

**UNDER THE NZ COPYRIGHT ACT 1994
YOU MAY MAKE OR RETAIN ONLY ONE
COPY OF THIS ELECTRONIC DOCUMENT
FOR YOUR PRIVATE STUDY OR RESEARCH.
NO FURTHER DISTRIBUTION IS PERMITTED
BY TRANSMISSION OR ANY OTHER MEANS.**

7

“Cherishing Hopes of the Impossible”: Mothers, Fathers, and Disability at Birth in Mid-Twentieth-Century New Zealand

BARBARA BROOKES

David Cameron, now the prime minister of Britain, said in 2004 that the realization that his eldest son, Ivan, was severely disabled hit him “almost like mourning – the loss of something – mourning the gap between your expectation and what has happened.”¹ The wealthy and highly educated Camerons were open about their son’s severe disability, Ohtahara syndrome (a combination of cerebral palsy and epilepsy). Six-year-old Ivan’s death in 2009 was marked in the English Parliament and occasioned an outpouring of sympathy for the Cameron family. David Cameron’s willingness to acknowledge his son’s condition signalled a new era in the acknowledgement of childhood disability, a move away from the shame that had existed in both the United Kingdom and many of its former dominions in the twentieth century.

The meanings associated with “disability” and, indeed, the word itself have been contested internationally by activists who reject “the medicalization of disability as individual pathology.”² In New Zealand, historian Margaret Tennant has been at the forefront of considering how the meanings of disability have changed over time.³ A focus on the social model of disability, growing out of the interdisciplinary field of disability studies, has highlighted the way society discriminates against the differently abled and how disability is not about individuals, or necessarily about health, but about the wider society. Historians, in turn, have begun to respond to Catherine Kudlick’s 2003 challenge that an examination of disability, just as crucially as an examination of gender, race, and

class, leads to central questions about our past, such as “what does it mean to be human?”⁴ An historical approach allows us to see how ideas about health were once closely tied to narrow conceptions of “normal development” and how people who deviated from the norm, such as children with Down syndrome, were regarded as “unhealthy” and best removed from society.

Disability from birth is not an individual but a family affair. Hence it raises issues that complicate binaries about gender and health. The birth of a child with congenital abnormalities shapes the intimate world of family life, and at the basis of the family is a historically specific, gendered contract between the woman and man. The traditional words of the marriage service that promise partnership “in sickness and in health” marked the couple’s commitment to each other through the impact of illness. But what of the care of children? For most of the twentieth century, when a child was disabled the burden of care fell upon mothers. As one father of a severely impaired son put it, the child’s “management” was “a woman’s role.”⁵ Fathers, as breadwinners, were expected to provide the necessities of life for their families, while mothers were entrusted with attending to the health of the rising generation.⁶ That these gendered responsibilities with regard to health have a long history is clear in Patricia Reeve’s analysis of working people in nineteenth-century New England and Marjorie Levine-Clark’s analysis of entitlement to relief in early twentieth-century England (see chapters 1 and 2 in this volume).

The differential responsibilities of parents with respect to family health have been shaped by the expectation that women’s primary role is that of mother. Rebecca Godderis’ contribution to this volume (see chapter 12) suggests that increased American attention to postpartum depression among women in the 1980s reflected a particular historical moment of rising concern about the disintegration of the family. The role of fatherhood is at the heart of Antje Kampf’s discussion of male infertility in Germany (see chapter 6). Both of these themes – of the depressed mother, and fathers’ contribution to their children’s heredity – are relevant to my analysis of parental responses to infant developmental delays in the mid-twentieth century. A child born with brain impairment could not be considered in isolation: parents were crucial to their future and mothers and fathers might disagree about where that future lay. At a time when an official committee could refer to a child with severe mental defect as “a being with human shape,” parents recognized that their mentally impaired children were, in effect,

disenfranchised as citizens because of biology.⁷ The right to education was one among a number of common expectations likely to be denied.

Parents in the mid-twentieth century looked to the medical profession for answers to developmental delays. From their perspective, their child had a health problem requiring medical expertise for diagnosis and assistance. They were complicit with the medicalization of disability while at the same time aware of the medical profession's limitations. Indeed they were likely to blame themselves – their own internal pathology – in the first instance for their child's difficulties, rather than the wider society. Many conditions were exceedingly difficult to diagnose, such as internal brain injuries that made no obvious markings on the body. Although the physical characteristics of infants with Down syndrome had been described in 1866, the reason these babies were different was unknown until 1959.⁸ Parents concerned about their child's development usually visited the doctor's office in search of explanations.

My focus here is on New Zealand from the 1940s to the 1970s and my interest is in how a particular form of family health crisis had gendered repercussions. Mothers and fathers reacted differently to the birth of a mentally impaired child, putting the marital relationship under great strain. Whether or not to keep a child at home might be one of the points of contention between couples, with fathers more likely to initiate institutionalization.⁹ In these decades, most medical professionals were men who identified with fathers and sometimes discounted the views of mothers.

The needs of mentally impaired children had implications for public culture, and in the 1950s their parents began demanding greater state resources for them.¹⁰ Parents contested the way their children were denied opportunities because of an accident of birth. I suggest that it was the actions of these united parents that helped to overturn the shame of disability and brought about significant social change. Activist mothers and fathers of disabled children believed that their children had the same rights as "normal" "healthy" children and, in particular, the right to education.

THE NEW ZEALAND CONTEXT

New Zealand was a British colony until it achieved dominion status on par with Australia and Canada in 1907. The country originally had a small population of Pakeha settlers (white New Zealanders), who from the 1840s onwards rapidly overtook the indigenous Maori people and

dispossessed them of their lands. Most of the settlers were emigrants from Britain. By the mid-twentieth century, New Zealand had a population of around two million, 120,000 of whom were Maori. The relatively small size of the population enabled a close engagement between citizens and the state. The advent of a Labour government in 1935 ushered in a commitment to a welfare state, and an ideal of the country as a good place to bring up children. Labour drew on a history of innovation in child health and welfare instituted by the national Society for the Promotion of the Health of Women and Children. The society (known as the Plunket Society) was founded in 1907 by the charismatic Dr Frederic Truby King, who developed an international reputation in infant welfare.¹¹

New Zealand prided itself on being a country where the possibility existed “for everybody to lead a happy life, free from fear of poverty.”¹² The introduction of the 1938 Social Security Act meant that visits to the doctor were heavily subsidized and maternity care was free from May 1939.¹³ Free prenatal and postnatal care by doctors led to the expectation that healthy children would result. A child born with disabilities therefore confounded such hopes. A 1947 Department of Health booklet entitled *Suggestions to Expectant Mothers* starkly warned, “A baby fed for the first nine months of its life on impure blood (due to any condition of ill health in the mother) comes into the world handicapped.” Mothers were to have plenty of fresh air, eat well, take exercise, and get plenty of rest and sleep.¹⁴

After 1907, if a child was born with a severe “handicap” (in the language and perspective of the time), such as spina bifida, Down syndrome, hydrocephalus, or cerebral palsy, he or she might be sent to the Sisters of Compassion, a Catholic charity, to be looked after in a home at Island Bay, Wellington.¹⁵ Other such children who survived might be sent to one of the country’s public mental institutions. By 1920, the minister of public health and education, C.J. Parr, was arguing for the separation of children from adults in mental hospitals and made arrangements for children to be concentrated in one institution at Nelson.¹⁶ By 1943, this facility, which accommodated a hundred children and accepted babies, was “always full” and had a waiting list. Many of the children had Down syndrome; some had microcephalus, and other types of congenital conditions. “No matter how young they are,” an observer commented, “as soon as they enter the home, they are given constant training in cleanly habits and taught to walk and feed themselves.”¹⁷

Every preschool child was supposed to be medically examined once a year by the Division of Child Hygiene. If abnormalities were detected in these inspections, or in examinations by school medical officers, children might be channelled into "special school, special classes, or other institutions as may be necessary."¹⁸ From 1929, the state aimed to segregate older mentally disabled children from the mentally ill and provided care for them at Templeton Hospital and Farm, in the South Island.¹⁹ Children who were regarded as uneducable were to be the province of the Mental Hospitals Department. Psychopedic institutions such as Templeton and Levin Farm (which opened in 1945 in the North Island) had a twofold purpose.²⁰ They relieved parents of the burden of care and the wider society of anxieties about reproduction of the "unfit." Just who was "unfit" was not always easy to determine.

When an abnormality was obvious at birth, how did parents respond to the news? How did mothers and fathers face the prospect of a family future different from the one they had imagined? How was the joint project of parenting reshaped by the advent of a child with mild to severe developmental difficulties? A pattern of a lack of diagnosis at birth, self-blame, unhelpful doctors, unsure prognosis, and institutional care as the answer shaped the experience of many parents in the mid-twentieth century. In the context of post-war optimism about building a better world, and with the baby boom leading to crowded maternity wards, the project of parenting could hold hidden hazards, such as a child's mental impairment.

DISABILITY AND HISTORICAL SILENCE

Oral history provides an avenue into the issue of disability and historical silence. As I was searching to provide a context for one mother's experience, I found a unique set of sources: public health research reports completed by fifth-year medical students at the University of Otago. A group of medical students interested in the impact of disabled children on families had privileged access to mothers and fathers who shared their stories of difficulty. The students wrote up their findings in reports that contain rich records, including photographs of children. The latter are a reminder of an absence of congenital disability in the visual record of the nation that mirrors the silence that once existed on the issue.

Here is one mother's story, bridging England and New Zealand.²¹ Helen was a medical student in London in the late 1940s when her son was born prematurely at eight months' gestation. She had hemorrhaged

during the pregnancy. She recalled, "It was a bit of a surprise having a very very handicapped child. He lived until he was six, but it was pretty much touch and go the whole time. He never ever managed to walk or feed himself, or talk or anything like that, he was very very badly handicapped."

Helen's general practitioner was no help in identifying what was wrong with her son and when she expressed her concern about his lack of normal development, he told her that "medical students were often rather stupid this way and often thought there was something wrong and there wasn't." At about six months, concerned that the infant wasn't focusing at all and that he might be blind, she asked her parents for help and they arranged for her to take the child to an ophthalmologist. Unlike her general practitioner, this specialist confirmed Helen's diagnosis, saying "medically you are quite right, he is 75% blind, there is little sight and the optic nerve hasn't developed." Helen determined to learn Braille and organize her life to assist her son, but further diagnoses were to follow.

Helen found it very difficult to talk about their son's condition with her returned serviceman husband, Patrick. When she did, he said that "he thought this child had been born damaged because of some of the things that he had done in the war." Helen did not feel the same kind of guilt, but she said, "But I did feel perhaps I got up when I shouldn't have got up, with the miscarriages, or I should have done something a bit better ... in order to have had a child that hadn't been damaged."

Her mother-in-law encouraged her to go to "healing services in churches in hope that the child would suddenly become better through God intervening." She did so reluctantly, to please her mother-in-law, but did not hold out any hope. The couple considered whether they should "ever risk having other children." Helen continued, "There were all these dreadful doubts which are hard to live with really. I have to admit at our worst times I considered organising a sort of mass [family] suicide ... Then I ... thought no, it's too bad for my own family if I do this, but I did ... think about it."

When her son was eighteen months old, Helen took him to a Harley Street pediatrician without her husband's knowledge. The expert pediatrician told her that her son had microcephaly and that nothing would change. He said to her, "You've got two choices and it depends really on your income and your attitude to life. He said you either give up your entire existence to looking after him the way you are now and that would be for keeps, it won't change. Or, he said, you do the opposite

thing, you contact the London health authorities ... It would all take time but he would be admitted to a paediatric hospital, psychopaedic hospital, they would definitely take him but probably not for another two years ... but he said ... I recommend the second because I don't think it's a useful way of spending your life looking after a child who is never going to really improve."

And so Helen put her son's name down for institutional care. He was eventually accepted, and the couple felt terrible taking him to the hospital in 1953. They visited him weekly and cried "in the bus all the way home." Someone suggested they consider emigrating to New Zealand, an idea that took root. They left the country, and Helen's mother-in-law visited their son every week until he died, aged six, from pneumonia. That decision to leave their child shadowed the parents in their new life.

The themes from this case study – the special responsibility of the mother and the importance of medical advice in the solution she sought – can be found in the lives of many parents of disabled children in the mid-twentieth century. But the knowledge of doctors, as this oral history suggests, was limited. In 1950, an international committee convened by the World Health Organization (WHO) noted the limited state of psychological medicine and the lack of "comprehensive public mental health" services.²² Few doctors were trained in child psychiatry, however, and the call for the early diagnosis and treatment of what the WHO termed "mental subnormality" was thus difficult to answer. The committee declared that "the most important single long-term principle" for future WHO work with regard to mental health was to encourage "the incorporation into public-health work ... [of] the responsibility for promoting the mental as well as the physical health of the community."²³ Perhaps in light of this directive, medical students studying public health in the fifth year of their course at the University of Otago, in Dunedin, New Zealand, were encouraged to explore the impact of what had become known as "intellectually handicapped" children in families.²⁴ The results of their forays into the community were recorded in research reports that were archived by the medical school.²⁵

A visit from a medical student to discuss their circumstances may have opened up an unusual opportunity for families, and mothers in particular, since they were the ones most likely to be interviewed because they were at home and provided the primary care.²⁶ Mothers usually lacked a narrative to make sense of their experience – or an audience willing to listen – which meant it remained outside everyday cultural understanding.

Two mothers reported suspecting that their babies had delayed development but found that their general practitioners dismissed their expert knowledge. In both cases the physicians sent them home with a “Don’t worry, my dear” and “We doctors can pick these children at a glance; your baby is perfectly normal.” Yet the professionals were wrong.²⁷ There was little medical training in identifying such conditions and the *New Zealand Medical Journal* contained only one case report on congenital abnormality from 1935 to 1955. That report noted hemorrhaging during pregnancy, strangulation by the umbilical cord at birth requiring resuscitation of the newborn, and a history of congenital abnormalities involving fused fingers in the mother’s family.²⁸ Both heredity and events during pregnancy and birth were clearly signalled as important in this case.

By the mid-twentieth century, professionals placed less emphasis on heredity as a cause of intellectual handicap, suggesting that the birth of a “handicapped child to intellectually average parents” was a “piece of bad luck.” Nevertheless, they counselled that “marriage is not one of the prospects to which these children can look forward” since they were unlikely to be able to rear a family successfully “even if it were desirable.”²⁹ The lack of study relating to children was one of the factors that prompted the founding of the New Zealand Paediatric Society, which held its first annual general meeting in May 1947.³⁰ International experts were all too aware that the wider community often held the misconception that “mental subnormality occurs only among the children of the sinful, depraved, or shiftless.”³¹

REACTING TO THE BIRTH OF A DISABLED CHILD

Women as mothers have been the focus of a number of historical works but questions about gender, children, and health have received far less attention.³² Leslie Reagan’s recent study *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America* is path-breaking in this regard. Reagan examines the “specter of tragedy” wrought by the new knowledge in the 1960s that rubella caused serious birth defects. She further develops Rayna Rapp’s insight that women are today’s “moral pioneers,” negotiating the decision making involved with the choice of abortion in the face of new knowledge about abnormalities derived from tests such as amniocentesis.³³

Before such testing was possible, it was the moment of birth that might reveal something of the prospect of a child’s future. But it was not

always easy to tell, and the hope of an untroubled future could fade as developmental delays began to occur. At a time when fathers were routinely excluded from the birthing room, mothers anxiously enquired of their health professionals, "Is the baby all right?" They might be the first to be told that it was not, sometimes in an "abrupt," "blunt," or "cruel" manner.³⁴ Sometimes doctors preferred to break the news to the husband man to man and to leave him to inform his wife.³⁵ Doctors might also be falsely reassuring and leave it to the Plunket (child welfare) nurse responsible for postnatal visits to break the news.³⁶ Such difficulties, because unexpected and tragic, often became unspeakable and, as a consequence, families became socially isolated. One mother recalled, "I had thirty-four baskets of flowers ... My room looked like somebody had died ... They weren't welcome to your new baby kind of flowers, they were pots of chrysanthemums, the kind of flowers that you send to people when they lose someone, when someone dies ... I didn't have one baby card, I didn't have one baby present and when a friend of mine came in with a pair of booties and bib I burst into tears. I said, 'You are the first person that's given me a baby present ... My baby is still alive and you are the first person that has acknowledged that.'" ³⁷

The reactions of others quickly converted the pride of new parenthood into an often unspoken shame. Mothers were the ones more likely to interact with the health-care system (and generally with male doctors) and the local community. They were on the receiving end of sometimes remarkably cruel attitudes toward the disabled. One mother was "abruptly" informed that her newborn "had 'no brain' and would 'never be any use.'" ³⁸ Eileen Coulthard's daughter, Trish, sustained brain damage at birth in 1941. In 1953 she took her daughter to a doctor for an assessment. The doctor's diagnosis consisted of the judgment, "I'm afraid your daughter is retarded." When Eileen replied that her daughter was "intelligent, she can do lots of things" the doctor's response was, "So can animals." ³⁹ Mothers had to cope as best they could with unhelpful responses from professionals and the wider community.

CHANGING ATTITUDES TOWARD INSTITUTIONALIZATION

For doctors in both Britain and New Zealand, institutionalization often seemed to be the answer to a range of congenital disabilities. The number of children with Down syndrome in the Nelson facility suggested the stigma attached to the condition and parental hopes that their children

would receive some training. Institutional care also meant that children would be cared for beyond the lifetime of their parents. The development of antibiotics during the Second World War increased the survival rates of children with compromised health. Hence new ways of thinking about disability had to be found in the post-war world.

Problems in raising disabled children rubbed up against the emphasis on a happy family life advanced in the late 1940s and 1950s. A happy family was a healthy family but a new importance ascribed to the role of mothers suggested that all children, whatever their health status, would benefit from their mothers' love. The child-centred family, promoted by a developing interest in psychological theory, stressed the role of mothers in the home. John Bowlby's 1951 book *Maternal Care and Mental Health* emphasized the importance of attachment in infant development and heightened concern about institutional care.⁴⁰ In 1951 the *New Zealand Woman's Weekly* introduced a new advice column entitled *The Psychologist's Consulting Room*, which encapsulated a shifting ethos toward considerations of mental health within the family. Radio also offered lessons on mental health. "It is a commonplace in psychology nowadays," a psychiatrist stated in a 1957 radio lecture on the family, "that adult personality and beliefs, customs and manners which characterise the social order are largely the outcome of childhood experience."⁴¹ New Zealand's pioneer of analytical psychotherapy, Maurice Bevan-Brown, M.D., emphasized in his book *The Sources of Love and Fear* how a child's early relations with its mother set "the pattern for all subsequent relationships."⁴²

When a child was severely disabled, the extent of care required might be beyond the emotional and financial capacity of most ordinary households. But those with less severe problems might also be institutionalized. A key factor in the decision was "the ability of the mother to cope" if a child stayed at home.⁴³

The impossible task of being the perfect mother became even more fraught when a woman was faced with a child who had a variety of unforeseen needs. The normal trait whereby a woman tended "lavish affection on the helpless" became subject to criticism when her attention was directed to a handicapped child, making her "blind" to the "important needs and rights of her other children."⁴⁴ A view that so-called "normal" children in the family would suffer if a disabled child remained at home was widespread. The demands of a disabled child were regarded as taking a mother's attention away from her other children, to their detriment, as if families had a closed and limited circle of emotional energy.

THE IMPACT ON FAMILY LIFE

The way in which parents learned of their newborn's disability could be crucial to their ongoing commitment to their child. The WHO 1953 Joint Expert Committee on the Mentally Subnormal Child noted, "The discovery that a child is subnormal will inevitably come as a profound shock to parents. In many cases they will feel a groundless personal guilt or will, half-consciously, blame their marriage partner for the child's condition."⁴⁵

The committee's recommendation was that parents should be given full and frank information, but if doctors knew little they were unable to provide such help. In a careful study, one female medical student interviewed ten families who had kept their child with Down syndrome at home and nine who had chosen institutional care. One further family, who had chosen institutionalization for their severely impaired daughter aged eleven, refused to be interviewed, wishing to "forget all about their child."⁴⁶ Not one of the nine of the families interviewed who had chosen institutional care believed they had been informed of their child's disability in a satisfactory manner. Six thought "they had been told too late" (one child was two when the family received the news) and the same number thought "they had been told very badly." Doctors had either been evasive or abrupt. One doctor had broken the news via the telephone. Six of the ten families who had chosen to keep their child at home were much more positive about the way in which they had learned about their child's disability.⁴⁷

Three out of nine families who had admitted their child to the local institution said they acted "partly because of a doctor's advice."⁴⁸ One mother, Mrs R, followed her doctor's recommendation that her eldest daughter, Wendy, be institutionalized because "she should be among her own kind." Here the doctor reinterpreted kinship, seeing it not as a familial bond but as a bond of difference. The four subsequent children in the family never saw their sister and rarely heard their parents discussing her: in effect familial kinship was denied.⁴⁹

Relations between couples could be severely strained: the nuclear family could implode under the weight of a child's disability. At a time when companionate marriage was promoted as an ideal, a husband might resent the amount of time his wife devoted to a child who deprived him of her company. One father refused to countenance his wife's wish that their child with Down syndrome accompany them on holiday.⁵⁰ Another father of a severely handicapped child "refused to

recognize the child for three weeks." He gradually came to accept this child and a second with a disability but "blamed the mother" for the children's disabilities "since her family have a history of mental deficiency."⁵¹ It seemed that someone was to blame and parents took on guilt in all sorts of ways. "I wonder whether it was because I went out too much before he was born?" said one mother. "I suppose I was too fond of dancing when I was young," said another. "I wonder if I've been too selfish?" was, apparently, a frequent question.⁵²

Sometimes men coped by leaving. One husband did not want a handicapped child in the house so left when the child was an infant.⁵³ Another avoided being seen in public with his disabled son, leaving him in the car when going shopping.⁵⁴ One father ignored his disabled daughter, born in 1959 with cerebral palsy. For him it appeared to be a "matter of pride." In this household the mother managed to preserve "family harmony." Determined not to institutionalize her daughter and assiduous in seeking aid, she remained optimistic in the face of an unsupportive medical profession that "scoffed" at her enthusiastic approach.⁵⁵

One couple, whose eldest daughter, Lorraine, was institutionalized in the 1940s, did not discuss her existence although the mother, Mrs D, kept visiting her. Harmony in the family was maintained through denial. The veil of silence across the existence of Lorraine was such that the mother would not be interviewed about her experience in her own home, only in a parked car. At the time of her interview in 1966, her two sons, aged 19 and 17, were unaware that they had an elder sister. Mrs D's doctor advised her "to stop visiting her daughter because it upset her too much." The strain of her ruptured relationship with her child was such that Mrs D said "she would have killed her next child had it been deficient."⁵⁶ Mothers were caught between the loving protection they felt for their children and the expectations of family members and a social climate that suggested they "get on with their lives," forget their disabled child, and commit them to an institution.

Doctors might encourage institutionalization. One, for example, "encouraged placement but left it to the father to force the decision."⁵⁷ The mother in this case was said to realize that "placement [was] the correct and rational decision" but had "not adjusted" to the situation, lavishing affection on her other children. The medical student sitting in judgment on her noted, "Placement has released her from introversion, but she is now introspective and regretful."⁵⁸ Of another devoted mother, who had created a happy home for her son, a male student casually wrote, "She could probably part with him without too much grief."⁵⁹

Early placement, in the medical view, saved parents – and mothers in particular – from distress.

Mothers in particular suffered from the medical profession's unhelpfulness. But perhaps male doctors saw no way to be helpful. In an address to the Royal Australasian College of Physicians in 1955, a leading expert on cerebral palsy and allied conditions noted, "The study, diagnosis, assessment and management of this group of conditions in the Dominion are in a very unsatisfactory state, and appear to be drifting away from the medical profession into the hands of ancillary workers and even the laity. The medical profession of the Dominion is ill-prepared to assume these responsibilities and, in the absence of men fully trained in neurological medicine, cannot get easily the help it needs to play its part."⁶⁰

With little exposure to the specialized field of developmental disorders, and at a remove from educational developments, the focus of general practitioners remained on the family as a whole. In the mid-twentieth century, families relied on the work of mothers to keep the home both in terms of domestic duties and emotional stability.

Here we might also speculate that male doctors identified with the difficulties facing fathers. This kind of identification is evident in one father's recollection of a consultant who said of his child with cerebral palsy, "Oh, I'm glad it's not my son."⁶¹ Men's self-esteem seemed particularly vulnerable to being eroded by their child's visible handicap.⁶²

None of the studies by the medical students clearly reveal a difference in immediate parental reactions determined by the sex of the disabled child. An American overview of fathers' attitudes compiled in 1983 by Michael Lamb, however, suggested that because fathers held out high hopes for their sons, they were "especially disappointed when they have retarded sons." Lamb found that fathers had a greater concern about their children's long-term prospects and that the birth of a disabled child made them feel a failure. Perhaps, Lamb posited, because bread-winning fathers were more distant from their children they had "fewer concrete reminders of their value and competence."⁶³

Struggles between marital partners are all too apparent in the interviews. One mother, clearly deeply attached to her severely disabled seven-year-old son (born in 1965), wept when discussing her decision to institutionalize her child. She had to choose between losing her son and losing her husband, who had threatened to leave the family if the boy was not sent to an institution.⁶⁴ Two mothers of daughters aged nine (born in 1963) and six (born in 1966), respectively, revealed that their

daughters were in care because “severe marital problems” would have arisen otherwise. One father made repeated efforts to have a child put in care but the mother did not share her husband’s enthusiasm for this solution.⁶⁵ According to one medical student, the extent of a father’s attachment to a child “seemed to have a great bearing on the decision” on whether to keep the child at home.⁶⁶

Some of the young medical students’ studies of the families of mentally disabled children are redolent with distrust of the motives of mothers. They saw the women as either indulging in “foolish overprotection” of their children or making “impossible demands” of them. A mother of disabled twins was judged by a medical student to exercise “intense overpossessiveness.” The student wrote, “She clings intensely to the twins with a determined devotion, more suggestive of resentment than love.” Yet a mother whose daughter was in an institution was described as “emotionally shallow and self-centred,” someone whose “maternal feelings wane” when faced with “heavy responsibility.”⁶⁷ Mothers were more likely to come in for criticism than fathers who retreated to the world of work daily and had respite from the burdens of care in the home. Mothers were said to “neglect their personal appearance, become homebound, give up their social contacts and holidays” and, as a result, age “prematurely.”⁶⁸ Mothers of only children who were handicapped were counselled to have another child to prevent them from being “too intensely wrapped up” in their disabled child’s needs.⁶⁹

Mothers occasionally refused to accept their child, but this was much more likely to be the response of fathers. A large-scale survey carried out in the early 1970s in New Zealand indicated that “mothers had sole responsibility for considerable numbers of the intellectually handicapped, and for an increasing proportion of those in the older age groups.” Examples ranged from a divorced 22-year-old mother working and caring for her son with Down syndrome with the help of her parents-in-law, to a 97-year-old Maori woman living in a rural township caring for her 20-year-old great-grandson “whom she had reared from childhood.”⁷⁰

Maori families, where support of the wider kin group was expected – and available – were much less likely to choose institutionalization for their children. The wider kin network meant that mothers were released from the primary expectation of care. “Significantly more” disabled Maori children “were the responsibility of other relatives, most notably grandparents.”⁷¹ Nearly one-fifth of intellectually handicapped Maori children were in the care of people other than their own parents compared with slightly over one-tenth of such Pakeha children.⁷²

LOBBYING FOR A BETTER LIFE .

Mothers of children judged too handicapped for special classes had taken initiatives as early as the 1930s to get access to education for them. In 1935 they led a deputation to the government saying that their children "had simply been turned out on the scrap heap and left there."⁷³ Little changed, however, until the founding of the Intellectually Handicapped Children's Parents' Association (IHCPA) in 1949. The title of the organization was significant: only parents or guardians were entitled to vote and hold office. They, rather than the so-called experts who had proved so disappointing to many, were to determine their future.⁷⁴

Parents sometimes worked together to find avenues of support. Margaret and Harold Anyon, whose youngest son Keith was born with Down syndrome in 1936, were told that he would never go to school. The doctor told Margaret that she "deserved something better." A well-educated and politically savvy woman, living in the nation's capital city, Margaret Anyon was tireless in her efforts to find treatment for her son.⁷⁵ She began a quest for educational opportunities for him that soon widened to involve other parents seeking help for their children. In 1949, the Anyons placed an advertisement in a Wellington newspaper inviting "parents and guardians of backward children" to a meeting. The children of those who attended were variously placed. Some were cared for at home, others were in institutions. Three were in special classes; one child was in Levin Farm. Eight children had Down syndrome, two children had cerebral palsy, one child had brain damage, and one had an unspecified condition.⁷⁶ No longer were these urban parents struggling to make sense of their issues alone: they shared a "social fund of knowledge" that empowered them to take their private stories into the public domain.⁷⁷ The IHCPA gave them a focus to bring about change and to contest existing definitions of "normal" development.

In seeking a wider range of solutions than the automatic institutionalization recommended by so many doctors, the IHCPA lobbied the government for an inquiry. Its members were particularly concerned with the anomaly that denied their children what was freely provided for "normal" children: educational, health, and social amenities. They also wanted a wider range of residential options and more research into disabilities. In 1951 the government set up a consultative committee of inquiry to consider the facilities available for intellectually handicapped children and appointed as chair Dr R.S. Aitken, vice-chancellor of the

University of Otago. The IHCPA was dismayed that the committee had no parent representative, no woman member, and no member with social work expertise. Once again male professionals with little hands-on experience appeared to be setting the terms on an issue that primarily affected women in the home. Eventually the government responded to the IHCPA's complaints by appointing Miss Jean Robertson, a senior lecturer in social science, to the committee.⁷⁸

The committee's report, known as the Aitken Report, stated unequivocally that residential care was the best option for those it termed "imbecile" children. The language of the report could only serve to incense parents who had looked to the government for assistance.⁷⁹ The report chided parents for holding unrealistic expectations. The authors were "glad" that the majority of parents they interviewed "realized and accepted the limitations imposed by the degree of mental defect, and did not cherish hopes of the impossible."⁸⁰

"Until recently," the Aitken Report asserted, "the parents of an imbecile child have more often than not been ashamed of their misfortune and prone to conceal their child from public attention; they have suffered from a confused feeling of guilt and sometimes from a fear of having more children, lest they too should prove to be defectives. The public in general has tended to regard the presence of an imbecile child as a stigma on a family." There was good evidence that the children were shunned in local communities. That such attitudes were in the process of changing was, the report optimistically continued, due to "the propaganda of the Intellectually Handicapped Children's Parents' Association."⁸¹

IHCPA members were bitterly disappointed that the government investigation for which they had lobbied had resulted in an affirmation of institutionalization. They responded with a publicity campaign about the needs of "handicapped children," publicizing their preferred term over the language of "idiots" and "imbeciles" still used in the Aitken Report. Historian Margaret Tennant quotes newspaper headings from the time designed to capture attention to the cause, such as "Shocked Parents Allege I.H. Children Driven into Mental Homes."⁸² Association members would not rest until the government recognized the need for enhanced educational and respite care facilities for their children.

Change at the official level – if not in the community – was rapid. In 1958, a subcommittee of the New Zealand branch of the British Medical Association produced a report debunking the Aitken Report's recommendations, finding no evidence that children did better in institutions

than in their own homes. This report was far more optimistic about the educational potential of mentally disabled children and far less confident about the precision of diagnosis in young children. That report enabled parents to “cherish hope” of what was once thought to be impossible: a future in which their children enjoyed integration into the community.

Mothers were central in the IHCPA movement, although the key officials were usually hard-working men, reflecting the gendered assumptions of the wider culture.⁸³ But women worked at the branch level, raising funds, seeking educational opportunities, and sharing information. They seized with relief upon Pearl Buck’s 1950 best-selling book *The Child Who Never Grew* (serialized in both the ubiquitous *Readers’ Digest* and the *Ladies Home Journal*), in which she urged parents of mentally disabled children “not to despair or turn away in shame. This child has a meaning for you and for all children.”⁸⁴ Buck was an extremely prolific and popular novelist who had been awarded the Nobel Prize for Literature in 1938.⁸⁵ In the late 1940s, she turned to autobiography, writing the story of the birth and early years of her “retarded” daughter, Carol, whom she had eventually decided would best be looked after in an institution. Buck’s book insisted that disabled children were not the result of heredity and she helped shift the view of such children from being potentially dangerous mental “defectives” to one in which they were regarded as innocent children locked in childish understanding.⁸⁶ Buck’s book quickly became a key text assisting parents to understand their child’s mental impairment free of the earlier stigmatizing attitudes.⁸⁷ In her book, many mothers found the words to express feelings that they had been unable to voice before.

CONCLUSION

In mid-twentieth-century New Zealand, gendered expectations shaped the care of developmentally delayed infants. A child’s impairment had a direct and taxing emotional and physical impact on mothers in particular and on the health of the family overall. The best care for the health of the child required family decision making, and unity between husband and wife on those decisions increased the likelihood that the family would achieve good outcomes for both the parents and the child.

A mother’s ill health or depression could lead directly to the institutionalization of a child.⁸⁸ Yet mothers might also resist institutionalization for their children, against the wishes of their husbands, in the belief

that they could provide a nurturing environment. In that case they had to manage not only the needs of the child but also the risks of a ruptured marital relationship.

There is a suggestion in the limited evidence available that the father's attitude, in the majority of cases, was crucial to whether or not a child was institutionalized. Loving fathers could assist in the care of their impaired child but the wider social context, which expected men to act as breadwinners, meant that they were usually unavailable for the quotidian tasks required in the home. For some men, institutionalization seemed to be the best way to preserve a "normal" family life: to protect other children and to give couples time together.

The believed beneficial nature of institutions for mentally impaired infants, however, came under review as new studies emerged in the early 1950s about the psychological importance of infant attachment. Studies like those of John Bowlby, the key figure associated with the term "maternal deprivation," led some doctors and parents to re-evaluate their assumptions about institutional care. New psychological theories about the well-being of children underpinned moves to seek a wider range of support services for the mentally impaired and their families.

Parents who cherished hope, in the face of some medical disapproval, worked hard to create support for their children's needs. Mothers and fathers who remained together and committed to providing opportunities for their children demanded that their expertise be recognized. Those who organized to fight for the rights of the disabled, and held out hope for the future, worked to overturn the shame that mothers and families had been made to feel. They refused to accept their status as lesser parents and sought assistance for their children in all sorts of ways. Organizations advocating for the disabled worked to shame the wider culture for its inability to accept difference, providing a framework for the current social, rather than medical, model of disability. Through their activism they provided a public narrative about disability that had the potential both to assist individual parents, but mothers in particular, and to bring about wider social change.

ACKNOWLEDGMENTS

I thank Diana Brown, Angela Findlay, and Elspeth Knewstubb, all of whom provided invaluable research assistance in the preparation of this chapter.

NOTES

- 1 Sue Lawley interview with David Cameron, *Desert Island Discs*, 2006, <http://www.bbc.co.uk/radio4/features/desert-island-discs/castaway/8d5bcfbc>. See also Alistair Jamieson, "David Cameron on son Ivan: 'We're going to get through this he's lovely,'" *The Telegraph* (25 Feb 2009), <http://www.telegraph.co.uk/news/4804307/David-Cameron-on-son-Ivan-Were-going-to-get-through-this.-Hes-lovely.html>
- 2 Snyder and Mitchell, *Cultural Locations of Disability*, 9.
- 3 Tennant, "Disability in New Zealand: An Historical Survey."
- 4 Kudlick, "Disability History," 764. On parenting and intellectual disability see Brockley, "Rearing the Child Who Never Grew."
- 5 A.M.G. "A Survey of Families with I.H. Children in Institutions and at Home," Preventative medicine diss., University of Otago School of Medicine, 1962, 30.
- 6 Brookes, "The Risk to Life and Limb: Gender and Health," 287.
- 7 *Intellectually Handicapped Children*, Report of the Consultative Committee set up by the Hon. Minister of Education, August 1951 (Wellington: Department of Education, 1953), 18. On the idea of "biological citizenship," see Rose and Novas, "Biological Citizenship."
- 8 Wright, *Downs: The History of a Disability*, 115.
- 9 A.M.G. "A Survey of Families with I.H. Children," 41.
- 10 Rapp and Ginsburg, "Enabling Disability," 537.
- 11 Brookes, "King, Frederic Truby."
- 12 Burchfield and Burchfield, *The Land and People of New Zealand*, 12.
- 13 Mein Smith, *Maternity in Dispute*, 119-20.
- 14 New Zealand Department of Health, *Suggestions to Expectant Mothers* (Wellington: E.V. Paul, Government Printer, 1947), 4-7.
- 15 Tennant, "Mary Joseph Aubert."
- 16 C.J. Parr, "Report on the Mental Hospitals of the Dominion," *Appendices to the Journals of the House of Representatives*, 1921-1922, vol. 3 H-I, 2.
- 17 J.M.E.J., "Study on the Problem of Mental Deficiency and Backwardness in New Zealand Children and the Measures Adapted to Deal with It," preventative medicine diss., School of Medicine, University of Otago, 1943, 55-7.
- 18 *New Zealand Official Yearbook*, 1947-49 (Wellington: R.E. Owen, Government Printer, 1950), 108-9.
- 19 Tennant, *The Fabric of Welfare*, 102.
- 20 Anne Hunt discusses the history of the Levin institution in *The Lost Years: From Levin Farm Mental Deficiency Colony to Kimberley Centre*.
- 21 Interview with H.A. Dunedin, 7 September 2006.

- 22 World Health Organization, *The Mentally Subnormal Child: Report of the Joint Expert Committee Convened by WHO with the Participation of United Nations, ILO, and UNESCO*, Technical Report Series, no. 75 (Geneva: World Health Organization, 1954), 4. Citing the World Health Organization Technical Report Series 1950, 9, 7.
- 23 World Health Organization, *The Mentally Subnormal Child: Report of the Joint Expert Committee Convened by WHO with the Participation of United Nations, ILO, and UNESCO*, Technical Report Series, no. 75 (Geneva: World Health Organization, 1954), 4.
- 24 This term was promoted by the New Zealand Intellectually Handicapped Children's Parents' Association; see Millen, *Breaking Barriers*, 14.
- 25 These research exercises were part of the students' coursework and contain a mine of information on all sorts of topics. The students were young and inexperienced and that has to be taken into account in reading the theses. I have not named the authors out of respect for the fact that they did not imagine their work would enter the public domain. Because most of the authors just used initials, it is difficult to determine the ratio of male to female authors.
- 26 In one of the studies, which involved twenty families, the father was present in six of the interviews. K. C., "A Comparison of Institutionalised and Home-reared Mongol Children," (preventative medicine diss., University of Otago School of Medicine, 1972, 11.
- 27 S.L.M. "The Intellectually Handicapped Child," preventative medicine diss., University of Otago School of Medicine, 1974, 4.
- 28 Hilda Northcroft, "Case of Congenital Abnormality," *New Zealand Medical Journal*, 36, no. 191 (February 1937): 59
- 29 Ralph Winterbourn, *Caring for Intellectually Handicapped Children* (Wellington: New Zealand Council for Educational Research, 1958), 25.
- 30 Paediatric Society of New Zealand, "History of the Paediatric Society of New Zealand," www.paediatrics.org.nz/files/History%20of%20Paediatric%20Society.doc
- 31 World Health Organization, *The Mentally Subnormal Child*, 36.
- 32 On motherhood in New Zealand see Bryder, *A Voice for Mothers*; Mein Smith, *Maternity in Dispute*; Donley, *Save the Midwife*.
- 33 Reagan, *Dangerous Pregnancies*, 103; Rapp, *Testing Women*, 306–11.
- 34 A.M.G., "A Survey of Families with I.H. Children," 44.
- 35 Winterbourn, *Caring for Intellectually Handicapped Children*, 39.
- 36 A.M.G., "A Survey of Families with I.H. Children," 18–19.
- 37 Bennett, "'An Emotional Roller-Coaster': Stories from Mothers of Young Disabled Children," 31.

- 38 A.M.G., "A Survey of Families with I.H. Children," 29-30.
- 39 Millen, *Breaking Barriers*, 19.
- 40 John Bowlby, *Maternal Care and Mental Health* (Geneva: World Health Organization, 1951).
- 41 *Listener*, 4 October 1957, 4.
- 42 M. Bevan Browne, *The Sources of Love and Fear* (Christchurch: Raven Press, 1960), 10.
- 43 Winterbourn, *Caring for Intellectually Handicapped Children*, 15.
- 44 Winterbourn, *Caring for Intellectually Handicapped Children*, 35.
- 45 World Health Organization, *The Mentally Subnormal Child*, 15.
- 46 K.C., "A Comparison," 9.
- 47 *Ibid.*, 21.
- 48 *Ibid.*, 20.
- 49 S.B.C., "The Families, the Doctors, the Community and 14 Intellectually Handicapped Children," preventative medicine diss., University of Otago School of Medicine, 1966, 4.
- 50 K.C., "A Comparison," 30.
- 51 A.M.G., "A Survey of Families with I.H. Children," 8.
- 52 Millicent Kennedy and H.D. Somerset, *Bringing up Crippled Children: Suggestions for Parents, Teachers and Nurses* (Wellington: New Zealand Council for Educational Research in association with New Zealand Crippled Children Society, 1951), 76-7.
- 53 M.R.M.B., "A Family Study of the Intellectually Handicapped," preventative medicine diss., University of Otago School of Medicine, 1966, 7.
- 54 M.R.M.B., "A Family Study of the Intellectually Handicapped," preventative medicine diss., 1966, 32.
- 55 A.M.G., "A Survey of Families with I.H. Children," 17.
- 56 S.B.C., "The Families, the Doctors, the Community," 13.
- 57 A.M.G., "A Survey of Families with I.H. Children," 25.
- 58 *Ibid.*
- 59 *Ibid.*, 12.
- 60 I.M. Allen, "Cerebral Palsy and Allied Conditions in Childhood," *New Zealand Medical Journal* 54, 303 (October 1955): 582.
- 61 Donald Beasley Institute, *Perilous Passage: New Zealand Fathers Talk about their Children with Disabilities*, 4.
- 62 Lamb, "Fathers of Exceptional Children," 135.
- 63 *Ibid.*
- 64 K.C., "A Comparison," 8.
- 65 S.L.M., "The Intellectually Handicapped Child," 12.
- 66 K.C., "A Comparison," 50.

- 67 A.M.G., "A Survey," 27.
- 68 Winterbourn, *Caring for Intellectually Handicapped Children*, 34-5.
- 69 *Ibid.*, 36.
- 70 A.A. Morrison, D.M. G. Beasley, and K.I. Williamson, *The Intellectually Handicapped and their Families* (Wellington: Research Foundation of the New Zealand Society for the Intellectually Handicapped, 1976), 100.
- 71 *Ibid.*, 103.
- 72 *Ibid.*, 103-4.
- 73 Rosemary Goodyear, "'The Individual Child': A study of the Development of Social Services in Education in Relation to the First Labour Government's Educational Policy," BA Hons diss., University of Otago, 1987, 85.
- 74 Millen, *Breaking Barriers*, 15.
- 75 *Ibid.*, 8.
- 76 *Ibid.*, 13.
- 77 Rapp and Ginsburg, "Enabling Disability," 538.
- 78 Jean Robertson was on the staff of Victoria University College. The other members of the committee were Dr L.S. Davis, director of School Hygiene, Dr G.M. Tothill, deputy director, Division of Mental Hygiene, and F.C. Lopdell, chief inspector of primary schools. Millen, *Breaking Barriers*, 22-3.
- 79 *Intellectually Handicapped Children*, Report of the Consultative Committee set up by the Hon. Minister of Education, August 1951 (Wellington: Department of Education, 1953), 20 (hereafter referred to as the Aitken Report)
- 80 Aitken Report, 18.
- 81 *Ibid.*, 34.
- 82 Tennant, *The Fabric of Welfare*, 156.
- 83 Earl, "Caring for their Children Forever," 56.
- 84 Buck, *The Child who Never Grew*, back cover. My thanks to Dave Earl for sharing his work on the Australian situation with me and, in particular, pointing out the influence of Buck.
- 85 Conn, *Pearl S. Buck: A Cultural Biography*, 207-15.
- 86 Earl, "Caring for their Children Forever," 7.
- 87 *Ibid.*, 40-1.
- 88 K.C., "A Comparison," 12.

Bodily Subjects

Essays on Gender and Health,
1800–2000

EDITED BY

Tracy Penny Light, Barbara Brookes,
and Wendy Mitchinson

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

© McGill-Queen's University Press 2014

ISBN 978-0-7735-4414-7 (cloth)

ISBN 978-0-7735-4415-4 (paper)

ISBN 978-0-7735-9641-2 (ePDF)

ISBN 978-0-7735-9642-9 (ePub)

Legal deposit fourth quarter 2014

Bibliothèque nationale du Québec

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

This book has been published with the help of a grant from the Canadian Federation for the Humanities and Social Sciences, through the Awards to Scholarly Publications Program, using funds provided by the Social Sciences and Humanities Research Council of Canada.

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 Canada Book Fund for our publishing activities.

Library and Archives Canada Cataloguing in Publication

Bodily subjects: essays on gender and health, 1800–2000 / edited by
Tracy Penny Light, Barbara Brookes, and Wendy Mitchinson.

(McGill-Queen's / Associated Medical Services studies in the history of
medicine, health, and society; 42)

Includes bibliographical references and index.

Issued in print and electronic formats.

ISBN 978-0-7735-4414-7 (bound). – ISBN 978-0-7735-4415-4 (pbk.). –

ISBN 978-0-7735-9641-2 (ePDF). – ISBN 978-0-7735-9642-9 (ePDF)

1. Women – Health and hygiene – History. 2. Men – Health and hygiene –
History. 3. Femininity – Health aspects – History. 4. Masculinity – Health
aspects – History. 5. Health – Sex differences – History. I. Penny Light,
Tracy, 1970–, author, editor II. Brookes, Barbara L. (Barbara Lesley),
1955–, author, editor III. Mitchinson, Wendy, author, editor IV. Series:
McGill-Queen's / Associated Medical Services studies in the history of
medicine, health, and society; 42

RA564.85.B63 2014

613'.0424

C2014-905960-4

C2014-905961-2

This book was typeset by Interscript in 10.5/13 Baskerville.

UNIVERSITY OF OTAGO LIBRARY
3 0020 10838916 6