 1960s and 1970s, Ceruzzi points out, wanted to liberate computing from its military and corporate masters: they were pursuing one version of the active politics of technology that we are recommending … Nelson, for example, combined technical and social radicalism, for instance in his influential proposal for 'hypertext' designed to help untrained people find their way through computer-held information organised in more complicated ways than in paper documents, and in one sense a precursor of the enormously successful World Wide Web. (MacKenzie and Wajcman 1999: 28–29)

The similarity between Castells' notion of network and the above activist shaping of technology are clear. While Castells was more abstract in his formulations and Mackenzie and Wajcman more concerned with immediate issues of gender, work and home, there is clear scope for social shaping even if wider industrial and information systems and nodes might caution use against over-optimism. Another author who connects technology and activism is Ulrich Beck. His formulation of a 'Risk Society', while noting the maldistribution of risk, helps foster the point that social actors in an era of 'reflexive modernisation' have to lead and if necessary agitate as, for example, in the furtherance of Green politics. Technology and science more fully has a key part to play in this, both in offering new technological futures and in challenging the current use of and surrounding technology systems of advanced capitalism (Beck 1992). If scientism, an ossified, class-dominated system, reflected the needs of the powerful and an uncritical rationality, reflexive modernity makes use of individuated spaces of critique. Unlike Weber, Simmel and Tonnies, the shift towards individuation offers new spaces of opportunities, rather than atomised social locations. Certainly the acknowledgement of activist and shaping roles has implications for any searching analyses of disability and technology.

The notion that neither technology nor social forces are determining is clear in Actor Network Theory (ANT). Pushing the epistemological envelope further than a dilute constructivist view that social factors and human agency matters in technology theory, ANT advocates note the inseparability and profound interrelationship of technology and society. Indeed and rather controversially ANT posits that non-human entities (actants), such as artefacts, can 'act' in a narrow sense, not that of sentient meaning-oriented behaviour, but that which can act on and influence human life and cognate systems as deeply as human life itself. Technology therefore is not a summation of human conception, design and adaptation, but is constitutive of social life. John Law, a key ANT writer, picks up the story:

> Actor-network theory is a disparate family of material-semiotic tools, sensibilities and methods of analysis that treat everything in the social and natural worlds as a continuously generated effect of the webs of relations

> within which they are located. It assumes that nothing has reality or form outside the enactment of those relations. Its studies explore and characterise the webs and the practices that carry them. Like other material-semiotic approaches, the actor-network approach thus describes the enactment of materially and discursively heterogeneous relations that produce and reshuffle all kinds of actors including objects, subjects, human beings, machines, animals, 'nature', ideas, organisations, inequalities, scale and sizes, and geographical arrangements. (Law 2007: 7)

For Law, artefacts, human operatives, raw materials, markets, trade routes and a mix of fixed and flexible specific technologies constitute wider actor networks. He provides the example of the Portuguese exploratory fleet which was made up of ships, goods, humans, navigation technologies, trade routes and the combative technologies to ease the acquisition of 'acquired goods'. Each for Law was important and clearly had their indispensable part to play in supporting exploration and exploitation for early European explorers (Law 1986). These systems are notable for their heterogeneity and interdependence and require a reordering of assumptions about structure and agency. To study such actor networks requires each of these factors and their interrelations to be understood. Pannebecker, for example, notes how hierarchies and sacred assumptions are challenged in ANT: 'a major advantage of the actor networks approach is the elimination of arbitrary distinctions and categories that often oversimplify technological complexity and reinforce disciplinary boundaries' (Pannabecker 1991:53).

Latour makes clear the post-structural logic of ANT by stating the imperative of going beyond 'the social' in the study of the intersection of society and technology (Latour 2005). The study of the social, as exemplified best in social shaping studies, is not adequate as the semiology of shaping constructs the social world as acted 'upon' or acting 'upon'; whereas ANT requires analyses to dare to invest all components of the network with influential and causal potency:

> in situations where innovations proliferate, where group boundaries are uncertain, when the range of entities to be taken into account fluctuates, the sociology of the social is no longer able to trace actors' new associations. At this point, the last thing to do would be to limit in advance the shape,

> size, heterogeneity, and combination of associations. To the convenient shorthand of the social, one has to substitute the painful and costly longhand of its associations. The duties of the social scientist mutate accordingly: it is no longer enough to limit actors to the role of informers offering cases of some well-known types. You have to grant them back the ability to make up their own theories of what the social is made of. Your task is no longer to impose some order, to limit of the corpus since the social is kept stable all along and accounts for the shape of technological change. (Latour 2005:10–11)

As with the shift towards ableism in disability theory above, ANT can be seen as aiding a movement beyond structuralist obsessions with established binaries, narratives and hierarchies; one which tries to read the very embedded languages of technology and networks. As with ableism, the attempt to cram everything back into Pandora's analytical box can be critiqued for affording an ultra-relativist stance on researching technology. Critics might say that some things surely are more solidly pervasive and forceful than others, such as consumer technologies, technologies of war, workplace technologies and global productive norms. This critique then might suggest such a celebration of semiotic heterogeneity that may be rather playful and lacking in urgency. This is of course a moot point, one requiring further critical appraisal; certainly ANT is here to stay and forms a key weapon in the theoretical armoury of researchers and writers on technology.

## Conclusions

Following the logic of the American field theorist Kurt Lewin who noted 'there is nothing so practical as a good theory' (Lewin, in Cartwright 1951: 588), and emphasising the element of practical value in theory, how does the above benefit us in taking forward the study of disability theory and technology theory? Firstly it is important to put one's theoretical cards on the table, by saying both structure and agency matter. Beyond that the nature of a technology and the socio-political context each matter in a macro-sociological sense. Generational, age, gender, subcultural and aesthetic considerations also need to be factored into a theory of technology. While not wishing to agree with everyone in the manner of the fabled Vicar of Bray, there are elements of each theoretical tradition that are of some value. Determinism, while clearly pre-sociological in its extreme forms and rarely supported by empirical data at its most abstract, is the idea that certain keynote technologies—the wheel, medical scanners, mobile telephony, texting and the internal combustion engine—represent technologies that have driven fairly predictably social adoption and individual and community behaviours. Technology makes things possible, including choice; however, cultures of use profoundly shape human behaviour—indeed the opposable thumb and mobile telephony can be seen as having been newly combined into predictable patterns of consumption and use (Campbell 2007). Simply look at the average train, bus or tram carriage across the globe. This of course is a dilute form of determinism, but it is a useful counter to extreme social constructivist theories that attempt to study and challenge everything. Indeed the two extremes of determinism and constructivism share the same concern with theorising, even if epistemologically distinct in other ways. The death of the grand narrative in post-structuralism could be seen to be a new grand narrative par excellence, while extreme constructivist theories are often pitched at high levels of abstraction.

Having said that dilute determinism has its uses, it is possible to posit a spectrum of theories and views that places it and soft constructivism very close together. The latter is more likely to start from the vantage point that we should question and problematise structuralist theories. However, it does not deny these structures in some instances, and agency and culture, society and economy, are clearly linked. The theory of affordances is a good example of attempts to comprehend perceptions without denying the material world and the nature of our connection with real technologies. The social shaping of the technology approach remains engaged with broader structures that shape social life-cognitive assumptions that lie behind the arms industry and also domestic technologies; however, the nuance at the heart of the social shaping approach necessitates struggle and re-evaluation. ANT rightly queries whether social science is just a study of the social and challenges us to think of the similarities between social actors and the nature and impact of objects. While the notion of 'actants' (Callon 2004) may be a theoretical concept too far for some, risking fetishising inanimate objects, the authors of ANT are right to note that technologies act on and shape social life and that causality is at the very least bi-directional.

In terms of framing our understanding of disability and technology, the above can provide a spectrum of thinking with which the reader can contextualise a given study, while the question of agency and structure can aid comprehension of just how enabling or disabling technology is. It is worth remembering that, for many disabled people in 'advanced' welfare contexts, the provision of technology may not be through a market mechanism or culture. This is a double-edged sword. Firstly it has meant that considerations of technology fit have been more pervasive than trying to foster the most expensive (or over-engineered) solution. Thus alongside market mechanisms, arguably the context to much technology research, are what Esping-Anderson (1990) dubbed decommodified systems of goods. The downside to this has been the tendency of such systems to operate with often rather awkward and arbitrary eligibility systems; and where a disabled person is eligible there has been a sense of you 'get what you're given'. This is hopefully changing with disabled people forming a large consumer market and embracing an empowerment of frames of reference in their daily lives. Thus heterogeneity is important here, but not at the expense of a firm focus on the politics of technology and the perpetuation of power in technology use (Boyle et al. 1977).

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# 3

# I'm Not Sure We've Been Introduced: Disability Meets Technology

Having looked at the theorising of disability and theories of technology singly, this chapter explores the intersection of and thinking on disability *and* technology. What then were the earliest conceptual constructions of technology and disability? Prior to the 1980s, academic research on disability and technology was largely confined to rehabilitation or occupational therapy focused work. This was largely but not entirely framed as technical appraisal of new or existing aids to living, including wheelchairs, orthotics, prosthetics, leg callipers and mobility aids. A small number of studies went beyond this technical evaluation brief to begin to conceptualise how technology was comprehended and the wider personal and social implications of it for disabled people. Put simply, people began to emerge from being mere biomedical units of assessment to acquiring the ontological status of social actors who in time became a key part of specific clinical research. It would be wrong, however, to assume a sort of linear progress towards greater social contexualisation of disabled people or any clear handing over of power to them; indeed the words 'patient' and 'service user' continue to have very different connotations and to shape research frameworks (McLaughlin 2009). The following captures the mental landscape of academic work before

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1980. As with a lot of the funded research on disability back then, it was sponsored by medical and royal societies which were the arbiters of much disability provision. This quote is taken from the *Proceedings of the Royal Society of Medicine*:

> Compared with the rapid development of motor driven vehicles, the development of vehicles propelled by the occupant has been minimal. This is true both of the bicycle as used by healthy people and also particularly of the wheelchair used by the handicapped. During the last two decades many attempts have been made to improve details which facilitate safety, comfort and adaptation to individual disabilities. The actual propulsion conditions, on the other hand, have been under examination only within the last few years. (Engel and Hildebrandt 1974)

Much of this work then was about producing more comfortable, impairment-focused technologies of mobility, posture and gait and ultimately as great an approximation to 'normalised function' as possible. There was little if any reference to choices, independence or the politics of technology (Berg 1998), and therefore this work risked producing over-engineered, or even stigmatised, solutions (Zola 1975). That time, it is worth remembering, was one of paternalism and 'professional expertise'. While much research was framed as technical, that is descriptive or evaluative in aiming to capture say wheelchair use, even in 1974 there is some early awareness of the wider environmental barriers that exist for disabled people. The above *Proceedings of the Royal Society of Medicine* also contains the following:

> The survey showed that some parts of the house were inaccessible in a wheelchair because of the design of the house and the size, shape and manoeuvrability of the wheelchair. Some wheelchairs were too wide to go through doorways, or could not be manoeuvred in the space available. (Platts 1974)

In the United States the National Academy of Sciences 'Artificial Limb Programme' supported by the Veterans' Administration helped foster both practical help and academic research from the 1940s, although technologies such as prostheses it is worth stating were crude and heavy.

The *Bulletin of Prosthetics Research*, latterly renamed the *Journal of Rehabilitation Research and Development* (JRRD) has over the decades been a key site of technical evaluation of prosthetics well beyond the original veterans' theme and in a way that aims to benefit a much broader swathe of disabled people (U.S. Department of Veterans Affairs 2013). The focus in rehabilitation research globally, until recently, was the immediate adaptation of affordable, safe and 'suitable' technologies for disabled people. Notions of suitability and degree of fit were of course clinician or administration-driven. Such a concern with functioning, although a far cry from a choices and rights approach, was concerned with important issues—from aiding independence (as a functional matter) to returning disabled veterans to as normal a life as possible, as the following attests:

> The Canadian programmes were developed by a coalition of physicians, veterans, and prominent civic and military leaders whose central philosophy was to 'return the patient to independent life beyond the confines of hospital or paraplegic colonies' (Botterell et al. 1946, p. 258). These new programmes revolutionized the life experiences of veterans with spinal cord injury and provided a framework for future civilian programmes. (Tremblay 1996: 150)

One could take the view that such approaches, even if concerned with wider configured barriers, are essentially normalising in their intentions. However, it would be harsh to assume such thinking was the key underpinning philosophy of all clinical engagements. In the UK, Anderson notes how the wheelchair took its place alongside rehabilitation and sport as one leg of the government's tripartite attempts at resettlement:

> Throughout the Second World War and the immediate postwar period, strenuous efforts were made to restore to the fullest degree possible the health of those wounded in the conflict. As a result of injuries received during the war, many people could not be returned to their previous condition, and there was an increase in the number of those who were classed as disabled. This growth, both in number and type of disablement caused by war, set the state generally, and the medical system specifically a new series of challenges. (Anderson 2003: 461)

Anderson's carefully documented archival history makes clear that wheelchairs were an important icon of post-war rehabilitation and that the state's push to reduce the 'burden' of war-injured disabled people underpinned this activity. Thus in the UK, compared to say North America, the period until the 1980s was characterised by a rehabilitation focus which helped to limit wider user insights and concerns. The 1980s, however, can be seen as a watershed in such thinking, at least with regard to a greater plurality and contestation of constructions of the benefits and use of technology. The decade witnessed a more open discussion of really quite polarised and increasingly abstract views of the role of technology in the lives of disabled people. This may likely have come to a head with the growing ubiquity of microchip technologies which took the focus well beyond the clinic and began to offer new technological futures in education, employment and transport systems. The distribution of these constructions of technology and disability broadly divide into rescue-fix narratives and the potential of new technologies to refine the wider environment that disabled people were negotiating. There are exceptions to this binary, however. Helle (1987), a Norwegian writer, evidences awareness of independent living ideas, despite working in a rehabilitation context, with a key concern being:

> How can modern technology be utilized by the physically disabled in their struggles for independence and normal social participation? … We want to be part of a process where disabled people win more influence on the technical developments in the field of rehabilitation. Therefore the research methods as well as the way of reporting results are so planned that it acts as a channel for the disabled to express their evaluations, opinions and experiences concerning modern technology. (Helle 1987: 334–335)

Notwithstanding debates around just what is 'normal' participation and 'modern' technology, this early work places the disabled person into a social context, problematises the role of technology and puts disabled people in a position of having greater voice in the evaluation and framing of research. So far we have seen little evidence of a deficit approach to technology giving way to more socially located understandings of the role and impact of technology. Much rehabilitation, clinical practice and computer science of the time continued to focus on disabled people's deficits and the fixative qualities of technologies. Narratives of technology benefits tended to revolve around a number of themes, principally rescue:

> Advances in the management of accidents, anaesthesia and surgery have led to many more people surviving major trauma or catastrophic neurological damage. Many are left with active brains locked into a severely physically disabled body … Technology that frees a disabled person is important to him or her and also to the carer. (Platts and Andrews 1994: 1182)

The notion of a rescue and release could only really emanate from a tragedy construction of disability. This is not to argue that rapid impairment is not tragic: individual prerogative has to allow for that without criticism of false consciousness. However, a generalised assumption of being locked-in and then technologically freed arguably perpetuated a negative construction of disability as a burden and something to be freed from (Calderbank 2000). In the broader literature, technology was seen to promise a new era for disabled people by freeing, compensating or augmenting functions. These analyses were often from the burgeoning computer science literature or from those interested in using new technology to support disabled people's clinical and vocational rehabilitation (Church and Glennen 1992; Cornes 1991; Pell et al. 1997; Tanenbaum 1986). Hazan captured the zeitgeist of the promise of new microchip technologies for disabled people:

> The evolution of low cost computing technology promises an unprecedented spectrum of opportunities for the developmentally disabled. From aids to independent living to flexible tools that can greatly increase the variety and quality of job opportunities, the rapidly evolving field of computing is pregnant with possibilities. (Hazan 1981)

Less technologically determinist insights pointed to the unquestionable benefits of much information and communication technology in extending the reach, stamina and environmental influence of the human body, disabled or not. Stonier, for example, in his important book *The Wealth of Information* notes that mechanical technology (the steam engine, the internal combustion engine) extended musculature; while microchip (digital) technology, especially in a post-industrial context, has the potential to extend the neurological reach of human activity (Stonier 1983). Stonier's image of post-industrialism is mirrored in the work of Daniel Bell (1974), while the implications for disabled people are that mainstream production systems become much less about physical prowess than about the ability to manipulate information and data. I picked up the story, writing that:

> Post-industrial theory suggests immense promise for disabled people, in that a society based on information would not only suggest that access to the stuff of social life would be easier with new technology, but that information is power. (Roulstone 1998: 19)

This is not to argue that post-industrialism equals post-politics, as we know from Bell's own analyses: in the unfolding of post-industrial landscapes, dominant politico-economic forces remain and productive ideologies prevail. However, the shift to desk-top and generally less physically intensive working for many offered some real potential in making the workplace a less hostile place for some disabled people. New technology, its potential to compress time, distance and space (Harvey 1999), has an important affinity with this shift to more accessible workplaces. It is important to note that these changes were not designed as systems to aid disabled people but were serendipitously valuable. Conversely, pre-existing dynamics of time and production methods ensured that the degree of potential was more limited than the more technologically determinist writings might suggest (Green 2002).

These more determinist-sounding works tend to frame disability as a deficit, one which is reduced by the ability of new technologies to redefine social spaces, including the workplace. Murray and Kenny, for example, noted that 'telework will create new opportunities for people with severe disabilities as well as enabling others who become disabled during employment to retain their jobs' (Murray and Kenny 1990: 206). Like all impressive theories this 'opportunity via technology' thinking has a kernel of truth in it: clearly some disabled people will be able to work from home. However, technology does not, as the evidence suggests, carry with it the power to redefine workplace power relations. To be fair to many of these writers (Hawkridge and Vincent 1985; Murray and Kenny 1990; Sandhu 1987) these combinations of futurology and promise reflect a commitment to enhancing the lives of disabled people. They did, however, fail to engage with the parallel developments in rehabilitation which often framed new technology benefits as inhering in their compensation of disabled people's deficits. Countering such thinking were first wave disability writers, some of whom were grappling as disabled people with the very issues they were writing about. They reframed new technology benefits in terms of their scope to redefine environments. Finkelstein set the scene for a fundamental reframing of technology, of its benefits as an aid to disabled people contending with a range of social barriers:

> The second historical phase, I suggest, was generated by the creation of a new productive technology—large scale industry with production-lines geared to able bodied norms … The most important stimulation for this development, however, has been the new electronic technology for automating the production-line. This technology enables the most severely physically impaired people to operate environmental controls which can enable them to live relatively independently in the community … In Phase 3, which is just beginning, able-bodies and impaired members of society will be reunified partly by changes in attitudes and attitudes research, and partly by the development and more universal distribution of new technology. (Finkelstein 1980: 7–37)

Finkelstein is clear that technology had become more widespread by 1980, that it could extend the reach of disabled people. It would be incorrect, however, to assume that he fetishised technology: he was clear that 'high technology' was on a spectrum from shoes, wheelchairs and motor vehicles as the development of human tools and was a means to independence and not a guarantor of such a state. In this way technology decision-making had to be more fully shaped by disabled people and professionals aware of the reappraised role of technology. Gleeson, a geographer sympathetic to the early disability studies canon, was less optimistic about the scope for enabling technology, noting:

> As the historical-geographical perspective maintains, technological change is always embedded in socio-political change. The present post-industrial/

> post-modern society in the West is as much characterized by corporate downsizing, firm 're-engineering', labor market deregulation, and growing socio-spatial polarization, as it is by new and empowering forms of IT. (Gleeson 1998: 104)

The redistribution of technology to support disabled people better was central to an enabling use of technology. I borrowed the term 'enabling technology' from information science when I framed it to mean technology that can enable disabled people to challenge and navigate better otherwise hostile environments (Roulstone 1998). In contrast to rehabilitation writers, who often emphasised augmentation and the correction or amelioration of body/brain difference, I referred to technology giving scope to the rehabilitation of environments:

> The research in exploring the exact functions of new technology, has discovered the enabling process has not changed the impairment objectively, and that the real function of technology lies in its potential to reduce the wider barriers faced by disabled workers. (Roulstone 1998: 132)

I did not argue that impairment was unimportant; my empirical work noted the complex relationship between impairment, technology and environments. I did, however, feel that barrier reduction was evident for disabled people and that these reductions, where mainstream (off-the-peg) technologies were concerned, assisted non-disabled people also, for example, automatic doors, lifts and ramps. Writing in the 1990s, I disaggregated the pre-existing technology focus, making clear the distinction between specialist technologies (puff-blow functions, eye movement prompts, screen readers, joy stick operation, tracker ball, Text type Minicoms) and mainstream technologies (personal computers, lifts, ramps). While the enabling processes were similar, the design, procurement and support dynamics for specialist technologies were very different and subject to professionally led 'solutions' and were often part of a needs-based economy (Stone 1984). I also made clear that technology enabled non-disabled people to see the added functional benefits of technology for disabled people in communicating what they were able to do. This psycho-social benefit was of course not always realised as 'technology jealousy' and continued constructions of difference were not erased. This then clearly rejects both technological and social determinism as extreme interpretations of technology and disability. Disablism for me was not necessarily erased or diminished by new technology use. Similarly, social shaping was nowhere monolithic and technology did seem to have potency in certain contexts. However, I argued that technology certainly can be read as beneficial at both a material level and as affording strong symbolic challenges to what disabled people can do and be seen to do. The devil of course lurks in the detail, with impairment, professional histories, movement struggles and the nature of 'technological solutions' all shaping the complexity of experiences.

An example of this complexity is Lane, writing contemporaneously with me, but on the professional dominance of Deaf people's lives (capital 'D' denotes identification with Deaf culture and the use of sign language). Lane notes how the early availability of cochlear implants (CIs) afforded a rather aggressive corrective professional impulse to 'cure' deafness given the perceived 'plight' of deaf people. She notes:

> many of the professionals associated with the disability construction of deafness insist that the plight of the deaf child is truly desperate, so desperate in fact that some professionals propose implant surgery followed by rigorous speech and hearing therapy. (Lane 1995: 82–83)

Of note here, Lane rejects professional and oralist dominance of techno-social decision-making, but also points the finger at disability studies writers who felt strong commonalities between disability and Deaf politics which some Deaf people roundly reject (Corker 2000; Davis 1995; Ladd 2003). Here distinctions between the pre and post-lingually D/deaf was an important consideration in technology and D/deafness debates as implants even at best and where welcomed are not a quick fix and deaf people are required to enter intensive activity in learning language and not simply to hear. Other strands of work linking disability and technology in this period include Adrienne Asch's critique of new reproductive technologies that afford earlier and sharper diagnoses of impairment. Asch suggests that technological advances had outstripped ethical and rights-based debates as to the rights and wrongs of say the termination of disabled foetuses:

> Professionals should re-examine negative assumptions about the quality of life with prenatally detectable impairments and should reform clinical practice and public policy to improve informed decision making and genuine reproductive choice. Current data on children and families affected by disabilities indicate that disability does not preclude a satisfying life. Many problems attributed to the existence of a disability actually stem from inadequate social arrangements that public health professionals should work to change … unreflective uses of prenatal testing could diminish, rather than expand, women's choices. (Asch 1999: 1649)

A similar sense of imposed solutions is evident in White and Lemmer's occupational therapy study of wheelchair services. Even though end users wanted technological support, there was evidence of unmet demand and a shortfall in design adequacy for some users. While a 'needs-based' (i.e. non-marketised) system was beneficial in providing access to technologies, the wider system was characterised as provider-driven and did not offer sufficient power-chair options (White and Lemmer 1998). Studies of wheelchair comfort and impairment reduction, written for physiotherapy and rehabilitation audiences, and clearly an important adjunct to issues of independence, are identifiable from the early 1990s (Harms 1990). These examples make clear the challenges of understanding the relationship between disability and technology, with some writers talking of imposed solutions, while others wanting both greater technological access and voice in service and equipment design. It is somewhat ironic that the wheelchair, perhaps the most iconic symbol of disability, has been seen to be limited in its enabling potential by the service and market structures that surround it. Sheldon, a disability studies writer in dialogue with Finkelstein and my earlier work makes clear the important but complex relationship between disability and technology but reminds us of the wider context in which disabled people live their lives and that technology is shaped by the same forces as exclude in other contexts:

> It is no surprise then that disabled people have a complicated relationship with technology. We are often excluded from mainstream technology, a factor said to have contributed to our current labour force exclusion and indeed, to the creation of the modern 'disability' category (Finkelstein 1980; Oliver 1990). At the same time we have become the recipients of an

> ever-growing business involved in developing and marketing technologies specifically for our ascribed needs. Many of us have been impaired as a direct result of modern technology. Others would not be alive today without it. All of us are now dependent upon it to satisfy even our most basic needs (Illich and Lang 1973). (Sheldon 2003: 156)

Sheldon blends together a cautious optimism in the potential of technology with a concern, one born out of disability politics, that pre-existing structures of exclusion may be exacerbated by new technologies. It is worth noting that Finkelstein (1980) and Roulstone (1998), whose fieldwork was completing in the early to mid-1990s, were working in a context where technology was often associated with computing and hardware. At this stage the enormous power of the World Wide Web, sophisticated mobile telephony (e.g. texting) and affordable software applications were not in common currency. The potential of technology in these analyses not surprisingly was more institutionally focused or based around professional or workplace encounters. The growth of mobile telephony, hand-held devices, portable communication and web access devices begs new questions in terms of the reach and capacity of new technologies. Sheldon's work captures the potential of the internet, for example, but suggests that access would be limited to the few (Sheldon 2003). While some people cannot access the Web, the dissemination of access to it has been greater than any of the first wave technology and disability analysts could have guessed. It is worth mentioning for accuracy that even within first wave disability studies there was some opposition to or scepticism about an enabling interpretation of technology (Oliver 1990; 1993a, b; Zola 1975). While some disability and technology writers acknowledge the potential for enabling technology, a number also point to the intervening variables of poor estimates of population need (LaPlante et al. 1997; Seelman 2000), of the stigma amplification of assistive devices (Söderström and Ytterhus 2010) and the over-stated potential to enable (Illich and Lang 1973; Thornton 1993). Others refer to the inadvertent role of technologies in furthering a digital divide (Dobranski and Hargittai 2006; Ellis and Kent 2008; Jaeger 2011; Goggin and Newell 2007; Seelman 1993). The journal *Disability and Society*, a publication offering new social interpretations of disability, from 1986 featured key articles critical of a technical or asocial treatment of technology and disability (see Roulstone et al. 2015).

The critique of rehabilitation, computer science and clinical writers earlier, as adopting a deficit approach by default, then featured significantly in the foundational works of Finkelstein, Sheldon and Roulstone. A careful historical scrutiny of the evidence suggests a growing plurality in the rehabilitation and computing literatures. A small number of writers were engaging with more socially situated writings in the 1990s and certainly the changing nature of technology and understandings of disability led to more substantial changes in the 2000s. For example, writers in a rehabilitation tradition were by the new millennium offering analyses which did not fall squarely on to deficit assumptions and technical fixes. Scherer, a US writer, has been key in bridging disability studies developments with rehabilitation studies as the following attests:

> Thanks in large part to the past century's advances in technology, people with disabilities can live independent lives, contribute to their communities, attend regular schools, and work in professional careers. This technological evolution has fomented a shift from a medical to a social model of technology delivery, an approach that puts as much emphasis on users' community reintegration as it does on their physical capabilities. This change means that those in the field can no longer focus on the delivery of technology as an end in itself, but must go one step further and partner with consumers and communities to ensure that assistive devices are put to their best possible use. (Scherer 2002: 1)

Scherer has been able to build an image of community and social needs and take the rehabilitation paradigm beyond body-fixes and normalisation. She argues perhaps most forcefully that a poor mismatch between technology and the disabled person limits the potential of technology and that better matching should be a key focus for para-clinical and clinical researchers and professionals (see Gelderblom et al. 2002). She makes plain in her work that over-engineered 'solutions' are just as disabling as under-engineered ones. The year 2003 witnessed the coming together of myself and Scherer at the International Conference on Spatial Cognition (ICSC) Rome conference on assistive technology and cognition. This event brought together researchers from disability studies, rehabilitation studies as well as activists from the European Disabled

People's Movement. The event helped challenge the idea that rehabilitation studies was somehow locked into a body-deficit paradigm and that some threads of this research bore similarities to disability studies writers' own work. By 2005, interdisciplinary teams of researchers and practitioners (Scherer et al. 2005) were embracing holistic perspectives on disabled people's intersection with technology to include psycho-social constructs and their connection to technological and social opportunity. Although this might be critiqued for shifting the focus back on to individualised psychology, the frames of reference used by some researchers was clearly including psychological and social factors in technology use. The journals *Technology and Disability* and *Disability and Rehabilitation* supported a growing number of articles from the 1990s which reframed the relationship away from purely technical or fixative narratives of technology gains.

These positive developments, it should be noted, have not been fully acknowledged in the disability literature. Certainly my own assessment of work, even in the 1990s when the deficit model approach was more in evidence, did not account for what statisticians call outliers—in this case, those writers and researchers who were forging ahead with new models of technology use. So, as early as 1995, Galvin was able to claim that the medical model of disability was largely passé in technology research, at least in the USA. While this is a significant overstatement and many rehabilitation writers remained in the fixative mode, Galvin's work makes clear the need to situate technology experiences in a disabled person's wider social and community milieu (Galvin 1995). Of note, and given the time Galvin was writing, technology was interpreted widely and taken to include wheelchairs, hearing appliances as well as computers. The work also comprehended technology, its intersection with a variety of impairments and a breadth of focus that disability and cultural studies only began to engage with to any degree from the late 1990s and early 2000s (Cherney 1999; Woods and Watson 2003). Pierce, a rehabilitation nursing researcher, explored the wider social barriers and lack of voice for disabled people in her phenomenological study of wheelchair use and social-attitudinal environments (Pierce 1998). Mitchell and Breeze, ergonomic health researchers, represent the early stages of a new design and evaluation paradigm for mobility technologies, focusing largely on wheelchair design. They note how design has tended to be incremental, linear and design-led and has not connected with user concerns. They argue that even an expensive design artefact such as a wheelchair may not be suitable for a disabled person, noting:

> The wheelchair is a product that is used by an extremely varied population, in ways, circumstances and environments that vary from each and every user … often the user's requirements are not fully known and the limitations of different models cannot be compared without a period of use. Shortcomings of design may not be discovered until sometime after the wheelchair has been acquired. (Mitchell and Breeze 1995: 56)

Another early manifestation of disability and technology research has been in the field of technology adoption or rejection. Philips and Zhao writing in a North American rehabilitation context studied the rates of adoption and rejection of technology. Their study established that orthotic and mobility devices were more likely to be abandoned, with aids to daily living less likely to suffer the same degrees of abandonment. Product design, degree of match with end user, changes in circumstances, degree of user involvement in assessment decisions and lack of after sales support were all mentioned. The study surveyed technologies which were drawn from both social work and open market sources. The ease of access to technology was cited as a factor increasing abandonment and disuse, which is counter-intuitive perhaps (Philips and Zhao 1993: 42–43). Anthea Tinker's gerontological studies of older people avoiding residential care by staying in their family home mentions the use and potential of alarm technologies as early as 1984 (Tinker 1984), although wider discussion was much more prevalent from the 1990s. Reswick's (1982) study of design and procurement processes represents a hybrid conception of technology that is able to reduce disability (taken to mean impairment) while also ameliorating environmental barriers. The work maps the difficulties faced by rehabilitation writers and disabled end users in influencing design and the availability of useful technologies of daily living. This is an issue that remains in many market and 'needs-based' procurement systems.

So far we have discussed the development of first wave disability studies thinking on technology and the slight shifts and convergences made possible by changes in rehabilitation and related research. How best can we summarise these fields, their grasp of technology? It would not be hyperbole to suggest that the reframing of technology by disability studies as an aid to a more enabling society represented a paradigm shift in moving beyond the individual, fixative and body-focused paradigm. Although it may have risked caricaturing the differences between first wave disability studies and rehabilitation and computer science researchers, its distinction between the historical concern of the latter with rehabilitating and freeing disabled bodies, and its contrast with a socially focused approach in the former, has arguably been an important heuristic development. Many writers in rehabilitation research continued to adopt a narrowly technicist and fixative stance (Cornes 1991; Myers 1982). The latter approach seems to have prevailed more strongly in work around the potential of computers for disabled people than say in the fields of wheelchair, orthotic or aids and equipment research. This arguably reflects the more high-flown rhetoric around the future potential of what was often dubbed 'high' technology (Winner 1986). Disability writers and researchers have arguably not unpacked the notion of technology as fully as might have been possible.

The currency of disability and technology studies is a key issue. The fast pace of technological change and the equally important changes in disability theories and models have ensured that important first wave writers' work requires more than simply a historical refreshment. In technological terms, we have not simply seen the power of data processing increased, but the attendant shrinking in size of those technologies. An Apple iPhone 5 has more than 2.5 times the data processing power than the Cray-2 supercomputer built in 1985. The Cray-2 was the size of two family saloon cars if its cooling unit were to be included (Havelund et al. 2015). Electronic activity, previously only executable on personal computers and laptops, can now be found as standard digital functions of 4G mobile phones which can process huge amounts of data, for example in streaming digital recordings as well as functioning as telephones, games consoles and storage devices. Questions of the intersection of technology, impairment and environment, which were once space-bound, have now of necessity to be 'mobile'. Studies of personal computers, for example, would once have been located at the workplace or in the home. Phone-based applications which may once have had military or specialist assistive constructions are often now embedded in standard phones or available at relatively low cost and can be used on-the-move (Chen et al. 2015; Pang and Kwong 2015). Indeed the very notion of when and where work and domestic-related activity takes place has been redefined by such technological developments. Phone applications are not simply to aid physical access such as GPS or infra-red navigation or alert systems for visually impaired individuals, but also have application for people with dementia and for those with mood disorders. There are ethical issues of course in the development and use of some of these telehealth type applications (Niemeijer et al. 2015), but they do also afford freedoms, such as the relative freedom to roam for people with mild to moderate dementia. The data on online access is just as stark. Internet usage in Europe rose from 63 % in 2009 to 75 % in 2014 (Eurostat 2014). In the USA in 2013: '83.8 percent of U.S. households reported computer ownership, with 78.5 percent of all households having a desktop or laptop computer, and 63.6 percent having a handheld computer' (US Census Bureau 2013). However, despite an absolute rise in numbers, the relative distribution of internet access is not even. In the UK, for example, 38 million people (76 % of the population) had Web access in 2014, compared to 21 million in 2006; the rate for disabled people, however, is 68 % (Office for National Statistics 2015). This then counsels caution in over-generalising internet use, as a number of writers have pointed out (Goggin and Newell 2003; Ellis and Kent 2011). We need to be cautious, however, especially in understanding impairment specific barriers online. The UK Disability Rights Commission (DRC) investigation into Web accessibility and usability discovered that 81 % of the websites studied did not meet the lowest priority standards laid out in the W3C web access guidelines. This established the following subsidiary findings:

- All categories of disabled user consider that site designs take insufficient account of their specific needs.
- Blind users, who employ screen readers to access the web, although not alone in being disadvantaged, are particularly disadvantaged by websites whose design does not take full account of their needs.
- Although many of those commissioning websites state that they are alert to the needs of disabled people, there is very little evidence of

> such awareness being translated into effective usability for disabled people. (DRC 2004: 9)

Lazar et al.'s study of web page accessibility in the US noted that, while less than 10 % of web pages were fully compliant with W3C guidelines, the majority only required minimal changes to be fully accessible or could be adjusted with ease by the end user (Lazar et al. 2003). It is important to note that these studies of web accessibility are now rather dated and need replicating. It is also worth stating that web accessibility is being addressed in many national contexts, including the UK where in 2011 the British Standards Institute standard was in part a response to the DRC research above. The Equality Act (EA) 2010 in principle outlaws inaccessible web content, especially where an organisation is moving its primary interface with user and customers to a web platform. The year 2011 also witnessed changes to enhanced web accessibility in Canada (Government of Canada 2011). Similar developments have taken place in the USA, Nordic countries and South Asia. In 2008 Web Content Accessibility Guidance (WCAG2) was updated to reflect the wider move to the Web2 platform. The exact degree of improved accessibility remains under-researched, however. For example, while Web2 was designed to afford greater user influence and interface, this bespoking feature at the same time worked inadvertently against the basic rules of web accessibility for people with a range of impairments. The commercial basis of web platforms, browsers and search engines can easily be forgotten in the context of government action which is largely still voluntary and based on majoritarian principles (Ellis and Kent 2011: 65–77). Where W3C type guidelines are absent, however, there may be real and widespread barriers to web access as computer science researchers discovered in their study of visually impaired individuals in Pakistan (Bakhsh and Mehmood 2012). Of note, a number of the studies exploring the scope for greater usability for disabled people has framed its research in terms of the balancing act of offering disabled people greater web access while not 'degrading' the web experience for younger non-disabled users (Johnson and Kent 2007). This assumed zero-sum starting point has not been applied to environmental redesign as it often helps non-disabled people. There are arguably some paramount concerns with assumed web design features which are seen to be in jeopardy by computing experts. While this was Johnson and Kent's premise for their study, their findings showed no degradation of 'normal' web design in developing greater access features for disabled people (Johnson and Kent 2007: 216). The disjuncture between the Universal Design movement and web designers is notable (Brajnik 2004; Imrie 2012; Newell and Gregor 2002; Petrie and Kheir 2007; Preiser and Ostroff 2007).

Despite the above concerns, the research on the benefits of technology for disabled people does require recognition of the significant impact and potential of technology in disabled people's lives. Critiques of web access might risk underplaying the more general spread and potential of online access and activity and often falls down on the side of social determinism in its reaction against futurological forecasts of technology benefits. The changing nature and impact of technology has been mirrored in a rapid pace of change in disability theorising. Reflecting the major shifts towards post-foundational theories of disability, writings on technology within disability studies have become more pluralistic and contested. Woods and Watson, UK researchers, undertook a sociological history of the wheelchair, noting that technology studies, disability studies and rehabilitation studies had never fully explored the social dynamics shaping even this most iconic of technologies. Technology for Woods and Watson were not simply material artefacts but were saturated with social meaning and symbolism, noting that 'wheelchairs are not simply technical devices, but also social and political machines entwined with socio-political conditions and expectations' (Woods and Watson 2003: 164). This point is also explored by Goggin and Newell using STS insights to frame a fuller analysis of wheelchair design and use. They note how determinist views present technology, design and social change driven by technology as neutral pre-sociological processes:

> Notions of neutral and autonomous technology are particularly important in defining and regulating disability … None of the literature on the wheelchair for example, has ever dealt with the context in which wheelchairs are made, what they are made of, why they exist in their current form, why they exist in the numbers they do, why there are variations in form and design, who controls access to the wheelchair … The classic history of the wheelchair written by Kamenetz (1969) ignores all these questions, taking the wheelchair as a given in a unilinear historical account. (Goggin and Newell 2003: 9)

At the same time, Corker applied a similar logic to disability itself, noting the historically unproblematic construction of the body in much first wave analyses which left out key facets of the relationship between the body and technology. Corker noted that the disabled body was treated in essentialist terms in first wave disability studies. As technology has to increase its scope to influence the becoming or unbecoming of disabled identities, a more fluid and reflexive account of disability and impairment is required, she asserted, if we are to understand these complexities (Corker 2002). Thus as disability is a fluid concept we need to be careful of saying we are interested in how technology acts upon the disabled subject as technology is constitutive of disablement. In problematising both technology and disability—their relational status and blurring their ontological boundaries—these works mirror ANT's notions of actants or hybrid entities. The Norwegian writer Moser develops this strand of thinking in arguing that:

> The point of departure is that 'disabled' is not something one is but something one becomes, and, further, that disability is ordered and enacted in situated and quite specific ways. A set of questions follows from this. First, there are questions about how people become, and are made, disabled in practice, and, in particular, what role technologies and other material arrangements play in enabling and or disabling interactions. Second, there are questions about what is made of disability (and ability), what is made of the disabled subject and body, and, even more specifically, what positions, capacities and competences are enabled through the mobilization of technologies. (Moser 2006: 374)

More recent post-structuralist ideas underpin the growing literature which challenges blanket assumptions on the widespread benefits of enabling technology, while foregrounding a critical construction of technology, meaning and ontology (Pape et al. 2002; Lopez and Domenech 2008; Rizzo et al. 2002; Seymour 2005). Lopez and Domenech adopt phenomenological insights to explore the complex relationship between pendant-worn safeguarding technologies and older disabled people's identities. They provide a rich almost anthropological image of people: making rationale but complex decisions about technology and in a way that could easily be misunderstood without qualitative and reflexive research methods. Notions of surveillance, identity, risk and resilience (Lopez and Domenech 2008; Niemeijer et al. 2010, 2011) are all be seen to add new dimensions in appraising the complex interplay between disabled individuals and technologies. Ideas from computing, philosophy and sociology posit notions of cyborg identities, a phenomenology of technology/disability, prosthetic selfhood and online identity (Bowker and Tuffin 2002; Coronel 2008; Goggin and Newell 2006; Johnson and Moxon 1998; Saltes 2013; Swartz and Watermeyer 2008). Drawing on Haraway's (1985) use of the cyborg as a metaphor which questions the assumed Cartesian dualism between mind and body, "representation" and "reality", culture and nature, these works explore complex issues of body–technology boundaries (Cromby and Standen in Gordo-Lopez and Parker, 1999). Once again these ideas draw on ANT's emphasis on interpenetrative boundaries in 'human'–technological relations. Haraway delineates her core thinking in the following:

> A cyborg is a cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction. Social reality is lived social relations, our most important political construction, a world-changing fiction. The international women's movements have constructed 'women's experience', as well as uncovered or discovered this crucial collective object. This experience is a fiction and fact of the most crucial, political kind. Liberation rests on the construction of the consciousness, the imaginative apprehension, of oppression, and so of possibility. The cyborg is a matter of fiction and lived experience that changes what counts as women's experience in the late twentieth century. This is a struggle over life and death, but the boundary between science fiction and social reality is an optical illusion. (Haraway 1991: 149)

Haraway then provides a contribution at two levels. Firstly there is the immediate requirement that cyborg entities are not seen as bodies plus technologies and vice versa. Cyborgs become hybrid entities in this process and require new frames of reference to comprehend them. Secondly the ideas are to be part of a broader politics of recognition that requires a reappraisal of say womanhood, struggle and legitimacy. Drawing on a cultural studies tradition, Haraway focuses on the blurred boundaries between 'fact' and 'fiction' which she argues characterise the popular imagination (Haraway 1991: 149).

Swartz and Watermeyer's excellent account of the potential of prosthetic technology to further emphasise the 'essential difference' between able-bodied and cyborg identities makes clear that simply aiding mastery of the physical environment does not nullify the attitudinal landscape. Noting that disabled people have often been seen as not quite human (the term 'post-human' is increasingly used, although not without contention), they note how the much vaunted use of a prosthetic limb by the South African athlete Oscar Pistorius can be viewed from the perspective of abnormalisation—that Pistorius is now either superhuman or sub-human (MacDougall 2006). The Steenkamp debacle only added to this sense that 'we knew' he wasn't normal or capable of being normalised. Swartz and Watermeyer note:

> At the heart of much discrimination against disabled people is an idea, explicit or implicit, that disabled people do not qualify to be seen as fully human. Similarly, with the advent of spare part surgery, including prosthetics and organ transplants, there are anxieties about what the boundaries of being an individual human being may be. If, for example, I have in my body the heart of another person, to what extent am I still me? If, furthermore, I am dependant on technology, through a pacemaker or a prosthetic limb, for example, to what extent can I be said to have a human body? When biotechnologies and new genetic engineering techniques allow human tissues to be bought and sold the body becomes more porous, and a site of exchange. (Swartz and Watermeyer 2008: 187)

We can also say that prosthetic identity need not be due to clear visibility of the prostheses. There is evidence of prejudice and mistreatment in disclosing individuals in say airport security that have metal plates in their cranium or a stoma bag which is picked up on the full body scanner (Marey et al. 2009). Stuart Blume's 2009 book *The Artificial Ear* reflects developments in STS towards more philosophical, less essentialist constructions in technology research. He relates the experience of his son's encounter with CIs and makes clear the ethical, personal and family standpoints that arise and which are studiously overlooked in certain medical rehabilitative narratives of heroic interventions and technologies. Blending technology assessment, critiques of professionals and the limits of children's rights in implant narratives, Blume makes clear the very different country and cultural contexts for cochlear uptake. While poorer countries have little resource for this very expensive technology, richer countries have witnessed a counter-narrative from Deaf activists which makes the relationship between technology, impairment, age, social capital and socio-economic context to be an important consideration. Ultimately Blume concludes that big business has taken the place of clinical professionals in driving forward narratives of technological and human need and the market response to that need:

> Despite the doctrine of informed consent to which we all now pay lip service, the social dynamic of momentum leads inevitably to a situation that excludes precisely the informed and reason choice that the doctrine requires. (Blume 2009: 196)

Further debate has taken place in a way that challenges binary notions of Deaf rights and professional-industry imperatives. Mauldin's ethnography of CI communities notes the shift from Deafness as a systems problem, inhering in the brain, to an issue of individuals' successes in drawing out hearing and speech functions via language training that follows implantation. Here the 'real treatment' is not the implant but language development training. She notes the 'neuropolitical' struggle to foreground oral/aural 'choice' over visual communication (e.g. signing) and the neurogovernance of parents and CI patients to approximate to normal communication patterns with CI assistance. So, although deaf people are not acted on in the way a deficit approach might suggest, and although agency is present, it is neurogoverned once implantation is accepted (Mauldin 2014). This is a rather bleak Foucauldian image of biopolitics being applied to CIs.

The notion that technology has to be comprehended in its wider social and economic context is also provided by Michailakis (2001) who explores in his study the changing relationship between disability, technology and economic opportunity in Sweden. Technology 'openings and closings' are evident in his work and he counsels caution in being over or indeed under-optimistic about the role of technology in disabled people's lives:

> There are, as in every important change, adverse effects, and in assessing these effects one may choose to look at them on a micro- and macro-level. As regards individuals with disabilities there are several advantages with ICTs and the information society that can be discerned on the micro-level. Most of the communication barriers that have long confronted blind and visually impaired persons can, with these, be removed. Since ICTs bring work to persons, rather than transporting persons to work, by telework at home or other location, thus avoiding problems of access to buildings, transportation, etc., they create new possibilities to work for persons with physical impairments … Looking on the macro-level, there are structural changes going on brought about by the development of information technology, and these structural changes are not always advantageous to persons with disabilities or to any other group. The increasing incorporation of information technology into work processes and production leads to profound changes at the workplace. Together with the introduction of ICT devices follows an increasing automation, robotisation and more complex information systems. (Michailakis 2001: 480–481)

As with much of the above, Michailakis makes clear the need to avoid over-generalisation in appraising the likely future role of technology in the lives of disabled people. Wider global economic trends and production imperatives may close off options for some, while new applications can open up the wider world to others. Impairment, place and economic location are all important here. The work of Vasilis Galis on the role of disabled Athenians challenging barriers to the Athens Metro makes clear the important role of redefining technology and disability. For Galis neither the medical or social model of disability had fully comprehended the role and meaning of technology (Galis 2011). Technology for Galis includes the core actions of technologies of the state. His empirical account makes clear how the ‘technology of state’ was contested in a new ontological politics. Changes to the technology of state decisions made possible user-involved coproduction of more tangible technologies and access features on the Athens Metro. The project also redefined disability beyond simply narrowly defined ideas, such as wheelchair users or those who use canes (to include older frail people), pregnant women and parents with buggies (Galis 2006). Gibson et al.’s melding of physical therapy and ethics studied young Canadian’s with Duchenne muscular dystrophy who are dependent on medical technologies. They borrow from phenomenology in seeing disability as both a bodily reality but also an identity that is managed. They note the complex layerings attached to the use of medical devices, the perceptions of others and the subsequent risk of cultural stigma that the technologies might inadvertently produce:

> Medical technologies and assistive devices have paradoxical effects because, although designed to sustain life and/or improve human function, they can also contribute to stigmatization and socio-material marginalization … In outlining the relationship between these two forms of injustice, Fraser's ideas reinforce the need for a disability ethics that considers not only socio-structural barriers but also the cultural and symbolic exclusion that is written onto the social landscape and the bodies of citizens. These are complex issues that involve a more thorough analysis than we have space for here. As a point of departure, we nevertheless suggest that complex problems of scarce resources must be considered within a larger social justice framework that includes the interrelationship between economic and cultural marginalization. (Gibson et al. 2007: 7)

Perhaps the most challenging segment of disability and technology studies is that sub-literature that deals with profound ethical issues of life, death and maintenance of life in persistent vegetative and minimally conscious states. Although not a major feature of this book, it is important to reflect on this facet of the research and the academic canon. Firstly notions of deficit and social rights at the heart of the medical and social models respectively clearly do not fit unproblematically into these analyses. If someone is being sustained by medical technology their impairment is not in doubt and it would be ludicrous to deny a deficit. A social model emphasis on the problem inhering in the physical environment is clearly not easily grafted on to this situation. However, each approach arguably needs to account for this scenario. If we acknowledge that impairment is not denied in both medical and social models of disability, and if as is increasingly the case many writers are rejecting the neat binary between impairment and illness, then surely disability studies has to acknowledge this issue (Mulvany 2000). If we say that sustaining life requires simply ethico-legal decisions about where life begins and ends then surely this has to account for advanced decisions and the wishes of the person being sustained. The development of Mental Capacity and Best Interests understandings and the notion of choices and rights at the heart of the Disabled People's Movement suggest that clinicians working in this field must review the preferences of individuals post-consciousness. Kaufman's US study of a hospital ward for people in a persistent vegetative state (PVS), completed in the 1990s, makes clear that, although the technology to sustain life was new, the cultural practices that surrounded the maintenance of 'normal' bodily actions—such as metabolism, nutrition and respiration—were well engrained. Here the technology quickly became emplaced in established cultures of medical practice. At this point the person with PVS was considered to be in a liminal state between life and bodily death and to have no entity, as a philosophical entity, at this stage (Kaufman 2000). Gray et al.'s 2011 study of perceptions of the worth of people in a PVS noted that they were seen as less important than those who had died, which is alarming:

> Most importantly, these results suggest that people's perceptions of PVS are out of step with objective biological functioning. A person in PVS, after all, is more functional than a dead person. Yet people seem to have difficulty thinking about such intermediate states in which modern medical technology blurs the line between life and death, allowing people to remain in limbo. As this limbo defies easy categorization, people rely more on intuition than on neurological evidence, which can lead to ethical quandaries. (Gray et al. 2011: 280)

However, over time, the notion of personhood, even in a vegetative or minimally conscious state, has arisen, largely it could be argued due to court cases determining key ethico-legal judgments, but also due to the Disabled People's Movement's opposition to assisted dying legislation. Kitzinger and Kitzinger (2015) explore the different perspectives of medical ethicists and patients' families in the case of an individual in a PVS. They interview 51 people with a relative in a PVS in the UK. They saw clear differences in attitudes to the withdrawal of nutrition, a process heavily mediated by technologies, noting:

> Most professional medical ethicists have treated the issue as one of life versus death; by contrast, families—including those who believed that

> their relative would not have wanted to be kept alive—focused on the manner of the proposed death and were often horrified at the idea of causing death by 'starvation and dehydration'. The practical consequence of this can be that people in permanent vegetative state (PVS) and MCS [minimally conscious state] are being administered life-prolonging treatments long after their families have come to believe that the patient would rather be dead. We suggest that medical ethicists concerned about the rights of people in PVS/MCS need to take this empirical data into account in seeking to apply ethical theories to medico-legal realities. (Kitzinger and Kitzinger 2015: 157)

In the case of individuals deemed to be emerging from a minimally conscious state there is a larger non-ethics literature dealing with more supportive use of technology (Lancioni et al. 2011). Here a specialist easy-function net-book computer was provided with Global System (for) Mobile (communication) (GSM) options with pre-programmed contacts to aid recall where brain injury may have affected memory and orientation. This is a clear instance where technology is providing possible solutions rather than merely creating new dilemmas associated with minimally conscious states. Lancioni et al. (2013) have also completed related work on leisure support for people post-coma using digital technologies.

## Conclusions

The above has provided an overview of debates at the intersection of disability and technology. I deliberately set out to move beyond social science, given that a good deal of the work on disability and technology is from clinical, rehabilitation, computation, ethics and employment studies. I have argued that, while a deficit approach to disability and technology was never pervasive outside of the social sciences, it has and continues to shape the way research is framed. Whether this is due to studies being focused on purely technical concerns, such as seat comfort and wheelchair design, or due to professional narratives overriding the phenomenon under investigation, there is evidence that such a focus does continue to pose a threat to the fullest understanding of the relationship between disability and technology. I have also suggested, however, that reified constructions of technology have been challenged in both the social sciences and rehabilitation sciences to some extent.

There has arguably been a convergence since the 1980s between social science and rehabilitation research towards more situated accounts of disability and technology, to account for psychological and social factors and for the user voice. The shift within social sciences has been towards a post-structural framing of disability and technology, although some of this work is unduly prolix and could be seen in its celebration of boundaryless selves to be something of a luxury in a resource scarce world. However, the notion that technologies act upon humans and other technologies has to be a valuable contribution to this field. The rejection of binaries and the Cartesian dualist construction of the body and mind have also been helpful. There is a risk that post-structural arguments in announcing the death of the meta-narrative is inadvertently creating its own meta-narrative. For example, can we discount material concerns? Can we simply say it is one of many factors in the colourful melange influencing technology use in a post-structural landscape? Or does this sound too apolitical and unengaged? We know that disabled people have less access to the internet and digital hardware. Can we be blamed for refusing to reject hierarchies of concern? We know that workplace technologies could help some disabled people overcome wider barriers. However, we also know that access to the workplace has both an embodied and social class gradient. The less extreme versions of social constructionism do of course afford multiple influences to be accounted for. The above has in essence rejected the historical significance of strong determinist views of disability and technology. Although we can see the promise of technology being presented with theoretical abandon, this was probably motivated by a genuine desire for disabled people to connect fully with technological and social opportunities, granted though that these accounts did at times seem to assume that technology was beneficial as an end in itself. Accounts for disabled people and the Disabled People's Movement have been clear, however, that technology is most beneficial as a means to an end for independence, and does not equal independence, choices and social mastery. As Galis suggests, technology is not an independent variable but is dependent on the wider social, economic and technological matrix of influences.

Technology clearly has potential for some disabled people sometimes. These benefits can be life-saving or constitutive of fundamental communications as the iconographic image of Stephen Hawking's synthesised speech makes plain. At other times technology is clearly often a means to a variety of ends. We know that access to technology is structured by wider socio-economic systems, by what Castells calls globalised spaces of flows that perhaps bypass the most excluded, and even further that exclusion. We know that technology can be enabling and disabling, afford openings and closings. We also know that binary and determinist schema on technology and disability need to be treated with major caution.

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# Part II

## Understanding Disability, Understanding Technology

# 4

# Employing Technology to Good Effect: Technology, Disability and the 'Palace' of Paid Work

The question of the interrelationship of disability, technology and employment is an important one given the centrality of paid employment in underwriting social citizenship and reducing the risks of economic exclusion (Lindsay and Houston 2013; Roulstone and Barnes 2005). Technology might easily be proffered as a panacea for reducing barriers to and opportunities within paid work. Employment, however, remains a domain of hierarchies, exclusion and at times is the apotheosis of the competitive spirit (Driffield 2013; Edwards and Edwards 1979). Yet technology, most notably microchip technology, provides the potential for a redefinition of workspace, time space, typical modes of energy use and even redefinitions of productivity—just what is produced and how (Castells 2011). Key to this potential is the embodied energy and power of microchip technology—both software and hardware—to redefine spatial transactions and the size of transactions that may once have been large, paper-based and physically demanding. Stonier is important here in noting that such changes go beyond simple mechanised technologies which extended human musculature to the extension of human neurology, cognition, data processing and comprehension. Whether such technologies extend or replace neurological function is a moot

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point, while microchip technologies also extend musculature of course. However, the point is well made by Stonier that such technologies both embody human qualities, while also superseding and supporting those qualities (Stonier 1983). Not only does technology change, often reducing in size, alongside increases in processing capacity, but it has both underpinned and had an elective affinity with broader changes to the nature of work (Moore 1965).

Employment and technological change might then be seen to symbolise greater degrees of control over a person's working life (Coombs 1991; Burgstahler 1992a, b). Indeed there are good examples of microchip technology supporting workplace access and job retention internationally (Roulstone 1993, 1998; Scherer 2006; Thornton and Corden 2002). Remote or teleworking is a good example of the flexible working made possible by new information and communications technologies. Meshur's Turkish study of 150 people with orthopaedic impairments points to disabled people's own belief in the power of remote working in allowing work-able solutions (Meşhur et al. 2013). Applications of Universal Design principles may also avert the need for retroactive interventions in the workplace where technological or smart building design embed access and better building navigation features (Mueller 1998). This potential to link technology and Universal Design is clear in Mueller's seminal assessment and perhaps begs questions as to the notion of assistive technology (AT) as a specialist phenomenon into the future:

> The terms assistive technology and universal design challenge designers, engineers, and technologists to consider the broadest possible use for the things they create, to make assistive technology as useful to non-disabled persons as to those with disabilities, and to make the products and environments we design as usable as possible for everyone, regardless of age or ability. (Mueller 1998: 37)

Technology—small, adaptable, personalised—may complement Universal Design features in the wider workplace and also make anti-discrimination law more easily substantiated where often modest technological adjustments can make the difference between work access and exclusion. This may be especially cogent in support of people with learning difficulties (intellectual impairment) into suitable employment (Wehmeyer et al. 2006). However, evidence also points to conditionality, disclosure risks and organisational funding conflicts (Roulstone and Williams 2014) which can detract from enabling workplaces. Technology is increasingly seen to play a part in the jeopardies involved in workplace change. Technology makes possible the eradication of certain 'labour-intensive' jobs, for example as in the vast reduction in bank teller roles globally. Rather than create what Brynjolfsson calls a 'digital Athens' where the most repetitive jobs are done by machines providing more easeful lives, changes in many US industries like banking have led to greater unemployment alongside the growth in global economies (Brynjolfsson and McAfee 2012). Technology has been associated in some employers and managers economic worldview to hold productivity gains that require increased work rates or downsized human resources. This is reflected in Michailakis' formulation:

> The effects of technological change in present society conditions are contradictory: the positive effects on the individual level are counteracted by the rationalisation of production at the societal level. (Michailakis 2001: 496)

Technology can, indeed, substitute one barrier with another. For example, the shift from DOS to Windows operating environments, while positive for many disabled people, presented major barriers to workers and jobseekers with visual impairments who felt more accustomed to the linearity and non-visual world of DOS (Griffith 1990). The shift to manipulable screen icons may present major barriers to those for whom hand dexterity is a challenge (Johnson 1965; Sears et al. 1990). The increased use of email from the 1990s and web-based organisational functions also present clear barriers, not simply to how work tasks are done, but also the volume of communication. It is unlikely that colleagues would send quite as many typed memoranda as they do emails today. The immediacy and functional capacity to send wide-circulation emails has led to a sense that many workers have to clear their 'inbox' before they can begin their 'real work' (Garton and Wellman 1993). Such technologies are no longer seen as optional or especially personal (note the term 'personal computer' here) as technological change seems as much a fait accompli as other major organisational changes such as restructurings and mergers (Driffield 2013). As Worthington makes clear in his book *Reinventing the Workplace*:

> The same technology that allows workers unprecedented freedoms to choose their time and place of work also opens them up to unprecedented accessibility, twenty four hours a day, seven days a week. The ubiquitous PDA (personal digital 'assistant') has an equal chance of becoming a tool of freedom or oppression. (Worthington 2006: Preface)

Technology sits amidst the matrix of workplace change. Indeed the 'iron cage of bureaucracy' (Weber 1905) is nowhere more apparent than when asking for a particular laptop or different specification PC and being dubbed a special case for so doing (Titchkosky 2011). It is common for disabled people to have to 'go through human resources' or even occupational health to get the technology adaptations they might want, even where an external agency is tasked to respond to workplace access needs. This, as the evidence below suggests, applies to countries as diverse as the UK, the USA and Sweden. In a more post-structural sense, as Moser points out, disability is not a thing to be acted upon but something that can be enabled or disabled through social practices. He makes clear that meanings and possibilities are as much psycho-social as they are technical. His Norwegian study of how bodies and technology interact:

> explores precisely what positions and capacities are enabled; how these are made possible in practice; the specific configuration of subjectivity, embodiment and disability that emerges; and the limits to this mode of ordering disability and its technologies. The argument is that in this context the mobilization of new technologies works to build an order of the normal and turn disabled people into competent normal subjects. (Moser 2006: 373)

To use more established ideas, this seems to be pointing to a normalising thrust, one which may mean technology provision may be aiding one form of access while closing another one down—that of diverse embodiment. This was indeed part of Erving Zola's early distrust of much technological and medicalising discourse in the 1960s and 1970s (Zola 1982). In order to comprehend the complexity of the interrelationship between disability, technology and employment we need to explore critically the role of technology in aiding disabled people to get closer to, sustain and retain paid work. We also need to highlight those factors that continue to limit both technology and employment access. What then does international evidence tell us about the contributory role of technologies in making paid employment possible (Bruyere et al. 2006; Cornes 1987; Galvin 1986; Nochajski et al. 1999; Roulstone 1998; Roulstone et al. 2003; Scherer et al. 2005)?

Here, we can distinguish between technology as a means to an employment end, and as an end in itself by sustaining more enabling employment. This distinction is often surprisingly absent from studies and writings in this area, as are failures to distinguish off-the-peg technologies from assistive (specially designed) devices (Roulstone 1998). This is important as the dynamics shaping design, access, use and possibly the redundancy of devices are very different. The distinct workings and philosophies of what Stone called 'work-based' and 'needs-based' systems also require critical reflection (Stone 1984). The extent to which technologies assist disabled workers and job seekers (Burgstahler 2003; Kruse et al. 1996; Sauer et al. 2010) needs to be appraised alongside considerations of the wider matrix of factors, including intersectional variables such as gender dynamics, impairment, education, technology design, benefits systems, workplace culture and the ability to combine paid work with eligibility for personal assistance. In the USA the added significance of the veterans' lobby needs also to be borne in mind (Bruyère et al. 2006; Fifield et al. 1989; Hedrick et al. 2006; McNaughton and Nelson-Bryen 2002; Strobel and McDonough 2003). Each of these variables contributes in shaping whether technology is enabling, disabling or 'neutral' (Pell et al. 1997).

We begin by challenging the popular assumption that some early technology and disability writers held that new technologies are an independent variable, their own motive force, pre-social or profoundly influential of social dynamics without being shaped bi-directionally. Technologies shape and are shaped by social dynamics. Compared with much disability and technology research, the area of disability, employment and technology is generally professionally driven, often based on a deficit model of disability and is rarely user-led or user-focused (McNaughton and Nelson-Bryen 2002; Sauer et al. 2010). Much research in this area is rooted in vocational rehabilitation, technology studies, medical rehabilitation, education studies (concerned with transitions to IT work) and ergonomics. There are, however, a growing number of studies that are rooted in sociology, social policy and philosophy, while some bio-medical studies have begun to offer more nuanced thinking (Loader 1998; Michailakis 2001; Roulstone 1998).

As this is an arena in which centralised policy underpins many country approaches to technological support (Langton and Ramseur 2001; McKinley et al. 2004; Mueller 1998), for example the UK Access to Work scheme, we need to look at the efficacy and impact (planned and unplanned) of policy on disabled workers inter alia in the USA, the UK and Sweden. It is also important to study the pathways between IT-based employment and disabled employees' and jobseekers' lives (Schartz et al. 2002). In summary, we need to examine the potential of digital technology in making paid work possible, any barriers in current technology use (Schneider 1999; Wehmeyer et al. 2006; Yeager et al. 2006) and assumptions about disability that may reduce the potential of such technologies.

## The Promise

In my book *Enabling Technology* (1998) I adopt a social barriers model of disability to reflect on the role and potential of new technology in reducing environmental and attitude barriers that may have limited disabled people's access to paid work. Although rejecting the notion of a brave new world of work (Giannini 1981; Hawkridge and Vincent 1985; Murray and Kenny 1990), I do convey the momentous changes that have occurred in the workplace which make possible more manageable desk-top working environments (Cornes 1987). The size and power of new technology makes possible a communication and information space that, if used effectively, can act as a microcosm of what was previously a much larger and more demanding work space (Weinberg 1990). I am clear, however, that these changes were not driven by the needs of disabled people. The shift from primary and secondary industries and from industrial to information societies has provided the context in which broader philosophical connections between a lot of paid employment, heavy and dirty work can be challenged (Lyon 1988).

In the 30 years from the mid-1950s to the mid-1980s the percentage of global workers engaged in knowledge-based work increased threefold to 60 % by 1985 (Scadden 1984). The key shift from the nineteenth century, one dominated by manufacturing and heavy industry, is embodied in the increased presence of information at the core of the majority of paid jobs by the late twentieth century (Jordan 1999). Jordan makes clear that, while information underpinned heavy technologies or production in an 'information society', information becomes the central principle by which production, consumption and more generally power is dispersed. The US Department of Commerce predicted that, by 2006, circa 50 % of American workers would be employed in sectors that manufacture or are heavily reliant on information technology, products and services (US Department of Commerce 1999). This may be an underestimate of the actual growth. Not only is information-based work and computer technology more ubiquitous by the 2000s, but the processing power of desk-top devices has grown exponentially. Gordon Moore, co-founder of the Intel Corporation, coined the term 'Moore's Law' in 1965, which claimed that the processing power of computers would double every two years. This prediction has proven to be broadly accurate (Disco and Van de Meulen 1998).

For Loader (1998), information-based work holds the promise of more flexible, malleable and controllable work for the average employee. However, Loader is also clear that flexibility can accrue more fully to employers and that much theory of the information society is apolitical:

> In the first place, many theories of the industrial society adopt an atheoretical attitude towards technological development. That it represents the march of progress and that the only downside is a ticket for the journey. To question the consequences of such technological innovation for social structures and economic activity is often regarded as having a negative 'mind-set' and at worst to be labelled a Luddite. Nothing it seems must muffle the clarion call of the cyber-visionaries. (Loader 1998: 6)

Cohen and Zeitzer (2008) make clear the policy potential offered by the greater ubiquity and relative cheapness of new technology. They note the affinity between technology as an access tool, the changing workplace and an enabling state in merging welfare and market mechanisms to support job seekers better:

> The increasing use of technology in workplaces all over the world has resulted in unprecedented opportunities for people with disabilities to remain in, or enter the work force. Technology can be the key that levels the playing field for individuals with disabilities if their needs are met through the proper assistive or adaptive accommodations. Governments are in a unique position to harness this prospect and promote the increased employment of people with disabilities. (Cohen and Zeitzer 2008: 45)

For Cohen and Zeitzer, active state involvement in subsidising AT and more accessible workplaces can combine to provide greater employability for disabled young people. They mention both overt and more subtle subsidy and promotion policies that can support disabled people and the role of government in applying sweeteners to contracts which foster greater technology workplace adaptations. Sections 501 and 503 of the US Rehabilitation Act (1973) is of course the policy that bests captures this potential, where, to win government contracts, employer disability provisions have to be evident in the proposed contractual submission (Gooding 1994). The Telecommunications Accessibility Enhancement Act (1980) also mandated federal employers to adopt accessible telecommunications. Further key legislative change has been evident in the USA:

> [in] Section 508 of the 1986 Amendments to the Rehabilitation Act, Congress directed federal government agencies to limit their purchases to information technology that is accessible or could support accessibility. In 1988, Congress took an additional step in recognition of the crucial role that access to technology plays in the lives of individuals with disabilities, with the Technology Related Assistance for Individuals with Disabilities Act. Title I of that Act provides federal funding for grants to states to increase access to assistive technology and accessible information technology. (United States Access Board 2014: unpaged)

Alongside title IV of the Americans with Disabilities Act (ADA) (1990), which mandated a nationwide relay service, the US legislation has helped provide responses to changes to technology design which although enhancing general telecommunications may have inadvertently shown less fidelity regarding improvements in say digital hearing support technology. Such developments represent unplanned potential to make the workplace a more inclusive place 'by design' (Steinfeld and Jordana 2012). According to Button and Wobshall (1993), with the passing of title 1 of the ADA (employment provisions) (1990), not only can technology substantiate the potential of the ADA, but is central to the realisation of modified and accessible working environments. They suggest that without such technological involvement many environmental barriers would remain in place (Button and Wobshall 1993).

In the UK, the Access to Work scheme is state funding for full or more typically part-subsidy of workplace support. This has been a key funder of technological support and has included specialist software and hardware devices as well as the provision of laptops and duplicate PCs that allow home-based working, usually for part of a disabled (or sick) employees' working week (but by agreement this can be full-time). In the financial year 2003–04, 34,800 sick or disabled people were assisted in the workplace at a cost of £55.8 million (Meager et al. 2007). The Disability Discrimination Acts of 1995 and 2005 (consolidated in the EA of 2010) have helped to provide momentum to the provision of technology as part of the Access to Work Scheme. However, some slowdown in the numbers supported was noted in 2011/12 when the scheme was withdrawn from large public sector employers, where it was assumed provision should be routinely made. The funding dropped from £105 million to £99 million during this period. However, overall figures have again increased since April 2012 as greater numbers have been deemed eligible. Much of the growth has been in employees with sensory and mental health impairments, and was in part due to the Sayce Review of Access to Work which described the scheme as the government's best kept secret and which tended to have a clichéd conception of disability as physical impairment (Sayce 2011:14).

Between April 2013 and March 2014, 35,450 sick and disabled people have been supported, with 12,630 of that figure being newly helped individuals. However, this falls well short of the target of 100,000 disabled people Sayce argued could be supported via direct out-of-work benefit savings where disabled people are helped into work through the scheme (Sayce 2011:10). There is no doubt that the direction of travel is away from blanket support for large public sector organisations, a reduction in the largest packages and towards a greater impairment diversity profile (Department for Work and Pensions 2014).

There has been minimal evaluation of the Access to Work scheme, though Thornton and Corden's study (2002) suggested that the main impact of the programme has been to support job retention, often in response to job or impairment change. Conversely there remains little evidence that Access to Work forms a key part of the support process when sick and disabled people apply for paid work. The UK government, following the Sayce Review (Sayce 2011), are said to be keen to use Access to Work to aid materially the shift to paid work. In Sweden the Tuffa project of the 1980s and 1990s (Malmsborg 1995) aimed both to foster technology availability and to develop the access technologies themselves by more co-produced design and contract compliance methods. The project had some successes, but was time-limited and failed to raise substantially employer and professional (e.g. occupational therapy) awareness of the potential and role of new technology in the Swedish workplace. However, the Swedish Labour Market Board has continued a form of this project and has embedded a small-scale version into its labour market policies. More recent evidence, however, points to a much less systematic availability for work-based or work-oriented technological support, with municipal variation, and in some localities a requirement to contribute financially to technology provision (Anderberg 2007).

Other writers refer to the potential of personal computers and assistive devices in bridging the perceived divide between the normative workplace and disabled worker diversity (Burgstahler 1992a; Shell et al. 1988; Schneider 1999). In concrete terms there is scope for greater access to communications and one assumes workplace knowledge via computerised electronic communications. Understood more generally this seems to equate in much of the work in the 1980s and 1990s to the potential for greater workplace independence, whether we take this to mean a greater scope to fulfil a range of tasks or a social model interpretation of being able to have greater choice in daily working life. This can be construed as the choice and inherent benefit made available by the greater accessibility of communications and information, although these are not developed in the early works cited above. The development and spread of the internet and its centrality in many knowledge-based jobs in the 2000s can only add at least in principle to this sense of having the world at one's fingertips. Governments have not been slow to recognise this potential. The UK Department of Trade and Industry (DTI 2006) (now the Business and Innovation Service) made clear the potential of access to ICT in affording skill maximisation since it 'determines the ability of an individual to derive benefits from public services and to operate effectively in society' (DTI 2006: 5). Around the same time the UK Office of the Deputy Prime Minister was trumpeting the value of ICTs in supporting a more inclusive employment context:

> ICT changes the nature of a considerable number of jobs, in a way that allows the development of a more inclusive labour market. It introduces opportunities for home working, more flexible working patterns, better engagement in the workforce of disabled people and a range of new jobs. (ODPM 2005: 12)

The claimed role for new technology, both mainstream and ATs in the workplace, comes from policy and academic sources. It is difficult when assessing governmental assertions of the promise of technology to disentangle evidence from aspiration, claim from visions of more inclusive workplaces. Few governmental pronouncements seem apolitical; nor do they all assume that the dissemination of technologies outside of the workplace will impact similarly and equitably in the world of work. However, there is some clear evidence that the rhetoric of promise is not matched by the reality of an increasingly open and inclusive workplace. Technology does tend to be fetishised and treated as the dependent variable in much of the early academic and policy writing cited above. Evidence is often very thin, while research designs are often small-scale, qualitative and sometimes fail to distinguish assistive from mainstream technologies. Much academic work on the promise of technology was published in the 1980s and 1990s when technological optimism was at its height, though this may say more about the zeitgeist than it does about the changing workplace. We need therefore to unpick what has worked, and how disability, technology and the changing workplace intersect. What are the barriers and what works in supporting disabled people into the contemporary workplace? We will begin by exploring what seems to work and what evidence is in place to support those claims.

## What Works? What Evidence?

Langton and Ramseur's collaboration between university and disability organisation makes clear the need to view technology in the wider context of job and workplace design—what might be dubbed a holistic model of technology potential. Note the disabled person being placed at the centre of the technology evaluation and wider workplace review:

> Job accommodation strategies can effectively open up opportunities for persons with disabilities. Assistive technology should be considered as one of the most important of these strategies to successfully accommodate job tasks. There are some fundamental steps to consider when embarking on the use of assistive technology. A well-developed technology assessment process can be instrumental in assuring that each step is considered and properly carried out. This process is most effective when the consumer is at the focal point of the assessment that includes a thorough job analysis of the essential functions of the job as well as an understanding of the functional capacities of the potential employee. Opportunities often exist for low cost, off-the-shelf products which help to increase the availability of needed resources, lower overall costs, and improve maintenance, repair and replacement options. (Langton and Ramseur 2001: 27)

I have earlier counselled caution about seeing technology as the dependent variable in any study of disability, technology and employment. This same caution could be applied to the prior degree of specialised technology training. Pell et al.'s study of 82 disabled Australians makes clear, via logistic regression analyses, that general computing skills, level of education and gender are more important than exposure to AT, even when this was part of the disabled person's workstation. As with much disability and employment research, the general level of education is a key and enduring variable, while mainstream access to technology training seems to hold greater social capital potential than specialist use. This is not to play down the ultimate value of AT, though this appears not to be the clinching factor in obtaining, retaining and thriving at work (Pell et al. 1997: 332). The University of Washington, USA, undertakes an action research project to get more disabled young people in their middle year in high school into science, engineering and numerical disciplines both to increase exposure to computers and to build self-confidence via internet accessibility work, mentoring, summer school and advocacy work supported by staff and fellow students on the Disabilities, Opportunities, Internetworking and Technology (DO-IT) programme:

> Through electronic communications and personal meetings, DO-IT Scholars are brought together with post-secondary student and career Mentors to facilitate academic, career, and personal achievements. DO-IT Mentors study and/or work in a variety of fields including computer programming, post-secondary education, statistics, physics, engineering, computer science, computer consulting, and biology. One Scholar describes mentors as people who 'provide us with useful contacts in academic, career, and personal areas'. … They help participants find their talents, interests, and confirm their goals … One Scholar is working part-time at Microsoft and in the Adaptive Technology Lab at the University of Washington. A DO-IT Scholar is now the editor of DO-IT News, the project newsletter. DO-IT Scholars and Mentors have formed the nucleus of an electronic community of people who share both a love of science, engineering, and mathematics, and the challenges of a disability. (See Burgstahler 1994; Burgstahler and Cronheim 2001)

Michailakis (2001) makes clear the importance of providing workplace technology accommodations for current employees who may have experienced impairment effects. His mixed-methods study of workers who had received subsidised ICT adaptations in Uppsala, Sweden suggests that assumptions that technology will open up opportunities may overstretch its potential, especially at times of economic downturn:

> These figures verify a well-known trend in the labour market for persons with disabilities, namely that those who already have a job who become

> disabled are better off than those who are trying to enter the labour market in the position of already being disabled. The present evaluation study has shown that the ICT-based accommodation of workplaces programme can bring many benefits for individuals with disabilities. (Michailakis 2001: 477)

Chapple and Zook's study of 200 interviews with IT employers, training programmes and business associations explored the changing global economy and successful ICT training programmes for 'disadvantaged' (including disabled) adults. They concluded that good soft skills training (social skills), good job-training matching, the quality of ICT training and the currency of ICTs in the training context are all important in helping to get disadvantaged people into sustained work (Chapple and Zook 2000). Again the generic seems to triumph over specialist training and support. However, it could be argued that disabled people with the greatest needs may be under-represented in these studies and thus are not factored into their findings.

Sauer et al. (2010) undertook a systematic review of nine studies on cognitive disability and AT. By focussing on an impairment that is likely to prompt the need for AT, the study was more inclined to support the value of it in this context as central to employment engagement and inclusion. Sauer notes how vocational and community support require further connection with employer and disabled people's conjoined needs (Sauer et al. 2010). Similarly, Yeager et al. note the importance of AT. Their participatory action research study of disabled Californians who attended centres for independent living illustrated the importance of AT in supporting access to and remaining in the paid workplace:

> A majority of working respondents reported using assistive technology (such as adapted telephones, wheelchairs, magnifiers, and adapted computer equipment) or services to perform job functions. The vast majority of those using job-related AT reported substantial benefits to their productivity and self-esteem. (Yeager et al. 2006: 333)

There does then seem to be apparently contradictory evidence, that generic technology and training seem to be more important where less severe impairment is evident, while more challenging impairment histories seems to lead to greater benefits from specially designed ATs. This could of course be read simply as a complex rather than contradictory situation that requires the intersection of context, impairment and technology to be understood. Indeed definitions of AT are themselves often not agreed. Wilbanks and Ivankova's recent study of AT in the workplace for people with spinal cord injury took it to include wheelchairs, lifts, hand tracker mouses and assistive software (Wilbanks and Ivankova 2014). On the other hand Schneider's German study asserts:

> The term assistive technology means any service that directly assists an individual with a disability in the selection, acquisition or use of assistive technology (AT) devices. The term includes:(a) evaluating the needs of an individual in the individual's customary environment; (b) selecting, designing, fitting, customising, adapting, applying, maintaining, or replacing assistive technology devices; (c) training in the context of implementing devices; (d) co-ordinating and using other services with assistive technology devices. (Schneider 1999: 159)

Thus a caveat is needed so as not to assume a shared benchmark definition is used in most research on AT and the workplace. This contrasts neatly with say domestic technologies, given that the workplace consists of the layers of workstation, one's own office or department and the wider workplace environment. Schartz et al.'s meta-analysis of disabled people in ICT jobs notes that employment matching and supporting access to employers that already successfully employ disabled people is a key predictor of good working with ICTs (Schartz et al. 2002). Thus matching and generic support in keeping a job can be more important than a form of technology at work. However, this is not the same as arguing that technology is unimportant. It is also an important truism that, for assistive and indeed some mainstream technology options, matching person and technology is also very important (Scherer and Craddock 2002). Lupton and Seymour's seminal analyses of disabled people and workplace accommodations to support job retention points to the need to develop an evidence base and response to disabled employees based on the precise and localised ways in which adjustments are made using new technology. They argue that debates have perhaps been too abstract and unevidenced (Lupton and

Seymour 2000). This sense of diversity is again evident in Wilbanks and Ivankova (2014; see also Lidal et al. 2007), with some seeing technology as part of a more basic struggle to develop work capacity, while others seeing it as the clear driver in opening up the workplace, as the following quote from their study makes clear:

> When I first got hurt, they brought all these different things, stuff I was going to need to write with, brush my teeth … and I just basically messed around with my fingers trying to figure out ways to eat and hold a pencil … I taught myself to type with one finger, my fingers do not work but I type with my index finger extended out and can type about 15–20 words a minute. Computers have really opened up the doorway for me, manual labor is not going to be a fit for me. (Wilbanks and Ivanova 2014: 5)

Other studies on spinal injured workers and jobseekers points to the necessity to adopt supported employment and community advocacy principles as new technology cannot itself overcome the limits of a readiness model of vocational support (Inge et al. 1998). In a similar vein, Schneider's 3 year study of supported employment agencies in a single region of the Federal Republic of Germany points to an elective affinity between technology and supported employment principles (Schneider 1999). My mixed-methods study of 78 disabled workers in the UK is both a mapping of the kinds of work being undertaken and a study of impairment diversity and their explicit relationship with workplace barriers. Drawing on a modified social model of disability, one that connected both social barriers and impairment, I provide rich data on the broader context and micro-level meanings and perceptions held by disabled people. Unlike previous research, I was concerned with paths into technology work, including via choice, rehabilitation, enforced work change and early user pathways. Not all participants felt they had benefited from technology; others felt they wanted greater access to and use of it. However, all could see the benefit of enabling technology in an abstract sense, and some were able to point to more immediate benefits and enablement as the following from a disabled chief experimental officer in a chemical plant notes:

> While I was chief experimental officer I was diagnosed as having multiple sclerosis. At the time I was doing chemical analysis and that became too much as analysis was quite a physical process. When I was in the laboratories I was learning spreadsheets. I eventually realised that the work would be better suited to my health. So I made a decision to request retraining. At the time I wasn't certain of the options with computerised chemical analysis, but I found the shift was straightforward as colleagues in other departments of Axxon [pseudonym] were already doing work with computer-based profiling. (Roulstone 1998: 69)

Another example is a systems engineer with spinal injury who discusses the spatial aspects of computer-based work:

> The main benefit for me is I am able to do a multiplicity of tasks in one place. This is made even easier by Windows as it has a clock and a calculator. I suppose I feel more in control of my work, and feel confident that I can get access to what my colleagues are doing without having to walk about … I can as the advert says let my fingers do the walking. (ibid.: 83)

My study was designed in a way to evince both benefits and barriers. It is towards barriers that the focus of the chapter now turns.

## Barriers to Enabling Technology

Despite the potential in new technology to redefine the nature and experience of work, there remains much evidence of the continued barriers to both work and technology. Without both elements of the equation, disabled people cannot realise this potential. We can sub-divide barriers into structural labour market barriers, including lack of access to IT labour or IT intensive jobs. An associated barrier is fractured or blocked pathways to higher skilled work due to poor educational and training opportunities. Barriers within paid work inhere in negative attitudes, high pay-back investment assumptions, poor self-esteem, inflexible working practices and unstable working environments. We shall explore these factors below.

One major variable which supports or weakens technology use and enablement are colleague and management attitudes and responses.

Collela's classic study of 'Coworker Distributive Fairness Judgments' (Colella 2001) provides a robust meta-analyses of the factors that are likely to support or limit reasonable adjustments in the workplace. Collela establishes that cost, perceived advantage accruing to a disabled colleague, the visibility of the adjustment, the impact on the co-worker, whether adjustments excuse colleagues from core job functions, and the amount of good will that pre-dates the accommodation are all important. Colella makes clear that the perceived 'desirability' of impairment is important and notes:

> For example, most people would agree that a large print computer monitor is an appropriate accommodation for someone with a severe visual impairment or that a ramp is needed for someone in a wheelchair. But would most non-disabled people believe that frequent absences are needed by someone with kidney disease? (Collela 2001: 109)

Indeed the question of tolerance of the extent, impact and symbolism of technology provision as reasonable adjustments is clear in much of the research findings. My early UK study found colleague jealousy, suspicion or plain curiosity to attach to technology provision (Roulstone 1998). Wider attitude barriers are seen in my findings to support the idea that technology potential is negated or lessened by wider workplace change, culture and cost-centredness:

> As time passes we will be using the PC for more and more functions, although we keep manual records of everything. You see my supervisor has been there 30 years, and she says as long as she's there a manual back-up system will stay. If I had a choice in the matter I would use a PC for all my paperwork, except signing dockets etc.; where a pen is still necessary. You see, I can see much more mileage in the machine than I am allowed to get. My boss has the final say in things. My disability doesn't get recognized in this respect. (Roulstone 1998: 99)

It could of course be argued that organisations and their cultures have changed. However, studies suggest otherwise. Schur et al.'s comprehensive documentation of the key variables that support disabled people point to the following pivotal factors:

1. Stereotypes;
2. Negative affect or discomfort in being around people with disabilities;
3. Perceived strain of communication;
4. Personality factors (tolerance);
5. Prior contact with disabled people (what some psychologists call proximity). (Schur et al. 2005: 10–11)

My study identified employers as the largest perceived barrier to enabling technology use, followed by professional (provider-assessor) and colleague attitudes. Existential concern about a disabled colleague's ability—overlooking technology potential, misapprehension of disability and at times the belief that technology could neutralise a person's deficits—were all evident in my study (Roulstone 1998). Of note, employer, professional, colleague and sometimes disabled employee constructions of disability and technology were largely based on a medical or deficit model of disability. Indeed to get ATs most workers have to be prepared to go via occupational health or local appointed health workers, especially occupational therapists, to get access to larger packages of workplace support. This seems an extraordinary hangover from the days of paternalist provision of 'specialist support' and to overlook how many disable people in the digital age are experts in their own needs. From my fieldwork in the mid-1980s, through to Michailakis in the early 2000s, the question of employers getting payback for their investments in new workplace technologies remain key tensions in enabling and disabled technology. Michailakis, while more optimistic overall than I am, perhaps in part as a result of the greater ubiquity of digital technologies in the later study, sees macro-level global economic developments as often challenging more localised micro-level benefits of technology (Michailakis 2001). Technology then is not immune from such evaluations and the perceived value of colleagues, their being seen to 'do their bit' in the workplace shapes the extent to which technology adjustments are seen as acceptable. This flies in the face of ADL, which not only affords positive advantages for some protected characteristics, but places employers under a duty to make reasonable adjustments (UK) or accommodations (USA) which in part aim to avoid wider disadvantages for disabled workers. Collela's and Schur et al.'s work is useful in synthesising a range of studies. In being located in a management and behavioural studies context respectively, they are more concerned with organisational response than either technology studies or disability rights. Their work is valuable, however, as a predictive model of when and how much technology is likely to be afforded and across a range of country contexts. What is not factored into this meta-evaluation is the time taken and nature of the provision of technology accommodations, as these can be very lengthy and disabling processes (Sayce 2011).

It is perhaps a truism that adjustments are meaningful where employment is readily available. The lack of accessible pathways to aid work for young disabled people is a major issue, with educational and training in technology subjects often difficult to access (Burgstahler 1992a; Horn and Shell 1990; Schneider 1999). The US National Science Foundation taskforce (1989) study of lab-based education established that laboratories were often inaccessible. University managers and employers lack information about the rights and needs of students with disabilities and their potential contributions to society (Leyser 1990) and have little knowledge of the characteristics and needs of disabled students (Dodd et al. 1990). Evidence from the USA suggests staff and managers in science, engineering and mathematics subjects are less accepting than those in social sciences and education (Fonosch and Schwab 1981). These of course are the very courses needed to give the greatest advantage in technical, number and technological skills. However, faculty attitudes have been found to be more positive when members have previous contact and more information about students with disabilities (Aksamit et al. 1987; Fonosch and Schwab 1981; Stovall and Sedlacek 1983). This reflects the positive role of proximity in the world of work more generally.

The intersection of new technology and pre-existing workplace and labour market dynamics leads unsurprisingly to disabled people being under-represented in the very jobs that may hold the greatest potential. Schartz et al. undertook a meta-evaluation of studies of the employment of disabled people in IT sector jobs, noting the under-representation of disabled people in this sector (Schartz et al. 2002). The association of the IT sector with elite educated, often able-bodied men, holds barriers for non-typical workers trying to get a foothold in IT work:

> The Information Technology Association of America' taskforce suggests that the image of the IT field as a domain of the highly educated and technical elite and the lack of appropriate role models keep members of under-represented groups … from pursuing training and education required for IT positions. (Schartz et al. 2002: 641)

It could be argued that this is no different to the relatively low employment of disabled people in other sectors (Blanck 2000). The US National Science Foundation study of 2002 established that disabled people represent only 5.8 % of the science and engineering labour force, compared to 20 % for the background population. There is little robust evidence to counter this assertion; however, it is noteworthy that the very sector that may have an affinity with some disabled jobseekers is equally hard to access. Research also suggests that disabled people are less likely to have access to a computer in their daily lives. Kaye's (2000) study of computer and internet use for the US Bureau of Labour noted 42.6 % of disabled people have computers and 26.4 % use the Internet, compared with 56.9 % and 44.0 % of their non-disabled counterparts. Bruyere and colleagues studied the accessibility of online recruitment with increased IT-based systems by surveying 433 human resource representatives:

> Survey results report that nine of the ten organizations use Web processes for job postings, eight out of ten for online benefits information dissemination, and about six out of ten for online benefits self-service and online employee training. (Bruyere et al. 2006: 397)

The study found that web accessibility was low, as was awareness of accessibility issues and training, despite W3C type standards. In an earlier study Bruyere noted how, contrary to enabling disabled people, new technologies, especially ATs, can emphasise 'difference' or what disabled people are 'lacking', which in turn acts as a stigma or low expectation of the disabled worker (Bruyere 2000).

## Conclusions

There is little doubt that, in the most abstract sense, new digital technologies, their size, power and manipulability, present major potential for disabled workers and job seekers. Whether as tools to help retain an established employee or as a means to aid the transition to paid employment, new technologies are now affordable technical solutions to the disability employment problem. There is evidence in many of the above studies of disabled adults gaining or retaining work, partly due to technological changes, whether longer run and diffuse, or partly due to targeted or specialist support. Technology, however, from the earliest microchip developments to modern hand-held communications devices, are all shaped and limited by the wider matrix of social and workplace dynamics. Workplaces are a key to social citizenship, but also represent the key locus of competitive and at times cut-throat behaviour. Whether technology can trump such a direction of travel is a moot point, for it has been one facet of global restructuring that may be reducing opportunities for traditionally marginalised workers.

In a less abstract sense, we know which factors limit or enhance the likelihood of technology being enabling—proximity, unconditional attitudes, flexible human resource practices, networked organisations and technology awareness are all important factors which can make or break the disability and technology nexus. In terms of research, although greater critical insights have been evident and rehabilitation studies has become less pervasive in formulating the evidence base, the funding and design of large-scale research studies, which can account for broader patterns of enabling/disabling technology and the localised nuances of use, are still required. Too often studies are either about say very specialised augmentative or AT studies at one extreme and undifferentiated labour market studies at the other. The need for a fuller more systematic evidence base on what works and what limits potential remains an urgent one. Evidence for which variables are most important requires further investigation. We know that for many disabled people a good standard of education (above level 2 for labour market purposes) and sound generic technology training and skills are all important. We also know that a place and training approach, whether in technology-rich work or not, is an important adjunct to labour market access, as is advocacy and communities or circles of support.

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# 5

# Disability, Ageing and Technology: They Think that Throwing a Pendant Alarm at You Equals Independence

> I don't want to be particularly conspicuous on account of my particular way of dealing with my disability or because of my disability for that matter. I really want to be known as yes, a person that has a disability but has a lot of attributes too. So I'd like to be known in context rather than just one part of me being known. Often the visible technology that I use attracts attention to that. (cited in Lupton and Seymour 2000)

Broadly, this chapter will explore the drivers, models, benefits, drawbacks and ethical considerations of the value of technologies for older disabled people. Telecare will be the principal focus here, although all technologies that play a supportive role in the lives of older disabled people will inform this chapter (Cortes et al. 2003; Newell and Gregor 2002). The major growth in domestic microchip technologies (often dubbed 'telecare') in the global North requires a significant recognition of these technological changes and their implications for disabled people. Much of the recent available literature focuses on telecare and ICT in the home or proximate to the home, such as GP tracking technology. The chapter will begin with an overview of the quite diverse narratives that frame the benefits of telecare for older disabled people.

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It will then explore how demography and policy change are driving forward access to and use of telecare, before looking at the barriers (and sometimes antipathy) towards the take-up of such technologies and the implications for future design, procurement and support of such technologies. I will also argue that telecare risks being seen as a new panacea, one that obviates the need for more extensive and humane social contacts and support. Before that, however, it is important to define just what 'telecare' is taken to mean. The Europe-wide interpretation of telecare is quite broadly:

> Sensors and monitoring devices, detectors, alarm systems, communication devices, video or imaging devices, smart phone apps and specialized medical devices connected with the internet. More advanced devices often use more than one technology and have more than one function. (Meidert et al. 2013)

A UK professional interpretation, one which links technology to function and independence, is provided by the Royal College of Nursing:

> Telecare uses a combination of alarms, sensors and other equipment, usually in the home environment, to help people live more independently by monitoring for changes and warning the people themselves or raising an alert at a control centre. Examples of telecare devices include personal alarms, fall detectors, temperature extremes sensors, carbon monoxide detectors, flood detectors and gas detectors. (Royal College of Nursing 2011)

Another helpful definition, again with a functional character, is provided by the Scottish Government Joint Telecare Project as:

> remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems. Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes, using information and communication technology to trigger human responses, or shut down equipment to prevent hazards. (Scottish Government Joint Telecare Team 2009: 1)

The SGJTP developed a typology, one based on a model outlined by the Welsh Assembly Government, that captures the waves of telecare interventions. First wave telecare was characterised by user-activated personal alarms synonymous with community alarm schemes; second wave telecare by sensors, alarms, detectors and environmental controls; third wave telecare was based on broadband, wireless and audio-visual interactive technology. Each successive wave is arguably technologically more sophisticated and less passive. However, as we will explore below, the ethical issues do arguably increase with environmental and interactive systems that do not so obviously attach to say community alarms (Scottish Government 2009).

Despite the above, there are definitional complexities and a muddle about just where the boundaries between telecare and telehealth begin and end. Broadly speaking, telehealth is more narrowly focused on monitoring health measures and sits more squarely within clinical and public health narratives than telecare. This explains close synonyms such as telemedicine (European Commission [EC] 2014a, b). Telecare is more concerned with technologies, both domestic and para-domestic, that afford greater safety and choices in that context. Telecare's value is underpinned by diverse narratives, but broadly is concerned with wider social wellbeing and independence. Caution is required, however, as some studies conflate, or see much closer synergies between, telehealth and telecare. Some studies use the term 'telecare' to mean 'telemedicine' (Botsis and Hartvigsen 2008; Jerant et al. 2001). It is also worth noting that, although most older people using telecare will be disabled, some would not embrace the term to describe themselves, thus the literature is replete with terms like 'frail elder' or 'dementia sufferers' or 'prone to falls', which can be seen as impairments to all intents and purposes (see Roulstone 2012).

## Narratives of Technology and Ageing

In an ageing society, one where impairment increases with age, we could view the potential of technological change in very different ways, firstly that small, microchip-based devices may help counter the cost of the health 'burden' of an ageing population (European Commission 2013a; McLean et al. 2011). The percentage of Europeans aged 65–79 is forecast to rise from 15 % in 2010 to 25 % in 2035 (OECD 2011). In 2014 just over 1 % of the world's population is aged 80 and above. Projections suggest this percentage will rise four-fold to 4.1 % by 2050 (United Nations 2014). However, we could also view technology as part of the matrix of options that can help older disabled people to have greater choices and control of their daily lives. We could reasonably assert that older sick and disabled people have often been tax payers who have helped fund a complex and far reaching welfare state. We could also argue more critically that spending money on telecare is more acceptable than using those same monies to fund what Wright-Mills called the military industrial complex or what I prefer to call discretionary technologies (Wright-Mills 1956).

These then are very different frames of reference and are based on narratives of the threat and cost of an ageing population. Mental images of 'ticking time bombs' and 'disease burden' abound, while concerns that professional-carer ratios will worsen are also common across Europe (While and Dewsbury 2011). Indeed there is an argument that to ignore such major demographic and social change, and its implications for the delivery of 'social care' for an ageing society, is reckless. Certainly the policy challenges are to square what seem to be inexorable cuts to adult social care with such an ageing population. It seems perfectly consistent to sustain both the view that telecare affords independence and to challenge the wider apportionment of state spending and to question why spending on social support has been cut so dramatically against a backdrop of greater 'eligibility'. In this sense we are counselled to go back to Marcuse's analyses of 'false needs' to ask questions as to just what a good society should do in developing certain technologies and markets and not others (Marcuse 1964).

However, another pragmatic perspective can be adopted, one which does not gainsay the growing number of the younger old (60–69 plus) and the older old (80–89 plus) in the global North, but which frames the prognosis differently (Forman et al. 1992). This approach, one rooted in much longer-term policy and programme change, points to the scope of technology to support ageing-in-place so that domestic technologies such as sensors, pendant (body-worn) alarms and GPS tracking systems can help support disabled older people and their family/support network in squaring the desire to age at home and to maintain independence. Generally the burden discourse is rooted in quite traditional constructions of disabled people as helpless and in need of professional or informal carer support. Notions of deficit, burden, cure-care and the need to 'solve' the disability problem are all cognate with the idea of disability as a burden. This approach, one which tends to conflate much disability with a health burden, what is essentially a medical or administrative model of disability, seems content to objectify aggregate personal challenges into images of burden, and as a drain on social resources. An example is provided in the following assertion from a major European study:

> Trials have shown that hospital admissions and mortality can be reduced by such devices. Telecare may therefore unburden the health care system and serve the patients' best interest in allowing them to live for a longer period of time independently and increase quality of life. (Meidert et al. 2013)

The alternative discourse, one that is rooted in a social model of disability, emphasises the cumulative impact of social barriers, institutionalisation and notions of cure-care as being further detriments to disabled people. Such approaches emphasise the right not to be institutionalised (in institutions or in one's own home), the importance of choices and self-determination in shaping social support. Within this alternative construction disability is seen as a product of a society and policy systems that fail to engage with the reality of impairment or disablement. A social model of disability and ageing has the potential to challenge alarmist 'burden' narratives and focus on just what a 'good society' might look like for disabled and frail adults. Not all writers who subscribe to a social model of disability see developing technologies as conducive to an enabling life. Of course the wider matrix of social values and factors are seen to shape new technology use.

As with all models and heuristic devices the picture is more complex than any one model can encompass. Certainly the use of a burden discourse can do little to enhance older disabled people's sense of inclusion and wellbeing. However, to ignore the potential of new technologies (old and new, basic and advanced) in helping square the challenge of what is undeniably a fast changing demographic profile would be remiss in the extreme. The austerity that has characterised the early twenty-first century does however add to the urgent need to recognise the value of low-cost domestic solutions in affording choices into later life. Indeed the advocates of the social model of disability, while helpful in emphasising the role of technology in supporting choices, have not commonly engaged their thinking with older disabled people. This leaves the reality of some bodily and cognitive challenges of ageing under-theorised and the response to technology sometimes rather under-explored. Clearly the complex interplay of age, technology and corporeal challenge is nowhere more difficult than in comprehending older disabled people's circumstances. This observation applies well beyond simply the potential of home-based technologies for disabled older people, and arguably characterises the limited engagement within a social model of disability of impairment and ageing. Older disabled people have tended to attract less attention from disabled people's organisations and disability studies (MacFarlane 1994; Proctor 2001; Zarb and Oliver 1993). However, the demographics of ageing with an impairment, alongside the growth in a choices agenda in later life, will continue to challenge social care and technological support systems (Arksey and Glendinning 2007). The latter leaves much scope for advancement in our ability to comprehend impairment, ageing, technology and disablement.

Of note, both narratives of burden and independent living can mask another powerful discourse, one that is arguably common at times of social and policy challenge—that the amount of promise invested in a given technology overstates the real benefits that can accrue from them. Thus telecare can be viewed as one in a long line of saviour or panacea technologies that policy-makers, practitioners and disabled people over-invest their faith in. The evidence below points not simply to limits on the availability and function of telecare, but also on immature markets and a resource scarce environment that characterises adult social support and the realities for many older disabled people. Telecare can help square cuts in adult social support and a growing older population, while at the same time being subjected to those very same harsh dynamics. We know that technology, especially within a technological determinist framework, has a tendency to be attributed with a potency for social transformation that lacks any evidence, whether we think of the 'missold' pedagogic benefits of the internet in education (Kaufman 1998), the role of CCTV in crime and harm reduction (Carroll-Mayer et al. 2008), or the equalising of power online (Spears and Lee 1994). Indeed the notion that new information and communication technologies can provide a clear technical fix has aroused scepticism for some time (Robins and Webster 1989). The attendant problem with telecare beyond that of availability and access is whether it does save money, professional investment and of course whether it does foster independent and health benefits. Much of the empirical evidence below is based on small-scale often qualitative research, while the recent randomised control trial of telecare and telehealth concluded that on the whole telehealth can be attributed with cost and health gains, the finances attaching to telecare are much less clear. We could of course take the view that benefits accrue well beyond cost savings—this is indeed borne out by the evidence. However, any social audit would have to account for the increased risks of loneliness (Nordgren 2014), surveillance and loss of independence. So, notwithstanding discourses of burden reduction and enhanced independence, the over-riding tendency in both approaches to assume benefits can continue to be reasonably challenged. This is especially important in social science terms in a telecare context where government–industry tie-ins are more developed than in many areas of social provision.

## Policy Drivers and Technology

A number of drivers for the increased use of telecare can be identified—internationally demographic and technological changes, pressure on social care systems, the Disabled Peoples' Movement and the independence and personalisation agenda—each of which converge around notions of ageing in place (Doughty and Williams 2001; Sixsmith and Sixsmith 2008). In the UK the massive decline in institutional care, the growth in aspirations of disabled people (Woolham 2006) and the costs of providing home-support have each converged to drive forward interest in telecare as a key strand of local policy and practice. Of course strictly speaking telecare does not substitute for support (or care), but simply affords alarms, alerts, communication devices and e-monitoring that can make ageing in place possible. It can of course help complement the wider matrix of social support. Carer organisations, a constituency dominant in the older people's domain, have noted the potential benefits of the peace of mind that alarms and sensors provide. This is not without new challenges, especially fears of surveillance that will be discussed below.

Another important driver for greater telecare take-up is the shift to greater self-direction and personalised adult social care in the UK. Although benefiting adults of working age more than older disabled people and people with long-term conditions, direct payments and latterly personal budgets are making possible greater choices and new forms of purchasing by service users and their representatives, which have major implications for social care commissioners and providers. The move to personalised social support was somewhat ironically the result of the limitations of the first wave of self-direction. The disappointing take-up of direct payments during 1996–2006 had meant that only 5 % of eligible people were in receipt of direct payments some 10 years after the 1996 Community Care (Direct Payments) Act was passed (Davey et al. 2006). Limited take-up, views that independent living had not taken strong root in adult social care and the growing demographic cost implications of an ageing population have led to redoubled efforts to 'modernise' adult social care and the recent emphasis on the compulsory offering of direct payments for those deemed eligible (DH 2009). Self-directed solutions then became more ambitious and contained strong rights-based ideas. Some key policy documents have reflected the policy shift to greater personal choice and control, for example the Green Paper Independence, Wellbeing and Choice (DH 2005) and the White Paper Our Health, Our Care, Our Say (DH 2006). These policy documents along with the earlier personalisation features of Valuing People (DH 2001) reflect the spirit of previous changes in adult social care by fostering personalised choices and the requirement for professionals to connect their work while placing disabled people at the centre of the decision-making process on social support (DH 2006). Together, demographic change, shifts towards greater choice and control and in some country contexts severe retractions of adult support funding provide multiple and growing impetus to explore telecare options for older sick, frail or disabled people.

Such developments are not confined then to the UK. There isevidence that governments in the global North, especially Europe,are investing significantly in telecare options to respond to the abovechallenges. The USA has witnessed some interest in telecare, butfrom a much lower baseline. The European Union funded Pacita (Parliaments and Civil Society in Technology Assessment) project has helped establish that demography, changing family structures (with low birth rates), greater labour mobility, fewer private care givers, have each been important in driving policy towards telecare adoption in Austria, Belgium, Bulgaria, Hungary, Ireland, Norway, Spain and Switzerland (Meidert et al. 2013). In a European context, the Europe 2020 Initiative: The Strategic Implementation Plan aims inter alia to reduce falls via telecare use, remote monitoring for integrated care and efforts to improve uptake of compatible telecare-health systems that will foster independence, active ageing and maximum mobility via global standards (European Commission 2013b).

For example in the UK the Preventative Technologies Grant (2006–08) funded £80 million of telecare investment based on a 'spend to save' philosophy and partnership principles (Department of Health 2004). The DH developed a key foundational policy entitled Building Telecare in England. The policy makes clear that it is based on the promise of telecare but also on the need to provide alternative solutions to social 'care':

> It is not realistic to plan to deliver care and support services in the way we do at present. We must embrace new ways of working both to meet the diverse needs and aspirations of people using services and to take full advantage of new and developing technologies. Telecare offers choice and flexibility of service provision, from familiar community alarm services that provide an emergency response and sensors that monitor and support daily living, through to more sophisticated solutions capable of monitoring vital signs and enabling individuals with long-term health conditions to remain at home. (Department of Health 2005: 3–4)

Of note the key target beneficiaries of telecare were those older disabled people with dementia, at risk of falls, vulnerable individuals, people with long-term conditions and those leaving hospital and requiring intermediate care. Such constructions and the very unclear constructions of disability in much DH policy make an exact mapping of telecare benefits for disabled people difficult. However, what is clear is that, while the net was cast widely in terms of impairment types, not all disabled people ageing at home and at risk of institutionalisation were targeted for support. This definitional confusion is made more fraught by the very different approaches to preventive telecare use across the UK, with some local authorities making it available without a social care and needs assessment, others making it available only for those older people who have had a social care assessment. However, despite this terminological challenge, key policy commentators coalesce around the value of telecare in avoiding institutional contexts. For example, Porteus asserts that in England 250,000 elderly, and one assumes sick/disabled older people currently in nursing home provision, could be supported via telecare to live at home or in extra care home settings (DH Care Services Improvement Partnership 2006). This study helped prompt greater funding for both telecare and an extra 52 care housing schemes across England. Some real caution is required, however, as the exact extent of continued local authority and professional engagement with telecare remains very patchy, even in the UK.

Shortly after the preventive technologies grant period came to an end (2009) the UK Department of Health acknowledged that the reactive rather than planned use of telecare and the commissioning and procurement were often driven by crises prompts and a culture of uncertainty in supporting 'upstream interventions through enhanced primary and community care-based alternatives; and focusing on "self-care"' (Goodwin and Clark 2009: 20). They go on to note that greater willingness to adopt telecare attaches to 'cases' where primary presentations include: 'dementia, falls programmes, intermediate care and re-ablement' (Clark and Goodwin 2010: 8). These then can be seen to support health as opposed to independent living ideals, although there may be some overlap here of course. Despite this patchy use and impact of telecare in the UK, 2007 witnessed the rollout of what the UK Department of Health called the Whole System Demonstrators Programme. This £50 million programme, alongside the 2008 Whole System Demonstrators Action Network (WSDAN), part research, part telecare rollout pilot, aimed robustly to demonstrate the value of both telecare and telehealth interventions compared to more traditional delivery models. The research element involved a randomised control trial of telehealth/care and traditional intervention arms with 6000 users studied. As noted elsewhere the telehealth aspect of the programme established robust benefits, but the superior benefits of telecare were not as discernible in the trial. This is reflected in the systematic international review of over 6000 telecare/health studies conducted by Barlow et al. (2007). Many of these studies emanated from the United States and reflect the broader European picture in noting the value and cost effectiveness of telehealth (such as vital signs monitors) but that ‘there is insufficient evidence about the effects of home safety and security alert systems’ (ibid.: 172).

Other European jurisdictions have embraced the felt need for telecare to support better health and independent living. The German federal government committed €30 million in 2006 under the Ageing Related Support Systems for Healthy and Independent Living (Altersgerechte Assistenzsysteme für ein gesundes und unabhängiges Leben) programme. Telecare is seen to offer greater technological and social choices for older people (they do not explicitly target telecare interventions at disabled/sick older people) to remain in their own home. Germany has been one of the more active countries in engaging with the Ambient Assisted Living programme which is based on a Europe-wide fund of €50 million to boost research on telecare (EC 2013c).

Not all Western countries are equally effective in increasing telecare use, however evangelical their policy stance might be. Audrey Kinsella’s comparative study of US/UK telecare policy and provision makes clear the lack of funding for preventive telecare use in the USA as much Medicaid/Medicare is provided for health needs and telecare/health at home is only instigated after a hospital stay. Thus the system seems to be more akin to continuing care hospital-driven policy. There are isolated policy developments that may aid telecare. The US federal Money Follows the Person project, one which stemmed from the Federal Deficit Reduction Act (FDRA) of 2005, and the New Freedom Initiative of 2001 have played small but symbolic roles in supporting greater choices, which can include telecare. Much policy activity is focused on better design and accessibility in the USA rather than questioning the best environments in which to age with an impairment (US Government 2007). The lack of social care protections in the US provides a less propitious context for more socialised responses to ageing in place. While the explicit use of telecare to foster choices, rather than simply counting as another choice, is some distance off.

## Benefits and Value of Telecare

Although not meeting the strict tests of benefits that inhere in a control trial there is much, albeit small-scale, research that points to the planned or unplanned benefits of telecare, most especially in supporting people with dementia and/or falls risk and their support networks to have greater freedoms and choices in daily living. Brownsell's study of 52 people at risk of falls found indirect benefits accruing from telecare trials in personal confidence both in home and community settings (Brownsell et al. 2008). Horton's study of monitoring devices of 35 people at risk of experiencing falls suggested clear benefits in offering peace of mind that fostered more confident ageing in place (Horton 2008). Clark's major study of 150 local authorities adopting telecare use for service users with dementia found that benefits clearly accrued for service users with dementia and their informal/paid carers in terms of greater choices, independence and in averting the need to enter a residential or nursing home. The role of telecare in supporting both paid and family carers was also noted in some instances. Sponselee et al.'s 2010 Netherlands study of factors leading to positive experiences points to health status (ability to comprehend telecare), marital status, current care configuration, technology-fit and the exact nature of daily challenges having predictive value (Sponselee et al. 2010).

## Technology and Disability Potential Unfulfilled?

It is perhaps not surprising that given generational factors older disabled people are perhaps the greatest challenge in realising the potential of telecare. Indeed the published evidence points to there being more barriers than benefits currently. This does not necessarily discount the inherent value of telecare, more simply it points up the need for good matching of technologies to a given service user and support matrix, an understanding of impairment effects and attitudes to telecare. The following provide a closer appraisal of those factors likely to limit or improve take-up and sustained use of telecare. We can explore the limits to its benefits under the headings of (1) introduction and exposure, (2) felt need for telecare, (3) technology and self-image, (4) comprehending impairment diversity, (5) inadequate design, (6) generational factors and (7) technology reaffirming or worsening isolation and loneliness. Intuitively, the manner in which often alien technologies are introduced into the homes and lives of older disabled people can be the make or break in forging interest or abandonment of telecare (Hocking 1999). If technology is introduced too quickly, is too technology-driven and takes little account of the idiosyncratic needs of a person then not surprisingly the chance of telecare being a long-term feature of a person's home is very low.

Bayer et al. (2007) note how the speed of introduction is probably the most important variable here, with a graduated approach as opposed to implosion type exposure being really important in reducing technology-redundancy. Clark and Goodwin (2010) to this end note the importance of the trialling of technologies if they are to be seen to fit with individuals' circumstances. This can obviate the expense and redundancy of technology that has little fit with an older disable person's homescape. McCreadie et al. (2002) alight upon the importance of the related point of good information and guidance to help orientate a person who may be technologically poor to adopt telecare. Of note, information and technology (aids, adaptations and equipment) were two of the original seven irreducible needs identified by early disabled people's organisations (DCIL 1980). Cowan and Turner-Smith (1999) and Daniels et al. (2010) point to the need for good training for older disabled adopters of telecare. The merging of these two important factors seems just as logical for older disabled people. Swedish researchers Magnusson et al.'s secondary review of available evidence (2004) identify the triplet of (1) user friendly technology, (2) information and (3) support in predicting telecare uptake and sustained use internationally. Mahoney et al.'s study of adopters/non-adopters highlighted that the greatest levels of adoption related to older, highly educated users who had a strong sense of control over the adoption process (Mahoney et al. 2001). This is an important finding as age was not the key dependent variable here; the high adopters were some of the eldest research participants in the study. Domenech and Lopez's (2007: 663) study of adoption refers to 'incriptions' and 'excriptions' of technology:

> One approach is to conceive immediate care delivering as dependant on how disciplined the home telecare service inscriptions are and therefore on how uneventful and smooth the assistance is. However, this paper aims to put forward a more complex explanation by pointing out that immediate care delivering is produced not only by expelling indeterminacy but also by taking advantage of it. In order to do this we use Bachelard's concept of ex-inscription to shed light on the practices and techniques that transform events into opportunities (rather than obstacles) for delivering immediate care to home telecare service users. (Domenech and Lopez 2007)

Here then a disciplined introduction of telecare suggests careful unfolding of devices and an almost anthropological gaze which connects the new with the established artefact and home. The felt need for a technology is also intuitively central to the decision to embrace, reject or simply leave technologies in their delivery box. McCreadie et al.'s major study of telecare makes clear that both provider and service user have to have some degree of symmetry of felt need for the technological transaction process to be successful (McCreadie et al. 2002). Mann et al. (2002) note how felt need is often a shorthand term to describe the felt boost that technologies may provide in aiding greater independence. The judgement as to this added independence is set against the investment of time and resource in acclimatising to a given technology. It is worth nothing also the extra emotional cost of having a telecare expert to add to the long list of professionals that disabled people have to co-exist with domestically. Such a further alteration to homescapes and the risk of over-technologising of the home does begin to raise issues of just how different some homes are from institutions (Milligan et al. 2011). The fear of being technologised and alienated from ourselves and our homescapes is supported by Zola's early scepticism about technological fixes for people with severe impairments (Zola 1982a). Zola noted poignantly: 'technology can also do too much for those of us with disabilities. The machines technology creates may achieve such completeness that they rob us of our integrity by making us feel useless' (Zola 1982b: 6).

Of course where the latter far outweighs the independence gains then adoption will simply not happen or a technology will be abandoned or brought out at times of professional visits. Lansley (2001) study notes the following adoption or rejection dynamics:

> the design of packages of telecare to suit the specific and expected future needs of individuals, their incorporation into the home and their effective use are not straightforward … The cost of installation, issues of who should pay, the disruption caused … For many moving from the theory of assistive technology … to the realities in practice will not be easy. (Lansley 2001: 440)

Lansley et al.'s study also makes clear the pivotal importance of good design in aiding adoption and sustained use. McCreadie et al. (2002) asserts quite reasonably that good design and the sense that a product is worthwhile engaging are two sides of the same coin. Doughty et al.'s (2000) study of design advances in falls sensors provides a practical sense in which design, wearability and the reduction of false (fall) alarms all sit together as aims. Their device is relatively inconspicuous, easy to wear/ detach and more effective than many of those which were evaluated before it:

> The fall detector we have developed is the size of a small radio pager. It uses a two-stage detection process which senses shock and the orientation of the wearer. A fall is detected within 20 s and triggers a radio signal to a community alarm system. Tests were devised using a jointed mannequin to simulate five modes of falling to understand the effects of impact at different parts of the body. This allowed us to select the appropriate trigger threshold and wearing positions for the sensor. Prototypes were evaluated with 20 people to observe false alarms. The final design allowed reliable detection in 180 different falling scenarios (Doughty et al. 2000: 51).

The obviating of expensive and worrying false positives and the confidence that the trigger to alarm is a genuine alert of a fall is key to the value of this device to both wearer, provider and call centre responders (Doughty et al. 2000). Design then can be further divided into functional effectiveness and aesthetic factors. Indeed these are often seen as important by end users. There have been some very helpful Universal

Design guidelines which are of value for mass produced telecare products (Von Niman et al. 2006).

In the arena of community alarms, designers for interventions in service users with cognitive decline have noted the value of icons rather than words in reducing mispressed buttons and false alarms. This could indeed increase the rate of real alarm reporting of course as Spanish research suggests (Ojel-Jaramillo and Cañas 2006). One important Scottish study (Taylor et al. 2012) noted the hitherto absent service user in telecare design. This is an extraordinary oversight given the power of tailored design and the importance of aesthetic fit with end users. The study of 17 service users/potential service users, suppliers and designers aimed to develop a wearable button alarm. The research provided iterative design workshops for product evaluation and development.

A key determinant of uptake and use is whether a given technology, its form, installation and broader presence is congruent with or conflicts with a disabled person's self-image or construct (Bayer et al. 2007; McCreadie and Tinker 2005). The way we construct our sense of identity has no doubt long-term antecedents, our formative years, generational factors and is based on family, kin and wider social network influences (Carsten 2000). The sense that some people are more or less likely to identify as sick or disabled is also important in establishing the imperative of adopting new technologies in our homes (Peters 2000; Watson 2002) It is perhaps not surprising then that the most extensive literature on telecare and ageing focuses around this fit or lack of fit with self-constructions. Heywood's study of housing design and adaptations provides a useful primer here. She notes how in her research dignity and control are more important than say access or technology features (Heywood 2004). This understanding of how humans and environmental adaptation interact and make sense of each other seems central to enabling technology provision and process. Sixsmith and Sixsmith (2000) note how individuals have to identify with a product if adoption is to be embraced. We speak of being or not being able to 'see ourselves' using certain technologies or styles of technology as aesthetic. These rather Meadean formulations (Mead 1934) capture the congruencies of technology and selfhood so that we constantly reflect on how our artefacts might appear in relation to ourselves. Although extra-domestic, the automobile, its stylistic and performance aesthetics, captures in a nutshell subtle differences in taste, technology and identity. Gergen in his book *The Saturated Self* (1991) makes clear that, in an age of social role and performance overload, the sense of what makes us 'us' is paramount, and how we are comprehended by others is of key importance in not straying too much from the constructions of others. Technology has to be understood in this context as potentially disrupting this management of identity. Boess and Lebbon (1998) make clear that design factors have to engage with this sense of self and importantly to offer health and wellbeing gains and not to affirm dependence.

Pape et al.'s (2002) international meta-analyses of telecare studies note how meaning is made. His research concludes the following have each to be accounted for in technology adoption: (1) the meanings service users assign to devices; (2) the user expectations of assistive technology; (3) any anticipated social costs; and (4) that disability is important in identity terms, but is not necessarily the defining feature of a person's identity. Domenech and Lopez's excellent ethnography of pendant alarm use provides an example of the identity and need constructions of older people that counters any view of linear decline in old age. Their study established that the older people researched were reluctant to wear the pendant alarm as this was seen to symbolise vulnerability. They were concerned that by wearing this it would symbolise unambiguously that they could not cope with what might be dubbed 'technological crutches'. The authors refer to the contrasted constructions of 'fragile and vigorous' bodies (Lopez and Domenech 2008). This word exhorts providers to understand the dual constructions of technology and selfhood. Indeed their findings points to the narratives of older people being entirely out of kilter with policy and industry constructions that telecare devices will aid ageing in place, reduce vulnerability and assist in healthy ageing. This study, more than any, captures the mismatch at both macro and implementation levels between official and personal narratives of telecare benefits.

It is increasingly recognised in disability studies and clinical studies that disability and age are heterogeneous phenomena (Gregor and Newell 2001; Watson et al. 2013: 121–205). This acknowledgement is incredibly important if technology applications are to be matched carefully not simply to people's psychological, home and aesthetic concerns, but also that in more practical terms that impairment and technology are matched. As Dickinson et al. make clear:

> 'Older people' are a diverse group … and technologies and research methodologies may vary widely depending upon the specific nature of the user group. Technology use among people 55+ varies considerably; as people age they are progressively less likely to use technology. Frail older people are more vulnerable to the negative effects of unsuitable technology as well as to potential discomfort in taking part in certain forms of requirements gathering exercise. Recognising the existence of such a vulnerable group, and the vital importance of accurate requirements gathering to ensure that any technology provided is appropriate. (Dickinson et al. 2003: 15)

The research suggests that impairment is also strongly correlated with use and redundancy of telecare; it also suggests that we need to be able to juggle with the realities of diversity in speaking of greater independence and also increased vulnerability as constituting this very diverse population. Of course choices and vulnerability are not opposites here (Brown et al. 1998). Mann et al.'s research (2002) points to the greater likelihood of uptake in people with musculo-skeletal or neurological conditions, impairments that are generally later-life onset. Pape et al. (2002) note that people with congenital impairment (e.g. cerebral palsy) have a high uptake and use, while those with progressive impairments tended to be more cautious and to take a more value and task specific view of telecare. This may challenge Mann et al.'s findings above and require further clarification. This makes any generalisation about greater use being determined by age of onset rather spurious. However, cognitive functioning and consistency of function are clearly important. Nochajiski et al.'s (1996) US study established that when you hold age constant cognitive function is the most important factor, similarly devices designed to aid cognitive function presented both personal and technological challenges compared with physical aids and devices designed to extend physical prowess or safety. Miskelly makes similar points about cognitive limits, while noting that telecare is often not well suited or designed for people with sensory impairments (Miskelly 2001).

Inappropriate or rushed telecare 'solutions' for people with say dementia may be needlessly distressing (Dewsbury 2001). However, other studies point to more positive outcomes, even in dementia where individuals are trained and supported to embrace or maintain the use of technologies (Nygard and Starkhammer 2007). This section has pointed to the importance of recognising difference, but not making assumptions about those differences. Some of the biggest adopters are those disabled from birth, those who are educated and the older old. Cognition is an important factor and needs to be accounted for: support, training and advocacy can of course help connect and match people with technology (Scherer and Craddock 2002). The importance of connecting technology with personal homescapes and self-constructs is made possible by good design, exposure, support, ongoing service and the matching of people and technology. The fear of isolation is a very real one where technology is seen to be part of a single-stranded attempt to reduce costs and risk further isolation (Pols and Moser 2009). Dewsbury and Edge sum up the importance of seeing the person on their wider psycho-social and environmental context. Without this there is a genuine risk of a 'technologisation of needs' and that such a one-dimensional approach might allow a person to 'function in society, rather than actively participate in it' (Dewsbury and Edge 2000: 11).

Alongside the risks of unplanned negative consequences of isolation, there are other real ethical challenges that relate to a wholesale or misplaced view of the panacea of telecare. The most significant risks relate arguably to loss of privacy, autonomy and dignity. This is most stark with the advent of monitoring technologies—indeed one person's monitoring is another's surveillance. The risk of furthering isolation is also very real where telecare is seen as a direct replacement for human social support (Abascal 1997; Rauhala and Topo 2003; Sorrell and Draper 2012). Roberts and Mort (2009) note how telecare only equates to one strand of what they see as the tripartite nature of care- monitoring, physical care and social-emotional care. Telecare can only respond at best to the monitoring aspect of this tripartite equation. If we take a wider construction of social support, rather than care, one encouraged by the 'care' legacy of paternalism, then independence requires choices, autonomy and rights. Just how these meld with monitoring and telecare is still not entirely clear: certainly telecare can only be one means to the end of independent living, while a technology-free option has to be meaningful if choices are to mean just that. Where a person lacks capacity or has significant support needs, health and social care narratives are currently better equipped to frame the monitoring and safety aspects of telecare. The latter is a very real risk where cost savings are seen as the main prompt for telecare investment. As Sheldon notes: 'it is clear then that technological systems must never be pushed onto people as a sticking plaster problem to deeper social problems' (Sheldon 2003:3).

There are many examples of commentators latching on to telecare—its power to save money as well as redefine domestic 'care' economies: 'telecare can reduce demand for care, reduce the burden on informal carers, and save money for the state and families. But it makes no sense at all to means-test its availability' (Samuel 2011).

In the same vein many stories have emerged as to the cost saving potential of telecare, which overlooks the wider role of social support, human contact and the limits of technology: 'the council is proposing a variety of care cuts. Introducing a telecare system to replace wardens is expected to save £532,000' (*Northern Echo*, 2011).

Such approaches risk countering the established verities of health (and one might add social care) ethics as contained in Beauchamp and Childress' (2001) formulation of ethics as synonymous with 'autonomy, beneficence, non-maleficence and justice'. In this sense technology should not add to social and decisional constraints; while those that lack capacity or need support in decision-making about technology use should be afforded real choice and control (Eccles 2010; Fisk 1997; Ganyo et al. 2011; Mort et al. 2013). The policies stressing choices and personalised lives that have emerged through the 2000s surely add support to this conditional approach to telecare and a cautious approach to ideas that approximate to panacea perspectives on telecare (see Perry et al. 2009 for an excellent appraisal).

## Conclusions

The notion of ageing in place, choices in later life and the potential synergy with enabling domestic technologies is a congenial one. We know, however, that the processes behind telecare procurement, provision and use are complex and that such technologies may result in loss of liberties and undue surveillance in domestic contexts. Telecare has its place, but should not be seen as a replacement for social support or the guarantee of wider social integration. Understanding the ways technologies are comprehended, embraced or rejected is central to our understanding of the value of telecare.

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# 6

# The Wheelchair: Enabled or Disabled? Houston, We've Had a Problem

In the previous chapter much of the higher rhetoric around technology and studies of technological benefits and barriers revolved around desk top technologies and technologies of communicative reach. These technologies are often market-mediated or at times facilitated by social work interventions, for example telecare. However, many technologies that sit at the heart of disabled people's independence are mediated by healthcare professionals and rely on bodily assessments in meeting eligibility criteria. This is nowhere more evident than in research and practices around what was originally dubbed the wheeled chair—the focus of this chapter. The wheelchair is both a master symbol of independence to some disabled people, but also the archetypal health technology to many clinicians. Some interventions also require the informed consent of disabled people and degrees of risk-taking in connecting with technologies. These risks are both physical in the case of limb lengthening surgery (Kitoh et al. 2014) or involve social risk in the sense of uncertain social response, for example as is the case with neuroprosthesis or exoskeleton developments (Breen 2015; Musicus and Davis 2013; Schearer et al. 2012). Technologies are rarely freely chosen and may be subject to wider systems of monitoring or surveillance. Indeed telehealth interventions, their

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design and function, are based on monitoring principles. Whether one views this as helpful in providing early alerts that can avert health crises or see these as further evidence of a nanny state or services externalising risk depends upon your standpoint, but these technologies seem to be here to stay (Goode 2014; Henderson et al. 2013; Kobau et al. 2012).

Although the percentage of officially disabled people who use wheelchairs is not that high, the absolute numbers using them is noteworthy; estimates of use for example in the UK vary from 640,000 (Audit Commission 2000), to 710,017 (Aldersea 1996) to 760,000 (Papworth Trust 2013), which amounts to 5–6 % of the current official figure for the UK disabled population. Certainly we know that the numbers using wheelchairs in the UK doubled between 1985 and 1995 (Aldersea 1996). Some caution needs to be attached to the differences between these figures, since they were completed at varying times and using different benchmarks. The US Census of 2002 established there were 2.8 million wheelchair users, amounting to 1 % of the population (US Census 2002). The US National Health Interview Survey did, however, establish that the number of Americans using wheeled-mobility devices, including wheelchairs and scooters, has quadrupled from 409,000 in 1969 to 1.7 million persons in 1995. The period 1973 to 2003 witnessed a six-fold increase in use of wheeled-mobility devices (LaPlante and US Access Board 2003). A study in France by Vignier puts the estimated percentage of wheelchair users at 0.62. Vignier explains the relatively low numbers in France:

> This more limited use in France might be due to various factors, such as a less adapted environment, a historical delay in developing wheelchair use, and stronger negative social representations of the wheelchair leading to resistance from potential users and lower levels of prescription by health-care professionals. Further studies will be needed to more accurately assess the impact of these different factors. (Vignier et al. 2008: 237)

The World Health Organization estimates that 10 % of the world's disabled population requires a wheelchair (WHO 2013). This figure hides major differences in regional dynamics and healthcare and should be treated with some caution. The stark differences in country prevalence of use is hard to explain, while the exact framing of the questions—for example: Have you ever used a wheelchair? versus Do you regularly use a wheelchair?—is an important variable, the question of what counts as a wheelchair may also vary cross-nationally. The apparent growth in wheelchair use may reflect changes in demography as its increase in use correlates with age and impairment (World Health Organization and World Bank 2011). Other factors in increased use are the cost and affordability of chairs, veteran and war injury administration activity, and changing attitudes about wheelchairs. What is clear is that, although wheelchair users are a minority of all disabled people, the wheelchair is central to the discussion of technologies of independence.

The UN (1994) Rule 4 and the UN (2006) Article 20 (personal mobility) and Article 26 (habilitation & rehabilitation) request member states to support the development, production, distribution and servicing of assistive devices and equipment and the dissemination of knowledge about them. It is to be noted that to make optimum use of a wheelchair, an accessible/barrier-free environment is equally important. At this point it might be tempting to reassert the judgement that health issues are not disability issues (Barnes and Mercer 1996; Grue 2014; Murray 2003; Thomas 2012). In the field of health technologies it is hard to escape the sense that technology, functional improvement, pain reduction and independent living are each inextricably linked. There is a literature that helpfully acknowledges the health needs of disabled people (Diesen et al. 2014; Emerson and Baines 2011; Grut and Kyam 2013; Reichard et al. 2011), though this treats disability and illness as separate entities. Although this has its virtues, as those studied are often people with learning difficulties (or intellectual impairments), this is more problematic where illness and disability lines are drawn less clearly, as is the case in arthritis, neurological disorders, spinal injury sequelae, brain injury and so on. Of course disability writers have often preferred the term 'impairment' to denote the effects of an abnormal body function. This inadvertently dodges the question of illness and health and the implications for technology studies. Some researchers use the term disabled *and* chronically ill as a useful shorthand which in one sense covers all eventualities, but it also skirts issues of how health, illness and disability intersect (Jan et al. 2012; Garthwaite 2011; McMaugh 2011). So, rather contentiously, the following is premised on a felt need to acknowledge that body dysfunction is often the trigger for 'proximate health technologies' such as wheelchairs, body-worn devices, stoma, prostheses, crutches, orthotics, hearing aids and sight aids. Some technological interventions are of course beneath the skin as it were, such as stents, shunts, by-pass surgery, internal fixation screws and plates.

We could of course simply say these are delimited and circumscribed health interventions. Relatedly it could be argued that the benefits of technology are at an individual level and do not alter a person's wider environment. However, as technology is part of the equation of just what provides independence for disabled people, these have to be accounted for. Certainly, the form and function of medical and rehabilitative technologies have changed dramatically through the course of the twentieth century, linking biomechanical with digital and electronic functions which carry potential for ever greater functioning and mastery of one's physical environment. There are of course very real threats to enabled lives, where technology is seen to drive moral and ethical concerns. For example, as Breen's analyses of exoskeletons notes:

> Even without an easily available cure option as described above, the advent of personal use exoskeletons may soon offer many of those with spinal cord injuries an opportunity to walk, albeit without being cured in the traditional sense. Granted, the currently available devices typically require the use of crutches, have substantial limitations, and are extremely costly. However, it is difficult not to reflect on the almost incomprehensible functional improvements and cost reductions of many other electronic devices over the past few decades. Those of us willing to consider signing up for the next or later generation of exoskeletons may be faced with an extremely difficult choice. To stand or not to stand? To walk or not to walk? Any response is fraught with challenges. Identity, social costs and perceptions, concepts of accommodation, even employment and academic deliberations would be topics for consideration. (Breen 2015: 1568)

Any person who has refused or vacillated over adopting the latest and much vaunted technology will know how difficult it is to seem to be resistant to what might be described as ableist to a disability problem.

Certainly many such solutions are over-engineered, expensive and risky. The risk of being seen as a technological laggard and thus wilfully dependent is a very real one. Thus the breadth of technologies, which I have preferred to call 'proximate health technologies', is wide and the enabling and disabling potential even wider. What then of the research and evidence on the impact and perception of proximate health technologies on disabled people? It is always tempting to concentrate as above on the very latest technologies and to overlook the more important and ubiquitous technologies such as the wheelchair. Still largely the province of medical eligibility systems, but also an iconic symbol of mobility and independence, the wheelchair is as diverse in format as any technology. From the very heavy manual wheelchairs of the 1910s to lightweight rigid-body chairs to large power chairs we can see the term already has definitional boundary issues. Wheeled-mobility aids are recorded as early as the sixth century BC in both ancient China and Greece where furniture and wheels were first merged, at least in recorded history (Koerth-Baker 2009). There are extant images of Confucius seated in an elaborate, but no doubt uncomfortable, wheeled chair. Kamenetz's classic history makes clear that wheeled chairs are a relatively recent historical phenomena with disability ostensibly being equated to lameness and physical dependence and carriages being early forms of assisted ambulance (from the Latin *ambulare*, meaning to walk about):

> Although wheels and chairs were known in prehistoric times, possibly 4000 BC, the sick and the disabled were probably always transported in a recumbent position. The vehicle for those who could not walk was the litter. Since the dawn of history it has hardly changed. Light, easily made, and easily carried by slaves, servants, soldiers, or members of the family, it was the ideal means for bearing the sick and the lame, overcoming the roughness of the ancient roads, avoiding the jolting of unconcerned beasts of burden and the shocks of unrefined carriages. (Kamenetz 1969: 205)

Greek and Roman physicians prescribed 'gestations' (*gestare* being Latin for developmental progress) to aid the recuperations of the sick or injured, and the wheeled chair probably has its origins in this recuperative context (Sawatsky 2002). Even here we see social standing and wealth being an important adjunct to a technology, rather like accessing massively expensive exoskeletons today. So, bath-chair-type technologies were in use in the eighteenth century at least, but only for the wealthy and those deemed worthy of carriage. The chair had a fixed body and would have lacked manoeuvrability and adjustment for physical difference. However, an adapted bath type chair was developed in the seventeenth century for the paraplegic watchmaker Stephen Farfler which could be hand propelled by pedals (ibid.: 209–210). Kamenetz notes the circular benefits of wheelchairs in responding to individual need but also in shaping broader social sentiment which in turn spurred new wheelchair design:

> Wheelchair improvements extended its use. Intensive rehabilitation of handicapped adults and children brought them from seclusion into more contact with the community, and their 'mobilization' in turn stimulated further improvements and a great variety of wheelchairs. (ibid.: 2010)

Kamanetz's optimism has been much criticised by more recent writers, noting that wheelchairs were very much designed as adjuncts to medicine rather than to facilitate independence and that disabled people had little or no say in the design regarding use and functional worth (Goggin and Newell 2003). Still, it is unlikely that any but the most well-heeled and influential in society were able to influence the design of any objects during the eighteenth and nineteenth centuries, making such retrospective judgements rather harsh perhaps. Overall wheelchairs began to be constructed out of lighter materials such as cane and with greater controllability. Bicycle and wheelchair technologies developed in a symbiotic way in the nineteenth century, though it was not until the early twentieth century, and in the age of the automobile, that wheelchairs began to take a recognisable modern shape. Everest and Jennings' lightweight wheelchair of 1933 was a key development in providing a truly portable chair which could be folded into a motor car and is more easily equated to independence and personally manageable technology. Everest was spinally injured in an industrial accident in his native USA and necessity was very literally the 'mother of invention'. The chair is virtually indistinguishable from the self or push propelled modern manual wheelchair.

The development of rehabilitation was spawned by the Second World War and helped take wheelchair function beyond recuperation towards physical prowess and wheelchair sport. Stoke Mandeville hospital in the UK in the 1940s pioneered the sports wheelchair which in time fostered lighter chairs that we associate with Paralympian sports even today:

> In 1943, Dr. Ludwig Guttmann was asked by the Government to establish a Spinal Injuries Unit at the Ministry of Pensions Hospital at Stoke Mandeville in Aylesbury, Buckinghamshire. The Unit was intended to treat soldiers and civilians injured during World War II. As part of his treatment for the injured veterans, Guttmann promoted different methods of rehabilitation, including sport. The first sport was a hybrid form of wheelchair polo and hockey, first played informally on the ward against the physiotherapists and then developed into a proper team game. (Mandeville Legacy 2014)

It is tempting to see Stoke Mandeville and the development of the wheelchair's use as a clear story of altruism and a 'wartime spirit'. Anderson's history, however, points to a regimented and statist concern to reduce the economic burden of the war injured. Sports and wheelchair-based rehabilitation were a means to that end of turning 'paraplegics into taxpayers' (Anderson 2003). Finkelstein also made clear that Stoke Mandeville was largely concerned with keeping disabled people out of wheelchairs. Obsessed with ambulation, the hospital had a reformist zeal, one which viewed wheelchairs as a last resort rather than as a helpful tool for disabled people, which Finkelstein experienced himself:

> From the moment of entry there was the usual bustle of white-coated staff going about their officious business. Everywhere, children with helpers struggling laboriously along 'walking'. Memories of Stoke Mandeville! How many hours did I spend in those endless corridors learning to 'walk' before returning home and promptly settling into a more active and rewarding life in a wheelchair? (Finkelstein 1990: 1)

Finkelstein, more than any other writer, arguably placed a question mark around the absolute sanctity of walking for disabled people (but see also Oliver 1993 a, b). While a personal choice where impairment or illness permitted, he was clear that a wheelchair is a tool like footwear or a motor vehicle which the mere suggestion of non-disabled people jettisoning would be absurd. Why then was wheelchair use seen to symbolise failure at worst, difference at best (Finkelstein 2004: 24)?

As late as 1986 the US rehabilitation writer Brubaker, writing for the US Department of Veterans Affairs, was able to say that wheelchair modification and design diversity was stymied by a provider problem of wanting to develop a generic design. Conservatism in wheelchair producers was due to a fear of product rejection, but at the same time they were slow to engage with users in developing for diversity (Brubaker 1986). Brubaker notes that much of the change in wheelchair design to afford greater manoeuvrability, lightweight frames and reduced roll resistance has emanated from the disabled sports community. The US biomedical engineer Rory Cooper and key researcher in this field notes the first development of electric wheelchairs was in the 1950s in the USA (see also Watson and Woods). However, he makes clear the path of development of these chairs has not been smooth or linear: that market-driven solutions often outweigh consumer concerns. He notes the imperative for many wheelchair makers is cost reduction; while this may be important for some disabled people, quality and fit with personal and environmental needs may be more important concerns (Cooper 1999). Cooper's later work makes clear that, although the design of wheelchairs has improved in terms of comfort and suspension, electronic control systems remain pegged back to technology developed some 30 years earlier, creating ride and stability problems for some users. This is important, he argues, as more disabled people are transitioning from manual to electric-powered wheelchairs when their impairment or illness deteriorates (200,000 such users in 2005 from a total population of 1.5 million wheelchair users) (Ding and Cooper 2005).

It is extraordinary that, outside of sport contexts, the involvement of disabled wheelchair users should have had such a limited impact on product design and usability. This is especially true as studies involving disabled people date back to the 1960s in the UK. For example, in 1965 the National Fund for Research into Crippling Diseases supported ergonomists and cybernetic researchers at Loughborough University in the UK to involve wheelchair users in the evaluation of current products and those being developed. The study found that diversity of need characterised the sample of end users (Platts 1971). Why, given the early engagement with end users, this did not become a standard core element of all but the most technical redesign processes is hard to fathom. More common research designs involved anthropometric measures of wheelchair users. Kenward's ergonomic study of wheelchair usability included 66 disabled children between the ages of 5 and 16 who were measured against wheelchair parameters. The study discovered a mismatch between child body variation and wheelchair parameters, which would require adjustable design features in future manufacturing approaches. There was no attempt to engage with the children's own views and measuring systems were expert-driven (Kenward 1971; see also Parkes 1966). One key factor in limiting user involvement in wheelchair design and usability studies is that of the extra costs of having end user co-researchers (Shah and Robinson 2007). The market-led nature of much technology development, histories of clinical and expert paternalism, the idea that 'we know best', taken alongside the cost of involving end users may begin to explain their relative absence from wheelchair research compared to say disabled worker–computer interface studies which have been much more likely to involve research partnerships (Buxton et al. 1986). The situation is summed up by the German researcher Buhler:

> In case of new technology prototype testing by users during the development [phase] can correct the aims by giving unexpected inputs. Although some research activities with user involvement are going on, it still needs more concern in industry and appropriate methodologies have to be established. (Buhler 1996: 187)

As we get closer to the present day we see slightly more user-involved projects researching wheelchairs. These are usually not about the overall chair design but about adaptations such as robotic features and voice-activated control. These features of course require finely calibrated development pilots and thus explain better the shift to user involvement. Although hard to quantify, there are also the more general shifts towards the philosophies of inclusive design and disabled people as co-researchers in wheelchair development. So, it appears the overall level of user involvement has been sluggish despite the promise of end users being able to offer authentic and naturalistic insights into current and future wheelchair design and design solutions more generally (Luck et al. 2001; Ringaert 2001). There are, however, a few notable exceptions to this. Buhler et al.'s study of 370 wheelchair users included young adults and older disabled people, and found that not only did end user involvement add realism and validity to the study, but also led to greater insights as to user diversity, personal needs and environmental challenges of using their wheelchair. Chairs were often not adjustable or bespoke to the disabled person's needs. Significant 'making do' was evident in the study findings (ibid.: 190–191). Hillman et al.'s (2002) study of a wheelchair mounted robot to assist daily living tasks is an increasingly common study design. This and similar studies are not focused on wheelchair technology per se, but additional devices which can extend the neurology and physiology of the user (Bailey et al. 2007; Desmet and Dijkhuis 2003; Di Gironimo et al. 2013; Huttenrauch et al. 2004; Pineau et al. 2011; Yoder et al. 1996). Clarke et al.'s UK development of a Health Technology Cooperative (HTC) successfully established end user, health professional, industry and academic partners to review a range of methodologies and substantive 'healthcare' technology challenges (including wheelchair design) for the cooperative to respond to:

> User involvement in device design, development and diffusion is important; however, it requires careful consideration and differentiation of the appropriate methodology when working with potential consumers who have disabilities. The authors are formulating a strategy to ensure effective and timely user involvement in projects as this is key to a technology pull and technology transfer within a healthcare technology co-operative. (Clarke et al. 2011: 362)

The framing of the wheelchair as a healthcare rather than a technology of independence requires further scrutiny, though the principles being applied in Clarke et al.'s work reflect a user-involvement philosophy of more than token significance. Alongside the more ubiquitous studies of robotically controlled 'high tech' research studies, there are a number of studies which retrospectively gauge the suitability of wheelchair design.

Bergström and Samuelsson's Swedish study of the satisfaction of 206 spinally injured users used the Quebec User Evaluation of Satisfaction with Assistive Technology 2 (Quest 2) tool to access the comfort and propulsion ease of manual self-propelled chairs. They found that satisfaction levels were higher regarding seating comfort and less satisfied with the ease of propulsion (Bergström and Samuelsson 2006). Chan and Chan's Chinese study of wheelchair user satisfaction was tested against degrees of community participation in a quest to establish which was most important in a disabled person's quality of life. They concluded that satisfaction with a person's wheelchair was less important than overall quality of life. This is fairly typical of what might be viewed as a rather over-elaborate methodology and, of course, in concluding that quality of life was more important it cannot discount the point that degrees of satisfaction with one's wheelchair may be constitutive of judgements on the quality of life.

Evans et al.'s (2007) study of electrically powered hybrid indoor-outdoor wheelchairs used a battery of a priori questions in a small scale qualitative study of young wheelchair user's degrees of enhanced independence and chair satisfaction. The responses were mixed with the research team noting that 'the development of disabled young people may benefit from the use of electric-powered indoor/outdoor wheelchairs, although the advantages may come at certain costs to young people's perceived and real safety. Recommendations to powered wheelchair providers include the demonstrated need for additional driving training as these young people mature' (Evans et al. 2007: 1281).

Kittel et al.'s Australian study, which focused on occupational therapy, explored wheelchair abandonment during the first five years following the original acquisition. Their findings mirrored those of wider studies on technology abandonment in assistive technology in establishing that poor matching between user and chair, limited design acuity, poor support in delivery and aftercare were all seen as factors making abandonment more likely. Papadimitriou conducted a phenomenological study of how a sample of spinally injured Americans ($n = 30$) began to identify with their wheelchair and embodied identity. Clearly a key role for occupational therapy and clinical prescribers is to understand this converging of body–chair boundaries and the psycho-social aspects of wheelchair procurement:

> Incorporating the chair into one's body involves skill acquisition learned during the participants' rehabilitation stay through routine exercise and training and by observing other patients or expert users. Although this skill acquisition may begin within the parameters of a medical institution, it is refined outside it. I have named this process 'becoming en-wheeled' because it is a form of learning to live through (the use of) a wheelchair in order to become newly abled. 'En-wheeled' is, as a concept, intended to point to a way of being in the world that is not merely mechanical or practical (as skill acquisition is often assumed to be) but also existential and embodied. (Papadimitrou 2008: 694)

More ergonomically focused studies are quite plentiful, with the functional capacity of disabled people as opposed to enhanced independence being the primary concern of much research. For example Thyberg et al.'s Swedish study explores seating difficulties among wheelchair users. The study established methods to identify seat issues better and how to help adapt chair seating to avoid secondary spinal or pain issues. It would be easy to dismiss such research as unimportant and being some distance from comprehending wider paths to independence and choice-making. However, adopting a sort of hierarchy of needs approach (Maslow et al. 1970), it could be argued that the reduction or eradication of discomfort and pain are prerequisites of independence. Kettle et al.'s UK study researched a total of 3082 wheelchair users between 60 and 90 years of age and established that little training, orientation and aftercare signposting was made available to many of those studied (Kettle et al. 1992). Other research which assists wheelchair use, but is not focused on wheelchair design, are simulated or virtual reality platform studies. Harrison et al. have studied the use of an iterative environmental design instrument that feeds back to the user possible hazards or building design features that may hinder or aid wheelchair access (Harrison et al. 2000).

An example of more user-focused study is provided by Brienza et al. (1995) This early study was based on focus groups of power chair users and technology developers to explore iterative design approaches. The study involved discussion of key issues for power chair users rather than a priori research agenda setting. The consensus was that priority should be afforded to design that increases wheelchair durability and reliability.

A focus group comprised of persons who use power wheelchairs and professionals working in the field were asked to participate in a brainstorming session to determine priorities for power chair redesign. Reliability and durability were seen as two important areas to focus attention on, while

> at the same time, there is a desire to enhance and advance the features of input devices and control systems. Many would say these changes constitute designing 'smarter' power wheelchairs, such as systems that can independently detect obstacles and can provide users with more feedback. (Brienza et al. 1995: 55)

The evidence seems fairly clear that the involvement of disabled people *ab initio* in wheelchair research is unusual and accounts for a fraction of the reported studies. Even where this involvement is evident it is post-production adaptation-type research or concerns studies into the addition of new applications such as robotic chair adaptions, speech or emotion-prompted movement and so on. Clarke et al.'s development of a design and review collective is exceptional in this context. So far we have only explored design and usability features as the focus of wheelchair research. One additional poor relation in research terms, arguably as many studies are market-driven, is the relative absence of studies of barriers to wheelchair acquisition. What though does the evidence have to say?

In England, the McColl Report (DH 1986) recommended that Artificial Limb and Appliance Centres should be integrated into the National Health Service, while in the same year the Royal College of Physicians 'Physical Disability in 1986 and Beyond' provided a blueprint for quality service standards and clinical training to support the provision of community equipment (Royal College of Physicians 1986). McMahon and Dudley's (1992) study of UK general practitioners (primary care) established that the majority of doctors knew little or nothing about prescription protocols for wheelchairs (McMahon and Dudley 1992). White and Lemmer's UK occupational therapy study of wheelchair access, 10 years after the instigation of the above reports, found that, although a newly devolved National Health Service wheelchair provision was providing many of those with permanent impairments with wheelchairs, the degree to which people obtained the chair they preferred was questionable, while cost constraint led to a stereotyped provision which aimed for uniformity across provider localities rather than a carefully-matched approach fostering greater wheelchair diversity (White and Lemmer 1998). Jelier and Turner-Smith's 1997 study of wheelchair services in England established that, despite the clear guidance levels of training, knowledge of prescription and procurement were very patchy (Jelier and Turner-Smith 1997). Eggers et al.'s (2009) US study of wheelchair provision models explored locality, impairment, clinical context and expertise to all be important, perhaps not surprisingly. The study, however, has little to say about the economics of access to wheelchairs where the state is a residual provider and the market much more pervasive than in say Western Europe. However, we know that socio-economic factors determine the degree to which wheelchairs are customised and made bespoke for certain social classes and ethnic groups in North America with Medicare/Medicaid recipients only funded for standard manual or non-programmable power chairs (Hunt et al. 2004). These, one assumes, are shadowed variables for poverty and socio-economic status. Bingham and Beatty's (2003) study of assistive technology provision and access in the US established that many health plans were inadequate to, or disallowed, the funding for key technologies such as wheelchairs (Bingham and Beatty 2003):

> Assistive equipment and medical rehabilitation are essential for maintaining health, functional ability and independence for many PWD, but PWD often exceed caps on coverage for these health services. As a result, almost one-half of all assistive equipment (such as wheelchairs, scooters, and assistive devices) obtained in the US is obtained without the help of a third party payer. Cost and coverage limitations of health plans have been identified as the most prominent barriers for people with disabilities seeking equipment. (Bingham and Beatty 2003:487)

Health plan coverage, the authors note, even when the funding of assistive technologies is firmly within a restorative or deficit model, emphasise maximum functional gain over a short period rather than independent living in the longer-term sense. More than 50 % of the 500 disabled people studied claimed they did not have access to assistive technology at the time of need, which is a very stark finding. Technically speaking current Medicare coverage pays for 80 % of wheelchair costs for older Americans as long as the provider is registered for Medicare supply (US Government 2015). Medicaid, the partner fund for working age healthcare support, can in theory cover these same costs, although it is subject to a means test and knowledge of both schemes and their facilitation of Durable Medical Equipment (the term which includes wheelchairs) are patchy. Some with modest incomes may be deemed ineligible for Medicaid support and have to self-fund or loan a wheelchair. LaPlante et al.'s definitive study of wheelchair use in the US noted that 50 % of individuals or their families self-fund wheelchairs (LaPlante et al. 1992). LaPlante's more recent analysis notes: '2.5 million people needed assistive technology devices they did not have, one person for every five people using assistive devices' (LaPlante and US Access Board 2003; LaPlante and Kaye 2010). Laferrier et al.'s (2010) study for the US Department of Veterans Affairs makes no mention of differential or graded access to wheelchairs, being concerned largely with the threshold between prosthetic and wheelchair use based on assessed functional need and the period of conflict in which a war injury was incurred. It is not clear from this if veterans are especially shielded from poor access to wheelchairs, or whether the research design appears depoliticised. Certainly US Public Law 104–262 makes provision for accredited veterans to receive support where they meet specified mobility and transfer (to chair) thresholds. But the issue then shifts to just who is accredited. These are complex and rather opaque criteria. Data on rejections and appeals are hard to obtain (US Department of Veterans Affairs 2008). Certainly the studies available mirror those in the UK military rehabilitation field in being concerned with returning veterans to maximum function and economic contribution (Laferrier et al. 2010).

What is often overlooked in discussions of wheelchair access is the gatekeeping role played by medical practitioners in the USA. While criteria for power chair access is reasonably clear (unable to mobilise for more than ten feet or self-propel in a manual chair), the threshold for manual chair access seems more contested. Thus any discussion of access has to be cognisant of this form of denied access where provision is based on stereotyped assumptions about which impairments merit wheelchair use. This point is not unique to the USA of course. The continued construction of wheelchairs as medical equipment is arguably evidence of a continued medical construction of issues that otherwise concern access and independence. Greer et al.'s recent study of federally funded wheelchairs points to the paradoxical situation that provider-dominated contexts can be procuring over-elaborate chairs in order to maximise their Medicare/Aid claim, while some with higher needs may be denied access to power chairs due to local interpretation of these schemes. Thus an inverse support law may be operating in this market-driven context:

> the Office of Inspector General, U.S. Department of Health and Human Services, issued four reports between 2009 and 2011 detailing fraud and misapplication of Medicare funds for powered wheelchairs, more than a decade after similar concerns were first raised by four contractors who process claims for durable medical equipment. Subsequent concerns have arisen about whether some impaired persons who need wheeled mobility devices may now be inappropriately denied coverage. (Greer et al. 2012: 141)

This points to very diverse uses and interpretations of the US Medicare programme in this context.

Access to an appropriate wheelchair might simply be seen as a binary of access or no access. It is important to remember that under-provision may attach to those who would benefit from a power chair or scooter but who have manual wheelchairs. Perks et al.'s Scottish study of wheelchair users with impaired upper limbs is a good example. Referring to this group as 'marginal users' the study established that such users constitute 15 % of the occupant-propelled population (Perks et al. 1994). Neri and Kroll's study of US healthcare barriers discovered that Medicare and health plans did not often cover repairs and aftercare, while the restriction to a replacement chair every five years for one wheelchair user meant she had to continue in an unsuitable manual chair for an extended period of time (Neri and Kroll 2003). The UK Audit Commission report *Fully Equipped—Assisting Independence* examined the provision of community equipment for disabled or older people and found systemic issues in the quality and philosophy of provision of wheelchairs and other devices. They noted that there 'were unexplained variations in all aspects of service provision, bearing little relation to underlying levels of need; the quality of services owed more to custom and practice, rather than to a considered view of the contribution that equipment services could make to the overall needs of the population; and eligibility criteria were often unclear to users, carers, voluntary organisations and staff' (Audit Commission 2002: 4).

Lezzoni et al.'s US study of 703 working age adults with multiple sclerosis found barriers to the acquisition and use of home-based wheeled-mobility aids (Lezzoni et al. 2010). Mortenson et al.'s (2013) US study of older disabled people seeking power chairs pointed to inherent ageist assumptions in the prescription context. Krantz et al.'s (2011) Swedish study of active chairs (lightweight robust models) noted the mismatch in worldviews of the functions and scope of wheelchairs. Samuelsson and Wressle provide a useful cost-benefit analysis of the benefits of power chairs in terms of paid employment and wider social contribution, noting that much research focuses on only the added cost of power chairs at the expense of wider costed benefits using an economic modelling (Samuelsson and Wressle 2014). On a more positive note, Sapey et al. (2005) note that wheelchair use in England had doubled between the mid-1980s and mid-1990s. They suggest this is in part due to changes in prescribing practice but more fully due to disabled people seeing the wheelchair in social model terms as a tool for living rather than as a symbol of failure:

> It is also possible that the increase was a result of changes in the prescription and allocation procedures within the NHS. In the past, institutional practices in the allocation of wheelchairs had led to such increases. For example, in Canada in the 1940s, a change to allocating wheelchairs to individuals rather than hospital wards not only led to an obvious increase in the numbers of wheelchairs in use, but also to the presence of wheelchair users in Canadian social and economic life (Tremblay 1996). In this way, a relatively simple change in prescription practice brought about significant social change. Woods and Watson (2002a) point to a similar rise in wheelchair use following the establishment in 1948 of the National Health Service, with its universal provision in Britain. (Sapey et al. 2005: 491)

## Conclusions

The broadening of the definition of prescriber of wheelchairs and the changing professional and service user attitude towards disability do signal some hope in terms of more flexible, less stereotyped treatment of the prescription process. The spread in use of wheelchairs and the ageing demography of the Minority World require greater attention to the question of access to appropriate wheelchairs, their fitness for purpose. The continued and arguably unrecognised binary differences between wheelchairs being constructed as ‘health technologies’ and ‘technologies of independence’ requires further scrutiny as does the politics of at times stereotyped and inflexible prescription. Of note, although notions of independence and wheelchair use pervade the disabled people’s movement—their histories—there is very little funded research that constructs its focus around wheelchairs and independence in the sense of aiding choices and freedoms. The term ‘independence’ is used in biomedical research to denote skills acquisition and enhanced social functioning and ‘participation’ (Chan and Chan 2007; Chaves et al. 2004; Rousseau-Harrison et al. 2009). There are only a small number of works which overtly connect the wheelchair with social freedoms and personal choices and control (Carlson and Mykelbust 2002; Gutman and Gutman 1968; Sapey et al. 2004; Woods and Watson 2003), while some works continue to frame new choices as coterminous with new social risks (Breed and Ibler 1982). There is an extraordinarily large literature developed over the last 25 years on wheelchair accidents compared to that of wheelchair and social barrier reduction (Calder and Kirby 1990; Edberg and Persson 2014). The balance of attention may hopefully shift further towards the impact of wheeled technologies on social barriers as enhanced social participation begins to align with a choices and rights agenda rather than a functional inventory approach.

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# 7

# To Augment or Not to Augment? That is the Question

The possibilities of technology to liberate, offer new social options but also to curtail and dehumanise are no more evident than in the following discussion. The chapter title—to augment or not to augment—aims to capture the widespread enthusiasm for technologies of augmentation by non-users and clinicians, alongside a huge variety of responses from disabled people and their communities. The following will explore these complex dynamics by looking at three technologies: the cochlear implant (CI), the prosthesis and limb exoskeletons. The term 'augmentation' is useful here as it is at once a technical appraisal of an addition or replacement (Chaur et al. 2006; Rapee et al. 2007), but it is also contested as it carries with it a notion of enhancement, bodily betterment and a greater human entity—which is at the heart of the contention over the need for and drivers of augmentative technologies (Starner et al. 1997; Salminen 2001; Salminen et al. 2004). The tension between these very different worldviews is nowhere more plain than in the discussion of CIs. Implants in sensorineural hearing loss (or hearing absence from birth) are perhaps one of the most powerful examples of neurological extension and enhancement to have been witnessed in the twentieth century. However, these developments have sparked one of the fiercest bioethical debates around the

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intersection of technology, d/Deafness and culture. The narrative of rescue is evident in some, though not all, clinical representations of the benefits of CIs, some going back to earlier social stereotypes of rescue and deafness, as here in the case of Wilson and Dorman who alight on key historic figures. The title of their work 'Cochlear Implants: A Remarkable Past and a Brilliant Future' provides obvious clues as to their worldview on CIs:

> **Beethoven:**
> For me there can be no relaxation in human society; no refined conversations, no mutual confidences. I must live quite alone and may creep into society only as often as sheer necessity demands. … Such experiences almost made me despair, and I was on the point of putting an end to my life—the only thing that held me back was my art … [and] thus I have dragged on this miserable existence.
>
> **Keller:**
> I am just as deaf as I am blind. The problems of deafness are deeper and more complex, if not more important, than those of blindness. Deafness is a much worse misfortune. For it means the loss of the most vital stimulus—the sound of the voice that brings language, sets thoughts astir and keeps us in the intellectual company of man. (Wilson and Dorman 2008: 16)

Wilson and Dolman go on to discuss how much better Beethoven's life would have been with a CI (2008: 17). From the available evidence, Beethoven's deafness was autoimmune mediated and, although it would be susceptible to CIs if adopted quickly enough, there is risk of the inflammatory processes acting detrimentally in implantation devices (Aftab et al. 2010). Wilson and Dolman were not of course making this direct link, but strongly implicit in their work is the sense that a cure-all at hand may rescue those 'lost in the world of deafness'. What then of the implant technology itself?

The CI was developed, at least in a rudimentary form, by the Italian physicist Alessandro Volta, the person credited with the unit of energy, the volt. Volta's battery device could be seen to stimulate a range of sensory nerves:

> at the moment when the circuit was completed, I received a shock in the head, and some moments after I began to hear a sound, or rather noise in

> the ears, which I cannot well define: it was a kind of crackling with shocks, as if some paste or tenacious matter had been boiling … The disagreeable sensation, which I believe might be dangerous because of the shock in the brain, prevented me from repeating this experiment (Volta A., 1800).

Volta's ideas were not honed into clinical use until the 1930s, but his contribution to the basic science is clear (Stevens and Jones 1939) It is estimated that there are 324,200 people worldwide who have been fitted with a CI. In the USA, 58,000 adults and 38,000 children have been fitted with CIs, almost a third of the global uptake (US Department of Health and Human Services 2014). Implants have been placed in children as young as 3 months old and the market is a multi-million pound phenomenon (Zeng 2004). These figures may seem small, but implants are not suitable for all types of hearing loss, and they are mainly triaged for those with profound or significant hearing loss or whose hearing has been absent from birth. However, the threshold for prescription has been relaxed, as Zeng points out:

> Cochlear implantation has continuously relaxed from bilateral total deafness (>110 dB HL) in the early 1980s, to severe hearing loss (>70 dB HL) in the 1990s, and then to the current suprathreshold speech-based criteria (<50 % open-set sentence recognition with properly fitted hearing aids). (Zeng 2004: 4)

The cost of an implant is also important in limiting take-up, with a unilateral device costing between £20 and 30,000 in Sweden, the USA and the UK. Bilateral implantation can cost double this amount. In the UK there are 10,000 recipients of CIs, the vast majority benefitting from a unilateral device (Crathorne et al. 2012). The duration of hearing loss or period post-birth with sensorineural hearing absence is also an important factor, as the efficacy of the device in stimulating the auditory nerve and the language-acquisition demands increase in a way that makes the cost-benefit analyses less favourable in clinical terms (Blamey et al. 2013; Lundin et al. 2014). Alongside clinical and cost issues the other major factor in limiting uptake has been the decision to forego an implant due to personal or family preference or cultural opposition to implanting as we shall see below. The issue of cultural opposition from Deaf communities is made more challenging where a child is pre-lingually without hearing. What then of the constructions of CIs beyond simple promise and rescue narratives. The following is discernible in the available literature:

- Clinical risk of implant narratives;
- Linguistic and performance risks;
- Cultural and normalisation risks of CIs.

## Clinical Risk of Implant Narratives

We shall begin with clinical risks. This is helpful as some writers wrongly present a picture of audiology and otolaryngology as hell bent on placing CI use ahead of a much wider range of options. Sparrow's notion of ethnocide suggests an almost monolithic attachment by audiological and ENT clinicians towards the adoption of CIs for eligible populations:

> As a result, the policy of promoting cochlear implantation in young children risks repeating the history of past policies of forced cultural integration wherein children were taken from one culture and prevented from learning its language but were also effectively denied the opportunity to assimilate into another culture. (Sparrow 2010: 460)

We shall explore more of these cultural risks below, but at this point the accusation of clinical dominance in the face of Deaf cultural opposition has to be tested prima facie. As with all technologies and professional narratives there is always a spectrum of positions from the zealously enthusiastic to the sceptical. Certainly a reading of the literature supports this idea. In addition to awareness that certain forms of deafness may not be 'treatable', there is a fairly substantial literature on the clinical risks of implantation and of the economic disadvantages of cochlear devices in certain circumstances. As early as 1991 Cohen and Hoffman were noting the complications of CIs in both adults and children. Infection, dizziness, necrosis and facial nerve problems were noted in this study, with older implantees and children younger than 7 years at raised risk (Cohen and Hoffman 1991: 710). This finding can of course be dismissed as old evidence given the date of the study, which may be a valid point given the possible improvements in implantation methods. A study by Reefhuis et al. (2003), however, found a 30 times raised incidence of meningitis for those who had a positioning device in implantation against the absence of a positioning device.

James and Papsin represent more recent opinion that implantation in children aged less than 12 months is clinically feasible; however, they note the importance of post-operative support as falls are more likely in this younger age group (James and Papsin 2004). Kempf et al. (1999) note the absence of serious risks in most CIs, but make clear that dizziness, tinnitus (persistent ringing of the ears) and vestibular instability are possible outcomes of surgery. Gastman et al. note the serious risks, albeit small, to damaging the carotid canal and artery in some implantations (Gastman et al. 2002). Blanchard et al.'s very recent retrospective review of 877 CIs between 1990 and 2012 found a failure rate of 5.7 %, which required reimplantation (Blanchard et al. 2014). The evidence seems to point to reduced risks over time, though the process of cochlear implantation is a major surgical intervention which carries continued risks. The procedure then is far from risk free and of course these risks are very much at the forefront of recipients and their parents' minds when deciding on the procedure. Certainly these clinical risks do challenge any blithe commitment to CIs, even where cultural opposition is absent. This is important as some writers do imply a sort of binary acceptance versus rejectionist stance on implants, but there are clearly shades between these standpoints. Failure can also be attributed to a limited gain in hearing and language development. This facet of failure is much less well documented in the literature and is clearly a key consideration. Certainly the literature does show that duration of deafness and extent of any residual hearing pre-implantation are both predictors of hearing outcomes (Van Dijk et al. 1999).

## Linguistic and Performance Risks

The decision to proceed with an implant then will no doubt be a worry for those concerned, and the clinical input ought to outweigh any risks, including post-surgical thriving. Another key construction of risk in the literature, one very much dominated by professional concerns, is that of the degree to which language development follows from cochlear implantation. This area is replete with strong proselytising narratives of just how plastic and responsive recipients have to be to 'enjoy the full benefits' of their implant. It is noteworthy that the problem shifts from the limits or over-claimed benefits of technology to psycho-linguistic limitations or even failures. Wilson and Dorman set the scene by showing just how important this professional neuroscience is to those who are under-performing in linguistic and developmental terms:

> A fundamentally new approach may be needed to help those patients presently at the low end of the performance spectrum, however. They may have compromised 'auditory brains' as suggested above and by many recent findings. For them, a 'top down' or 'cognitive neuroscience' approach to implant design may be more effective than the traditional 'bottom up' approach. In particular, a top-down approach would ask what the compromised brain needs as an input in order to perform optimally, in contrast to the traditional approach of replicating insofar as possible the normal patterns of activity at the auditory nerve. (Wilson and Dorman 2008: 17)

It is unclear whether the notion of a compromised brain is premised on a hard-wired or functional deficiency. The notion of replication of normal patterns of hearing and speech suggests the latter. This approach is countered by the fairly substantial evidence that key developmental factors may be at work, with a number of studies pointing to a correlation between the length of time a child has without hearing and implant-based language gains (Cheng et al. 1999). Fryauf-Bertschy and colleagues found greater language recognition in those implanted before the age of five (Fryauf-Bertschy et al. 1997). An attendant risk that appears from this early diagnosis and implant 'success' narrative is that early screening may be justified and in turn contribute inadvertently to debates between implantees and rejectionists:

> Young age at intervention and oral communication mode are the most important known determinants of later speech perception in young children after cochlear implantation. Early identification of candidate children necessitates implementation of universal neonatal screening programmes for hearing impairment. (O'Donoghue et al 2000: 466)

This is a very specific interpretation of the assumed link between early intervention and the need for screening; another reading of the evidence is the sooner the better, should a family be favourable to that. Although optimal intervention (with greater risk in small children) would be before the age of two, successful language acquisition can take place say between years 2 and 5 (Svirsky et al. 2004). Connor et al.'s study for example, while noting the added gains below 2.5 years, also note that implantation before age seven, compared to post-7 years implantation, produced a significant difference in language acquisition (Connor et al. 2006). The imperative to screen for deafness is then a rather more complex issue that a purely clinical interpretation might suggest. The costs of such screening need also to be accounted for.

The literature on post-implantation language, speech and hearing development tells us much about the wider construction of the 'communication challenge' that surrounds the lives of implantees. The words 'performance', 'success', 'failure' and 'development' run through many of the keynote articles on post-implant progress in CIs. This apparently technical and 'objective' language masks arguably a very much more constructed landscape, one where attribution is often attached to implantee's failure to thrive or develop communicatively. Terms like 'neuroplasticity' are used in the literature which could be challenged as at odds with developmental neurology approaches which emphasise hard-wired understandings in say autism (Clark 2006). The following sums up the dilemma here as the question of attribution is crucial given discussion of terms like 'poor' and 'performance':

> active auditory training may be needed to more fully exploit CI patients' auditory plasticity and facilitate learning of electrically stimulated speech patterns. Some early studies assessed the benefits of auditory training in poor-performing CI patients. Busby et al. (1991) observed only minimal changes in speech performance after ten 1-hour training sessions; note that the subject with the greatest improvement was implanted at an earlier age, and therefore had a shorter period of deafness. (Fu and Galvin 2008: 200)

Certainly although no doubt well intended, there is a clear sense in which having a CI takes implantees into a world of professional scrutiny from the assessment and eligibility phase through to post-operative processes of language and interpersonal performativity. Indeed some researchers even refer to performative utterances in post-implant speech development (Goggin and Newell 2003: 11; Lichtert and Loncke 2006).

## Cultural and Normalisation Risks of Cochlear Implants

It is perhaps unsurprising that, given the increase in implant expertise and clinical enthusiasm alongside the development of strong cultural constructions of capital 'D' Deafness, real conflicts in the hearing and Deaf worldviews ensue. For many post-lingually deaf, those with no links to Deaf culture and who have been used to speech-based hearing, this is a less pressing issue; but for those who are pre-lingually deaf, identify as culturally Deaf and whose children may be born without hearing, CIs represent at best a distraction and at worst a threat to key cultural and linguistic traditions. Tucker provides a really good overview to drag us out of the clinical worldview:

> Because cochlear implants have the potential to ameliorate or eliminate ramifications of deafness, they are opposed by Deaf culturists, who view efforts to 'cure' deafness or ameliorate its effects as an immoral means of killing Deaf culture … The theory of Deaf culture is primarily premised on a shared language—American Sign Language (ASL). Individuals who communicate via ASL clearly do speak a different language. American Sign Language is visual rather than spoken … Many members of the Deaf cultural community strongly desire to have Deaf children, who will be a part of their parents' Deaf culture. (Tucker 1998: 6)

Of course this fundamental reappraisal not only challenges the technology of CIs, but the medico-legal systems that underpin say the US Federal Drugs Administration's 2012 endorsement of CIs. There begins not simply a technological mismatch of worlds but a wider incomprehension of incommensurate perspectives on the Enlightenment idea of perfectibility. Notions of perfectibility and performance then sit at loggerheads in a sort of cultural stand-off. Deaf activists find the medico-legal landscape colonial, and certainly in the early days of resistance clinicians and educationalists found the rejection of ‘helpful’ rescuing technologies difficult to comprehend. This has been especially true where Deaf parents state their active preference for Deaf children and where the child’s future decision on implants is left to the child. The evidence above on earlier, if not early, implantation before the age a d/Deaf child could reasonably make a decision perhaps places this formulation in doubt. Critics might suggest that the denial of bilingual (sign and oral traditions) is denying a child a plurality of communicative engagement well beyond simple performativity and function. Cheney provides a sense of the potency of the backlash:

> A position paper published by the National Association of the Deaf (NAD), one of the largest organizations of members of the Deaf culture, articulated the “official” response to the FDA decision: “The NAD deplores the decision of the Food and Drug Administration which was unsound scientifically, procedurally, and ethically” (1). The scientific objection rested on the ‘experimental’ quality of implanting children without evidence of material benefit, the procedural objection claimed that the FDA failed to thoroughly investigate the implications of the implants by not requesting the input of Deaf organizations, and the final objection argued that experimenting on children unable to consent to the procedure was unethical. (Cheney 1999: 26)

Cheney then points to the power of the FDA to endorse a technology and their ability to turn issues of politics into technological assessments, a point that Marcuse makes in his early philosophy of technology (Marcuse 1964). Issues of ethics, consent and Deaf community engagement at a supra-individual level are all important he claims. Of course this can be seen to present technology policy as simply happening to D/deaf people. But as the backlash suggests, agency has been at the core of the debates and counter-narratives around CIs. Walter Nance explores the ethics of the convergence of selective birth preferences and thus pits cochlear technology against selective childbirth technologies as weapons in the struggle for very different imagined futures:

> It turns out that some deaf couples feel threatened by the prospect of having a hearing child and would actually prefer to have a deaf child. The knowledge that we will soon acquire [due to the Human Genome Project] will … provide us with the technology that could be used to assist such couples in

> achieving their goals. This, in turn, could lead to the ultimate test of nondirective counselling. Does adherence to the concept of nondirective counselling actually require that we assist such a couple in terminating a pregnancy with a hearing child or is this nonsense? (Bartels et al. 1993: 93)

Although arguably an over-reaction, one which was only partially correct in reading the future interplay of technology, ethics and choice, Tucker explores the possibility that anti-discrimination legislation may refuse or fail to protect those who have chosen to have an impairment which is known empirically to place themselves at a disadvantage socially (Tucker 1998). Organisational theorists Garud and Rappa aim to look at how professional, organisational and technological forces interact, in what they refer to as the intersection of artefacts and beliefs about technology which have reinforced and arguably over-inflated the value of CIs:

> The historical development of cochlear implants serves as an illustration of the model. The evidence suggests that there is a reciprocal interaction between beliefs, artefacts, and routines that gives rise to two cyclical processes. One is a process of inversion at the micro level of individual cognition wherein evaluation routines designed to judge specific artefacts begin reinforcing researchers' beliefs. Once evaluation routines become the basis for constructing individual reality, technological claims are perceived as relevant only to those who employ the same routines while appearing as noise to those who employ different routines. (Garud and Rappa 1994: 360)

The circular influence of routines and artefacts feeds off itself in a way that leads to dominant technological practices. This may explain how for example some clinicians and researchers emphasise the benefits of implants without much recourse to any evidence of their limitations and ethical challenges. Perhaps the strongest critique of CIs and the subcultural practices that surround their use is the work of Robert Sparrow. His 2010 work 'Implants and Ethnocide' is a hard hitting cultural critique of technological and professional determinism alongside an appreciation of Deaf culture. He argues that the spread and enthusiastic, almost messianic, approaches to CIs run the risk of cultural ethnocide. Using what might be seen as an ethnographic gaze he presents a future dystopian view of the eradication of Deaf culture and deafness and creates an imagined world far removed from the 'cold objectivity of the operating theatre'. He asks readers to:

> Imagine that you are a member of a minority linguistic community. You might think of yourself as a Native American in the USA or as a non-Han ethnic minority in mainland China. In the not-too-distant past, members of your community have been imprisoned and tortured for daring to use their own language. Perhaps in response to the persecution they have faced in the past, members of your group tend to be fiercely proud of their cultural community. Despite this, members of your community face a number of profound social and economic disadvantages. It is harder for them to complete their education, find a job or achieve the level of material success that is typical of members of the larger community. In part, this is because they are subject to morally pernicious discrimination from members of the dominant community. However, it is also the predictable consequence of being a minority surrounded by another culture whose members speak a different language. (Sparrow 2010: 455)

Sparrow makes plain the risk not simply to the sub-culture of Deaf people but also the new jeopardies faced by those who have been incompletely transitioned to the hearing world. For example, alongside the limits of the technology itself and the major struggle to acquire spoken and aural skills and to normalise them they also run the risk of being in a permanently liminal state. Although not stated in his work, it is obvious to many in the hearing world that the pre-lingually deaf have learnt to hear and speak because of the tone of their speech. Obviously a person's refusal to abandon sign language would set people apart in other ways. This then is not Sparrow being anti-technology: he reserves his concerns for those who grow up in and identify as culturally Deaf and as a linguistic minority. Sparrow makes clear his belief that the technology and surgical implantation will improve, and that, in the face of the prospect of ever greater acuity of devices, the tension between signing and oralism will only increase. He favours a bilingual baseline for Deaf people which affords their retention of cultural preferences alongside choices to engage with oralism. Certainly the idea that a person would forfeit rights to services and the protection of the law is abhorrent to Sparrow. What is not so clear is whether he would in the face of the enhanced technologies support augmentation or fiercely oppose it longer term? Or indeed what his view is on the most controversial issues of selection of a deaf child to fit in with culturally Deaf families.

The Norwegian academic Patrick Kermit comes at the issue in a different way. Drawing on the philosopher Alex Honneth, his reading of the ethical and practical debates around CIs is less concerned with Deaf culture and medical colonisation and more concerned with the wider normalisation process in education and speech and language professional activity, as well as the fitting and risk attendant on implants. Alongside the failure of implants in a general sense, he refers to the challenges of training a person's brain to connect with nerve impulses as sounds and to articulate speech. He presents a situation in which CIs are seen as a panacea for issues well beyond say the auditory nerve and the cochlear cilia:

> The priority accorded to speech lessons might have been justified had the children actually achieved an age-equivalent level of spoken language. The problem is one of grasping that meaningful language acquisition goes far beyond the mere ability to perceive and produce words and sentences. Rehearsing lip reading and articulation may suffice as a way of mastering the technical aspects of producing and perceiving speech, but such rehearsal hardly suffices as a means to learn language in a more complete sense … It is understandable that Deaf people are skeptical about pediatric cochlear implantation. Their own stories about the attempts to rehabilitate deaf children are stories about unreflected use of deaf children as a means to an end the children themselves had never consented to; that of normalization. As normalization is still a clearly articulated goal for deaf children receiving implants, the question of the relationship between the means and ends in this process is still relevant. (Kermit 2012: 369)

Kermit argues that it is the rehabilitation process itself, its underlying philosophy of imperative correction and the process that undermines choices, as to what disabled children in particular can do, how they do it and in a way that is unconditional and authentic. We are not, Kermit argues, more authentic for having been through a rehabilitation or habilitation of speech, nor are we less worthy if we are not able to accord to constructs of normality. These are very useful perspectives. In the case of Sparrow and Kermit, it could be argued that they are essentially correct, but that clinicians and therapists are professionals with a pragmatic orientation who want to aid social survival in the wider world of normative values. It could also be argued that professionals adopt a sort of majoritarian pragmatism in supporting cochlear implanting. There is little evidence of an anti-sign language stance in any of the clinical literature above, although is very plain in the speech and language studies. Conversely it could be argued that writers of disability studies and philosophers are recklessly denying opportunities for greater hearing and reducing the odds of social marginalisation. Both criticisms hold some water. An irreducible point perhaps is that choice is paramount, whether to pitch or not for implants. Advocated choice even for young children may be possible. Certainly it is wrong for parents who align with Deaf culture to insist on a d/Deaf child in the same way as it is wrong to insist on a religion for one's child before he or she can engage with the implications. Both clinicians and parents could conceivably be over-bearing in this context.

It is equally wrong to persist with attempts to foster speech where there is little chance of its development. Technologies should not drive ethical decisions but be subject to them. The notion of screening for hearing absence is a contentious one, and the evidence supporting a widening of screening is not in my view clear in the literature. Scepticism about CIs is a right for all, as is a balanced meta-assessment of the applications and benefits of such implants. We should not ignore the fact that much social science debate has focused on pre-lingually deaf children, though the majority of recipients have been post-lingually deaf and adults. There also needs to be some caution in asserting that markets drive and pervade CI narratives (Goggin and Newell 2003: 11), as there is not much evidence for this in the literature: where professional dominance was evident it was framed by a rescuing narrative and at the same time was concerned with matching, cost and likely future performance. The latter was especially true in decommodified health services, but even in market-based systems insurance coverage also ensured a rationing of access. A large number of studies were concerned with technical features of efficacy and the likely benefit of implants, and to describe most CI worlds as technologically or clinically determinist would be quite inappropriate. This is not of course to play down the very real concerns of people who identify as culturally Deaf as their position has to be accounted for. The wider literature provides some helpful and balanced insights which take technology and ethical issues seriously and which perhaps are under-acknowledged in the 'critical' literature (Christiansen and Leigh 2002).

## Exoskeletons and Prosthetics

The question of the melding of the human and 'man-made' artefacts in the prosthetic body has also attracted a great deal of attention. Although the roots of the first 'mass' prostheses can be traced to the world wars and the war injured, the science of prosthetics has progressed well beyond the sphere of rehabilitation and is likely to feature in sports and Paralympian literature as it is in disability or clinical literature. The affordability, wearability and materials technology has afforded new opportunities for social and sport participation. The focus in this section will not be on sport and prosthetics as this subject is well documented (Chockolingam et al. 2011; Grogan 2012; Howe 2011; Miodonick 2007; Swartz and Watermeyer 2008; Rodenberg 2010), but will draw down narratives and evidence from that arena as one manifestation of prosthetics and the prosthetic self. I will begin by exploring just what a prosthesis can be taken to mean and the narratives that surrounded its development. I then engage with the highly abstract but insightful thinking which argues beyond the prosthetic as mere artefact to notions of identity: the prosthetic, the cyborg and the hybrid self (Haraway 1985). We will explore more recent technologies of prosthesis through electrical stimulation and exoskeleton developments and will look at the intersection of technology, social systems, ethical dilemmas and resistance.

Given the contributions from philosophy, cultural studies and the theoretical end of disability studies it might be understandable to simply enter the world of prosthetics at an abstract level of the newly merged human–artefact hybrid, one which can no longer be pigeon holed as neither fully natural nor fully manufactured. However, what this level of analysis often studiously ignores is the nature of actual prosthetic artefacts. In this way and rather bizarrely discussions of new cyborg or hybridized identities can bypass empirical, historical, personal and professional stories that are absolutely central to issues of technology and disability. What made prosthetics stick? What were the techno-social constructions that made this alliance of human and artefact acceptable and meaningful? Why do some former military combatants now wear shorts with prostheses? Is it the new embodied heroising of former service staff? Or, in the age of welfare reform, is it something more socially ironic where some ex-service staff are denied access to mobility benefits as they have what can be seen as effective aids to mobility and a correctible body? So it is rather surprising that very little is written from a social science perspective that actually focuses on prosthetics themselves. This is perhaps a comment on the social sciences post the linguistic turn.

There are a small number of exceptions to the above. Norton's (2007) review of early historical evidence provides what on the surface seem to be examples of prosthetics:

> In 424 BC, Herodotus wrote of a Persian seer who was condemned to death but escaped by amputating his own foot and making a wooden filler to walk 30 miles to the next town … The Roman scholar Pliny the Elder (AD 23–79) wrote of a Roman general in the Second Punic War (218–210 BC) who had a right arm amputated. He had an iron hand fashioned to hold his shield and was able to return to battle. (Norton 2007: 11–12)

Strictly speaking, given the limited knowledge of adhesion and fit with vestigial limbs, these artefacts such as hand hooks and 'peg' legs would best be described as crude appendages which must have felt distinctly makeshift and more aesthetic than functional; however, some basic functional advantage was clearly afforded by providing more mobility and a greater chance of survival in combat. This was somewhat ironic as limb loss was largely incurred in battle. By the late Middle Ages, the more complex prosthetics were associated with crafts such as watchmaking, where large springs and clips would be utilised. Norton notes the first key breakthrough in terms of a precursor to modern prosthetics in the work of the French military surgeon Ambroise Paré who:

> introduced modern amputation procedures (1529) to the medical community and made prostheses (1536) for upper- and lower-extremity ampu-

> tees. He also invented an above-knee device that was a kneeling peg leg and foot prosthesis that had a fixed position, adjustable harness, knee lock control and other engineering features that are used in today's devices. (Norton 2007: 12)

The first combination of functional knee-joint and articulated foot with artificial 'tendons' from knee to foot were perfected by James Potts in 1800 and became known as the Anglesey Leg as it was later used by the Marquess of Anglesey following his injuries sustained in the Napoleonic Wars (Norton 2007: 13). Thurston's detailed history of early artificial limbs makes clear that spiritual and religious worldviews shaped their use, with many cultures using them as spiritual conveyances that appeared to help maintain a quasi-normal physiognomy where the original limb was buried and disinterred later to make the spirit whole again (Thurston 2007: 1114). Thurston notes that before anaesthesia amputation was a painful and hazardous enterprise and thus absolute numbers surviving amputation were low. Many upper and lower limb prostheses for those that did survive were often rudimentary crutch type devices, which were often over-sold and were in reality disappointing to use, as an early nineteenth century user noted:

> After employing at great expense one of those London manufacturers of mechanical contrivances, who profess to remedy all defects … Although I could walk exceedingly well in a room or on smooth ground … such legs are not suitable for rough work. Finding the springs, which move the foot, continually giving way, I finally gave up using the artificial leg; and have since been enabled with the more homely-looking wooden pin. (Thurston 2007: 116)

Another contribution to a detailed and critical history of prosthetics is provided by Katherine Ott and colleagues in the powerful *Artificial Parts, Practical Lives*. This collected edition brings a social science lens to technology while retaining a sense of the material and immediate social change in prosthetic developments (Ott et al. 2002). Ott et al. note how the use of prosthetics following the major wars of the nineteenth and twentieth centuries was itself made possible by improvements in antisepsis, nutrition and anaesthetics (see Hamilton 1982; Risse 1999; Rushman et al. 1996). They points out that conflict in this period and the surgical remediation of limb loss led to greater empirical awareness of what aided the application of lower limb prostheses (which constitute the majority of prostheses): good soft tissue survival and the presence of a stump with which to attach a prosthesis and so minimise pain and discomfort. The development of plastic surgery and of rehabilitation medicine following the world wars each in turn supported surgical interventions (Ott et al. 2002: 14–15). This is not to suggest linearity in the science of prostheses, nor to point to automatic access to or indeed a desire to elect for a prosthesis, some war injured preferring to forego such a rehabilitation process. As with all technologies external to the disabled body, prosthetic limbs were sometimes abandoned as the personal decisions about the physical economy of walking and no doubt stigma were enacted. Ott et al. make clear the acceleration of prosthetic medicine and the rise of psysiatrists, a professional philosophy based on heat and light treatment, developed after the Second World War to treat the 2000 survivors with paraplegia, compared to only 400 in World War One (Ott et al. 2002: 15). Modern rehabilitation science ostensibly grew out of the Second World War with the Stoke Mandeville Hospital being established by the German expatriate Ludwig Guttman in 1944. The US Department of Veterans Affairs established the Walter Reed Hospital Artificial Limb Lab in 1918, but antecedents of modern rehabilitation were founded in the demilitarised hospitals of the 1940s onwards. Ott et al. make the point that unlike allopathic medicine's emphasis on its ability to cure (Ott et al. 2002; see also Stavrakis 1996; Woods and Watson 2003), prosthetic and rehabilitative medicine is symbolic of a 'failed cure', and therefore a focus on retained function. Disability studies have probably not fully engaged with that nuance as the latter professions may have more in common with say the concerns of the social model of disability which try to provide access to greater social activities. There are no doubt rescue narratives in there somewhere, but they are not, it has to be said, clear evidence of actual rescue—as there are in say early stories about the saving potential of CIs—more a utilitarian focus on returning the war injured to mainstream society (Anderson 2003; Gutman 1968). In the UK, the

Tomlinson report of 1943 placed most attention on the return to mainstream economic activity (Roulstone and Prideaux 2012).

The period following the Vietnam War, a period in which survival rates were high and medical technology advancing, witnessed more nuanced and contested understandings of the biomechanics of adduction of the trans-femoral joint to a lower limb prosthesis, which afforded mobility and stability (King 2009). Much of this work was funded by the US Department of Veterans Affairs and reported in their house journal the *Bulletin of Prosthetics Research*, which in time became the *Journal of Rehabilitation Research and Development* (JRRD). Unlike Cassandra Crawford's fascinating book *Phantom Limb*, I could not discern the proselytising message about the need for rebirth through prosthetic technology. Compared to say cochlear implantation I could find no rescue metaphors on an equivalence to Beethoven or Keller. It is difficult to understand this gap given Crawford's depiction of a gathering of the Amputee Coalition of America's annual conference: 'these manufacturers and some forty others inundated attendees with messages about the possibilities of rebirth through prosthetization' (Crawford 2014: 3).

Lusardi et al. are typical of the rather technically focused, function maximisation approach in stating that their principal objectives in assessing and fitting prosthetics and orthotics is to meet the needs of patients requiring rehabilitation, to be patient-centred and to be aware of cost constraints (Lusardi et al. 2013: 1). Here then the industry zealots seem some distance hence and healthcare systems across the Minority World seem not to be driven by a sort of prosthetics dividend or a slave mentality to the cult status of two-legged ambulation. This again contrasts with some writers in the CI field, and say educational psychologists working with disabled children, to normalise their 'patients'. Perhaps there is a sense of shared necessity in much rehabilitation work around restoring basic function. This requires further exploration; certainly the technological determinism evident in new writings on exoskeletons feels very different to the writings on prosthetic devices. Granted there is also an absence of user-led work in the prosthetic field, simply a commitment to amputees once the intervention has been clinically arrived at. The impulse to the prosthetic self, as Smith and Morra (2006) put it, seems if anything to be driven by personal preference or necessity; the philosophical implications that follow are of course a source for debate but, for most people with say bypass surgery, a prosthetic leg or a pacemaker may simply be just something 'they have', despite all the theorisation of the prosthetic self. Gregor may be helpful here in discussing the distinction between restoring function and augmentation beyond normal parameters:

> The first is the patient type who wishes to be fixed to the norm and sees his or her own biological reality as a defect, for whom medical care, rehabilitation and technological devices, including assistive or prosthetic devices offer a fix towards or up to the norm. The second is the transhumanist type who 'sees their own body, as well as the "normal" human body as a "defect" in need of not just fixing to the norm but in need of augmentations above the norm with the addition of new abilities' facilitated by the use of new technologies. (Wolbring cited in Karpin and Mykitiuk 2008: 413)

The notion of 'patient type' reflects Mitchell and Snyder's concept of normalising the body that lacks a function in a way that restores or brings someone for the first time closer to normality. These then are adding layers of complexity where augmentation equals going beyond the normal. In truth the above literature from clinical rehabilitation, although clearly within a corrective narrative, shows no signs of aligning itself say with interventions in cosmetic surgery, breast enlargement or sports prostheses. Whereas Wolbring, Karpin and Mitchell are concerned with the boundaries of technology, normality and abnormality, Haraway's work argues that technology and body cannot be separated in the cyborg entity. Her *Manifesto for Cyborgs* (1985) and Penley and Ross' *Technoculture* (1991) challenge the assumed binary between the human and 'man-made' artefact, arguing that they have been hybridised. Not only do Penley and Ross offer a new way of seeing hybrid selves, but they also suggest new forms of social advocacy and protest that these hybrid forms present. Drawing on the notions of electronic pirates they suggest that 'handicapped' people in being immersed more fully in techno-culture can engage in social counter-narratives at the level of the body and technology simultaneously (Penley and Ross 1991: XV1). Haraway on the other hand argues in a very brief application of her cyborg concept to disability that 'perhaps paraplegics and other severely handicapped people can (and sometimes do) have the most intense experiences of complex hybridisation with other communication devices' (Haraway 1991: 178). On technology she states:

> Communications technologies and biotechnologies are the crucial tools recrafting our bodies. These tools embody and enforce new social relations for women world-wide. Technologies and scientific discourses can be partially understood as formalizations, i.e. as frozen moments, of the fluid social interactions constituting them, but they should also be viewed as instruments for enforcing meanings. The boundary is permeable between tool and myth, instrument and concept, historical systems of social relations and historical anatomies of possible bodies, including objects of knowledge. Indeed, myth and tool mutually constitute each other. (Haraway 1991: 231)

Adding an additional assertion of a social possibility for disabled people onto an already very abstract post-identity construction of hybrid 'normal' citizens, we can see a range of limitations to Haraway's work. What is unquestionable is the reality and promise of prostheses in and around the human body, from the nano-particle level to exoskeletons. It could also be asserted that such prostheses in turn have a possible impact on consciousness and self-concept and in a positive as well as negative way. It can also be confidently asserted that this new consciousness may foster new social action and use different means and technologies of advocacy. However, it could just as clearly be argued that technology, its very ubiquity, leads to a matter of fact and taken-for-granted relationship between disabled people and technology. Perhaps more concerning is Haraway's generalisation of disabled people and technology. The above makes clear the complexity of both these constructs and that to simply say they are now hybridised may be seen as 'theory in retreat' or more generously theory in search of evidence. Reeve, one of the most exciting and grounded writers on disability and technology, highlights the main problems with Haraway's work:

> Although Haraway's cyborg has been widely used in feminist science studies and other fields, 'disabled cyborgs' are largely absent (although see Moser, 2000; Moser, 2005). Ironically, whilst the cyborg is supposedly

> about 'transgressed boundaries' and 'potent fusions', the starting point in any cyborg discussion is inevitably a 'fully functioning human and a fully functioning machine' (Quinlan and Bates, 2009:51), an assumption which remains invisible and unquestioned. One of the reasons why there has been little utilisation of the transgressive cyborg figure within disability studies to date is because of a well-documented history of how technology was problematically associated with normalisation, rehabilitation and cure (Goodley, 2010). (Reeve in Goodley et al. 2012)

In a refreshingly clear exposition of just how human and artefact entities are novel, Swartz and Watermeyer exhort us to reappraise this relationship. We can see within their formulation, however, both risks and opportunities: to erase assumptions about difference but also to increase that sense of categorical difference where a disabled person is enhanced in a way that might further stigmatise or abnormalise:

> Disabled people have a history of being viewed as not entirely human. In the age of spare part surgery and increasing sophistication of drugs, there are increasing concerns about what it means to be human, and, in particular, in what distinguishes people from machines. These concerns have clear resonance with anxieties about disability, and with disabled people being seen as not human. (Swartz and Watermeyer 2008: 188)

This same principle applies to the development and narratives surrounding exoskeletons and nerve-stimulation prosthetics. Exoskeletons convey more than any other technology the marriage of human and made technologies and feature in the science fiction imagination such as in Robert Heinlein's early book *Starship Troopers* (1959) through to the most recent Iron Man franchise. The image of robotic invulnerability is central to the superhero persona. It would be facile of course simply to dismiss exoskeletons in disability terms (sometimes called wearable robots) as over-engineered normative technologies. While an understandable concern, there are spinal injured individuals who exert agency by making clear they would like to 'walk again' whatever the social disruption and troubling of normative values such technologies may provoke. It might also be easy to say their enthusiasm is born of false consciousness or a response to internalised oppression. Both of these assertions are misplaced of course. We have to take seriously different orientations to technology and disparate worldviews, just as we might wince at the idea of a spinal injured tetraplegic wanting to end his or her life; however difficult that is to us, choices and rights cannot mean only stereotyped and officially sanctioned choices. The same is true with exoskeleton technology. We do, as social scientists however, need to understand what is being sold to us as choices and the reality of the technologies and the narrative systems that accompany then. Unlike localised or manual prosthetics, exoskeletons have sparked some media interest and the corrective sentiments at the heart of their accounts reminds us that technology is still seen in the public mind to offer pathways to normalcy:

> With exoskeletons, people with disabilities can and do experience much more than they might have otherwise had reason to believe possible, such as walking. Exoskeletons also promise to allow able-bodied people, such as soldiers, to run faster and carry more than the average human body otherwise would. (Dale 2014)

Exoskeletons or wearable robots are diverse devices which are based on a marriage of mechanics, electronics and micro-computing and which aim to bring electronic support or stimulation for body regions—as both upper and lower body robots or full skeletal robots (Pons 2008). Pons and colleagues distinguish between empowering robotic exoskeletons, orthotic robots and prosthetic robots, which extend power, restore function or substitute for lost function respectively. Early exoskeletons were designed to augment 'normal' perambulation as opposed to restoration or augmentation post-trauma. Yagn's 1800 patent is an early example of a lower limb exo-device made of leaf springs which flexed when the runner put his or her foot to the ground. This looks in essence like the spring motion of modern sport prosthetics but for the whole leg not just sub-knee prostheses. Exoskeleton research began in the 1960s with the US Department of Defense developing what was essentially a powered suit of armour. Dollar and Herr (2008) provide the following summary of the development of the defensive exoskeleton:

> In 1963, Zaroodny of the U.S. Army Exterior Ballistics Laboratory published a technical report detailing his work on a 'powered orthopedic supplement'… His exoskeleton device was intended to augment the load-carrying abilities of an able-bodied wearer such as a soldier. While mainly a concept paper, Zaroodny identified and began to address many of the fundamentally difficult aspects of implementing such a device, such as a portable power supply, sensing and control, physical interface with the human, and the affectation of the biomechanics of locomotion. (Dollar and Herr 2008: 146)

Although dogged by technical (and no doubt ethical) considerations, this line of research is continuing; the other line of exoskeleton development is in the field of rehabilitation and restoration of function. Rocon and Pons (2011) point to the early work of Wagenstein in the 1880s in developing a non-military pneumatic exoskeleton to aid rehabilitation. These two precursors have merged to support advanced if controversial robotic devices. As with prosthetics more generally there is not a great deal of hype or technology-push in this arena, which is partly explained by the cost of the current technologies and also by the provision systems, which whether insurance based or decommodified both limit access to such devices at present. Dollar and Herr present fairly typical caution as to the values of current exoskeleton robots, noting the restricted value for those with limited or no function, but little augmentative value for enhancing function:

> To this point, the reported advantages of complete, autonomous exoskeleton systems are largely anecdotal. Indeed, there is a marked lack of published quantitative performance results for exoskeleton devices that reportedly improve human locomotion. The few exceptions give results that do not confirm any benefit of current designs. Considering this, one is left to wonder what the real advantages of these complicated, expensive systems really are. Certainly, there is value in an exoskeleton that enables the wearer to perform a task that he or she could not otherwise perform. However, if exoskeletons intended to facilitate tasks that could otherwise still be performed by the wearer (e.g. load carrying) do not reduce the metabolic cost and/or fatigue of the operator, they have very little value. (Dollar and Herr 2008: 155)

To date much of the 'promise' of exoskeletons has been aired in the robotic industry's own media rather than in the clinical evaluation realm. Even here the cost and limits of technologies is not hidden in some instances:

> A new powered exoskeleton that enables people with severe spinal cord injuries to stand, walk, sit and climb stairs has been developed by Vanderbilt University's Center for Intelligent Mechatronics. Its light weight, compact size, and modular design promise to provide users with an unprecedented degree of independence. When they reach a location where they want to walk, they will be able to put on the exoskeleton by themselves without getting out of the wheelchair. When they are done walking, they can sit back down in the same chair and take the device off or keep it on and propel the wheelchair to their next destination. (*Kurzweil News* 2012: 2)

Of note, although the article alludes to the enhanced independence the exoskeleton can afford, it nowhere explores just what this means in practice. The hype in the mainstream media in Europe and North America about such 'bionic technologies' is not matched by the wearers. The following user is dubbed 'Ironman' by the children who see him using the exoskeleton, but his comments are more measured:

> 'My kids have started calling me "Ironman"', said Brian Shaffer, who was completely paralysed from the waist down in an automobile accident on Christmas night 2010. 'It's unbelievable to stand up again. It takes concentration to use it at first but, once you catch on, it's not that hard. The device does all the work. I don't expect that it will completely replace the wheelchair, but there are some situations, like walking your daughter down the aisle at her wedding or sitting in the bleachers watching your son play football, where it will be priceless,' said Shaffer, who has two sons and two daughters. (Cited in Salisbury 2012)

Breen's recent appraisal of the moral and ethical implications of transformative exoskeletons makes clear that new future dilemmas may arise if the technology becomes cheaper and widespread. What for example can spinal injured individuals expect by way of reasonable adjustments and legal protections if they have refused to avail themselves of rescuing technologies which offer, if not a cure, an augmentation of their bodies?

> The ability, whether merely perceived or not, to abandon one's impairment, coupled with the apparent choice not to do so, is likely to create a significantly increased resistance to the overall acceptance of people with disabilities. Based on the many current challenges associated with these issues, any refusal to accept whatever cure is offered may provide additional support for those who argue that those with disabilities are using those disabilities to gain some advantage. (Breen 2015)

## Conclusions

The above has required us as readers to reflect on the specifics of impairment, disablement and technology. The emphasis in CI debates required a foray into the clinical evidence and narratives on implants as the critiques of these assert their technical limitations and risks as well as positing cultural risks to Deaf culture. The discussion of prosthetics is less charged and the literature divides more neatly into technical appraisals, historical accounts and a small number of social science insights. This perhaps reflects the point that such prosthetics are often the product of clinical systems and of necessity post-trauma or illness. However, we have seen the threat of possible over-engineered whole body exoskeletons, but also acknowledged the potential for some disabled people. We have explored the philosophical and cultural studies literature on the cyborg and, although noting the changing relationship between human and made entities and the blurring of these lines, found little of substance to add to disability related understandings from say disability or rehabilitation studies. This may of course change and cognitively driven applications that direct the physical world via electronic switching and so on may require a revisiting of these ideas. The willingness to embrace augmentation will depend on the technology, the attitude context and the sense of whether augmentation is an extension of an identity violation/ discontinuity with a disabled person's sense of self.

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# Final Reflection

The question of the importance of technology for disabled people is a complex and broad-ranging one. Although the book has not focused on every aspect of these relationships, I hope that it has provided a sense of the potential, current benefits without ignoring the drawbacks for disabled people. The evidence suggests that technology intersects with disability in complex ways, for example we need to understand the impact of say digital technology on disabled people in particular, but very few studies adopt a non-disabled control group. Thus beyond survey evidence the best data emanates from careful qualitative studies of the role and meaning of technology. Without this we could not draw specific inferences on the general benefits of technology that the wider population report. There is much evidence of technologies, both ‘high’ and ‘low’ tech, offering new horizons for some disabled people. However, new technologies bring with them new demands. How many of us are surrounded by desktop or hand-held technologies that audibly signal for our attention? At times it feels as though we are servicing technologies rather than technology servicing us. In terms of communication, it often feels impossible to keep on top of the myriad forms of e-communication, while Twitter, Facebook and wider social media straddle both home and

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work life. To what extent then have digital devices offered the promise of compressing space and distance only to lengthen the time taken to service these technologies? How much of our day is spent without these technologies?

Notwithstanding the expectations that accompany digital technology, there are many in-principle benefits in terms of processing large amounts of data and communications in one place. There are unplanned benefits in terms of texting for d/Deaf people, better wheelchair design/functionality and access features embedded in off-the-shelf technologies. The extent to which pre-existing social dynamics and divisions shape the experience of technology remains an important question. However, there has been no widespread evidence in this review of research that these dynamics remain the same as say 20–30 years ago. The spread of technology, processing capacity and reduced cost smooth the path to enabling technology. However, there remain maldistributive forces that continue to limit access to even iconic technology such as the wheelchair. Clinical judgement and wider narratives continue to shape just who can have access to wheelchairs. Many tools for independent living continue to be framed as 'health technologies', although I sense this is changing. The World Wide Web offers some disabled people the opportunity to present images of themselves that foreground online belonging, rather than risk a master status of disabled being imposed upon them. However, the internet provides a breeding ground for hate and cyber-bullying. New technologies such as cochlear implants, life sustaining devices and pre-birth diagnostics suggest benefits may inhere from cradle to grave, but they provoke new ethical dilemmas as to just who we can be and which technologies we can freely embrace or reject. New fears arise where a disabled person adopts a rejectionist stance: Will they still be afforded full social rights when they could be 'cured' of an impairment? It is clear that social forces continue to shape technology in a way that requires vigilance, evidence and at times continued activism to ensure it fulfils its enabling potential.

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