

Healing the World's Children

Interdisciplinary Perspectives on Health
in the Twentieth Century

Edited by Cynthia Comacchio, Janet Golden, and George Weisz

HEALING THE WORLD'S CHILDREN

McGill-Queen's/Associated Medical Services Studies in the History of Medicine, Health, and Society

Series Editors: S.O. Freedman and J.T.H. Connor

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Health in the Twentieth Century
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Interdisciplinary Perspectives on Child Health in the Twentieth Century

Edited by

CYNTHIA COMACCHIO, JANET GOLDEN,
AND GEORGE WEISZ

McGill-Queen's University Press
Montreal & Kingston • London • Ithaca

© McGill-Queen's University Press 2008

ISBN 978-0-7735-3399-8 (cloth)

ISBN 978-0-7735-3400-1 (paper)

Legal deposit third quarter 2008

Bibliothèque nationale du Québec

Printed in Canada on acid-free paper that is 100% ancient forest free
(100% post-consumer recycled), processed chlorine free

McGill-Queen's University Press acknowledges the support of the Canada Council for the Arts for our publishing program. We also acknowledge the financial support of the Government of Canada through the Book Publishing Industry Development Program (BPIDP) for our publishing activities.

Library and Archives Canada Cataloguing in Publication

Healing the world's children : interdisciplinary perspectives on child health
in the twentieth century/edited by Cynthia Comacchio, Janet Golden, and
George Weisz.

(McGill-Queen's/Associated Medical Services studies in the history of
medicine, health, and society; 31)

Includes bibliographical references and index.

ISBN 978-0-7735-3399-8 (bnd)

ISBN 978-0-7735-3400-1 (pbk)

I. Children – Health and hygiene – History – 20th century. 2. Child health
services – History – 20th century. I. Comacchio, Cynthia R., II. Golden,
Janet Lynne, III. Weisz, George IV. Series.

RJ101.H42 2008

362.198'92'000904

C2008-900447-7

This book was typeset by Interscript in 10/13 Sabon.

For our children and grandchildren

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Acknowledgments

The essays in this collection grew out of the AMS-McCord Colloquium, “Comparative and Interdisciplinary Approaches to Child Health in the Twentieth Century,” and the conversations begun there in October 2004. Organized jointly by the McCord Museum and McGill University, in Montreal, the meeting was sponsored financially by Associated Medical Services (AMS) of Toronto. Associated with the opening of the museum’s exhibit, *Growing up in Montreal*, the colloquium brought together scholars in history, anthropology, sociology, medicine, film, cultural studies, and art history. We are very grateful to Dr Victoria Dickenson, executive director of the McCord Museum, and her hard-working staff, and to Dr William Seidelman, past president of the AMS, who co-hosted this gathering of international scholars in the interests of child health, historical and contemporary. We also thank Phil Cercone, executive director, and Joan McGilvray, coordinating editor, at McGill-Queen’s University Press, for their guidance in seeing this project through. Needless to say, we appreciate the devotion of our contributors, for agreeing to participate in this project and for their efforts to rethink, revise – and meet our deadlines. Finally, we dedicate this volume to our children and grandchildren, with love, and with hope for a future that is good for all the world’s children.

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INTRODUCTION

Healing the World's Children

CYNTHIA COMACCHIO, JANET GOLDEN,
AND GEORGE WEISZ

At the historic 1990 World Summit for Children, the United Nations Convention on the Rights of the Child sought to inscribe in international law an irrevocable state commitment to the protection of the young. “Children must get the best possible start in life. Their survival, protection, growth and development in good health and with proper nutrition is the essential foundation of human development. We will make concerted efforts to fight infectious diseases, tackle major causes of malnutrition and nurture children in a safe environment that enables them to be physically healthy, mentally alert, emotionally secure, socially competent and able to learn.”¹ The statement and the document it drew from represented one of many attempts to assure child health and well-being in their every conceivable sense that served as a leitmotif of the twentieth century.

By 1900 the child welfare movement was becoming increasingly organized and active across Western Europe and North America. When Swedish reformer Ellen Key heralded the new century as the “Century of the Child”, this historic designation became the rallying cry of reformers who looked with tremendous enthusiasm and optimism toward a world in which the lives of children everywhere would be significantly improved.² The subsequent casualties of World War I – “the war to end wars” – gave particular urgency to child welfare campaigns. Many were pro-natalist in tone and outlook, generally focusing on state assistance for healthy maternity and on the elimination, largely through preventive, educational methods, of infant and maternal mortality the world over.³ The League of Nations published the Geneva Declaration of the Rights of the Child in 1924, declaring that “mankind owes to the Child the best that it has to give.”⁴

Following the century's second horrific world war, the Declaration of the Rights of the Child, adopted by the United Nations General Assembly in

1959, reaffirmed those noble aims: “[to] the end that [the child] may have a happy childhood and enjoy for his own good and for the good of society the rights and freedoms herein set forth, and calls upon parents, upon men and women as individuals, and upon voluntary organizations, local authorities and national Governments to recognize these rights and strive for their observance by legislative and other measures.”⁵

Looking backward, the historical record shows indisputable advances in health, education, social welfare, and social justice for children as the century progressed. The decline in infant and child mortality constitutes the most dramatic expression of these triumphs; more progress was made during the second half of the century in reducing stunningly high death rates than in any previous time. By 2000 the mortality rate of children under age five internationally was half what it had been in 1960; immunization was successful in preventing some two million child deaths annually; and such childhood scourges as diphtheria and poliomyelitis were virtually eradicated.⁶ In many ways, then, the prospects of all the world’s children have improved significantly since 1900.

Yet we know that in other respects the balance sheet is less impressive than Ellen Key and her contemporaries would have envisioned for the Century of the Child. Notwithstanding spectacular advances in medical science and technology, diagnostics and therapeutics, it is discouraging to note that millions of children under five still die annually from such age-old preventable causes as diarrhea, malaria, pneumonia, and malnutrition. Remarkably, pneumonia alone continues to kill each year more than two million, or nearly one in five children under the age of five years around the world.⁷ Diarrhea annually claims another 1.9 million children.⁸ Moreover, new threats just emerging as the century drew to its end seriously marred the record of achievement and present continuing challenges: HIV and AIDS currently affect millions of children in the developing world, with devastating results for present and future societies. In 2001 alone, an estimated 800,000 children were newly infected with HIV, almost all by mother-to-child transmission. Fourteen million children had been orphaned by AIDS by that time.⁹

Despite greater attention to children with disabilities and programs on their behalf, a 1999 Canadian report was highly critical of the lack of substantive improvement in the lives of the estimated 535,000 children in Canada suffering from long-term emotional, physical, or mental disabilities.¹⁰ Famine, war, disease, exploitation and abuse, entrenched poverty, and repressive or neglectful governments have too often afflicted and destroyed, as they continue to do, the lives and well-being of children.¹¹

Was the child-saving project of the twentieth century a grand if well-intentioned failure, as some scholars have recently charged?¹²

Perhaps instead of framing the question in this way, we would do better to aim for a clearer understanding of both the successes and the failures, with due attention to the shifting contexts of demography, economics, medicine, technology, and the myriad socio-cultural factors that influence the life and health of children. That is what this book aims to do. In presenting these essays, we hope to investigate a number of methodological possibilities for interpreting children's health status and needs and thus to promote discussion about child health and welfare, past, present, and future. We approach this subject from a variety of disciplinary and national backgrounds. We seek to understand the historical development of ideas, campaigns, policies, and laws concerning children for what these can tell us about past societies: the way in which a society regards its children reveals much about collective identity as well as national aspirations. Equally important is the light that such study casts on our contemporary responses to childhood and children.

Thinking about the past as a way of dealing with contemporary health issues raises a number of questions. Is there sufficient commonality of experience to justify comparing eras and nations? In evaluating the twentieth century record, we recognize that there are many "twentieth centuries," as evidenced in this collection. Each reflects particular national interests and histories, demographic shifts as measured in birth rates, family size, and the social profile of disease and death, material resources as well as human capital, and uneven developments in science, medicine, technology, education, social welfare, and the professions. Also vital, and closely related to issues of power, are questions concerning the categories of knowledge that we possess about child health in the twentieth century and the fundamental matter of who constructs these categories.

This is certainly true of our sources. The questions that have been and continue to be asked in censuses, epidemiological surveys, or even clinical trials reflect specific choices about what is important and what can be ignored. But this is equally true of social scientists who seek to bring a certain critical distance to the subject. As our contributors to this collection demonstrate, different approaches necessarily shape findings in different ways.

Anthropologists use ethnography to investigate children's experiences and perceptions, structuring categories around what was done and what was felt. Art historians uncover layers of meaning as they explore the connotations of particular visual representations and, at the same time, the cultural presumptions that shape the style and content of a painting, drawing,

photograph, or other artifact. Studies of media portrayals of children examine the intended messages, whether these are issued directly or obliquely, and, ultimately, how they are circulated and received. For historians, categories turn on events and contexts that are specific to time and place, sometimes measured by the analysis of quantitative data, at other times examined qualitatively through the critical study of sources that seem far more subjective and mediated.

Above all else, we want to know about the children themselves. They are the heart of the matter, but their voices are too often muted or missing. Although the singular achievement of the *Century of the Child* was to acknowledge the enormous value of children as “national assets,” as future citizens, this acknowledgment tells us astonishingly little about how their “best interests” are to be understood, protected, and advanced. Growing awareness of this paradox has fuelled the academic study of children and childhood, with much cross-fertilization as scholars borrow across disciplines, investigating neglected facets of this vast subject area. As the historiographic reviews that open this collection indicate, many scholars interested in age relations and the evolution of family life, and those examining medical and health care developments, share a common purpose: by situating children squarely at the centre of analysis, they are compelling the reassessment of some interpretations, enriching others, and unearthing new findings. They are committed to approaching children as active agents in their own lives and in history. To varying degrees, in different times and in different cultures, children despite their subordinate status are not merely and consistently silent, passive, and powerless. Their needs, rights, personal goals, and everyday lives cannot be presumed to be those represented through cultural ideals and prescribed practices, whether traditional and transmitted from one generation to the next or newly developed in response to momentary interests and anxieties.

Where health is concerned, this means seeing children as actors and decision-makers as well as recipients of care, objects of study, or victims of neglect and exploitation acted upon by others, usually adults. Children shape their own lives and the lives of those around them, within families and within the wider society. If they have left little in the way of direct personal testimony, neither are they altogether mute and invisible. By paying attention to their “absent presence” in the everyday lives of past societies, by listening for the silences that reveal much in what is not expressed about them, by layering often disparate and fragmented bits of evidence from multiple sources, by borrowing the analytical instruments and approaches of disciplines such as anthropology, sociology, psychology, and literary criticism, to

name only a few, we come closer to seeing children and letting them speak for themselves, rather than viewing them primarily through the eyes of adults and hearing only what those seemingly omniscient observers have to say about them.¹³

Even as we proceed with our discussions about disciplinary approaches to child health, historical and contemporary, we must concede the difficulties of our task. How do we interpret the roles of states and nations, religious groups and secular agencies, volunteers and professionals, and attempt to assess their proportionate influence on child health? Will the policy-makers and providers, their ideas and programs, be judged by the intentions that motivated them? By the consequences of their decisions? By their ability to resist or assist the interests of other participants, at times supportive, at times competing or conflicting, from patients to advocates, lobby groups, politicians, governments? What about the roles of family, kin, and community?

For all the sophisticated methodologies, critical analysis, academic scepticism, and willingness to try; for all the attention given to such key variables as race, region, class, culture, gender, age, education, access to knowledge, technology and care, physical and mental condition, diagnosis and prognosis; for all the commitment to tell a child-centred story, there is simply too much to be studied, too many ways of examining and knowing, too much that we do not yet know and can only discuss tentatively, too many questions still unframed as well as unanswered. What follows, however, is not merely an accounting of what is known and a tallying of what remains to be discovered. Taken as the sum of its various essays, *Healing the World's Children* presents, rather than a snapshot, a kaleidoscopic image of child health during the twentieth century. We see the swirl of many elements, at times similar, at times contrasting, at times interacting toward the same goals, sometimes contradicting, opposing, or impeding, but always in a state of motion, as each of the essays in this collection's five thematic sections indicates.

Since historical research remains at the heart of our enterprise, we begin with three comprehensive overviews of the historical literature on child health. Drawing from their extensive backgrounds as active, innovative scholars in childhood history, Neil Sutherland and Catherine Rollet examine the expansive historiography on child health in North America and Europe, respectively. Anne-Emanuelle Birn considers a more recently inaugurated but flourishing body of literature on Latin America. Each author maps out the existing scholarship within a particular regional context. The works discussed range from demographic analyses of mortality and

morbidity rates to historical accounts of efforts to improve child survival to fine-grained studies of particular aspects of children's lives and the ways in which age, race, socioeconomic status, and gender have shaped their experiences of health and well-being over time. These essays suggest the ways in which, in order to investigate children's lives in a manner that gives them rightful primacy in their own stories, scholars are turning to autobiographies, memoirs, and visual images as much as to the more traditional sources: official documents, prescriptive literature, and quantitative data. As with the traditional evidence, and approaches to it, each type of source and each method of analysis present both new insights and questions.

Along with new approaches and sources, new areas of study are developing. In the second section, two scholars scrutinize the changing meanings and representations of childhood disability, abuse, and exploitation in the twentieth century. Laurie Block, a filmmaker and disability activist, examines the relationship between disability and charity in the early twentieth-century United States. The "selling" of disability, as Block terms the efforts of philanthropic organizations, was infused with morality tales and imagery adroitly manipulated by those with advertising expertise. And, as sociologist Didier Fassin explains in his analysis of images of children with AIDS in post-apartheid South Africa, such efforts to manipulate public understanding are still underway. The image of "child as victim" has always provoked both a moral calculus and a pragmatic one: as governments and private groups struggle to provide for those who need their assistance, appeals for support to a public rendered sympathetic or guilt-stricken by representations of suffering children are common and effective. Yet these essays also warn of the dangers of casting groups of children solely as victims in need of charitable assistance.

The third section turns to one of the principal questions of recent childhood studies, that of children's agency. As the essays by Block and Fassin suggest, children's actual lives and actions, as much as adult perceptions of them, have helped to shape the efforts made on their behalf. The "sick-bed" culture of children is often depicted through the perspective of the caregiver, whether parent, doctor, or nurse. It is critical to listen for children's voices in order to understand how they experience episodes of illness and how they think about the meanings of health. Historian Mona Gleason uses the memories of Canadian adults to compare their recollections of their experiences of illness, pain, and injury suffered as children with the writings on these subjects in medical books and, more particularly, those disseminated in the health curricula developed for schools. Memoirs,

personal writings of various kinds, and oral histories are integral to this story. Anthropologist Myra Bluebond-Langer and scholar Megan Nordquest Schwallie rely even more directly and immediately on oral testimony, as Bluebond-Langer interacts with children with terminal cancer in Britain and the United States, interviewing them and their caregivers for a long-term ethnographic study. In both essays, however mediated by memory or the interview process, we hear children's voices and understand their actions. In the words of Bluebond-Langer and Nordquest Schwallie, they are "actively engaged in social worlds they create and the worlds others create for them."

Assessments of children often begin by defining and measuring what is "normal" in minds and bodies according to the established scientific standards of the day. These assessments fundamentally shape the ideas and practices of medicine, psychology, social science, state policy, and public initiatives. In the fourth section, two articles by historians analyze how social meanings, classifications, definitions, and diagnoses are arrived at, as well as their broader consequences. In his analysis of a particular episode during the Great Depression in the United States, Richard Meckel indicates how child health, as well as its absence, was defined and approached at a time of widespread material deprivation. Jeffrey Brosco traces the changing definition of mental retardation in the United States and its consequences for initiatives ranging from scientific inquiry to programs of education and training.

The final section presents two historical essays that rely on representations of children in paintings and photographs as their principal source. Loren Lerner's essay explores artistic representations of sick children intended for public viewing, while Vincent Lavoie considers photographic images of deceased children, many of which were professionally produced and meant to serve as "*memento mori*" or memorializations for family and kin. By uncovering ideas and practices that are difficult to glean from the customary documentary materials, the authors demonstrate how visual imagery is critical to the study of child health in the twentieth century. Lerner focuses on the renowned surgeon, artist, and socialist Norman Bethune and his circle of Montreal literary and visual artists, who expressed their beliefs about socialism, medicine, science, citizenship rights, and the dignity of the child in the images they portrayed. Lavoie traces the practice and gradual disappearance of postmortem photography of children taken by amateur photographers, often family members, as these were eclipsed by a new, carefully staged iconography of death that became a specialty of professional photographers.

Together, the essays in this volume, interrelated and often complementary in subject matter and method, constitute something of a cross-section of views, ranging widely in disciplinary and national scope, in time and place and culture, about the sources, arguments, and approaches employed by scholars and students who seek new ways to understand the history of child health as well as its contemporary implications. This new scholarship, much of it by scholars whose primary field is not child health, both testifies to and underscores the practical value of studying children and their experiences of health, illness, disability, and abuse. It suggests new ways to think about the pressing concerns of our own world, where the rights to health and security of our most vulnerable citizens – and thus our collective futures – lie.

If the Century of the Child brought recognizable improvement in the health of the world's children, a quick glance backwards shows how much more remains to be done, and how quickly new problems arise to take the place of those seemingly vanquished. Like the child-savers of Ellen Key's time, advocates in our own day are pressing for initiatives to continue the ongoing, ever-important fight to realize the health and well-being of all the world's children as an unquestioned human right. The UN Convention on the Rights of the Child is the most widely ratified international treaty in history; six of the eight UN Millennium Development Goals directly address child welfare concerns; the 2002 UN Special Session on Children culminated in an agenda for global action entitled *A World Fit for Children*.¹⁴ Healing the world's children is not merely the subject of our studies: it must be our shared objective. In the future, scholars will decide whether we have done better than our well-meaning predecessors.

Cynthia Comacchio

Janet Golden

George Weisz

NOTES

- 1 United Nations Convention on the Rights of the Child, Article 24. This convention was ratified by 191 states as of 2002, with the exception of Somalia and the United States. The international human rights treaty calls for the development of national policies and programs to ensure the health and security of all young people under the age of eighteen; see Canadian Association for Community Living and Inclusion International, *A World Fit for All Children*.

- 2 Ellen Key (1849–1926), a Swedish feminist, teacher, social reformer and essayist, wrote the international bestseller *The Century of the Child*. Originally published in Sweden in 1900, this work effectively became the manifesto of “child-savers” internationally. On Key, see Dekker, “The Century of the Child Revisited,” 133–50.
- 3 The three historiographical essays in section 1 of this collection detail the various campaigns of the early twentieth century in North America, Europe, and Latin America.
- 4 League of Nations, Geneva Declaration of the Rights of the Child, 26 September 1924.
- 5 United Nations, Declaration of the Rights of the Child, 20 November 1959.
- 6 Save the Children, *Seventy-Five Years of Save the Children*.
- 7 Wardlaw, Johansson, and Hodge, *Pneumonia: The Forgotten Killer of Children*, 6–7.
- 8 Gerlin, “A Simple Solution,” 42–3. The other leading causes of death of children under five, excluding neonatal deaths, are malaria, 853,000 annually; measles, 395,000; and HIV/AIDS, 321,000.
- 9 An estimated 11.8 million young people aged fifteen to twenty-four were living with HIV in 2002. Girls are particularly vulnerable; in many countries in sub-Saharan Africa, young girls have infection rates five to six times higher than boys of the same age group. See the report by the World Health Organization, “Children and Young People Are at the Center of the Epidemic.”
- 10 Picard, “Report Critical of Way Disabled Children Treated,” 1. The 138-page report, *The UN Convention on the Rights of the Child: How Does Canada Measure Up?*, was produced by the Canadian Coalition for the Rights of Children for the UN Committee for the Rights of Children. An update issued in 2003 was somewhat more positive on Canada’s record, noting that Canada had made “some level of progress toward the implementation of the UN Convention on the Rights of the Child” but also that “a substantial gap remains between the promise and the reality of children’s rights in Canada” (3).
- 11 Save the Children, *Seventy-Five Years of Save the Children*, 4. More than 600 million children in the developing world live in families that must survive on less than \$1 a day; one in six children in the United States and Canada lives in poverty.
- 12 See, for example, Sealander, *The Failed Century of the Child*; Dekker, “The Century of the Child Revisited,” 133–50; for Canada, see Sutherland, “Reflections on a Century of Canadian Childhood,” 175–87; Strong-Boag, “Long Time Coming,” 124–37.
- 13 Leonore Davidoff uses the expression “absent presence” to denote the influence of families in history even when they are not the explicit subject matter; see introduction to *The Family Story*, edited by L. Davidoff, 21–3.
- 14 United Nations, Declaration of the Rights of the Child; Innocenti Research Centre, *Report on Children and Disability*, vi; Canadian Association for Community Living and Inclusion International, *A World Fit for All Children*.

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PART ONE

Historical Perspectives on Child Health

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1

North American Perspectives on the History of Child Health in the Twentieth Century

NEIL SUTHERLAND

This survey emerged from an extensive but nonetheless impressionistic reading in the substantial literature that has developed on the subject of child health in North America during the twentieth century. I must emphasize that the subject permits other summaries and interpretations. After setting the stage with brief accounts describing children's illness and death, I discuss the following topics that emerged from my rummaging: a summary of what I see as the broader context; the literature dealing with the decline in infant mortality; the role of schools in improving the health of children; the emergence of notions of "normality;" the mixed story of caring for seriously disabled children; the persistently unsatisfactory state of the health of Aboriginal youngsters; the social and medical aspects of sexual abuse; the work of some of the major actors, and especially differing opinions on the roles of women and of medical specialists; and a final brief comment on transnational dimensions of child health care.

Hidden away in the historical literature are sick, disabled and dying children, and their anxious or grieving families. As more than one historian has commented, children themselves are seldom present in history, even when it is about childhood. We rarely hear what John Spargo described a century ago as children's "bitter cry," or hear "*La voix de l'enfant s'élève contre vous!*" – the theme of a child welfare exhibit held in Montreal in 1912.¹ A few brief glimpses, then, give us a sense of lives and deaths embedded in the data. First, let us look at some examples in the context set out by Samuel Preston and Michael Haines in their account of child mortality in the late nineteenth century.²

In my wife Janet's family album, there is a faded photograph, taken in 1874, of two infants bundled up on a chair – children of Janet's great-grandparents – outside their home in Watford, Ontario. Twins Leander

Dufferin and Beatrice Anne Harvey were dying of “summer complaint,” (cholera infantum), and there was nothing their mother, Anne, or physician father, Leander (a recent graduate of the University of Pennsylvania medical school), could do for them. In the not uncommon practice of the time, their parents summoned a photographer to provide them with a visual memorial of those they were about to lose.³

A generation later, and at the very point of transition from palliative to scientifically based care, the child Laura Goodman Salverson contracted diphtheria. As an adult, Salverson vividly described her experience of the disease: “I awakened with a horrible, choking sensation, that rapidly increased. My body was on fire, my head spun with queer noises, and nothing that anyone could do eased my growing misery. The old doctor ... wrung his hands in despair. He had thought this a case of aggravated croup, he said, but now surmised the ‘infant-killer had picked me for its victim.’” Although the doctor had heard of the recently invented antitoxin, none was available in rural Manitoba. A more experienced physician then entered the case: “I remember the insufferable tent, made of heavy blankets, where my father was to hold me over a tub of boiling water, kept at white steam heat with hot stones. I remember it so well because, in my choking agony, I clutched at papa and moaned ‘Take me out papa – I’m gone any way!’” Eventually a surgeon came and inserted a tube in the child’s throat. On a later morning, “awakening from a foggy sleep, I overheard voices: ‘She will live,’ someone said, ‘but I’m afraid her voice may be lost’” After a six-week bed-ridden period of absolute silence, Laura was at last allowed to try to speak.⁴

Children were well aware of the realities of death. In her diary for Sunday, 30 July 1865, twelve-year-old Julia Stone of Helena, Montana, wrote, “At two o’clock in the morning a highway Robber was hung on a large pine tree. After breakfast we went to see him.”⁵ If few children actually saw the aftermath of an execution, they customarily attended funerals of family members and classmates, sometimes even acting as pallbearers. It is not surprising that they incorporated death into their play.⁶ Wrote Ethel Spencer, “I have vivid memories of harrowing games during which our children [dolls] became desperately ill and died.” Funerals were especially popular, with a doll named Becky the ever-willing victim. “No day was too short for a funeral,” reported Alice Kent Trimpey.⁷ Indeed, as most adults can recall, doll and pet funerals remained part of childhood throughout the next century.

Finally, there is the pain of one child of our own time. Recently, as part of his research for a pamphlet for the Arthritis Society, Brian Stewart conducted a telephone interview with a seven-year-old girl: “I already know

her symptoms, that she often has very painful attacks. But I don't ask her about her pain. Instead, I ask about catching up with school work on the days she must stay home, about how she likes her therapy in a hot pool, about how she would love to play soccer but can only watch. She is cheerful until the very end of the interview. Then she says spontaneously, 'Oh, it hurts so much.'"⁸

Many more examples of children's perspectives are found in anecdotal accounts in autobiographies and in reports made by physicians, parents, or teachers.⁹ Occasionally youngsters appear as "cases" in the scholarly literature. Thus Joan Jacob Brumberg examines the "embodiment" of American girls, and Mona Gleason employs adult memories to explore how perceptions of their bodies shaped youngsters' attitudes towards gender, sex, race and class.¹⁰

Mortality statistics lay bare the bones of my extensive topic. Their most striking revelation is the very sharp decline in infant and child mortality in the past century. "At the beginning of the twentieth century in Canada," writes Cynthia Comacchio, "one in five babies lost its life before its second birthday."¹¹ For the United States, Richard Meckel writes, "an informed estimate would be that somewhere between 15 and 20 percent of all American infants born in the second half of the nineteenth century died before they could celebrate their first birthdays."¹² Even for those who survived infancy, childhood mortality was very high. For 1900–1902, Harvey Graff estimated "more than 12 percent of American infants died before reaching one year; more than 18 percent died before their fifth birthday."¹³ In Charles King's estimate, "Before the twentieth century, nearly one-half of all live-born children died before they reached adolescence."¹⁴

The passage of a hundred years transformed these rates. By 2001, infant mortality in Canada had dropped to 4.6 per thousand live births and in the United States to 6.8.¹⁵ Such precision also reflects the increasing accuracy and comprehensiveness of birth and death registration over the century.

The second revelation about child health over the century is how the decline in mortality varied according to the race, class, ethnic group, gender, and geographical location of families. Alisa Klaus notes that mortality rates were higher in urban areas, industrial cities, and mining towns than in small towns and rural areas, higher among poor children than middle-class ones. In the United States, African-American children had a mortality rate "more than twice as high as that of whites."¹⁶ The infant and child mortality rates for Canadian First Nations youngsters were probably even higher.

Although the rates for African-American, First Nations Canadian, and other less privileged children dropped over the century, they still remained

far above the average. In the 1980s, for example, the infant mortality rate of the “most poor” in British Columbia was twice that of the “least poor,” and that of the Native population four times that of the most favoured group.¹⁷ Although the Native rate declined, by the end of the century infant mortality rates were still “more than twice as high amongst First Nations as non-First Nations people,” and post-neonatal mortality rates “were 3.6 times as high.”¹⁸ A recent study shows the racial disparity still prevailing for Black Americans: in 2001 the infant mortality of black infants was still more than double that of white groups.¹⁹

Both the overall decline in juvenile mortality and the unevenness of this decline rest in the interrelationship of a complex series of events. Among the most important of these are a rising standard of living; improved sanitation; the declining morbidity of some diseases; families, schools and communities increasingly employing effective public health measures; a string of laboratory discoveries; and improvements in medical practice. In turn, the complexity of the change is matched by the complexity of the literature that sets it out.

Historians in both the United States and Canada have written about the efforts to reduce infant and childhood mortality. In addition to the already cited works of Comacchio, Meckel, Klaus, and King, William Rothstein discusses what he describes as the “risk factor,” especially with reference to diphtheria, infant mortality, and industrial insurance.²⁰ Denyse Baillargeon has demonstrated the connection in Quebec between a nationalist ideology and the effort to reduce infant mortality.²¹ Janet Golden has shown how wet-nursing, for a time so important in preserving the lives of premature babies, was gradually commodified from the end of the nineteenth century until the need sharply declined after the World War II.²² A collection of essays edited by Alexandra Stern and Howard Markel (many cited below) range over diverse aspects of the topic.²³

Given that the greatest reduction in death rates was among infants, it is not surprising that their care has received more attention than that for older children. Nonetheless, historians on both sides of the border have analyzed campaigns to control and treat such diseases as diphtheria, measles, and polio, which found most of their victims amongst school-aged children.²⁴ And children benefited from improvements brought about by efforts to improve conditions that were debilitating but not necessarily fatal. Families, heeding a growing body of advice directed at them, began such practices as providing youngsters with regular doses of cod liver oil and vitamins. Teachers and school nurses made health inspections, looking for evidence of infectious disease or chronic, treatable conditions, such as

goitre or head lice. They distributed iodine tablets and encouraged healthy practices through hand-washing and tooth-brushing drills. School dentists fixed teeth. Sanatoria and orthopedic wards and hospitals treated tubercular children and those with physical disabilities.²⁵

The role of the school, however, was not always benign. Meckel and Sutherland have discussed the dual role schools played both in spreading disease and as theatres for teaching and practising preventive medicine.²⁶ Schools, for example, played a major role in spreading diphtheria. Especially in the late summer and early autumn, as children came together in classrooms, on playgrounds, and at the funerals of peers, infected youngsters passed this highly contagious disease on to classmates. On the other hand, when public health authorities decided to inoculate youngsters to protect them from some infectious diseases including diphtheria, they found their subjects conveniently gathered in schools. Mental hygienists also took advantage of assembled children in their effort to undertake what Sol Cohen has described as the “medicalization” of education.²⁷

Mona Gleason has shown how the school’s preventive work and teaching were biased on both racial and class lines.²⁸ Jeffrey Brosco shows how weight charts produced an “epidemic” of malnutrition.²⁹ Rothstein has described the misguided enthusiasm for tonsillectomies, “millions of which were performed after 1920 with the idea of preventing rheumatic fever.”³⁰ In Canada some physicians conducted mass tonsillectomies, especially for poor and rural youngsters. Communities assembled children at a local schoolhouse.³¹ William Macklon described his own experience in rural Saskatchewan: parents “dragged their petrified children” to the school “and they ran the whole kaboodle of school kids through the operation using the two teachers’ desks pulled together for an operating table.”³²

Over the whole of the century, schools were also enlisted in efforts to improve children’s fitness through both diet and exercise regimens. Concern was triggered by the poor physical condition displayed by the military conscripts and recruits of the two world wars. Both countries gradually responded by introducing school lunch programs, compulsory military drill, physical education in schools, and community recreation programs.³³ These efforts showed very limited success. In the second half of the century the focus remained on the connection between diet and fitness but now emphasized youthful obesity over under-nourishment. As Judith Sealander has sceptically observed, “muddled versions of social science theories justified public policies, whose primary achievement was to encourage the growth of several new professions, among them physical education and nutrition science. American [and Canadian] kids just grew fatter and flabbier.”³⁴

An increasing fascination with adolescence was accompanied by an interest in the health of teenagers. As Cynthia Comacchio has shown, in spite of the fact that health surveys “emphasized that the age group from 12 to 24 enjoyed the soundest health and lowest mortality rates of all age groups,” physicians nonetheless “medicalized” adolescence.³⁵ Thus, she explains, medical professionals “formulated a body of shared ideas and approaches to the all-encompassing ‘health’ of the young.”³⁶ Heather Munro Prescott provides an overview of even more extensive developments in adolescent health in the United States.³⁷

New practices in child health also played a vital part in the emergence of a new medical profession: the public health nurse. Nurses made post-natal visits, conducted well-baby clinics, and gradually assumed responsibility for school medical inspections. There they looked for evidence of infectious diseases, measured and annotated such physical characteristics as vision, weight and height, readmitted children who had been absent from school, and conducted follow-up home visits.³⁸ Eventually, however, nurses became prisoners of records that health authorities demanded and endlessly summarized (and celebrated) in their reports; records became ends in themselves. A mid-century survey by the Canadian Public Health Association concluded that record keeping had come to consume nurses’ time “out of proportion” to other duties, and especially to home visits to the newly born.³⁹

These records and their related reports indicate another characteristic of the twentieth century childhood: the gradual application to children of the supposedly scientific concepts of “normality” and “normal child.” Initially drawn from scientific literature, these terms soon became a central characteristic of all fields of modern professional childcare.⁴⁰ Indeed, and as Mona Gleason has shown, classifying records quickly led to classifying children themselves.⁴¹ Thus a famous early Canadian pediatrician, Dr Alan Brown, entitled his 1923 text on childrearing *The Normal Child: Its Care and Feeding*.⁴²

In consequence, the twentieth century brought increasingly fine distinctions among children. From such traditional broad categories as infancy, childhood, and youth, the new century employed criteria that tightly sorted them by age, sex, nationality, race, social class, weight, height, grade, and intelligence. Thus “normal” children were those whose score fell between an upper and lower point on statistically derived scales in each category. A normal child was one who at a particular age was at a certain level in school, whose height and weight fell within an appropriate range, and whose “intelligence quotient” (IQ) lay at some satisfactory point on a scale revealed by such devices as the widely used Stanford-Binet tests – tests

tightly tied to middle-class English-speaking culture. A “normal” child came from a “normal” family.⁴³ Implicit in the notion of family normality was that the “norm” was a white, middle-class two-parent family in which the mother served as a full-time homemaker.⁴⁴ Implicit too was a need to keep records of how children had been sorted: which children had been vaccinated, which were in the “right” grade for their age, which were in severely disrupted families, and so on.

The Dionne quintuplets were born to a francophone Catholic family on a northern Ontario farm in May 1934. By means of the enormous, worldwide body of literature their birth and early years inspired, the girls served to popularize notions of “modern” child care, including the role of norms of various sorts.⁴⁵ Soon after they were born, the girls were subjected to intensive investigations as to their “fit” within the various categories of normality. As early as 1937, psychologist William Emmett Blatz, of the University of Toronto’s St George’s School for Child Study, published an edited collection of studies on such topics as the quintuplets’ mental growth, social development, and language acquisition.⁴⁶ On the other hand, the sad story given witness in the girls’ own perspective on their lives took a long time to emerge.⁴⁷

Sorting and classifying also produced “abnormal children” – those who fell outside boundaries derived from statistical analysis of whole cohorts. Some came in for special treatment, such as free milk for the underweight, free eyeglasses, “fresh air” classes, hearing aids, and dental care, all relatively benign. Other treatments, including assignment to “special” classes, schools, and total institutions of various sorts, could have pernicious effects such as abuse and sterilization that were life-long. Nonetheless, many blind and deaf youngsters benefited from the very specialized care provided by schools established for them.⁴⁸ These schools, however, tended to persist even after expertise became diffused enough for such special education to be available locally. As the example of British Columbia’s Jericho Hill School for the Deaf and Blind testifies, youngsters in such schools were also vulnerable to abuses.⁴⁹

Improving infant health seems to have been particularly effective in saving the lives of premature and of physically and mentally handicapped infants and children.⁵⁰ Until the twentieth century, the vast majority of severely handicapped youngsters perished in infancy or early childhood. When improvement in their chances for survival came, however, it was two-dimensional. As Philip Ferguson explains, there is “not simply a one-directional consideration under which improvements in medical care and general public health mean only that fewer organically impaired babies are

born today and fewer children are left impaired from childhood diseases that are now controlled." In fact, Ferguson continues, the "same general improvements in health care mean that severely retarded children survive infancy and childhood today who would have quickly perished in earlier years. The example of Trisomy 21 and neural tube defects like spina bifida come quickly to mind."⁵¹

Ensuring long-term survival brought the need to provide some survivors with long-term care. For much of the century, parents and health care workers argued that these new sorts of care could best be delivered by special institutions.⁵² Consequently, there was a continent-wide expansion in long-term care facilities. Many institutions that took care of handicapped youngsters originated in the nineteenth century when states and provinces had gradually moved those described as "the chronic insane or harmless incurables" from poor-houses and jails into purpose-built institutions, especially those for the deaf-mute, the blind, and the feeble-minded. By 1898, nineteen states had institutions for feeble-minded children, and by 1920 all but four states supplied public care.⁵³ These institutions eventually grew into large ones, often with thousands of inmates.⁵⁴ For most of the twentieth century both professionals and parents worked to extend and improve the treatment provided in them. An international effort to set and apply standards was central to this endeavour.⁵⁵

During this period institutional care of afflicted children was intimately connected to two other aspects of child health: eugenics and abuse of various sorts. Those influenced by eugenics feared that the mentally handicapped would, as they matured, increase the "decadent stock." In 1924 Alberta's deputy minister of health, W.C. Laidlaw, expressed a widely held sentiment: "I certainly think that some steps should be made to prevent the marriage of mental defectives, even those of a slight degree of mental deficiency. They cannot breed up, and they are sure to breed down."⁵⁶ This negative side of eugenics, which led to a variety of efforts to sterilize the supposedly "unfit," has deservedly received severe criticism. Martin Pernick has shown both the shape of the debate in the medical community and how the fear of "defective" babies entered popular culture through motion pictures, especially the long-lived 1916 film *The Black Stork*, still being shown in the 1940s.⁵⁷

Both Canadian and American youngsters were sterilized. In Canada, and in addition to privately arranged operations in most parts of the country, legislation passed in Alberta in 1929 and in British Columbia in 1933 led to approximately 1,000 compulsory sterilizations before these provinces ended the practice.⁵⁸ Wendy Kline has reports that in the United States

between 1931 and 1939, "over twenty thousand institutionalized patients were sterilized, nearly triple the number sterilized between 1920 and 1929."⁵⁹ Although the victims of sterilizations were mostly girls, Alexandra Minna Stern notes that vasectomies were performed at the Indiana Reformatory in the 1890s, as apparently was also the case in California.⁶⁰

Institutional care sometimes involved another form of abuse, that of medical experimentation on the inmates. In the early 1800s, some institutionalized children were used in assessing the merits of inoculations for smallpox and for measles.⁶¹ Susan Lederer has described many experimental efforts made in the United States between 1870 and World War II.⁶² Some procedures considered acceptable at the time would not be allowed now under regulations governing the use of human subjects.⁶³ Other procedures tried in these years were sharply criticized even at the time, especially by antivivisectionists who were in the forefront of those opposed to medical experimentation on both animals and humans. Among their many targets were experimental tests involving lumbar punctures of youthful patients in the Boston Children's Hospital, injecting "charity children" with the germs of bovine and human tuberculosis, and employing "balloon catheters, X-rays, duodenal tubes, and other apparatus" to study normal digestion in children housed in the Hebrew Infant Asylum in New York City.⁶⁴ Alfred F. Hess, the pediatrician who conducted this latter investigation, justified the use of institutionalized children in experiments by arguing that living in institutions produced "conditions which are insisted on in considering the course of experimental infection amongst laboratory animals, but which can rarely be controlled in a study of infection in man."⁶⁵

Despite criticisms and investigations, medical scientists continued to employ institutionalized children as research subjects. Among postwar experiments, those conducted in New York's Willowbrook, an institution for mentally handicapped children, were probably the most notorious. In that study, one that went on over many years, researchers tried to develop a hepatitis vaccine by studying youngsters who had been deliberately infected with the virus.⁶⁶ Such experiments perhaps exemplify the argument made by Jordan Goodman, Anthony McElligott, and Lara Marks that, to some, "the body has not only become the object of scientific enquiry, but it has also been seen as a raw material to be configured into its final and useful form."⁶⁷

Although much medical experimentation took place in institutions, it is also important to note that non-institutionalized children also served as experimental subjects. Susan Lederer describes cases in which physicians tried out new treatments on themselves or on their own children. Perhaps

the most controversial experimental practice on private patients was what was described as the “gender reassignment” of boys who lost their penises through botched circumcisions, children doubly victimized by medical science.⁶⁸

The history of special care is also connected to that of sexual abuse. While sexual abuse has always been a forbidden but sometimes ill-defined or unrecognized practice, its incidence has been difficult to determine. Indeed, as Hughes Evans argues, citing the work of Henry Kempe and Suzanne Sgroi, “most pediatricians were unable to recognize the magnitude of child sexual abuse, and they did not feel a professional mandate to address it.”⁶⁹ Nonetheless, some physicians, such as one in Lancaster, Pennsylvania, “treated boys as young as ten years old and upward for venereal infections.”⁷⁰ In fact, physicians had to abandon the strongly held belief that gonorrhea could be transmitted by non-sexual contact before understanding that its presence in both girls and boys was a clear, undeniable indication of sexual abuse.

The problem of abuse is compounded if the abused are young or disabled in some way. They may not understand that what is happening to them is abusive. If they do, they may not have either a means or a mechanism to report or otherwise bring it to an end. Others are clearly frightened of the consequences of complaining or reporting, realistically fearing sanctions from those about whom they complain. Still others hold back because they are ashamed of what happened and even wonder if they share some responsibility for the abuse. Naïve caregivers may fail to recognize evidence of abuse of their charges.

Institutional care increases opportunities for abusers. Children in total institutions, residential schools, hospitals, orphanages, and custodial homes are therefore in particular need of properly supervised care. Badly treated children in families may find haven and solace in their extended families, in school, and from amongst their peers; children bullied in school by peers or vicious teachers may find a haven in a loving home. But maltreated youngsters in total institutions have no one to turn to. Those who are severely disabled often have no way of articulating their grievances.⁷¹ In turn, and as revealed in public investigations, an institutional culture usually protects itself in the face of criticism.⁷²

Nonetheless, and in response to their extreme vulnerability, it appears that the care of the disabled was more closely supervised than that of children in other institutions. Increasingly rigorous standards were set for their residential care, and external evaluations became common. Parents of children in such institutions, almost from their opening, established groups that

supported the care of their children. As they visited youngsters, raised funds, and lobbied governments, parents understood how their children were cared for. This close relationship suggests that many such institutions came closer (but still probably not close enough) to meeting the goal of good child care than did other total institutions.⁷³

Afflicted children came to benefit from the work of those whom Wendy Kline characterizes as “positive eugenicists.” This group emphasized such non-invasive measures as improving the home environment, marriage stability, reproductive morality, and the like. Kline concludes that positive eugenics triumphed during the baby boom of the 1950s.⁷⁴ Consequently, in the second half of the century, the consensus on what was proper care shifted to a major effort to move incarcerated children out of long-term institutional care into family and community settings.

This transformation was mightily enhanced with the election of John F. Kennedy to the presidency of the United States in 1961. One of the president’s sisters was mentally handicapped, and the family campaigned vigorously to improve the care of those who shared her affliction. According to Edward Shorter, their work, under the leadership of Kennedy’s sister Eunice Shriver, played a major part in the move away from institutional care.⁷⁵ The Kennedy family did not work alone. As Shorter notes, “parents and their organizations were instrumental in several key aspects” in the move “to deinstitutionalize children with MR.”⁷⁶ In a closely related development, Jacqueline Vaughn Switzer notes how new notions regarding the individuality of those in care, and the related controversy as to the reproductive rights of the disabled, also helped them to a fuller citizenship.⁷⁷ In Canada, the widely circulated CELDIC report of the Ontario Commission on Emotional and Learning Disorders in Children popularized new notions of care.⁷⁸ Eventually, these changes in attitude and related changes in treatment brought about the closure of many large institutions on both sides of the border and their replacement with assisted home care, group homes, and the like.⁷⁹

Some studies have tried to estimate the incidence of child abuse outside of total institutions, or to compute trends. A 1989 Canadian study comparing the 1940s to the 1980s concluded that such abuse “is not increasing but, in a new social climate, more children and their families are coming forward.”⁸⁰ In 1983, as part of its investigation into sexual offences against children, the Badgley Committee had the Canadian Gallup Poll conduct a national survey employing questionnaires answered anonymously and privately. On the basis of this survey, the committee concluded, “at some time during their lives, about one in two females and one in three males have

been the victims of unwanted sexual acts. About four in five of these ... happened ... when they were children or youths." Although this and other findings of the committee came under sharp criticism for combining trivial with extremely serious examples of abuse, its data clearly showed that many children in the years covered by its study concealed, or were forced to conceal, what happened to them.⁸¹ Sometimes even caregivers felt it better to look the other way than bring on outcomes for themselves and even for the abused that they viewed as worse than the abuse itself.

If the incidence of abuse may not have changed a lot over the century, our concerns about its effects have substantially increased in the last several decades. As the notes below indicate, there is now an extensive literature on its incidence in families, schools, and child-care institutions. They reveal that residential schools, and especially those for First Nations youngsters, were particularly pernicious theatres of abuse.

Investigations of abuse in residential schools are part of the recent explosion of interest in First Nations studies in Canada, including the effects of poor health and disease on this population. Marlene Lux and Mary-Ellen Kelm have shown how both reserves and residential schools contributed to the very high mortality, especially from tuberculosis, amongst First Nations youngsters.⁸² Kelm explains that the "bodies of Aboriginal children were indeed transformed by the residential school experience. But the residential schools did not produce robust workers, as they had promised, but rather weakened children and adolescents. Waves of communicable diseases and endemic tuberculosis found easy prey amongst overworked, underfed and abused students: 'Graduates' frequently convoked not to the waiting world of agricultural labor, but to the sanitarium, the hospital and the grave."⁸³

This scandal was not a recent discovery. In 1904 Dr Peter H. Bryce, who as secretary of the Ontario Board of Health had been a vigorous advocate of improvements in infant and child health, began lobbying for improvements in residential schools. He noted that tuberculosis was the principal cause of Indian mortality. Later, as a federal medical officer, he continued campaigning, reporting, for example, that 28 per cent of those who attended the Sarcee Boarding School in Alberta between 1894 and 1908 had died, mostly from tuberculosis.⁸⁴ Bryce conducted his investigations in the context set by the cold-hearted views of his superior, Duncan Campbell Scott, deputy superintendent of Indian Affairs. In 1912, Scott wrote of the effects of tuberculosis in the residential schools: "It is quite within the mark to say that fifty per cent of the children who passed through these schools did not live to benefit from the education which they had received therein."⁸⁵ Although Bryce effected some improvements before Scott had him replaced in 1913, conditions in many

schools, especially those managed by the Anglican Church, remained very poor. In 1920, Dr F.A. Corbett found conditions so bad at the Sarcee school – an unsanitary building and twenty-nine of its thirty-three inmates suffering from tuberculosis – that he recommended its closure.⁸⁶

Concerns about disease were intimately connected to those about diet. In his history of Canadian residential schools, J.R. Miller wrote that from “the earliest days of the modern residential schools until they were phased out, the deficiencies of school food were a source of complaints and protests.” Although noting that such complaints are characteristics of all institutional settings, “in the case of residential school food, both the specific complaints and their severity go far beyond what is usually encountered among the denizens of other institutions.”⁸⁷

The condition of Native American children in the United States was no better. David Jones’s recent broad survey of epidemics among American Indians provides the context, and his extensive annotations are a fine introduction to the literature.⁸⁸ Jones’s overall conclusion applies as much to Canada as it does to the United States: “Whether the prevailing diseases were acute infections (such as smallpox and measles), chronic infections (such as tuberculosis), or the endemic ailments of modern society (such as diabetes and alcoholism), American Indians have always experienced higher rates of disease than their European and American contemporaries.” Jones concluded that the “existence of disparities regardless of the underlying disease environment provides a powerful argument against the belief that each disparity reflected an inherent susceptibility of American Indian populations. Instead, the disparities in health status must reflect the disparities in wealth and power that have endured since colonization.”⁸⁹

Like their Canadian counterparts, Native Americans suffered high rates of infant mortality. In his case study of infant mortality on the Yakima Indian Reservation between 1914 and 1964, Clifford Trafzer concluded that confinement “on the reservation led to changes in subsistence, child care, and housing [that] contributed to infant deaths resulting primarily from pneumonia and gastrointestinal disorders.”⁹⁰ He also showed that the infant mortality rate on the reservation was much higher than that of whites and, although “the difference is not as great, over a period for four decades the Yakima experienced an infant mortality rate per 1000 live births higher than that of nonwhites in the United States.”⁹¹

As was the case in Canada, residential schools and Indian orphanages harboured disease and even contributed to its spread.⁹² Writing of the half century between 1875 and 1928, David Wallace Adams explained that “Indian populations generally and Indian children specifically were being

ravaged by disease. The situation was especially acute at boarding schools, where epidemics of tuberculosis, trachoma, measles, pneumonia, mumps, and influenza regularly swept through overcrowded dormitories, taking a terrible toll on the bodies and spirits of the stricken ... Every off-reservation school had its own graveyard. Thus disease and death were also aspects of the boarding school experience.”⁹³

The treatment of eye diseases among Native American children provide particularly troubling examples of inappropriate treatment. Marilyn Holt noted that early in the twentieth century physicians of the Indian Health Service “devoted considerable time to identifying conjunctivitis, commonly referred to as pinkeye, and trachoma,” that, if untreated, led to “scarring of the eyelids, clouding of the cornea, and blindness. Highly contagious viral and bacterial forms of these eye diseases spread rapidly among children leading to local epidemics.”⁹⁴ From 1924 to 1927, the Office of Indian Affairs conducted a national campaign to eradicate trachoma from Indian communities. However, as Todd Benson reports, “the trachoma campaign was based on the use of radical surgical technique known as tarsectomy, in which the surgeon treated the disease by cutting out the tarsus, the supportive tissue under the eyelids.”⁹⁵

Despite warnings that the procedure should be done only on carefully selected patients by highly skilled surgeons, the OIA required that “all our physicians to learn how to perform the approved operations ... or give place to those who learn.”⁹⁶ The result of this directive was disastrous: “At least three thousand people had their eyesight destroyed or damaged.” Rather than take any responsibility for this situation, the OIA placed the entire blame for its failure onto its Indian patients. As Benson concludes, “Government physicians had demonstrated an absolute faith that medical science could compensate for alleged Indian racial inferiority and provide a cure for trachoma. Then, when the campaign failed, those same supposed racial defects served as a convenient scapegoat.”⁹⁷

In 1926, Lewis Merriam directed an independent study on Indian policy in the United States. The Merriam Report was harshly critical: “The survey staff finds itself obliged to say frankly and unequivocally that the provisions for the care of the Indian children in boarding schools are grossly inadequate.” As to health, the report noted the “outstanding deficiency is in the diet furnished the Indian children, many of whom are below normal health. The diet is deficient in quantity, quality, and variety.” The dormitories were also inadequate: crowded, with inner rooms shut off from “light and air.” Toilet facilities were “fairly frequently not properly maintained or conveniently located. The supply of soap and towels has been inadequate.”⁹⁸

What has been called “the Indian New Deal” brought some improvement in the lives of American Indians. However, as Margaret Szasz notes, they “benefited not because their plight was unique but because they were part of a national plight.”⁹⁹ Despite the benefits, Jones concluded, “American Indian health remained poor.” Their care still fell below national standards; “age-adjusted mortality exceeded the national average for pneumonia, influenza, and tuberculosis.”¹⁰⁰ The Kennedy Report of 1969 concluded the residential schools still helped perpetuate “the cycle of poverty which undermines the success of all other Federal programs.”¹⁰¹

Let me now turn briefly to those many individuals and groups who worked to transform the health of children in the twentieth century. Among their number are social reformers of various sorts, journalists, sanitary engineers, statisticians, laboratory scientists, physicians, including family doctors, obstetricians, neonatologists and paediatricians, public health physicians, and public health nurses; the list of those who made a difference is a long one with a rich literature devoted to their work.

Since their role has to some degree been contested or, at least, subject to varied interpretation, of the major players I want to discuss briefly the women now sometimes referred to as “progressive maternalists.” These women are of particular interest because their role in reform was greater than some historians have allowed. As Klaus argues, “American women did not aspire to be [just] the ladies’ auxiliary of the infant health movement; they participated not only as fund raisers and service providers but also as activists who believed they had a mission to arouse the general public to take responsibility for children’s lives.”¹⁰² On the other hand, as Veronica Strong-Boag has explained, reform groups often failed to cooperate with each other: “They often battled alone, unable or unwilling to look beyond their own ranks.”¹⁰³

Despite their differences, most late nineteenth century reformers understood that reducing infant and childhood mortality included tackling unsatisfactory social conditions, especially poverty. On the other hand, most physicians saw addressing the conditions under which children actually lived as outside their mandate. As Meckel explains, during the years from 1880 into the second decade of the new century, there was a “narrowing of reform focus, from conditions in which infants lived to the condition of that which they were fed.”¹⁰⁴ When this turned out to be an “inadequate strategy, infant mortality was redefined and reconceptualized as a problem of motherhood, on the principle that good mothering could counter the many morbid, social, and environmental conditions influencing infant survival.”¹⁰⁵

In turn, medical professionals tried to ease activists out of any central role in the task they came to more narrowly describe as “the medical definition and control of maternity and infant care.”¹⁰⁶ As Comacchio explains, the “medical profession’s avowed intent to position its members within the family circle as maternal tutors was furthered by official and popularized child care information aimed directly at mothers.”¹⁰⁷ This eventuated, Brosco says, because “there was substantial agreement among men and women, lay and medical reformers, that their work should be based on scientific knowledge. Leading female reformers, for example, argued that the future of the nation rested on mothers learning and applying ‘scientific motherhood.’ This consensus ultimately reinforced the role of pediatricians – whether male or female – as the expert in child health.”¹⁰⁸

Nonetheless, if women and other reformers were put to the side of the strictly medical dimension of the effort (as physicians themselves defined it), they persisted in tackling fundamental issues over the whole of the century. And not all physicians accepted that they should turn a blind eye to social effects on health. Klaus noted, “The consensus among historians of the Children’s Bureau is that the urban studies [community surveys of those who had borne children in the last year in a number of communities], in concluding that poverty was the single most important factor in infant mortality, challenged the assumption of early infant health programs that maternal ignorance was the primary cause of infant mortality.”¹⁰⁹

Even before Depression-induced measures, reformers worked to have the circumstances of families improved through legislation governing birth and death registrations, the working conditions of women and children, worker’s compensation, and veterans’ and mothers’ pensions. Volunteers also organized and did much of the work connected with the travelling health clinics that toured rural areas.¹¹⁰ In the 1920s in the United States such clinics operated with matching grants provided under the Sheppard-Towner Act, described by Meckel as a “relatively conservative federal welfare measure establishing the formula that American maternal and infant care programs have essentially followed ever since.”¹¹¹ In Canada, clinics were run or sponsored by provincial boards of health, and by such volunteer organizations as the Red Cross, Women’s Institutes, and Parent-Teacher Associations. In both Canada and the United States through the 1930s, the wars years, and after, provincial, state, and national governments initiated measures in social security, unemployment insurance, public housing, child and family allowances, food programs, and the like that directly or indirectly affected the health of children.¹¹²

In the closing years of the nineteenth century, Canadian and American “child-savers” had set themselves the task of re-making their societies – “to make a generation” – by transforming childhood. Their fourfold agenda for the coming “century of the child” posited transforming child-rearing, child welfare, schooling, and child health. In each area they met a measure of success, none more so than in improving child health. It is thus fair to say that a century of efforts transformed the lives of all Canadian and American children. Nonetheless, the continuing disparity in mortality statistics is one indication that even in this area success was but partial.

My survey also prompts me to make some further overall observations. First, in discussing broad dimensions of change, it is clear that when we look to explain it, we must not confine ourselves too narrowly. As Jones succinctly puts it, “Every therapeutic act must be understood with an appreciation of the elusiveness of medical efficacy ... Some interventions have obvious power, such as the antibiotics that contributed to the twentieth century’s ‘golden age’ of medicine. The implementation of these technologies, however, has never been simple or obvious: social, economic, political, and technical obstacles have shaped the utilization, and thus the final efficacy of all medical technologies.”¹¹³

Second, this chapter has revealed substantial gaps in the history of child health over the last century. Some gaps are undoubtedly due to my incomplete survey of what has already been written. Others reveal work that historians need to do. Some topics may not have yet emerged as coherent subjects for comprehensive investigation. While such causes of the accidental death of children as lead paint and gunshot wounds have been studied, perhaps the topic should be broadened into childhood trauma generally. Put together, the widespread persistence of injuries and deaths in the home, from automobile accidents, from household poisons, from farm and other machinery, from playground and sporting activities, and from drowning reveal themselves as a major dimension of childhood and youth.¹¹⁴

In this connection, an era of increasing environmental concern suggests the need for investigations of environmental factors that have affected children’s health. Studies of the long-term effects on children of the Love Canal disaster in New York State and the tar ponds in Nova Scotia would help in assessing the effects of other sites of long-term storage of chemicals.¹¹⁵ Lead and mercury poisoning has affected many children, including those on First Nations reserves in northern Ontario. We know how asbestosis affected the lives of adults who worked with asbestos, but what effect did it have on the children in the mining towns or in the schools in which it was used for insulation?¹¹⁶ In the United States, Delores Huff reports that amongst the

Navajo, "there has been an unexplained dramatic increase in the number of abnormal births and severely handicapped babies since the onset of uranium mining."¹¹⁷ Was this true of other areas of uranium mining? Of other forms of mineral extraction, such as sour gas wells?

Historians of medicine share with other historians a preference for narratives dealing with successes over those that were misguided or ill conceived or failed because of faulty practices. For example, enough time has passed to permit a social history of the thalidomide scandal and its long-term effects. Although the drug was not authorized for use in the United States, it was prescribed in Canada.¹¹⁸ The sad Canadian story produced some early case studies.¹¹⁹ Now we need an account of how those affected were able, mostly successfully, to construct their lives despite the serious effects of the drug on the development of their bodies. We need this account, and those of similar examples, not only for the stories they tell but also for the examples they may provide for the treatment of other serious physical conditions.

In this regard, Canadians are prone to argue that their system of universal medicare provides better care than what prevails in the United States. If so, then there should be measurable differences between the health of Canadian children and their American counterparts. Here global comparisons of the two systems, or even comparisons between individual states and provinces, would be less useful than detailed, comparative studies focused on particular diseases, treatments, subjects, environments, or social interventions.

While the movement to improve child health was a transnational one, the literature I have sampled touches only very lightly on this dimension of it.¹²⁰ Although it has been charged that missionaries were perhaps half in love with suffering, missionary organizations from both countries established clinics and hospital in many parts of the world, many of which focused their work on women and children.¹²¹ Americans and Canadians were major presences and contributors at a series of international congresses such as the Third Congress on Infant Mortality in Berlin in 1911. Both nations cooperated in the child health work of the League of Nations and later the United Nations.¹²² Canadian psychiatrist Brock Chisholm served as the first director general of the World Health Organization.¹²³ Since the principal responsibility for child welfare lay with the states and provinces, this international work is only lightly integrated into the national literatures.

Two final points should be made. As a concatenation of measures played a role in the decline in mortality and morbidity over the twentieth century, a comprehensive history of the period must include an assessment of both their role alongside that of narrowly "medical" developments. Perhaps it is best to see changes in infant and child mortality and morbidity as a matter

of overlapping layers: medical at one level, voluntary activities at a second, and the outcome of changes in public policies at the third, with social and economic change at the outer edge.

Further, I suggest that a comprehensive history demands a more critical, analytical strain. Much, but by no means all, of the historical literature on child health has a celebratory air. A measure of celebration is surely in order, because much was accomplished. On the other hand, the persistence of variations amongst groups by race, ethnicity, class, gender, and geographical areas are flaws embedded in the accomplishments. To make clear these differences, and the reasons behind them, is not just a matter of sharpening our understanding of the past. Clear hindsight can help ensure that these unwanted variations disappear. If the twentieth century was only in part a century of the child, then perhaps the promise in the slogan can be brought closer to fulfillment in the twenty-first.

NOTES

My thanks to Veronica Strong-Boag, Eric Damer, Helen Brown, Michael Marker, Janet Sutherland, and an anonymous reviewer for helpful comments.

- 1 Spargo, *Bitter Cry of the Children*; Turmel and Hamelin, "La grande faucheuse d'enfants," 439. See also Strong-Boag, "The Spotlight on Children," 6; Graff, *Conflicting Paths*, 24–5.
- 2 Preston and Haines, *Fatal Years*. For Canada, see Sutherland, *Children in English Canadian Society*, ch. 4.
- 3 Such photographs have triggered a debate as to their meaning. Archivist Eleanor Brown has written that it "is readily apparent that the Victorian middle class found immense comfort in their icons of mourning. Images of their dead children, the adoption of ritual mourning colours, clothes, flowers, symbols and emblems all served as an important means of self-identification for a class desirous of acceptance and recognition as an important socio-economic factor in society, in addition to the sentimental memorialising that is synonymous with its culture" ("Victorian Visual Memory," 28). I think this conclusion complicates a simple matter. Families want an actual memorial of loved ones and turn to the best means available to them. With a camera, families could supplement or replace the traditional lock of hair with a photograph. See Ward and Ward, *Images of Childhood in Old Postcards*, 9. Vincent Lavoie discusses this subject in his chapter "From the Final Sleep to First Steps" in this volume. On visual representations of sick children, see Lerner's "When the Children Are Sick, so Is Society," also in this volume.

- 4 Salverson, *Confessions of an Immigrant's Daughter*, 29–35.
- 5 Quoted in West, "Heathens and Angels," 379.
- 6 See the photograph of boys and girls escorting a coffin in Lewis, ed., "I Want to Join Your Club," 184.
- 7 Spencer, *The Spencers of Amberson Avenue*, and Trimpey, *Becky My First Love*, both quoted in West and Petrik, *Small Worlds*, 122–3.
- 8 *Globe and Mail*, 5 May 2003, 16.
- 9 A fine collection of letters from concerned mothers appears in Ladd-Taylor, *Raising a Baby the Government Way*; see also Lewis, *Dear Editor and Friends*.
- 10 Brumberg, *The Body Project*; Gleason, "Embodied Negotiations," 113–38.
- 11 Comacchio, "Nations Are Built of Babies," 3. My own estimate for Canada is that "probably one out of every five to seven Canadian babies died in the first year or two of life" (Sutherland, *Children*, 56–7).
- 12 Meckel, *Save the Babies*, 1.
- 13 Graff, *Conflicting Paths*, 28.
- 14 King, *Children's Health in America*, xi.
- 15 Statistics Canada, "Infant Mortality," CANSIM, table 102–0504, 2007–05–14; for the United States, see National Center for Health Statistics, "Supplemental Analysis." For a critical analysis of current birthing practices see Wagner, *Born in the USA*.
- 16 Klaus, *Every Child a Lion*, 13.
- 17 British Columbia, *Report on the Health of British Columbians*, 26.
- 18 Statistics Canada, *The Daily*, 9 November 2004.
- 19 Woolf, et al., "Health Impact of Resolving Racial Disparities," 2078–81.
- 20 Rothstein, *Public Health and the Risk Factor*.
- 21 Baillargeon, "Entre la 'Revanche' et la 'Veillée' des berceaux," 113–37; Baillargeon, *Un Québec en mal d'enfants*. See also Turmel and Hamelin, "La grande faucheuse d'enfants," 439–51. Turmel's explanation for some of the differences between francophone and anglophone work in childhood history is that "Quebec's academics and historians came to examine childhood as an object mostly through research on family, and, above all, the rural family" ("Historiography of Children in Canada," 516).
- 22 Golden, *A Social History of Wet Nursing in America*.
- 23 Stern and Markel, eds., *Formative Years*.
- 24 Hammonds, *Childhood's Deadly Scourge*, 42–7; Cliff, Haggett and Smallman-Reynor, *Measles*; Gould, *A Summer Plague*.
- 25 See Golden, *Infant Asylums and Children's Hospitals*; Adams and Theodore, "Designing for the 'Little Convalescents,'" 201–43. On the childhood experience of hospitalization and treatment, see Myra Bluebond-Langner, "'It's Back': Children with Cancer," in this volume.

- 26 Meckel, "Going to School, Getting Sick," in Stern and Markel, *Formative Years*, 185–207; Sutherland, *Children*, ch. 3; see also Lewis, "Physical Perfection for Spiritual Welfare," 135–66, and Gleason, "Size Matters," in this volume.
- 27 Cohen, "The Medicalization of American Education," 249–71.
- 28 Gleason, "Race, Class, and Health," 95–112.
- 29 Brosco, "Weight Charts and Well Child Care," 91–120; see also Sutherland, "Social Policy, 'Deviant' Children," 80–91.
- 30 Rothstein, *Public Health*, 187. See also English, *Rheumatic Fever*.
- 31 Richardson, "Alberta's Provincial Travelling Clinic," 245–63. Among the photographs included in this article is one showing a group tonsillectomy.
- 32 Macklon, *The Fledgling Years*, 14.
- 33 Sealander, *The Failed Century of the Child*, ch. 8; Comacchio, *The Dominion of Youth*, 113–6.
- 34 Sealander, 294.
- 35 Comacchio, "'The Rising Generation,'" 139–78.
- 36 Ibid., 140.
- 37 Prescott, *A Doctor of Their Own*.
- 38 On weight and height records, see Brosco, "Weight Charts and Well Child Care," 91–120. The work of school nurses in British Columbia is described in Sutherland, "Social Policy," 80–91. On Depression-era efforts in the United States, see Meckel, "Politics, Policy and the Measuring of Child Health," in this volume.
- 39 *Report of the Study Committee*, 30–7.
- 40 For the role of statistical data in medicine generally, see Rothstein, *Public Health*, part 1.
- 41 Gleason, *Normalizing the Ideal*.
- 42 Brown, *The Normal Child*.
- 43 Brian Low's *NFB Kids* shows how propaganda was used to introduce these notions into popular culture.
- 44 See Gleason, *Normalizing the Ideal*, especially ch. 4.
- 45 Strong-Boag, "Intruders in the Nursery," 160–78.
- 46 Blatz, ed., *Collected Studies on the Dionne Quintuplets*.
- 47 Soucy, with Annette, Cecile and Yvonne Dionne, *Family Secrets*; see also Berton, *The Dionne Years*; Gervais, *Les jumelles Dionne et l'Ontario français*.
- 48 There is an extensive literature on such schools, mostly celebratory rather than analytical. For an example of the former, see Chandler, *A Century of Challenge*; for the latter, see Crouch, *A Place Their Own*.
- 49 British Columbia, *Jericho Hill School*.
- 50 See, for example, the effect of the introduction of the incubator, in Baker, *The Machine in the Nursery*.

- 51 Ferguson, *Abandoned to Their Fate*, 13; in this regard, perhaps we need a history of the effects of the fairly recent practice of prenatal screening. See the article in this volume by Block, "Cure and the Contempt of Goodwill."
- 52 The major role played by parents in expanding institutional services in British Columbia, for example, is outlined in Adolph, *In the Context of Its Time*.
- 53 Crissey, "Legacy of the Residential Institution," 4; see also Scheerenberger, *History of Mental Retardation*.
- 54 Of American institutions constructed before 1950, 72 percent had 1,000 or more beds. The Ontario Hospital School at Orillia had 1,800 beds. See American Association on Mental Deficiency, *Standards for State Residential Institutions*.
- 55 See, for example, Child Welfare League of America, *Standards for Services*.
- 56 Alberta Department of Public Health, *Report*, 1924, 14. For Canada, see McLaren, *Our Own Master Race*; see also Sutherland, *Children*, ch. 5. For the United States, see Black, *War against the Weak*.
- 57 Pernick, *The Black Stork*, Ch. 8.
- 58 McLaren, "The Creation of a Haven for 'Human Thoroughbreds,'" 127-50.
- 59 Kline, *Building a Better Race*, 107.
- 60 Stern, "Better Babies Contests at the Indiana State Fair," 127; for the practice in California, see Fox, *So Far Disordered in Mind*, 30.
- 61 Lederer, "Orphans as Guinea Pigs," 96-123.
- 62 Lederer, *Subject to Science*.
- 63 Modern regulations, including the Nuremberg Code and later guidelines, are described, discussed, and evaluated in King, Henderson, and Stein, *Beyond Regulations*.
- 64 Lederer, *Subject to Science*, 62, 89; Lederer, "Orphans as Guinea Pigs," 115.
- 65 Quoted in Lederer, "Orphans as Guinea Pigs," 115.
- 66 Howell and Hayward, "Writing Willowbrook," 190-214.
- 67 Goodman, McElligott, and Marks, "Making Human Bodies Useful," 21.
- 68 The principal proponent of the practice was Dr John Money of Johns Hopkins University Hospital. Money and his supporters described and defended the practice in a number of publications, including Coleman's *John Money*. In the critical literature, see Diamond and Sigmundson, "Sex Reassignment at Birth," 65-79. The sad case of David Reimer, a Money patient in the late 1960s, is described in Colapinto, *As Nature Made Him*.
- 69 Evans, "The Discovery of Child Sexual Abuse," 233-59.
- 70 Spargo, *Bitter Cry*, 184-5.
- 71 See, for example, Robb, "Dilemma of the Mentally Disabled," 1-12.
- 72 In Canada the most notorious example of both physical and sexual abuse was at the Mount Cashel orphanage in St John's, Newfoundland. See Newfoundland, Royal Commission of Inquiry *Report*, 1992.

- 73 For the United States, see Kugel and Shearer, *Changing Patterns in Residential Services*; for Canada, see Simmons, *From Asylum to Welfare*; Richman, *Psychiatric Care in Canada*.
- 74 Kline, *Building a Better Race*; although he does not use the term, the notion of positive eugenics is implicit in O'wram's *Born at the Right Time*.
- 75 Shorter, *The Kennedy Family*.
- 76 Ibid., 195.
- 77 Switzer, *Disabled Rights*, especially ch. 7.
- 78 Commission on Emotional and Learning Disorders, *One Million Children*.
- 79 For the United States, see Scheerenburger, *Deinstitutionalization and Institutional Reform*.
- 80 Feldman, et al., "Is Childhood Sexual Abuse (C.S.A.) Really Increasing?" 29-33; see also *Globe and Mail*, 28 June 1989, 5. In this volume see Fassin, "Suffering Children."
- 81 Canada, Committee on Sexual Offences, *Sexual Offences against Children*, 175. See also Law Commission of Canada, *Restoring Dignity*; also Sutherland, *Growing Up*, 90-2.
- 82 Lux, *Disease, Medicine, and Canadian Plains People, 1880-1940*; Kelm, "A 'Scandalous Procession,'" 81-112; for the broader context see Waldram, Herring, and Young, *Aboriginal Health in Canada*.
- 83 Kelm, "A 'Scandalous Procession,'" 103.
- 84 Titley, *A Narrow Vision*, 84.
- 85 Quoted in Miller, *Shingwauk's Vision*, 133.
- 86 Titley, *A Narrow Vision*, 88.
- 87 Miller, *Shingwauk's Vision*, 290-1.
- 88 Jones, *Rationalizing Epidemics*. Except when referring to specific tribal identities, I follow Jones's lead in using the terms "American Indian" and "Native American" that he explains are "common usage," 235n3.
- 89 Ibid., 19; 176-81.
- 90 Trafzer, "Infant Mortality," 76.
- 91 Ibid., 87.
- 92 Although legally distinct, "even the Indian Bureau as well as historians have regarded orphanages and boarding schools as one and the same ... Since they demonstrated similarities and sometimes shared populations, there was often very little that separated the boarding school from the orphanage in operational procedures." See Holt, *Indian Orphanages*, 253. Among close similarities between the two were their inadequate diet and the prevalence of infectious diseases.
- 93 Adams, *Education for Extinction*, 124-5.
- 94 Holt, *Indian Orphanages*, 202-3.

- 95 Benson, "Blinded with Science," 52.
- 96 Ibid., 53.
- 97 Ibid., 69.
- 98 Merriam, *The Problem of Indian Administration*, 11-14.
- 99 Szasz, *Education and the American Indian*, 42.
- 100 Jones, *Rationalizing Epidemics*, 218.
- 101 Quoted in Szasz, *Education and the American Indian*, 151.
- 102 Klaus, *Every Child a Lion*, 136; for the work of Canadian women see Kealey, ed., *A Not Unreasonable Claim*; Baines, *Women's Reform Organizations in Canada, 1870-1930*. There is an enormous literature on the work of American women. See, for example, Curry, *Modern Mothers in the Heartland*; Cimballa and Miller, eds., *Against the Tide*.
- 103 Strong-Boag, "Spotlight on Children," 9.
- 104 Meckel, *Save the Babies*, 5.
- 105 Ibid., 220.
- 106 Klaus, *Every Child a Lion*, 88-9.
- 107 Comacchio, "Nations Are Built of Babies," 92; see also Mitchinson, *Giving Birth in Canada*. Much has been written on the nature of "scientific motherhood." To sample its content, see Meckel, *Save the Babies*, especially ch. 4 and 5; Arnup, *Education for Motherhood*.
- 108 Brosco, "Weight Charts and Well Child Care," 110. See also Brosco, "More Than the Names Have Changed," in this volume.
- 109 Klaus, *Every Child a Lion*, 213.
- 110 See ibid.; Richardson, "Alberta's Provincial Travelling Clinic," 245-63; Comacchio, "Nations Are Built of Babies," ch. 7; Sutherland, *Children*, ch. 6.
- 111 Meckel, *Save the Babies*, 7-8; the act came into effect in 1921 and lapsed in 1929.
- 112 Even after compulsory schooling had gathered most children into schools, some parents, often of the most vulnerable children, evaded school. Family allowances, introduced in Canada in 1944, required school attendance and made enrolment almost completely universal, thus bringing a particularly vulnerable group of children into the purview of public health measures conducted through schools; see Marshall, *The Social Origins of the Welfare State*.
- 113 Jones, *Rationalizing Epidemics*, 9-10.
- 114 English, *Old Paint*; Hemenway, *Private Guns, Public Health*.
- 115 See Mazur, *A Hazardous Inquiry*; Barlow, *Frederick Street*.
- 116 See McCumber, *An Air That Kills*.
- 117 Huff, *To Live Heroically*, 196.
- 118 The literature is surprisingly thin. A search in the University of British Columbia Library catalogue for "thalidomide" brought only seventeen items, most dealing with newspaper stories in Britain and related lawsuits they triggered. A Google

search brought only 558 items. In contrast, a library search for Salk vaccine brought 280 items. For thalidomide, see Folb, *The Thalidomide Disaster, and Its Impact on Modern Medicine*; Trent and Brynner, *Dark Remedy*; Golden, "Framework as Prison," 261–3.

119 Roskies, *Abnormality and Normality*.

120 My very limited reading in the area included Birn, "'No More Surprising Than a Broken Pitcher?,'" 17–46; Weindling, *International Health Organizations and Movements*. See also the overviews provided in this volume: Rollet, "Recent Work," and Birn, "Historiography of Latin American Infant and Child Health."

121 Two recent examples are Bliss, *Beyond the Stone Arches*; and Phillips, *The Lady Named Thunder*.

122 See Black, *Children First*.

123 See Irving, *Brock Chisholm*.

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Recent Work on the History of Childhood in Europe

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Since the pioneering work by Lloyd de Mause, Peter Laslett, and Philippe Ariès, to mention only the best-known authors, research on children's history has become more plentiful and varied in Europe. It is of course somewhat artificial to deal with European research as a separate subject, since research, methods, themes, and networks have become progressively more internationalized. Nevertheless, given the profusion of work published over the past three decades throughout the world, a synthetic view of what has been accomplished in Europe these past fifteen years seems necessary and justified.¹

Research on childhood today can be divided into four broad domains, corresponding approximately to the fields identified by the sociologist Claude Javeau.² A first domain concerns infant mortality and more generally mortality from childhood to adulthood. Following a number of pioneering works, this rather voluminous body of research moved increasingly into international comparisons. The underlying question is to what extent and in what ways changes in children's health and mortality influenced what demographers call the "demographic transition."

A second domain deals with the daily lives of children; its methods of investigation are not specifically demographic, but the interpretation of the findings is influenced by demography. The influence of anthropology and medieval history is also very critical. The key question is how children lived during the demographic transition, at home, school, work, in hospitals, and during their free time; in short, what were their cognitive and emotional environments? Their situations showed great diversity during the nineteenth century. In more recent times a certain levelling has taken place because of the influence of schooling. Nevertheless, inequalities persist.

The third body of research revolves around the question of public and private interventions, especially those initiated by the state. Until recently, state

intervention was limited to the protection of abandoned children. Now such interventions have become more and more numerous and make up a relatively coherent set of measures intended to promote children's health and welfare and guarantee their education, among other things. But why has the state sought to interfere in the sacred area of the family, what were its objectives, what rights did it claim? And as well, what were the risks of state intervention into the very heart of the family? Finally, and largely dependent on this last point, a fourth domain stands out: children's rights. Over the past fifteen years scholars have examined this domain closely, often assessing children's rights along with the rights of women. Have children finally become full-fledged persons? What is the definition of childhood today?

The review that follows on European research during the past fifteen years is the point of view of a French historian-demographer; it cannot be considered an exhaustive panorama of all European research on childhood during that period.

CHILDREN'S SURVIVAL

The question of children's survival has, through the study of historical demography, clearly dominated European research. That question has been predominant within the scholarly community and has provoked new methods of study. Research done in the early 1990s determined the direction the field was to take in subsequent years. Following a monograph on infant mortality and survival in Belgium by Godelieve Masuy-Stroobant,³ other national studies arrived on the scene: Catherine Rollet's⁴ work on France and Richard Meckel's⁵ study of the United States, both published in 1990; a year later, a collection of essays on the decline of European mortality appeared.⁶ That same year, Preston and Haines published their groundbreaking study on infant mortality in United States.⁷ These publications marked the beginnings of an international community of scholars devoted to the study of infant mortality.

Supported by UNICEF, a working group was created by l'Instituto degli Innocenti in Florence. A first conference organized in that city in 1992 concluded that the available data did not yet reveal the reasons for declining infant mortality rates in European countries and that more studies were needed. The book resulting from the conference⁸ reveals both the similarities and differences among national situations; there are points at which the declines in mortality rates are similar in several countries, whereas regional and social situations as well as modes of intervention are diverse. The following year a special issue of the *Annales de démographie historique*

(1994) published the papers delivered at seminars in Montreal and Paris in 1992, illustrating the proliferation of projects and also the efforts to rationalize research with respect to the quality of data, explanatory frameworks, and regional and international comparisons. A second symposium held in 1994 in Florence resulted in a collection of twelve essays⁹ stressing the complexity of the causes of the decline in mortality rates and the need for a multidisciplinary approach. That same year, a symposium in Louvain-La-Neuve (Belgium) was dedicated to the theme of inequalities in health care for children, a burning issue to this day. The volume that resulted collected individual studies of the consequences of war on the differential mortality rates of children in Belgium, France, the Netherlands, and Russia.¹⁰

The European group, along with a number of North-American scholars, continued its work by organizing a third meeting in Florence in 1996 and laid the foundations for a significant collection of monographs on infant mortality in Europe and North America, together with statistical appendices. This meeting, bringing together some thirty scholars and their findings, displayed the turn taken by research over the past decade. Nearly all European countries are by now represented by one or more studies of infant mortality and its social and historical characteristics. Individual monographs have given way to comparative studies that employ various methods and present varying findings and differing interpretations. Of note is the development by members of this network of methods for assessing survival during childhood, with particular efforts by those from Italy and Sweden. The most recent meeting was held in Madrid in 1999, devoted to producing the book *A Matter of Survival*. Unfortunately that volume has not yet been published, reflecting the fact that the enthusiasm of the 1990s for the topic has subsided somewhat; quantitative studies of infant and juvenile mortality in Europe have become rare.

However, some very interesting studies have appeared. These focus on specific aspects of childhood survival concerning newborn babies, for instance, or the role played by smallpox, rather than on large-scale comparisons.¹¹ Other monographs are based on national or regional studies. It should be noted that during the same period, detailed studies were carried out based on localized data utilizing new methods of statistical analyses and introducing new questions. Scholars found ways of answering old questions by using new techniques of analysis. Computerized records and cut interpretation of findings using new techniques resulted in studies such as those of Renzo Derosas (2000) on Venice, Jean-Pierre Bardet and his team on the Vernon region in Normandy (1994), and Michel Oris and George Alter (2001) on the Belgian countryside.

To illustrate how radically the fate of babies changed during nineteenth and twentieth centuries, I will give some specific details. Scarlett Beauvalet-Boutouyrie has examined the conditions surrounding birth in a nineteenth-century French hospital. Using the archives of the maternity ward of Port-Royal Hospital, Beauvalet-Boutouyrie shows how medical intervention became more and more common starting in 1840, replacing the dogma of non-interference that had prevailed until then.¹² New technologies such as forceps, surgical procedures, and anesthetics explained the growing interventionism, which coincided with a recrudescence of fever epidemics, especially between 1850 and 1870. The author argues the two were linked. It would take doctors half a century to admit that their actions could cause death and that they needed to follow rigorous rules of cleanliness. With antiseptics and hygiene, acts that killed could become acts that saved. In her book, Beauvalet-Boutouyrie develops this theme, showing under what conditions the babies of extremely vulnerable mothers were born. The sizes and weights the author calculates for the 1835–37 period (2.8 kg and 45.5 cm on the average for both boys and girls) were considerably lower than in other European hospitals.¹³ In this period, 10 per cent of the low birth-weight infants died during their first week of life. This high mortality rate existed despite efforts made since the beginning of the eighteenth century to save low-weight babies: the first attempts at neo-natal reanimation were made at the beginning of nineteenth century, but with little success. In any event such efforts were discontinued, resuming only at the end of the nineteenth century but with more encouraging results.¹⁴

Iceland offers a particular interesting case study. Olöf Gardarsdottir of the Innocenti group provides a strikingly instructive example of what is currently being done in Europe from a methodological and thematic point of view.¹⁵ Correlating long-term historical analysis and the specifics of individual data has allowed her to highlight Iceland's unique experience, giving us the solution to a double enigma: why was it that Iceland had such a high infant mortality rate before the epidemiological transition (until the nineteenth century), and why did that rate decline so rapidly that in the twentieth century it was lower than in many other European countries?

In Iceland before the nineteenth century, 300 in 1,000 children on average died before the age of one, with extraordinary peaks during certain critical years of up to 800 per 1,000. What factors explain the radical change that took place in the middle of the nineteenth century? Were they socio-economic, cultural, or the result of social policies? In the fifteenth century it was usual to entrust the newborn baby to the midwife right after it had been baptized; she kept it for several weeks, which allowed the mother to

get back on her feet faster. In the meantime, the midwife fed the newborn on cow's milk, often enriched with cream, then very soon began solid food (pre-chewed fish in a little cloth bag). That system was an original adaptation to local conditions of infant feeding methods used in certain parts of Sweden, Finland, and Southern Germany. But little children, in Iceland as elsewhere, suffered the consequences of artificial feeding from birth: many died during the first weeks of life and the overly high death-rate compared to levels observed elsewhere in Europe continued throughout the first year and beyond.

Using a model developed by Robert Woods and Nicola Shelton (1997), Gardarsdottir has calculated that the level of infant mortality was 250 per 1,000 in Iceland, whereas it was 100 per 1,000 in England and Wales during the pre-transitional period.¹⁶ The higher Icelandic figure was due to obstetric risks and premature births but especially to the lack of mother's milk and an inappropriate diet; the children died of diarrhea and dehydration. In addition, according to the author's very fine analysis, the mortality linked to umbilical tetanus accounted for 25 per cent of Iceland's infant mortality each year.¹⁷ However, things changed radically in 1847, when a small maternity hospital directed by a doctor and a midwife trained in Copenhagen opened in Iceland. Their organization and personalized counselling had an immediate effect on the risk of tetanus, and the mortality rate dropped very rapidly. A neonatal mortality rate that oscillated between 100 and 200 per 1,000 during the first half of the nineteenth century dropped to less than 150 after 1847 and stabilized below 100 in the 1860s. A true revolution had occurred, thanks to careful observation of the situation and the implementation of an effective response.

Over and above a very high basic level, infant mortality fluctuated considerably because of the island's vulnerability to periodic infections. Due to its (relative) accessibility and the increase in population, infantile illnesses became endemic in the nineteenth century and were much more lethal, before completely disappearing in the twentieth. The transformation of the public health system monitoring children was certainly one of the major reasons for the improvement in their survival.

According to the author's analysis, epidemiological, economic, social, and political factors work together to explain the radical change that occurred. The actions of doctors and perhaps mainly of midwives were crucial to altering old behaviour patterns. The change became obvious in the mid-nineteenth century, with the decrease of neo-natal, post-neonatal, and infantile mortality: the neonatal mortality rate dropped below 100 per 1,000 from 1871-75 and below 50 per 1,000 at the start of the twentieth

century. From the moment that certain conditions were met (public health monitoring, changes in infant feeding, and other improvements), the survival rate rose to the level of the most developed countries. The interaction between natural constraints, a centuries-old socioeconomic system, cultural values promoted by the churches and elites, and the concrete arrangements of family life turns this story, on the scale of a small but easy to observe population, into a case study both of the epidemiological transition and of public intervention.

Although it varied by nation and within regions, all of the European countries entered the first phase of the demographic transition at the latest by the end of the nineteenth century, thanks to the combination of socioeconomic transformations and cultural factors supported by public and private policies. Instead of sometimes over 200 per 1,000 deaths in the nineteenth century, infantile mortality typically dropped to less than 100 per 1,000 between the two world wars.

CHILDREN'S DAILY LIFE

The second research domain that has been well developed over the past fifteen years is the study of the daily life of children from birth to adolescence. What becomes of those children who manage to survive beyond the first years of life? We must look further than studies strictly limited to infant mortality and consider the other ages of childhood and youth. What are the familial, social, and economic contexts in which they develop? What education do they receive? From birth to adulthood, how are the years of childhood distributed? The underlying idea is certainly that each period of history produces its own type of "puericulture," of child-raising culture, a culture reflecting the social and intellectual organization of the era. Thus has it been possible to reconstitute the life context of children in the Middle Ages as well as in modern times and to see how these contexts produce different visions of childhood.¹⁸

Using legal sources, for instance, the historian Anne-Marie Sohn in *Chrysalides* (1996) casts a new light on the question of wanting a child in the nineteenth and twentieth centuries and thus on the child's place in the family. She reconstructed the way that nineteenth-century mothers and fathers were motivated by a calculated ideal – neither too many children nor too few. Being childless was a curse, and resorting to semi-religious magical practices to activate fertility remained commonplace until medical tactics replaced them in the twentieth century. The norm privileged by the French middle classes was a minimum of one child but not more than four, and the

ideal was to have a boy and a girl. Family life and parent-child relations have also been subjects of recent research. Eric Mension-Rigaut's thesis on childhood in the castle gives a good idea of the particular climate in which the children of the aristocracy and the wealthy bourgeoisie lived near the end of the nineteenth and in the twentieth centuries: the distance between parents and children, the presence of servants and tutors, the veneration of ancestors, the celebration of large families, and discipline are all discussed.¹⁹ Utilizing autobiographies, Denis Darya Vassigh has tried to reconstitute the different parent-child relationships that typified families between 1850 and 1914.²⁰ Partly confirming the hypotheses of Lloyd de Mause,²¹ he points to three models emerging from the autobiographies: a traditional model, one geared toward social mobility, and one defined by relative indifference. Many children in the nineteenth century, in various milieux, experienced the second model, which consisted of families doing everything possible to elevate their social status. From the moment of birth, a child was a permanent investment.

But family life is not limited to parent-child relations: in his thesis, Vincent Gourdon defends the idea that while relationships between grandparents and grandchildren did not originate in the nineteenth century, the interpretation of these relationships changed.²² The stratified and somewhat imposing relationship that the French painter Greuze depicts turns into one of complicity and friendliness. Grandparents lost their authority, and only on rare occasions took the place of parents.

Certain concrete aspects of children's daily lives have been minutely examined. For example, nursing and bottles now have a history, initiated by the works of Rima Apple²³ and Valerie Fildes in the late 1980s (1986, 1988) and illustrated by the exhibit organized in the Fécamp Museum.²⁴ The bottle appears as the alternative to the breast, as a product of industrial engineering, and as a toy. Even the milk, its control, and modes of sterilization have been the subject of several research projects. Similarly, children's clothing, bedrooms, babies' sleep, and enuresis have been fully studied. Children's games and books are privileged areas for studying gender and class differences. Games are gendered: each toy assigns a predetermined role to the child, the boy being made for war, horses, and drums, the girl for dolls and toy kitchens, later on playing nurse or schoolteacher. But games also transmit social messages: children of the middle and upper classes imitate life in society; those of the working class actually live it before their time through child labour.²⁵

The history of children's literature has been completely transformed in recent years. Stéphanie Gil-Charreaux's thesis²⁶ on French children's books

between 1870 and 1914 picks up where Françoise Huguet's catalogue²⁷ based on the library of the National Institute for Pedagogical Research (INRP) left off. These works show that the last third of the nineteenth century was a golden age for children's literature, in France as well as in Great Britain and Germany. There were many publishing houses, and they competed to attract new readers – toddlers, for example, in the case of Hachette or Hetzel in France. The school system supported this literature by distributing books as prizes, and Father Christmas filled little shoes with books.²⁸ But by the end of the century, that universe was no more: many publishing houses closed as commercial concentration became the rule.

We cannot presume that all children lived in families. A number of babies were abandoned, and other children left their homes at early ages. The problem of abandoned children and how to care for them in the nineteenth and twentieth centuries,²⁹ as well as the problem of wet-nurses, continues to attract researchers, not only because of the wealth of information available in the archives but also because of the scientific questions that such behaviours elicit. On the question of why children born out of wedlock were abandoned, for example, David Kertzer proposes an intriguing interpretation: abandonment was chosen by religious authorities as a way to deal with extramarital sex.³⁰ They were preventing the children of sin from leading normal lives. The anthropologist Anne Cadoret, exploring the lives of the children sent to public foster homes in Burgundy (Morvan), convincingly shows the strategies of those families who took in children after World War II and analyzes the consequences:³¹ these foster children upset the genealogical order because, arriving long after the birth of the last children, they were nonetheless considered almost as brothers or sisters.

Other lesser-known aspects of the life of abandoned children have begun to be explored, for instance, concerning their family name³² or the way they integrate in professional or family spheres. Giving a decent name to the hundreds of thousands of abandoned children every year in Europe was no easy task: the administrative determination to keep track of children entrusted to the public authorities was limited. Those children were potentially important resources for agriculture or the military, but "humanitarian" interests predominated in the nineteenth century, as the number of children involved diminished.

There has been recent work on day-nurseries (*crèches*), but historical investigations have not been well developed despite a masterful in-depth study by Jean-Noël Luc on the "asylums" (the ancestors of nursery schools).³³ The material for a study of nurseries exists in the regional and municipal archives and would allow us to understand one of the main domains of female

investment in children. Luc shows, for instance, that the first nursery school was opened by women of the well-off Protestant bourgeoisie (Emilie Mallet, for example, daughter of the cloth manufacturer Oberkampf). Luc enriches our knowledge about the universe of slightly older children who, sometimes as early as the age of two, were put in an “asylum.” Their experiences of constraints, collective drills, repetition, and long hours without moving were far from the ideals of the institutions’ female founders. The little ones in these institutions were numerous: 650,000 between the ages of two and five when the first nursery schools opened in 1881. Only after the grand transformation of these institutions undertaken by Pauline Kergomard at the end of nineteenth century did the children benefit from a different sort of pre-schooling. Luc’s study clearly shows how the creation of the asylum corresponds to the recognition of a second stage of childhood: in fact, the young child (after age two or three) became a subject of interest for educators before doctors began to take an interest in babies. This disparity in professional views of children in the nineteenth century is significant.

Though much has been written about education, I will discuss only the studies of religious education and of the boarding school experience. Some work has been done on the milestones of religious life: baptism,³⁴ holy communion, and confirmation. Holy communion is the subject of books edited by Jean Delumeau³⁵ and the study by Pierre Gaspard.³⁶ These volumes plunge into systems of representations, feelings, emotions, and beliefs. It is not easy for historians to discover how children perceived religious rituals, but autobiographies³⁷ and diaries³⁸ afford some insight into these emotional domains. The “most beautiful day of your life,” as the Christian educators like to call it – was it really so fulfilling for children? A moment of intense emotion, of turmoil, sometimes of doubt, holy communion also meant leaving childhood behind and entering the adult world,³⁹ which is doubtless not completely painless. For Protestants the more important ritual was confirmation, and it too deserves study and raises questions.

The majority of children were in day schools toward the end of the nineteenth century, even though access to schooling differed by nation. A minority continued to be educated in boarding schools. A word about living conditions in boarding schools, particularly the ones for girls: Rebecca Rogers’s ground-breaking study, *Demoiselles de la Légion d’Honneur*,⁴⁰ revealed a source that proved to be a goldmine for me:⁴¹ the boarding-school ledgers for the daughters of the Brittany nobility who were sent to an establishment in Orléans for their entire youth, age six or seven to eighteen. A systematic study allows us to grasp the experiences of these young ladies, their family relations (thanks to the record of the number of stamps bought), their

eating habits, the costs of their education, their clothing, their health, and their religious training. This seemingly austere source has proved to be a very lively archive indeed.

A conference organized in Paris in 2000 opened up the field of the growing child (*L'enfant qui grandit*). Many papers dealing with the living conditions of children beyond the nappy age, inside and outside the family, provoked animated discussions and were published in 2003.⁴²

Certainly, the influence of anthropologists and historians of the Middle Ages, following the road charted by Philippe Ariès,⁴³ played a crucial role in the development of this kind of history of childhood. One of the central ideas in this field is that childhood, which was quite short before and during the Industrial Revolution (ending at age six or seven), was extended during the nineteenth century through compulsory education and changes in family life. By the end of the century, children had come to represent a precious property for their families and for society; childhood now lasted twelve or thirteen years. Thus in half a century the duration of childhood had doubled.

STATE INTERVENTIONS

A third theme of the historical literature is that state intervention has been in the best interests of the child. As is well known, child labour laws were the first instance of state intervention in industrialized countries, beginning with Great Britain.⁴⁴ Serge Chassagne⁴⁵ presents a synthetic overview of the labour laws passed in France in the nineteenth century, namely the law of 1841, expanded in 1874 and again in 1892. Research on workplace inspectors constitutes another important contribution to the history of child labour. Using autobiographical narratives, Jean-Louis Lenhof provides a new perspective on the way that certain children – those who wrote – felt about being put to work in the factories at a young age.⁴⁶ Far from being a form of slavery, it seems that labour gave these children a feeling of freedom, autonomy, and pride. Lenhof demonstrates the great difference between factory work and work on a machine at home: it is this latter proto-industrialization that brought about the worst working conditions, for children as well as for adults.

Considerable research has been done on state initiatives in child health, the social and legal protection of minors, and the process of medicalization.⁴⁷ Some studies are limited to a region or city or a specific population. Books discuss sanitary interventions on behalf of children, such as the improved training of midwives, creation of dispensaries, provision of medical

advice about babies, distribution of milk (*gouttes de lait*),⁴⁸ and modernization of hospitals (although little has been written about children in hospitals), among other topics. Research shows the accomplishments of welfare systems that have benefited young children and their mothers since the end of the nineteenth century. Anne Cova's thesis on the policies in favour of mothers⁴⁹ links their development to the women's rights movement. She paints a detailed picture of the legislation protecting women in the workplace between the two world wars.

Anne Carol focuses on aspects of state policy linked to eugenics, showing the crucial role played by the obstetrician Adolphe Pinard in creating a uniquely French approach designed to combat depopulation and degeneracy and to improve the human race by practising ante-natal "puericulture."⁵⁰ The eugenics inspired by Francis Galton came to France rather late. After that, an educational as opposed to a harder and more interventionist current became the dominant model in France. Only one measure of "active" eugenics has survived: the introduction in 1942 of a compulsory prenuptial medical examination.

Susan Pedersen has carried out a comparative historical study of policies relating to families in France and Great Britain,⁵¹ showing the considerable difference in approach in the two nations. Studies of health policies have stimulated work on professional groups that grew out of such policies. For instance, public health inspectors and later inspectors of social affairs are the subjects of Virginie De Luca's thesis.⁵² She demonstrates their slow transformation into a professional group in the nineteenth century, the development of their own professional culture around demographic questions and the struggle against infant mortality, and the influence of these civil servants' expertise on social legislation during the Third Republic. We are lacking for this period a history of midwives, a professional group that has been far more successful in France than in many neighbouring countries and especially North America.⁵³ Such a history would update Jacques Gélis's important work.⁵⁴

Examining strategies to create a recognized profession inevitably leads to questions about gender relations in the workplace. One might expect a rapid feminization of professional groups devoted to child welfare, allowing women to recapture roles they have held since time immemorial. In reality, the feminization of professions relating to childhood has taken considerable time, has not been without resistance, and has allowed for the lengthy persistence of hierarchies between positions held by men and those held by women.

Analyzing work on the role of the state in children's lives in the various Western countries, I proposed a sketchy international comparison that needs to be completed.⁵⁵ Though the time frames of the decline of mortality rates are similar, as noted above, the methods used to lower child mortality and improve living conditions have varied to a large extent. In my view these disparities are connected to differences in the degree of state intervention among nations, to the role played by doctors, and to women's place in society. Patterns emerge: on one hand, there is the Anglo-American model in which state intervention is weak and discontinuous, the doctor's role is important, and women's positions are strong; on the other hand, we find a Latin model in which state intervention is strong and women's positions are limited in the face of doctors' dominant role. France exemplifies the second model, the United States the first. But the variation in styles of intervention does not impede progress; in virtually all the industrial countries there has been considerable progress backed by an increasingly shared vision of children's rights.⁵⁶

CHILDREN'S RIGHTS

Children's rights are inextricably linked to the interests of the state. It is precisely because the society at large is worried about security that it is concerned with juvenile delinquency. Because it is painfully aware of its own demographic future, it fights against the death of children, infanticide, and infant mortality; because it seeks to preserve the strength of family structures, it is concerned with child abuse. These concerns underlie children's rights and appear in the first declarations of these rights. Works examining these questions have proliferated over the past few years, perhaps because advances in quantitative demographic studies provoked more qualitative research. At the same time, interest in children's rights represents a new way of looking at children. No longer seen as solely under the control of the family or state, they are instead autonomous *subjects*.

Child protection has taken on new forms, both repressive and preventive. The suppression of infanticide and of quasi-infanticide was a first step in policies aiming to guarantee the child's survival. Annick Tillier's thesis on infanticide in Brittany between 1825 and 1865 is an important landmark.⁵⁷ As with other studies, the use of legal sources has proven extremely valuable in illuminating daily life. Tillier shows that the rural world was the main theatre of infanticide in Brittany, primarily involving seduced women who become pregnant as a result of ephemeral love affairs. But they were

neither the poorest nor the most naïve. Though generally illiterate, they did not lack intelligence in organizing their legal defence, depending on oral transmission to gain some knowledge about legal medicine and criminal procedures. Before sending the accused women to the civil courts, the village community used all possible means to protect its own good name: it was the task of women to keep an eye on the silhouette of women living alone, as well as on their linen. The protagonists in the trials included the accused woman who defended herself, the magistrates who looked askance at the apparent insensitivity of the accused to their infants, and members of the jury who willingly forgave those whom they saw as the victims of an unfair law that exonerated men from all responsibility. Tillier's work suggests new ways of understanding of infanticide and the need for more research in other French and European regions of the nineteenth century. Attempting a comparative analysis, Katherine Lynch examines the meaning of infanticide, of abandonment, and neglect in European societies. She describes as well the material resources and cultural values that shaped the actions of populations and institutions such as foundling homes.⁵⁸

It is difficult to compare these qualitative studies to Philippe Chassaing's quantitative study of infanticide in London. The author shows that this crime against newborn babies comprised 40 per cent of all murders committed in England and up to 60 per cent of those committed in London – startling figures indeed! The chronology of this category of crime stands out clearly: its rapid increase up to the middle of the nineteenth century, then a levelling off, and a decrease from 1880.⁵⁹ We can assume that a similar pattern existed in France.

Studies concerning the protection of children separated from, abandoned, or voluntarily placed by their parents can be categorized as historical studies of children's rights, as can studies of violence against children. The question of child abuse has recently been the subject of several interesting research projects: in France by Anne-Marie Sohn⁶⁰ and Georges Vigarello,⁶¹ and in Great Britain, Harry Ferguson.⁶² Long invisible because of widespread belief in the right of fathers to chastise their children for their own good, and in the status of little girls as the personal property of their fathers, physical abuse and sexual violence only came to light in the last quarter of the nineteenth century. Zola's novel *Assommoir* inspired a press campaign against unnatural parents who abuse, mistreat, or corrupt their children. Using archives and parliamentary debates, Sylvia Schaffer closely examines the genesis of the Law of 1889 on morally abandoned children. This law allows authorities to deprive unsatisfactory fathers of their parental authority, a first blow to the sacred rights of the father as

defined in the Napoleonic Code. At the same time, it allows the state to intervene in the very heart of the family unit, as the law defines the child as a possible victim of his or her parents. The boundaries between private and public life and between the interests of the father and those of the child are explored in this well-documented book.⁶³ Despite new laws, fathers still retained the right to imprison their rebellious children. The right of paternal punishment has been studied in great detail by Pascale Quincy-Lefebvre.⁶⁴ And, as Georges Vigarello has shown, for many years it was the violence accompanying incest or rape that stirred public opinion rather than the sexual abuse itself.⁶⁵

Even delinquent children have little by little come to be seen as victims of their milieu, but efforts to prevent abuse have had a hard time overcoming repressive approaches to this problem. The archives of institutions (Mettray, Aniane, Belle-Isle, in France) permit scholars (Quincy-Lefèvre 1997) to uncover the ideals of their promoters – to rehabilitate delinquent children by having them till the land. These archives allow scholars to describe children's actual living conditions, which deteriorated toward the end of the nineteenth century. Some of the establishments, directed by unscrupulous men who exploited the children, created scandals and caused authorities to withdraw their support. Several closed down before World War I, but it was not until after World War II that effective laws were passed protecting young people caught in the legal system (*Protection judiciaire de la jeunesse*). Certain institutions have been the subjects of detailed monographs. They make one realize how hesitant, and sometimes how contrary to the interests of the child, the magistrates' decisions and the theories propounded by the medical examiners could be, not to mention the limits of state funding for this purpose. Protection of children and work with delinquent children moved in fits and starts.

Some historians have concerned themselves with children as moral and physical victims of war with a significant focus on World War I, including the enlistment of children.⁶⁶ There have been studies as well of children orphaned by war (Faron 2001); a recent study examines children in World War II.⁶⁷

Studies of the international aspects of children's rights are now underway, seeking to identify the different moments when people become aware of their necessity, the different ways in which countries have granted children rights, and the factors influencing these rights. Based until now on the proceedings of international meetings, this work could be further enriched in the future by examination of the archives stored in the various countries and used to prepare these conferences.

CONCLUSION

During the past fifteen years, several writers have produced grand compilations, some aimed at the general public, demonstrating how much our knowledge of children's history has progressed. The work edited by Egli Becchi and Dominique Julia has a second volume devoted to the contemporary era that explores some little known facets of the history of childhood:⁶⁸ children as depicted in movies, for example, or the history of handicapped children. British authors have published several short synthetic treatments of the history of children and childhood in England⁶⁹ and the Western countries.⁷⁰ Some Spanish⁷¹ and Italian⁷² authors have also published "histories of childhood" from specific national or regional perspectives presenting broad overviews of children's lives, including work, school, survival, families, community initiatives, hospitals, and state involvement.

During these fifteen years quantitative and qualitative research has proliferated in Europe and elsewhere, elucidating different aspects of the history of child health that cannot be separated from the history of families, women, education, and work, or that of state intervention. Quantitative research has been thoroughly revamped, thanks to the utilization of specific databases that permit a fine-grained analysis of major changes in children's lives and, more generally, the demographic transitions that have followed from the decrease in the death rate. Today we can attempt to evaluate much more accurately the behaviour of families with regard to their children, showing changes through time and regional variations, at differing levels of analysis – individual, community, and global. Qualitative research, thanks to the diversification of sources, has also made considerable progress in understanding children's living conditions from every point of view, revealing the changes in the way they are perceived by families and society as a whole as a result of the decrease in both birth rates and mortality, restrictions on child labour, and the extension of schooling. State investment has been an important factor in these developments, and the various professionals concerned (in the domains of health and education, for example) now assist families in raising their children. Scholars have analyzed in detail these processes of socialization (and normalization) of childhood and families between the mid-nineteenth and the mid-twentieth centuries, pointing out how long it takes for a new conception of childhood to emerge, including the idea that children have rights of their own, independent of their parents' rights.

Questions and criticisms have also been raised. Over the past two centuries, have children in Europe been somehow "infantilized," becoming

objects that the public authorities control for their own good as well as for the good of the nation? Has the view associated with the sociologist Emile Durkheim presenting children as unfinished products that must be fashioned, educated, and socialized been replaced by one that sees children as full-fledged persons, legal subjects with cognitive, psychological, relational, and emotional resources of their own?⁷³ What role has been played by the legal system, by psychology and psychoanalysis, in the changes that have come about in the way children are presently perceived? In a recent essay the philosopher Alain Renaut makes a very convincing argument about the progressive emergence of the child as a person – one who is equal to adults but who is also a paradoxical person, needing adults in order to become what he/she is.⁷⁴ At the outset of the twenty-first century, is his book the sign of a substantial change in the way the multiple facets of children's lives are being understood? If so, it is not yet clear toward what new vision of the child we are currently headed.

NOTES

My thanks go to Gabrielle Varro of the CNRS for translating this paper into English.

- 1 Nevertheless, I will include some references to North American work on the subject.
- 2 Javeau, "Enfant, enfance(s), enfants," 25–9.
- 3 Masuy-Stroobant, *Les déterminants*.
- 4 Rollet, *La politique et l'égard*.
- 5 Meckel, *Save the Babies*.
- 6 Schofield, Reher, and Bideau, *The Decline of Mortality*.
- 7 Preston and Haines, *Fatal Years*.
- 8 Corsini and Viazzo, *The Decline of Infant Mortality*.
- 9 Corsini and Viazzo, *The Decline of Infant and Child Mortality*.
- 10 Masuy-Stroobant, Gourbin, and Buekens, *Santé et Mortalité*.
- 11 Skold, *Two Faces of Smallpox*.
- 12 Beauvalet-Boutourye, *Naître à l'hôpital*.
- 13 Ward, *Birth Weight*.
- 14 Rollet, *L'educazione sanitaria*.
- 15 Gardarsdottir, *Saving the Children*.
- 16 Ibid.
- 17 The case of Vestmannaeyjar Island is a strange one: situated at the southern end of the country, that island had an exceptionally high mortality rate due to tetanus. The risk that a newborn baby would die of tetanus, an illness transmitted by a bacteria

that thrives on animal excrement, was maximal between the fourth and the fourteenth day, causing the death of two-thirds of the island's babies (600/1000 between 1816 and 1846).

- 18 Turmel, *Adulthood Hegemony*.
- 19 Mension-Rigaut, *L'enfance au chateau*.
- 20 Vassigh, *Les relations adultes-enfants*.
- 21 Mause, *The History of Childhood*.
- 22 Gourdon, *Histoire des grands-parents*.
- 23 Apple, *Mothers and Medicine*.
- 24 Musées municipaux de Fécamp, *Les biberons*.
- 25 Becchi and Julia, eds., *Histoire de l'enfance*.
- 26 Gil-Charreaux, "Evolution du Marché."
- 27 Huguet and Havelange, *Les livres pour l'enfance*.
- 28 Perrot, *Ethnologie de Noël*.
- 29 See the collection *Enfance abandonnée et société en Europe, XIVe-XXe siècle*.
- 30 Kertzer, *Sacrificed for Honor*.
- 31 Cadoret, *Parenté plurielle*.
- 32 Bardet and Brunet, *Noms et destins*.
- 33 Luc, *L'invention*.
- 34 Fine, *Parrains, marraines*.
- 35 Delumeau, *La première communion*; Delumeau, *La Religion de ma mère*.
- 36 Gaspard, *Les trois âges*.
- 37 Vassigh, *Les relations adultes-enfants*.
- 38 Lejeune, *Le moi*.
- 39 Until a decision of Pope Pius X in 1910, holy communion took place quite late, at about twelve or thirteen years old for many children. Until Pius X decided to advance it to age seven, the ceremony meant the end of childhood for many children: they stopped school and went to work.
- 40 Rogers, *Les demoiselles*; see also: Rogers, *Salon to the Schoolroom*.
- 41 Rollet, *Cost of Educating Children*.
- 42 Bardet et al., *Lorsque l'enfant grandit*.
- 43 Aries, *L'enfant et la vie familiale*.
- 44 Lavalette, *A Thing of the Past?*
- 45 Chassagne, *Le travail des enfants*.
- 46 Lenhof, "L'enfant et les mutations du travail industriel."
- 47 Rollet, *La politique*; Cole, *The Power of Large Numbers*; Schaffer, *Children in Moral Danger*; Reid, *Health Visitors*; Ferguson, *Cleveland in History*; Arnup, *Education for Motherhood*; Bock and Thane, *Maternity*; Comacchio, "Nations Are Built of Babies"; Cooter, *In the Name*; Klaus, *Every Child a Lion*; Koven and

- Michel, *Mothers of a New World*; Ladd-Taylor, *Mother-Work*; Lindenmeyer, "A Right to Childhood"; Michel, *Children's Interests*.
- 48 Perdiguerro and Bernabeu Mestre, "La Gota de Leche."
- 49 Cova, *Maternité et Droits*.
- 50 Carol, *Histoire de l'eugénisme*.
- 51 Pedersen, *Family, Dependence*.
- 52 De Luca, *Aux origines de l'état providence*.
- 53 Marland and Rafferty, *Midwives*.
- 54 Gélis, *La sage-femme*.
- 55 Rollet, *Fight against Infant Mortality*; Rollet, *La santé et la protection*.
- 56 Fildes, Marks, and Marland, *Women and Children First*.
- 57 Tillier, *Des criminelles au village*.
- 58 Lynch, *Infant Mortality*.
- 59 Chassaigne, "L'infanticide."
- 60 Sohn, *Du premier baiser*.
- 61 Vigarello, *Histoire du viol*; Vigarello, *Une prise de conscience*.
- 62 Ferguson, "Cleveland in History."
- 63 Schaffer, *Children in Moral Danger*.
- 64 Quincy-Lefebvre, *Familles, institutions et déviations*.
- 65 Vigarello, *Histoire du viol*.
- 66 Audoin-Rouzeau, *La guerre des enfants*.
- 67 Ericsson and Simonses, *Children of World War II*.
- 68 Becchi and Julia, *Histoire de l'enfance*.
- 69 Hendrick, *Children*.
- 70 Cunningham, *Children and Childhood*.
- 71 Borrás Llop, *Historia de la infancia*.
- 72 Filippini and Plebani, *La scoperta*.
- 73 Gullestad, *Imagined Childhoods*.
- 74 Renaut, *La libération*.

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3

Historiography of Infant and Child Health in Latin America

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The proliferating historical studies of child health in Europe and North America over the past decades have made the need to examine the “hidden history” of child and infant health and well-being in other parts of the world all the more pressing. Latin America offers an extremely useful venue in which to assess whether the better-documented patterns of child and infant health and mortality in modern Europe are generalizable to other settings, to gauge the extent to which the colonial period’s institutional, social, and cultural legacy has permeated more recent state-building approaches to child health and well-being in different countries of Latin America, and to explore the interaction of domestic and international ideas and practices around infant and child health in the late nineteenth and twentieth centuries.

Although the history of infant and child health is rapidly becoming its own sub-specialty in the history of medicine and health, scholars of Latin America have for the most part viewed child health through other historical lenses: those of colonial, class, and state power, institutions and regulation; the formation of social and racial identities and markers; women’s public engagement and feminist movements; the building of “welfare” states and economies; and cultural accounts of childhood.

Latin America is of course extremely diverse, yet several common themes have shaped the region’s responses to the problem of infant and child mortality and health.¹ These include the region’s pre-Columbian and indigenous heritage; the powerful legacy of colonial class and racial relations, institutions, and practices; an early but incomplete modern state-building effort; and considerable engagement with international efforts and movements in the areas of pediatric medicine and public health, social rights, and human welfare.

PRE-COLUMBIAN AND COLONIAL PERIODS:
FROM CHILD CELEBRATION TO CHILD CIRCULATION

There is little available historical material concerning child health and well-being in pre-Columbian societies, though anthropological and iconographic studies as well as various codices and natural histories compiled by Spanish colonists suggest that birth, reproduction, and child health were important elements of social and religious prestige among indigenous cultures. The Maya, for example, considered children to be a sign of good fortune and paid special attention to infant health.² Aztec children even had their own medical god, Ixtlilton, a deity unknown elsewhere in the world.³ That children were also ritually sacrificed in some Mesoamerican societies was likely a sign of their sacred worth. Various pre-Columbian populations are known for their adherence to hygienic precepts, including bathing rituals following childbirth, widespread breastfeeding for the first several years of life, testing the milk of wet-nurses, monitoring the nursing mother's diet, and treating ailments with a combination of magic and empiricism;⁴ such measures may account for a life expectancy estimated by some at almost ten years longer than that of medieval and early modern Europeans.⁵ Others consider pre-Columbian health conditions to have differed little from those in Europe.⁶ The historical demographer Robert McCaa argues that it was high mortality among the Nahua that led to adaptive mechanisms such as infant marriage and complex family structures.⁷

The survival of child health practices and beliefs following Spanish and Portuguese colonial conquest of the region was uneven. Some were lost through population decimation and forced displacement, and some were repressed by the colonial state and regulatory apparatus. Others survived intact through intergenerational transfers and the continued role of midwives in maternal and newborn care. Certain practices (such as the killing of child sorcerers among the Arawak⁸) were attributed to pre-Columbian cultures even though they were invented only during the colonial period, while still others became part of a syncretic approach to maternal and child health. In the Audiencia of Guatemala and other parts of the Viceroyalty of New Spain, for example, miraculously healed children attained a divine-like status, with the colonial church mediating and interacting with indigenous concerns for sick children and the supernatural signs associated with their recovery.⁹

For the more than three centuries of Iberian control of what is now Latin America, the footprints of child health and well-being – and of children in general – remain mostly hidden.¹⁰ Sonya Lipsett-Rivera has noted that

information on childhood in Latin America in colonial sources tends to be prescriptive rather than descriptive, telling us far more about the values of colonial authorities than the experiences of children's lives.¹¹ Elizabeth Kuznesof has suggested that the minimal attention to child welfare in this period stems from colonial codes that relegated child-rearing to the private domain, leaving a thin paper trail for researchers.¹² Only when children encountered the judicial system through crime and delinquency,¹³ petitioned royal courts, such as the Audiencia of Quito, for state protection,¹⁴ or became public charges as foundlings and orphans in charitable or municipal institutions did they generate records. These records have permitted a growing literature about the most marginal and sickest children, but they leave unexamined the lives of the majority of the young during the colonial period.

Children are estimated to have constituted between one-third and one-half of the population of the Spanish and Brazilian colonies in the Americas by the eighteenth century; however, even at census time, there were few accurate counts of children, who may have remained undeclared or were typically included in the same category as unwed adults (potentially, their own parents!). The routine accounting of births and child deaths is likewise sparse: despite centuries of missionary zeal and the Catholic Church's status as a pillar of Spanish and Portuguese empires, most parish registries for colonial Latin America reveal little detail of the rates or patterns over time of infant and early childhood mortality, except indications that it was staggeringly high, and even more so among indigenous populations and African-descended slaves, some 80 per cent of whom failed to reach five years of age.¹⁵

One of the principal explanations for this incomplete documentation has to do with the elevated rate of illegitimate births in Latin America. In the past (and continuing to the present) up to 50 per cent of children in some areas were born out of wedlock, as compared to historical rates of illegitimacy in Europe that rarely exceeded 10 per cent. Though illegitimacy fluctuated by race, place, and social class, it was an important feature of virtually every setting of the region. Whether attributed to defiance of colonial authority, the strictures of slavery, cost and effort, cultural irrelevance, alternate patterns of family formation, or the status of women, out-of-wedlock births had significant implications for infant and child survival. According to Nara Milanich, colonial law reflected the social opprobrium attached to illegitimacy, yet the legal treatment of illegitimate children varied significantly by whether they were the offspring of adultery or of parents who were technically able to marry. In the former case, children usually lived in matrifocal households, which often faced economic and

legal marginalization. Illegitimate children could be enslaved, abandoned, or taken under state tutelage – or they might be rotated among various kin and strangers, forming temporary family-like attachments.¹⁶

Although illegitimacy did not have universally negative consequences for child health and well-being in Latin America, the greater likelihood of abandonment of illegitimate infants and children (the literal translation from Spanish for abandoned infants is “the exposed” [to the elements and to charity] rather than “found[lings]” in English) undoubtedly resulted in higher rates of mortality. Across colonial Latin America, civil authorities allowed for anonymous abandonment of newborns to foundling homes, often through revolving windows or in hidden alcoves. Formalized abandonment was favoured as an alternative to infanticide throughout the colonial period and, in the case of Argentina, until the late nineteenth century.¹⁷ Abandonment was even encouraged in some settings. Colonial authorities favoured high fertility among certain indigenous groups in Mexico; elites took in the “excess” infants and raised them into a separate and more docile workforce that competed against other indigenous labourers, thus forcing down wages.¹⁸ Abandonment also increased during epidemics, when, for example, parental deaths in certain parishes of Quito contributed to the abandonment of almost one-third of newborns. Even in better times, foundlings (from both married and unmarried parents) constituted one-sixth of births.¹⁹

Since foundling homes and hospitals were church-run in this period, the surviving records of these institutions offer some evidence of child and infant mortality patterns. In colonial Havana’s Casa Joseph, the secret depository system was intended to prevent infanticide, but many foundlings died perhaps even crueller deaths than the babies tossed into the sea by desperate mothers. Despite expectations that the religious orders running orphanages would oversee a cadre of wet-nurses and caregivers for their charges, children left at these homes suffered malnourishment, neglect, disease outbreaks, and worse. In the early eighteenth century, mortality among abandoned children at the Casa Joseph averaged almost 40 per cent per year. Similar or far higher rates have been documented from institutional registries in Brazil, Argentina, Chile, and elsewhere during the colonial period.²⁰

The demand for a legal means of abandoning infants – including by well-off classes – kept such institutions open despite appalling track records, mismanagement, and disputes with government authorities. This puzzle of wide public support for “death sentence” orphanages may be partially explained by the orphanages’ key role in providing information about, access to, and even oversight of informal mechanisms for the placement and circulation of

children. As has been shown for Chile, Brazil, and other settings, extensive child circulation systems based at orphanages placed parentless children in foster care, as adoptees, and as child servants working in private homes, with their legal status and placement determined by race and social origins.²¹ For instance, while rates of abandonment and infant mortality increased in the nineteenth century during times of crisis at Mexico City's orphanage (known as the house of "indifference," or "lovelessness"), few children lived in orphanages for long periods.²²

Of course, child circulation also existed in Europe and elsewhere. Perhaps uniquely in Latin America, these practices not only survived, as incipient state measures to protect abandoned children were adopted in the region's new Constitutional republics (and the monarchy of Brazil) in the early nineteenth century, but child circulation networks remained integral to child protection efforts into the twentieth century.²³ Combined public and private means of coping with high illegitimacy and the care of abandoned children through child circulation was thus an enduring child health legacy from the colonial era.

Even before the independence movements of early nineteenth-century Latin America, the colonial regimes of the eighteenth century had begun to redefine their relationship and responsibilities to children, with implications for child health and well-being. In Mexico, for example, the moral and social position and trajectories of children under indigenous and early colonial authority were defined before birth by class, race, gender, and legal status, but by the late 1700s the male family head's primary purview over children began to be supplanted by state interest in raising productive citizens.²⁴ At orphanages this meant enhancing the civil status of orphans, regulating the system of wet-nurses who breastfed abandoned infants, and starting in 1804, under orders of the viceroy, vaccinating children against smallpox. The prospect – if not the realization – of state-led child protection efforts thus emerged prior to the region's decolonization.

NATION-BUILDING, MATERNALIST FEMINISM, AND THE HEALTH OF THE CHILD

The wave of insurgencies and full-scale war that undulated through Latin America between 1800 and 1825 brought independence to most of the region's Iberian colonies (important exceptions being Puerto Rico and Cuba). Continued warfare, political turmoil, and in some settings foreign occupation thus restricted the contours of state building. In the mid-nineteenth century, following decades of instability, the region began to see growth in

trade, foreign investment, and economic development, yet the social order and agrarian basis of most of the population remained largely unchanged from the colonial period. Moreover, the weak and unstable states of newly independent Latin America typically decentralized political power to local jurisdictions. In child health terms, this situation meant there was little effort to document or address problems, particularly in rural areas.

By the second half of the nineteenth century, attention to child and social welfare increased in the capitals and larger cities, initially with limited participation of most central governments. Since political administrations in this period were often short lived, it was charitable and religious agencies – with considerable involvement of middle and upper class women – that provided the institutional base and continuity for measures to protect (particularly) urban children from abandonment and destitution in Chile, Argentina, Uruguay, and other countries.²⁵

The moral discourse around these efforts was framed in the mid-nineteenth century within an ideological discussion of the building of Latin America's new states and, in the twentieth century, by the creation of welfare societies. Less utilitarian than European empires concerned with productive industrial workers, fit soldiers, and colonial overseers, Latin American interest in child health nonetheless had a practical side. Political and social elites recognized the importance of child health in maintaining order and so accepted the role of charitable institutions in jump-starting what might become government welfare roles and responsibilities.

In most Latin American countries, both conservative Catholic women and middle- and upper-class liberal women played an important role in maternal and child health advocacy well into the twentieth century. Region-wide and national movements for women's equality, ranging from communist to liberal-elite orientations, did not deny femininity and motherhood but rather embraced these roles. Partly based on Catholic spiritual values, these efforts (also referred to as "mother-feminism") protested "laws and conditions which threaten[ed women's] ability" to bear children and nurture their families, such as war, drugs, prostitution, urban misery, adultery, and exclusion from suffrage and property ownership.²⁶ In Brazil the abolitionist movements and pro-motherhood/pro-child health efforts were closely intertwined, with the practice of slave wet-nursing contested by slave women, elite women, folk healers, and doctors.²⁷

As was the case in Europe and North America, Latin American maternalist-feminist movements were most influential in urban settings where middle-class women transformed social concerns into public policy and mobilized to improve and regulate social conditions for poor children and their

mothers. In Argentina, starting in the 1820s, for example, the elite women's voluntary Beneficent Society was a major player in the contentious arenas of social policy and public health. For over a century it influenced state assistance to women and children, based on a maternalist approach of protection and dependence. In Uruguay, the social-assistance societies operated by elite women were less centralized but initially survived the nationalization of public assistance in 1910, becoming purveyors of government-funded services before the full development of the state's scientific welfare bureaucracy.²⁸ In countries where hospitals and infant asylums were secularized and placed under full or nominal government control early on – for instance, Mexico beginning in the 1860s – women's social assistance efforts, marshalled by activist first ladies, also played a vital part in supplementing state activities and transforming child welfare from charity to public benefit.²⁹

By the late nineteenth century, children's health and welfare had become appealing issues to public agencies in many countries. During times of longer political stability, such as under the dictatorial rule of Porfirio Díaz in Mexico from 1873 to 1910, or with the emergence of the Brazilian republic in 1889 (a year after slavery was abolished), responsibility for moulding children into modern citizens was realized by increasingly centralized state institutions intent on controlling delinquency and improving child-raising.³⁰ In these settings and far beyond, public welfare agencies began to oversee policies regarding child and social welfare. A flurry of juvenile protection measures were passed, giving the state new legal powers over family life and displacing responsibility away from the church and private spheres.³¹

Not all countries deployed such state power in the name of children's health. In the 1880s, Chilean legislators rejected compulsory smallpox vaccination – in spite of wide agreement that it would lower the nation's deplorable child mortality rates – as a means of limiting presidential potency.³² Moreover, previous practices of child abandonment in privately run religious orphanages persisted, particularly in provincial towns where abandoned infants faced poor prospects for survival. For example in Puebla, Mexico, almost half of the young charges abandoned at the San Cristóbal orphanage between 1860 and 1880 died there.³³

Specific concern with infant mortality as a medical, social, and ultimately political problem emerged in several Latin American countries in the 1870s, almost simultaneously with the “discovery” of infant mortality in Europe and North America. Although, as we shall see, there was little capacity at the time to capture national demographic trends accurately, incipient

municipal vital statistics, principally in Latin America's leading cities – as well as data compiled at children's and women's hospitals, asylums and orphanages, charitable agencies, and welfare offices – provided evidence of the severe problem of infant and child deaths and disease.³⁴ Initially, women reformers and charity workers had used this information to leverage public and private resources for maternalist assistance and welfare activities. Now their voices were joined by those of male physicians trained in the new specialty of children's medicine, who had begun to take on formal roles at children's welfare institutions and public health boards.³⁵ Well aware of – and becoming active participants in – international debates around children's health and welfare, Latin American public-health doctors donned demographic hats and began to examine patterns of childhood mortality.³⁶ With shocking figures of death and misery in hand, they joined forces with – or overshadowed – women caretakers of poor children in publicly advocating for child-health measures. This rhetoric found increasing resonance in political circles but was rarely accompanied by the concomitant resources to combat child misery.

One of the earliest studies of urban infant mortality was undertaken by Dr Emilio Coni of Buenos Aires in 1879.³⁷ Coni, a member of the Buenos Aires City Council before becoming head of the city's Public Assistance office in 1892, documented disease, injury, vice, and lack of parental guidance among tenement children, then spearheaded legislation protecting children in tenements and the workplace.³⁸ Through these efforts, he and many of his fellow doctor-reformers exposed dire social conditions and advocated increased legislative and medical control of the behaviour of the poor. The child-health movement in Argentina, as elsewhere, incorporated humanitarian, medicalized, and repressive approaches to child-raising. At the same time, doctors managed to increase their own social and political prominence as well as their professional standing.

As Cecilia Muñoz and Ximena Pachón have exemplified for Colombia, most Latin American doctors who analyzed infant mortality patterns in the late nineteenth century identified two sets of intertwining underlying factors, social misery and maternal ignorance, and called for their improvement through social reform and greater medical and public health attention.³⁹ Children's ill health – as much as high rural or indigenous mortality or workplace death and disease – became a window on the class divide. In some settings, for example, Bolivia, ethnicity and race persisted as explanatory factors for high infant mortality, and physicians blamed indigenous mothers for child deaths well into the twentieth century.⁴⁰ Elsewhere, doctor-activists – for instance, Miguel Mendoza López in the provincial city of Guadalajara, Mexico, followed a more radical path to resolve the infant

mortality problem, calling for workers' rights, economic redistribution, and political solutions to redress the extremes of privilege and poverty⁴¹ several decades before the emergence of better-known Latin American advocates of social medicine such as Chile's Salvador Allende.

In drawing attention to child health, physicians found themselves at the centre of the nationalizing mission. In post-slavery Brazil, as Tamera Marko has argued, children portrayed as future wage-labourers became the focus of nation-building. Pediatricians in turn were transformed into new overlords of both worker and national health.⁴² Brazil's father-son physician team, Carlos Arthur Moncorvo de Figueiredo and Arthur Moncorvo Filho, were academic town-criers (with five hundred publications between them) and tireless advocates of the state's accountability for child health and welfare. Between the 1870s and the late 1920s, the Moncorvos led a crusade in favour of centralized state control over child welfare institutions. Their systematic push for the state's *in loco parentis* role of safeguarding poor children from the misery and delinquency typical of Brazil's cities was based on an equation of child health and well-being adding up to national health and well-being.⁴³

Likewise, in Mexico City starting in the late nineteenth century, juvenile delinquents were moved into vocational schools where they learned a trade and were disciplined in the ways of a hygienic life free of vice and filth. In the same period, day-care centres began to be established in the capital for the offspring of single mothers who were toiling long hours in apparel, cigarette, and other factories. Exercise, nutrition, hygiene, and medical surveillance formed part of the centres' overall schooling efforts. With a continued emphasis on child health and development, they became part of the nation's children's welfare system in the wake of Mexico's 1910–1920 revolution.⁴⁴

In most places, child-saving measures were more consistent with state building than social revolution. Brazil's internationally inspired child-saving movement, as Irene Rizzini has demonstrated, put more emphasis on reducing the social threat of delinquents by re-educating them as labourers than on inclusive educational policies that might have lowered Brazil's social inequalities.⁴⁵ Yet in saving children through reform and protectionist measures – even when ambivalently implemented – advocates in Brazil, Venezuela, or Colombia claimed that state-led efforts to improve the moral and work prospects of indigent youth would move these nations into the modern era.

Many countries of the region employed school hygiene measures to similar ends in this period as a symbol of children's importance in the forging of a national identity⁴⁶ and the promotion of civility, modernity, and citizenship.⁴⁷ As articulated at Mexico's first Hygienic Pedagogy Congress in

1882, healthy schooling required that school buildings be clean, well-ventilated, supplied with running water or full sanitation systems, and include a gymnasium or other facility for exercise. School medical inspections carried out under the aegis of Mexico's Superior Board of Health were ideally suited to these national goals, as Ana María Carrillo has shown.⁴⁸

Medical inspections conducted on school premises had the advantage of requiring minimal separate resources or infrastructure compared to other public health activities, and while the inspections usually revealed severe child health problems such as high rates of tuberculosis,⁴⁹ school hygiene activities could also be limited to administering smallpox vaccines on site or verifying vaccination certificates for school attendance. Moreover, state responsibility was circumscribed to those children who attended school, leaving the vast majority of poor and rural children – arguably the sickest – outside of the inspection system. In Panama, for example, despite the symbolic value of children's health in nationalist rhetoric and the practicality of school-based inspections, only a fraction of children were reached until legislation for compulsory school medical service was passed in 1925.⁵⁰

In Brazil, Mexico, Uruguay, and other countries, children's health education became the essential counterpart to medical inspection starting in the 1920s and '30s, with children seen as a conduit to family health.⁵¹ School health also captured the interest of international organizations that had hitherto paid little attention to child health. The Rockefeller Foundation's influential International Health Division recognized the importance of these efforts, even though it was focused on public health education and disease campaigns rather than child health per se. At São Paulo's Institute of Hygiene in the 1920s, the Rockefeller Foundation actively supported rational school hygiene efforts aimed at the moral, physical, and intellectual regeneration of the primary schoolchild. At Rockefeller-sponsored rural health units in Mexico in the 1930s, nurses and other personnel were encouraged to teach personal hygiene measures to children as a means of inculcating sanitary values across generations.⁵²

Surfacing at a time of growth and institution-building in the nations of Latin America, child health became a central component of the modernizing agenda that would last over several generations.

CHILD HEALTH TAKES CENTRE STAGE: PUERICULTURE, PAN-AMERICANISM, AND PEDIATRICS

The child-saving movements that emerged in the late nineteenth century were fortified after 1900 when the purview of public health boards and

departments expanded and national health agencies became one of the pillars of the nascent welfare states of many countries in the region.⁵³ Many of the Latin American physicians who advocated for public health and child well-being now had official standing in their own countries. Their prestige boosted by engagement in international conferences, debates, and networks, they began to wield considerable policy influence. Physicians and reformers discussed and sometimes partially adopted measures developed overseas, but they also recognized the limits of these approaches amidst conditions of poverty and social disorder. Financial impediments to state action in the early decades of the twentieth century meant that feminist reformers and other private sector actors continued to play significant roles in child health. The child and maternal health agenda that solidified in these years – including regulation of wet-nursing and adoption, oversight of foundling hospitals, establishment of children's outpatient and inpatient clinics, pregnancy surveillance, midwifery training, obstetric control, and maternal education, among other measures⁵⁴ – arose from a sometimes uneasy mix of feminist and maternalist ideas, indigenous cultural practices, nationalist concerns, physician advocacy, and growing professional power.

But new developments were also afoot. Late nineteenth and early twentieth century Latin American efforts drew from, coincided with, and shaped both regional and international discussions tying children's health and welfare to the national destiny. At the time, French influences predominated throughout the region in both medical and social welfare domains. In infant and child medical specialties, as in clinical medicine generally, Latin American medical schools followed France's model: French texts were used in classroom training, and the most brilliant students went to study in European hospitals and research institutes with the "masters." A small but committed group of elite doctors from throughout Latin America attended European medical and child health congresses, interchanges that later turned towards North America.⁵⁵

As in Europe and North America in this period, child health was an area of burgeoning interest. Dozens of new positions and departments of child and infant medicine were founded in Latin America in the 1890s. With wider adoption of the designation of pediatrics around 1900, the specialty continued its ascendance with national training programs, a new cadre of professional pediatricians, national pediatric associations and congresses, and the founding of the region-wide *Archivos Latino-Americanos de Pediatría* in 1905, soon accompanied by a suite of new national pediatric journals.⁵⁶ Obstetrics, too, began to be professionalized with the development of tools and techniques seeking (though not necessarily with success) to

make childbirth safer.⁵⁷ meanwhile obstetricians and other doctors used their newfound authority to resurrect their longtime effort to squeeze out midwives, who until then were almost exclusively in charge of maternal care and childbirth throughout the region.⁵⁸

Engaging with Adolphe Pinard's notion of puericulture⁵⁹ – scientific child-rearing that was both medically recommended and socially oriented – Latin American doctors and social reformers also followed the French administrative and juridico-institutional approach to children's welfare. French standards for infant well-being and maternal protection were widely discussed in Latin American legislatures, policy circles, and professional meetings. For example, starting in the early 1900s, French-style milk stations – *gotas de leche* – were established by doctors in Uruguay, Argentina, Colombia, Mexico, and other countries, serving as community-based clinics for infant and child health.⁶⁰ Although these and other child health and welfare provisions were modelled on the French bureaucratic tradition (which had replaced Iberian administrative systems in the nineteenth century), most Latin American countries never achieved the French ideal of centralized management and policymaking and universality of benefits.⁶¹

The coincident rise of pediatrics and state-run child health measures brought almost all children – not only the abandoned and marginalized – and mothers under state purview. This intrusion of professional authority over the traditional domestic and communal landscape of infant welfare had complicated consequences, perhaps most evidenced in the area of infant feeding. Through the late nineteenth century, maternal breastfeeding was near universal throughout Latin America (with the exception of the social extremes of abandoned infants and elite strata, where wet-nursing was often utilized); the medicalization of maternity initially called for scientific guidance of existing infant feeding practices. Circa 1900, however, doctors' growing endorsement of artificial feeding as safe and nutritious, coupled with the free milk provided by the *gotas de leche* in popular neighbourhoods, led increasing numbers of women to shorten or forego breastfeeding (or combine breastfeeding with baby formula or cow's milk – *alimentación mixta*).⁶² Of course, breastfeeding alternatives were important for women who could not produce breast milk or who were impeded from breastfeeding by their employment in the formal labour force. Still, as infant mortality rates began to be scrutinized, some critics questioned medical and state incentives favouring artificial infant feeding. Uruguay's Dr Luis Morquio went so far as to blame infant mortality on the *gotas de leche* and sought to resurrect universal breastfeeding as a form of "infant social security."⁶³

Campaigns for children's health were also magnified by changes in the demographic landscape as sizable waves of immigrants from Europe, Asia, the Caribbean – and the rural hinterland – arrived in Peru, Brazil, Mexico, Argentina, and generally across the Americas. In many settings immigrants were perceived to be a threat to national aspirations. Political elites in late nineteenth and early twentieth century Costa Rica, for example, blamed their country's perennial labour shortage on high infant mortality and saw this as the primary reason the country had to resort to accepting Jamaican, Nicaraguan, Chinese, and other immigrants believed to be degenerative influences.⁶⁴ Child health was thus viewed as a pressure valve on immigration and a precursor to improving the country's racial stock. Indeed, public health and eugenics advocates shared a language of alarm about demography and degeneration with state builders and social reformers,⁶⁵ making doctors instrumental figures in national modernizing projects.

If eugenics served as an important ingredient in the region's support for maternal and child health, it was also an arena where international disagreements played out. Anglo-Saxon eugenics, as applied in Britain, Scandinavia, North America, and most infamously, Nazi Germany,⁶⁶ was principally informed by Mendelian genetics. Improving a society's genetic stock entailed breeding out bad genes through sterilization and prohibitions on procreation (so-called "negative eugenics"). Though these ideas were controversial in the United States and elsewhere, the precepts of "negative eugenics" were effectively translated into social policy, with thirty-one of forty-eight U.S. states passing compulsory sterilization laws between 1907 and 1937.⁶⁷

Eugenics in Latin American countries reflected French approaches more than Anglo-Saxon genetics. As Nancy Stepan has argued for Mexico, Brazil, and Argentina, eugenics was interpreted through neo-Lamarckian ideas about the inheritance of acquired characteristics and implemented through the practices of puericulture and homiculture – the latter a Cuban-coined extension of Pinard's concerns to all age groups. Latin eugenics stressed reforming the social and moral environment of prospective parents and children rather than blocking reproduction *per se* (though prenuptial certificates became obligatory in some localities). Children raised well might not only overcome an unfavourable genetic background but would also pass on these new traits to future generations, improving the larger society. This so-called "positive eugenics" movement, with its emphasis on sanitation, health, sound marriage, and the scientific improvement of the circumstances surrounding conception and childhood, closely – if disturbingly – overlapped with concerns over maternal and child health.⁶⁸

The differences between North American and Latin American approaches to eugenics surfaced at the First and Second Pan American Conferences of Eugenics and Homiculture, held respectively in 1927 in Havana and 1934 in Buenos Aires. Most Latin American delegates rejected U.S. support for sterilization and the “improvement” of heredity, favouring instead a focus on bettering home environments and increasing the state’s role in social welfare.⁶⁹ Yet these divisions did not lead to an abandonment of eugenics in Latin America. Indeed, protecting the health and welfare of children – following paternalistic more than coercive approaches – became the central tenet of Latin American eugenics and facilitated the entry of concepts of eugenics into state policy.

French-influenced Mexican eugenicists dominated the Mexican medical establishment and a wide array of government agencies. Education and criminal justice, to mention just two arenas, joined health and medicine in making eugenic ideas central to Mexico’s project of national (re)construction following the 1910–1920 Revolution.⁷⁰ State public health initiatives aimed at children were particularly infused with eugenic thinking. The now-expanded School Hygiene Service closely observed the physical and mental development of school children, and the Infant Hygiene Service – under the leadership of Dr Isidro Espinosa y de los Reyes – emphasized puericultural training, home visits, and the medical monitoring of mother and child as a means to reduce infant mortality. Though wide-ranging, such measures were mostly implemented in the capitals and larger cities,⁷¹ with rural children neglected by both child health and eugenic activities until the 1930s, or in some cases, the 1950s or beyond. By comparison, the steps taken by most other governments around the world were more tentative than France’s; still, Latin American state efforts to take on responsibility for infant and child well-being could not be sustained under existing financial and governing circumstances.

In Latin America, eugenic puericulture was part of an ambitious region-wide effort – often more rhetorical than real – to bolster the rights, conditions, and health of children, which drew from leadership, research, exchanges, and cultural and economic realities of the Americas. Again, public health physicians and maternalist feminists spearheaded these movements, competing and partially converging over time. Such Pan-American and Latin American networks were not unique to child health; they formed around topics ranging from medicine and hospitals to housing, sociology, commerce, crime, history, literature, Jews, coffee, highways, electricity, and democracy (kicked off officially by the first International American Conference held in 1889 in Washington, D.C.), engendering active organizations at both national and regional levels.

In the medical arena, child hygiene and pediatrics enjoyed an increasing presence at the Latin American Medical Congresses, which were inaugurated in Santiago de Chile in 1901 and had a special child medicine section by the fifth region-wide meeting in Lima in 1913.⁷² In public health circles, it took somewhat longer for children's health to gain attention. In December 1902 the International Sanitary Bureau (known from 1923 as the Pan American Sanitary Bureau and from 1958 as the Pan American Health Organization) was founded in Washington with the support of the United States and ten Latin American countries, eventually reaching the membership of all of the republics of the region. Physician representatives to the quadrennial conventions began expressing their concerns with childhood illness and high infant mortality starting in 1907.⁷³ Following World War I, they demanded that maternal and child health become part of the bureau's official agenda. However, the U.S.-dominated bureau focused its priorities on the protection of commerce from epidemic outbreaks through the development of a Pan American Sanitary Code, and it took almost thirty years to respond to the beleaguered efforts of Latin American delegates to highlight child health concerns.⁷⁴

Meanwhile, women reformers and child health advocates and reformers had taken their organizing elsewhere. In the wake of two aborted efforts to institutionalize an international association for childhood protection in Brussels (in 1907 and 1913), a group of Latin American maternalist feminists, who viewed the lot of children to be inextricably linked to the rights of women as mothers, organized the first Pan American Child Congress in Buenos Aires in 1916. The meetings and the larger movement served for almost half a century as a vibrant hemispheric forum for Latin American reformers, feminists, nurses, policy-makers, sociologists, physicians, lawyers, and social workers devoted to improving the health and welfare of poor and working-class children and their mothers.⁷⁵ The eight congresses that met between 1916 and 1942 influenced the passage of dozens of laws protecting children and their mothers, delineating children's rights in such areas as adoption, infant health, and child labour, and implementing a mix of public and private measures.⁷⁶ They helped generate similar efforts internationally at the League of Nations through Uruguay's Dr Paulina Luisi and other South American delegates who had been involved in the congresses before heading to Geneva.⁷⁷

By the time of the second congress in 1919 in Montevideo, pediatricians had upstaged the feminist reformers. In 1927 the Child Congress organizers' decade-long dream of founding a permanent Instituto Internacional Americano de Protección a la Infancia (International Institute for the

Protection of Childhood) was realized in Uruguay, with the support of the League of Nations. The first of its kind in the world, the institute collected and disseminated research and policy information pertaining to the care and protection of mothers and children. Its widely circulated journal, library, and health education materials, and the subsequent child congresses it organized rapidly established a strong reputation for the institute and generated a large network of informants and collaborators throughout the region and the world.

From the late 1920s until the 1940s, the institute pioneered innovative social legislation relating to the health and welfare of children under the leadership of Uruguayan pediatrician Luis Morquio and others. Uruguay served as a policy incubator, in 1934 passing a Children's Code that spelled out children's rights to health, welfare, education, and decent living conditions and created specific centralized institutions to run and oversee child and maternal aid programs. Morquio and his colleagues were frequently invited to share their research and policy ideas with Europeans, serving as exporters as well as importers of childhood-related scientific theory and practice. The *Boletín del Instituto Internacional Americano de Protección a la Infancia* became a leading venue for comparative child health and child policy, with an array of international experts covering worldwide child health issues. The League of Nations Health Organization sponsored several of the institute's infant mortality and nutrition studies, and Morquio was named president of Geneva-based Save the Children in 1930.⁷⁸

Encouraged by mutual interests and the cross-fertilization of ideas through the child congresses and the institute, many Latin American countries began to hold national child conferences and set aside a day or week of the child (*Día del Niño*) to draw attention to matters of child health and social welfare and generate wider support for the development of centralized institutions and legal protections for child health and welfare. In the 1930s, some countries such as Chile established extensive maternal and child health measures, covering several months of paid maternity leave, an allowance for nutrition and infant health services, and exclusive infant access to maternal milk until age five. By 1940 most of the region's republics, including Argentina, Bolivia, Brazil, Chile, Colombia, Costa Rica, Cuba, Ecuador, Mexico, Nicaragua, Paraguay, and Venezuela, had specific bureaus or agencies dedicated to maternal and child health protection.⁷⁹

While these bureaus are mentioned in various institutional histories,⁸⁰ there remains much to be analyzed regarding such national efforts as well as the movements and influences that existed alongside the public sector. For example, the Rockefeller Foundation's international health activities in

Latin America in the first half of the twentieth century, though not aimed specifically at maternal and child health, entered this arena through involvement in nursing and graduate public health education, community health centres, rural health, and the forerunner of later family planning efforts.⁸¹ Indeed, maternal and child health efforts were shaped by complex international interactions in this period. As demonstrated by María Soledad Zárate, the increasing displacement of French and European medical (and social medicine) models by U.S. influences – evidenced in Chilean obstetrics – involved a complex system of filtering and refashioning to suit local priorities, social and political conditions, and expertise.⁸²

In most settings, growing national attention to child health in the 1930s and '40s did not exclude competing ideologies and approaches. In Argentina and other countries with a strong church, the development of a children's welfare state did not part from the moralistic teachings of Catholicism but incorporated values of family moralism and marriage as a means of decreasing illegitimacy and improving fertility and child health.⁸³ Revolutionary maternalism in Mexico was interlaced with growing medicalization and state control over mothering practices,⁸⁴ yet the diffusion of eugenic puericulture beliefs and practices necessarily took place through religious, civil society, and private channels.

In the first half of the twentieth century, the proliferation of Pan-Americanism played an important part in framing regional approaches to child health in scientific, cultural, political, and legal terms. Notwithstanding powerful nationalistic rhetoric and the persistent advocacy and region-wide solidarity of professionals and reformers, however, a full-blown child-centred welfare state was perennially impeded by difficult political and economic conditions, leaving an ongoing role for private action.⁸⁵

DEMOGRAPHIC PERSPECTIVES AND THE INTERNATIONAL CONTEXT

Another angle on child health in Latin America in the republican period comes from nascent studies in historical demography. Typically employing French bureaucratic templates, a few countries, some states and provinces, and many capital cities and other municipalities started in the late nineteenth or early twentieth century to collect statistics and study demographic trends. Peru and Mexico passed vital statistics legislation in the 1850s, Argentina founded its Civil Registry in 1871, Uruguay in 1879, and Brazil in 1888. More sporadic than systematic, and capturing far more urban than rural demographics, these registries nonetheless revealed extremely

high infant mortality rates.⁸⁶ Demographers have pointed out that in most settings there was significant under-registration of births (especially for illegitimate births and those in poor and isolated households), as well as extreme under-reporting of infant deaths in the early hours, days, or months of life,⁸⁷ suggesting that uncorrected mortality figures are unreliable. Certainly, as discussed above, these figures served as ammunition in contentious debates over depopulation, fitness for employment, and racial, ethnic, and national identity, yet they have been of limited use for historians interested in analyzing pre-war national patterns. For example, though in Buenos Aires data began to be compiled in the 1850s and were relatively complete by the 1870s,⁸⁸ and statistical annuals covering Brazilian state capitals and regions began sporadic publication in 1894, neither Argentina nor Brazil compiled reliable national-level records until the 1940s.⁸⁹ Peruvian and Mexican registries, as those in most Latin American countries, did not achieve national coverage until the 1950s.⁹⁰ Uruguay's Civil Registry serves as an exception to this timing with regular national coverage by the 1880s and infant mortality data available from the 1890s; ironically, Uruguay's scarce censuses makes infant (and child) mortality more reliable than adult mortality, for which a population denominator is difficult to ascertain.⁹¹

The paucity and deficiencies of Latin American vital statistics data before World War II make demographic analyses of child and infant mortality in the region challenging. In some cases, there are municipal or regional mortality series starting around 1900 that allow for partial analyses by age and or by cause (covering leading childhood ailments such as diarrhoea or respiratory infections) in settings including Buenos Aires, Santiago de Chile, Rio Grande do Sul (Brazil), Tandil (Argentina), Medellín, and Rio de Janeiro.⁹² A series of surveys sponsored by the League of Nations Health Organization (LNHO) in the late 1920s and comparable to LNHO studies sponsored in Europe provide detailed assessments of the specific and underlying causes of infant mortality in Argentina, Brazil, Chile, and Uruguay.⁹³ Other local studies examine the roles of labour patterns, social structure, land tenure, production and export, and hunger in infant mortality.⁹⁴

The most closely examined case of infant and child health comes from Uruguay. Infant mortality there circa 1900 was lower than that of all recorded countries except Norway and Sweden, but it then fluctuated around the same level for almost four decades, whilst other countries saw sustained declines. In all likelihood it was Uruguay's early successes in this arena that initially left child well-being lagging in its early welfare state measures. Eventually, however, the regularization of public health services, monitoring of milk, water supply, and sewage, regulation of tenements, the implementation

of the Children's Code of 1934, and the introduction of specific diarrhoea control measures and a family wage in the 1940s all contributed to improvements in Uruguayan infant mortality.⁹⁵

Investigations of Uruguay's infant mortality conundrum, as well as a comparative analysis of Montevideo and Buenos Aires, showed that infant mortality declined faster in Buenos Aires than in Montevideo in the first decades of the twentieth century despite Uruguay's greater centralization and welfare orientation,⁹⁶ suggesting that Latin American child health patterns differ from the more studied cases of Europe not only in timing but also in levels, causes, and approaches. A recent study of mortality in early twentieth century Cuba also points to tailored public health measures – in terms of policy one-upmanship between political parties – as far more important determinants of infant mortality than the combined effects of economic growth, changes in the standard of living, and maternal hygiene cited in the European context.⁹⁷

Undoubtedly only the beginning of child-specific demographic perspectives on Latin American health, these studies defy the diffusionist characterizations of historical studies of development and child health.

FROM THE PRIVATE SPHERE TO THE WELFARE STATE, AND BACK?

The late nineteenth and early twentieth centuries served as a watershed for children's health policy in Latin America. In the process of forging modern identities and societies amidst the challenges of immiseration, immigration, urbanization, and social disorder, state interests recognized and began to address the problems of child health that had long been relegated to the private domain. Women social reformers, medical professionals, and other advocates served as active policy-makers and purveyors of child health measures domestically *and* interacted with Latin American and other international counterparts. Mindful of national imperatives and foreign developments, Latin American ideas and activities also circulated overseas, with these interchanges reaching a crescendo in the interwar period.

If the overarching framework of Latin American attention to maternal and child health by the 1920s and '30s was of state institution-building, it was inevitably an arrested effort. In contrast to Skocpol's portrayal of a transition from maternalism to state paternalism in the United States,⁹⁸ Donna Guy points to a more complex history. Public policies for children were central to the rise of the Latin American welfare state, but children's welfare remained a hybrid of public paternalism and private maternalism.

Because the welfare state was never all-encompassing in Latin America, the mix of private and institutional responses to child health and well-being (state, medical, and charitable) has remained characteristic of the region.⁹⁹

It is important to note that the factors shaping child health policy in Latin America – French models and international interactions, eugenics, maternalist reformers and pediatricians, and state-building forces – have for the most part been examined from an urban viewpoint, inevitably masking other perspectives. Studying welfare state measures may lead to rural-urban differences, indigenous populations, and the historical legacy of slavery and persistent hierarchies of race being overlooked. For example, despite Brazil's myth of racial harmony, there are and were persistent differences in infant and child mortality – and social welfare – along a racial continuum, even when controlling for socioeconomic factors.¹⁰⁰

The end of World War II marks a breakpoint for the history of children's health in Latin America – and the endpoint for this analysis – for a number of reasons. The region's children's rights movement culminated in the 1948 Pan American Children's Code, co-authored by the Instituto Internacional Americano de Protección a la Infancia, the Pan American Sanitary Bureau, and the U.S. Children's Bureau. Signed at the Ninth Pan American Child Congress in Caracas in 1948, the code stipulated that “all measures necessary must be taken in order to assure that all children, regardless of race, color, or creed, enjoy the best health conditions, based on adequate hygiene, together with the necessary good housing, sun, air, cleanliness, and clothing in order that they may benefit from the opportunity to live healthy, happy, and peaceful lives.”¹⁰¹

Like Latin American child health measures in general, the Pan American Children's Code drew from and influenced both local and international sources. It incorporated some principles from the Declaration of the Rights of the Child developed by Save the Children founder Eglantyne Jebb and adopted by the League of Nations in 1924; other principles derived directly from Uruguay's Children's Code adopted in 1934. Moreover, the Pan American Code, with its advocacy for all the ingredients of child well-being, inspired subsequent international children's rights efforts, particularly the 1989 Convention on the Rights of the Child.

While the recent history of Latin American social policy is one of persistent gaps between passage and implementation or enforcement of social protection policies and legislation, the Pan American Children's Code nonetheless marked a new era in the recognition of the support for children's health and welfare as a state responsibility. The development of vital statistics capacity in almost all countries of the region also meant that children's well-being could now be monitored through routine demographic analysis.

Following World War II, changes at the international level brought a new spotlight to children's health in Latin America and other developing regions. Newly founded United Nations agencies, particularly the World Health Organization and UNICEF, put maternal and child health high on their agendas.¹⁰² After the problems of European refugees were addressed, these agencies concentrated on fighting poverty (and communism) in developing countries, leaving less room for the interplay of child health ideas and practices to and from Latin America, as had transpired in the previous period. The proliferation of bilateral agencies and nongovernmental organizations in the context of the Cold War turned health cooperation into an ideological tool, with Latin America as contested terrain. With a growing technical armamentarium, including vaccines, antibiotics, contraceptives, and later oral rehydration therapy, international agencies became deeply involved in the promotion and delivery of children's health services as part of "population control" and "child survival" strategies. Yet the region's most successful models of child health improvement in the postwar era, those of Cuban socialism and Costa Rica's multi-pronged approach of nutrition programs, abolition of the military, and social redistribution, drew far more from domestic welfare policy-making than from international aid.¹⁰³

Although the history of child health in Latin America – amidst its diversity – may be summarized as one of a never fully realized ideal of state responsibility for social welfare, the emerging literature discussed here portrays the countries of the region confronting the problem of child health amidst a constellation of legacies, constraints, and influences. Over time, child health ideologies, institutions, and practices drew successively and sometimes simultaneously from indigenous traditions, colonial patterns, state-building concerns, technical developments, racial and medical ideologies, and domestic and international innovations. Far from being derivative of outside efforts, the region's child health approaches interacted with broader tendencies and movements while being forged locally – and in turn reverberated widely.

NOTES

My thanks go to Kristin Ruggiero for her helpful comments and to George Weisz, Cynthia Comacchio, and Janet Golden, who co-organized the colloquium that inspired this article: Comparative and Interdisciplinary Approaches to Child Health in the Twentieth Century, the McGill/McCord/AMS Colloquium

held in Montreal in October 2004. I am also grateful to Bronwyn Underhill for the preparation of references. Funding for the research and writing of this paper was provided by the Canada Research Chairs Program. This is an expanded and updated version of my article "Child Health in Latin America: Historiographic Perspectives and Challenges," *História, ciências, saúde – Manguinhos* 14 (2007): 677–708.

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- 52 Rocha, "Educação escolar"; Birn, "Skirting the Issue."
- 53 Márquez and Joly, "A Historical Overview."

- 54 Blum, "Public Welfare"; Torroella, "Alimentación"; Birn, Pollero, and Cabella, "No se debe llorar"; Zárate Campos, *Dar a luz*; Zulawski, *Unequal Cures*; Ungerer, *Começar de novo*.
- 55 Castillo Troncoso, "La visión de los médicos"; Birn, "Uruguay on the World Stage"; Aróstegui, *Enfermedades de la infancia*.
- 56 Delgado García, "La cátedra de patología."
- 57 Zárate Campos, "L'assistance clinique et sanitaire."
- 58 Carrillo, "Nacimiento y muerte."
- 59 Lefaucheur, "La puériculture"; Schneider, "Puericulture."
- 60 Muñoz and Pachón, *La niñez en el siglo XX*; Rollet, "Le modèle de la goutte de lait."
- 61 Klaus, *Every Child a Lion*.
- 62 Carrillo, "La alimentación 'racional.'"
- 63 Birn, "Doctors on Record."
- 64 Palmer, *From Popular Medicine to Medical Populism*.
- 65 Castillo Troncoso, "La visión de los médicos."
- 66 Broberg and Roll-Hansen, *Eugenics and the Welfare State*; Stern, *Eugenic Nation*; Mazumdar, *Eugenics*; Proctor, *Racial Hygiene*; Leon, "Hopelessly Entangled."
- 67 *Eugenic News*.
- 68 Stepan, *The Hour of Eugenics*; Reis, "De pequenino"; Sapriza, "La hora de la eugenesia"; Rodriguez, *Civilizing Argentina*; Nari, *Políticas de maternidad*.
- 69 Stepan, *The Hour of Eugenics*.
- 70 Stern, "Responsible Mothers"; Stern, "Unraveling the History of Eugenics"; Saavedra, "Historia del movimiento."
- 71 Miranda, "The Public Health Department."
- 72 Almeida, "Perspectivas sanitárias."
- 73 Ulloa et al., "Report."
- 74 Birn, "No More Surprising."
- 75 Guy, "Politics of Pan-American Cooperation"; *Conferencias internacionales*. Early congresses stressed legal issues (relating to immigration, mandatory schooling, child health protection, and prohibitions on treating children as criminals), subsequently turning to social concerns, including eugenics, the causes of family disintegration, children in the workplace, care and education of indigenous children, and combatting poverty. Later congresses focused on provision of social security measures, government protections for poor families, and the building of libraries and recreation centres.
- 76 Guy, "The Pan American Child Congresses"; Ehrick, "Madrinas and Missionaries."
- 77 Scarzanella, "Proteger a las mujeres."
- 78 Birn, "O nexo nacional-internacional."
- 79 García, "La medicina estatal"; Márquez and Joly, "A Historical Overview"; Mesa-Lago, *El desarrollo de la seguridad social*.

- 80 Amézquita Alvarez et al., *Historia de la salubridad*.
- 81 Black, *Taking Care of Baby*; Birn, *Marriage of Convenience*; Vessuri, "Enfermería."
- 82 Zárate Campos, "L'assistance clinique et sanitaire."
- 83 Di Liscia, "Colonias y escuelas."
- 84 Blum, "Dying of Sadness."
- 85 Guy, "The State"; Blum, "Conspicuous Benevolence."
- 86 Mitchell, *International Historical Statistics*
- 87 McGuire and Frankel, "Mortality Decline in Cuba."
- 88 Mazzeo, *Mortalidad infantil*.
- 89 Brasil, *Evolução e perspectivas*.
- 90 Hakkert, *Fontes de dados demográficos*.
- 91 Rial, *Población y desarrollo*; Pellegrino, *Caracterización demográfica*.
- 92 "Cuadro comparativo"; Alvarez and Miguez, "Morir en la frontera"; Bonow, *Indicadores de saúde*; Celton, "Enfermedad y crisis"; Reyes Londoño, "La salud y enfermedades infantiles"; Antunes, "'Grow and Multiply'"; Cavalcanti, *Condições de vida*; Alves, *A mortalidade infantil*.
- 93 Debré and Olsen, "Société des Nations"; Campbell, *Infant Mortality*; Scarzanella, "Los pibes."
- 94 Puerto, "Henequen Monoculture."
- 95 Birn, "Doctors on Record."
- 96 Mazzeo and Pollero, *La mortalidad infantil*.
- 97 McGuire and Frankel, "Mortality Decline in Cuba."
- 98 Skocpol, *Protecting Soldiers and Mothers*.
- 99 Guy, Editor's Page.
- 100 Sowards, "Assigning Racial Labels"; Wood and Lovell, "Racial Inequality"; Maio and Santos, *Raça, ciência e sociedade*.
- 101 "Puericultura."
- 102 Gillespie, "International Organizations."
- 103 Morgan, "International Politics."

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PART TWO

Constructing Health and Disability

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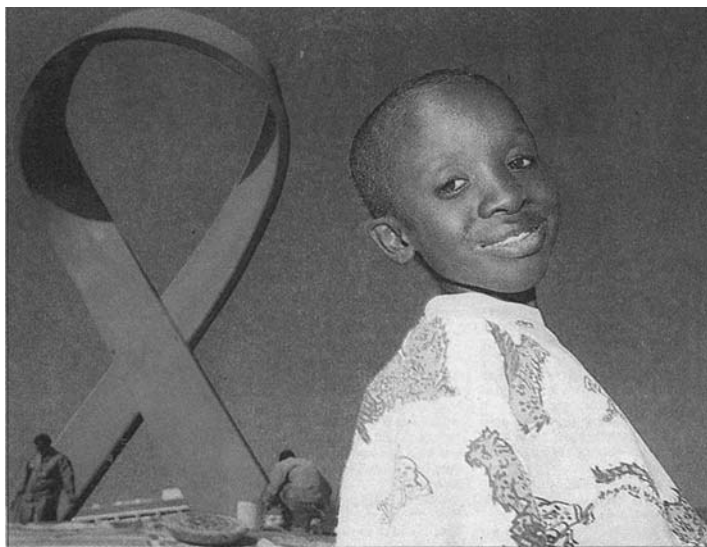
AIDS Orphans, Raped Babies, and Suffering Children: The Moral Construction of Childhood in Post-Apartheid South Africa

DIDIER FASSIN

During the opening ceremony of the Thirteenth International Conference on AIDS on 9 July 2000 in Durban, first city of the Third World to host this global meeting, it was not the South African president Thabo Mbeki who appeared as the star of the event but a young South African boy. Whereas the president was ostensibly despised – half the audience left in response to his so-called denialism as he started to speak – the boy received a standing ovation when he took the floor. He started his speech with these words: “Hi, my name is Nkosi Johnson. I live in Melville, Johannesburg, South Africa. I am eleven years old and have full-blown AIDS. I was born HIV positive.”

The story – his story – that Nkosi told the audience was one most South Africans knew already, as he had become one of the most popular figures of the epidemic. But this time it was told for the world. It evoked how Nkosi had been abandoned by his biological mother in a black township and adopted by a foster mother belonging to the white upper class, how he had been rejected from the school he was supposed to go to, how he went to the funeral of his biological mother when she died of her infection, and how he got involved in the day care centre created by his foster mother for AIDS orphans. Stumbling through words with emotion and hardly audible because of technical problems, he concluded, “Care for us and accept us – we are all human beings. We are normal. We have hands. We have feet. We can walk. We can talk. We have needs just like anyone else – don’t be afraid of us – we are all the same.” For the international audience of physicians, scientists, and activists, his call for compassion could not have been more moving.

A few months later Nkosi’s agony became a media chronicle. Every day his health status was commented upon in the press. At some point the



Ribbon of courage: young Nkosi Johnson, who has Aids, takes a break before he attends the 13th international Aids conference, which starts in Durban today

PHOTOGRAPH: GRANT ERSKINE

‘I will say to Mr Mbeki: give AZT to pregnant mothers’

4.1 Nkosi Johnson, an iconic figure, both victim and hero. Photograph: Grant Erskine, *Sunday Independent* (South Africa), 9 July 2000.

world learned that the boy had called President Thabo Mbeki to his bedside, trying to convince him to accept antiretroviral drugs for the prevention of mother-to-child transmission of the infection, which might have been avoided in his case, and for the treatment of patients like himself living with the virus. His illness had become a political passion play: Nkosi was suffering to save other children from the disease or from death.

However, in the following days, it emerged that he had actually been in a profound coma for some time and that his foster mother had been writing the messages for him, using his image to support the activists’ cause against the government.

This sad episode is a landmark in the South African history of AIDS. Through Nkosi Johnson’s iconic figure, it establishes a new place for childhood in the epidemic. Until the late 1990s children had been almost absent from the AIDS public scene.¹ In the 1980s, when the first cases appeared under the apartheid regime, the disease was seen as limited to marginal

groups, mainly white male homosexuals; the presence of the infection within the black population remained invisible and was later denied. In those days African children were on barricades and in demonstrations, heroes for one side, villains for the other one.

In the 1990s, as the epidemic became more and more worrying in the townships and former homelands, as national HIV prevalence rates increased from less than 1 percent to more than 20 percent, sexually active adults became the target of prevention and information programs. This fact is even more remarkable if one considers all the statistical data that were coming from antenatal clinics, with blood samples being taken from pregnant mothers through routine tests. During those years children seemed to be completely absent from the public sphere in which AIDS was passionately discussed. Only in 1998–99 did they enter it through the question of the prevention of vertical transmission, as evidence began to appear on the efficacy of antiretroviral drugs in clinical trials from the Third World. From then on, childhood became a major issue, restructuring the field of the politics of AIDS.

However, it did not do so through a monolithic perspective. In fact, three distinct figures progressively emerged: suffering children, abused babies, and AIDS orphans. All three are associated with the images of innocence and vulnerability that have characterized the compassionate construction of childhood in contemporary societies² – innocence, because children have not been tarnished by the corruption of the social world, and vulnerability, which calls for the protection of society. In the case of AIDS, the association of the infection with guilt and impurity on the one hand, with risk and danger on the other,³ reinforces by contrast the dual representation of innocence and vulnerability of children in the context of the epidemic: when adults are to blame, children are to be cared for.

These images raise sympathy in national as well as in international audiences. However, they remain ambiguous in five distinct but convergent ways: 1) They essentialize categories without allowing the understanding of their historical meaning. 2) They evade the social aspects of these conditions, which are only considered from an emotional perspective. 3) They talk of the innocence of children to reinforce the stigma on guilty and irresponsible parents. 4) They express their vulnerability to avoid discussion about the underlying unequal distribution of the disease. 5) And whatever compassion they may arouse, they are never very far from producing reprobatation. In the end, these representations tell us less about children than about the moral economy of contemporary societies.

My purpose here is thus to apprehend the “cultural politics of childhood”⁴ in post-apartheid South Africa and, more specifically, to understand the

moral grounds of such politics. My method combines an analysis of the images of childhood with the ethnography of children's experience. It is based on a systematic study of the South African press around AIDS issues between 1994 and 2004, and on interviews with families living with HIV in two townships, Soweto and Alexandra, and two former homelands, Lebowa and Gazankulu, from 2002 to 2004. I employ a constructionist approach, denaturalizing and historicizing representations, with a realistic perspective, making sense of social issues as well as everyday life.⁵ Children have become arguments in the public making of causes in the field of AIDS activism, but they are also subjects confronted by the inequalities and violence of South African society.

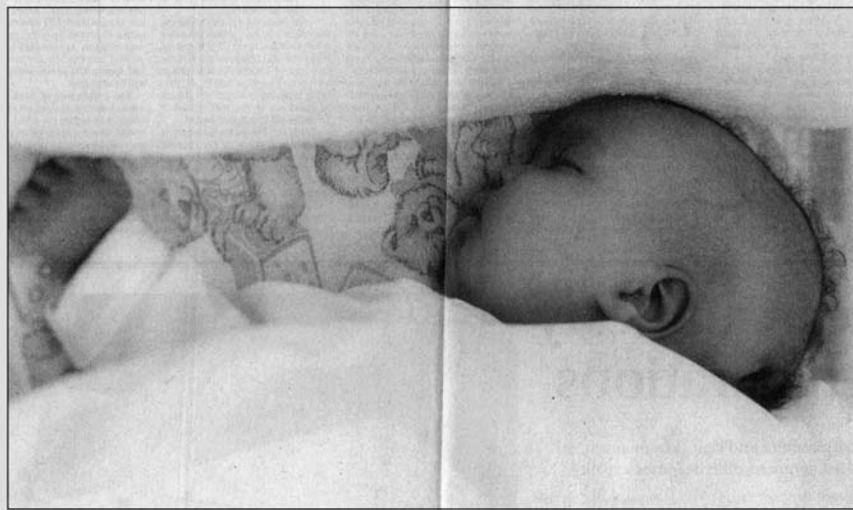
Before going further in presenting the results of this research, I want to avoid a misunderstanding. Criticizing the common rhetoric of childhood, revealing the way images are shaped and used in the debate, and in the end showing how moral issues around children correspond to a social construct do not signify adopting a relativistic perspective on the tragedies that children experience as sick, abused, or orphaned. The dozens of biographies I have collected in my fieldwork have indeed convinced me of the reality of these tragic facts. I therefore believe that constructionism, when informed by empirical work, is not contradictory to realism. In fact I would assert that it can be seen as a form of hyperrealism. Demonstrating how facts are constructed is only getting a little deeper into their reality.

SUFFERING CHILDREN

In early 1999 a series of headlines stigmatizing the government's policy on AIDS ran on the front page of most South African newspapers. They all referred to the same issue: "The High Cost of Living Babies," as the *Weekly Mail & Guardian* put it on 14 May of that year. At that time the estimation of HIV-infected persons was close to five million, including almost 100,000 children.⁶ The first results of a clinical trial conducted in Thailand had just established that an antiretroviral drug, AZT, given to the mother and the child at the moment of delivery and a few hours after birth, could reduce the rate of maternal transmission of HIV by half: 10 per cent of children were infected instead of 20 per cent. A second clinical trial that included a South African site, the Soweto Baragwanath Hospital, was on its way, and its coordinator was declaring to the press that she had every reason to be optimistic about the positive effects of the protocol. She even went as far as to criticize the minister of health for being too slow in implementing the programs. Within a few months, it became routine for AIDS activists to

Leave science to the scientists, Mr Mbeki

Consensus on the cause of Aids cannot be achieved by political negotiation – science doesn't work that way



4.2 “Eight-month-old abandoned girl in an hospice.” *Sunday Independent* (South Africa), 25 June 2000.

accuse the government of “genocide,” referring to the deaths of thousands of children that supposedly might have been avoided by the wonder drug.

Things, however, were not so simple. International specialists still seemed to hesitate on the recommendation to promote the drug. Certainly the protocol to prevent mother-to-child transmission had been proved effective in rich countries, but simplified versions used in the developing world were still to be tested in “real conditions.” Generalized breast-feeding might ruin the positive results obtained with drugs during delivery; long-term side effects or viral resistances were unknown.⁷ Simultaneously, the World Bank as well as bilateral agencies were asking for more clinical trials: the economic and organizational feasibility of national programs to reduce maternal transmission had to be evaluated. The World Health Organization was even suggesting that condom promotion was more “cost effective” than any other means of prevention.⁸ In South Africa, nevertheless, nothing was heard of these messages of caution. Doctors as well as AIDS activists were immediately convinced that the “magic bullet”⁹ against transmission to children had been discovered. If this was the case, why did the government not implement it?

During the years that followed, suffering children became the main argument opposed to the national policy. Newspapers ran polemic headlines such as "Suffer the little children," "Babies too poor to live," "SA's AIDS babies tragedy grows."¹⁰ Press articles displayed terrible statistics, with epidemiologists calculating that 18,000 lives could be saved each year by the prevention program and economists calculating that it would cost \$50 for each saved life. Images of infants were shown, sometimes crying in hospital cribs, sometimes surrounded by technical devices like drip infusions and oxygen masks. A paper by three prestigious academics refuting the president's arguments was illustrated by a photograph of a sleeping baby, said to be an "eight-month-old abandoned girl with AIDS." The picture was reproduced a few days later for the opening of the Thirteenth Conference on AIDS with the following caption: "Innocent victim: This infant has AIDS and, when old enough to understand, will have to be prepared to accept the terrible truth about the future."¹¹ Clearly, the innocence of children was opposed to the blame upon adults; "sexual promiscuity" had become the leitmotiv of discourses on AIDS in Africa.¹² Activists took the case to court, asking the mother of an infected child to be the complainant against the minister of health.¹³ On 14 December 2001 the Pretoria High Court ordered the government to implement national programs to prevent mother-to-child transmission and thus spare the lives of thousands of children by reducing their exposure to the virus.¹⁴ The state had the obligation to "protect" its most "vulnerable" citizens.

The emphasis placed exclusively on children as "innocent" and "vulnerable" victims, the counterpart to the adult world represented as guilty (the parents) and responsible (the government), has practical consequences. At a collective level, the idea of preventing children's infection was never discussed along with the possibility of treating the mother. On the contrary, it appeared that using short-course antiretroviral drugs, if effective in reducing the risk of transmission to the child, implied a high risk of resistance to most common antiretroviral drugs for the mother. Saving children thus meant endangering women: this fact was long neglected and obscured. At the individual level, in hospital wards, the contrast is sharp between the compassion generally shown toward babies and the indifference, sometimes the cruelty, demonstrated toward mothers, who are often rebuked, even insulted, when they deliver. As they give birth, women are often blamed for the pleasure they were supposed to have had while conceiving the baby.

This disequilibrium in the relative value of sufferings and lives is embedded in the long history of mother and child health. Even when international institutions started to show interest in maternal mortality and to implement

Suffer, little children

A relative of the nine-month-old Louisvale baby who was raped comforts Gertruida Rens and her granddaughter Valencia. It was to Rens's home that the baby's grandmother brought the child the night she was assaulted. In the weak light of Rens's lounge the women discovered a bleeding, gaping wound as they parted the infant's legs

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4.3 Cover story of the “nine months old baby who was raped.” *Weekly Mail & Guardian* (South Africa), 9 November 2001.

programs to reduce it, half a century after having “discovered” infant mortality (a fact quite significant in itself), the main argument given to justify the new policy was that saving a mother would save her children.¹⁵ Indeed, the moral economy of AIDS is inscribed in a continuum.

ABUSED BABIES

In no other configuration is the innocence of children so starkly juxtaposed with blame upon adults as it is in the case of sexual abuse. On 9 November 2001, the tragedy of a nine-month-old infant raped by residents of her township near Cape Town provoked national shock. Photos of the traumatized family were avidly displayed by the press: in the most pathetic one, two women cover their faces with their hands, supposedly because they are crying but more probably because they are hiding themselves from the shame of the publicity given to the story. The caption is: “A relative of the

nine-month old Louisvale baby who was raped comforts Gertruida Rens and her granddaughter Valencia. It was to Rens' home that the baby's grandmother brought the child the night she was assaulted. In the weak light of Rens' lounge the women discovered a bleeding, gaping wound as they parted the infant's legs."¹⁶ The intolerable aspect of the case was thus turned into sensationalism.

Soon after the rape, six men were arrested in the neighbourhood, all drunk: two were suspected of being the perpetrators and the other four were considered as accomplices. The two suspects were a family friend and the child's own great-grandfather. The event opened a debate on the moral state of the South African society. In the following months many other cases of infant and child rapes were published. Each time, journalists would rival each other in providing horrific details about the act and its physical consequences.¹⁷ The shocking realism of these descriptions, however, contributed to overshadowing the mundane reality of sexual abuses.

In South Africa in recent years, rape has become a major concern. This is not to say that it did not exist before, but it was very seldom reported, especially in the townships and the homelands. Under the apartheid regime, women's and children's rights were not an issue, all the more so among non-whites. In the context of the AIDS epidemic and under the pressure of feminist and human rights organizations, the issue of sexual violence has become crucial. Several studies have shown it to be particularly frequent: a survey conducted by the Health Department reveals that 7 per cent of women declare having been abused, this figure being higher in younger women; two separate studies indicate that between 1.2 per cent and 1.6 per cent of women have been raped before the age of fifteen.¹⁸

This delicate topic has become extremely controversial. By calling South Africa a "nation of rapists" in an article published by the *Weekly Mail & Guardian* on 7 April 2000, the well-known journalist Charlene Smith, who was herself a rape victim and denounced it publicly, gave rise to a virulent polemic by Thabo Mbeki, who accused her of racism.¹⁹ In fact, although she had not mentioned racial features in her paper, she explicitly referred to the "African culture and tradition," and it was clear for any reader that she was talking about black men.

The theme is a recurrent one in South African history. As early as the first decade of the twentieth century, stories had been reported in the press of African men abusing white women. Commentary insisted on the uncontrolled passions and unrestrained sexuality that came to be qualified as "black peril," a notion occasionally repeated and scientifically discussed by medical doctors, social psychologists, and cultural anthropologists.²⁰

Whether naturalized (as an essential quality of the savages) or culturalized (in terms of traditional values and beliefs), sexual violence appeared as characteristic of African young men, even if, in the case of the nine-month-old girl, the perpetrators of the rape were old Coloured men. The fact that this supposed hypersexuality could turn into child abuse was simply interpreted in terms of a radicalization of behaviours already beyond norms and was finally inscribed in a larger frame of barbarity.

The process of reification of sexual violence and its qualification in terms of dehumanization of criminals thus avoids any historical analysis of the genealogy of violence in South African society. One should certainly not underestimate the previous existence of violence in traditional nations whether in the form of ethnic wars or internal conflicts. However, the imposition of power and domination by the brutalization of society became systematic under the white authority, and did so long before the official beginning of the regime of legalized racism in 1948.²¹ In the second half of the twentieth century, apartheid became the normal mode of government. Racial segregation on a territorial and thus political basis implied that the monopoly of legitimate violence by the state changed in the townships and homelands as delegation of authority was given to local African administrators who were often corrupted and discredited. In parallel, the economic needs of industrial capitalism provoked massive migrations of fathers and also mothers toward the mines and the cities, leaving children without parental authority. During the 1980s, adolescents and youths became involved in riots and demonstrations against the apartheid regime, while repression became more and more brutal on the black population. Although political violence does not necessarily have psychological effects on children,²² their socialization in a violent context displaces what is considered by them as normal and induces reproduction of experienced interactions. Naturalization and culturalization thus induce a dehistoricization and therefore a depoliticization of sexual violence. What is left is an incomprehensible representation of inhuman African men making easy prey of innocent and vulnerable children.

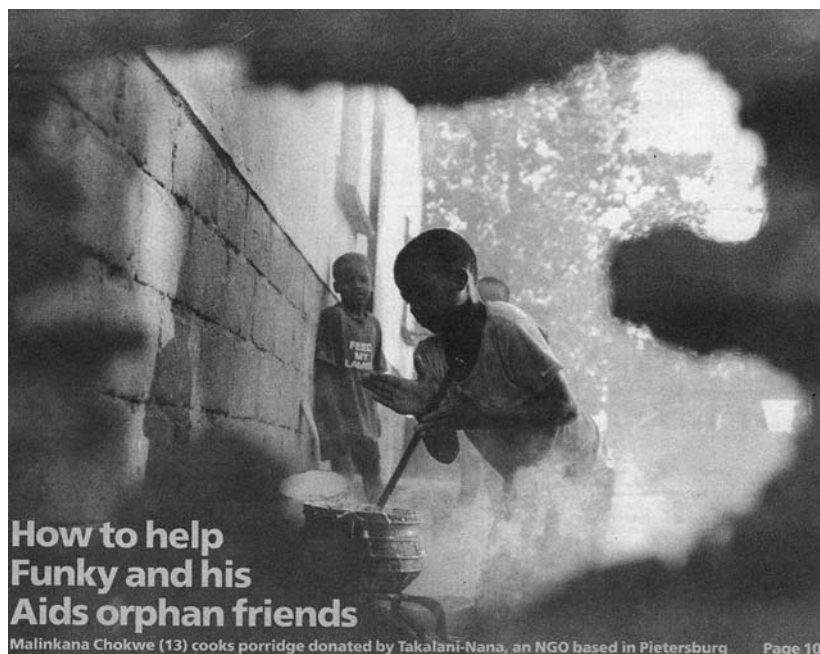
AIDS ORPHANS

At the climax of the controversy about the prevention of mother-to-child transmission, the government spokesman, Parks Mankahlana, commented on the burden it would be for South African society if the program were to be implemented, to have more and more children left without parents. This terrible reasoning was hardly evoked in the public debate, maybe because

of the intolerable implications it had even for discussions. However, as years passed, it became increasingly obvious, as it is in many countries of the continent, that orphans have become a major issue for social policies. With around six millions adults infected and, for the majority of them, a low probability of receiving effective treatments, the official projections of the number of children left without one or both parents are catastrophic. According to the principal demographic research centre of the country, it is estimated that by 2015 this number could reach almost two million maternal orphans.²³ Statistics are extremely difficult to interpret: definitions of orphans vary from one study to the other; hypotheses for projections are often hazardous; logically, results are somewhat contradictory.²⁴ However, most share the intention to bring a tragic picture of the situation constructed around the figure of the “AIDS orphan.”

This new image gives a terrible picture of South Africa’s future – even more so if one considers the frequent association of “orphanhood” with the representations of “unsocialized, uneducated, in many cases unloved and struggling to adulthood.”²⁵ Orphans may become street children, delinquents, criminals, and even soldiers for African conflicts. They are thus a potential peril for national as well as international security. The frontier is thin between the child without parents arousing compassion and the adolescent inclined to deviance considered as an object of repression.

Beyond this moral instability of the category of “AIDS orphan,” the question must be raised of its empirical validity. First, many orphans have lost their parents from other causes of death than AIDS: the only national survey on the subject, known as the Nelson Mandela study, revealed a rate of 3 per cent for maternal orphans and 8.4 per cent for paternal orphans. Considering that HIV affects more women than men, this statistic implies that most children who have lost their father, and probably a part of those who have lost their mother, have become orphans because of violent death – in particular homicide – and other medical causes.²⁶ Secondly, being raised without one’s parents is not a new reality. The experience of family separation was quite common under the apartheid regime; in my interviews, many men and women say that they have been raised by a grandmother or other relatives, because of their parents’ absence or death. In a study recently conducted among youths, one-third declared that they had never lived with their father, and one-third had spent less than half of their childhood with their mother. Political violence as well as economic exploitation were the two main factors of these family disruptions.²⁷ It is thus clear that the category of AIDS orphans on which compassionate discourse is expressed remains problematic, as it seems to elude both orphanhood’s other causes and its historical background.



4.4 “Funky and his AIDS orphan friends.” Photograph: Nadine Hutton, *Weekly Mail & Guardian* (South Africa), 18 January 2002.

Besides, the description of the consequences of the phenomenon hardly corresponds to what can actually be observed. The practice of fosterage, inherited from past situations just evoked, keeps functioning in most families. Even children who have lost both parents – or who have lost one and been left by the other – are generally living with relatives, most often a grandmother. They are not the anomic street-children often feared. As a group of experts has written, these orphans are more in “need of cash” than in need of care.²⁸ Under the South African welfare state, foster-care grants have been developed in order to face the material dimension of the affliction. In fact, when children are eligible for this grant, they become an important source of revenue for their relatives, often awakening forgotten family sentiments and interests. In several cases I studied, the grant had caused problems among relatives, as it provoked competition for scarce economic resources. Much higher than the average salary of a rural worker, it was greatly appreciated and appeared to be a good incentive for the insertion of orphans in their own family.

Thus the question of orphans is much more complex and ambiguous than what international reports consensually and pathetically assert. It contains

elements of compassion and fear, of history and oblivion. Significantly, the unanimous sympathy that the abandoned children provoke has its limits: when an orphanage was created in the suburbs of Durban in 2001, the neighbours sent an urgent application to the city council demanding that the children be removed since they “devalued” the white local residents’ properties. “They are from the underprivileged black communities and they should go back there,” the residents declared.²⁹ The moral economy of orphanhood cannot be understood if disconnected from the political economy of the post-apartheid and its persistent racial segregation and inequality.

NOTES

- 1 For a history of AIDS in South Africa, see Fassin, *When Bodies Remember*.
- 2 Among many studies on the subject, see Cunningham, *The Children of the Poor*.
- 3 On these issues, see Fassin, “Le domaine privé de la santé publique” and “Idéologie, pouvoir et maladie.”
- 4 To quote Scheper-Hughes and Sargent’s *Small Wars*.
- 5 A discussion of the necessary combination of both points of view is presented in Fassin, “The Politics of Life: Beyond the Anthropology of Health.”
- 6 For an early view of AIDS among children, see Preble, “Impact of HIV/AIDS on African Children.”
- 7 See, for instance, Gibb and Tess, “Intervention to Reduce Mother-to-Child Transmission of HIV Infection.”
- 8 See, in particular, Creese et al., “Cost-Effectiveness of HIV/Aids Interventions in Africa.”
- 9 To use Brandt’s expression about syphilis in *No Magic Bullet*.
- 10 *Saturday Star* (South Africa), 30 January 1999; *Weekly Mail & Guardian* (South Africa), 16 October 1998; *The Citizen* (South Africa), 10 January 2001.
- 11 *Sunday Independent* (South Africa), 25 June 2000, and *Saturday Star* (South Africa), 8 July 2000.
- 12 See Packard and Epstein, “Medical Research on AIDS in Africa.”
- 13 *Weekly Mail & Guardian* (South Africa), 19 October 2001.
- 14 See Annas, “The Right to Health and the Nevirapine Case in South Africa.”
- 15 See Herz and Measham, *Programme pour la maternité sans danger*.
- 16 *Weekly Mail & Guardian* (South Africa), 9 November 2001.
- 17 *Star* (South Africa), 9 September 2002.
- 18 See Jewkes and Abrahams, “The Epidemiology of Rape and Sexual Coercion in South Africa.”
- 19 *Sunday Times* (South Africa), 9 July 2000, and *City Press* (South Africa), 8 October 2000.

- 20 Illustrations can be found in Butchart, *The Anatomy of Power*.
- 21 Details are given in Thompson, *The History of South Africa*.
- 22 As demonstrated by Daves, "The Effects of Political Violence on Children."
- 23 See Johnson and Dorrington, *The Impact of AIDS on Orphanhood in South Africa*.
- 24 See Bray, *Predicting the Social Consequences of Orphanhood in South Africa*.
- 25 See Barnett and Whiteside, *AIDS in the Twenty-First Century: Disease and Globalization*.
- 26 See Shisana and Simbayi, *Nelson Mandela/HSRC Study of HIV/AIDS*.
- 27 See Reynolds, "The Ground of All Making: State Violence, the Family and Political Activists."
- 28 See Meintjes et al., *Children in Need of Care or in Need of Cash?*
- 29 *Daily News*, 23 August 2001.

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Cure and the Contempt of Goodwill: Reason and Feeling in Disability Narratives, 1850–1950

LAURIE BLOCK

Walking in public spaces with my daughter always prompted certain encounters that, after a while, we could anticipate. These incidents arose because of her visible disability, a “difference” that generated a loss of the anonymity typically possessed by families or individuals moving about. Strangers would come up to us and say things like, “Well, she’s doing just fine, isn’t she?” Or, less secure and with elevated rising tones near the question mark, “She will be okay, won’t she?” Children’s queries were often blunt and usually directed to her: “What’s wrong with you?” – said with genuine curiosity but sometimes with aggression, revulsion, or fear, a range heard in remarks by adults too. At various ages she used a wheelchair, a walker, braces with crutches, and was generally quite an alert, lively, talker.

Being a consistent object of public notice with the loss of privacy involved takes some getting used to. Now in her twenties, my daughter reports that the questions continue, but with different emphases. The askers, then as now, seem to have little awareness that their articulations are usually unwelcome and hardly unique. They don’t recognize their queries to be reflections of their own needs rather than my daughter’s, though holding a door might indeed be useful and politely acknowledged with thanks.

Did the askers, when she was a child, want to know if she was ill? Doing well in school? In need of surgery, health insurance? Her actual life was not the real subject. Why did strangers feel the need to so publicly address her existential condition? And why was it her job or ours to make people feel confident that the world or chance was kind, that risk could be faced confidently, lived with comfortably, that she and we did not suffer constantly?

My daughter, by age ten, had divided the public into performance categories. There were the need-to-smilers, high-fivers, and little-hand-wavers,

the downright rude, the over-helpers, and the cool people with whom she felt safe to be herself. This was more than a taxonomy of etiquette or tone. Integrating these negotiations into her own world view became part of her (and as relatives, our) development toward independent adulthood as a disabled woman. At the same time, they reflect long historical traditions.

Prevailing cultural assumptions about life lived with a chronic, incurable physiological impairment that alters typical human functionality have not generally been brought to the surface in the way that similar assumptions about race, gender, or sexual preference have. But long-standing public expressions about the experience of people with various disabilities – in gestures, manners, verbal or visual rhetoric, institutional practice and structures – have shaped how the able think about the disabled, how the disabled individual's identity develops from childhood on, and how the disabled think about the able. All this is not the same as the individual's experience of his or her impairment.

In this article I consider three “fables” about disability that often focus on children, and the relationship of these fables to an early twentieth-century group of individuals with polio at Warm Springs, Georgia. These young men and women clearly articulated the importance of differentiating between physiological impairment and the social and cultural forces that generated forms of discrimination that functionally disabled their economic productivity and cultural opportunities as citizens. Their attempt to identify cultural and environmental factors causing disablement was barely heard, though these same issues would become central to much later disability rights legislation and social transformation. This Warm Springs grassroots activist group flourished as manifesto writers for only four years, but they had goals similar to those that Susan Schweik ascribes to later twentieth-century disability activists who struggled to develop “narrative alternatives to and repudiations of the dynamics of mendicancy.”¹ The contemporary activists participate in what Schweik calls a “radical forgetting of the figure of the beggar”² in disability history, but for the earlier group, that was almost impossible – they lived with it up close and personal. To understand “the dynamics of mendicancy” in disability identity development for the individual across generations, I look at how three culturally dominant narratives about adults and children with disabilities – the three fables – became intertwined with each other in the decades between 1930 and 1950.

Affliction narratives, menacing burden narratives, and cure narratives all come into popular culture accompanied by visual illustrations, and this visual storytelling is critical to their enduring power. Each draws from popular culture trends burgeoning in a distinct chronological period, but all

have taproots older than the early nineteenth century. Affliction narratives are plentiful throughout Christian literature and iconography where suffering is a central subject. Menacing burden narratives rework myths, legends, folk traditions, and (some might argue) religious traditions about demons and evil. Cure narratives draw upon spiritual tales, miraculous healing stories, and tales in which people protect themselves against demons. All three narratives concern themselves with impaired material bodies, matters of economic dependence and independence, and redemption, although each does so with different emphases.

Once established, none of the forms entirely disappeared, though different periods invested in one or another more emphatically. Nowadays, when considering the needs or prospects of children and adults with disabilities as individuals or as a demographic category, people commonly employ these storied modes in their everyday thinking, but rarely do they recognize the narratives' embedded presence that functions to shape convictions of belief. Though my focus is American, each of the forms described here has migrated across international borders.

All three narratives instruct, and all three describe moral universes. They overtly or covertly prescribe the responsibilities and obligations the disabled have to the able and vice versa, often while telling a story about a particular, if idealized, child – a child who sometimes grows to adulthood, sometimes not. Each has proven sticking power. They move across media from print pages to film screens. Sometimes they hop from one “diagnostic” category to another – from blind to “crippled” in the nineteenth century, from polio victim to autistic in the twentieth. Each describes a relationship to the experience of suffering, real or imagined. All have been available in a broad range of forms – in children's literature, news reports, silent and sound films, disease-of-the-week TV soap operas, advertisements for pharmaceuticals, radio and TV public service announcements, memoirs, and philanthropic fundraising for diseases. Despite the profound late twentieth-century changes in legal and institutional practices that significantly transformed social-cultural opportunities for people with disabilities, these older, pre-disability-rights era narratives retain a powerful grip on us all, able and disabled.

THE AFFLICTION NARRATIVE³

From 1820 to 1870, itinerant peddlers selling Bibles also distributed Protestant pedagogical tract literature and chapbooks widely read in American Protestant Sunday Schools. Published and distributed by the American

Sunday School Union and other religious publishers, these were among the first mass-market texts in the United States and were produced to help children learn how to live a virtuous life. They were also used to teach basic literacy to immigrants and African American adults. The volumes were compilations of short stories, and in them tales about blind, deaf, “idiot,” and invalid children and insane adults sat side by side with stories about the dangers of drinking and worse vices, the importance of good work habits and cleanliness, and the difficulties that feelings of envy and avarice produce.

Affliction tales focus primarily on poor children, though sometimes the middle-class child receives significant attention. Occasionally someone with sensory or mobility impairment might even be wealthy. Both boys and girls are main characters; supporting roles go to parents, family friends, siblings, and the crucial “friendly visitors” (mostly women) who periodically arrive to help a lame or feeble-minded child learn to dress or feed himself or read – life skills with economic value to all involved. Some “visitors” perform nursing care, but more often they teach a craft like knitting or basket-weaving and dispense spiritual advice. When professionals appear, they are associated with death: the minister commits souls to Christ; the doctor pronounces that little can be done, or perhaps recommends a special school for a deaf or blind child, even one who is “feeble-minded.” Occasionally an operation in a hospital is performed.

The range of interventions available to these “incurables” is not vast, education being always the most powerful tool. Further, learning independent living skills such as self-care, improved mobility, and literacy is tacitly recognized as having value, as it means that another family member becomes free to work more hours as a weaver, fisherman, or cook. The caregiving required for someone who cannot do these basic life tasks is portrayed as time consuming, even if valued. The activities that the friendly visitors provide are not unlike the services described today in individual education plans (IEP).⁴ Their efforts sometimes read like a basic early childhood occupational or physical therapy program done nowadays with developmentally delayed youngsters. The unnamed woman who patiently teaches “Poor Matt” in nine lessons to plait straw also gives him a penny “to test his memory” when she returns.⁵ She watches closely “to see how much strength he possessed” in his hands. “His movements were weak and uncertain,” and at first he gets weary, but as his skills improve, he succeeds beyond expectation, and his family begins “to hope that he might one day be able to earn a little money by this simple art, and to relieve them of part of the burden of maintaining him.”

These early pedagogical affliction narratives are set deep within a Protestant Christian theological universe where suffering is assumed to be consoled

by faith in Jesus, a consolation available to both sufferers and witnesses. Matt's visitor's reward for her service is "joy." Much is made in these stories of the importance of Christ's example for able and disabled: both his miraculous benevolence and his physical suffering are vehicles for earthly redemption.

Mary Ellis's tale⁶ is typical of the more overtly theological affliction narrative. Mary has a significant curvature of the spine, but her pain is social. The narrator explains how she admires the agility of the other girls but then feels sad and suffers bouts of depressing envy. Her mother advises her to see how her own efforts might be blessed by the grace of God, "that even little children are not without influence in the world ... God treats his children as these require ... God has rightly withheld some earthly comforts from you, yet this need not, of necessity, make your future life miserable. There are many blessings given abundantly to you, for which you should render the grateful thanks of a cheerful temper, willingly striving to do all the good which it is in your power to do." Mary's mother explains how "she feels her daughter's trials" as she is so close to them. Mary takes the talk to heart and "begins to figure out ways to help her sister be content." She helps her mother with chores and talks with God, and her social life does indeed improve. The story assures its readers that Mary will surely find comfort and a place in heaven.⁷

Despite their Christian didactic character, the bulk of the stories teach secular precepts as well as spiritual ones: 1) The cause of the incurable's condition is natural and lies within an individual's material physiology; it is organic and not divinely willed or fixed.⁸ 2) The natural (organic-material) realm is governed by its own laws, though indeed it is created by God, and it is something humans must come to terms with. Disabled persons (like Mary) must accept uncomplainingly that their condition is God's will, though having a natural cause. 3) An unpleasant behaviour or appearance of the incurable individual must be accommodated generously by the able-bodied. 4) Benevolence to the disabled – an act of kindness or monetary donation – earns the able a benefit, grace, a chit raising him or her closer to God, or, at least approval from loved ones who recognize the good deed done. This does not require identifying or empathizing with the disabled; the narratives emphasize *sympathy*, a more hierarchal relationship.⁹ 5) The disabled individuals must put up with steady streams of rudeness and wrong assumptions; they must display patience and benevolence to the able. This submission, often hard won, models to the able how God's grace can empower. Invalids of cheery demeanour and good spirit become living symbols of God's benevolence. 6) *Use What You Have*¹⁰ was one of the

most commonly distributed tracts, and its title insists on how the afflicted ought to develop skills, of course in order to be able to independently earn their daily bread. These stories assume that many of the children in them will grow to adulthood and need a livelihood, a skill such as basket-weaving or broom-making or reading, writing, accounting. Almost no attention is paid to how the built or social environment might limit the disabled person's possibilities, though occasionally tools – assistive technologies – make reading or eating easier. And usually, if a child is severely cognitively or physically impaired, he or she dies by the story's end. Heaven is the reward.

Many of these tract society stories are illustrated. Idealized children are pictured indoors and out, in beds looking forlornly at windows; sometimes they are pushed in a wheelbarrow outdoors as they play with able-bodied peers (figure 5.1). In other stories the lame or hunchback children endure unwanted attention or are pictured isolated from a group; sometimes they work at making baskets or at a clerk's table. These universalized faces, when death is inevitable, turn upwards, cherub style. The pictures enliven the story and reinforce pious behaviour expectations.¹¹

Central to all Protestant affliction narratives was a theological ordering of roles and responsibilities: if God's will is accepted, his loving kindness embraced, individuals find ease, peace, comfort in the community and in heaven. Everyone, including the most deformed or debilitated, the friendly visitor and the sibling helper, has a useful, however meagre, role to play in the community's well-being. All those who belong to the congregation of Protestants are members of God's universe and deserve, by extension, recognition of their humanity. For able and disabled alike, accepting Christ is the first necessity for entering this community; together with God they can perfect their individual and community existence.

In the historical period when these narratives were most popular, diagnoses were relatively simple. The named conditions are few, the terms general – deaf, blind, lame, hunchbacked, crazy, “not able to think thoughts” and therefore idiot, insane. *Diagnosis* describes and defines the patterns of a specific physiological condition. But *prognosis* is the story of how a condition will unfold over time. In affliction narratives, the distance between diagnosis and prognosis is minimal. There is little that can be done for the material body's impairment, medical interventions are rare, but incurability is acceptable; so too is death. And the “visitor's” spiritually motivated educational interventions do improve muscle strength, eye-hand coordination, communication capacity, matters critical to all rehabilitation regimes even now. But in an affliction story the concept of time includes both this life and the hereafter:



5.1 Illustration from nineteenth-century tract story.

the reversal of fortune is not the moment when someone becomes ill or has an accident but is rather the child's spiritual crisis, which is resolved when God's will or love is accepted and suffering is transformed into something enduring. The behavioural changes that follow then promote "spiritual healing."

The affliction narrative's transformative encounters function as symbolic emblems of a moral good available to all, able or disabled. Love of God or God's grace provides the children, through interdependent communion with the divine, the strength and resilience they need. Impairments, and those who have them, function to facilitate acknowledgment of the binding connection between the sacred and secular realms. The individual's impairment

is physiological, but the suffering encountered is relieved by divine experience, pious practice of beliefs. Both God and the community – able and disabled alike – witnessed and participated in these narratives. The illustrated pages in the stories were vehicles for remembering, but they functioned almost like icons. Viewers engaging them had an encounter not simply with a representation but also with the presence of the divine in the world. Both visual and verbal narratives embodied the sacred relations of the community for those who read and believed with conviction the world view the stories conveyed.

As commercial literature for women and children became more available and popular,¹² affliction narratives were secularized. The stories grew more sentimental, but their logic of spiritual acceptance and submission, the importance of benevolence, and the pressure to become useful and not express anger persisted. The crisis experienced by characters with incurable impairments, children or adults, continued to be internal, an individual's responsibility. The agents of change remained human helpers facilitating spiritual dialogues. Even when these stories left their religious origins and professionals began arriving with real tools that did indeed change bodies, the genre retained its redemptive drive and prescriptive behaviours, especially for its disabled characters.

Sentimental secular commercial affliction stories after 1870 retained a plain-spoken directness about physical infirmity and death – discomfort, foul smells, unsightly sores, unrelieved pain – that would stun contemporary readers of children's books. And it is imaginable that as late as 1900, Protestant Sunday school libraries might still proffer *The Lame Girl*, *Little Humpy*, or *Patience*.¹³ But by the first decades of the twentieth century, patrons attending the new Carnegie public libraries might prefer Dickens, or *The Secret Garden* and *Pollyanna*.¹⁴ At the same time, these sentimental fictions were migrating to new media, and on the stage and in film the action became more melodramatic, the language euphemistic. The books-to-film genre included works like Bulwer Lytton's *Last Days of Pompeii* (1912), with Nadia, the blind servant girl. But soon these affliction narratives were reworked into contemporary modern life – Charlie Chaplin's *City Lights* (1931). On the big screen they acquired an expanded audience, one where all ages, both genders, rural and urban folk across economic class, ethnicity, race, and religion participated.

THE MENACING BURDEN NARRATIVE

An ordered calm prevails in affliction narratives as faith, pious practice, and virtuous behaviour provide characters with a spiritual means to overcome

impotence in the face of uncertainty, physiological pain, constancy of grief, and death. But these demands upon behaviour are so rigid and predictable that modern readers may find them suffocating. Still, these stories allow for individual plasticity. Characters change themselves, and there is a mid-nineteenth-century margin of Protestant community inclusiveness: membership is available to all believers. The result is a vision of a kinder world than the one offered by a different story structure developing during roughly the same period. Menacing burden narratives undo the pious ties that bind and unleash unpredictable terrors and chaos into everyday life. The characters in these stories struggle to reduce the causes of terror through acts that involve submission of their wills, sacrifice, renunciation, even their own deaths (often inevitable). However, such actions are not motivated by faith, God, or the quest for a sacred place in the hereafter. Though there are supernatural forces in some of these stories, they are almost always maleficent. Evil in these tales is inherent; it lives in the material, living, and breathing world.

Characters in this literature are notably prone to revenge, rage, and obsessions of all kinds. They move forward through their lives on a determined, fixed trajectory. The plots involve battles between beauties and beasts, human creatures consumed by compulsion and vice, maimed bodies and minds. Impaired characters play both heroic and villainous roles, but the reversals of fortune are not framed as abstract emblems of virtue or vice. In affliction narratives, characters undergo symbolic change from one state (ignorance) to another (enlightenment through being saved). In menacing burden narratives, characters are fixed; each is symbolic of either good or evil, virtue or vice. Crime, sex, drugs, drink, revenge, kidnapping, murder, and violence drive these plots. One finds them in works like Poe's *Hopfrog* (1850) in which a dwarf seizes the opportunity to viciously avenge his mistreatment by an equally vile royal court; in Wilkie Collins's *The Moonstone* (1868), a murder and theft tale that turns on a case of epilepsy; in R.L. Stevenson's *Dr. Jekyll and Mr. Hyde* (1886), a tale of irreducible evil within; and in Conan Doyle's *Hound of the Baskervilles* (serialized in 1901–02), in which Dr Watson describes the visual marks of a criminal who “thrust out an evil yellow face, a terrible animal face, all seamed and scored with vile passions.”

These stories about disfigured and defective incurables who burden society as criminals or victims have old roots. But this one is bifurcated: one shoot drives deep into tales of the marvellous, myths and legends where werewolves, half-animal, half-human creatures, and demons live alongside tricksters and the Brothers Grimm's grotesques, and another shoot locates inherent evil in the “real” world. In the nineteenth century this aim was

entwined with the global enterprise of morphological categorization of the natural world, work popular among amateurs and professionals engaged in the life sciences.¹⁵ Its environments, tools, and ambitions – laboratories, scientists, statistics, criminologists, cameras, microscopes, the ideas of Lombroso, Malthus, Galton, Vidocq – were incorporated by the creators of gothic sensational works for entertainment. By the century's end, Darwin's theories of evolution would take on a life of their own across the cultural landscape and provide additional conceptual and aesthetic fuel.

Like sentimental commercial affliction literature and the more realist-naturalist tradition of Dickens, these loud, thrilling, speculative novels flew off new presses that produced cheap books.¹⁶ They could be found in dime novels and newspapers, and by the early twentieth century would dominate pulp fiction in the form of detective and horror novels. Like sentimental melodramas, they also quickly migrated to the stage and early screen. The most famous examples of book-to-film transformations are Mary Shelley's *Frankenstein* and Victor Hugo's *The Hunchback of Notre Dame*. The actor Lon Chaney (1883–1930) became the period's master at portraying the cinematic rage and misery felt by the maimed and depraved. Playing “The Frog” in George Loane Tucker's *The Miracle Man* (1919), he is best remembered in *The Hunchback of Notre Dame* (1925) and *The Phantom of the Opera* (1925). In *The Penalty* (1920) he plays an amputee gangster and in *The Unknown* (1927) a carnival knife thrower, Alonzo the Armless, both of whom take a terrible revenge when rejected.

It might seem easy enough nowadays to dismiss these extreme narratives about chaotic, obsessive, and destructive behaviours let loose in society, but they seemed all too vivid to residents living in the densely populated, sometimes fetid, urban bustle of the 1890s to the 1920s, when social dangers were real and plentiful. Out and about on those streets after dark, it was not always easy to recognize, to read visually, the character of the anonymous individuals one encountered. The atypical bodies of the characters in menacing burden fictions and films were read by the audience not as individuals but as “allegories.” Carolyn Bynum describes this as a process where the “bodies [become] signs of a characteristic or a character located within.”¹⁷ The stories offer no possibility for change. Redemption or transcendence, sacred or secular, is unavailable. The tale unfolds, and the audience witnesses a descent into a damnation that occurs here on earth.

The United States in 1900 was increasingly urban, multi-ethnic, and diverse in religious belief. Modern life slowly eroded traditional Protestant, agrarian republican ways of recognizing the virtuous citizen, the “regular”

and “true” characters of one’s “place.” Village and small-town social support structures were unable to meet the needs of growing urban neighbourhoods. To cope with the issues they perceived, Progressive-era reformers fixed attention on human attributes that might function as signs of predictable developmental outcomes.¹⁸ They measured craniums, studied height and weight, and eventually tracked outcomes for preschool and kindergarten pupils. Increasingly, the dangers and threats were thought a consequence of heredity, and these features were believed to be visually identifiable and unalterable. They were not just signs of danger and violence but of the degeneracy and weakness that would produce generations of social and economic dependency. “Good environment and the introduction of a strong strain of blood does not eliminate the stigmata of hereditary degeneracy except for the particular individual,” said Dr G.C. Woodruff, superintendent of the Medical Lake, Washington, Institution for the Feeble-Minded, writing in 1908 to the state legislature in Olympia, Washington. He continued: “But the germ plasm of a defective ancestry will continue on through many generations and break forth with renewed vigor in an individual or a family when the conditions are ripe for it to manifest itself. The matter has been neglected so long and defectives have become so numerous, that how to meet the situation is now a perplexing problem. At every session of the legislature, the increasing numbers of dependents to be provided for is appalling. We have simply been trying to dam up the stream at the mouth instead of cutting off the supply at the fountainhead.”¹⁹

Bodies that could not measure up to the long-hour workweek needs of industrial labour were not simply out of luck: they were a social burden. Acute poverty and physiological impairment were deeply intertwined in a world with few safety nets. The presence of the homeless or infirm poor – from children to aged veterans – was thought to threaten national social stability. Blue and white collar workers, social scientists and the professional classes, churchgoers, newspaper reporters, and politicians all described their discomfort with the lowlife found near the docks or under bridges in Chicago, Seattle, or New York. For the poor (young or old), it became increasingly difficult to rely on extended family or church parish networks, and not much help was available. In 1915, only 25 per cent of U.S. public funds were spent on relief outside institutions like almshouses or public hospitals for the feeble-minded and the insane. Blue Cross Blue Shield, the first major health insurance program in the United States, would not arrive until 1932. Federal social welfare supports would not begin until the Social Security Act in 1935.²⁰

It was not only the homeless who contributed to the imagined decline in society's well-being. John Kellogg, a healthy lifestyle advocate and creator of cornflakes, described the deterioration he saw in American vigour and health:

The great number of men, women, and children confined in counting-rooms, stores, factories, and at various sedentary employments, is developing a deformed creature which might be termed "the sedentary man" ... This class is already many hundred thousand strong, and is growing daily, through the mad rush of young men and women from the country into the cities and towns, attracted by the unhealthful amusements and so-called advantages of city life ... What will be the condition of civilized nations four or five centuries hence, when society is entirely composed of degenerates, and when the whole lump of humanity is permeated with the leaven of physical, mental, and moral perversion?²¹

Positive progress had a negative shadow. The destructive effects of spinal tuberculosis, malnutrition-causing rickets, work accidents, untreated syphilis, and fetal alcohol exposure put tremendous pressure on children and adults trying to find work. When these conditions were brought to light, they were shocking. But if sensational melodramas fancifully flaunted an era's fears, the pragmatic solutions offered by reformers who tried to arrest the chaos and ruin generated by rapid change created gothic consequences for some people's actual lived experience.

Progressive-era reformers like Kellogg constantly fretted about bad bodies, brutish backward behaviours, darkness in the (possibly unredeemable) lower social classes. The reformers' language is confrontational, exaggerated, even inflammatory to our ears. Their concern concentrated its most intense anxiety around "bad heredity," those dysgenic physiological traits that were thought able to be passed from generation to generation. Though there were many ways to fall into social dependency, there were few ways – beyond hard work – to get out of it. Even though the working classes in 1910 might practise physical culture at the YMCA, bake an Angel Cake at a Settlement House, or eat biscuits from a box, as a group their lower physiological place and social prospects were thought to be predetermined, matters of "race" and "germ plasm." With nature, not nurture, getting most attention and decreasing faith in spiritual forces as an agent for individual change, public social sympathy waned and fuelled intense dread about our collective biological future. The famous statistician C.R. Henderson described the problem he perceived in 1899: "The supreme test of philanthropy is not found in the blind and instinctive satisfaction of a kind



5.2 Girls at Letchworth Village, 1932. Photograph by Margaret Bourke-White.

impulse, nor in the apparent comfort of dependent persons, but rather in the welfare of the community and of the future race ... We ... admit that every human being, even criminals and idiots, are members of the social body ... But we know perfectly well that there is a deadly conflict between certain current methods of philanthropy and the common welfare. The agents of charity have during more than a thousand years poisoned the fountains of human life by false theories and methods of giving.”²²

In this view, the agents of charity revered in affliction narratives had failed to sort the dross of society from the gold. They had not isolated the weak and wicked from the useful, better remainder. That was the new era’s job, as these reformers saw it. Children with good heredity could be trained toward fitness on playgrounds or sent to orthopedic hospitals. Unfit feeble-minded mothers prone to having babies out of wedlock could be sterilized. By 1900 the young “defectives” sent to special training schools arrived at custodial warehouses supported with meagre public funds, and increasingly these children graduated to the adult residential institutional facilities called “colonies” or “hospitals” that dotted rural communities, as prisons do now (figures 5.2 and 5.3).

Progressive reformers poured their faith into science and technology’s transformative power to eliminate the causes of suffering. Scientists were



5.3 These men working the rock piles all lived at the Templeton Colony of the Fernald School, Massachusetts, ca. 1900. Photographer unknown.

the instrumental agents of change. Divine assistance might be sought on Sundays, but in this twentieth-century world to be chronically misshapen, impaired, and “dependent” was a cold fate. It was to become the “useless invalid” who lived “bound” to a wheelchair, “bedridden,” a “hopeless cripple,” or “feeble-minded.” The exceptions are those who, as in *The Secret Garden* and *Pollyanna*, are cured. The least fortunate, like Lenny in Steinbeck’s *Of Mice and Men*,²³ (1937) are eliminated for their transgressions.

It was in the child’s body especially that the consequences of the material gains in twentieth-century public health would eventually become visible across the lifespan. But in this period between 1875 and 1930, the child who did not fit the picture of the hopeful prospects of “getting modern” was hardly secure. What happened in rural or urban locales to the eccentric neighbour’s child who might not be able to speak? To the girl who developed – like Mary Ellis – a curvature of the spine? How did communities

regard the blind beggar, the lame match girl, the newsboy with a tubercular hip? Articulating how the child with an incurable problem would find a livelihood as an adult and become productive in industrial urban society was increasingly difficult.

The longing for efficiency and salvation through scientific medical intervention, the aversion toward ordinary biological processes and the impaired body that is visible even in the era's advertising, the idea of an ongoing hereditary contamination of the population, all come together in an extreme way in the story in Chicago in 1915 of a doctor, Harry Haiselden, who campaigned to eliminate the unfit at birth. Haiselden's efforts have been painstakingly reconstructed by Martin Pernick in *The Black Stork*.²⁴ "Nature has blundered," reported the *Chicago Daily Tribune* on 17 November 1915. The "error" was the birth to parents named Bollingen of a baby with congenital abnormalities requiring surgery. The physician in charge, Dr Haiselden, made it known to the public that he would allow "death to be nature's means of righting its mistake"²⁵: "Dr. H.J. Haiselden, chief of the hospital staff, will allow the baby to die. He will not aid or hasten nature toward the inevitable fatality. His role is that of onlooker ... Dr. Haiselden boldly champions the right for physicians to snuff out the lives of babies born deformed or with the stigma of imbecility upon them. He not only thinks this is the right of physicians, but a duty they owe to the future. He believes in up building the race by allowing only the fit to survive."²⁶

The case was unusual in the way that a physician deliberately used the press to draw attention to his actions. Two years later, in 1917, Haiselden made and starred in a dramatic film about the need to eugenically control the population. Called *The Black Stork*, the work was repackaged in 1927 as *Are You Fit to Marry?* The Haiselden-Bollingen baby euthanasia case generated uproar. Respected Chicago reformers, medical experts, and the general public voiced opinions. A small minority – the Catholic Church hierarchy and Jane Addams among them – challenged the assumptions Haiselden proffered about the meaning of a life lived with significant impairments, though most professionals simply opposed his publicity-seeking and his declarations that many doctors commonly acted as he did. Haiselden's prognosis in the Bollingen case was that the child was "marked plainly for insanity and uselessness."²⁷ In this logic, death eliminated the menacing burden and served both the parents' and the majority population's needs.

Progressive-era medical experts and social reform commentators in these cases did not discuss how medical or nursing care might be paid for, or how individuals with significant impairments sometimes thrive better than

expected – a discussion heard in early nineteenth-century affliction narratives when education was thought an appropriate intervention. By 1900 the pragmatic interventions once available to Poor Matt had nearly disappeared. Almost no one pondered ways to ameliorate the child's mobility or learning problems, though by the 1920s the Rockefeller Foundation's investments in child development would make significant discoveries about nature and nurture, and a 1930 Hoover administration's White House Conference on Child Health and Protection would transform the agencies managing "the physically and mentally handicapped." But almost no one, until after World War II, would look at the environment and think "curb cuts" or "access to bathrooms," though blind and deaf children were guaranteed some assistance.

Then as now, the outcome for a child born with significant problems was uncertain. But with absolute confidence, Haiselden and his supporters were convinced that if allowed to grow into adulthood, children with disabling incurable conditions would experience unbearable psychic stress that would make them social outcasts unable to survive the brutal competition of modern life. No one would wish such "wasted lives" upon loved ones or friends. This is not so far from the stories told in the films of Lon Chaney. The majority of humanitarians weighing in on Haiselden's actions accepted his choice. The older belief in the mutual humanity of able and disabled in Protestant affliction narratives had faded, and in modern cities those older social networks willing to help families with significant needs in the community were unravelling with the pressures of vastly increased populations with needs.

REDEMPTION AT WARM SPRINGS: AN INTERLUDE

Let us briefly interrupt our account of narratives in order to examine a cluster of affluent polio survivors gathered in Warm Springs, Georgia, in the mid-1920s, their upbringing shaped by the affliction and menacing-burden narratives, as represented in fiction and manifested in actual social practice. The future president of the United States, Franklin Roosevelt, was one, soaking in the hot springs at a rundown spa known as the Merriweather Inn. Steeped in eugenics – positive and negative – and witness to the carnage of World War I, FDR and his companions all shared the hopes of Progressive-era moderns, only to find themselves assigned a "crippled" fate as useless invalids. It was an assignment they were unwilling to accept. Resisting and then articulating their concerns about this identity proved

difficult; yet their efforts are nonetheless important as a precedent, a source for ideas that would take almost two more generations to realize.

The “polios” (as they called themselves) in Warm Springs didn’t deny the seriousness of their health issues or the impairments to their physiology. But their most critical struggle, they claimed, involved healing sorely wounded spirits. Practically speaking, they claimed that they faced significant limits beyond their own bodily health. Wheelchairs were very heavy and could take them nowhere: curb cuts and accessible bathrooms did not exist. Nor were these tools for mobility easy to come by. The Sears & Roebuck catalogue of 1933 offered a Colson Wheelchair Model C-31-B “built to give the utmost in comfortable, economical service.”²⁸ Sears delivered the fifty-pound-plus chair to the nearest railroad depot. If you lived in a New York City walk-up apartment, and assuming you had the cash to pay for it, you likely never left home with it.

Roosevelt was four years into his recovery from polio in 1924 and already actively resisting the cultural expectations that came with his invalid status. He had not taken his mother’s classic affliction-narrative advice to accept his condition with grace. The shame she felt when she advised him to keep out of the public’s sight belonged to the Progressive era’s aesthetic distaste for impaired bodies. But the Warm Springs mineral waters and the company he found there made him feel great, and on his second trip in 1926, he brought an orthopedic surgeon, more physical therapists (a new profession), and brace-makers (another profession responding with fresh ideas). He also bought the old spa, hired managers and an architect, and threw his energy into creating an accessible, modern, scientific rehab centre.²⁹

Many Warm Springs “polios” from this period report similar experiences: they arrived feeling sceptical and improved in ways not imagined. They insisted the improvements were not simply matters of physical well-being. They consistently referred to “the spirit of Warm Springs,” describing themselves as nearly born again. A key to their sensibility was that they were no longer alone with the work of transforming a self. “Identity” is not in their vocabulary, but identity transformation is the process they describe. Often financially privileged and educated, these young people discovered that the opportunity to talk openly about their problems with peers, often for the first time since their diagnosis, was eye opening. With mutual support, their focus shifted quickly to matters related to independent living and securing productive futures. They did not for the most part expect to be cured. They labelled themselves “polios” and worked to articulate what it meant to survive while

not being cured. They partied a lot, and talked about hope returning and how to retain or extend that sense beyond Warm Springs' borders, where using wheelchairs or braces and crutches would be arduous.

The Warm Springs Foundation established in 1927 began to seek financial help from others in 1931. To do that, it created a patient advisory committee to provide its board of directors with the perspective of those with polio experience. This group was chartered as the National Patients Committee (NPC),³⁰ and its slogan was "Every Patient a Polio Crusader." Committee members had all received treatment at Warm Springs, and the NPC newsletter pledged "to create an agency which will definitely secure recognition from the leaders of government, business and society to the necessity and *logic of equal opportunity* [my emphasis] for and a rational attitude toward those who are physically handicapped. Constructive effort of this nature is bound to open up and develop avenues for occupation and remuneration for all victims of polio and especially for those who right now are willing to assume the responsibility of unselfish leadership in this work."³¹

The NPC's innovative work from 1931 to 1934 is well-documented in *The Polio Chronicles*, a professionally produced newsletter advocating correspondence courses and offering advice on using vocational rehabilitation services or on home-grown inventions that would adapt a typewriter, open a garage door, or drive a car with hand controls. It provided state of the art medical information about polio rehabilitation nationwide. Summing up, one writer urged his colleagues to "Send the gospel that physical handicap of polio does not make one a 'cripple.'"³²

The *Chronicle's* writers loved fun and distrusted pity. Their language reveals how they had to push themselves towards "overcoming" by overthrowing internalized negative interpretations of their own experience. They expressed frustration and anger – sometimes politely, sometimes passionately – at the stigma assigned to them, the social exclusion that resulted not only from attitudes but from discrimination arising from environmental and cultural factors: "Looking at life from a wheelchair, while it has its handicaps, is, notwithstanding, an interesting adventure, as any member of the wheelchair brigade will testify. Obviously, it is the common lot of us who are bound to our chairs to be stared at. In public we feel as conspicuous as the animals in a circus parade, but even so, what one of us would remain sequestered on that account? But far more important than our attitude toward others is our attitude toward ourselves. We cannot afford to indulge in self-pity ... Life is too full and interesting to lament at any length over the loss of leg power."³³

Thomas Couser describes such life-writing usefully as “anticipatory” and “plaintive.”³⁴ The term plaintive, “in an etymological sense ... is not mournful, but complaining,” and anticipatory in that the “personal testimony ... demonstrates the lack of, and need for, disability rights laws.” But Couser is writing about contemporary advocates working within a cultural world where the benefits providing social welfare entitlements – public or private – are established and civil and human rights laws are available for some, if not all. The Warm Springs writers lived in a world where neither social supports nor civil rights laws existed or were yet imagined. They were struggling with rewriting their own internal identity narratives, and to do so they had to go outside the cultural and legal narratives of their day. And so they talked among themselves, with their hero, FDR, and his architect, Henry Toombs.

Although they wholeheartedly supported and contributed to advancing medical rehabilitation techniques, they looked with notable passion and insistence at how social conditions powerfully limited their access to the social economy and its opportunities. With insight and conviction, they tried to explain why it was critically necessary to separate the impairment of their physiology from the disablement caused by cultural attitudes and the built environment. They offered civic solutions, ways to create equity for people with disabilities that would not fully blossom until after 1975.³⁵ But in these voices from segregated Georgia, the future was speaking. They refused categorically to believe that a diagnosis of polio meant a prognosis of “useless invalid”: “Many people fail to appreciate that we can find many interests in life, for on seeing us engaged in some absorbing task, they are wont to remark, ‘Isn’t it fine that there is something you can do to take up your time?’ ... just as if there weren’t scores of fascinating things to be done with hands and mind.”³⁶

Life lived inside a built environment that was accessible was critical to this eye-opening hope. Between 1928 and 1934, Toombs, Roosevelt’s architect, built ramps into all the Warm Springs buildings. Doorways had no thresholds; windows were at wheelchair height; ramps, handrails, and wide steps led even into the swimming pools. Bathrooms were accessible; personal care assistance was available. To my knowledge, this place was like no other built environment in the United States. Not even rehab hospitals built between the 1930s and the 1970s were so universally designed. One Warm Springs resident called it a “stairless Eden.” “Architects make things hard when they design public buildings, theoretically for the use of all the people,” she declared. “Look at the post offices, courthouses, railroad stations, churches and the

Federal edifices in Washington! All of them with smooth slippery staircases up to their doors ... Beauty of design in entrances seems to sacrifice ease of access." At Warm Springs everything was on the level, literally.³⁷

No matter how forward thinking, these voices soon faded. Given the small size of the U.S. health care infrastructure in 1932, the isolation of individuals with disabilities, and the tendency for advocacy activists to cluster around specific diagnoses, these voices in Georgia were barely heard. But this turn of thinking cracked open a narrow passageway, an accessible path leading to different narratives and social realities.

THE CURE NARRATIVE AND THE CONTEMPT OF GOODWILL

At the beginning of the twentieth century the need for modern clinics providing medical care was felt to be urgent in the United States. Building them was the focus of local charities' efforts to make their communities modern, a trend that historian of philanthropy Peter Hall calls the "democratization of change."³⁸ Women's clubs, Kiwanis, Masons, and Rotary clubs, the BPOE and ethnic working men's associations, secular civic service organizations that extended the effort of church organizations, and friendly societies all busied themselves developing services. They raised financial resources for clinics and for summer camps for the poor and "handicapped"; the funds created the local YM and YWCA and the infrastructure to make scientific health care available. From 1900 to 1945 funding for social welfare safety nets and scientific research, public and private, was not large. Modest workmen's compensation programs and disabled veterans' pension programs existed for people with disabilities, but families dealing with chronic disabling health problems lived within their means or depended on private charitable help.³⁹

The majority of these secular civic activists were often middle class, the owners of businesses on Main Street or their wives. They spoke about their work in terms of good citizenship, duty, and service. Their clubs provided fellowship, a chance to get ahead, find business and social allies, and have fun. Their problem-solving skills included know-how with bureaucracy, the building trades and its materials, capital management, a commitment to efficiency, and media savvy. Big bills for the jobs that needed to be done were largely still paid by individual donors, and this involved one-to-one, face-to-face giving. Large donors had hospitals, laboratories, rooms, chairs, and tables named after them. But small donors, at the watermelon festivals and strawberry suppers, paid for equipment, ramps, books, toys, and medical bills. Commonly, it was children who were the beneficiaries of direct services.

By the 1920s in scores of American cities, Community Chest chapters coordinated fundraising to bring dollars to many different organizations with less competition and more efficiency. Local settlement houses or soup kitchens, the Salvation Army, the YM and YWCAs, clinics for crippled children, the Lighthouse for the Blind – all would split the revenues. Professional fundraisers working on these charitable drives often began their careers in advertising or journalism. Copywriters pitched their causes in words and pictures. But their goal was to get donors to give their dollars freely, and their campaigns implied the same utopian faith in scientific efficiency seen in this period's consumer product ads. These pitches also harked back to the affliction narrative. In a 1921 Community Chest campaign in Cincinnati, Ohio, a modern mass mailing was used to acknowledge donors with thank-you notes. The postcard shows a lame girl in a blue dress leaning on a crutch, and the printed message on the other side reads: "I know that you are happy to have done your share to relieve suffering ... All of your friends and neighbors should have the same privilege ... Will you help to extend the same privilege ...? I am glad you are one of those who cares."⁴⁰

The recipients of charity were not represented at board meetings, but a disabling condition guaranteed a person – rich or poor – membership in the invalid club. In these early decades of the twentieth century, the most worthy recipients needing attention were dependent children. They were innocents who couldn't be held responsible for their condition. But the line between pitiable affliction and menacing burden was thin, as a Shriners' speech of 1938, commemorating ten years of hospital building, reveals: "We want to give you some idea of what the Shriners of North America have accomplished for the most pathetic of all human beings, a poor and penniless crippled child who has no other chance in the race of life to have its little broken body mended, except within the merciful walls of a Shriners Hospital for Crippled Children."⁴¹

Even in *The Polio Chronicles*, whenever the question of fundraising comes up, the polios eerily slid into an appeal based on sympathy and pity for their affliction, as if there were no other way to ask for financial help. It was, however, in the mass-marketed appeals for funds produced by the National Infantile Paralysis Foundation in the 1930s to the 1940s that affliction and menacing burden narratives were integrated and transformed into something new: the *cure narrative*.

When FDR became president, he turned direct management of the Warm Springs centre over to Basil O'Connor, his able-bodied law partner. O'Connor set his sights nationally and created a new organizational machine, the National Infantile Paralysis Foundation (NIPF). The Warm Springs

Foundation would focus exclusively on Georgia's rehab centre; NIPF's scope was the nation and polio itself. The consequences were significant for the Warm Springs National Patients Committee. By 1935 the multi-colour, high-styled *Polio Chronicle* was no longer published and a less sophisticated newsletter took its place. National Patients Committee members were not invited to comment, nor were they ever asked to advise the new NIPF about its goals or public relations strategies.

To get the country interested in polio, O'Connor decided to host a party, a shindig an entire nation might attend – not one party but many, a decentralized national fundraising event, scheduled to coordinate with FDR's birthday. The strategy was to have different local committees around the country plan their own dances and charity balls. National headquarters would help maximize public relations and provide financial and strategic resources to different geographical localities. The incentive for involvement was that fundraisers could use the majority of dollars they raised to support individuals with polio who needed rehabilitation or help with independent living in their communities. This local focus increased the likelihood that volunteers would be found. If not enough of them showed up, the local Democratic political machine provided the labour. The local focus also meant that many people could participate, regardless of class, race, ethnicity, or creed. Even if the donations were small, the funds helped to provide a solution to Depression-era economic pressures on traditional community philanthropists. Birthday Ball parties were held between 1934 and 1945, years when the polio epidemics increased. Polio survivors were never the largest category of people with mobility impairments, but NIPF funds were diagnosis specific. Only those with polio or who survived the acute phase of the disease got financial help.

At the beginning the public relations experts at NIPF were winging it. They created a *Birthday Ball Magazine* to describe the organization's goals and to be an event souvenir. Local small businesses and individuals bought advertising space on its pages, and in 1936 the cover bore a sponsorship logo from the liquor producer Seagram (figure 5.4). It was a party! At that time, corporations didn't underwrite health charities, and no "walks for a cure" existed to promote in-house teamwork or community relations. Early *Birthday Ball Magazine* covers retain echoes of the affliction narrative. Children are idealized, mothers mythologized. FDR is the only disabled adult present. The woman in figure 5.4 takes a Columbia-like pose, but her demeanour is ambiguous. The children surrounding her are not afflicted, neither rich nor poor, and are clearly innocent. The scene, a dreamscape, is not about affliction, cure, or giving money.



5.4 *Birthday Ball Magazine* covers by Howard Chandler Christy. Produced for the National Committee to Fight Infantile Paralysis, 1936, 1938.

NIPF provided polio survivors with support care, medical services, and assistive technologies that facilitated independent living. It developed and disseminated scientific knowledge about how to understand and treat polio, though in the 1930s the research agenda for a vaccine was barely underway. NIPF's pitching savvy was audible in the sophisticated use of radio. Always, on the eve of a Birthday Ball, FDR gave a radio speech outlining NIPF's goals and accomplishments. Then he graciously thanked everyone who came or gave. Broadcast nationally, these speeches lent the local parties an aura of being a national happening: you could hear the president at home or in a ballroom. Everywhere dance bands played.

FDR's pitch differed from those given by actors who would read from scripts written by O'Connor's public relations team. The president spoke from inside the polio survivor's experience. His tone was calm, straightforward. His goals were pragmatic, though his concerns were genuine, even passionate. "The problem of infantile paralysis is not an immediate emergency," he said in 1937. "It is with us every one of the 365 days of the year. It is an insidious and a perfidious foe. It lurks in unexpected places and its special prey is little children ... 70 per cent of all the money that has been

raised has gone and goes to the care of children crippled by infantile paralysis within their own communities.”⁴²

Note that 70 per cent of the money went for support, only 30 per cent to research. FDR and his Warm Springs peers had discovered that it was possible to live life productively as polio survivors; the majority of NIPF funds helped to assure that the invalid did indeed have a future. The Warm Springs pioneers had moved themselves beyond useless invalidism by focusing on rehabilitation and community access in the built environment. NIPF funds helped pay for these things one individual at a time, first with medical hospital bills, then with equipment at home, school, or the workplace. Despite this reality, the NIPF's public agenda did not address the social practices that limited opportunities for people with disabilities but focused public attention on medical treatment, coordination of scientific research, knowledge sharing, and making resources more widely available. That its work gave people with polio greater possibilities for independent living was barely mentioned in the public-relations campaigns. It would have required publicists able to imagine a narrative that described a life lived ably with a disability and children with disabilities who became adults with disability as part of their identities. Providing funds to individual families helped polios to meet not only the cost of the acute stages of their illness but the long after-care, including architectural accommodations, assistive technologies, and even summer recreation opportunities. But this less glamorous work of ramps, wheelchairs, braces, lifts, and equipment that enabled school attendance was rarely discussed directly with the public, even though the March of Dimes (MOD) made polios the only group of disabled Americans able to afford these necessities in the mid-twentieth century.

How the NIPF's work was presented to the general public involved specific decisions, and these presentations of disability are central to the radical forgetting process Schweik refers to. They are part of the struggle with “mendicancy” versus “rights” in disability life writing that she and Couser both explore in their work.⁴³ In 1938 a critical turn in the NIPF's message-making took place when a new professional public-relations team was hired. Tom Wrigley, from Universal News & Hearst, Dorothy Ducas, also a Universal veteran, and Robert Berger from radio became the NIPF's Public Relations, Radio, Motion Pictures and Fund Raising Department. Under their leadership the organization's fundraising pitch shifted away from FDR tributes to unashamed sentimental appeals on behalf of victimized crippled children promoted in all media: local and national newspapers, magazines, radio, and Hollywood. In the process both affliction and menacing burden narratives were combined and transformed.

In the new campaigns, intense energy was focused on the most innocent: the future of the child polio “victim” was grim. No child with polio was portrayed as having an independent life after the traumatic days of diagnosis and early rehabilitation. The children would learn to walk, but what happened after they went back home was rarely discussed. Only cures – seemingly miraculous – were acceptable for the public to consider. In March of Dimes posters, children are shown stepping out of their chairs, walking with crutches but not using braces, or walking with braces but no crutches – which in practice cannot provide stability for walking. Sometimes a wheelchair is visible, but it’s clearly best when a child finishes treatment and stands upright or walks away from the chair.

But what happened to the child for whom walking was not a possibility? What happened to those who could not throw away their braces, wheelchairs, or iron lungs? Their story was never told beyond the hospital ward where treatment was initially provided. Prevention was the MOD’s best answer: a vaccine that eliminated the problem. There is, however, a significant difference between eliminating a virus that threatens the able-bodied and helping those who have already acquired the condition. MOD fundraising barely acknowledged this: in the mid-twentieth century, a disabled child who grew into disabled adulthood was just not imaginable, let alone worthy of civic support.

The NIPF fundraising campaigns brought the acute phase of polio and the research lab close to viewers. The children in MOD posters and films were real. Photographs introduced audiences familiar with idealized cripples to actual disabled children, making their problems seem intimate and personal. But this photography was consciously and creatively planned. It was designed to get consumers – viewers – to give away their money. The kids were posed, though their needs were real and urgent. Their clothes were provided by the organization, and when a girl’s youth and vulnerability could be enhanced by an above-the-knee skirt, it was done. Sometimes poster children were asked to walk without crutches for the camera, increasing their instability and the sense of vulnerability visible in their gait.⁴⁴ In radio and films produced by MOD, all the narration and dialogue was scripted.

Two critical elements govern the narratives in late 1930s and 1940s NIPF publicity: a captivity-bondage theme and compressed time. Everyone pictured is *caught* in a medical technology nightmare. When the camera pans the quarantined polio ward, what is captured is the moment of trauma when an individual’s and a family’s fortunes are reversed. The stories make it seem to viewers that this quarantined ward or rehab hospital is where the polio survivor will live forever. They are shown crowded wards or individual

patients alone in cribs; close-ups include the smiling faces of children, but the smiling teen looking up while Mom combs his hair, his body in the great tube of an iron lung, does not reassure the viewer.

The NIPF stories were not about a disease controlled, but its uncontrolled paralysing threat: *This might happen to you, to your child*. To audiences unaccustomed to medical technology and modern hospitals but familiar with the segregation of the disabled in institutions, this imagery shocked. What kind of hell was this? When the child with polio looked out at the audience, caged inside the bars of a crib, the subtext was: *You can free the child*. Similar confinement and liberation imagery was common in NIPF posters and films. In the films the timeframes of therapeutic procedures were rarely explained; a workout on the parallel bars might last a half hour daily for a month, but the majority of viewers unfamiliar with physical therapy did not know this. They watched a child's legs strapped to boards, listened to the iron lung whoosh, and silently cheered for the boy working out on parallel bars to make his muscles kick forward.

This imagery is reminiscent of abolitionist visual rhetoric where shackles are symbols of bondage, or temperance stories where the bottle is the icon of evil.⁴⁵ In the March of Dimes rhetoric, viewers are brought into a moment of extreme trauma where time stops. Polio reverses all good fortune. In a 1938 radio talk the well-known actor Dana Andrews identifies himself as a parent; the script employs techniques developed in 1920s advertising of speaking to the audience in the first person to create intimacy and provoke shared assessments: "Every time I hear the words infantile paralysis, or see a child wearing braces, I find myself seeing not the crippled child but one of my children. David, Cathy, or Steven. I can't help wondering, what if it were Cathy? ... Today those three kids have a special little game they play together ... But what if Cathy were wearing braces? It takes three to play that game, and how long would it be before Cathy lost the companionship of her two brothers? And after that, what if she grew up handicapped? Those thoughts aren't pleasant, but I guess you parents have all had them."⁴⁶

But what did happen to children with polio? Did their siblings really cease interacting with them? These promotional campaigns collapse the affliction and menacing burden narratives into one tale: the diagnosis of polio transforms the child as he or she acquires a "crippled" identity – a state of invalid being that implies a future outside the realm of typical community connections, a beyond where resilience and pleasure are simply not possible. By giving to the NIPF, donors might prevent such a fate from knocking at their own door. That salvation would require a vaccine, which (despite NIPF ambiguity) was not a cure but a preventative.

In the NIPF script the search to find prevention becomes a pitched battle, a war. The enemy is the illness; failure is a future as an invalid, a terrifying personal burden. Dana Andrews concludes: "There isn't a parent who at one time or another doesn't think that his child can do just about anything or be anybody he or she might choose ... Oh, maybe not president ... The dreams vary, but it all boils down just to this. We all want our children to have an easier time of it than we did. Not to lack for a thing, to have every advantage. In short, we want them to be happy. Well, happiness means health, which brings me right back to that child wearing braces and that uneasy feeling. It's when I see a crippled child, or see one of those pictures in the paper (I'm sure you've seen them). It's then that I feel a chill run down my spine, it's then that I begin to wonder, could it happen to my children? That's when the danger of infantile paralysis really hits home. That's when you realize that polio could wreck every dream you had for your children."⁴⁷

Andrews's testimony was heard on the radio in kitchens and living rooms; he was seen in the dark of movie theatres. MOD celebrity narratives like his often followed a similar arc. Happy children play outdoors, but an evil fate stalks them – a dark cloud passes over the pond. Scenes follow that symbolically express entry into the Valley of the Shadow: the world of trauma and medical technology, a hospital ward where ordinary daily life halts and nightmare envelops the residents. Sometimes statistics of "victims per state" roll over the screen. The virus is an "evil," the children are of course innocent, but deliverance is in the hands not of God but the new redeemer, the lab scientist. Hope is learning to walk, but cure is redemption: only the ability to throw away those crutches is acceptable. Only then can the victim truly "come back" into the human fold.

Cure narratives give all the active responsibilities to able-bodied viewers. As in the affliction narrative, recipients of charity must be gracious. No argument or bad behaviour can be expressed; the work to be done is physical therapy. All those with polio smile; only the able-bodied whimper and need consolation as they wait in line for a vaccine in late 1950s newsreels. The benevolent donation no longer involves the mutual obligations of community inclusion: donating to the cause – the NIPF organization – is a means of protecting givers from contamination by untamed chance. They can abandon the old Protestant Christian theological requirement of inclusion, the notion that all people (if they accept the Protestant word) are God's creatures, and instead place their faith in science. The caregiving witnessed by audiences watching NIPF public service announcements is almost entirely professionalized, and like the stairs commonly pictured at the hospital entrance, the barriers in the built environment would keep the polio

survivors confined to their homes and out of sight. The Warm Springs insights about social, institutional, and environmental infrastructure barriers had been lost. The National Patients Committee's aspiration to foster equal opportunities and a rational attitude toward the handicapped had been banished. The voices of children and adults living productive lives with polio and speaking for themselves were inaudible.

March of Dimes fundraising rhetoric echoed religious narratives about suffering but gave redemptive agency only to scientists and science. The good works offered to the campaign's consumers – the donors – were not the liberating use of wheelchairs as tools of mobility or ramps built into an entrance but a dream of helping create a world without polio, a world with fewer risks. NIPF propaganda ignored much of the actual work of the organization, the 70 per cent of funds that paid for independent living, that helped people stay in school, on the job, active in community life.

After the polio vaccine was discovered, this financial scaffolding supporting independent living for the polio community dissolved as the March of Dimes redirected its mission to birth defects – despite the fact that many polio survivors remained and their needs had not vanished.⁴⁸ After the organization withdrew this critical support, a grassroots advocacy community of people with polio began to evolve, including many young adults who were in school with the help of NIPF aid. More than a few of the leaders of the nascent disability rights movement in the United States in the 1960s and 1970s were members of the last generation of polio survivors, but hardly any knew about the dream of inclusion voiced so clearly at Warm Springs in the early 1930s.

Each of the narratives analyzed above has shaped cultural and personal attitudes toward disability and lives lived with chronic illness. The beliefs inherent in these narratives persist and can be heard in the questions asked today of anyone, my daughter included, with a visible disability. Despite the transformations both in attitudes and the environment since the rise of the disability-rights movement, regardless of how significantly special education has changed the prospects of many young people with disabilities of many types, we have few shared narratives about how life does go on, sometimes flourishing, even with incurable impairments. As more diseases can be treated but not cured, as chronic conditions become ordinary, as genetic screens make it typical practice to study fetuses and our own bodies for signs of future conditions and illnesses, it becomes increasingly critical to understand how our narrative concepts about affliction, burden, and redemptive cure impact the lives of children and adults, and how and why they function as a component of individual and social identity.

NOTES

- 1 Schweik, Susan, "Begging the Question," 58.
- 2 Ibid.
- 3 This discussion is based on several hundred stories across disability categories in volumes found at the American Antiquarian Society (AAS) during a Lila Wallace Artist's Fellowship in 1996. The works cited here are from the AAS's children's books produced after 1820 but catalogued between 1985 and 1996 with grants from the National Endowment for the Humanities. That reference information made searching for individual stories and illustrations possible. "Affliction narrative" is a term describing nineteenth-century commercial, sentimental, non-pedagogical literature dealing with similar themes but whose audience was largely women. See Klages, *Woeful Afflictions*.
- 4 An Individual Education Plan (IEP) is the written statement required by U.S. federal law for all children with a disability as they move through the public school system. It describes the activities to be done by school personnel to facilitate each child's progress toward specific goals, both for academic and independent living purposes.
- 5 Ingelow, *Poor Matt: The Clouded Intellect*.
- 6 Mary Ellis.
- 7 Ibid.
- 8 See, for example, "Crazy Ann," in Woodworth's *The Boy's Story Book*.
- 9 On the role of sympathy versus empathy in Protestant pedagogical literature and visual culture, see Morgan's *Visual Piety*.
- 10 *Use What You Have*.
- 11 Morgan, *Sacred Gaze*; Freedberg, *Power of Images*.
- 12 Two key works about the sentimental affliction narrative genre and disability are Klages's *Woeful Afflictions* and Holmes-Stoddard's *Fictions of Affliction*.
- 13 Kennedy, *Jessy Allan, The Lane Girl; Little Humpy; Patience and Her Friend*.
- 14 Hodgson Burnett, *The Secret Garden*, 1911; Porter, *Pollyanna*, 1912. Each story would migrate to the screen, and *The Secret Garden* as a film would be remade and reissued several times across the twentieth century.
- 15 On degeneracy and eugenics, see Pick, *Faces of Degeneration*; Kevles, *In the Name of Eugenics*; Paul, *Controlling Human Heredity*. On the life sciences in popular culture, see Barber, *Heyday of Natural History*.
- 16 For the history of media in the United States, see Starr, *The Creation of the Media*; Schudson, *Discovering the News*; Tucher, *Froth and Scum*.
- 17 Bynum, "Shape and Story."
- 18 Cravens, *Before Head Start*; Lovett, *Conceiving the Future*; Paul, *Controlling Human Heredity*; Trent, *Inventing the Feeble Mind*.
- 19 Brechen, *From Segregation to Community Integration*.

- 20 All these statistics come from a very cogent essay by Larry Dewitt of the Social Security Historian's Office.
- 21 Kellogg, *Are We a Dying Race?*
- 22 Henderson, "Relation of Philanthropy to Social Order," 1-15.
- 23 Steinbeck, *Of Mice and Men*.
- 24 Pernick, *The Black Stork*.
- 25 "Doctor to Let Patient's Baby Defective Die."
- 26 Ibid.
- 27 Ibid.
- 28 "Colson Wheelchair."
- 29 See Cutlip, *Fund Raising in the United States*; Gallagher, *FDR's Splendid Deception*; Turnley, *Roosevelt and the Warm Springs Story*.
- 30 Botts, "Announcing the New National Patients Committee," 4.
- 31 Charter, National Patients Committee, Georgia State Archives.
- 32 Pledge of the Warm Springs Alumnus, August 1931, 4.
- 33 Thrall, "Observations from a Wheel Chair."
- 34 Couser, "Undoing Hardship."
- 35 The 1975 Education for All Handicapped Children Act was the first federal guarantee to a public education for all disabled children, and Section 504 of the Vocational Rehabilitation Act, 1973, was the first federal legislation to mandate, among other things, that all organizations or programs receiving federal funds guarantee accessibility in their offices. The Americans with Disabilities Act in 1990 would extend civil rights protections and mandates for accessibility, among other things, in the built environment universally.
- 36 Donnelly, "Playing Polio at Warm Springs," 3-7.
- 37 Ibid.
- 38 Block, interviews with Hall for "Inventing the Poster Child."
- 39 See Cutlip, *Fund Raising in the United States*, for a wide-ranging overview of individual non-profit organizational fundraising campaigns between 1900 and 1960.
- 40 Postcard, Community Chest.
- 41 Shriners' National Convention Speech, 1938.
- 42 Roosevelt, radio speech, 30 January 1937.
- 43 Couser, "Undoing Hardship"; Schweik, "Begging the Question."
- 44 Block, interviews with former NIPF poster children, especially Cindy Jones, for "Inventing the Poster Child."
- 45 Thanks to Dr Graham Warder, Keene State College, for this link to temperance imagery.
- 46 "Guest Star Time," FDR NIPF Birthday Ball Event.
- 47 Ibid.
- 48 Laurie, "National Policy Explained," 3.

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PART THREE

Hearing Children's Voices

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“It’s Back”: Children with Cancer Talking about Their Illness When Cure Is Not Likely

MYRA BLUEBOND-LANGNER
AND MEGAN NORDQUEST SCHWALLIE

Jeffrey Andrews was five years old when he was diagnosed with acute lymphocytic leukemia. He died less than two years later. Those years were marked by relapses in both spinal fluid and bone marrow, aggressive chemotherapy, frequent visits to outpatient clinics, and hospitalizations as physicians tried not only to treat the cancer but also to relieve the pain and discomfort wrought by the disease and the side effects of treatment. In the months preceding his death, Jeffrey was constantly shouting at his mother. Nothing she did seemed right. The TV was too loud; no, it was too soft. There was too much ketchup on the burger. No, he wanted to sit up looking at the TV, not out the window. It was “Get this, get that.” When asked, “Why do you always yell at your mother?” he replied, “Then she won’t miss me when I’m gone.” When his mother was asked, “Why does Jeffrey yell at you all the time?” she replied, “He knows when I can’t take it in that room anymore. He knows that if he yells at me, I’ll leave. He also knows I’ll come back.”

Jeffrey’s case is just one example from an extensive body of research indicating that children with cancer not only know about their illness and condition but also know that adults, especially their parents, are often uncomfortable talking to them about it.¹ Children observe the cultural taboos on talking about their illness and death, and they shield their parents from their awareness of what is happening to them and what might happen. In this chapter we look at what children with cancer know about their illness, how they acquire information, and how they talk about their illness and condition with parents and clinicians. We then consider the implications of ill children’s understandings of their condition and patterns of communication for involving them in decision-making about their care and treatment.

A NOTE ON METHODOLOGY

The case material, interpretations, and analyses presented in this chapter are drawn from several studies involving children with cancer undertaken by the lead author over the last thirty-six years.² These studies were prospective and ethnographic,^{3,4} characterized by attention to children's everyday lives and particularly to children's interactions with others. Bluebond-Langner followed her subjects in hospitals, clinics, and their homes, observing and talking with them about their experiences. Additional information about the children and their experiences came from review of their medical records and conversations and interviews with medical staff, parents, siblings, and peers.

By observing and talking to children over time in a variety of situations, Bluebond-Langner was able to grasp the processual character of their experiences as well as the ways in which the period of the illness (e.g., diagnosis, relapse, terminal phase) and situation (e.g., interaction with another child with cancer, clinic visit with the oncologist, conversation with a parent at home) figured into the children's understandings of their illness and what they said about it. For example, while they might freely discuss the deaths of other children in the company of peers, they did not necessarily do so with their parents. Thus, through an ethnographic approach, Bluebond-Langner was able to elicit and document children's perspectives and experiences and to analyze them in terms of the context in which they emerged.

CHILDREN'S UNDERSTANDINGS OF THEIR ILLNESS
AND THEIR PROGNOSIS

Mary, an eight-year-old girl diagnosed with leukemia, was lying in her bed in the hospital as her mother and an occupational-therapy student packed up after a month-long stay. From across the room the student held up some paper dolls that Mary a few days earlier had said looked the way she did before she became ill. The student asked, "What should I do with these, Mary?" Mary snapped, "Give them to me." She placed them between sheets of tissue in the tissue box, whispering, "I am burying them in their grave in the Kleenex box." Her mother, on the opposite side of the room, did not appear to hear.

After Mary's death her mother found in Mary's bedside table a list in Mary's handwriting of children she had known who had died and which of her belongings she wanted others to have after she had died. Mary's mother then realized that despite her efforts to keep from Mary all knowledge of her condition and that of other children – by keeping the hospital door

closed at all times, not letting Mary go to the playroom or play with others at clinic – she must have known she would die.

Children's acquisition of information about their illness is part of an interpretive process involving changes in their physical condition, their views of themselves, and their experiences.⁵ In observing the behaviours of others, children come to the conclusion that they have a very serious illness. As one child stated, "I'm really sick, you know. Everybody cries when they see me." Another remarked, "Nanny stares and shakes her head at me." Children learn about their condition and treatment not only from observing adults' behaviour and listening in on their conversations but also from listening to their peers talk together about their conditions and treatments. Away from parents and clinicians, children readily exchange information regarding treatment regimens and side effects and their condition. At such times, it is not uncommon to hear children make statements of the following sort:

"Prednisone makes me eat like a pig and act like a brat" (boy, age seven).

"There is blood in my pee from the cytoxan. Maybe the platelets will help" (boy, age seven).

"I'm going to die soon. They are trying to help my blood, but it is making my liver bad" (girl, age nine).

With each new illness experience, the children had more questions. The death of a peer was amongst the most salient of these experiences, often prompting children to ask the staff questions reflecting concern about their own condition. For example, after seeing what was going on outside another patient's room the night before, Tom, age seven, said to the nurse who came into his room that evening, "Jennifer died last night. I have the same thing." The nurse replied, "But they are going to give you different medicines." "What happens when they run out?" Tom asked. She answered hurriedly before leaving, "Well, maybe they will find more before then."

After the death of a peer, children revealed their thoughts and concerns through "disclosure conversations." These conversations followed a particular format. The child initiated the conversation by mentioning someone who had died or was in danger of dying, and made an attempt to establish the cause of death through a statement, question, or hypothesis. The conversation ended with the child comparing the deceased to him/herself, as in the following conversation between Scott, age six, and Bluebond-Langner:

SCOTT: You know Lisa

MYRA: (*nods*)

SCOTT: The one I played ball with. How did she die?

MYRA: She was sick, sicker than you are now.

SCOTT: I know that. What happened?

MYRA: Her heart stopped beating.

SCOTT: I hope that never happens to me, but.

A child's awareness of the possibility of death from cancer did not necessarily mean that the child assumed or concluded that he/she too would die, despite having the same disease as the friend who died. Take, for example, Lakshmi, who was diagnosed with Juvenile Myelomonocytic Leukemia (JMML) when she was three years old. After receiving aggressive chemotherapy and a bone-marrow transplant with donor cells from her mother, Lakshmi went into remission and was well for about a year. Then, at five and a half, she relapsed. Four months after the relapse, while Lakshmi and Bluebond-Langner were colouring in the hospital playroom where Lakshmi was receiving further treatment, she casually remarked, "Alexa died. You don't know her. She had JMML just like me. I am going to get more cells." She returned to colouring and then added, "From my mom, and be all-better."

Notice that Lakshmi began with the mention of someone who has died – Alexa. She made attempt to establish the cause through a statement or a hypothesis. JMML is the proposed cause of death. She compared the deceased to herself but did not assume that just because they both had the same disease, she would die. Lakshmi held out hope that she would recover, based on her previous experience, when she went into remission after receiving cells from her mother.

It is noteworthy that Lakshmi's mother also held out hope and in fact did not make the connection Lakshmi did until Lakshmi was dying. Two days after Lakshmi died, her mother said, "It wasn't until we were in the hospital this last time that it hit me that all the children we knew died. And I don't think it was until Lakshmi asked me if she was going to the same place as Alexa. Then I realized that, all the time, all the treatments – we were just buying time. She wasn't going to be cured, but I didn't think that then. Maybe it was just too scary. Or maybe I just didn't want to think that she wouldn't be cured."

Across studies, age was not a significant factor in children's understandings of their illnesses or conditions.⁶ Similarly, neither gender nor diagnosis nor the hospital where treatment was given was at all predictive of what children knew. Making similar observations, David Bearison chose not to include children's ages, diagnoses, or even information about their cultural and economic background when introducing their cancer narratives.⁷ Children's experiences (e.g., relapses, recurrences, contact with peers, deaths of peers) over the course of the illness were far more relevant to their knowledge and

understanding. For example, in response to the question, "How does chemotherapy work?" a fifteen-year-old boy, newly diagnosed with leukemia, responded vaguely and not totally accurately that "it killed, uh, bacteria and all that." A fourteen-year-old boy who had been in treatment for five years at the same hospital answered more fully, "Well what it does is, it actually kills the fast-growing cells in your body. It kills the cancer cells. And you throw up a lot because the cells in the lining of your stomach and your intestines are growing fast too, and they get killed too. When I had ABVD, I threw up really bad for a while, and most of my hair fell out."⁸

In much the same way as with understandings of care and treatment of their illness, children's awareness of their prognosis and understandings of their approaching death were closely tied to their experiences (e.g., multiple relapses and increased time in the hospital, failed treatments, the death of peers). Near the end of their lives, they were often very concerned with the time they had left, getting angry when people took too long to remember things or answer questions or bring things to them. As one staff member commented, "They demand because they know time is short. It's as if they know that if they wait too long, they might be dead by then. They're not just being difficult. That child knows something." Some children were very direct about their fear of wasting time, saying things like, "Don't waste time," or "We can't waste time." These statements demonstrate the different meaning time takes on for ill children near the end of life, giving rise to a sense of urgency not usually articulated at a young age.

Thus, understanding and explaining terminally ill children's views of their prognosis and their understandings and perspectives on death require looking beyond the dominant age-graded, developmental models commonplace in the literature.⁹ Not only do these models fail to give proper attention to the way in which experience shapes understanding but they also assume a linear progression in which the individual first comes to understand sub-concepts such as irreversibility, finality, nonfunctionality, universality, inevitability, and causality and then graduates to a "mature," adult understanding of death.¹⁰ The models, and the assumptions upon which they were based, proved especially problematic in interpreting terminally ill children's views on death; one would find the same child holding views both expected and unexpected for his or her age.

For example, one five-year-old boy who was concerned with separation, who talked about worms eating him, and who refused to play with toys from a deceased child told Bluebond-Langner that the drugs had run out. He repeatedly told other people, "Don't waste time. I can't waste time." Similarly, a nine-year-old girl who correctly told her peers that the medication was

damaging her liver, thereby hastening her death, also gave the cleaning woman pictures she drew of herself on blood-red crosses, never mentioned the names of deceased children, and could not bear to have her mother leave her for a moment. To hear a five year old speak about worms eating him and being concerned about separation is predictable from the developmental perspective – but discussion of drugs running out is something that according to developmental models would not occur until much later, in middle childhood. Likewise, that a nine-year-old girl could state that drugs were damaging her liver and thereby causing death is not terribly surprising, but a taboo on names of deceased children is more problematic in terms of an age-graded, linear model.

ILL CHILDREN'S COMMUNICATION ABOUT THEIR ILLNESS

If children know more than adults think they do, more than parents are comfortable with them knowing, how do they manage this awareness in their interactions with others, especially their parents? Identifying the perspectives of children is especially complex when dealing with an aspect of a child and a family's life that engenders at once reactions of avoidance and concealment, not to mention profound sorrow and grief. Parents and their ill children often interact in a context of "mutual pretense" – a term used by Glaser and Strauss¹¹ to describe the context of interactions that exists among dying adults, their families, and medical staff when each party knows what is going to happen but does not openly acknowledge it to one another.¹²

In the context of mutual pretense, children can appear to be or to act as what they are not – growing up like other children. They may say things they may not believe to be true or that they know not to be true. They may feign ignorance of what they well understand. For example, when seven-year-old Adam's parents brought his Christmas presents to the hospital weeks before the holiday, he remarked "Santa has lots of children to see, he just came here first," rather than acknowledging the suggestion that he would not be alive on Christmas. In mutual pretense, difficult issues are avoided. Children avoided discussions of their condition, the future, and deceased children in conversations with those they thought would be uncomfortable with such issues. Instead they focused on safe topics, spending a great deal of time on present-oriented topics such as TV shows, the weather, food, and parking. When difficult topics emerged, such as the recurrence of a tumour, care was taken so that neither party broke down. For example, in response to the physician's remark, "The tumour is growing

again,” one child said, looking over to his mother, “Yes, but it grew before, and the chemo helped, so maybe this new medicine [a Phase I trial] will work.”

All parties endeavoured to keep the interaction normal. Often they used props to sustain the illusion. Homework books sat by the bed long after there was a chance that the child would return to school. To limit risk of breakdown, interactions were brief. And when the rules for maintaining pretense became impossible to follow and breakdown appeared imminent and was not desired, some way was found to avoid or terminate the interaction. This seemed to be one of the functions of distancing strategies – angry outbursts, withdrawal, banal chitchat – common at this time. The children protected their parents from their own fears and doubts. For example, they did not always share with their parents their concerns about the new drug or treatment “not working,” in part because they knew how important the new therapy or treatment was to their parents. One thirteen-year-old boy said of a Phase I trial of STI-571, “I don’t think the drug is working, but I want to try something, and my mom thinks it will work.”

Even in those cases where there was open communication as opposed to mutual pretense, it was not there at all times in all situations. While one sixteen year old and his parents had previously discussed death, including what they would like when they died, when the tumour progressed and various options for care and treatment were being considered, neither the boy nor his parents raised the topic of death, let alone funeral arrangements.

IMPLICATIONS FOR CARE AND TREATMENT
OF ILL CHILDREN: INVOLVING CHILDREN
WITH LIFE-SHORTENING ILLNESSES IN
DECISION-MAKING ABOUT CARE AND TREATMENT

Research on children’s everyday illness experiences, including their knowledge of their disease and prognosis and how they communicate what they know, has important clinical implications for the care of sick children and their families. Among the issues this chapter has direct bearing upon is the question of the role of the child in decision-making regarding care and treatment.¹³ While professional bodies have recommended that children be involved in decision-making, how best to involve them has not yet been specified.¹⁴ The few guidelines that exist reflect a concern with age and development to the exclusion of other equally and in some cases more relevant factors including the complex family dynamics governing communication about a child’s illness.

When children with life-limiting illnesses and their parents engage in mutual pretense, protecting each other from difficult topics, they also limit free discussion of treatment possibilities and outcomes. Even in circumstances of open communication and choice, children may ultimately defer to their parents' wishes.¹⁵ As Sanford Leiken has written,¹⁶ "This lack of assertiveness in voicing their authentic choices ... [raises] serious questions about whether one can justifiably speak of 'assent' when children or young adolescents are concerned." However, this does not mean that children cannot participate meaningfully in the decision-making process; rather, the guidelines for involving children need to address children's varying abilities, knowledge, and experiences with the illness as well as everyday social and cultural realities.¹⁷

Bluebond-Langner, DeCicco, and Belasco¹⁸ have put forward a model – "shuttle diplomacy" – that takes into account not only the abilities of the child but also the social realities that govern communication between children and adults, especially children and their parents. Though first introduced by Bluebond-Langner¹⁹ as a way of dealing with communication with well siblings of children with chronic and life-limiting illnesses, and later applied to the issue of involving children with life-shortening illnesses in decisions regarding their participation in clinical research,²⁰ this model is also applicable to the issue of involving chronically and terminally ill children in treatment decisions. The model proceeds from the perspective that all parties need to be respected in decision-making; the process should be free from deceit and coercion; and children, like any other patients, have a right (if they wish to exercise it) to know about the procedures that they undergo.²¹ The goal is to elicit the perspectives of children and to incorporate their views in the decision-making process in an ethical and meaningful manner.

The model stresses the importance of considering the inclusion of children in the decision-making process at the start of care and at each new illness or treatment development. Briefly, in this model the physician meets first with the parents and explores with them what information they want or do not want given to the child. This is important not just because of what is involved in terms of talking to the child but also because in talking with parents about what they do not want the child to know, the physician becomes aware of misunderstandings about various care and treatment options and even the prognosis, as well as other issues in the family that may be effecting choice of care. In short, it is an opportunity not to be missed.²²

The physician should open the dialogue by ascertaining and acknowledging the parents' position, especially in those cases where they want information about the prognosis, the likelihood of cure, or the nature or efficacy of the proposed treatment withheld from their child. In the course of the conversation, the physician might note that from his or her experience,

the child knows the likely outcome. The physician could give examples of ways that children indicate their desire to know more from their parents as well as the cues that children give to indicate what they know and their desire for more information. The physician might ask the parents what they would be most afraid of if a particular subject came up. He or she might suggest that perhaps further discussion with the child, either with them present, or with the physician alone, would be helpful for all of them, if not now, then perhaps in the future.

The parents might continue to refuse to have discussions with the child or to have the physician have discussions with the child that include the child's prognosis, side effects, or efficacy of treatment. However, the groundwork has been laid for further discussions, and insights have been gained that will serve the physician in other situations as they arise with these parents and their child.

The physician needs to make clear, both in the meetings alone with the child and in the meeting with the parents and child present, that while the child will be listened to by both the parents and the physician, and the child's desires will be taken into account, the decision is not the child's alone to make. Not insignificantly, this also relieves the child of an inappropriate burden. The child is involved in the process but does not determine the outcome.

This does not mean that the child cannot disagree with the parents. The child can, but needs to know just how this dissent will be taken into account, for we must never forget that from a legal standpoint, if the child is a minor, the ultimate decision is with the adults.

In this shuttle diplomacy framework, there is room for dissent, and room for negotiation. If negotiation fails to bring about a satisfying result, the child has been included in a meaningful way, not set up for something he or she cannot have. The child's inability to determine the outcome has not kept the child from being an active player. And the fact that the child has been told that he or she is not the final or ultimate decision-maker may relieve second thoughts later on.

The approach and framework we have outlined can be used with adolescents, who can easily become cynical when their desires are solicited but not acted upon, as well as with children younger than seven or eight years old, for it acknowledges their understanding and capacity and remains open-ended.

In sum, the focus of the child's participation in this framework is not on soliciting his or her willingness to agree to participation – for what does that accomplish in the absences of ability to dissent and to have one's decision acceded to? Furthermore, obtaining a child's assent does not guarantee that the child has genuinely participated.

The reality is that decisions will be made with which children do not agree. The guidelines and regulations concerning their involvement in the decision-making process must recognize this from the outset. If the child does not agree with a decision, the best one can hope for is that he or she accepts the process by which it was made. To secure this, the other participants, especially the physician, must be honest with the child about the process and how it works.

In conclusion, we recommend a shuttle-diplomacy approach for involving children with life-limiting illnesses in decisions about their care and treatment. Many important decisions in life, decisions that are ethical, have been and are made in a negotiated framework.²³

IMPLICATIONS FOR THEORIZING ABOUT CHILDREN AND CHILDHOODS

The findings presented in this chapter show children to be active agents capable of interpreting their experiences, the actions of others, and the world around them. Ill children's words and deeds lend credence to the "new" view of children put forward by scholars in childhood studies.²⁴ In this view, the emphasis is placed on children's active engagement in the social worlds they create, while at the same time the worlds others create for them are fully acknowledged and considered. Children's views and behaviours are looked at in the temporal, social, and cultural contexts in which they emerge. Children are seen "as at once developing beings, in possession of agency, and to varying degrees vulnerable."²⁵ This perspective is of fundamental importance not only for future studies of children and childhoods but also for the development of policies that affect their lives.

NOTES

Support for the research presented in this paper was provided by grants from the Fannie E. Rippel Foundation, Olivia Hodson Foundation, Stanley Thomas Johnson Foundation, Johnson & Johnson Family of Companies, and REACH Fund of Great Ormond Street Hospital and ELS Counselors.

- 1 Beale, Baile, and Aaron, "Silence Is Not Golden"; Bearison, "*They Never Want to Tell You*"; Bluebond-Langer, *The Private Worlds of Dying Children*; Bluebond-Langer, DeCicco, and Belasco, "Involving Children with Life Shortening Illnesses in Decisions"; Dixon-Woods, Young, and Heney, *Rethinking Experiences of*

- Childhood Cancer*; Kubler-Ross, *On Children and Death*; Woodgate, "Part 1," "Part 2"; Sourkes, *The Deepening Shade*; Sourkes, *Armfuls of Time*; Silverman, *Never Too Young to Know*; Kreicbergs et al., "Talking about Death with Children."
- 2 Bluebond-Langner, *The Private Worlds of Dying Children*; Bluebond-Langner, Perkel, and Goertzel, "Pediatric Cancer Patients' Peer Relationships"; Bluebond-Langner, Perkel, et al., "Children's Knowledge of Cancer"; Bluebond-Langner, DeCicco, and Belasco, "Involving Children with Life Shortening Illnesses"; Bluebond-Langner, Belasco, et al., "Understanding Parents' Approaches."
 - 3 Those looking for a general introduction to ethnography and participant-observation may find Bernard's *Research Methods in Anthropology* helpful (322–64).
 - 4 For a fuller discussion of the ethnographic methods as employed by Bluebond-Langner in studies of children with cancer, see note 2 above.
 - 5 For a detailed discussion of the process of acquisition of information, changes in self-concept, and experiences from diagnosis through death, see Bluebond-Langner, *The Private Worlds of Dying Children*, 166–97.
 - 6 Ibid; Bluebond-Langner, Perkel, and Goertzel, "Pediatric Cancer Patients' Peer Relationships"; Bluebond-Langner, Perkel, et al., "Children's Knowledge of Cancer."
 - 7 Bearison "They Never Want to Tell You," 25.
 - 8 Bluebond-Langner, Perkel, and Goertzel, "Pediatric Cancer Patients' Peer Relationships"; Bluebond-Langner, Perkel, et al., "Children's Knowledge of Cancer."
 - 9 See Brent et al., "The Development of the Concept of Death"; Koocher, "Children's Conceptions of Death"; Nagy, "The Child's Theories Concerning Death"; Speece and Brent, "The Acquisition of a Mature Understanding"; and Wass, "Concepts of Death" as examples.
 - 10 Summarized by Bluebond-Langner and DeCicco in "Children's Views of Death"; Kenyon, "Current Research."
 - 11 Glaser and Strauss, *Awareness of Dying*.
 - 12 For a more detailed discussion of mutual pretense, see Bluebond-Langner, *The Private Worlds of Dying Children*, 198–230. Other researchers (Grootenhuis and Last, "Children with Cancer"; Van Veldhuizen and Last, *Children with Cancer*) have referred to the protective strategies utilized by sick children and their families and physicians as the "law of double protection."
 - 13 Freyer, "Care of the Dying Adolescent"; Institute of Medicine, *When Children Die*; Hinds, Pritchard, and Harper, "End-of-Life Research."
 - 14 American Academy of Pediatrics, "Informed Consent"; Royal College of Pediatrics, *Withholding or Withdrawing*; Society for Adolescent Medicine, "Code of Research Ethics"; Canadian Paediatric Society, "Treatment Decisions."
 - 15 Scherer, "Capabilities of Minors"; Susman, Dorn, and Fletcher, "Participation in Biomedical Research."

- 16 Leiken, "Minors' Assent," 4.
- 17 Bluebond-Langner, DeCicco, and Belasco, "Involving Children with Life Shortening Illnesses."
- 18 Ibid.
- 19 Bluebond-Langner, *In the Shadow of Illness*.
- 20 Bluebond-Langner, DeCicco, and Belasco, "Involving Children with Life Shortening Illnesses."
- 21 Ibid., 337.
- 22 Ibid.
- 23 Ibid., 338–9.
- 24 See Bluebond-Langner and Korbin, "Challenges and Opportunities"; James, "Giving Voice to Children's Voices"; Christiansen and James, *Research with Children*; Pufall and Unsworth, *Rethinking Childhood*; James, Jenks, and Prout, *Theorizing Childhood*.
- 25 Bluebond-Langner and Korbin, "Challenges and Opportunities," 242.

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Size Matters: Medical Experts, Educators, and the Provision of Health Services to Children in Early to Mid-Twentieth Century English Canada

MONA GLEASON

One of the key insights from the growing field of body studies for our understanding of children's historical experiences, particularly from feminist and postcolonial scholars, is that social processes are written upon and taken up by and through bodies.¹ Sociologist Pierre Bourdieu called such unconscious and embodied reproduction of social structures "habitus." For Bourdieu, the concept of habitus encompasses all the ways human beings learn to be in the world – ways that are often taken for granted and assumed to be "natural" – and how, in turn, such embodied knowledge contributes to social reproduction.² In the process of colonization, the work of Mary Ellen Kelm, Anne Fausto-Sterling, and Jeanne Illo demonstrates in differing geographical and temporal contexts, constructing seemingly "natural" differences between acceptable and unacceptable bodies has been central to the success of colonial and capitalist expansion.³ Similarly, as the work of Alison Jones and Kuni Jenkins on the imposition of English handwriting techniques on the indigenous Maori of New Zealand in the nineteenth century eloquently reminds us, corporeality and racialized notions of "civilization" are intimately interconnected.⁴

Attention to the treatment of children's bodies provides a window on how such processes of social reproduction – including those fashioned by race, class, and gender – unfolded in the past. Children are typically constructed as embodied creatures *par excellence*. Indeed, the entire history of Western approaches to child rearing is a history of shaping, training, controlling, adorning, feeding, disciplining, and cleaning small bodies in particular ways.⁵ Historically and contemporarily, mothers are held primarily responsible for the exhausting demands of children's bodywork. Whether

or not a mother carries, delivers, and breastfeeds her child, she is inaugurated into a social arrangement in which the boundaries between her body and those of her children are blurred.⁶

Alongside mothers, the state has authorized certain professionals – among them doctors, nurses, and teachers – to shape, control, train, treat, and discipline children's bodies.⁷ During the latter half of the nineteenth century in Canada, increasingly specialized medical services for children evolved and culminated in the reduction of infant mortality and improved sanitation and nutrition.⁸ Such improvements, however, were predominately enjoyed by white middle-class Canadians, and, as has been argued in other contexts, focused on blaming the inadequate mothering skills of poor immigrant women.⁹ Doctors and nurses worked to control the spread of contagious diseases, promoting vaccination, despite considerable resistance, and eventually directing their energies toward "preventative medicine."¹⁰

Schoolteachers acted as both allies and enemies in this struggle for healthy children. With the advent of legislated school medical inspection, starting in British Columbia in 1910 and spreading around the country, teachers were expected to recognize signs of illness in students and to report them to doctors or – in the case of many rural and remote schools – to undertake examinations of the children themselves.¹¹ Conscientious teachers did so as best they could; others did not. The experience of children in institutional care, including First Nations children in numerous residential schools across the country, testifies to the uneven and inequitable distribution of concern for children's health.¹² By the early 1900s, health would enter the Canadian public school curriculum.¹³ Health textbooks from the period warned, "You have learned enough about your body by this time to understand that when people are sick, it is generally their own fault; either they have not been taught how to care for their bodies, or they are heedless in spite of this knowledge."¹⁴

Despite contemporary anxieties surrounding numerous aspects of Canadian children's health, including levels of obesity, diabetes, asthma, sudden infant death syndrome (SIDS), maternal smoking, substance abuse, and the dangers of anti-depressants for young people, scholars have yet to fully mine the rich history of children and health in the Canadian context.¹⁵ Within the small but growing field of the history of children and childhood in Canada, how children interacted with medical experts and educational systems designed to increase, safeguard, and promote their health remains largely unexplored.¹⁶ This paper undertakes to address this considerable gap in our understanding of children's experiences in the Canadian past. I argue here that the process of building healthy children in early twentieth-century English Canada was complex and contradictory. While state-sanctioned experts

used health discourse to legitimize traditional relations of power, they downplayed and/or ignored the extent to which healthy children were a responsibility left largely to individual families, and particularly, individual mothers. Despite this chasm between professionals and familial strategies, professional judgment around health was a powerful social force shaping ideals of acceptability, and often it determined the nature and tenor of medical treatment that children enjoyed or endured.

To flesh out these critical contentions, the sections that follow focus on three perspectives and three interrelated sources: attitudes toward children's bodies and their health care on the part of conventional medical practitioners; the ideological priorities promoted in health curricula used in Canadian schools; and the memories of adults regarding their own experiences with health and illness in childhood. Twenty years have passed since distinguished historian of medicine Roy Porter remarked that "the sufferer's role in the history of healing – in both its social and cognitive dimensions – has been routinely ignored by scholars."¹⁷ By giving critical attention to childhood memories of health and sickness, a reflection of youthful reactions to these formative experiences might begin to take shape and the meanings attached to them may be more fully explored.

SIZE MATTERS: MEDICAL EXPERTS AND THE CHILD'S PROBLEMATIC BODY

Coming to terms with medical professionals' attitudes toward children's bodies and their health means giving serious attention to size and age as potent categories of critical analysis.¹⁸ Professional attitudes toward both bodily size and chronological age shaped concerns regarding healthy bodies and provided powerful justifications for the treatment that children received. Feminist and postcolonial body scholars fruitfully underline the consequences for women and First Nations peoples of the tendency to construct white male bodies as the measure of normalcy and health.¹⁹ Much of what we know in this regard, however, is predicated on the adult body. Textbooks on pediatrics used in Canadian medical schools, such as Kenneth Fenwick's *Manual of Obstetrics, Gynaecology, and Paediatrics* (1889), legitimized the assumption that notions of normalcy and health were not characteristics readily associated with small, and particularly infant, bodies. By virtue merely of not being adults, children were thought to be vulnerable, out of control, and in other ways pathologically different from the normal adult. Canada's high infant mortality rate and an international campaign to combat such waste of human life made professional anxiety around infants and

the resulting impression of their extreme vulnerability perhaps more understandable. As Neil Sutherland has argued, by the turn of the twentieth century, “probably one out of every five to seven Canadian babies died in the first year or two of life.”²⁰ What is nonetheless striking about professional discourse around children’s bodies and their health in this period, however, is the intensity of assumptions regarding children’s inherent unpredictability: their feeding is problematic, they suffer from “nervous complaints” that come on without warning, they are unreliable sources of information about their own health and are not to be trusted by doctors, and they need to be closely monitored for any number of conditions.²¹

Kenneth Fenwick, for example, conveyed the impression that children – based on assumptions about their small, young bodies – were principally medical problems: “In childhood the tissues are softer, more vascular, and more succulent; the glandular, lymphatic and capillary systems are extremely active; the skin and mucous membranes are softer; more delicate and more sensitive; the brain is large, vascular, and almost fluid in consistency; there is excessive nervous excitability due to want of controlling power; and reflex sensibility is excessively acute.”²² In Fenwick’s text the volatility of children’s bodies is unmistakable and typifies the message that medical students received in Canada at the turn of the century: physicians must be extra cautious around small bodies.²³

Aside from, or perhaps in conjunction with, the volatility of children’s bodies, medical practitioners focused closely on the vulnerability of their small patients. In *Diseases of Childhood* (1926), Hector Douglas Cameron warns, “at the moment of birth there is risk both of trauma and infection.”²⁴ Young children, he states, are born vulnerable to a triad of complications that vex the doctor and parent alike throughout childhood: dietetic disturbances, infections, and severe emotional unrest.²⁵ In 1949, Alan Brown, physician-in-chief at Toronto’s Hospital for Sick Children, and Fred Tisdall, his colleague there, advised doctors in *Common Procedures in the Practice of Paediatrics* that “the physical examination of infants and children presents many problems quite distinct from those encountered in the examination of adults.”²⁶ Young patients, they directed, needed to be thoroughly “inspected” from head to toe. “Judging the child’s cry – its intensity and tenor – is a valuable tool for the diagnosing doctor. Much information can be obtained by observing the child while the mother is being questioned. If the patient is crying vigorously or taking an interest in its surroundings you know at once that it is not acutely ill. In regard to the character of the cry, with a little practice it is possible to determine whether it is due to the patient being hungry or in pain or whether it is merely the result of fright or temper.”²⁷

Not only were children vulnerable to any number of physical threats but they did not give up their secrets easily. As Fenwick reminded his readers, the diagnosis of medical problems was hard enough in adults, never mind the additional complications that infants and children presented for practitioners: "The task is one which requires patience, good nature, and tact for the helpless silence of the infant, the incorrect answers of the older child, the fright, agitation, or anger produced by your examination, or even mere presence, render it difficult to detect the real aberration of function." Toss in the fact, as practitioners did, that the mother represented unreliable sources of information about the condition of the child, and they would surely find the diagnosis of illness in children daunting. As Dr O.M. Moore warned his colleagues in 1941, "children under ten years of age are inaccurate in describing and localizing pain, and in designating areas of tenderness to the physician ... they are particularly susceptible to suggestion, and for that reason should be asked no 'leading' questions unless it is unavoidable."²⁸

Some children, depending on assumptions about racial and class inferiority, were deemed more pathologically problematic and vulnerable than others. Medical professionals at the time tended to blame First Nations' supposed racial inferiority for their poorer health, whereas scholars have since focused on the process of economic and political marginalization endured by many Aboriginal peoples as a more plausible cause.²⁹ Racialized assumptions influenced the treatment or lack thereof that children received. Children of First Nations descent in British Columbia, for example, suffered higher rates of infant mortality and tubercular infection than non-Aboriginal children from the turn of the century up to the 1960s.³⁰

That children's bodies were inherently pathological by virtue of their difference from adult bodies is thus a salient feature of early professional discussions in Canadian paediatric practice. Professional journals aimed at nurses added other nuanced dimensions onto this projection of the vulnerable and volatile child's body. In April 1909 the feature article in the country's leading professional nursing journal, *The Canadian Nurse*, was an anonymously written account of one nurse's experiences in the children's ward of an unidentified hospital. Her accounting of the various children and families she encountered on the ward puts issues of race and class at the forefront. The anecdotes in her account were intended to simultaneously entertain and instruct. She describes how Dennis, a three-year old boy of Irish descent, was undressed "by main force and put in the tub. He evidently, to judge by his struggles, thought we were going to drown him. Probably he had never seen so much water collected in one place before. Also he dreaded to part with that outer covering of dirt; it had been his

own for so long it was well-nigh impossible to take it from him.”³¹ Although Dennis eventually “learns” to be a proper patient, he cannot simply wash away his racialized and classed identity. Drawing on entrenched stereotypes surrounding Irish-Canadians, the author notes that he will likely become “a prizefighter one day for he had just the figure for it!”³²

Similar in its cautionary tone, a feature story entitled “The Little Brother” by Vancouver based writer Rene Norcross appeared in *The Canadian Nurse* of February 1915. Short stories featuring nurses were not a usual feature of the journal. The story revolves around the hospitalization of Mah Too, a fourteen-year-old Chinese boy who had arrived in Vancouver a month before. Very early in the short tale, the author makes clear that the presence of Chinese patients in Vancouver hospitals at this time was not unusual: “Indeed, there was some inclination to regard them [Chinese] as unavoidable nuisances to be dealt with as kindly and patiently as possible.”³³ But Mah Too was young and vulnerable and, significantly, he was singled out for his “astonishing prettiness.” The author takes great pains to establish that he was not a typical Chinese patient. Even Fenton, the orderly of the Men’s Medical, “whose natural feelings towards Chinese patients was that of a well-conditioned terrier towards rats, never passed Mah Too without a smile.”³⁴ Eventually, the boy’s condition deteriorates and he requests, rather pathetically, that he be discharged and allowed to return to Chinatown with his brother, Mah Soon. His doctor’s response was prophetic: “Confound it, that means cutting in half what little time he has left ... He’ll be put into a six by eight hovel with an atmosphere you could cut with a knife and fork and a jabber like a sawmill going on day and night.”³⁵ The hospital surgeon listening nearby offered a sage response: “Perhaps that’s what he misses.” Mah Too’s request is granted, and within a week of returning home, he is dead. There the story ends.

Like the experience of Dennis, race structures the story of Mah Too and the meanings conveyed through it. The specific cause of his suffering, whether diphtheria, tuberculosis, or perhaps pneumonia, is irrelevant. Mah Too’s pathology is his racial identity. The story conveys the message that being Chinese and living in Chinatown in Vancouver at the turn of the century is the illness. That the boy is young, small, beautiful, and dependent on the judgments of those around him makes his demise even more tragic. If only he had stayed within the protective bosom of the hospital, immersed in the superior ways of nurses and doctors trained in Western medicine, he might – according to the tenor of this cautionary tale – have stood a better chance of surviving. But he goes home to Chinatown and in so doing turns his back on the “proper” moral regulation of his young

body. He transgresses boundaries between clean and unclean, healthy and unhealthy, white and non-white, moral and immoral, civilized and primitive.

Conventional medical practitioners of the time conceptualized children in professional discourse as problematic; their bodies were mysterious entities to be deciphered. Social relations of race and class complicated children's health care and occasionally threatened to sabotage it. Children's families were often characterized as complications in need of management. Set firmly within particular social relations, medical experts laid claim to superior knowledge regarding how children's health was to be managed.

EMBODIED CITIZENSHIP: HEALTH CURRICULUM AND THE PROVISION OF MORAL VALUES

Like doctors and nurses, teachers were expected to help build healthy children. Their expertise in general took two official forms: identifying contagious diseases amongst their students, and presenting a prescribed curriculum to cultivate and maintain healthy bodies. Their first duty, that of doctor in absentia, had its roots in turn-of-the-century efforts on the part of public health officials to control the spread of deadly contagious diseases such as smallpox, scarlet fever, and tuberculosis.³⁶ The early evolution of health curricula in Canadian public schools served the priorities of public health concerns.³⁷ The notion of promoting "hygiene" – the science of sanitation – was an integral part of efforts to control contagion amongst individual bodies and in neighbourhoods and communities.

School textbooks, including those used in furthering lessons in health, reflect a great deal about "whose knowledge" counted as meaningful in the past.³⁸ Like their medical school counterparts, public school textbooks reflected the ideological context in which they were conceived and made available.³⁹ Baldus and Kassam remind historians that while examining textbooks cannot tell us how they were taught in the classroom or how they influenced pupils, they can intimate something of the ideological priorities that motivated their production and distribution.⁴⁰ The authorized textbooks in use in Canada from the later years of the nineteenth century to the mid-twentieth can tell us much about educational attitudes toward healthy and unhealthy bodies.⁴¹

From 1880 to 1915, health textbooks produced for and/or used in Canadian schools reflected a social context of considerable change and upheaval. Industrialization and the increasing economic gap between rich and poor, the arrival of new immigrants into expanding cities, the temperance movement, and war in Europe made public schooling an attractive bulwark

against social unrest. Compulsory public schooling for children spread across the country, starting with Ontario by the mid-nineteenth century, Manitoba and New Brunswick in 1871, British Columbia in 1872, Newfoundland and Nova Scotia in 1874, Quebec in 1869 and 1888, the Northwest Territories in 1901, and Alberta and Saskatchewan in 1905.⁴² The values and priorities conveyed in health textbooks in this period reflected this broader social milieu. More than this, however, state-sanctioned textbooks promoted particular notions of the healthy body and healthy habits in order to solidify traditional relations of social power in the midst of social change.

Three recurring themes in the textbooks used between 1880 and 1913 exemplify attempts to use the health curriculum to shore up particular class interests and suggest that children's bodies were potent sites of social reproduction or habitus. First, the health lessons conveyed are firmly predicated on notions of Cartesian dualism: the mind and body are distinct and coexist in a hierarchical, mind-over-body relationship. This made possible the recurring reminder that self-control and an acceptance of one's station in life were signs of good health. In *The Essentials of Health: A Text-Book on Anatomy, Physiology, and Hygiene* (1909), for example, children learned that "what every boy and girl should aim to do is put his [*sic*] body under the control of his mind in matters relating to his own health. That is to say, he should so apply his understanding of the uses of the various organs of the human body and the effects of this or that treatment upon them, that he is able for the most part to avoid those things which will be harmful to his health and cultivate those things which will help to upbuild his physical and mental manhood ... Control of our own bodies, then, based upon a proper understanding of them, is the first step toward the attaining of true manhood or womanhood."⁴³

Influenced by tenets of the Christian temperance movement, this particular passage called upon girls and boys to view abstinence from alcohol and tobacco as part and parcel of their healthful journey to appropriately gendered adulthood.⁴⁴ Despite the veneer of equality between the sexes contained in advice such as this, the social context meant that girls and boys would be expected to tread along different life pathways. Girls were to parlay healthful habits into motherhood and marriage while boys were to prepare for public roles of leadership and governance.⁴⁵

Following on this theme, the textbooks place the blame for sickness and disease on the failings of the individual. Whether the result of ignorance, wickedness, or wilful disobedience, poor health is presented as partly a matter of choice. Dr A.P. Knight, professor of physiology at Queen's University in

Kingston, Ontario, and author of *The Ontario Public School Hygiene* (1910), reminded young readers: "one thing is certain, that, if nations or individuals break the rules of health, they will be punished ... Nature will take no excuse for not knowing the rules."⁴⁶ In *How to be Healthy*, a 1911 textbook written by Manitoban doctor J. Halpenny and used in schools all over Western Canada, good health and vigour were unmistakably moral virtues reserved for those who chose to live "a sensible, normal life." By extension, those who struggled with poor health were cast with the pallor of immorality, bad choices, and weak wills. Students were instructed, "when real difficulties come to us, let us meet them manfully, and win or lose, but never hold onto them or brood over them. This is the cause of much ill-health. Our right to be happy must not be interfered with by anything ... Once we begin to brood, our power to do difficult things and our course to face the trouble begins to fail. Thus we weaken ourselves."⁴⁷ Equating moral weakness with ill health took on heightened meanings in communities where racialized minorities – particularly First Nations peoples, by virtue of their "Indianness" – were thought simply incapable of looking after their health.⁴⁸

Third, the texts in this period attempt to use the notion of "science" in the form of germ theory, eugenics, and sanitation to legitimize unequal social relations. The message that germs and disease cause illness, for example, is often mixed with tenets of eugenics and the dangers of race suicide. Gage's *Health Series for Intermediate Classes* (1896), authorized for use in middle schools in Manitoba and British Columbia, seized on the discourse of heredity to dissuade young Canadians from indulging in alcohol: "Probably no one ever suffered from all the diseases produced by alcohol, but all habitual drinkers sooner or later experience one or more of them. And their children are more likely to inherit stronger appetite for narcotics and a weaker will with which to control it ... The taking of a single glass of liquor, the eating of brandy sauce or wine jelly, may rouse his inherited desire, though its predecessor may not have discovered that the taint is in his blood; the appetite, becoming uncontrollable, may bring its owner to a drunkard's grave."⁴⁹

By 1910, authorized health texts conceded that environmental factors – the state of cleanliness, health habits, and dwellings – had an important part to play in determining the state of individual health. Still significant, however, was heredity stock. As Dr Knight wrote, "If you have followed the teachings of this book thus far, it must be clear to you now that our lives from birth until old age are shaped largely by two great influences: (1) by what we inherit from our parents, grandparents, or other ancestral relatives, and (2) by our environment, that is, by our surroundings."⁵⁰

Between the end of the World War I and the beginning of the World War II, some notable shifts occurred in the social values and messages conveyed in authorized health textbooks. By and large the Christian temperance discourse that blamed ill health on personal wickedness and inferior inheritance was replaced with a more nuanced set of dictums. By 1925, for example, youngsters discovered that “now boys and girls should be happy, and they should not worry about sickness at all ... they should know that, even though they carefully carry out the rules of health, healthy bodies alone will not protect them from certain diseases.”⁵¹ This shift reflected changes in medical science and the ideals of progressivism or the “new education” that swept through North America in the 1920s. Taking its cue largely from developments in child psychology, progressive educational philosophy sought to abandon what was understood as the worst of “formalist” or traditional pedagogy – strict classroom discipline and learning by memorization and drill – and to replace it with child-centred learning that focused on investigation, cooperation, and mutual respect.⁵² In conjunction with the influence of progressivism, political and social turmoil in the face of the Great Depression, increased immigration, and another world war, educators looked for opportunities to promote new understandings of democratic citizenship. Health textbooks presented a particularly effective forum in this regard.

Like that produced and/or circulated in the earlier period, the health curriculum between the wars reflected state-sanctioned values, priorities, and goals. It also reflected social anxieties and fears that plagued those in positions of social influence. In particular, the theme of democratic citizenship – what it was and how it was to be achieved – began to shape the content of the texts. The “usefulness” of a health curriculum became a more overt concern and suggests that at least some educators questioned its efficacy. The authors of the *Ontario Public Health Book* (1925) surveyed the province’s teachers to determine how to present a health curriculum in a more engaging manner. They learned that “a suitable book in hygiene should be interesting to the pupils, free from technical terms, and contain only such physiology as is necessary; and that its aim should be to arouse a desire for proper living, to develop health habits, and to teach the pupils of our public schools some simple means for the prevention of disease.”⁵³

The belief that successful health teaching relied only minimally on physiological knowledge is significant and tended to characterize textbooks used in primary grades. *Wide-Awake School*, published in 1931 and authorized for schools in Quebec and British Columbia, is a good example of this newer approach to health pedagogy. Written in the form of a chapter book, it

tells the story of the schoolchildren of Drowsy Town and their efforts to improve their health and that of their community. When they are challenged by the children in the neighbouring town to lower their school absenteeism, miraculous transformations take place. Thanks to the efforts of the Drowsy Town children to be healthy and thereby stay in school, the community itself is saved. According to the mayor, "we older people are trying to keep up with this health procession by cleaning up Drowsy Town. We now have clean streets. We are making a great fight to get rid of flies and mosquitoes; a garbage man has been hired to collect all the garbage every Monday morning, and we have dug several ditches to drain the swamps. You have noticed that screens are on the windows and the town seems a different place from what it was a year ago. We owe much of this to you, because you were first to wake up."⁵⁴ In the context of the "new education," health pedagogy becomes a vehicle for lessons in "waking up" civic responsibility and citizenship. Healthful habits are those that not only improve the individual's well being but radiate outward to strengthen entire communities.

Ultimately, the goal of forming positive "health habits" was to foster happiness in oneself and service to others. Aside from presenting the material in the form of stories, teachers were encouraged to have their students fill out health scorecards and to compete amongst themselves and other classes for health points. (See appendix, figure 1.) The health scorecard promoted in *Health Essentials for Canadian Schools* (1938), part of the Canadian Hygiene Series, and prescribed by the minister of education for use in British Columbia, encouraged student participation in forming "health habits." The scorecard was divided in sections such as posture ("3: books carried at arm's length, extended downward, and changed from one hand to the other, 1 point"), food ("10: no coffee, 2 points"), exercise ("15: one half hour (at least) of enjoyable outdoor recreational activity each day, 5 points"), and home environment ("27: quiet room for study, 2 points").⁵⁵

Good health was now overtly connected through able-bodiedness to democratic citizenship. The significantly titled *New Ways for Old* (1938) placed self-conscious emphasis on the connections between health, civic pride, and belonging to the nation: "New beliefs about what education should do have made great changes in schools. Learning the three R's was the chief activity of the old schools, but the aim of the new schools is learning to live ... Learning to live in a modern school, means that each boy and girl may grow strong and sturdy, in mind and body, and may become the best person possible for him to be, for his own sake, and for his home and community."⁵⁶

Although a health curriculum such as this prided itself on being innovative ("the aim of the new schools is learning to live"), several more traditional

notions regarding healthy bodies endured. Cartesian dualism, the separation of body and mind, and self-control continued to influence how children and young adults were encouraged to think about their embodied selves. “No matter what you wish to do in the world,” suggested J. Mace Andress and Elizabeth Breeze in *Health Essentials for Canadian Schools* (1938), “your ability to control your own mind and muscles must be the basis of your success.”⁵⁷ It is significant to note, however, that children who lacked embodied control – the disabled or the mentally ill – could be easily set aside as only partial participants in “home and community.”⁵⁸

Behind admonishments regarding diet, study habits, and care of the body, textbooks gave credence to white middle-class assumptions and anxieties regarding gender, race, and class at work in the interwar years. Textbooks aimed at a high-school audience, for example, targeted girls’ presumed interest in “beauty” as an opportunity to promote particular attitudes toward health and gender. Authors discouraged young women from turning to the ever-expanding array of beauty products aimed at young consumers. Far from being healthful, they were warned, some products were potentially lethal. “Some of the creams advertised for their miraculous powers contain lead, from which poisoning may arise,” cautioned one writer. “No magic should be expected.”⁵⁹ A 1938 textbook warned young women that the inexperienced use of makeup might damage wholesome reputations: “The best-looking people are usually the well-groomed and natural-looking ones. Scarlet cheeks and lips take away from the interest of one’s eyes, and from the natural harmony of one’s features. A natural glow is more attractive than the most artful make-up.”⁶⁰ Securing a “natural glow” was presumed to be an important goal for young girls. All “natural glows,” however, were not equally acceptable. The appearance of acne, a condition that plagued teenagers of both sexes, is discussed solely as a failure to adhere to good health habits. Those youngsters unfortunate enough to suffer from acne would have learned that “skin disturbances are common especially among young people who do not choose a well-balanced diet, or those who neglect sleep, rest, or outdoor exercise, or their habits of personal cleanliness.”⁶¹

Home settings and eating habits associated with urban Anglo-Celtic middle-class traditions were promoted as the healthiest and therefore most socially acceptable. Foods such as potatoes, beans, spinach, onions, string beans, squash, cauliflower, parsnips, turnips, daily rations of lean meat, eggs, and whole-grain breads are singled out as healthy fare.⁶² In *Healthy Citizenship* (1935), the authors offered detailed descriptions of “good housing” that included a free-standing home, a garden plot, surrounding

yard, lots of sunlight and fresh air, and a sleeping-porch.⁶³ Children would also learn that particular furnishings, including newer lightweight carpets and draperies, domestic technology such as vacuum cleaners, and washing with ample amounts of hot water characterized the healthy home. Families in more crowded circumstances, in apartment complexes or perhaps multi-family dwellings without modern conveniences, who ate foods not sanctioned in the health curriculum, would not find themselves reflected in state-sanctioned notions of good health. Through the health curriculum, food, and space became not only racialized and classed but acted as indices of membership within the bounds of Canadian citizenship.⁶⁴

HEALTHY BODIES REMEMBERED

While medical training textbooks, professional journals, and school curricula disseminated particular ideas about the nature of children's bodies and their health, it is difficult to know how and whether these ideas made their way in the everyday lives of children and their families. How were children treated by doctors? What did children take away from health lessons in schools? Did they develop the health habits their textbooks recommended?

To make more visible the reception of expert attitudes and advice regarding healthy bodies, this section highlights memories of adults who were born or grew up in Canada in the early to mid-twentieth century.⁶⁵ Of the themes that emerge through these childhood memories, the most striking is the degree to which promoting and maintaining good health was experienced as a family responsibility, and particularly a responsibility fulfilled by mothers. Visits from doctors and nurses were few and far between or something to be avoided; schools tended to be remembered as rather unhealthy places, even more so in isolated communities; and lessons in health tended not to stand out. Nevertheless, some informants vividly remember experiences of illness, pain, and injury, and not always negatively. The memories suggest that expert discourse on healthful living and healthy bodies was often at odds with the needs and capacities of families. Nevertheless, the dictates of professionals represented powerful benchmarks against which families measured their ability to conform.

Family strategies to deal with illness or to prevent it emerge as central themes in a number of the childhood memories. This was particularly true in sparsely populated areas. Rural families lived in virtual isolation from each other. Verne Nelson, born in 1913 in Bruce, Alberta, recalled "all we knew we learned from our young parents."⁶⁶ For many remote communities, professional health care was any number of miles away and, in an era before

socialized medicine, potentially expensive. People had to make do as best they could. In 1915, at the age of fifteen, Mike Harbuz suffered a broken leg while working on the family farm. When neighbours travelled to fetch the closest doctor in the next town, he was not at home. Rather than do nothing or risk an amputation, Harbuz was taken to a neighbour known as a "good bone setter." He was walking with crutches some three months later.⁶⁷

Even when epidemics of contagious diseases befell a family or whole communities, parents and neighbours, not necessarily professional doctors and nurses, endured the burden of care. When Mike Harbuz's father failed to find a doctor to help with a spreading epidemic of scarlet fever in their town in Alvena, Saskatchewan, he took the advice of a local priest instead: "Dad went to Rosthern for the doctor but he stopped at the Fish Creek store to see the French priest. The priest told Dad to get some wine and tea. A couple of teaspoons of wine in a cup of hot tea should be fed to the children until the tonsils were better. In a week, with the hot tea and wine, we were all better."⁶⁸

While fathers were important, mothers were more routinely expected to take the lead in safeguarding their family's health. Eileen Scott, born in 1919 in Brandon, Manitoba, endured many illnesses as a child and looked to her mother as her primary health-care provider: "She saved my life on more than one occasion by knowing what to do."⁶⁹ The fact that many mothers "knew what to do," however, did not lessen the stress and strain of tending to sick children. As Verne Nelson recalled, when she, her siblings, and her relatives contracted measles, "our mothers, bone-tired, moved from one sick child to the next, carrying drinks, chamber pots, and hot water bottles and tending to the unending demands of feverish, peevish, and often desperately sick children ... they had little rest and no relaxation."⁷⁰

Cultural traditions shaped by ethnic and racial identities were decisive forces in the kinds of care children received and the meanings such care conveyed to them. Non-white traditions, because they stood outside boundaries of sanctioned practice, carried with them the stigma of social unacceptability, quackery, and backwardness.⁷¹ In an era when entrenched racism shaped the experience of Chinese immigrants who came to Canada, Sing Lim, born in Vancouver's Chinatown in 1915, recalled that neighbourhood herbalists provided traditional ingredients for healing. Cultivating familiar and effective methods for treating sickness was a matter of survival. Lim recalled the remedies of Mr Kwong as "mostly vegetable ... hundreds of little drawers contained herbs: ginseng, seeds, dried buds and blossoms, taro roots, bark and seaweed ... other drawers held stranger things: dried insects, rhino skins, dried snakes, and lizards, and animal horns."⁷²

When Minnie Aodla Freeman, an Inuit born in 1936 on Cape Horn Island in James Bay, developed impetigo as a young girl, the prospect of receiving care at the hands of white medical practitioners was a source of stress. She recalled that "the word *naniasituk* began to be mentioned often by my grandparents ... it can mean medicine, nurse, doctor, or a person who tends the sick ... to me, it meant horror, fear and pain."⁷³ Even into the 1950s, parents continued to figure prominently as healers in some families. In keeping with traditional First Nations practice, for example, one Secwepemc informant from the Sugar Cane Reserve in Williams Lake, British Columbia, recalled that his mother often prepared medicine: "I think most of the remedies, my mom made them. And some of them were from different plants that she would gather ... Or, she would buy certain things and make things ... there was a hot kinda tonic that she made – I think it had ginger and honey and some other stuff in it."⁷⁴ William Macklon, born in 1919 in Kinley, Saskatchewan, and one of five children, succinctly encapsulated how many Canadian children in the early decades of the twentieth century experienced medical care: "For the most part doctoring was a domestic art practised by mothers, and every kitchen cupboard had a medicine shelf where she kept her favourite remedies ... what she kept depended largely on the ethnic makeup of the family."⁷⁵

It was often at school, rather than at home, that children encountered more formalized medical interventions. These experiences were both empowering and terrifying for children. Schools themselves were remembered as rather unhealthy places. In the early 1920s in Wildwood, British Columbia, Ingrid (Andersen) Cowlie attended a one-room schoolhouse that housed six grades. While the authorized health curriculum of the time warned teachers and children about the dangers of contagious diseases, Cowlie remembered that "the school had no electricity or running water. Water was brought in a bucket from my place, the Andersens. It was kept in an enamel container with a tap. We all drank out of it from the same cup! Near the school were two outhouses, one for the boys and one for the girls."⁷⁶ Cowlie's recollections are not unique. Many schools across the country were notorious for lack of proper sanitation, washroom facilities, and even enough physical space for the number of students in attendance.⁷⁷ Kay Hodgson recalled that at the Cranberry Lake School in Malaspina, British Columbia, "we had outside toilets until 1933 – and no place to wash our hands!"⁷⁸ Many schools were remembered as places where disease and illness spread effortlessly from child to child. In a one-room schoolhouse in Saskatchewan in the mid-1920s, recalled Robert Collins, "We huddled in double-knit sweaters, feet like blocks of ice, noses always

clogged, mouths stained black from Smith Brothers cough drops, hacking and sneezing in a cacophony of misery.”⁷⁹

For First Nations children, residential schools could be places of extreme risk to health, particularly their spiritual health. As Minnie Aodla Freeman recalled of her time at St Thomas Anglican School in Moose Factory in the 1940s, “their bannock was terrible ... I forced it all down ... a few times I could force myself ... out it would come with the force of a strong leak in a canoe, all over the floor ... I would be put to bed, my forehead would be felt and my temperature taken. That’s when I felt most lonely, in this great big bedroom with two hundred beds in it.”⁸⁰

Despite Minnie’s largely negative experience of residential school, the health and hygiene lessons offered in classes made a significant difference to her family. When her father was struck down with pneumonia, she was able to put what she had learned about health to good use by making a mustard plaster to ease his suffering. She credits this plaster with helping her father recover.⁸¹ Marion Gallagher attended school in Victoria, British Columbia, in the 1930s and recalled “all our belongings had to be labelled and a fresh, clean, ironed cotton handkerchief brought to class every day!”⁸² Robert Collins’s experience was, however, very much the opposite. According to him, the teacher rarely discussed health. When it was brought up, the subject matter was distinctly forgettable. “We raised our fingernails for inspection,” Collins remembered, “and lied about whether we had brushed our teeth, drunk eight glasses of water and slept for eight hours ... so much for the subject known as Health.”⁸³ An informant who grew up in the 1940s in Barrie, Ontario, when asked if she recalled being examined by a school nurse, said, “Not that I remember. I think I can remember a nurse coming to the school – what was it for – to talk about, to talk about hygiene I think. Maybe it was for shots. I don’t recall. Whatever it was, it didn’t make a big impression anyway.”⁸⁴ Similarly, an informant who attended a First Nations band school in the British Columbian interior in the 1950s stated, “I remember rolling this big barrel of skimmed milk and carrying boxes of some kind of crackers or pilot biscuits or something home that the school provided ... so that was the school’s nutrition program.”⁸⁵

Within some families the experience of illness could mark a time of mediated pleasure for youngsters. Being sick often challenged standard hierarchical relationships between adults and children and introduced quite different dimensions. Anna Friesen recalled from her childhood in Winnipeg in the 1920s, “Softly Mother’s hand felt my fevered cheeks, then rested lightly on my forehead. Then she pulled up my blanket and tucked it gently around me. After pausing motionless beside me awhile, she tiptoed away. I felt as if an angel

had visited me, and my illness seemed inconsequential.”⁸⁶ A female informant growing up in Vancouver some thirty years later had a similar tale: “I do recall the times of illness as actually special times when I received my mother’s sole attention ... as the last of five kids, I savoured the feeling of closeness it brought ... she [my mother] was always kind and patient when I was ill and I will never forget the feeling of her small cool hand on my fevered brow!”⁸⁷

For Ruth Cook, a Tsimthian woman born in 1931 near Prince Rupert, who attended residential school, the experience of illness depended very much on context. At home, she recalled, “you never had to worry if you got sick ... you always had an uncle or an aunt, or the grandparents were there to lend a helping hand.”⁸⁸ Such memories suggest that, from the point of view of some children in particular circumstances, times of illness were not simply times of unmitigated distress. They could be far more complex, reflecting the centrality of family culture and of sentimentality in influencing children’s experiences with health and illness.

CONCLUSIONS

From the point of view of those with considerable social power, such as doctors, nurses, and teachers, children’s bodies in the early part of the twentieth century were conceptualized as weak and susceptible to serious medical problems. They were also seen as socially “primitive” and in need of civilizing. To intervene in their care and treatment – in the doctor’s office or in the classroom – was to inculcate acceptable moral values. Through the body, medical practitioners and educators attempted to legitimize and reproduce traditional hierarchies of power.

When the discourse of professionals is positioned alongside the memories of adults, the fissures between are imbued with additional meanings. On and through children’s bodies, social acceptability, civilizing and colonizing techniques, interests of the state, and so-called “good health” were written and operationalized and vied for space. The lived memories of adults who grew up in different communities in Canada suggest that the family’s primacy in the embodied care of children was simultaneously denied, downplayed, and disparaged even as it was employed for social reproduction.

The theoretical scaffolding that helps support my interpretation of these interconnected perspectives places the body – and in this case, the small bodies of children in times of health and illness – at the forefront. The way conventional medical experts, teachers, and parents thought about and treated children’s bodies reproduced social relations of power, social

priorities, social fears, and social prejudices. Both the connections and chasms between the health dictates of experts and familial realities worked to legitimize dominant-subordinate relations. As intertwined forces shaping children, expert discourse and familial strategies regarding health contributed to children's embodied habitus. Through the body, children learned and took up their various places in the hierarchal world of their families. As one informant born in Winnipeg in 1913 suggested, "Learning to be healthy? We didn't know a blessed thing about vitamins or things, just 'eat your carrots, they're good for you!'"⁸⁹

APPENDIX

My Health Record

Name _____ School _____
Grade _____ Teacher _____

Directions: (1) Count one for every point of the Daily Health Program you have kept each day. (2) Pupils who are up to average weight who are gaining properly may have credit for milk and rest at school, without taking them.

(3) Add one point for four glasses of water drunk between meals. (4) Count one off for each of these health faults:

(a) Putting pencils in the mouth or anything except for eating, drinking, or cleaning teeth. (b) Sneezing or coughing without using handkerchief. (c) Going a whole day without going to toilet. (d) Eating candy or pickles between meals. (e) Drinking stimulating drinks such as tea, coffee, and coca-cola.

Wash

Clean teeth

Milk for breakfast

Cereal for breakfast

Fruit for breakfast

Milk at school

Rest at school

Out-door play after school

Wash for supper

Milk for supper

Fruit or green vegetables

Stay at home all evening

<p>Clean teeth</p> <p>Bed at (7–8–9)</p> <p>Sleep with open windows</p> <p>Score for day (20 is perfect)</p> <p>Weight</p>

Source: J. Mace Address, *Wide-Awake School* (Boston: Ginn and Co., 1931), 33.

NOTES

I would like to thank Natalie Chambers and Lori MacFadyen for their invaluable research assistance and the Social Sciences and Humanities Research Council, Government of Canada, for funding support.

- 1 Schiebinger, "Introduction," *Feminism and the Body*, 1–24; Turner, *The Body and Society*, 103–25.
- 2 Bourdieu, *Distinction*.
- 3 Kelm, *Colonizing Bodies*; Fausto-Sterling, "Gender, Race, and Nation," 203–33; Illo, "Fair Skin and Sexy Body," 219–25.
- 4 Jones and Jenkins, "Disciplining the Native Body," 34–46.
- 5 See, for example, Arnup, *Education for Motherhood*; Comacchio, "Nations Are Built of Babies."
- 6 Nakano-Glenn, Chang, and Forcie, *Mothering: Ideology, Experience, and Agency*; Griffith and Smith, "Constructing Cultural Knowledge."
- 7 In the Canadian context, see Gleason, "Race, Class, and Health," 95–112; Gleason, "Disciplining the Student Body," 189–215; Gleason, "Embodied Negotiations," 113–37.
- 8 Young, "'Little Sufferers,'" 129–42; Duffin, *History of Medicine*, 303–36.
- 9 On the centrality of class and race to attempts to "fix" families, see Comacchio, "Nations Are Built of Babies," and Ball and Swedlund, "Poor Women and Bad Mothers," 31–52.
- 10 On resistance to the push for Canadian children's vaccination in the early twentieth century, see Arnup, "Victims of Vaccination?" 159–76.
- 11 Gleason, "Race, Class, and Health," 98–107.
- 12 See Law Commission of Canada, *Restoring Dignity*; Kelm, *Colonizing Bodies*.
- 13 Smith and Peterat, "Reading between the Lines," 242–67.
- 14 *Gage's Health Series*, 159. This was authorized for use in the schools of Manitoba and British Columbia.
- 15 An important exception is a recent issue of the *Canadian Bulletin of Medical History* 1 (2002) devoted to children's health. For a commentary on the paucity of

attention to the history of children in Canada generally and their health experiences specifically, see Strong-Boag, "Spotlight on Children," 5-16. For contemporary reportage on various aspects of children's health, see Gram, "Fitness Gets a Failing Grade;" Picard, "Toxic Soup;" Mittelstaedt, "Taking Shots at Vaccination;" Bramham, "Depressed Kids;" Leblanc, "Chrétien Pledges Aid for Innu;" Macdonald, "Twelve Gas-Addicted Innu Children."

- 16 Notable exceptions include the classic study done by Sutherland, first published in 1973 and reissued in 2000. He focuses mainly on the role of public health in shaping attitudes toward children and their families in English Canada over the turn of the century; see Sutherland, *Children in English-Canadian Society*. See also Comacchio, *Nations Are Built of Babies*.
- 17 Porter, "The Patient's View," 175-98. See also Strong-Boag, "Spotlight on Children," 5-16.
- 18 On the use of age as a category of analysis see Chudacoff, *How Old Are You?* The interdisciplinary potential of age consciousness as an interpretive factor is explored in *Childhood and Old Age: Equals or Opposites?* edited by Povlsen et al.
- 19 See, for example, Mitchinson, *The Nature of Their Bodies*; Mitchinson, "Problematic Bodies," 266-86; Kelm, *Colonizing Bodies*.
- 20 Sutherland, *Children in English-Canadian Society*, esp. ch. 4. See also Comacchio, *Nations Are Built of Babies*, 16-42.
- 21 See for example, Grey, *Queer Questions Quaintly Answered*; Race, "Milk Supply," 378-83; Moore, "Child Welfare Work," 634-5; Wiggins, "Management of Posture," 47-51; Wishart, "Problem of the Deaf Child," 254-60; Moore, "Peptic Ulcers in Children," 462-6.
- 22 Fenwick, *Manual of Obstetrics*, 192.
- 23 See also Chapin and Pisek, *Diseases of Infants*; Ashby, *Health in the Nursery*.
- 24 Cameron, *Diseases of Childhood*, 6-7. This text was utilized by teaching staff at the University of British Columbia's Faculty of Medicine.
- 25 Ibid.
- 26 Brown and Tisdall, *Common Procedures*, 7. The first edition appeared in 1929. The fourth edition was revised to reflect the arrival of sulpha drugs, and to reflect "a better understanding of the fundamental principles of mineral metabolism" (preface to fourth edition).
- 27 Ibid., 7.
- 28 Fenwick, *Manual of Obstetrics*, 193-4; Moore, "Peptic Ulcers in Children," 462.
- 29 Bell, *The "Medicine-Man"*; Ferguson, "A Tuberculosis Survey," 381-3; Vivian et al., "Nutrition and Health of the James Bay Indian," 505-18; Read, "Preventive Pediatrics," 721-6; Bain, "Canada's Native Children," 1237-8; Moffatt and Herring, "Historical Roots," 1821-32.
- 30 See British Columbia, *Thirty-Fourth Report* R18-19. In 1929, 31 per cent of all deaths in Native communities were caused by tuberculosis, compared to 6.7 per cent

in the rest of the province. See also Moffatt and Herring, "Historical Roots," 1821-32.

31 Fuller, "In the Children's Ward," 176-7.

32 Ibid., 176.

33 Norcross, "The Little Brother," 436-8.

34 Ibid., 436.

35 Ibid., 437.

36 On the evolution of school medical inspection in the Canadian context, see Gleason, "Race, Class, and Health."

37 Smith and Peterat, "Reading between the Lines," 242-3; Sutherland, "'To Create a Strong and Healthy Race,'" 304-33; Smith, "Dampness, Darkness, Dirt, Disease," 195-218.

38 Apple and Christian-Smith, "Politics of the Textbook," 1-21.

39 Baldus and Kassam, "'Make Me Truthful, Good and Mild,'" 327-58.

40 Ibid., 327-8.

41 The proscribed texts explored in this section convey themes, concerns, values, and beliefs repeated in other authorized books. They include, in order of publication, Provincial Board of Health of Ontario, *Manual of Hygiene for Schools and Colleges*; Gage, *Gage's Health Series for Intermediate Classes*; Stowell, *Essentials of Health*; Halpenny, *How to Be Healthy*; Knight, *Ontario Public School Hygiene*; Fraser, *Ontario Public Health Book*; Ritchie and Caldwell, *Physiology and Hygiene*; Andress, *Wide-Awake School*; Andress and Evans, *Healthy Citizenship*; Andress and Breeze, *Health Essentials for Canadian Schools*; Wood, Lerrigo, and Lamkin, *New Ways for Old*.

42 On the history of schooling legislation in Canada, see Wilson, Stamp, and Audet, *Canadian Education*; Johnson, *A Brief History of Canadian Education*.

43 Stowell, *Essentials of Health*, 253. This text was "prescribed for use in the Public and High Schools of British Columbia" (preface).

44 On the significance of the temperance movement in Canada, see Christie, *Holds of Faith*.

45 Mitchinson, *The Nature of Their Bodies*; Strong-Boag, *New Day Recalled*.

46 Knight, *Ontario Public School Hygiene*, preface.

47 Halpenny and Ireland, *How to Be Healthy*, 54.

48 Kelm, *Colonizing Bodies*.

49 *Gage's Health Series for Intermediate Classes*, 39.

50 Knight, *Ontario Public School Hygiene*, 229.

51 Fraser and Porter, *Ontario Public Health Book*, 11.

52 Sutherland, "The Triumph of 'Formalism,'" 175-210.

53 Fraser and Porter, *Ontario Public Health Book*, preface.

54 Andress, *Wide-Awake School*, 181.

55 Andress and Breeze, *Health Essentials for Canadian Schools*, 12.

- 56 Wood, Lerrigo, and Lamkin, *New Ways for Old*, vi.
- 57 Andress and Breeze, *Health Essentials for Canadian Schools*, 242.
- 58 On assumptions regarding able-bodiedness and access to citizenship, see Meekosha and Dowse, "Enabling Citizenship," 49–72.
- 59 Andress and Breeze, *Health Essentials for Canadian Schools*, 243.
- 60 Wood, Lerrigo, and Lamkin, *New Ways for Old*, 282.
- 61 Ibid. 275.
- 62 Andress, *Wide-Awake School*, 134.
- 63 Andress and Evans, *Healthy Citizenship*, 51–2.
- 64 On the racialization of Canadian citizenship, see Denis, "Indigenous Citizenship," 113–28.
- 65 Memories are drawn from both autobiographical and oral history testimony. I consulted approximately thirteen autobiographies for memories regarding health and illness and included data gathered from five oral interviews. On the problems and potentials associated with autobiography as an historical source, see Sutherland, *Growing Up*, esp. ch. 1, 3–23; Sturrock, *Language of Autobiography*, 1–19; and Coe, *When the Grass Was Taller*.
- 66 Nelson, *Barefoot on the Prairie*, 3.
- 67 Harbuz, *Ukrainian Pioneer Days*, 15–16.
- 68 Ibid., 13–14.
- 69 Scott, *Porridge and Old Clothes*, 26.
- 70 Nelson, *Barefoot on the Prairies*, 39–40.
- 71 On the denigration of non-white medical practices amongst First Nations communities, see Bell, *The "Medicine Man"*; Kelm, *Colonizing Bodies*. See also the discussion of the dangers of traditional health practices in McCullough, "Chatelaine's Baby Clinic," 54; Campbell, "The Spastic Child," 471.
- 72 Lim, *West Coast Chinese Boy*, 18.
- 73 Freeman, *Life among the Qallunaat*, 98.
- 74 Interview 2, 26 February 2004, transcript, 6.
- 75 Mackon, *The Fledgling Years*, 18.
- 76 Cowlie, "Memories of the First Wildwood School," 110.
- 77 In the British Columbian context, for example, see Gleason, "Race, Class, and Health."
- 78 Hodson, "Malaspina Cranberry Lake School," 118.
- 79 Collins, *Butter down the Well*, 45.
- 80 Freeman, *Life among the Qallunaat*, 104.
- 81 Ibid., 125.
- 82 Gallagher, "School Days in Victoria," 276.
- 83 Collins, *Butter down the Well*, 42.
- 84 Interview 3, 27 February 2004, transcript, 9.

- 85 Interview 2, 26 February 2004, transcript, 1.
- 86 Friesen, *The Mulberry Tree*, 14.
- 87 Interview 5, 14 February 2001, transcript, 2.
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PART FOUR

Measuring Child Health

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More Than the Names Have Changed: Exploring the Historical Epidemiology of Intellectual Disability in the United States

JEFFREY P. BROSCO

Few people in the United States have devoted more attention to improving public policy for persons with disabilities than Eunice and Sargent Shriver. When John F. Kennedy was president, his sister Eunice and brother-in-law Sargent used their informal political clout and personal resources to ensure that the federal government invested substantial resources in programs for persons with intellectual and other developmental disabilities. In part because Eunice and John's sister Rose had a neurodevelopmental disability, the Kennedy family has focused its considerable financial and political might on developmental disability issues over the past five decades.¹ It was not surprising, then, that at a board meeting in 2002, the still-active Sargent Shriver would ask whether their work had made any difference. Using the scientific terminology for mild intellectual disability (ID) common in the early twentieth century, he asked, "What happened to the morons? What have we done for the morons?"*

Perhaps Shriver's questions were merely personal – a public servant reflecting on decades of service. As a historian and developmental pediatrician, however, I was fascinated by the policy implications of his questions. Although the disability rights movement began with local grassroots efforts by families as early as the 1930s, Shriver sensed correctly that it was the Kennedy administration that instituted major federal involvement in developmental disabilities.² In the early 1960s, Kennedy appointed a panel on

* Personal communication, Best Buddies Board Meeting, Miami, May 2002. In this essay I have chosen to use the term "intellectual disability," though there is not yet consensus on its use to replace the more familiar American English term "mental retardation." "Developmental disability" refers to a broader category of disabling conditions that do not necessarily include impaired cognitive ability, such as cerebral palsy and autism.

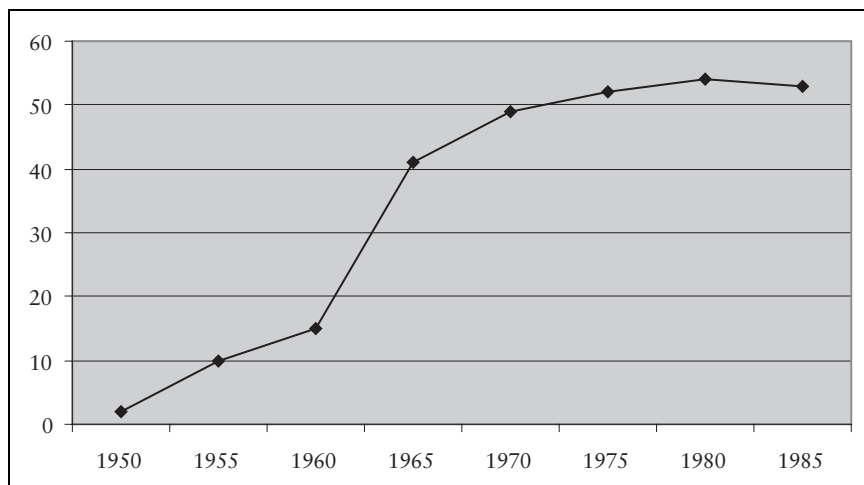


Figure 1.

Number of United States federal programs for persons with developmental disabilities.

intellectual disability, which recommended an emphasis on training a special education workforce and investing in scientific research. The panel boldly predicted that their recommendations would lead to a 50 per cent reduction in the number of persons with ID by the year 2000. Since 1960 the number of federal ID programs has grown to more than fifty, with overall spending topping \$40 billion per year (figures 1 and 2). The nation's investment in the research laboratory has led to specific medical interventions to prevent ID – but what was the overall impact on the number of persons with ID?

Shriver's seemingly simple question is not so easily answered. Exploring the historical epidemiology of ID in the United States over the past century is not merely a question of counting persons with ID then and now. It also requires understanding why investment in science to prevent ID made sense in the mid-twentieth century, how definitions of medical conditions reflect broader historical trends in U.S. history, and how investments in public health, educational, and economic programs may have had a greater impact on the prevalence of ID. In some ways Shriver was asking a much broader question: Is the American health care system's traditional focus on technologically sophisticated medical interventions delivered at the hospital bedside or doctor's office the best approach to improving child health? This chapter offers one preliminary answer to this key public policy question.

There is a limit to using historical epidemiology to answer Shriver's question, and it is implied in his use of the antiquated meaning of the word

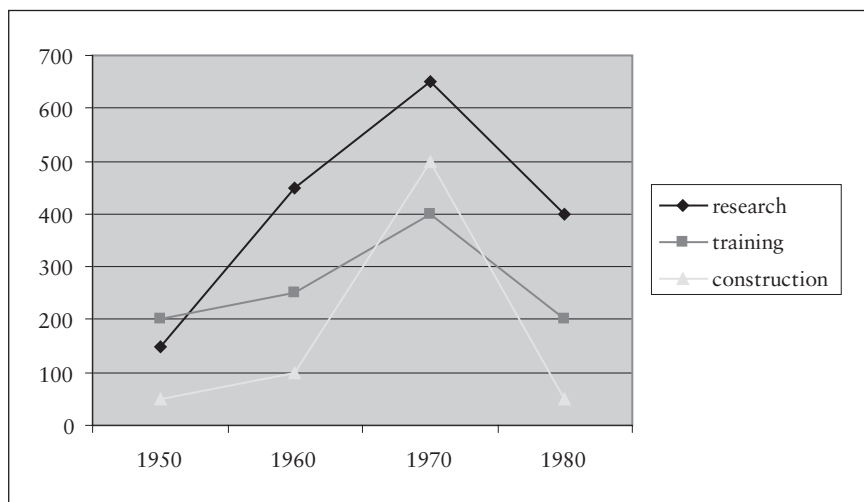


Figure 2.

Federal spending for persons with developmental disabilities (thousands of U.S. dollars, 1980).

Note: The peak in construction funds reflects the building of dozens of “University Affiliated Facilities,” institutions devoted to research, training, technical assistance, and policy development.

“moron” to mean mild ID. Since the 1960s the disability rights movement has led to dramatic improvements in the lives of persons with developmental disabilities, and changes in attitudes, laws, and practice are surely more important than the prevalence of any one condition. Nonetheless, investigating the historical epidemiology of ID reveals much about the history of medicine in the twentieth century. As Charles Rosenberg and others have argued, the boundaries of specific medical diagnoses are constructed by a complex interaction of social, political, and scientific factors.³ The historical epidemiology of ID in the United States highlights this interaction between science and politics and provides a historical platform for future policy discussions on the relative value of scientific medicine.

INVESTING IN SCIENCE: CHILD HEALTH AND MEDICINE IN TWENTIETH-CENTURY UNITED STATES

Intellectual disability was primarily an issue for families and local governments in the United States until the early 1800s, when states opened

institutions where persons with ID could live if their families were unable to care for them. Hundreds of these large institutions were built with public funds in the nineteenth century when physicians and advocates convinced politicians and philanthropists that ID could be cured with the proper environmental treatment. Short stays and dramatic improvements were the exception, however, and by 1900 chronic underfunding meant that most of these institutions became warehouses where persons unable to care for themselves lived for decades, neglected and maltreated. Reports of deplorable conditions in large state-funded institutions began in the 1880s and continued through the twentieth century.⁴

One solution was to avoid the institutions, and in the 1930s families across the United States began to advocate for home supports for their children with ID. By 1951 there were more than 125 local parent organizations in the U.S. and Canada, loosely held together by the desire for peer support and the conviction that the public schools had a responsibility to aid children with disabilities.⁵ The National Association of Parents and Friends of Mentally Retarded Children (later NARC) was founded in 1950 to advocate for disability rights on the state and national level. The disability rights movement grew throughout the twentieth century, and one key battle has been to support community living options for persons with developmental disabilities. Though nearly all of the large state institutions for persons with ID have now closed, in the 1960s more than 500,000 persons still lived in such facilities, and state governments were still grappling with the enormous financial and human costs of custodial care.⁶

Scientific medicine seemed to provide an answer: the prevention of ID through early detection and treatment of medical conditions could both improve health and eventually reduce the need for state institutions.⁷ Phenylketonuria (PKU) was an instructive example. In 1934 Asjborn Folling reported that an inborn error of metabolism characterized by high levels of phenylpyruvic acid in urine could cause ID, and several years later George Jarvis reported finding the same substance in the urine of fifty persons with ID at the Village State School in Thiells, New York. Treatment could prevent the neurological impairment associated with PKU, but only if started in the newborn period. In 1961 universal infant newborn screening became practical when Robert Guthrie, a microbiologist and pediatrician, introduced a semi-quantitative phenylalanine assay that could be applied to a drop of dried blood. Advocacy groups like NARC lobbied state governments to implement newborn screening programs for PKU, and by the mid-1960s nearly every state had one in place – even before there was widespread evidence of the effectiveness of such programs.⁸ Although PKU was relatively

rare, many experts believed that it was simply one example of how investing in scientific medicine would reveal the causes – and cures – of ID.

It is hardly surprising that ID was viewed as a problem to be solved primarily by science and technology. Discoveries in the laboratory had helped the military victory in World War II and, it seemed in 1962, would soon put a man on the moon. Scientific medicine in particular seemed to offer unlimited hope for the future. The emergence of wonder drugs such as penicillin in the 1940s and vaccines against polio of the mid-1950s confirmed decades of faith that science would deliver better health. The Salk and Sabin polio vaccines in particular were critical to the public understanding of the power of the laboratory to prevent disease and improve health. For the first half of the century, families lived in fear of summer epidemics of polio. Communities across the United States closed swimming pools and quarantined the ill in hopes that what started as mild viral illness would not become a local epidemic of death and disability. By the late 1950s, polio epidemics had disappeared, and medical science was credited in headlines across the country.⁹

The more general decline in childhood mortality also seemed to confirm the value of scientific medicine. The so-called “mortality transition” describes the dramatic epidemiological shift in North America and Europe from the early 1800s to the late 1900s. In this two-hundred year period, early childhood deaths due to infectious diseases decreased, while deaths from cancer and heart disease later in life increased. For example, in 1900 the infant mortality rate was still well over 100 deaths per thousand live births in most American cities, and nearly every family knew the tragedy of childhood death. By 1960 the infant mortality rate in the United States was less than thirty per thousand births, and childhood deaths were relatively rare.¹⁰ The net effect of the mortality transition was an increase in average lifespan from less than fifty years to greater than seventy, and the trend continues today. Some authors have noted the relatively small role of antibiotics and vaccines in the decline of infant and child mortality,¹¹ and debate is ongoing on the contribution of improved nutrition, education, and sanitary practices in the mortality transition more generally.¹² There is no doubt, however, that the remarkable improvement in child health meant that, by the mid-twentieth century, families and physicians no longer faced daily deaths caused by infectious diseases. American society could thus consider investing large-scale resources in relatively rare conditions such as PKU, which affected fewer than one in ten thousand individuals.

The 1962 report of President Kennedy’s Panel on Mental Retardation included many recommendations beyond investing in scientific medicine to

prevent ID. Education, public awareness, clinical and social services, and a new legal and social definition of ID were among its 112 recommendations. Unlike the fate of many government commissions, the panel's recommendations were generally carried out, largely due to the efforts of Eunice and Sargent Shriver, as well as pediatrician Robert Cooke.¹³ Investment in prevention and cure, however, was the primary focus of the federal government's efforts, as symbolized in the creation of the National Institute for Child Health and Human Development in 1962. With the help of political leaders such as Representative John Fogarty of Rhode Island, federal investment in understanding the biology of ID rose dramatically.¹⁴

THE IMPACT OF SPECIFIC MEDICAL INTERVENTIONS

Many specific medical interventions have been designed to prevent ID in the last fifty years, including newborn screening programs, vaccines, and advances in nutritional and pharmacologic treatments. Table 1 includes more than a dozen medical conditions that commonly lead to ID, as well as treatments that can reduce the chances of an individual with those conditions meeting the criteria for ID. A number of other conditions can be detected through prenatal or preconceptional screening; in these cases the family can elect therapeutic abortion (table 2). As Duane Alexander points out in his review of the benefits of biomedical interventions to prevent ID, not all of these treatments have their origins in federal research funding, but all have benefited from the national decision to focus on biomedical research.¹⁵

Two colleagues and I selected seven conditions to study in detail: congenital syphilis (CS), Rh hemolytic disease of the newborn (Rh disease), measles, *Haemophilus influenza* type b meningitis (H. flu), congenital hypothyroidism (CH), phenylketonuria (PKU), and congenital rubella syndrome (CRS).¹⁶ We chose these seven conditions for several reasons: (1) all were recognized in the 1950s as specific causes of ID with a high probability of finding or implementing a cure;¹⁷ (2) they account for all of the relatively high-incidence conditions noted in table 1; (3) they are the commonly discussed "success" stories in the prevention of ID;¹⁸ and (4) interventions for these conditions depend largely on care provided through the individual doctor-patient relationship, i.e., they exemplify the traditional biomedical approach to preventing disease or complications in each individual patient.

Tracing the historical epidemiology of these conditions is difficult because there are no longitudinal research programs that track the condition-specific incidence of ID over the last fifty years in the United States. However, there have been cross-sectional studies of each condition at different points in time;

Table 1. Causes of ID with Specific Medical Interventions

- Congenital syphilis (screening and antimicrobial therapy)
 - Measles encephalitis (vaccination)
 - Kernicterus (maternal treatment for Rh incompatibility)
 - Bacterial meningitis (vaccination, antibiotics)
 - Congenital hypothyroidism (newborn screening/treatment)
 - Phenylketonuria (newborn screening/treatment)
 - Congenital rubella syndrome (vaccination)
 - Galactosemia (newborn screening/treatment)
 - Tuberculosis meningitis (nutrition, antibiotics)
 - Whooping cough (vaccination)
 - Fetal hydantoin syndrome (no phenytoin during pregnancy)
 - Pelvic irradiation (limited x-rays during pregnancy)
 - HIV encephalitis (reduced perinatal transmission)
 - Stroke in sickle cell disease (transfusion therapy)
 - Brain tumours (reduced radiation therapy)
 - Metabolic disorders (transplant/gene therapy)
-

Table 2. Causes of ID with Available Prenatal/Preconceptional Screening

- Down syndrome
 - Neurofibromatosis
 - Tuberous sclerosis
 - Fragile X syndrome
 - Tay-Sachs disease
 - Maple syrup urine disease
 - Duchenne muscular dystrophy
 - Other rare genetic abnormalities
-

taken together, these disparate studies allow us to construct estimates of the incidence over time. Although our specific data sources varied for each condition, in general we used a common set of variables to construct estimates of the condition-specific prevalence of ID over the last fifty years: (1) the incidence of the condition, (2) the number of cases of ID likely to arise from that condition (natural history), (3) the efficacy of the intervention to cure the condition, and (4) the population-wide availability of the intervention.

As depicted in figure 3, congenital syphilis and Rh disease are the most significant acquired causes of ID that have a specific medical intervention. Although the trends for congenital syphilis, measles, and CRS have been

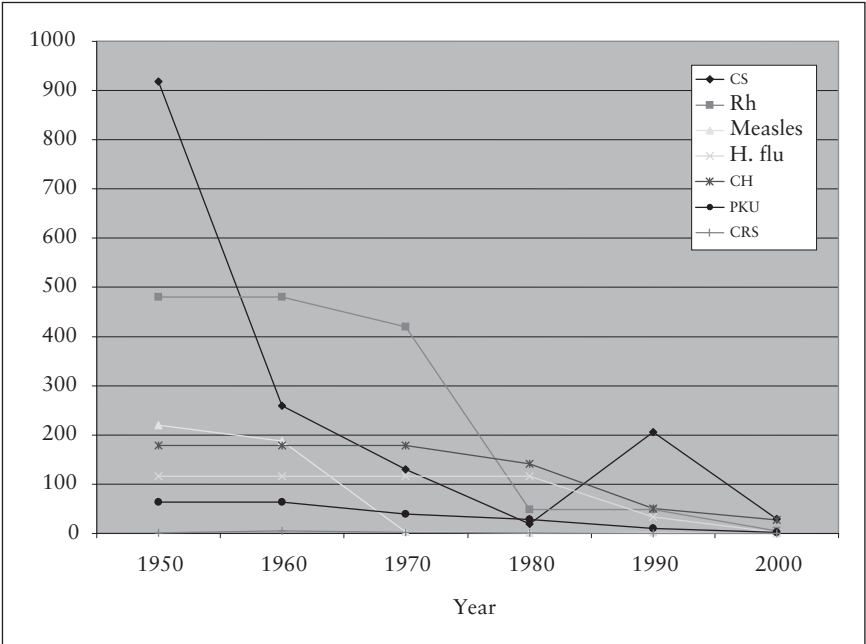


Figure 3.
Estimated prevalence of ID in the United States by selected causes (per million children).

cyclical, ID due to these infections has fallen dramatically over the past fifty years. The peak number of cases of ID due to CRS was 450/million in the epidemic years 1964–65. Rh disease, H. flu, CH, and PKU also cause many fewer cases of ID than they did in the 1950s. The net effect of medical interventions in these seven conditions is a significant decrease in the number of cases of ID.

To gauge the impact of medical interventions on the seven disease-specific causes of ID, we compared the prevalence of these conditions to the overall prevalence of ID. In figure 4, the seven disease-specific causes of ID are combined and compared to one estimate of the prevalence of ID in the U.S. school-age population, 2.27/1000 children. Because the prevalence of each of these disease-specific conditions is relatively low, together they account for a relatively small proportion of the total number of cases of ID (approximately 10 per cent). If other preventable conditions that cause ID are considered (table 1), the impact would be only marginally greater, given that these other conditions have such a low prevalence. We did not consider causes of ID for which prenatal or preconceptional screening is available

(table 2). We chose not to consider these conditions (e.g., Down syndrome) because there is a difference between the unambiguous good of a medical intervention that prevents ID in an otherwise healthy individual and the more controversial intervention that prevents the birth of an individual likely to have ID. Furthermore, our initial data review did not suggest substantial changes in the incidence of Down syndrome over the last fifty years.

Based on these seven conditions, one might conclude that the impact of specific medical interventions is a small but significant decrease on the number of persons of ID. There are more factors to be investigated, however, before reaching conclusions. Medical interventions over the last fifty years may also have contributed to a rise in the prevalence of ID. The increased lifespan of persons with ID, for example, increases the prevalence of ID: children with Down syndrome now live well into adulthood.¹⁹ Furthermore, the clinical successes of neonatologists and cardiothoracic surgeons, among other clinicians, mean that many children who would have died in infancy one or two generations ago now survive to school-age and are frequently diagnosed with ID and other neurodevelopmental disabilities.²⁰ Our preliminary data suggest that the dramatic rise in the survival of the smallest infants (<1500 grams) over the last fifty years has increased the prevalence of MR approximately 5 per cent, if the overall prevalence of ID is assumed to be 2.27 per cent.²¹ Thus, based on our investigation of specific conditions, it appears that medical interventions have lowered the prevalence of ID approximately 5 per cent over the last fifty years.

THE CHANGING DEFINITION OF ID

Given the difficulty of tracking the incidence of dozens of specific medical conditions, perhaps the best way to answer Shriver's question is to look at the overall prevalence of ID. Have we attained the Kennedy panel's goal of a 50 per cent reduction in the number of persons with ID? The astute reader will have been rightly suspicious of figure 4, as we implied that the prevalence of ID has been constant over the last fifty years. We chose a single number only to simplify the comparison of the disease-specific causes of ID to the total prevalence of ID.* In fact, there are no longitudinal studies

* 2.27 per cent represents the number of persons that would be predicted to score two standard deviations below the mean on a standardized IQ test. This definition of ID – an IQ less than 70 – is the one used by authors of most studies of the seven specific medical conditions. Furthermore, estimates of the prevalence of ID from studies that meet current epidemiological standards have ranged between 1 per cent and 3 per cent for the U.S. school-age population.

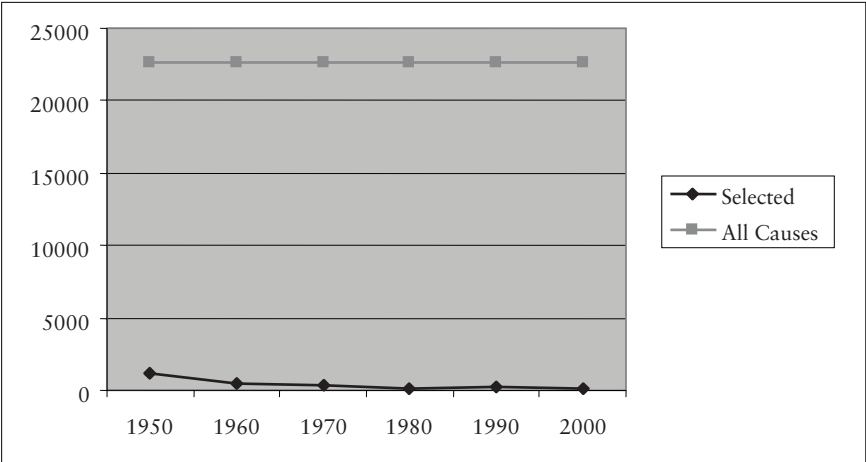


Figure 4.
Cases of ID expected to arise by ten years of age from selected and all causes
(per million births)

of ID prevalence until recently, and even these studies differ on exactly how many people meet criteria for ID.²² If for our comparison we had used the different estimates of the prevalence of ID in specific communities over the last century, our graph would have looked like figure 5, with prevalence estimates for ID ranging from 1 per cent to more than 30 per cent of the total population.²³

Why have estimates varied so dramatically over the last hundred years? When determining the prevalence of any medical condition, there are methodological issues that significantly affect outcomes.²⁴ Prevalence is the number of persons who have a condition (the numerator) within a certain population (the denominator) at a certain point in time. The denominator is usually straightforward: how many people are in the population at risk for the condition. Inaccuracy in this number, however, can certainly affect the prevalence. For example, the decrease in the infant mortality rate in the early twentieth century occurred in part because birth registries improved: as the denominator increased, the rate of infant deaths per thousand births decreased (Meckel 1990; Brosco 1999).

The numerator is affected principally by case ascertainment and case definition. Case ascertainment refers to the methods used to find all the persons with the condition, and can be based on administrative databases, clinic attendance, or active case finding. The resources devoted to case ascertainment can dramatically affect the prevalence, especially for low prevalence

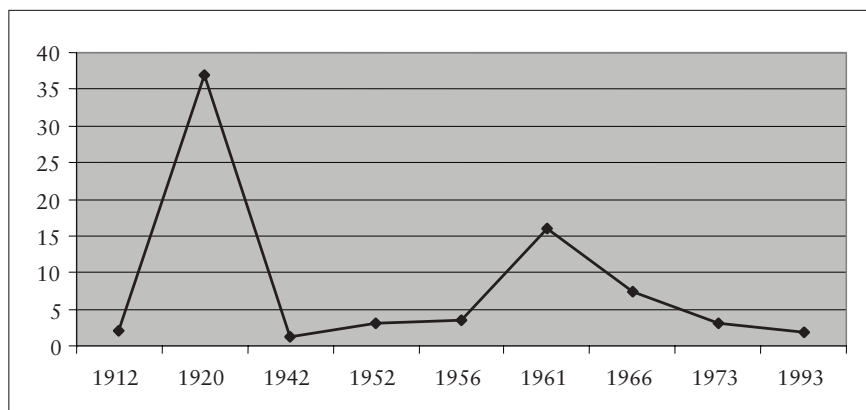


Figure 5.
Cross-sectional estimates of the prevalence of ID in the United States
(per 100 persons)

conditions.* Case ascertainment of ID was a particularly significant variable in the prevalence of ID early in the twentieth century because ID was thought to be a low prevalence condition and there was no easy way to find persons with ID. Although many lived in institutions and some attended public schools, many more persons with ID were cared for by families at home and did not come to “official” attention – in part because of the stigma of having ID and also because there were not many federal or state programs supporting children living at home.²⁵

Although there are many other factors that can influence prevalence, I argue that case definition is the most important factor in the wide variation in prevalence estimates of ID. Case definition is simply the criteria used to determine whether a person truly has the condition; the criteria for ID have changed significantly over the last hundred years. For example, the most recent edition of *Mental Retardations* (2002) is the tenth attempt by the American Association on Intellectual Disability (AAID) to define Intellectual Disability since 1908.²⁶ The American Psychiatric Association’s *Diagnostic and Statistical Manual* has also offered different definitions since the first *DSM* in 1952.²⁷ The federal government currently uses a functional definition of developmental disability – though not all government programs use

*If the predicted prevalence is 5/1000 and five new cases are found, that would double the prevalence. If the predicted prevalence were 500/1000, five new cases would make only a slight difference.

the same definition, and states do not necessarily use the federal definitions. The one constant over the last hundred years has been that each generation changed the terminology: from *feeble-minded*, *moron*, and *idiot* in the early 1900s, through *mental defect* and *mental retardation* in mid-century, to the *levels of support* model informed by today's disability perspective, each generation has struggled to choose terms and define boundaries.

In general there have been three broad approaches to defining ID: medical conditions, cognitive ability or IQ (intelligence quotient), and adaptive/social functioning.²⁸ Each approach has been used in some way since the early twentieth century, and each approach has affected estimates of the prevalence of ID. Published reports of ID prevalence before 1910 typically came from physicians who worked in institutions and schools for persons with ID. They were experts in specific medical conditions such as Down syndrome or "cretinism" (hypothyroidism), and they believed that experienced clinicians could detect findings of ID on physical examination. Indeed, some argued that they could see ID in the faces of children as they strolled through schools of supposed "normal" children. The earliest estimates of the prevalence of ID were based on institutional populations and clinical diagnoses by experienced physicians, and were in the range of five per thousand children. The medical approach to ID continues today with physicians who seek to discover "underlying conditions" causing ID and to administer medical treatment – such as thyroid hormone replacement – for persons with ID. With the discovery of Fragile x and other specific genetic causes of ID the last five decades, the number of routine laboratory and imaging studies continues to increase, thus emphasizing the continuing role of the physician in the diagnosis of ID.

Psychologists have long argued that intelligence can be measured by standardized IQ tests, and that persons who score well below the mean – usually defined by two standard deviations or 70 on most tests – meet the cognitive criteria to qualify for a diagnosis of ID (figure 6). Current measures of IQ began with in the work of Alfred Binet in the late nineteenth century. Binet was a French educator who hoped to identify young children who had difficulty learning and therefore needed special education. He tried using head measurements, the standard quantitative approach of the time, but failed to find significant correlations between head size and school performance. He next devised a series of simple tasks that could typically be performed by children of certain ages, such as drawing a circle or placing blocks in a pattern. Binet did not believe that ability to perform these tasks measured intelligence, but he concluded that children who could not do them needed more attention from teachers. He explicitly warned against using his tests to make

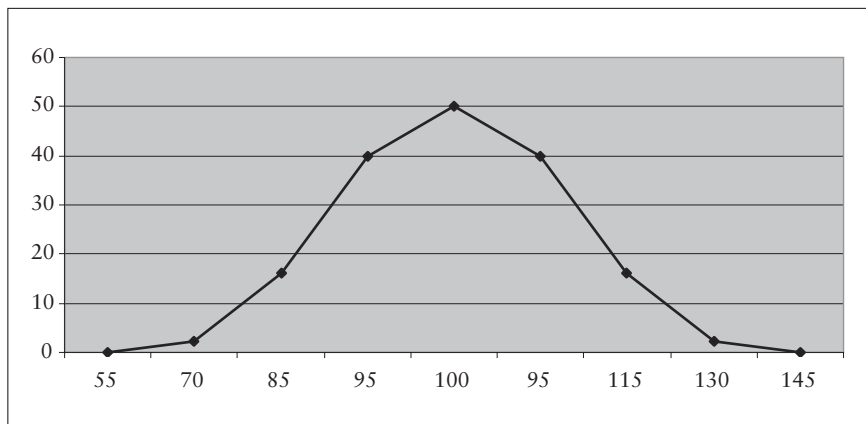


Figure 6.

Bell curve demonstrating normal distribution

Note: Most IQ tests are constructed such that mean score is 100. Approximately 16 per cent of the population taking the test will score 85 or below (1 standard deviation), and 2.3 per cent will score 70 or below (2 standard deviations).

comparisons between children or to make judgments regarding a child's potential for learning or achieving as an adult.²⁹

American psychologists and physicians adopted Binet's testing techniques but ignored his warnings about the limits of measuring intelligence. Instead they agreed with Charles Spearman's contention that intelligence was a single unitary process with a biologic reality to be found in the substance of the brain. In 1904 Spearman argued that statistical correlations among various kinds of tests proved the existence of a single, underlying cognitive ability, named *g*. Simply put, people who scored well on one kind of cognitive test – for example, remembering digits – tend to do well on other kinds of tests – for example, arranging patterns. Each of us, argued Stanford University professor Louis Terman and other psychologists, has a certain amount of general intelligence – a single, measurable capacity that changes little if any over time. In the early twentieth century Terman applied his “Stanford-Binet” test to enough children to believe that he had a statistically sound measure of intelligence. Henry Goddard used such tests to discover a new entity, the “moron” – an individual who appeared to be normal but in fact had very low cognitive ability as measured by standardized tests. Using such tests on school children, Goddard argued that ID was much more common than previous estimates by physicians.³⁰ When Yale professor Robert Yerkes used an IQ test on thousands of American military recruits during World War I, he

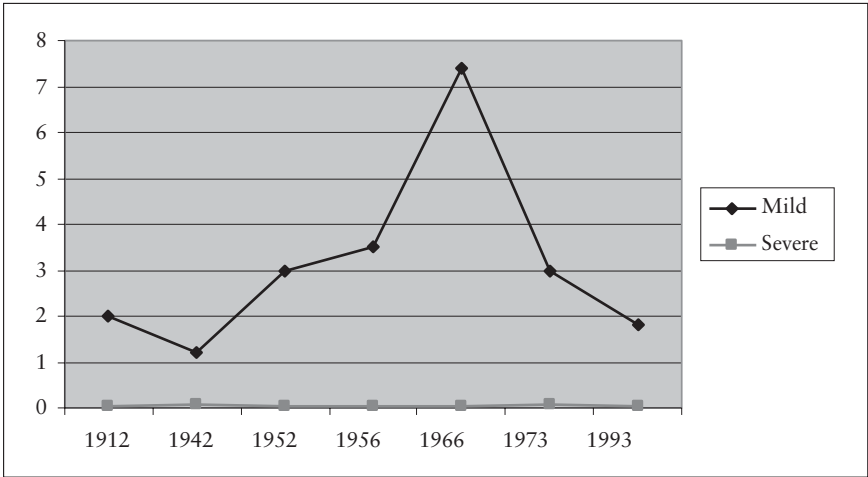


Figure 7.
Moderate-severe vs. mild ID: cross-sectional estimates in the United States
(per 100 persons)

found astonishing results: approximately a third of these young men could be classified as morons and thus met the definition of ID.³¹ This accounts for the high prevalence estimate in figure 5 in 1920.

Herein lies one key to the relationship between the definition of ID and the prevalence of ID. Estimates of the prevalence of ID by physicians were relatively low because they focused on moderate and severe ID: “idiots” and “imbeciles” in the scientific terminology of the time. The prevalence of moderate-severe ID has been relatively constant over the last hundred years (in and outside the United States), at a rate of approximately five per thousand.³² With the advent of IQ tests and the discovery of the “moron” came estimates of the number of persons with mild ID that ranged between 70/1000 and 370/1000. Because of this large difference in rates between mild and moderate-severe ID, variation in estimates of total prevalence in the last century is largely explained by the difficulty in distinguishing between “normal” individuals and those with mild ID (figure 7). For example, even if IQ scores constitute a more objective measure of intelligence, changes in cut-off scores contribute to the wide variation in prevalence: shifting from 70 to 75, a difference within the known accuracy of such tests, doubles the number of persons with ID. When Rick Heber wrote for AAID in 1959 that one standard deviation below the mean (a score of 85) should be considered instead of two standard deviations (70), the number of persons with ID potentially rose to 16 per cent of the population (figure 6).

Heber and the AAID committee were arguing for a new definition of ID, however, one that included consideration of a person's ability to function in everyday life. Clinical experience suggested that some individuals with IQ scores in the 60s seemed generally indistinguishable from their higher-scoring peers, while other individuals with scores in the 70s needed significant support with everyday activities. Rather than use an arbitrary cut-off of 70, Heber and his colleagues believed that ID could be considered in any individual with below-average cognitive ability (less than 85) but who also had substantial difficulty in adaptive functioning. This "adaptive/social" model of defining ID has been used informally for over a century, although it has been overshadowed by scholarly reports using the medical and IQ approaches. In the nineteenth century institutions for persons with ID, for example, physicians focused on medical aspects of the condition, but other personnel were more interested in an individual's ability to function, and in particular what support a person needed in daily life.³³ Historian Molly Ladd-Taylor has argued that family court judges in the 1940s gave this functional definition of ID at least as much weight as medical diagnosis or psychological testing.³⁴

Adding a measure of adaptive functioning can dramatically alter the estimated prevalence of ID. For example, in the early 1970s, Jane Mercer and colleagues compared rates of ID in three populations in southern California: whites, blacks, and Mexican-Americans.³⁵ Based on a measure of cognitive ability alone, 4.4 per cent of blacks and 14.9 per cent of Mexican-Americans had IQ scores in the ID range, compared to fewer than 2 per cent of whites. However, when persons scoring in the ID range were tested according to behavioural skills such as how to take a bus, hold a job, stay in school, do one's own shopping, or read books and magazines, the percentage of blacks and Mexican-Americans scoring in the ID range dropped dramatically, while the rate for whites did not change (figure 8).

As might be surmised from the previous example, estimating rates of ID in specific populations has social and political consequences. Over the last century some American scholars have argued that there are important differences in the intelligence of specific ethnic/racial groups, that these differences are genetically determined, and that U.S. educational and political policy must conform to these facts. In his study of U.S. military recruits for World War I, for example, Yerkes concluded that recent immigrants from southern and eastern Europe scored 10 to 15 points lower than "native" Americans (northern Europeans who had emigrated to the United States before 1870). African-Americans on average scored even lower than recent immigrants, and both groups therefore had high rates of ID. Political leaders

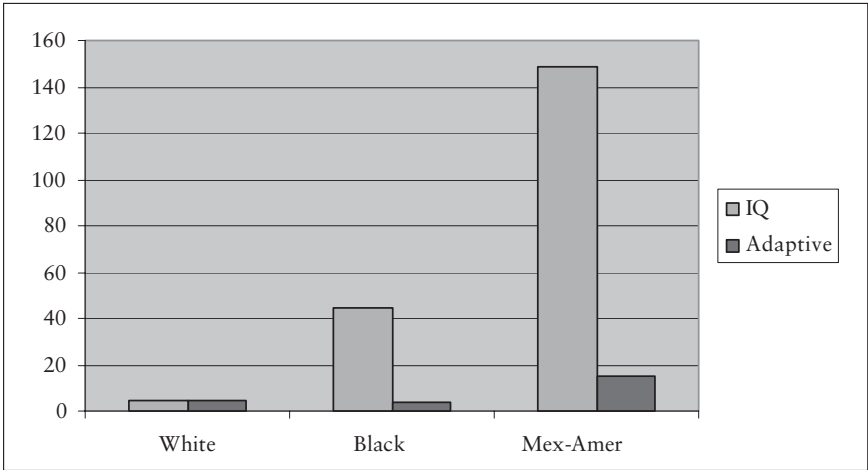


Figure 8.
Effect of adaptive functioning on prevalence of ID (per 1,000 persons)

used these reports to make calls for a host of policies such as immigration restriction.³⁶ IQ testing of recruits during World War II provided similar evidence when nearly half of the 716,000 men rejected by the military because of “mental deficiency” were non-whites – a rate six times that for whites.³⁷ In 1969, Arthur Jensen emphasized reports that the average African-American scored 15 IQ points below the average Caucasian; he concluded that remedial education should be abandoned. More recently, Murray and Herrnstein concluded their book *The Bell Curve* (1994) with a series of policy statements based on their interpretation of the evidence linking race and average group intelligence. Each generation has seen scholars from a variety of disciplines dispute such arguments and fault the authors for presenting political views as “scientific” facts.³⁸

More generally, the politics of the projected prevalence of ID in turn affects the definition of ID. Indeed, a number of scholars have pointed out how the definition of a developmental disability can only be understood in the context of social welfare policy.³⁹ For example, broad definitions leading to high prevalence rates suited early twentieth-century eugenic reformers because they could argue that immigration restriction and sterilization of persons with ID were a logical response to the alarmingly high rates of ID among immigrants and to the genetic roots of ID. In the 1960s, ironically, advocates for persons with ID were eager to accept Rick Heber’s expanded definition of ID. Unlike the eugenic scholars, they believed that

environmental intervention could prevent or improve ID: the high prevalence helped them argue for federal resources for ID programs. In contrast, disability policy experts within the U.S. government have sometimes pushed for narrow definitions to limit the number of persons eligible for services. Thus definitions of ID were narrow in the 1930s when the Depression severely limited available funds.⁴⁰ In the 1980s conservative politicians within the Reagan administration argued that government programs had grown out of control, and a more narrow definition of ID again prevailed (figure 5).

Given the challenges of definition, it seems impossible to determine whether there has been a true change in the number of persons with ID: no study has used a consistent definition over the last fifty years, so any reported changes in prevalence cannot be attributed solely to “true” changes in numbers. We can conclude that the definition of ID cannot be divorced from the political and social consequences of choosing any one definition. Indeed, the relationship between definition and policy is made explicit in AAID’s most recent report defining ID: an entire chapter is devoted to explaining the consequences of its proposed definition on eligibility for various educational and financial support programs.⁴¹ From the historians’ point of view, each generation’s choice of how to define ID also defines contemporary attitudes and approaches to persons with developmental disabilities.

THE “FLYNN EFFECT” AND THE IMPACT OF IMPROVED PUBLIC HEALTH

One way to avoid difficulties with changing definitions over time is to retrospectively apply a single, seemingly objective definition, such as “2 standard deviations below the mean on a standardized measure of cognitive ability (e.g., $IQ < 70$).” Although this approach is used to define ID for longitudinal medical studies, there is strong evidence that even this approach cannot provide consistency over decades. According to the so-called “Flynn Effect,” IQ scores have been steadily rising since the early twentieth century. In the 1980s James R. Flynn and others reported an increase of at least three IQ points per decade among diverse populations in the twenty nations where IQ trends have been studied (figure 9).⁴² For example, all eighteen-year-old men in the Netherlands take a specific IQ test as they enter compulsory military service; using scores from the last half-century, Flynn calculates that the mean IQ of Dutch men has increased more than 20 points.⁴³ Indeed, IQ tests are periodically re-standardized – deliberately devised to be a little bit “harder” than the previous version – in order to keep the mean at 100.

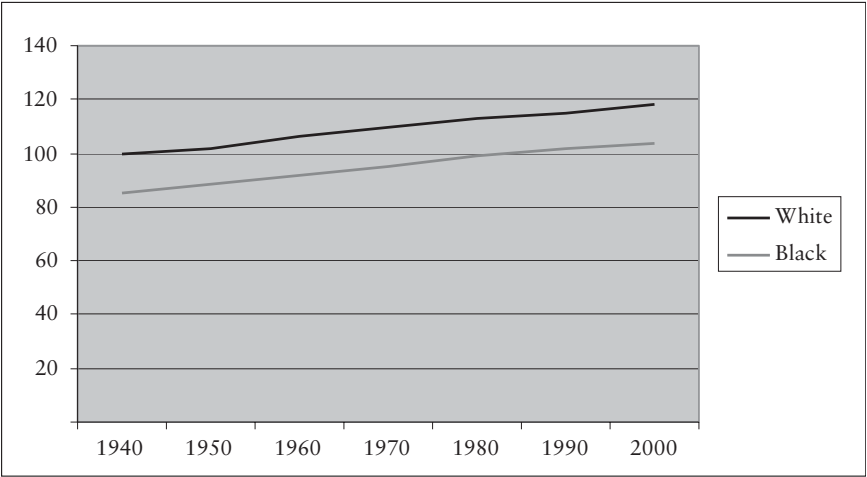


Figure 9.

The Flynn Effect: mean IQ scores

Note: If mean IQ scores of blacks and whites are plotted over the last sixty years using a test standardized in 1940, scores have risen at least three points per decade. There has been little change in the relative mean scores of blacks and whites, though achievement scores for blacks have risen dramatically in the last fifty years (not shown).

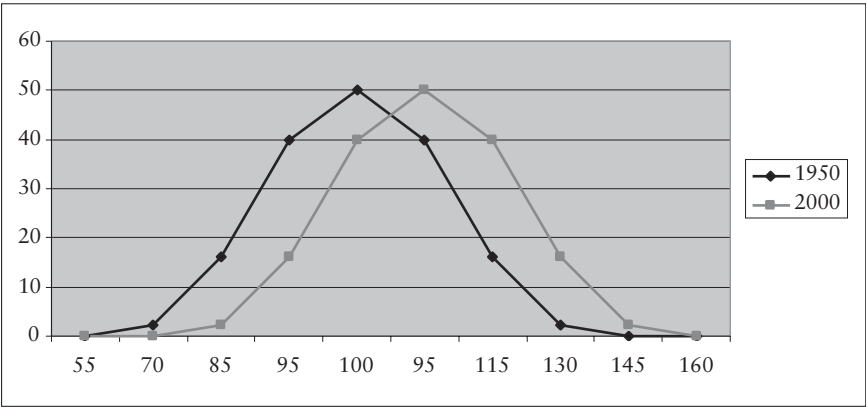


Figure 10.

Apparent consequence of Flynn Effect on prevalence of IQ

Note: As the mean IQ shifts 15 points higher, the number of persons in the Year 2000 taking a 1950-standardized exam who score below 85 decreases from 16 per cent to 2.3 per cent; the number scoring below 70 approaches 0.

This shifting of the IQ distribution curve has important implications for the prevalence of ID. In figure 10, we compare a hypothetical “Year 2000” cohort with one from the “Year 1950.” When the entire distribution of IQ scores is shifted a modest fifteen points, one can see that many fewer persons in the Year 2000 cohort would fall below the IQ cutoff point for ID if given the IQ test devised in 1950 – whether we used one or two standard deviations below the mean (figure 10). Thus, one way to interpret the so-called Flynn effect is to consider that some persons who currently qualify as ID would not do so if given an older, simpler version of an IQ test. Indeed, Kanaya and colleagues conducted such an experiment and found this to be true: schoolchildren were more likely to be diagnosed as ID when given the WISC IV test than when the same children took the early version of the test. Flynn estimates that the number of American children eligible to be classified as intellectually disabled might have decreased from 8.8 million to 2.6 million in the period from 1948 to 1977.⁴⁴

Such reductions are not apparent, of course, because IQ tests are adjusted periodically to ensure that there is a normal distribution, and therefore 2.27 per cent of the population always scores two deviations below the mean. If ID is defined principally by scoring substantially below the mean in cognitive ability, even if the entire population shifts, a small minority of the population will always qualify as having ID. This is true for any condition, such as hypertension or obesity, that relies on quantitative differences from peers as the principle component of diagnosis. Indeed, herein lies the argument for a public health approach to such conditions: if we apply clinical solutions (e.g., reduced salt in diet, increased exercise) across an entire population and “shift the curve,” it is possible to reduce the burden of disease more greatly than by focusing on interventions for high-risk individuals.

Could similar reasoning be applied to the prevalence of intellectual disability? Although there is substantial debate on the causes of the Flynn effect, some scholars argue that it is related to population-level changes in health and environment over the last century. Poverty, early home environment, malnutrition, discrimination, cultural values, and inferior educational opportunities are all remediable causes of lower achievement on standardized tests (table 3). In the United States since the 1960s, a number of federal, state, and philanthropic programs have sought to improve the general environment for growing children (table 4). These broad-based public health and education programs may have helped shift the IQ curve higher and thus reduced the number of persons who would meet criteria for ID.

For example, nutrition is associated with cognitive ability: low overall caloric or protein intake as well as absence of micronutrients such as iron

Table 3. Causes of ID with Potential Public Health Interventions

<ul style="list-style-type: none">• Child abuse/neglect (public education and intervention)• Fetal alcohol effects (public health education)• Iron-deficiency anemia (nutrition programs)• Lead intoxication (environmental intervention)• Malnutrition (nutrition programs)• Neural tube abnormalities (folic acid before pregnancy)• Traumatic brain injury (child restraint systems)• Near-drowning (water safety instruction; pool enclosures)

Table 4. Examples of United States Federal Programs That Aid Children Growing up in Poverty

<ul style="list-style-type: none">• Medicaid (health insurance)• Head Start (early education program)• WIC (nutrition for women, infants, children)• Aid to Families with Dependent Children (AFDC, now TANF, provides income support)• Earned Tax Credit (provides income support)• School lunch program (nutrition)• Housing Urban Development programs (improved housing; lead abatement)• Department of Education (improved education, especially for children with ID)• Civil rights legislation and judicial decisions (improved education, housing, etc.)
--

in the diet all cause lower performance on tests of cognitive ability.⁴⁵ In general, increases in IQ over the last century are matched by increases in mean height, and some scholars have linked the simultaneous rise to improvements in nutrition.⁴⁶ More recently in the United States, school lunch programs have helped reduce the prevalence of hunger among children, and there is evidence that the prevalence of iron-deficiency anemia has decreased since the introduction of iron in baby formulas and the existence of programs such as WIC, which provides nutritional supplements for pregnant women and their young children.⁴⁷ Direct relationships are difficult to prove, however, and some scholars point to inconsistent evidence that improvements in nutrition largely account for the Flynn effect.⁴⁸

Ingestion of lead is also clearly associated with impaired cognitive development. As Christen Warren and others have reported, the amount of lead in American homes and neighbourhoods has been steadily decreasing over the past century.⁴⁹ For example, nearly half of the children living in some

American cities in the 1940s had lead levels above 40 µg/dL; today most children have levels less than 10 µg/dL, though even small amounts of lead are considered to affect IQ scores.⁵⁰ Perhaps the steady decline in lead exposure accounts for the population shift in IQ in the United States: given higher lead levels in poor and minority neighborhoods, this explanation may also help explain more precisely why poverty and race/ethnicity is related to lower IQ scores. It is likely that reduced lead exposure is part of the explanation for rising IQ scores; however, there has been a similar increase in IQ scores in nations where lead was largely eliminated from the environment in the early 1900s.

Family income and maternal education are two of the most reliable predictors of IQ scores, and improvements in these areas may also account for the Flynn Effect. Overall, it appears that there have been gains in economic well-being across the American population over the last fifty years, though the data on child poverty is mixed. According to the U.S. Census Bureau, the poverty rate for children in 1959 was 27 per cent and, after the 1960s war on poverty, had fallen to just below 15 per cent by 1970. However, the child poverty rate climbed above 20 per cent in the 1980s, fell to 15 per cent in the 1990s, and in 2005 was 17.6 per cent.

The quality of education of a population is even more difficult to measure, and national high-school graduation rates remain fairly low.⁵¹ On the other hand, since the 1960s there have been efforts to improve the quality of education for children living in poverty or segregated by race, and children with developmental disabilities in particular have benefited from federal laws and courtroom decisions that together provide a strong legal base for a free and appropriate education.

No simple relationship between specific environmental factors and IQ should be expected, based on current models of cognitive development. The complex interplay of genetic and environmental factors suggests that having one or two “risk factors” for low cognitive achievement may not affect IQ much, but with each additional risk factor, IQ scores are likely to decline.⁵² It is tempting to lump together all the positive changes in children’s early environment and conclude that public health and anti-poverty programs have shifted the IQ curve and reduced the prevalence of ID. However, while IQ scores have risen over the last fifty years, standardized measures of achievement have not risen as quickly. In general, such tests of math, reading, or other specific academic skills (e.g., the SAT) are more closely associated with a child’s home and educational environment than non-verbal IQ scores. Paradoxically, rises in IQ scores are principally due to subtests that measure the components of cognitive ability that are considered by many scholars to be

least affected by education and environment. The term “fluid intelligence” refers to activities that do not require language or prior knowledge, such as pattern recognition; in contrast, “crystallized intelligence” captures the store of knowledge that each of us learns over time. Some scholars – including Flynn himself – have interpreted the large gains in scores of fluid intelligence and smaller gains in crystallized intelligence to conclude that rising IQ scores do not represent true gains in cognitive ability.

Other scholars have argued that fluid intelligence depends on abstract reasoning, cognitive flexibility, and rapid decision-making – all traits that emerge from specific cultures and educational practices. For example, research in Africa in the 1970s demonstrated cultural practices that emphasized social intelligence, compliance with society, and slow deliberation in decision-making; these traits would lead to lower scores on most tests of fluid intelligence.⁵³ Carmi Schooler has argued that increasing environmental complexity such as urbanization and educational opportunities are empirically associated with increasing IQ scores.⁵⁴ Patricia Greenfield and others have looked specifically at the increasing visual complexity of industrialized environments – movies, television, computers – and concluded that it is not surprising that scores on pattern recognition tests are rising.⁵⁵

In sum, then, the Flynn Effect provides suggestive but not conclusive evidence of a reduction in the number of persons with ID over the last fifty years. It does provide definitive evidence, on the other hand, against simplistic arguments about hereditarian differences in group mean IQ scores. As Ulric Neisser has reasoned, IQ scores either do or do not accurately reflect innate intelligence. If they do not, arguments based on group IQ scores are suspect. If IQ scores do truly measure innate intelligence, the rapid rise in scores over the last six decades demonstrates the critical importance of environment, because such large, complex genetic changes could not occur in less than a century.⁵⁶

CONCLUSION

In a 1964 speech Sargent Shriver recalled the work of the Kennedy administration in the early 1960s: “For the first time in history mental retardation – the least understood, most feared and most neglected scourge of mankind – came under the guns of the chief executive of the most powerful government in the world.”⁵⁷ Since then the U.S. federal government has devoted substantial resources to laboratory research, medical interventions, and workforce education to prevent ID and improve the lives of persons living with developmental disabilities. The mid-twentieth century attention to ID was partly a

response to epidemiologic shifts in child health in the United States: the dramatic decrease in infant and child mortality allowed the nation to focus on low-incidence conditions such as ID. The choices of the Kennedy and Johnson administrations in their approach to “combating mental retardation” reflected optimism that medical science and government programs could prevent many cases of ID and improve the lives of persons with developmental disabilities. What, Shriver asked nearly forty years later, has been the outcome of this investment in science and medical intervention?

As demonstrated in this chapter, applying laboratory findings to specific medical conditions did indeed prevent thousands in the United States from developing ID over the last fifty years. Preliminary research suggests, however, that medical interventions have also led to more individuals with ID, and that overall medical interventions for specific conditions have had a relatively small impact on the general prevalence of ID. This does not mean that the nation’s faith in science was misplaced: thousands of lives have been saved, and the astonishing complexity of neurodevelopment is slowly being revealed. The potential for preventing ID in many more individuals remains, though it may now centre on the elusive promise of gene therapy.

Perhaps more importantly, scientific understanding of neurodevelopment has led to public health interventions to improve nutrition and housing and reduce exposure to toxins such as lead and alcohol. Furthermore, federal programs to alleviate poverty and hunger may have had a greater impact on the number of persons with ID than specific medical interventions, a finding not unlike that of Thomas McKeown’s work on the mortality transition.⁵⁸ Indeed, if the “Flynn Effect” represents a true increase in cognitive ability over the last half century, the American federal government of the 1960s and ‘70s may deserve more credit for the war on poverty than for specific developmental disabilities programs. The irony is that the medical profession has remained firmly focused on specific medical interventions, despite calls from a vocal minority for a shift in focus to poverty, education, nutrition, and psychosocial issues.⁵⁹

This brief exploration of the historical epidemiology of ID is clearly based on a medical model, which assumes that one of our most important goals is to prevent ID. Obviously this is but one very limited approach, and indeed is subordinate to providing appropriate supports and services to persons with disabilities. The Kennedy panel itself called for investment in education and social support for persons with developmental disabilities. While it may be difficult to measure the cognitive impact of de-institutionalization and special education programs, individuals with disabilities and their advocates have convinced the nation of the fundamental soundness of the disability

rights movement. The late twentieth century was characterized by a spectacular change in attitudes towards persons with disabilities, and laws such as the Americans with Disabilities Act of 1990 and the reauthorization of the Individuals with Disabilities Education Improvement Act in 2004 enjoy broad popular support. Surely this is the most salient change for persons with ID in the United States over the last fifty years, and the best answer to Shriver's questions.

NOTES

Versions of this work were presented at the Pediatric Academic Societies' Annual Meeting in Toronto, May 2007; the Charles E. Culpeper Lecture Series, University of Minnesota, Minneapolis, September, 2003; and the Comparative and Interdisciplinary Approaches to Child Health in the Twentieth Century Colloquium, Montreal, October 2004. The author thanks audiences at each of these forums for their comments. Michael Mattingly and Lee Sanders were co-authors in determining the changing epidemiology of ID due to specific conditions. I also thank Lee Worley, Louis Elsas, and Charles Mitchell for their comments on this manuscript. I was supported in this research by a Robert Wood Johnson Foundation Generalist Scholar Award and a grant from the U.S. Maternal and Child Health Bureau's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children.

- 1 Berkowitz, *Politics of Mental Retardation*; Shorter, *Kennedy Family*.
- 2 Shapiro, *No Pity*; Berkowitz, *Disabled Policy*.
- 3 Rosenberg, "Tyranny of Diagnosis"; Rosenberg and Golden, *Framing Disease*.
- 4 Trent, *Inventing the Feeble Mind*; Grob, *From Asylum to Community*.
- 5 Trent, *Inventing the Feeble Mind*.
- 6 Ibid.
- 7 Paul, "A Double-Edged Sword."
- 8 Brosco, Seider, and Dunn, "Universal Newborn Screening."
- 9 Rothman, *Beginnings Count*.
- 10 Meckel, *Save the Babies*.
- 11 McKeown, *Rise of Modern Population*, and McKinlay and McKinlay, "Questionable Contribution."
- 12 Link and Phelan, "McKeown and the Idea," Colgrove, "McKeown Thesis," and Szreter et al., "McKeown Thesis."
- 13 Shorter, *Kennedy Family*.
- 14 Braddock, *Federal Policy*.
- 15 Alexander, "Prevention of Mental Retardation."

- 16 Brosco, Mattingly, and Sanders, "Impact of Specific Medical Interventions."
- 17 Heber, *Epidemiology of Mental Retardation*; Stern, "Mental Retardation," Levinson and Bigler, *Mental Retardation*, and Alexander, "Prevention of Mental Retardation."
- 18 Alexander, "Prevention of Mental Retardation," Brockley, "History of Mental Retardation," Centerwall and Centerwall, "Discovery," Crocker, "Prevention of Mental Retardation," Lakin, Braddock, and Smith, "Trends and Milestones," Moser, "Prevention of Mental Retardation," and Scheerenberger, *History*.
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Politics, Policy, and the Measuring of Child Health: Child Malnutrition in the Great Depression

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Child health: how do we define it and how do we measure its status and trends? These questions, although essentially epidemiological and statistical, have been highly politicized in the twentieth and twenty-first centuries, often at the heart of rancorous public debates on the adequacy of the state's commitment to public welfare and on the relative responsibilities of parents, community, and government to protect and promote the survival and physical welfare of society's youngest members.¹ In this chapter I examine how issues of child health measurement and description were at the centre of one such rancorous debate that occurred in the early 1930s as the Great Depression was deepening, and centred on whether or not the state was adequately responding to the potential harm to child and general health posed by mass unemployment among wage earning families.

In 1933 the United States Public Health Service (USPHS), in conjunction with the Milbank Memorial Fund, conducted a survey of the health of white urban working-class families. Ultimately involving a house-to-house canvass of twelve thousand families in ten cities, including a coal mining centre and a cotton mill town, the survey was larger and more comprehensive than any previous American attempt to measure the incidence of sickness and disability. It provided a model for the first national health survey, which was conducted by the USPHS two years later.² It also had a specific purpose, evident in its focus on wage-earning families, especially in areas hard hit by the waves of layoffs that had been surging across the country since the stock market crash four years earlier. As Surgeon General Cummings explained at a 1934 meeting of the League of Nations Health Organization, the 1933 urban working class survey was designed to provide an adequate answer to a pressing and much debated question: what impact, if any, was the Depression

having on the health of the American people? Additionally, Cummings noted, the USPHS hoped that the survey would settle an increasingly bitter epidemiological and policy debate concerning whether childhood malnutrition was on the rise, and with it childhood sickness and disability.³

Whether or not child health was worsening as unemployment spiralled upward had been a contentious issue in the United States since early in the Depression when child hygiene advocates began expressing concern that the deepening economic crisis could reverse the gains of the previous decades and cause significant and lasting damage to the health and welfare of the nation's young. Two dangers seemed paramount. The first was that declining tax revenues and charitable giving would force deep cuts in both privately and publicly funded child health services. The second was that the well-being of children in families of the unemployed would be seriously and permanently harmed by their parents' increasing inability to provide what was necessary for healthy physical and mental development.⁴

Among the earliest to raise these concerns was Grace Abbott, chief of the U.S. Children's Bureau. In the fall of 1930 Abbott gave a speech before the American Academy of Political and Social Science in which she warned that increasing unemployment among the nation's wage earners posed a serious threat to American children. A few months later at the White House Conference on Child Health and Protection, she termed unemployment a child welfare issue and called for a federal commitment to the relief of the unemployed.⁵

Behind Abbott's conviction that spreading unemployment posed a significant threat to the health of American children was a study the bureau had done eight years earlier on the effects on child health of the postwar recession of 1920–22. One of the first to be conducted under Abbott's tenure as chief, the study found that as the families of the unemployed exhausted their savings, children were forced out of school to work, healthy diets were sacrificed to frugality, health problems and physical defects were ignored, and childhood anxieties and nervousness were magnified by uncertainty and lack of security.⁶ These findings convinced Abbott and several other prominent child welfare advocates that the loss of family income due to unemployment placed children at serious risk by robbing their parents of the ability to maintain a family environment conducive to healthy physical and mental development. Indeed, as the USCB historian Dorothy Bradbury later recounted, the 1922 report early convinced the bureau to centre its attention during the Depression on lost rather than low income, to promote the provision of adequate relief for families with an unemployed head, and to make ensuring economic security for all American families the key to maintaining the health and well-being of the nation's children.⁷

Yet even in the social welfare community, Abbott's early call for federal relief intervention initially found few supporters. As she herself later noted, through early 1932 many of those in welfare work, like most Americans in general, considered the economic crisis a temporary one and were confident that local public and private relief agencies could meet whatever need arose.⁸ More significantly, there existed little if any hard evidence that the health of children, or of Americans at any age, was being adversely affected by the Depression. Indeed, data collected and published by the census bureau seemed to indicate quite the opposite, showing that the standard indices of child health – age-specific and disease-specific mortality rates, as well as the rates of reportable diseases like tuberculosis – were continuing to decline. As a consequence, infant and child mortality, as well as mortality from such traditional scourges as diphtheria, scarlet fever, and measles, were lower two years into the Depression than they had been at the beginning.

For the most part the nation's public health experts read the vital evidence optimistically, seeing in the declining death and reportable disease rates proof that the campaigns they had led to sanitize water and food supplies, control the transmission of contagious diseases, and educate the populace to live healthily and consume medical services had succeeded in minimizing the impact of this latest economic downturn. Indeed, although they occasionally expressed concern that if the crisis continued long enough, it might eventually have a negative effect on national health, they more frequently expressed the conviction that science had significantly triumphed over economics. In an October 1932 address delivered upon his retirement as president of the American Public Health Association, Louis Dublin called the preceding twelve months "a year of real achievement in the promotion of public health" and declared it especially "gratifying to note the very favorable health conditions" that continued to prevail even as the economy worsened. Indeed, Dublin concluded, there seemed little reason to doubt that public health would continue to improve, whatever the economic climate. Other health experts agreed. An editorial in the *Journal of the American Medical Association* in 1933 cited Dublin's positive assessment with approval and noted that the vital data continued to contradict warnings that the Depression was undermining public health in general and child health in particular.⁹

Further undercutting warnings by Abbott and the bureau that the number of ill-nourished American children was increasing in step with unemployment was what by the 1930s had become common wisdom among experts on nutrition and child health as to the causes, extent, and diagnoses of malnutrition. Employing the findings of food scientists who were breaking

nutriment into its constituent elements and physiologists who were charting out how those elements were used by the body to develop and operate, a number of child health experts in the emerging specialty of pediatrics had in the early years of the century succeeded in popularizing the idea that good nutrition was the most crucial determinant of child development and well-being. As the prominent turn-of-the-century pediatrician L. Emmett Holt repeatedly asserted, "the health, growth, and physical development of children, and to a considerable degree their mental development and progress, depend upon their nutrition."¹⁰ Or, as S. Josephine Baker, a pediatrician and public health official, would often explain: "The most important of all the basic causes of ill health during childhood is a lack of proper bodily nutrition."¹¹

One result of this popularization was to draw the attention of child welfare and hygiene advocates to nutrition as both a cause and measure of childhood disadvantage. In his *Bitter Cry of Children*, arguably the most influential American Progressive-era child welfare exposé, John Spargo pointed to poor children's lack of access to nutritious food as the primary reason that so few achieved the physical and mental development that would enable them to escape their poverty.¹² At the same time, school hygiene reformers identified undernourishment as a major cause of backwardness and grade retardation, and pioneered special classes and clinics for the seriously malnourished and penny lunches to counter the inadequate diets of so many poor schoolchildren.¹³

Another result of the new importance lent to good nutrition was to make weight gain a major focal point of infant and child health surveillance. In his 1897 *Diseases of Infancy and Childhood*, a work which through its many revised editions served as the standard American pediatric text of the first quarter of the twentieth century, Holt had advised that regularly weighing babies was among the best ways to gauge health and proper development. Many physicians took that advice, and soon infant scales were one of the most common features of the family doctor's office.¹⁴ By the second decade of the century, weighing older children to gauge and monitor their health had also become common, especially as part of newly established school hygiene programs and of that part of the fight against tuberculosis that centred on identifying tubercular and pre-tubercular children.¹⁵

As regular weighing became a popular way to monitor infant and child health, it encouraged the design and construction of standard weight tables and charts to assist private physicians, clinic personnel, and school nurses in judging whether or not a particular child was developing at a rate and to an extent that could be judged as healthy. At first the tables and charts

standardized weight gain according to age, but wide variations in weight among healthy infants of the same age proved this ratio unsatisfactory. Much better, it was discovered, was the ratio of weight to height, which was soon widely adopted and used by both physicians and parents to evaluate whether infants and children were developing at a normal pace over time.¹⁶

During the First World War and postwar years, child health and welfare advocates began employing these weight-to-height tables as a screening tool to identify children who were unhealthy, and in particular were malnourished or at risk of malnutrition. Leading the way was the Children's Bureau when, as part of its 1918 Children's Year campaign, it mounted a nation-wide weighing and measuring drive "to draw the attention of parents, physicians, public health nurses, and the community to the babies and children under school age who are shown to be under-nourished – that is, who are under the average weight for their height – or who are discovered to have defects or diseases related to poor nutrition."¹⁷ As the medical historian Jeffrey Brosco has shown, this use, or rather misuse of developmental indices as one-shot screening tools contributed to the identification of a supposed epidemic of malnutrition in postwar America. Comparing the weights of various populations of children to published age-to-weight ratios, and defining malnutrition as from 5 to 10 per cent under the weight-to-height norm, a wide variety of child health and welfare investigators compiled data purportedly demonstrating that anywhere from 20 to 80 per cent of the nation's children were suffering from malnutrition.¹⁸

Although acknowledging that malnutrition could result from a number of causes, including hereditary inefficiency at processing foodstuffs, nervous indigestion, nasal and pharyngeal obstructions, carious teeth, and lack of sufficient food, those who argued in the 1920s that an epidemic of childhood undernourishment was sweeping through America tended to identify one cause as primary. Childhood malnutrition was epidemic, they asserted, not because physical defects and abnormalities were widespread among the young or because many American children lived in families who could not afford to feed them properly; it was epidemic because of the prevalence of poor diets and the consequent failure of many American children to consume and digest essential foodstuffs. Moreover, noting that weight-to-height surveys of various child populations showed that underweight was as common in rural and suburban areas as it was in cities and industrial towns, nutritionists of the time contended that malnutrition had less to do with social and economic position than with lack of nutritional knowledge among parents and bad eating habits among children. This redefinition of malnutrition as the consequence of ignorance and bad habits loosened the

age-old association it had with poverty and particularly with worsening economic conditions, whether brought on by crop failure or industrial recession. Indeed, some health experts asserted an obverse association, claiming that childhood malnutrition had become epidemic in the 1920s because increased prosperity allowed the widespread consumption of refined but innutritious foods.¹⁹

Finally, many in public health and medicine discounted the early alarms associating rising unemployment with increasing childhood malnutrition because they had grown increasingly sceptical of social agency use of one-time measurements of height and weight to identify the undernourished. Along with producing heightened awareness of the importance of good diet, the 1920s childhood malnutrition epidemic eventually provoked a backlash among health professionals against what they termed the overuse and misuse of weight and height to diagnose malnutrition. One consequence of this backlash was the production of ever more elaborate and differentiated weight and height tables. Another was the gradual formation of a consensus that childhood malnutrition could only really be detected through a careful clinical consideration of a child's complete physical aspect, including but not limited to the texture of the skin, the amount of subcutaneous fat, the hemoglobin count, the quality of the hair, and the development and condition of muscle and bone. The increasing adoption of this clinical definition made suspect the claims of social service organizations as to the incidence and trends of malnutrition. The *Journal of the American Medical Association* grew particularly disdainful of such claims, repeatedly editorializing during the mid-1930s, "there exists little if any clinical evidence to justify hysteria about the increase in malnutrition due to the depression."²⁰

Faced with mortality statistics suggesting no decline in national health, the common wisdom that malnutrition was largely unconnected to family income or national economic conditions, and a growing conviction among child health experts that most screening estimates of childhood malnutrition were suspect, the bureau sought to gather data that would support its conviction that the Depression posed a serious danger to child well-being. It thus lobbied Hoover's newly appointed Emergency Committee on Unemployment to give it responsibility for collecting statistics on relief and for surveying conditions in the coal mining regions of several states where wage cuts and mass layoffs had predated the stock market crash by at least two years. Within months, the bureau had sufficient data to suggest if not prove a number of disturbing developments. One of these was that as local authorities and private charitable agencies scrambled to find funds to meet

burgeoning relief expenditures, they often cut support for the infant, child, and maternal health and welfare programs. As Abbott complained in a *New York Times* interview, such “false economies” were eviscerating school hygiene programs, shutting down day nurseries, and reducing maternal and child hygiene services.²¹ More ominously, the relief statistics seemed to suggest that the incidence of childhood sickness was increasing among children in large part because childhood malnutrition appeared to be on the rise, especially in families where the father had lost his job and had been unable to find another. As the bureau noted in its annual report for 1930–31, “whenever unemployment persists, the under-nourishment of children has been the rule.”²²

Prompted in part by the bureau’s findings, a number of charitable and advocacy organizations, as well as state and municipal welfare and public health agencies, also began investigating the health status of the children of the unemployed, focusing especially on whether malnutrition was on the rise among them. In the fall of 1931 some of the results of these investigations started to appear in the popular and professional press. As the school year began, the *Chicago Daily Tribune* and other midwestern newspapers reported on the difficulties faced by school-aged farm children and their families in the nation’s heartland, where drought and falling agricultural prices had brought hard times well in advance of 1929. Many of these children, the papers reported, were either dropping out of school or attending sporadically, often looking ill dressed and ill fed. In September 1931 the *New Republic* and the *Christian Century* began running a series of poignant accounts of the deprivations faced by unemployed miners’ children and quoted data collected by the Children’s Bureau suggesting that under-nourishment among schoolchildren in coal mining districts had increased close to 25 per cent.²³ Other publications ran similar pieces, making aiding starving miners’ children something of an early Depression era *cause célèbre*. One result was that for the expressed purpose of aiding malnourished and sick miners’ children, the Save the Children Federation was founded in late 1931 by several nationally prominent social welfare figures, including Carl C. Carsten, head of the Child Welfare League of America, and Robert Lynd, the Columbia University sociologist and author of *Middletown*.²⁴

Also beginning to appear in the press were accounts of rising childhood malnutrition in cities. In September 1931 the *New York Times* reported that milk consumption in the city was down 20 per cent from the year before and that the Association for Improving the Condition of the Poor had found considerable evidence that malnutrition among children seemed to be on the rise in the city’s tenement districts. In October the quarterly of the

Pittsburgh Public Nursing Association noted that a recent survey of doctors involved in child health conferences in that city had revealed a significant increase in cases of malnutrition, rickets, and childhood tuberculosis. The following month, the National Organization for Public Health Nursing sent out a news release announcing that returns from a questionnaire it had sent to its member organizations indicated that "two years of financial depression and unemployment have taken their toll in under-nourishment of children and young mothers."²⁵

During the winter of 1931-32, with unemployment approaching 20 per cent and local government and private relief agencies facing insolvency, these and other accounts of malnourished and sickly children played a significant part in Congressional debate over whether or not to appropriate federal funds to assist localities in meeting their relief needs. As the nation suffered through the second year of the Depression, the existing system of local tax-supported relief combined with private charity was proving grossly insufficient to meet the needs of the burgeoning number of unemployed. As a consequence, a few state governments had begun to establish relief administrations to channel state funds to the hardest hit communities. But state coffers were not bottomless, and pressure soon mounted for direct federal relief. In support of one of the earliest bills that would have provided such relief, Senator Robert M. La Follette of Wisconsin, the bill's cosponsor, offered a Children's Bureau report summarizing the evidence of increasing nutritional deficiency among the nation's children and argued on the floor that "if we permit this situation to go on, millions of children will be maimed in body, if not warped in mind, by the effects of malnutrition."²⁶ Delivered against a backdrop of hunger marchers advancing on the capital, La Follette's argument was a powerful one, but not powerful enough to overcome the resistance in Congress to involving the federal government in social welfare. With the strong backing of President Hoover, opponents of the bill, which would have provided the states with \$375 million in relief assistance, were easily able to defeat it.²⁷

Hoover's refusal to be swayed by reports of malnourished children was rooted in large part in his fiscal conservatism and seemingly unshakable faith that relieving distress was best done by donor-supported private agencies with some assistance from local government. Yet it is also clear that both he and his close advisors strongly believed that the nation's children faced no looming health crisis and that, indeed, their health was improving. Not that Hoover doubted the existence of pockets of deprivation: like many Americans, he seems to have been moved by the plight of children of

laid-off miners and had been instrumental in the fall of 1931 in securing for the American Friend's Service Committee a \$225,000 grant from the American Relief Administration to feed and clothe schoolchildren in the hardest-hit coal communities of six states. He also encouraged the Red Cross, which had taken on the relief of farm families in drought-stricken areas, to fund school lunches in communities where the undernourishment of children seemed greatest.²⁸ But even into the third year of the Depression he remained unconvinced that more than these types of narrowly targeted private philanthropic efforts were needed, arguing that what was being done was sufficient and that there was no credible evidence that either child health in general was deteriorating or that child malnutrition was increasing. Indeed, through the end of his term in office, Hoover and his advisors repeatedly cited figures from the Census Bureau showing infant and child mortality dropping as proof of the efficacy of local relief, modern medicine, public health, and the educated parent in protecting the nation's children. They frequently emphasized the lack of connection between economic and nutritional status, explaining as Hoover had at the 1930 White House Conference on Child Health and Protection: "The ill-nourished child in our country is not the product of poverty, it is largely the product of ill-instructed children and ignorant parents."²⁹

Along with other opponents of direct federal relief, members of the Hoover administration also repeated an opinion expressed by some popular health advisors, that declining family income during the Depression was actually improving health by leading to simpler and better eating. That certainly was the position taken by Dr Ray Lyman Wilbur, Hoover's Secretary of the Interior and chief health policy advisor in the cabinet. In a speech Wilbur gave in early 1932 at the annual meeting of the National Conference of Social Work, he parried charges that the administration's opposition to direct relief was hurting children and asserted that "unless we descend to a level far beyond anything that we at present have known, our children are apt to profit rather than suffer from what is going on." Declaring that little evidence existed to support the "dire prophecies" of a rising tide of childhood malnutrition, Wilbur suggested that the exact opposite seemed to be happening because the current adversity had inspired in both individual parents and the overall community a heightened interest in the nutritious feeding of children.³⁰

Debate over the impact of the Depression on child health and nutrition continued into the early years of Franklin Delano Roosevelt's presidency, initially centring around a Child Health Recovery Conference that the

Roosevelt administration sponsored in 1933. In calling the conference, which was attended by close to 150 of the nation's most prominent child welfare advocates, public health officials, and pediatricians, Secretary of Labor Francis Perkins admitted that the evidence supporting the claim that child health and nutrition had deteriorated as the Depression deepened was fragmentary and open to question, but argued that it was still reasonable to conclude that "somewhere in the neighbourhood of one fifth of all pre-school and school children are showing the signs of poor nutrition and inadequate housing and lack of medical care."³¹

Not all attendees, however, agreed. While voting as a body to recommend that federal relief funds be made available to the states so that they could mount campaigns to locate and assist undernourished children, particularly those "children in families on relief and those in families who though not on relief are nevertheless in need," several attendees expressed strong reservations about the assumptions on which the conference had proceeded.³² Echoing the sentiments of a number of his colleagues, one doctor complained that far too much attention was being focused on malnutrition and suggested that reports of its increase were too often ill documented and wildly exaggerated. Another complained of the lack of any reliable data on whether childhood sickness had increased as the Depression deepened, characterizing mortality data "as far too blunt an instrument" to provide useful information. A USPHS physician in attendance agreed with both men, but noted that as they spoke, the service was tabulating the results of a survey of working-class families that it hoped would authoritatively answer most questions about the impact of the Depression on both the health of American children and on that of the general population.³³

As Surgeon General Cummings made clear in his 1934 talk before the League of Nations Health Organization, the survey was in large part motivated by the USPHS's growing conviction that the standard health indices were failing to provide a meaningful measure of the impact of the Depression on the nation's physical well-being. For at least a year, many in public health had been expressing concern that declining death and reportable disease rates might be masking the beginnings of a widespread deterioration of health, particularly among children. A 1933 editorial in the *Journal of the American Public Health Association*, recalling the optimism of Dublin the previous year, warned that, despite the vital data, such a positive outlook seemed increasingly unjustified. A few months later another editorial went further, suggesting that the deep cuts in public and personal child health expenditures brought on by the deepening economic crisis inevitably would be paralleled by significant declines in the nation's healthiness. Of

particular concern, the editors contended, was the future health of children, for in every state child health programs had been slashed, and many parents were eschewing preventive health care for their children and consulting the doctor only in dire emergencies. The editorial also warned that while most of the existing data on childhood malnutrition were suspect, a recent careful review by the USPHS suggested that undernourishment might indeed be on the rise among the children of the unemployed.³⁴

The survey was also clearly intended to challenge the complacency of those government leaders and health experts who kept uttering assurances based on the continuing drop in death rates during the early years of the Depression. In particular, as a preliminary report on the survey noted, USPHS health analysts had become increasingly impatient with "the comfortable conclusion drawn by many that the physical well-being of the American people not only has not suffered but, in view of the continued decline in mortality, may have been benefited by the economic catastrophe. Such a conclusion, based upon mortality statistics alone, obviously is open to question. Death rates are not sensitive indices of the immediate effects of deleterious conditions."³⁵

Better indices of health and ones more sensitive to economic trends, USPHS health analysts argued, were sickness rates, especially when combined with information on income, regularity of employment, and consumption of medical, hospital, nursing, and dental care. Even better were rates of disabling illness, that is, illness that prevented an adult from going to work or a child from going to school for several days, typically five to seven. Such data, although available for a few studied communities and specific company workforces, had not yet been collected for the general population – a project in which the USPHS had expressed considerable interest but had been unable to undertake with its limited funds and personnel. Hence, when Milbank officials offered to provide financial assistance and additional physician field researchers if the service would join with it in conducting a health survey, its offer was quickly accepted.³⁶

The result was a series of comprehensive reports which when combined demonstrated unequivocally that, especially among families who were on relief or who had suffered a substantial drop in income, both general health and health services consumption had declined significantly since the start of the Depression. Indeed, when tabulated, the collected data showed that relief or newly impoverished families experienced a rate of disabling illness that was on average 56 per cent higher than families from the same areas whose incomes had remained relatively stable since 1929. Similarly, the studies showed that the newly poor were purchasing far less medical and

dental care than they had in 1929 and were relying instead on whatever free care could be secured from hospitals, dispensaries, and private physicians and dentists.³⁷

Milbank and USPHS field researchers also found that what was true for the general population was especially true for children. The children of the newly poor contracted respiratory diseases at a higher rate than the children of neighbours who were either well off or chronically poor and seemed to suffer the highest rate of disabling diseases, that is, diseases that kept them home from school or in bed for at least five days.³⁸ Most significantly, the survey revealed that children from families on relief suffered a significantly higher rate of nutritional deficiency. Recognizing that the difficulty of diagnosing malnutrition prevented information on its incidence from being collected in the same manner as information on other diseases – by asking a family informant, usually the mother – Service and Milbank physicians selected from families interviewed in the general health survey a thousand New York and Pittsburgh school and preschool children and gave them careful physical examinations, which, as Service physicians later reported, gave little importance to weight and height but placed “special emphasis on amount of subcutaneous fat present, texture of skin and hair, muscle tone, evidence of old rickets,” and hemoglobin count.³⁹ What was found generally confirmed the alarms of the child hygienists. As Cummings reported in 1934, “Considering the nutritional status of children in relation to the *per capita* income of families during the four year period 1929–1932, data indicate that those whose family *per capita* income remained unchanged show a higher percentage of good nutrition than those who dropped from a high level in 1929 to a lower level in 1932.”⁴⁰ The journal *School and Society* was more emphatic in its assessment of the implications of the examinations, bluntly editorializing, “The much discussed question of whether school children are actually undernourished has been answered in the affirmative.”⁴¹

The USPHS/Milbank survey findings on child sickness and malnutrition, along with those on sickness and disability among adults, had three immediate effects. First, they provided a shot in the arm to what had thus far been desultory local efforts at providing relief families with food and instruction on preparing healthy meals. Second, they added further support to the Roosevelt administration’s decision to focus on ameliorating the effects of unemployment rather than the effects of chronic poverty. Third, they clearly demonstrated the value of morbidity and disability data as sensitive measures of short-term health trends and of the effects of deleterious social and economic conditions.⁴² Indeed, soon after he received the prelim-

inary report on the survey, Surgeon General Cummings began lobbying for the authority and funding to conduct a much larger and truly national survey. His lobbying found a sympathetic response among those in the Roosevelt administration pushing for the inclusion of some form of health care assistance within Social Security. After being named head of the administration's Interdepartmental Committee to Coordinate Health and Welfare Activities, Josephine Roche also argued for a national health survey, declaring that declining death rates were misleading and that "any assessment of the nation's health requires that illness rather than deaths be the basis from which to draw conclusions."⁴³ Harry Hopkins, the head of the Federal Emergency Relief Agency, went even further, providing the USPHS with a \$3.5 million grant to hire the personnel necessary to conduct a national survey and tabulate the results.⁴⁴

Launched in the winter of 1935, the survey recorded the recent medical history of some 865,000 white families in ninety cities and twenty-three rural areas. The methods were essentially the same as those employed in the earlier USPHS/Milbank survey. Also the same were the results. The incidence of disabling illness was highest among members of families whose economic status had deteriorated markedly over the previous years. Moreover, the survey found that this was especially true for children less than fifteen years of age. In its extensive report on the "Disabling Diseases of Childhood," the Service noted that while mortality among the young was continuing to drop, the frequency of illness remained high among all children and was especially so among children of relief families.⁴⁵

Although referenced repeatedly by New Deal health reformers, the USPHS/Milbank survey and the National Health Survey were not sufficient to overcome opposition to the adoption of a national health program. However, particularly the findings on child health did provide powerful support for maintaining and expanding the unemployment insurance program established by the Social Security Act. Pointing to the higher incidence of malnutrition and sickness among children of the unemployed, the social welfare activists of the Roosevelt administration characterized unemployment insurance as a child welfare measure necessary for the protection of the nation's young.

Additionally, while not completely displacing mortality figures as indices of health trends, the surveys provided a nuanced way of measuring and describing child health that remains in use in the basic U.S. assessment of national health trends, the annual health interview survey that has been conducted every year since 1956.

NOTES

- 1 See, for example, Brosco, "Policy and Poverty," 1381-7; Baker, "The Hunt for Disability," 663-703; Fee, "Public Health in Practice," 570-606; and Meckel, *Save the Babies*.
- 2 The study methodology was based on various smaller sickness surveys the USPHS had been conducting since the early 1920s, as well as on a survey of 9,000 families for 1928-31 conducted by the Committee on the Costs of Medical Care (Perrott and Collins, "Sickness and the Depression ... in Birmingham," 281-98). For an early USPHS study, see Sydenstricker, "The Incidence of Illness," 279-91.
- 3 Cummings, "Health and the Economic Depression," 2-3; Sydenstricker, "Health and the Depression," 275.
- 4 Breckinridge, "Children and the Depression," 130-33; Areson, "Status of Children's Work," 91-2.
- 5 Conrad, "Health Services," 127; Lindenmeyer, "A Right to Childhood," 171.
- 6 Lundberg, *Unemployment and Child Welfare*.
- 7 Bradbury, "Five Decades of Action," 25.
- 8 Abbott, *From Relief to Social Security*, 20; Brown, *Public Relief*, 79-80.
- 9 Dublin, "The Health of the People," 1124, 1134; "Health and the Depression," 1318.
- 10 Meckel, *Save the Babies*, 48-61; Holt, quoted in Baker, *Child Hygiene*, 412.
- 11 Ibid.
- 12 Spargo enumerated many reasons why poor children were entrapped by their poverty, but he maintained that the most important one was lack of the benefits of good nutrition. That also was the claim of Robert Hunter, the author of *Poverty* (1904), who wrote the introduction to John Spargo's *The Bitter Cry of Children*, x-xi.
- 13 Meckel, "Open-Air Schools," 91-6.
- 14 Holt, *The Diseases of Infancy and Childhood*, 15; Brosco, "Weight Charts and Well Child Care," 94; Halpern, *American Pediatrics*, 87-8.
- 15 Reese, "After Bread, Education," 496-525; Meckel, "Open-Air Schools," 92-4.
- 16 Brosco, "Weight Charts and Well Child Care," 98-9.
- 17 U.S. Department of Labor, Children's Bureau, "Children's Year," 3.
- 18 Brosco, "Weight Charts and Well Child Care," 100-2; Terman and Almack, *The Hygiene of the School Child*, 96-102; Baker, *Child Hygiene*, 412-16.
- 19 Brown, "A Study of Malnutrition," 27-30; Emerson, *Nutrition and Growth in Children*, 2-10; Rich, "Why the Nutritional Problem?" 242-6; Coolidge, "Starving amidst Plenty," 46.
- 20 Brosco, "Weight Charts and Well Child Care," 101-6; "The Depression and Death Rates," 13.

- 21 Abbott, *From Relief to Social Security*, 68; Brown, *Public Relief*, 71; "Children and the Depression," 5. See also Abbott, "The Child," 952-5.
- 22 Quoted in Breckinridge, "Children and the Depression," 127.
- 23 Fox, "Health of Miners' Children," 1148; Fox, "Strikers' Children," 103; King Coal's Innocent Victims," 12; U.S. Congress, Exhibit A: U.S. Children's Bureau, 3095-97
- 24 "Save the Children Federation," 657.
- 25 Breckinridge, "Children and the Depression," 128-30; Abbott, "The Child," 953; *Congressional Record*, 3097.
- 26 Abbott, *From Relief to Social Security*, 226; Brown, *Public Relief*, 90-4; *Congressional Record*, 3095.
- 27 The House rejected the bill in January; the Senate followed the next month. See Brown, *Public Relief*, 371-2.
- 28 Wilbur and Hyde, *The Hoover Policies*, 372; Abbott, *From Relief to Social Security*, 113-17; Brown, *Public Relief*, 75.
- 29 Brown, *Public Relief*, 108; Hoover, "Address of President Hoover," 10.
- 30 "Does Depression Improve Health?" 41; Wilbur, "Children in National Emergencies," 27, 29.
- 31 Perkins, quoted in "Proposed National Conference on Child Health Recovery," 401.
- 32 *Proceedings of the Child Health Recovery Conference*, 7; Elliot, "Child Health Recovery Program," 178-80.
- 33 *Proceedings of the Child Health Recovery Conference*, 32; "Child Health Recovery Program," 40-4.
- 34 Cummings, "Health and the Economic Depression," 32-3; "The Depression and Health," 247-8; "The Depression and Public Health Expenditures," 755-6; Jacobs, "Is Malnutrition Increasing?" 784-8.
- 35 Perrott and Collins, "Sickness and the Depression ... in Birmingham," 281.
- 36 Sydenstricker, "Health and the Depression," 277; Perrott and Collins, "Sickness and the Depression ... in Birmingham," 281-4.
- 37 Perrott and Collins, "Sickness and the Depression ... in Ten Cities," 220-1; Perrott, Sydenstricker and Collins, "Medical Care during the Depression," 105, 107, 114.
- 38 Perrott and Collins, "Sickness and the Depression ... in Ten Cities," 223; Sydenstricker, "Health and the Depression," 274-9.
- 39 Kiser and Stix, "Nutrition and the Depression," 301.
- 40 Cummings, "Health and the Economic Depression," 46.
- 41 "Under-Nourished Children in New York City," 7.
- 42 Perrott and Collins, "Sickness and the Depression ... in Birmingham," 281.
- 43 Roche, quoted in Engle, *Doctors and Reformers*, 101.
- 44 Furman, *Profile of the United States Public Health Service*, 382.
- 45 Ibid., Holland, "Disabling Diseases," 144.

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PART FIVE

Representing Children in Health and Sickness

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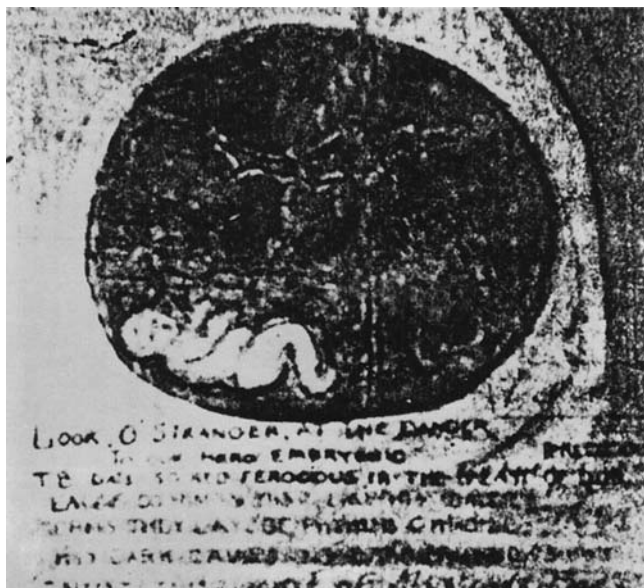
When the Children Are Sick, So Is Society: Dr Norman Bethune and the Montreal Circle of Artists

LOREN LERNER

During the Great Depression and into the 1940s, Montreal artists were questioning the social responsibility of the artist and, by extension, the social role of art. Creating and disseminating images of poor and sick children were for them significant means of conveying their dissatisfaction with society's neglect of fundamental values, a neglect exacerbated by widespread economic and social conditions.

Norman Bethune, a physician and artist who was dedicated to radical social change, was an important catalyst in raising the consciousness of Montreal artists. In December 1926 Bethune had become a patient at the Trudeau Sanatorium in Saranac Lake, New York.¹ He was thirty-six years old and sick with tuberculosis in both lungs. In the fourteen years prior to his stay at the sanatorium, he had studied medicine at the University of Toronto, volunteered during the First World War in the Royal Canadian Army Medical Corps, completed postgraduate surgical studies in several hospitals in London, England, and set up a private practice in Detroit, Michigan. It was in Detroit that he discovered he was ill.

At the Trudeau Sanatorium, convinced he was dying, Bethune painted a mural about his life and death on the walls of the small cottage he shared with four other patients. Instead of dying, however, he found his own cure in the *Surgery of Tuberculosis* by John Alexander, a thoracic surgeon and professor at the University of Michigan. Alexander had written about William Carson, a physician who lived and worked in Liverpool in the early 1800s. As early as 1821 Carson was recommending that his patients undergo pneumothorax collapse therapy, an unconventional surgical procedure that involved collapsing the lung to give it time to recuperate. Bethune insisted that his doctors perform this procedure on him, and on 10 December 1927 he was discharged from the sanatorium fully recuperated.

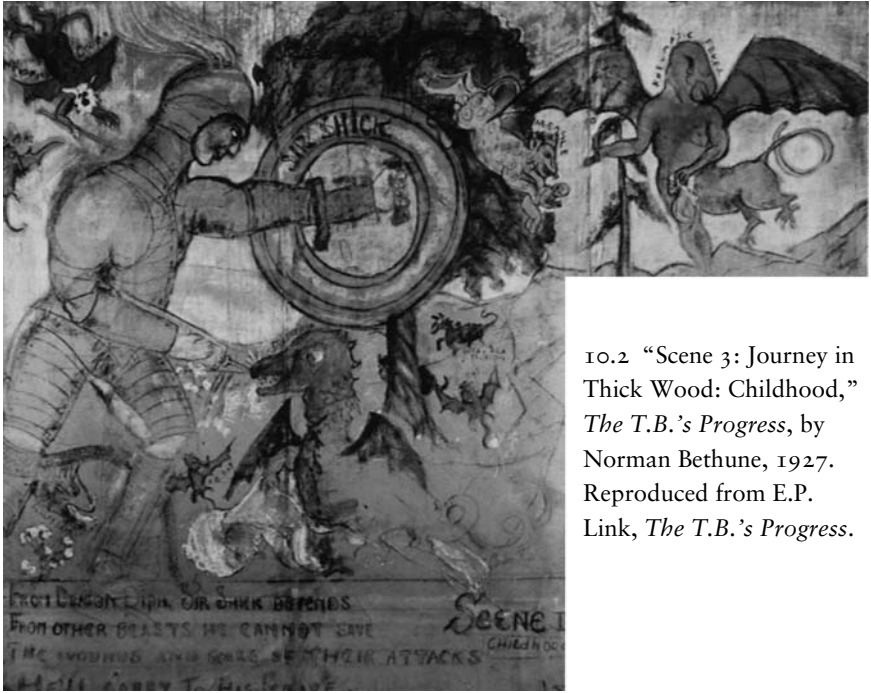


10.1 "Scene 1: Womb and Foetus," *The T.B.'s Progress*, by Norman Bethune, 1927. Reproduced from E.P. Link, *The T.B.'s Progress*.

In the August 1932 issue of the medical journal *The Fluroscope*, Bethune explained the sanatorium mural as a series of "continuous coloured drawings, five feet high and sixty feet long, [that] ran around the walls, fitting in the spaces between the roof and the wainscotting of the doors and windows." He named the work *The TB's Progress*, "a drama in one act and nine painful scenes."²

The first scene (figure 10.1) is of Bethune's "pre-natal existence." The womb is a dark cave where the infant is already stricken with the tubercle bacillus. Here Bethune refers to the notion of inter-uterine infection developed by the German pathologist Julius Cohnheim, although he recognized that Cohnheim's effort to trace every new growth of abnormal tissue in later life to embryonic or fetal defects and lesions was scientifically improbable. Nevertheless, "for the sake of artistic design," Bethune could not resist depicting the disease as a prehistoric reptile with bat wings and sharp teeth attacking the unborn child.

The second scene shows Bethune entering the world in the arms of a beautiful guardian angel. Together they face the Angel of Fate, who determines

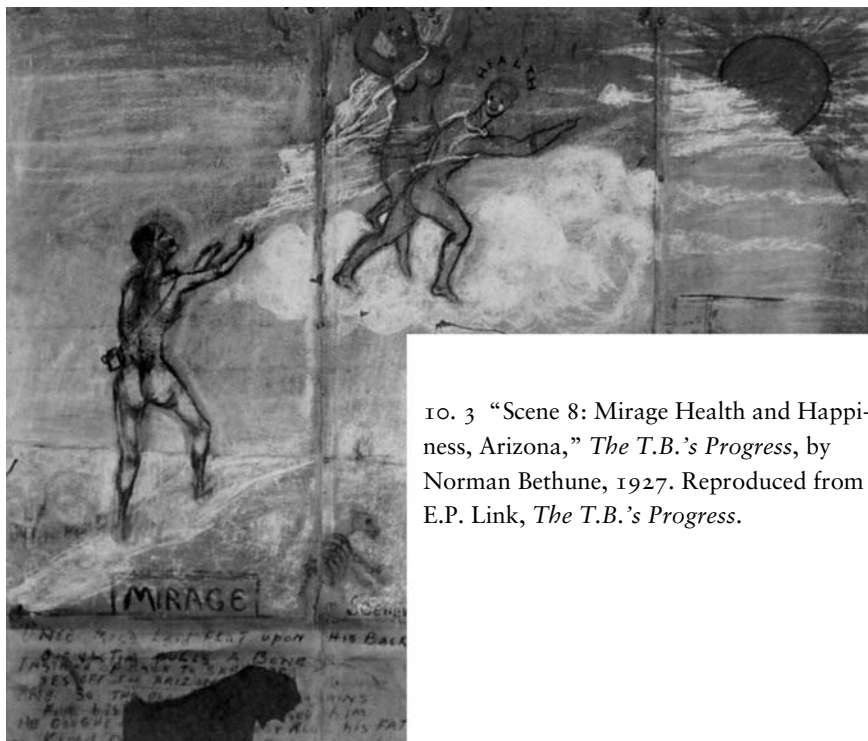


10.2 "Scene 3: Journey in Thick Wood: Childhood," *The T.B.'s Progress*, by Norman Bethune, 1927. Reproduced from E.P. Link, *The T.B.'s Progress*.

his future while other angels turn away weeping. Bethune explained that this notion of predestination was also suspect, "probably a relic of my Scot ancestors."

The third scene (figure 10.2) shows Bethune's childhood as "a dangerous journey through thick wood where lurk wild animals." Based on the theory that childhood diseases can create a predisposition for tuberculosis, he pictures these "cruel terrifying creatures ... the Mump, the Whoop, the Dipth, and the Scarlet ... [that] either lurk behind trees, or fly in the sky ready to pounce down on the child." Charging into the scene from the left to defend the child against the Dipth dragon is Sir Schick, a knight in shining armour. This is a reference to Béla Schick, a Hungarian-American pediatrician who in the early 1900s developed a test that eventually led to the eradication of diphtheria.

Bethune's years as a young man are the subject of the fourth scene. Out of the woods of his childhood he sails across the "Sea of Adolescence" toward the "the beauteous creatures" Fame, Wealth, Love and Art who live in a castle on the nearby rocky cliffs. But before he can enter the castle, he is attacked by the bats representing tuberculosis (as in figure 1).



10.3 “Scene 8: Mirage Health and Happiness, Arizona,” *The T.B.’s Progress*, by Norman Bethune, 1927. Reproduced from E.P. Link, *The T.B.’s Progress*.

The next five scenes are an enactment of Bethune’s battle with the disease. Hemorrhaging and chased by “swarms of TB bats,” he falls into the “Abyss of Despair.” Entering another castle, the “Trudeau Sanctuary,” he is protected by the doctors who practise in this special place. Though temporarily cured, he becomes “very thin and weak” and travels briefly to Arizona with “a small sputum cup strapped to his cadaverous body” (figure 10.3). Finally, he returns to the city where “people are like black ants on the street” and “the air is filled with TB bats” that attack him once more.

The tenth and final drawing depicts Bethune as child again: “the Angel of Death [is] holding me in her arms and looking down on me with a kindly and benign expression on her face. She is not a dark angel, but just as beautiful and bright as the other angels at my birth.” In the churchyard cemetery Bethune’s tombstone rests among those of the men who shared his Trudeau Sanatorium cottage.

Bethune defined *The TB’s Progress* as an “allegorical story of my past life and what I thought my future would be.” Its prototype was of course *Pilgrim’s Progress*, the seventeenth-century classic written by John Bunyan

while imprisoned in a Bedford gaol for the crime of holding a religious service not in conformity with the Church of England. In *Pilgrim's Progress* the hero experiences trials and temptations on his journey to the Celestial City. An allegory of the religious journey in search of salvation, the story was still used during Bethune's time as an important tool in raising Protestant children.

After leaving the Trudeau Sanatorium, Bethune lived in Montreal and worked from 1928 to 1932 in thoracic surgery at the Royal Victoria Hospital under Dr Edward Archibald. In January 1933 he was appointed chief of pulmonary surgery and bronchoscopy at Sacré Coeur Hospital in Cartierville, not far from Montreal. There he performed lobectomies and pneumonectomies, introducing surgical instruments he invented, and instituted pneumothorax as an active treatment of tuberculosis with collapse therapy. But he recognized that doctors alone could not cure their patients of TB because "external environmental forces" such as "poverty, poor food, unsanitary surroundings, contact with infectious foci, overwork and mental strain" were outside the domain of the medical profession.³

In the summer of 1935, with an interest in learning more about communism, Bethune travelled to the Soviet Union to attend sessions of the International Physiological Congress. The experience convinced him that government should implement a social system that would care for all patients regardless of their ability to pay. As an ardent champion of socialized medicine, he formed the Montreal Group for the Security of the People's Health, a small coalition of doctors, nurses, and social workers. The Montreal Group addressed the lack of decent medical services for the unemployed and poor in Depression-ridden Montreal by preparing a comprehensive program of health care that involved the cooperation of physicians, nurses, social and charitable agencies, public health officials, government officials, the Montreal Unemployment Commission, and the church.⁴ Although the program was considered revolutionary, it was a logical outgrowth of Bethune's upbringing as the son of an evangelical Protestant minister.⁵ His beliefs as a social activist stemmed from the religious Social Gospel ethic that arose in the 1890s and developed into a social welfare movement in Canada that sought to better the lives of the poor.⁶

When the Montreal Group failed to convince the Quebec government that providing medical care and related services was one of the fundamental functions of a society, Bethune became increasingly upset at the indifference of the state. He came to believe, as did the intellectuals and artists who were his friends, that communism was the political alternative for improving the nation's social and economic life. In 1936, with the Spanish Civil

War drawing people together in social protest, he resigned from his post at Sacré Coeur Hospital to serve in the war as a medical volunteer. In Spain he developed a mobile blood transfusion service – the first of its kind – that played an important role in the conflict. He returned to Montreal in spring 1937 an avowed communist. Determined to help the “people’s struggle,” he sailed for China in January 1938 to join Mao Zedong and the Red Army in Yan’an. As he operated on wounded soldiers on the front lines, performing surgery without gloves, his finger became infected. On 12 November 1939 he died from septicemia.

Bethune’s mural drawings at the Trudeau Sanatorium tell his life story to a large extent through the narrative of a child: the “hero embryonic” with attending angels at his birth, “Adolescence [on] troubled seas” and, finally, in the arms of “Sweet Death, thou kindest angel of them all.” At important junctures in Bethune’s intellectual and professional development, the image of the child recurred, intermixed with his vision of art, science, and social progress.

In *Night Operating Theatre* (figure 10.4), painted in 1936, the dramatic beam of light that illuminates the circular stage of the operating area emphasizes the creative, even artistic, activity of the surgeon. In this bird’s-eye view from the observation deck of an operating room, Bethune shows himself performing emergency surgery on a child in the middle of the night. The position of his body and extended arm recall an artist working on a canvas. Bethune believed that the surgeon had much in common with the artist; four years earlier, in the *American Review of Tuberculosis*, he wrote, “Modern surgical craftsmanship with its new leisure and as an immediate consequence, its new precision, permits and encourages the artistic sensibilities of the operator. These artistic desires and their approximate satisfaction are contained, to a large extent, in what is known as ‘surgical technique.’”⁷

Bethune painted *Night Operating Theatre* in response to a work by his friend and fellow artist Fritz Brandtner entitled *Dr. Norman Bethune: Operation at Sacré Coeur Hospital, ca. 1933* (figure 5), commemorating Bethune’s first operation at the hospital. Surrounded by nuns, he looks intently at the child’s open chest, his hand touching the cavity in a gesture reminiscent of Christ’s healing touch. Dr Georges Deshaies, an attending thoracic surgeon whom Bethune was training, seems to rest his chin on Bethune’s shoulder as he intently observes the surgical technique. From Bethune’s other side, a nun with glasses looks on. Others in the room glance at the operation or gaze elsewhere with expressions of concern. In this tight-knit group of nurses and physicians, the tension is palpable, in marked contrast to Bethune’s composure.



10.4 *Night Operating Theatre*, by Norman Bethune, 1934. Oil on canvas. Royal Victoria Hospital Medical Library of the McGill University Health Centre, Montreal. Photograph courtesy of the Royal Victoria Hospital Media Services Department.

As a thoracic surgeon Bethune often operated on children suffering from tuberculosis. His devotion to these patients is recorded in his personal notes; he reveals an artistic sensibility when he writes about visualizing the child's body as a work of art. On 26 November 1935, recalling removing an entire lung from a child, he wrote, "My child is well. It was a very beautiful operation. I felt very happy doing it. The entire right lung was removed, the first time this has been done – in a child of 10 – in Canada and the 45th operation of its kind ever been done in the world. Isn't that nice? Yes, I will sleep deep tonight – last night was a 'nuit blanche' – not whether I could do it but whether I should. I decided I must at 4 A.M., slept well I felt refreshed and 'tight' and went at it like a canvas – my picture full in my mind."⁸

Clearly aware that his medical accomplishments were inspired by the creative process, Bethune saw creativity as a natural resource to be nurtured in children. As a physician, he wanted to cure children; but he also believed he could improve their health by helping them develop their artistic faculties. In the spring of 1936, soon after he moved to a flat at 1154 Beaver Hall Square, he and Fritz Brandtner opened the free Children's Art Centre in



10.5 *Dr. Norman Bethune: Operation at Sacré Coeur Hospital*, by Fritz Brandtner, 1933. Oil on canvas. Photograph of the painting from the National Film Board of Canada, Phototèque Collection, Library and Archives Canada, PA-114792.

Bethune's large living room. Three afternoons a week children came to paint with Brandtner, later with another artist, Marian Scott, assisting. On Saturday mornings Bethune took the children on expeditions to art galleries and museums, or on picnics or walks around the city to see factories and other interesting buildings. His goal was to introduce the children to subjects that could later become the focus of their paintings.

The idea of the child also helped Bethune express his political beliefs. In December 1935 he spoke to the Montreal Medico-Chirurgical Society about communism and the health system in the Soviet Union. "Now, Russia is going through her delivery and the midwives and obstetricians have been so busy keeping the baby alive, that they haven't got around as yet to cleaning up the mess, and it is this mess, this ugly, uncomfortable and sometimes stupid mess, which affronts the eyes and elevates the noses of those timid male

and female virgins suffering from frigid sterility of the soul, who lack the imagination to see behind the blood the significance of birth.”⁹ Bethune compared the radical transformation of Russian society with the mixed reactions of witnessing a birth. “Creation is not and never has been a genteel gesture,” he emphasized. “It is rude, violent and revolutionary.”

His reports from Spain in 1936 and 1937 use the image of the suffering child to convey the atrocities being committed against the civilian population. Writing about the mass evacuation from Malaga – an account accompanied by Montreal photographer Hazen Sise’s chilling images of sick and dying children – Bethune vividly illustrated the misery inflicted on the people: “Children with bloodstained rags wrapped around their arms and legs, children without shoes, their feet swollen to twice their size crying helplessly from pain, hunger and fatigue ... Two kilometres of misery. Imagine four days and four nights, hiding by day in the hills as the fascist barbarians pursued them by plane ... How could we choose between taking a child dying of dysentery or a mother silently watching us with great sunken eyes carrying against her open breast her child born on the roads two days ago.”¹⁰ The anguish of the children Bethune described in this eyewitness account is the sustaining image for his denouncing the evils of fascism.

Finally, in China in 1938 and 1939, he joined with Chinese authors and artists in bestowing on young people the task of transforming society. The poet Emi Siao gave Bethune a copy of a letter written to the Lu Hsun Art Academy, dated 2 September 1939, about encouraging young “art workers” to become trained in the arts, theatre, music, and literature. Siao’s letter spoke of the admiration he and Bethune shared for the two hundred young people being trained at the academy to be sent out to educate the masses. “Art is not for Art’s sake here, nor is there that flora of ‘Ivory Towers.’ On the contrary art is directly linked with the struggle, with the people, with their task, their hopes and their ambitions.”¹¹

Identifying himself as an artist, Bethune associated with other artists, encouraging them to share his vision that only through improving the life of children could society improve itself.¹² For him, children were the source of hope for a better world; they signified both the present illness and future health of a society and were the guiding force in defining national social and political ideals.

FRITZ BRANDTNER

Bethune met Fritz Brandtner when he bought Brandtner’s painting *Sunflower* on exhibit at the Art Association of Montreal. The two men quickly became

friends, sharing ideas about how to foster a better, more humane society. Brandtner had immigrated to Canada in 1928 from Danzig, Germany, where he taught figure drawing in the Architecture Department of Danzig University. He settled first in Winnipeg and in 1934 moved to Montreal.

In the autumn of 1935 he and Bethune embarked on their first joint project – developing a model city for tuberculosis patients healthy enough to leave the hospital but not well enough to return home.¹³ The city was to include all the facilities needed for rehabilitation such as living accommodations, clinics, a recreation centre, and workshops where patients could learn a trade. The project was abandoned as financially unfeasible in its design stage.

Their next project was the Children's Art Centre in Bethune's living room, where the focus was less on teaching art and more on helping children to develop their imaginations and release their creative energies. Small classes of ten to fifteen students ranging in age from eight to fifteen years worked on large sheets of wrapping paper spread on the floor. They painted what was on their minds or what they had observed at galleries and museums or during their walks around the city.

When explaining why they paid so much attention to children's art-making, Brandtner and Bethune argued that this kind of activity contributed to the optimal development of the child. They believed that for children to grow in a natural, healthy way, their creative aspects had to be nourished. The emphasis for Brandtner was on mental growth, on the "value of training the hand as a means of developing the mind."¹⁴ He saw observation, imagination, and reasoning as the faculties of the mind that made it possible for a child to visualize a form and find a way to express it. The child needed "to experiment always, to see what it can discover, and to feel that the immediate result isn't the most important thing but rather what it has learned." Reflecting on the centre years later, Marian Scott confirms that they all subscribed to the idea that if underprivileged children were given a choice of colours and the freedom to express their ideas and feelings through drawing, even for a short time, it could help them face hardships later in life.¹⁵

In 1938, Brandtner expanded the centre's art program to include weekly classes at the Iverley Settlement, the Negro Community Centre, the Neighbourhood House, the Griffintown Club, the Verdun YMCA, and the orthopedic ward of the Children's Memorial Hospital. With financial assistance for his activities from private donors and community groups, he helped sensitize Montrealers to the creative abilities of children from disadvantaged homes and to the remedial potential of art in improving lives. In

1939, reviewing an exhibition of the children's work at the Art Association of Montreal, the critic Robert Ayre reminded the viewer: "As you enjoy these paintings you might reflect that the youngsters didn't make them for your pleasure but for their own ... Remembering where they live, I think you will agree that by his encouragement and stimulus, Brandtner is doing something valuable for the community."¹⁶

Brandtner's most challenging achievement was teaching art to the children who spent months or years at a time on the chronic orthopedic ward of the Children's Memorial Hospital (figure 10.6), confined to their beds with conditions that required braces and successive surgeries.¹⁷ He encouraged the children to recall what they had experienced before entering the hospital and to imagine life outside the hospital by looking at picture books. In June 1941 an exhibition of their paintings was mounted in the fifth-floor auditorium of the Henry Morgan department store.¹⁸ Pictures of warships, trains, airplanes, automobiles, and other moving vehicles were much in evidence, contrasting sharply with the immobility of the young artists. Also popular were everyday scenes of farms, factories, and hockey games, as well as representations of hospital events such as a man selling balloons or Santa coming for a visit.

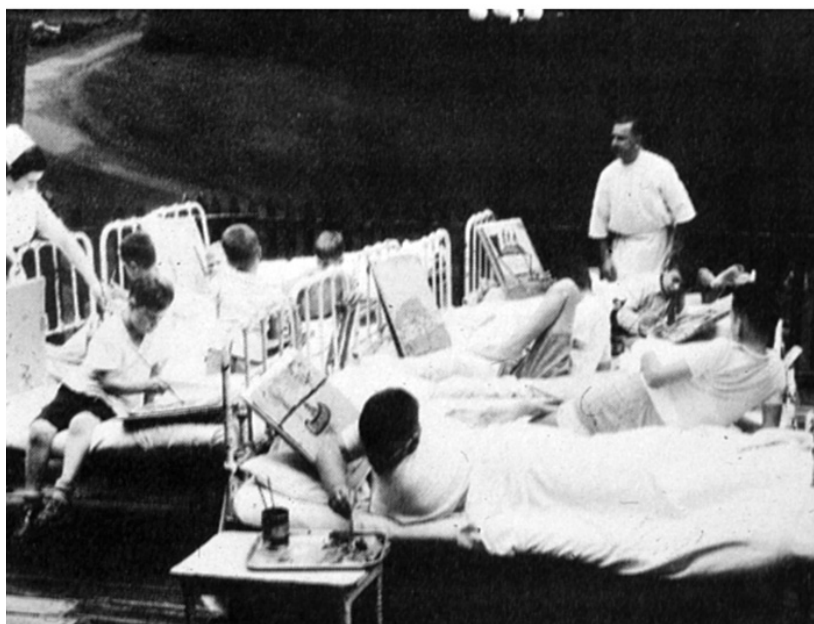
In the opinion of Dr DeBelle, a physician at the hospital, Brandtner's program was far more beneficial than the recreational and occupational therapies that had been used to date, and in some cases it changed the whole outlook of the child. Unfortunately, following the Morgan's exhibition, the program was terminated because of lack of funding.

Brandtner and Bethune linked the positive growth of a child to nurturing that child's creativity. According to this progressive thinking, children were reservoirs of an unlimited capacity for creative fulfilment and goodness. As Brandtner wrote, "the present world conditions show more and more the necessity for an education system which would teach our children to think, to consider, to discuss, to judge and then to act, not only individually but cooperatively."¹⁹

In 1936, as Brandtner and Bethune were setting up their Children's Art Centre, another art educator, Arthur Lismer, was teaching children's art classes at the Association of Montreal (now the Montreal Museum of Fine Arts). Lismer started from a similar premise, that stifling children's creative growth was detrimental to their health. "Growth is the fundamental process of all life," he wrote. "The creative character of childhood is a powerful yet tender plant – feed it on patent food, regiment it, support it with crutches ... [it] becomes a forced and sickly plant, non-creative of further growth."²⁰ In recognizing the organic primacy of the aesthetic impulse in



10.6 *Children from the Orthopaedic Ward of the Children's Memorial Hospital, Montreal. Reproduced from Jean-Marie Marcotte's "Sur le plancher d'un studio," La Revue moderne 21 no. 8 (December 1939): 19.*



children, he, along with Brandtner and other like-minded art educators, believed that the capacity of children to create art was linked to the health of their society.

LOUIS MUHLSTOCK

In 1937 Brandtner organized an exhibition in Montreal's Sun Life Building entitled "Produced in Canada." Amongst the artists showing were Brandtner, Jori Smith, Marian Scott, and Louis Muhlstock. Born in a small town in Galicia and raised in Montreal from the age of seven, Muhlstock studied painting in Paris from 1928 until 1931, when his mother became ill and he returned to Canada. Unable to afford models, he drew the homeless and unemployed in the parks and streets of Montreal. He visited the waiting rooms of hospital clinics: "I used the rows of waiting people as models, stealing my notes while hidden behind a newspaper or magazine."²¹ His depictions of the human condition were sympathetic and compassionate as well as aesthetically pleasing.

Through his association with Brandtner, Muhlstock had known Bethune since the early 1930s and often saw him at exhibitions.²² While Bethune's Montreal Group was addressing the deplorable state of health care for the poor, Muhlstock was recording his observations of the sick and destitute. Four of his portrait drawings appeared in the January 1936 issue of *Canadian Forum*, a magazine that advocated vigorous social criticism. In *Vieux Canadien*, the artist shows us a sorrowful old man; in *Victor Sartori* he records the pensive mood of a middle-aged man; in *War* we see the faces of three frightened young men, and in *Paranka*, the melancholic face of a young female patient at the Montreal General Hospital (figure 10.7).

The study of *Paranka* was one of a series of chalk and charcoal drawings first shown in Muhlstock's 1935 solo exhibition at the Art Association of Montreal.²³ He describes the encounter with his subject:

She was a patient who had been there for fourteen years, in a crib. She was a twenty-one year old who weighed about forty-five pounds ... It was a pituitary gland disease that reduced her to a skeleton ... *Paranka* had no vision at all. Her eyes were wide open and the nurse asked her to sit up ... she was going to have her picture taken. And so she sat for five or ten minutes and then took the sheets and just covered her head completely and just curled up like a little animal ... sheltered and that was the end of it. I couldn't draw any more. And I came back the next day, and I tip-toed in, quietly, and when I began to draw she heard the sound



10.7 *Paranka*, by Louis Muhlstock, ca. 1932. Charcoal on laid paper. 41.8 x 31.5 cm. Estate of Louis Muhlstock.

of the charcoal on the paper, and so she recognized the sound and she did that same thing again, just covered herself; and there was no more. I went back, I sat patiently again, moved further back from the cot that she was in and drew. And so for five or six sessions I was able to come back and observe her and I got to know her face.²⁴

With a few delicate strokes Muhlstock captures the fragile beauty of Paranka's features – the heart-shaped head, the dark eyes, the long slender nose and the small mouth – even as she partially shrouds her head with a sheet and averts her eyes, retreating into her own thoughts. Though she is blind, emaciated, dwarfed, and crippled, there is little in the portrait to

"Bloody Instructions"

Protestant Education in Quebec

ERIC WISEMAN

UNDER THE PROVISIONS of the B.N.A. Act, the complete autonomy in the sphere of education is guaranteed to the provinces. The Government of the Province of Quebec is naturally entitled to exercise this right in the most complete and free manner. The interests of an English-speaking community are not to be sacrificed to the demands of a French-speaking community. The setting up of a system of dual control, The Council of Education for the Province of Quebec, the Council of Education for the English-Speaking Community, the Education of All-Canada Council. Each of these bodies will have to be consulted in the future, and apart from the six-official district members of the B. N. C. Committee, the members are appointed by the Government of the Province. The members of each committee have the force of law when they are in agreement. The Government of the Province has a Department of Education, headed by the Minister, who is responsible for repairs to the Provincial School System. The Department of Education, but is bound to comply with the

This is a complicated issue, especially as no nation has yet been made of the Superintendent's Office. The Superintendent of Education is not a Deputy-Minister, while the Minister of Education is not a Superintendent of Education. It is comparatively simple to make the Superintendent of Education responsible for education in the Province rather than the State. This is the view the Government has taken. It is the view of the people who have the power to vote their representatives. Or does it lie with the Superintendent of Education? The Superintendent of Education is not a Deputy-Minister, while the Minister of Education is not a Superintendent of Education. It is comparatively simple to make the Superintendent of Education responsible for education in the Province rather than the State. This is the view the Government has taken. It is the view of the people who have the power to vote their representatives. Or does it lie with the Superintendent of Education?

"Dear . . . I beg to inform you that I have been instructed by the Government of the Province to request your resignation as a member of the Protestant Committee of the Council of Education.

Yours truly,

is imperative that a Royal Commission be instituted. The salient features of Protestant Education in Quebec can be reviewed briefly under three headings: Teachers, Finance, Curricula and Health. The Protestant Committee has claimed in the

(signed) W. F. Fernald.

December, 1997

Offshore

It was this letter which created the state of affairs which has been called anything from an "incident" to a "crisis". After three weeks of Baldwinianque wailing-sighs, Premier Duplessis published a statement to the effect that the government of the Province had never authorized the letter, that the wording of the letter was inaccurate, that the government would never violate the autonomy of the committees, and finally that all the members of the Protestant Committee "who have received these regrettable letters will please consider them as never having been written."

Abramsdabra! Let there be no letter, and behold there is no letter! The crisis is over! Public indignation has been assuaged! Constitutional rights have been upheld! All's well with Protestant Education in the Province of Quebec!

But is it? Dame Rumer's volubility has been remarkable, but her suppositions are negligible beside the all-important fact that a bright spotlight has been thrown upon Quebec education. There emerges into bold relief a united group of Protestant teachers, protesting in every sense of the word, dissatisfied and clamoring for a Royal Commission to investigate Protestant education throughout the whole province.

During the height of the crisis, the Quebec Association of Protestant Teachers held their annual convention in Montreal, and with one voice demanded a Royal Commission. To the average newspaper reader this must have appeared rather strange, as

rent page have had already been given to statements made by various members of the Protestant Committee to the effect that "what has been done for education by the Protestant Committee" compares favourably with that of other sections of the country," and that "the claim that Protestant Education is behind the times is an incredible distortion of the facts." Why, therefore, the agitation? The claims of the defendants have been briefly stated above. In view of the immense importance of education to future generations of Canadians, it is a matter of public interest that the claims of the plaintiff teachers be examined closely and given all possible publicity. If their case can be proved, it

The Protestant Committee has claimed in the

press that it "has raised the level of work in the

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Louis Muhlstock

five cents to fifty cents per month for each pupil. Text books too have to be provided by the pupils unless they are indigent. In Nova Scotia all text books are free to the end of Grade Seven.

In Quebec the root of all evil is the small-unit financial system. Until the burden of finance is spread more evenly over the entire community, there

There can be no standard mill rate of taxation, (rates vary from less than five mills in 266 poor municipalities to 50 mills in 14 richer districts); most assessments for Quebec is 13.7 mills; for Nova Scotia, 29.1 mills); there can be no effective betterment of teachers' salaries; there can be no progress in education. Education was put fairly on the shoulders of the provinces by the B.N.A. Act. The time has now come when the Quebec Government must bear its burden, and bid, come what may, to those many school teachers

The deficiencies of the Protestant system in curricula would make an impressive agenda for any educational conference. The mere suggestion of them, which is all that can be attempted here, is a sufficient plea for a Royal Commission. As a result

of a survey, made by the Canadian Teachers Association, of 19 High Schools and 66 Intermediate Schools, it was found that less than 30 per cent. of the High Schools and about 60 per cent. of the Intermediate Schools had manual training courses, with approximately the same percentage in Domestic Science for girls. In B.C. manual training and Domestic Science are compulsory in grades seven and eight, and in Ontario in grade nine, in the latter provinces special grants being provided by the government. In Nova Scotia nearly all schools have a manual training department.

In health-care, mental hygiene, physical medicine and medical inspection, the Quebec Protestant Schools compare very favourably with those of other provinces. Hygiene is taught as a classroom subject in the first three years of the primary school period each day in the rural schools. Lack of playground equipment, however, means organized games are not possible in the rural schools. The system of medical or dental inspection. In New Brunswick, to quote a report of the Superintendent of Education, "The medical officer visits the schools actually visit every classroom and examine every child in the Public Schools of the province. The medical officer is not a visiting physician, but a permanent member of the staff of the school. In Nova Scotia where the children are isolated," Dr. Nava describes every urban and city school has medical and dental inspection of some sort. The lack of health services in the rural schools is a serious problem. The task of initiative on the part of the Committee of Public Instruction. Its importance for the physical health of the children is recognized and will be met by all the teachers.

Courses in Music and Art are held in about 60 per cent. of the 50 Protestant Schools surveyed by the C.T.F. In Nova Scotia there are regular courses in grades one to nine, while in N.C. music is given equal status with other subjects for the High School diploma.

In Vocational Training the enrollment figures speak for themselves. Of the 300,000 boys and girls between the ages of 15 and 19 in Quebec, only 72,000 are enrolled in any kind of school, and of these only 4,000 are in Vocational Schools.

There are no libraries in the majority of rural schools in Quebec. The Superintendent's report for 1935 says: "It is well known that our children

have no time for reading, and this explains their weakness in composition. This deficiency will continue as long as the source of evil remains. A small library is necessary to make children seek and love good reading." The Education Act of 1903 allows the Government to appropriate \$2,000 a year out of the Superior Education Fund to aid in establish-

10.8 *Young Boy with Tuberculosis*, by Louis Muhlstock, ca. 1932. Charcoal on laid paper. Estate of Louis Muhlstock. Reproduced in Eric Wiseman's "Bloody Instructions, Protestant Education in Quebec," *Canadian Forum* 17 (December 1937): 305.

suggest that she is afflicted with a terrible, incurable disease. By treating his subject with dignity and reverence, Muhlstock reveals the special qualities that illuminate this deeply suffering young woman imprisoned in the body of a child.

Muhlstock's drawings of children were strategically placed by the editors of *Canadian Forum*. In November 1937 *Young Girl from the Slums* (ca. 1932) was used to illustrate a short story about a young woman who reluctantly gave up her baby and "felt as if her heart had gone with it."²⁵ The drawing of a boy (ca. 1932, figure 10.8) was chosen to accompany an article by Eric Wiseman's, "Bloody Instructions: Protestant Education in Quebec."²⁶ Wiseman's article describes the deficiencies of the Protestant school system, including the subsistence salaries, inadequate pensions, shortage of playground equipment, and lack of medical and dental inspections.

Both drawings are of adolescents. The *Young Girl from the Slums* looks to be about fifteen, the boy a little younger, perhaps twelve. In this era adolescence was beginning to develop as a field of study, and physicians were starting to devote special attention to the emotional transitions and psychic adjustments of the adolescent child.²⁷ In keeping with the times, Muhlstock

concentrated on the faces of these adolescents to draw attention to their personal thoughts and feelings.

In *Young Girl from the Slums* the subject fixes the viewer with a penetrating gaze. Despite her tired demeanour and somewhat dishevelled hair, her inquiring expression exudes strength of character. However, the untitled portrait of the boy (called *Young Boy with Tuberculosis* by Muhlstock²⁸) depicts the gaunt face and pursed lips of someone trying to stop himself from coughing. His eyes are downcast as he leans his head on one shoulder. He appears to be on the cusp of adolescence, half boy and half man. His gloom and melancholy, typical of the fluctuating emotions of adolescence, are exacerbated by his weak physical condition.

During the Depression, *Canadian Forum* frequently printed articles about the health and welfare of Canadian society with recommendations for social and economic change.²⁹ The harsh conditions experienced by the poor provided ample evidence of the connection between poverty and health. As early as 1931 in Canada, nearly half a million families were living well below the subsistence level.³⁰ By 1934, infant and maternal deaths were on the rise, and it was evident that child welfare services were unequal to the crisis. Yet in the genteel pages of *Chatelaine*, a popular Canadian women's magazine with an emphasis on fashion, decoration, and healthy family living, the Depression barely existed. A rare account of the social conditions of Montreal's poor was given in an article by Rene Norcross called "My Adventure with the V.O.N. [Victorian Order of Nurses]." ³¹ Norcross wrote about accompanying a nurse on home visits: "I glanced about and found that we were in a squalid quarter of town among dilapidated houses fronted by rotting, tumbledown fences ... Children of Asia, Africa and Central Europe played and squabbled, laughed and cried, on the broken, littered sidewalks ... the house smells of garlic, the mother's bed is untidy, too many children are rushing around, the mother does not know how to feed or care for her baby and so on." Norcross concludes, "In short, the environment and ignorance of the poor immigrants breeds sickness and death."

This "squalid quarter of town" was the neighbourhood Muhlstock grew up in when his family emigrated from Galicia. "We first lived in a 14-dollar-a-month unheated house on St. Dominique, in the slum part of the city," he writes. "Our house was on the west side of the street, and we lived in the basement, where no sunlight ever shone in; and for about 14 years we lived in that kind of ambience."³² This was the area that Muhlstock painted and continued to depict throughout the Depression. In an interview given late in his life, he recalled how when he painted in the lanes behind the houses

the neighbourhood children would gather around; he befriended them³³ and included them in his paintings. It was important for him to portray these children as thoughtful, beautiful individuals who deserved kindness, respect, and admiration.

Muhlstock's interpretations were an attempt to counteract society's prejudices against immigrants, poor people, and those marginalized due to disease, disability, circumstance, or any number of reasons. His portraits of the severely disabled Paranka, the boy with tuberculosis, and the girl from the slums all ask the viewer to be sensitive to the human condition. It was with this in mind that in his 1935 exhibition of drawings at the Art Association of Montreal, he chose to show *Paranka*, *European Youth*, *Young Polish Immigrant*, *Coloured Girl*, *Unemployed and Child*, and *Young East-Side Boy*.

At the same time he was exhibiting these portraits, Brandtner was arranging shows by students with similar backgrounds and experience at the Art Association and elsewhere in the city. As Brandtner's students' work attested to the aesthetic impulses and creative potential of underprivileged children, Muhlstock's portraits sensitized the public to the innate beauty and natural intelligence of all children, despite their origins and physical circumstances.

JORI SMITH

Recalling Bethune sixty years after his death, Jori Smith described him as "a great friend of ours. He was so kind."³⁴ Part of Bethune's circle of artist friends, Smith was involved in the League for Social Reconstruction and deeply concerned about the Civil War in Spain. She also knew Brandtner, who included Smith's painting called *Child* in the "Produced in Canada" exhibition he organized in 1937.

By the time of the exhibition, Smith was known for her "sad and lovely"³⁵ paintings of the children of Charlevoix County, a French-Canadian community in rural Quebec. She painted the regional people and landscape of Charlevoix from 1930 until 1940, returning to the county for extended periods to continue her explorations. Critics referred to the "the formal and spiritual significance of form"³⁶ of her paintings, particularly her sympathetic portraits of children. The children she painted were sorrowful for good reason. According to Smith, who at the age of sixty-three wrote her memories of Charlevoix County,³⁷ poverty and childhood diseases were omnipresent in that part of Quebec. Babies died so frequently that "in the many cases that I witnessed, no great regret was ever expressed."³⁸ Fifteen or more children in a family was common, so "that if a few died now and

then, well ... As they saw it, after a proper christening, the baby would go off in a white box to join the heavenly chorus of sisters, brother and cousins.”³⁹ Tuberculosis was rampant. “I watched a child die of tuberculosis just down the road from us. During her long, debilitating illness, no doctor had ever been sent for and no special care was ever given her. All day long, she would sit in the kitchen, only rarely summoning the energy to drag herself out into the verandah to sit in the sun. When she died, there was no mourning, no lamentations. Her mother said only: ‘Elle est ben [sic] mieux au ciel, elle ne souffre plus.’”⁴⁰ Smith went on to write, “There was a philosophical acceptance of calamity ... Things could always be worse.”⁴¹

Smith’s only painting of an obviously sick child, ca. 1935–45, shows a young boy in bed under a heavy blanket, peering out at his parents seated nearby. The mother looks at the child from the end of the bed; we see only her back, which directs our attention to the child. The father’s distraught expression as he looks at his child is mirrored in the face of another man who may be the doctor.

While in Charlevoix, Smith did not paint portraits of the very sick children she wrote about, though in her sketchbooks was a small watercolour of Blanche Tremblay (figure 9), a thirteen-year-old girl paralyzed by polio. Smith’s characterization of Blanche is a poignant description of an exceptional child. Seen from a distance, perhaps because Smith did not want her subject to know she was being painted, Blanche is a tiny figure slumped in a rocking chair. The child, Smith wrote, “spent her days sitting in a special rocking chair by the stove. Her large head balancing awkwardly on her small misshapen body, her eyes never ceased to follow everything we were doing with intelligent, sometimes malevolent interest.”⁴² Unable to speak, Blanche had learned “to express herself eloquently with her eyes alone, using a language which the others had learned to interpret ... Her eyes were so extraordinarily bright and penetrating in their wisdom – no, wisdom is not too strong a word – that I too, often sensed that she had access to the inner vaults of my mind.”

Blanche is not portrayed on canvas, perhaps because her condition was too pathetic for public viewing. But her fragility and all-knowing innocence is captured in Smith’s portrait paintings of other Charlevoix children. The subject in *Rose Fortin* (1935, figure 10) appears to be tensely aware of the importance of being painted. Her pale, sallow complexion is accentuated by her plain grey shirt and the contrast between the pink chair and red background. A simple bow in her roughly cut hair is her only adornment. Her large almond eyes, at once tired and perceptive, framed by long arching eyebrows, are the key features of the portrait. Smith told Talbot Johnson, the painting’s owner, that Rose died as a child.



10.9 *Girl Sitting in Rocking Chair (Quebec)*, by Jori Smith, ca. 1935. Watercolour with pencil on wove paper. 9.2 x 7.9 cm. Library and Archives Canada, accession no. 1996-13-543.

Smith's vision of the children of Charlevoix was selective. She imagined it as a beautiful, primitive place where history stood still, and the rural children in her paintings represent an intimate connection with that world. "It's about what I witnessed in Charlevoix County in those very important years from 1930 to 1940," Smith explains. "I'll tell you why they were important. They [the residents] were living exactly as in the eighteenth, seventeenth centuries, like their parents and like their grandparents ... away, isolated in the mountains." Smith's portraits were meant to communicate to the viewer what it felt like to live in a less civilized world seemingly untouched by the Depression and city life. The contradiction of "sad and lovely" in her portraits derives from this oscillation between her aesthetic response to a simple life and a more realistic reaction to disease and death in this rural community.



10.10 *Rose Fortin*, by Jori Smith, 1935. Oil on canvas. 50.8 x 40.6 cm. Collection of Talbot Johnson. Photograph by Brian Merrett. Collections Imaging, Montreal. Reproduced from Jori Smith's *Charlevoix County, 1930* (Penumbra Press, 1998), plate 3.

Smith in her Charlevoix portraits and Muhlstock in his portrayals of urban youth observe children with great empathy. Like Bethune, they have a deep concern for young people who are negatively affected by social conditions; however, their motivation for painting as they did was different from what Bethune admired at the Lu Hsun Art Academy in China, where he felt the art was directly linked with the struggle and the people, their hopes and their ambitions. While Smith and Muhlstock were investing their subjects with beauty, dignity, and worth for their own reasons, Bethune was increasingly convinced that the role of the artist was to be the receptor and

transmitter of the people's struggle. The artist must not only become involved in the proletarian protest but must share the people's emotions and convictions and ultimately communicate them.

The relationship between art and socialism, so prevalent during the Depression as well as in the activities of Montreal artists, persuaded some viewers to interpret the work of Smith and Muhlstock as being politically motivated. This was confirmed by the use of Muhlstock's work in the pages of *Canadian Forum* and by articles by writers like John Fairfax about the social role of art. In the August 1936 issue of *Canadian Forum*, Fairfax's words reflect Bethune's convictions: "Art for man's sake has to replace art for art's sake."⁴³ According to the new social movement in art, artists could no longer be neutral or individualistic, catering to a privileged few. Instead, they must become socially minded in order to perform a useful function. In contrast, painting children was meaningful for Smith and Muhlstock not because it was politically useful but because it affirmed the dignity and individuality of the person. They believed their intimate portraits could stimulate in viewers the aesthetic contemplation of a tender life that was inviting, wholesome, and hopeful.

MARIAN SCOTT

Of all the artists Bethune knew in Montreal, Marian Scott was probably the most intellectually and emotionally in tune with him.⁴⁴ The child in her mural entitled *The Endocrinology* (1943, figure 10.11) is obviously closely linked to Bethune's original beliefs about the intersection of art, medicine, and social progress. The wife of Frank Scott, an ardent social critic, poet and McGill law professor, she was influential in encouraging Bethune's art practice as well as his early communist beliefs.

The Endocrinology came about at the behest of Dr Hans Selye, a longtime friend of Marian Scott's who was with Bethune at the 1935 conference in Russia. Selye was a specialist in the physiology of stress, better known scientifically as the "general adaptation syndrome." His interest in the body's first reactions to disease led him to examine its internal responses to stress-inducing circumstances.⁴⁵ He asked Scott to create a mural for the conference room of the Department of Histology in McGill University's School of Medicine.⁴⁶

The Endocrinology was unveiled on 26 June 1943. In the inaugural issue of *Canadian Art*, Selye wrote on "Art as an Inspiration to Science," and Scott wrote on "Science as an Inspiration to Art."⁴⁷ Selye showed how art strove to give direction to human activity while Scott encouraged artists to develop



10.11 *Study for The Endocrinology*, by Marian Scott, ca. 1941–45. Gouache on paper. 37 x 46 cm. Collection of Bruce and Deborah Whiteman, Santa Monica. Reproduced from Esther Trépanier's *Marian Dale Scott: Pionnière de l'art moderne* (Québec: Musée du Québec, 2000), 36.

a better understanding of the creative forces of science. In preparing the mural, Scott had lengthy conversations with Selye and his colleagues about scientific research in the field of endocrinology. She took copious notes about the biological system and experimented with imagery that would best communicate cellular life. In the process she developed a visual vocabulary that represented medical research liberating humanity from disease.

With its floating forms of babies and pregnant bodies, Scott's mural has a distinctive feminine feel that makes strong references to the fertility of life. A male nude strides into the centre of the composition, obviously a symbol of scientific progress. His bold form and outstretched arms are uncannily reminiscent of Bethune's drawing of himself in *The TB's Progress*: in the eighth scene Bethune reaches out to the allegorical female figures of Health and Happiness who float, like Scott's figures, in a celestial space. Scott's mural reflects Bethune's devotion to children and belief in medical advancements to improve society. For her, like Bethune, the sympathetic response to a child was an act of creation and healing that fostered a more humane environment.

The legacy of Bethune and his circle of artist friends continues today. Bethune was ahead of his time in understanding the social causes of diseases and believing that the state was responsible for its citizens' health. His Montreal Group for the Security of the People's Health, with its demands that the government create a safety net for social welfare, developed the blueprint for today's medicare system. To this day, his *Night Operating Theatre* hangs in the library of the Royal Victoria Hospital. In this key setting the work continues to inspire generations of doctors and nurses. Though the murals that Brandtner painted in one of the wards at the former Children's Memorial Hospital no longer exist, the idea of enlivening the walls of children's hospitals with colourful paintings lives on in Montreal. The philosophy behind Bethune and Brandtner's Children's Art Centre, which emphasized the artistic development of the child, was central to the development of Art Education at the Faculty of Fine Arts at Concordia University. Further, Brandtner's work with children in the orthopedic ward anticipated the use of art in the therapeutic care of children and in the programs in Creative Art Therapies at Concordia and the Université du Québec à Montréal.

NOTES

- 1 See Bethune, *The Politics of Passion*; Shephard and Lévesque, eds., *Norman Bethune*; MacLeod, Park and Ryerson, *Bethune: The Montreal Years*; Stewart, *The Mind of Norman Bethune*; Allan and Gordon, *The Scalpel, the Sword*.
- 2 Stewart, *The Mind of Norman Bethune*, 13–17. Reprinted from *The Fluroscope* 1, no. 7 (15 August 1932). The murals were later sent to the University Hospital, University of Michigan, in Ann Arbor, and have since disappeared.
- 3 Stewart, *The Mind of Norman Bethune*, 26, "A Plea for Early Compression in Pulmonary Tuberculosis," reprinted from the *Canadian Medical Association Journal* (July 1932).
- 4 Montreal Group for the Security of the People's Health, "Medical Care."
- 5 Allen, "The Religious Setting of Norman Bethune's Early Years," in *Norman Bethune*, edited by Shephard and Lévesque 22–31.
- 6 Riendeau, *Brief History of Canada*, 211–12.
- 7 Allan and Gordon, *The Scalpel, the Sword*, 89. Reprinted from "A Phrenicectomy Necklace," *American Review of Tuberculosis* 26 (September 1932), 319–21.
- 8 Stewart, *The Mind of Norman Bethune*, 9. Reprinted from a letter to Scott, 6 November 1935.
- 9 Ibid., 39. Reprinted from "Reflections on Return from Through the Looking Glass," 20 December 1935.

- 10 Bethune, *The Crime on the Road Malaga-Almeria*, Julie Allan fonds.
- 11 Emi Siao, letter to Lu Hsun Art Academy, 12 September 1939, Norman Bethune fonds.
- 12 See Robertson, "The Crystal and the Thought"; *Fritz Brandtner, 1896–1969*; 100 *Years of Fritz Brandtner*; *Fritz Brandtner: A Gift*.
- 13 Park, in MacLeod, Park, and Ryerson; *Bethune: The Montreal Years, An Informal Portrait*, 102.
- 14 Brandtner, "Children's Art Center [*sic*] of Montreal."
- 15 Scott, "Children's Art School," and "Children's Art School."
- 16 Ayre, "'They Start with Reality; Not Imitating, but Making a Picture,'" M7.
- 17 Scriver discusses the pediatric service and illnesses that were treated in Montreal hospitals in the 1930s: severe gastroenteritis, extreme malnutrition, vitamin-D deficient rickets, scurvy, pneumonia, congenital syphilis, typhoid fever, and tuberculosis. See Scriver, "The Royal Victoria Hospital, Montreal," 79–84; and Scriver, *Children's Hospital*.
- 18 "Painting Done by Handicapped at Children's Memorial Shown." See also "Kids and Paint"; Marcotte, "Sur le plancher d'un studio," 18–19, 36–8; and "Creating New Worlds."
- 19 Brandtner, "Children's Art Center of Montreal."
- 20 Lismer, "Children and Art," 12. Both Lismer and Brandtner were influenced by Franz Cizek, the Viennese art educator who believed that children should be given the freedom to work out their original ideas; the role of the teacher was to help them develop their creative faculties.
- 21 Hill et al., "They Could Split Rock," 114.
- 22 Ibid., 118. For an introduction to Muhlstock's art, see Nadeau-Saumier, *Muhlstock* and "Louis Muhlstock"; and Hill, *Louis Muhlstock*.
- 23 Nadeau-Saumier, "Louis Muhlstock," 76.
- 24 Hill, introduction to *Louis Muhlstock*.
- 25 *Canadian Forum*, 282.
- 26 Wiseman, "Bloody Instructions," 304–6.
- 27 Goldbloom, physician-in-chief of the Children's Memorial Hospital and professor of pediatrics at McGill University's Faculty of Medicine, was interested in both adolescent physical and mental development. See Goldbloom, "Problems of the Adolescent Child," 336–9.
- 28 Nadeau-Saumier, "Louis Muhlstock," 166.
- 29 For example, Riddell in "Nurses and Nursing" insists that all children should have equal access to health: "There should be no discrimination in the distribution in the essentials of nursing care and preventive methods in diseases of children" (9–10).
- 30 Comacchio, "*Nations Are Built of Babies*," 158.
- 31 Norcross, "My Adventure with the V.O.N.," 52.
- 32 Hill et al., "They Could Split Rock," 114.
- 33 Nadeau-Saumier, taped interview with Louis Muhlstock on 9 November 1983.

- 34 See Smith's comments on Bethune in Abley's "Painter Jori Smith's Passion for Art Still Glows," A7.
- 35 McInnes, "Contemporary Canadian Artists," 130.
- 36 *Saturday Night*, 13 November 1937.
- 37 Smith, *Charlevoix County*, 1930.
- 38 Smith, 19.
- 39 Ibid.
- 40 Ibid., 25.
- 41 Ibid.
- 42 Ibid., 39–40.
- 43 Fairfax, "Art for Man's Sake," 23–4. For a selection of articles on art and socialism from the 1930s, see Shapiro, ed., *Social Realism*.
- 44 Hill et al., "They Could Split Rock," 118. For an in-depth study of Marian Scott's art and life, see Trépanier, *Marian Dale Scott*.
- 45 Selye, *The Stress of Life*.
- 46 Trépanier, 164–9.
- 47 Selye, "Art as an Inspiration to Science," 17–19; Scott, "Science as an Inspiration to Art," 36–7.

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From the Final Sleep to the First Steps: Postmortem Portraiture and Childhood and Amateur Photography

VINCENT LAVOIE

The contemporary mass media enjoy an almost total monopoly over images of death: natural catastrophes, terrorist acts, various extremes of violence, and lesser but “newsworthy” calamities form the backdrop of contemporary representations of human mortality. At times our screens are inundated by bodies: unidentified, faraway, vague, or indeterminate identities the electronic media too often carry to us anonymously, as if they lacked distinctive features or qualities. All that we retain of these denigrated bodies are place names: Kigali, Baghdad, Beslan. The sensational images may spark commotion or apathy, fear or compassion. Rarely if ever do they invite us to step back and consider them in depth. We regard the pain of others as a distressing and recurring spectacle that angers, annoys, or bores us; often we are not sure exactly which emotion is inspired.

Perhaps these media depictions of death, rooted in the tradition of photojournalism, have led us to forget that at one time serene representations of death capable of consoling the living and guiding them through the process of mourning were customary.¹ These photographic images, perused at leisure and preserved for one’s circle of close friends, one’s family, or oneself, are postmortem portraits executed shortly after the subject’s death. They are portraits in the strict sense of the term, that is, representations that are not, in the words of Félix Tournachon-Nadar, “some insignificant visual reproduction ... but the most familiar and favourable resemblance, an intimate resemblance.”² Postmortem portraits are tributes to the deceased, depictions that photographers painstakingly embellished by touching up the hair and hands in some cases, adding a decorative border or their own famous signature in others.

From as early as the 1840s, when photographers primarily made portraits, the postmortem “photo shoot” came to be seen as a final

opportunity to glean images of the deceased. The commercial success of portrait photography largely contributed to the popularity of the genre, to the extent that the portrait quickly became an occasion for expressing varying intentions, one of which was to preserve a picture of the deceased for posterity. The practice was widely and unabashedly advertised as one of the services offered by photography studios.³ Nor was it rare to find in the shop windows of the age's photographers, particularly in Europe, portraits of dead people on display for curious passersby.⁴

Postmortem photography falls within a tradition that includes the death mask, a mould made from the face of the deceased, and the posthumous painted portrait, historically reserved for the aristocracy and political and religious figures, soldiers, scholars, and writers. Photography, which in the nineteenth century made inroads into all sociocultural sectors, gradually came to include official mortuary representation. The technology's capacity for reproduction and the marketing potential that this entailed were significant assets for the burgeoning commemoration industry. A photograph showing Napoleon III on his deathbed was widely reproduced and circulated in *carte de visite* format, a practice that enjoyed great popular success under the Second Empire. It is important, however, to point out that mortuary photographs of public figures were an essentially European phenomenon. North American social structures and the ways in which political institutions operated were not as conducive to inspiring public fondness for mortuary representations of statesmen. The reaction of Edwin M. Stanton, secretary of war under American president Abraham Lincoln, perhaps best exemplifies this stand: Stanton ordered that photographs of the president's body taken by photographer Jeremiah Gurney be confiscated. Such reticence toward postmortem photographic portraits – if not, as in this famous case, outright banning – inspired hoaxes and faked postmortem portraits of the president. One photographer resorted to the subterfuge of a double for the deceased Lincoln. This modest-sized tintype (2 $\frac{3}{4}$ x 3 $\frac{1}{4}$ inches), which, moreover, cannot be reproduced – tintypes were direct-positive photographs on metal plates – was clearly not intended for public consumption. Executed most likely for close associates, this fake postmortem portrait, whether we think of it as a whimsical image or a personal memento, points to the customary nature of the practice.

In America, as in Europe, postmortem photography democratized mortuary representation, extending to all social classes the privilege of contemplating the faces of the deceased (figure 11.1). More particularly, by virtue of this democratization, it introduced mortuary representation into the stock of family funeral rites. This meant that families henceforth possessed images



11.1 *A.E. Gagnon's Dead Child, Montreal, 1882.* Wm. Notman & Sandham. Silver salts and albumin process.
II-64070.1 Musée McCord Museum.

that could help them through the mourning process. Photography was called upon to play a crucial role in the case of infant mortality, not only because such a tragedy seemed intolerable and mourning an extremely difficult task but also because the final portrait was in many cases also the first.

In the nineteenth century, prior to the expansion of amateur photography and the proliferation of family albums, children often died before there was time or opportunity to take their pictures. In such circumstances, the production of a portrait became a moral obligation if not an ontological necessity; a photographer would be asked to come immediately to record the

child's image. It was then common practice to commission a mortuary portrait showing the child with eyes open, as if to simulate life. To bolster the impression of vitality, the child could even be shown involved in some form of play. No cosmetic artifice – from Sunday-best attire to elaborate hairstyling – was spared to make the child's final portrait as attractive as possible. People showed no hesitation in asking photographers to retouch or to add colour highlights at strategic points such as the child's cheeks, where a flesh tint might recreate a semblance of life. These manual touch-ups, applied directly to the surface of the print and sometimes quite expensive to do, attest to the economic and symbolic investment in the image made by those who commissioned it. In fact the entire stock of these artifices expresses a refusal of fatality, a denial of death, a negation of this sad fate.

Producing the illusion of life appeared as an imperative – a theological imperative, if we consider Christian teachings with respect to infant death. Remember that baptizing dead children was prohibited, and that without baptism the child was condemned to wander in Limbo, that neutral zone between paradise and purgatory invented by twelfth and thirteenth century theologians. Baptism is a collective initiation rite that makes the child a member of the community. Baptized children could die in peace and be laid to rest in the parish cemetery – a condition that had to be satisfied if the parents were to properly go through the process of mourning. The bodies of children who died before the sacrament could be administered to them were hastened to sanctuaries, often dedicated to the Virgin, where the dead child was laid out on an altar stone and surrounded by candles, and where parents and other faithful prayed out loud. These prayers and incantations were believed to infuse life into the child, but only for the brief moment it took to receive the sacrament of baptism.⁵ Sometimes the postmortem portrait appears to have been taken at the instant of reprieve, that salutary moment that the photograph preserves over time, for posterity.

Up to about the 1880s, postmortem photographs simulating life or sleep (another way of depicting death in an attractive manner) mainly showed the upper part of the body (figure 11.2), especially the face, in accordance with the codes of the individual portrait. The conventions of the studio portrait also applied in situations where the death of a child became the occasion for a final family portrait (figure 11.3). Individual and group portraits alike functioned as devices designed to deny death and present sublimated representations of the real, that is, as a necessary fiction for the withdrawal into the self that mourning requires.

Toward the end of the nineteenth century, the arrival of funeral professionals, the expansion of the field of thanatology, and the opening of



11.2 *Mrs. Hill's Dead Baby, Montreal, 1889.* Wm. Notman & Son. Silver salts and albumin process. II-90209.1 Musée McCord Museum.

funeral parlours – all phenomena that would influence social perceptions of death – transformed the codes of mortuary representation (figure 11.4). This would henceforth be characterized by complicated tableaux featuring the ritual means used to honour the deceased – flowers, accessories, and other arranged elements. Sometimes the artifice became so ostentatious that it was hard to locate the deceased in the midst of it all. The representation of the corpse itself became more discreet, as if death had to be overshadowed in order to highlight the artifices of the funeral industry. This distancing of the deceased corresponded to a sort of social eclipse of death, a phenomenon that became ever more common throughout the



11.3 *Lady and Captain Crowie's Dead Baby*, copied in 1868. Silver salts and albumin process. Wm. Notman. I-31741.0.1 Musée McCord Museum.

twentieth century, as Philippe Ariès has shown in his works on death in the Western world.

By this time, people were more likely to have photographs of the child that were taken during his or her lifetime,⁶ which may have made the production of a postmortem portrait in the strict sense of the word less imperative. Death began to be a nuisance, so much so that the corpse was forced to leave the “living room” for the funeral parlour, in accordance with the wishes of families who henceforth preferred to delegate the management of funeral matters to a third party – a consequence of increasing specialization and the division of labour. But this remained essentially an urban phenomenon; rural families



11.4 *Mr. Cleghorn's Dead Child, Montreal, 1900.* Silver salts and gelatin dry plate process. Wm. Notman & Son. II-133755 Musée McCord Museum.

continued to pay tribute to their deceased within their homes and opted for a figurative protocol more in line with the tradition of the postmortem portrait. As one proof of the democratization of photographic practice, a portrait of a grieving family, frequently taken by the father, attests to an evolution in the customs applying to mortuary representation. Not only was the practice no longer the exclusive prerogative of studio photographers – and in the 1920s, fewer of them were offering this service – but it provided an occasion for the family itself to create its own photographic memorial. In this case, the family became both the author and subject of the image, a development that could not fail to affect the symbolic value attached to the photographic act.

The photograph is characterized by a relationship of physical contiguity with reality that is specific to it. Every photograph is the result of a physical imprinting on a light-sensitive surface. Like a death mask, the photograph is a trace, a physical and chemical excision that bears the mark of its object. According to Roland Barthes, “the photograph is literally an emanation of the referent. From a real body, which was there, proceed radiations which ultimately touch me, who am here ... A sort of umbilical cord links the body of the photographed thing to my gaze.”⁷ This is how photographs touch us.

Children are one of the favourite subjects of amateur photography (the greater part of it dedicated to capturing happy moments); this is hardly surprising, given that this type of photography is practised essentially in family settings. And it makes little difference whether such pictures have artistic merit so long as they are intended for one's family and friends. On the other hand, they do take on an undeniable affective dimension, due to the privileged relationship uniting the photographer and his or her model(s). Is not the very act of photographing those close to us a mark of affection? Another photograph illustrates this relationship of intimacy and reciprocity specific to family photographs. The child's gesture, reaching out toward the author of the image, perfectly conveys this touching complicity (figure 11.5).

A gradual disappearance of the corpse characterized the evolution of mortuary representation in the nineteenth century. While still occasionally produced, the postmortem portrait was withdrawn from the public sphere and confined to the deceased's intimate circle, ending up in personal family archives. The display value of the postmortem portrait in fact diminished with the arrival of the new century as a novel iconography of death began to make its way into illustrated newspapers. It is useful to posit the hypothesis of competition between mortuary portraiture on the one hand, which individualizes and honours the individual, and media representations of death on the other, where the individual subject serves merely as a metonym for collective catastrophe. This split appears to be specific to the early twentieth century, when morbid depictions replaced mortuary representations. It no longer seemed possible, or indeed acceptable, to present death in a benevolent light. Today the media morgue of television shows us only traumatic deaths, even when they fit the portrait genre. Remember the hideous and grotesque postmortem portraits of the sons of Saddam Hussein, as reconstructed and broadcast by the Iraq occupation forces. The political and military uses of these postmortem portraits obviously go against the grain of the ritual functions historically attached to this practice.

The images of death as something serene – as the final sleep – are polar opposites of those left to us by the twentieth century. Coverage of current events has reminded us of the importance attributed to press photographs in the constitution of a collective memory. I am referring to the numerous publications that reproduced some of the most famous press photos of the twentieth century. Whether we are talking about the photograph depicting the heroic death of a Republican soldier during the Spanish Civil War or that showing an alleged Viet Cong executed in the streets of Saigon, the principle is the same: photographs of current events crystallize history's decisive episodes around images of death. This is so much so



11.5 "Copied for Mrs. Fortin," by unknown amateur photographer, 1911. Silver salts and gelatin dry plate process. Wm. Notman & Son. II-185199.0 Musée McCord Museum.

that these images – and they are legion – sometimes sum up a whole epoch all by themselves. The taking of lives and the taking of photographs are blended in one emblematic instant, because the representation of the fatal moment expresses the perfect conjunction of two acts, that of the photographer on the one hand and of the shooter on the other. David Hume Kennerly, who won a 1972 Pulitzer Prize for a series of photographs taken in Vietnam, once said that every photographer dreams of capturing that instant, that magic moment of passing from life to death.⁸ Capturing the "decisive moment," to use Henri Cartier-Bresson's famous concept, lies at the heart of photojournalistic "masterpieces," whether we



11.6 *Mrs. Barnett's Dead Child, Montreal, 1911*. Silver salts and gelatin dry plate process. Wm. Notman & Son. II-184955 Musée McCord Museum.

are speaking of photo reportage or journalistic photos of events as they occur. This moment is what gives photography a historical legitimacy, if not a monumental character.

Postmortem portraits do not constitute representations of events in the journalistic sense. These photographs were taken in situations devoid of any real sense of urgency or danger, situations characterized more by slowness, duration, and the fatal immobility of the subject. The postmortem portrait spurns photographic immediacy, the cornerstone of current-events photojournalism and amateur photography. In this respect, it runs counter to a certain conception of photographic modernism based on the capture of movement – that paradigm of snapshot photography that the twentieth century would come to celebrate over and over through new iconographies

of domestic happiness and images of mass catastrophe. The postmortem portrait of a child, being neither a picture of family happiness nor that of a massive tragedy, is incompatible with the twentieth-century mentality. Talismanic, meditative, and private, the depiction of dead children is an archaic practice in terms of the hallmarks of modernity – speed, repetition, and serialism – which are also characteristics of photography, the technical image par excellence.

Could any image contradict the very idea of progress more powerfully than that of a dead child? Herein lies all the drama expressed by the photograph (figure 11.6), in which we see a child lying on his bed, as if resting, surrounded by his playthings. Carefully placed beside him are a pocket watch and a toy locomotive, cardinal symbols of time and speed which this little boy, who has only just entered the twentieth century, is taking with him.

NOTES

I wish to thank the McCord Museum, Montreal, Quebec, for permitting me access to the William Notman Photographic Archives and providing the photographs for this paper. All photographs appear with the permission of the McCord Museum.

- 1 Batchen, *Forget Me Not*, 60–5.
- 2 Tournachon-Nadar, “Mémoire pour la revendication de la propriété exclusive du pseudonyme Nadar,” 240.
- 3 The practice of postmortem photography was advertised until the 1880s; see Ruby, *Secure the Shadow*, 59.
- 4 Bolloch, “Photographie après décès,” 115.
- 5 Morel, “Représenter l’enfant mort du Moyen Âge à nos jours,” 83–104.
- 6 Children can also be users, authors, and producers of images, as we see from turn-of-the-century advertising vaunting the simplicity of the process. Up to the very end of the 1880s, the practice of photography was effectively reserved for professionals, the curious and enlightened dilettantes who feared neither the noxious fumes of chemicals nor the long hours spent in the darkroom. The arrival of Kodak cameras revolutionized the practice of photography, making it easier to take photographs without knowing more than the rudiments of the technique. This was the beginning of amateur photography and instant photography. The instant photograph, which would draw upon a range of themes associated with the accidental and the unforeseen (jumps, falls, collisions – subjects particularly dear to amateur photography

and photojournalism), inaugurated a new economy of the photographic act in which the action of the user was limited to a brief pressure of the index finger: "You press the button, we do the rest," as the famous Kodak ad promised.

7 Barthès, *Camera Lucida*, 80–1.

8 Kennerly, *Battle Eye*, 7.

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