"To Make the Crooked Straight": The Crippled Children Society in Southern New Zealand, 1935–2007

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Abstract

This article examines the history of the New Zealand Crippled Children Society, focusing on the Dunedin branch and highlighting how this voluntary organization has evolved in relation to a widespread change in attitudes and policies towards disability in order to meet the changing needs of its consumers. While taking account of the historical and social context, this study examines the origins of the society in Dunedin in the 1930s and its initial aims as a charitable organization for children affected by polio. It then maps the progress and changes made by the society over time, concentrating on the major upheavals of the late 1980s and 1990s, up until the early twenty-first century which saw the implementation of the New Zealand Disability Strategy (2001) and the UN Convention on the Rights of Persons with Disabilities (2006) These show how the society adapted to changes in government policy, public attitudes and professional opinion while preserving its original ethos.

Charities have to move with the times, and medical charities the more so as the nature of illnesses, their treatment, and social attitudes towards them change, sometimes quite rapidly. This is particularly the case with organizations that deal with disability, of which the Dunedin branch of the New Zealand Crippled Children Society is a good example. It started as a fundraising organization intended to assist a new medical specialism. Significantly, it was one with an advocacy role that became more important over time as the society became more closely tied to the state provision of medical and social services. As its head office put it in 1940, the "function of the State [was] to care for the crippled child; it was the special privilege of the Society to look after the interests of the crippled child." The history of such organizations has often charted a transition from a "medical based" approach to a "social based" one, but the Dunedin example suggests that the reality was less clear-cut or straightforward than this implies. Elements of both approaches existed from the outset, and the transition from one approach to the other was less abrupt and absolute than the received picture has it. The adoption of the "social model" of disability coincided with the introduction of neoliberal market-based financing and organization driven by changes in government policy. The state of the branch's funds meant there was no choice but to accept the new competitive funding model imposed by the government. The society was also influenced by changing perceptions and language around disability and impairment since its inception and the influence of the social model of disability; the emergence of the disability rights movement (DRM); and the UN Convention on the Rights of Persons with Disabilities (2006).

This study looks at the effect of these changes at the local level by examining one of the four main cities of New Zealand, Dunedin. By the time the local branch of the Crippled Children Society was established in 1935, Dunedin had ceased to be the largest and wealthiest city in New Zealand. It did, however, retain many head offices of national businesses as well as a strong tradition of support for social and medical charities among businesses, churches and the wider community. Importantly, the city had the only university-based medical school in the country,³ and a specialized orthopaedic department was set up at the public teaching hospital in the early 1920s. The city experienced relative economic decline in the course of the century. As in the rest of the country, the tradition of private philanthropy weakened, and there were

few large reserves of private wealth to draw upon.⁴ The Crippled Children Society, though much better funded than many other charities, was like them still heavily dependent on state funding. The Dunedin branch was the first to encounter serious financial problems and to undergo thorough reorganization in the early 1990s. Its example was subsequently followed by other branches throughout the country.⁵

Disability History: Medical and Social Models

It is the aim of this study to highlight how this voluntary organization has evolved in relation to the widespread change in attitudes and policies towards disability in order to meet the varied needs of what it came to call its "consumers." New Zealand's public and voluntary institutions were often modelled on those of the United Kingdom, and in some cases were explicitly linked to those of the mother country. The policies adopted by New Zealand institutions have often been influenced by publications and visiting experts from other English-speaking countries, not least Britain and the United States. The neoliberal policies adopted from the 1980s onwards, for instance, were enthusiastically adopted from British and American sources. In the disability sector, American thinking has been particularly influential. The original idea of the Crippled Children Society came from the United States, and the radical reevaluation of the status of disability that came to a head in the 1980s was "[i]nspired by the academic and sociopolitical trends of the civil rights era" there. This change has been seen as having effectively constructed a divide between past and present modes of thinking.8 The "medical model" of disability represented the dominant thinking before the 1980s, while the "social model" of disability became the post-1980s paradigm. Piotr Miexejewski points out that these "two models have been highly influential on how mainstream society has viewed people with disability: the first positing disability as something to fix, and the second conceptualizing disability as an integral component of normal society."9

Until the 1980s, the historical assessment of disability in a global sense came almost exclusively from outsiders: educators, medical professionals, and policy makers and analysts. This, it has been argued, resulted in an interpretation of disability exclusively, or primarily, as an issue of pathology. Those who adhered to, or advocated, this model examined and expressed disability as a defect or illness that necessitated medical intervention in order to cure or at least alleviate the problem. This medical paradigm views all disability and related issues as residing within the individual. Seriously discriminatory implications have been detected at the heart of this model. From a solely medical perspective, disability is something to be cured; those with a disability are dependent on the medical profession "not just to 'get better' but also to 'be better."10 In the early twentieth century, the New Zealand government's attitude towards disability was often marked by the language of eugenics, linking "disability, intellectual, and to some extent, physical, with degeneracy, inferiority and low morality." ¹¹ The medical model's view of disability was to see it as a personal problem and a medical issue, concentrating on the condition, the impairment and the inabilities of the person. People were seen as victims of their defects, ¹² and they "and their families were expected to be grateful and to accept decisions by social work professionals funded by rich benefactors". 13 The medical profession was powerful and the disabled were expected to be passive recipients of their expertise. 14

This model was not seriously questioned or challenged until the 1970s. ¹⁵ Disability rights groups then began with increasing intensity to argue that disability was a civil rights issue. The medical model was criticised for promoting a "negative, disempowered image of people with disabilities, rather than casting disability as a political, social and environmental problem." ¹⁶ Concentrating on the physical disability, this interpretation viewed important issues such as

relationships to work, family, public life and education in terms of the condition of the person, more often than not "neglecting the role of social, legal, economic, religious, and political factors that affect the success or quality of life for disabled individuals."¹⁷

The social model of disability emerged from this thinking in reaction to the medical model. It argues that disability is a social construction:

disability is often less about the physical or mental impairments than it is about how society responds to impairments . . . The social model of Disability in fact rejects the notion that people with disabilities are inherently "defective" and solely in need of rehabilitation; rather, Disability is seen as a common factor in life. ¹⁸

The "disability" is seen as being the social and physical environment: "the barriers to participation, unequal rights, discrimination, oppression." ¹⁹ Rather than the individual requiring medical intervention to alleviate the negative and disabling effects of any given defect, the social model instead strongly demands intervention directed at society and not the individual.

New and different models of disability developed in the United Kingdom and America. In Britain, activists preferred to adopt a structural analysis of disability in which the distinction between (social) disability and (biological) impairment was far more sharply made and which permitted disability to be redefined as social oppression. ²⁰ In America, disability activists generally adhered to a minority group model rather than the social structural oppression model of the British. ²¹ These activists believed that the obstacles they confronted were the result of social attitudes rather than their individual impairments.

Closely related to the social model were the affirmative and cultural models, and all three signified the start of a new way of viewing disability. The affirmative model, using the social model as its base, provided a framework for the understanding of day-to-day personal interactions. The cultural model of disability extended the social model and saw disability as the result of stigmatization: using a theory of deconstruction, disability was regarded as culturally defined and the solution was considered to be diversity. In other words, all those in society formed the foundation of this model, not just disabled people. Full acceptance could only occur if disabled people were seen as integral parts of society. 23

Theories of oppression exist for various minorities in society, and disability can be identified as a marker of discrimination alongside gender, ethnicity, age, sexuality, and social class. Postmodern approaches to disability theory examine differences between disability and impairment and identity and difference, incorporating a renewed discourse around impairment. For example, the "normal–abnormal" dichotomy has been discounted by some postmodern theorists, and the social model's dichotomy between impairment and disability has continued to be reviewed.²⁴

In New Zealand, any discussion of models of disability must include mention of Māori concepts of health and disability. Māori notions of health and disability are holistic in nature, "locating individuals within the whānau context and, therefore, emphasising interdependence, recognising determinants of health (including cultural and spiritual determinants), incorporating a focus on continuity between the past and the present, and viewing good health as a balance between interacting variables."²⁵

Up until relatively recently, Māori were suspicious about Pākehā (European) social service providers such as the New Zealand Crippled Children Society as their culture and language were mainly ignored by the organization, which also required their integration into Pakeha culture.²⁶ The holistic attitude of Māori towards health based upon the "interactions of spiritual (taha wairua), mental (taha hinengaro), physical (taha tinana) and family (taha whānau)" that shaped their attitude toward disability were not recognised by the early leaders of the society.²⁷

Pragmatic Beginnings: New Zealand Crippled Children Society

The name Crippled Children Society makes the relationship with people with disability explicit: it was a society dealing with crippled children, not a crippled children's society. ²⁸ A later children's charity was even more forthright: the Intellectually Handicapped Children's Parents' Society, founded in 1949. In both, the children were seen as passive recipients of assistance, in the context of their families and wider society, rather than as participating individuals. The 1930s to the 1960s in particular saw the foundation of a range of medical charities in New Zealand, as in other comparable countries. Following the early examples of the Institute for the Blind (1890) and the Plunket Society for the Health of Women and Children (1907), several charities such as the Soldiers' Civil Re-establishment League and the League for the Hard of Hearing were set up in the interwar years, in 1930 and 1932 respectively. These organizations acted as both advocates for people with disabilities and providers of services to them. They were dominated by medical men and the "charitably inclined." Towards the end of the century, increasingly more specialized disability organizations began to proliferate "as disabled persons themselves began to organise and push for a consumer voice in decision-making." ²⁹

An important change in the nature of charitable organizations in the 1920s was the development of international service clubs. They supported a range of good causes, as opposed to individual charities devoted to a specific object. Rotary clubs spread rapidly throughout the Englishspeaking world, reaching New Zealand in 1922. They were prime movers in the foundation of the Crippled Children Society, which was modelled on similar societies formed by their counterparts in North America from 1913 onwards. 30 It was widely recognized among specialists that there was a need for dedicated rehabilitative treatment for children affected by poliomyelitis, then known as "infantile paralysis." It was thought that about 5,000 children were affected by the virus throughout the country. 31 A draft constitution and rules for the Crippled Children Society were submitted to the national Rotary Conference in March 1935.³² It was kick-started by a donation of £50,000 from Lord Nuffield, the British motor magnate and philanthropist who visited New Zealand that month. He was reported to have thanked God that he "was not born a cripple myself. I cannot imagine anything more dreadful than being born a cripple, and having no one to put me straight."³³ This was one of the largest donations ever received by a New Zealand charity and put the new society clearly on the map.³⁴ Unlike some other medical charities such as the British Empire Cancer Campaign Society, 35 the Crippled Children Society was not linked to a British parent body.

The Wellington orthopaedic surgeon and Rotarian Alexander Gillies had brought the need for treatment for those suffering from poliomyelitis to the attention of his local Rotary Club in 1930, adding that the children's training and future employment were at that time completely neglected. Employment even for able-bodied adults was a problem in these years of the Great Depression, but in 1932 Rotary Clubs throughout the country were urged to enlist public interest and support "in the problem of the cripple." ³⁶

Following the example of other branches of Rotary throughout the country, the Dunedin club held a public meeting on 30 April 1935 in the Town Hall.³⁷ It was attended mainly by Rotary members and other philanthropically minded local businessmen and professionals, including several physicians. Among the latter were J. Renfrew White, the leading orthopaedic surgeon; Sir Louis Barnett, the retired Professor of Surgery at the university medical school; and Charles Hercus, who was to become its Dean in 1937. The Anglican Bishop of Dunedin, William Fitchett, was a member of the governing committee, but despite the mayor himself also being a clergyman, the churches were not as conspicuous as were the medical and business communities in the promotion of the new society.³⁸ This was an example of the wider development in this period in which social charities became less associated with the churches and instead were linked with service clubs, businessmen's associations or women's organizations.³⁹ There is no record of the attendance of any people with disabilities or parents of children with disabilities at this initial public meeting or any of the subsequent early meetings of the new society.

The Crippled Children Society both supplemented and complemented the role of government in the treatment of the disabled. 40 The Dunedin branch was one of seventeen that had been formed by July 1935, each of them based on the local public hospital board districts. The society worked closely with the public hospital and education authorities, seeing its role as facilitating the provision of specialized medical care to disabled children and advice to their parents, and making sure that advice was followed. 41 It quickly adapted to the major transformation of government welfare policy embodied in the Social Security Act of 1938, which introduced a range of benefits. The state met the expense of the treatment of disabled children in the public hospital system, while the society identified cases suitable for treatment, provided transport for them to hospital or therapeutic centres, and maintained contact with their families. The society took advantage of its organisational and operational independence to "investigate and try out new methods" in clinical work and the training and employment of the disabled. 42 Within a year just over 1,400 children had been registered nationwide, though this represented only about 28 percent of the estimated number of polio cases alone. 43 The Dunedin branch was rapidly successful: by 1938 about two hundred children were registered, and the society was spending more than £700 on them annually. 44 The branch's share of the income from the Nuffield donation was about £100 a year, 45 yet half the society's income came from the government. 46 Though the Crippled Children Society was unusually well funded, this high level of dependence on state funding was typical of New Zealand social charities.

The Otago University medical school and public teaching hospital were central to the development of the local Crippled Children Society. Renfrew White was a pioneer of orthopaedic surgery in New Zealand, establishing a specialized orthopaedic department at Dunedin Hospital in 1920. He was also a famously energetic lecturer in the medical school. Born locally, "Eefie" White had graduated from the Otago medical school in 1912 and moved on to postgraduate study in England, where he specialized in orthopaedic surgery. In the course of the First World War he gained considerable experience in several military orthopaedic hospitals in bone, joint, nerve, and muscle injuries. On his return to Dunedin in 1918 he continued to treat wounded soldiers in the military wing of the public hospital, where he was visiting surgeon in orthopaedics. ⁴⁷ White embodies the philanthropic paternalistic attitude which was characteristic of the founders of the Crippled Children Society in Dunedin. He, like many of his peers, dedicated his time and expertise to the benefit of children suffering from physical disabilities.

From its inception in 1935, the Dunedin branch of the society was essentially pragmatic and philanthropic in its aims. It saw its role as merely "an agency whereby the facilities of modern medical science and its associated departments are made available to those children who may benefit from them." Medical specialists had a great deal of influence, not least Renfrew White. He told the initial public meeting that from a:

Medical viewpoint [there was an] urgent need of medical attention in the earliest stages of crippledom and for constant vigilance and examination until maturity was reached. A Society which could undertake the work of keeping in touch with cripples, of keeping records and statistics of all cases, and generally keeping cripples in close touch with the hospital and medical authorities would be doing . . . splendid and worth while work.⁴⁹

The society's founders were confident that at least some disabilities could be solved by surgery and physiotherapy. These classic aspects of the medical model of disability were, however, combined with the desire to influence public attitudes towards disability, to inform and educate the community about the needs of crippled children. Vocational training and employment went hand-in-hand with the medical aspects of the society's work. ⁵⁰ A Vocational Guidance Committee was formed to assist those "cripples whose medical treatment has been completed" ⁵¹ in finding employment and a place in wider society and help them avoid becoming dependent on state benefits. ⁵² The committee resolved that it was its "duty to explore the educational as well as practical aspect of the problem." ⁵³ The indigenous Māori populace was also considered from the beginning, ⁵⁴ though it formed a much smaller proportion of the population in the Dunedin district and the wider Otago province than in the northern provinces.

Returned soldiers who had been wounded in the First World War raised public awareness of disability while "removing some of its stigma." The 1920s and 1930s saw a sudden increase in particular types of disability and these too ultimately altered public sensibilities. This development was further reinforced by the polio epidemics of 1916 and 1924–25. These events "nudged young, previously fit individuals into the ranks of the disabled" ex-servicemen were often well educated and "had not grown up with disability and with the assumptions of childlike dependency attached to those disabled from birth." Advances in medical techniques made during and immediately after the war were confined chiefly to returned servicemen in the initial postwar years but quickly became available to civilians, "heralding an era of surgical intervention in disability."

Though in retrospect the Crippled Children Society saw its initial role as having been to deal with the consequences of polio, ⁶⁰ in 1935 disability as the result of disease was given no more prominence than that resulting from accidents or congenital malformation. ⁶¹ The most recent polio epidemic had been seven years earlier, though only two years later in 1937 there would be another major national outbreak. There were further epidemics in 1948–49, 1952–53 and 1955–56 before the availability of effective vaccines in the late 1950s and a mass immunization campaign in the early 1960s eradicated the virus in New Zealand.

The medical model of disability adhered to by the Crippled Children Society—and society more generally—is very evident in the minutes of its early meetings. A degree of discrimination was inherent in the medicalized attitude towards people with disabilities. Those considered incapable of being educated were excluded, as were the "mentally deficient." The society "stressed the necessity of overcoming disability by training, in order that disabled children would become recognized as being paying propositions to employers." Retired professor of surgery Sir Louis Barnett also pointed out there was always a proportion of the disabled who

would not be prepared to take advantage of medical assistance. He found it "amazing how people became used to their deformities, found they had certain compensations, and refused to submit to changes." ⁶⁴

The attention of the society was almost entirely directed towards obtaining and funding medical treatment for children and providing them with transport to hospital for physiotherapy. ⁶⁵ It was one of the first voluntary agencies in the country to provide wheelchairs, and was involved in developing technical improvements to them. ⁶⁶ Large-scale fundraising was required to enable a few children to be sent abroad for specialized treatment unavailable in New Zealand, while specialized therapeutic treatment was available locally for less serious cases. ⁶⁷

Evolution within the Crippled Children Society

The physical consequences of polio dramatically declined in the 1960s once the disease had been eliminated. Naturally, the society continued to assist children, but it adapted to changing circumstances by broadening its role to increasingly help adults and deal with a wider variety of physical disabilities. Despite its name, from the outset the society's attention had not been strictly confined to those under the age of 21.⁶⁸ By the late 1950s, the society concentrated on orthopaedic disabilities, hare lips and cleft palates, heart disabilities in "marked degree," and crippling neuro-muscular disorders.⁶⁹ It explicitly excluded those who had "defects of the vital organs" and the "mentally deficient." The latter had gained an equivalent organization in 1949 with the formation of the Intellectually Handicapped Children's Parents' Society.

Government policy continued to shape the policies and role of the Crippled Children Society for the rest of the century. In 1972, the Accident Compensation Act introduced a state-funded no-fault compensation scheme for those disabled as a result of accident or medical misadventure. The Disabled Persons Community Welfare Act of 1975 handed over provision of services to disabled people to the Department of Social Welfare. The medical model of disability persisted, however, and was encapsulated by the symbol used by the Crippled Children Society, a silhouette of a small boy on crutches accompanied by an able-bodied girl of the same age.

Though there were no formal links with Crippled Children Societies in other countries, the local branches were aware of international developments. The United Nations' International Year of Disabled Persons was observed throughout the country in 1981 by highlighting different aspects of life for the disabled. The publicity department of the national office ran a disability awareness accident-prevention programme aimed at primary-school children.⁷² The Dunedin branch made it clear that the aim of the year was not to "invoke sympathy but to nurture understanding and practical support and help for people with a handicap." The local news media had raised a positive profile of disability, and many other groups within the community had been supportive.⁷³ In the same year Julie Johnson, the Otago Southland recreation coordinator, initiated a "buddy programme" which matched an able-bodied person "with a disabled person to enjoy together normal everyday and recreational activities of young people in the community. As the emphasis today is on full participation and equal opportunities for disabled people this programme is very valuable in providing the sort of assistance and support needed."⁷⁴

The Crippled Children Society in general moved with developments in the attitudes of wider society, not in advance of or in opposition to them but by nudging them in the desired direction. It had become more active in the 1970s in pushing for improvements in access to buildings and vehicles. This can be seen as an early sign of a shift away from the medical model of disability, yet it was also an aspect of the desire to change the attitudes of wider society towards the

disabled that had been part of the society's thinking since its inception. The society took on a few people with disabilities as staff members from the late 1960s, and they helped develop policies to promote mobility and accessibility. In 1968 the Dunedin Executive, in conjunction with the national body, held a meeting of "interested parties with the view of bringing to the notice of architects, engineers, builders and social workers the desirability of removing architectural barriers to handicapped persons in many public buildings throughout the city and country districts." The national body introduced an award for building design in 1977 which incorporated wheelchair access and two years later the Crippled Children Society and the New Zealand Institute of Architects introduced the "Barrier Free" campaign. These efforts by the national body and regional branches did much to raise awareness and improve building access for people with disabilities. Operation Mobility" was also introduced in 1977 by the national body. As implemented by the Dunedin branch, the scheme offered special car parking concessions for those who had serious difficulty walking.

Dramatic Change: The Social Model of Disability and Competitive Funding

Major changes to the principles and role of the society, in common with the rest of the social service sector in New Zealand, came in the early to mid-1980s. "Goal posts were shifted regularly, and the way things had been done was challenged."⁷⁹ Some of the change was driven by government policy, and some by the society itself. The local branches of the society had from the start been autonomous, independent of the national office in the capital, Wellington. However, the branches' international outlook and awareness of trends in attitudes towards disability largely came through the national organization, through which local branches were kept aware of international developments. The presidents of each of the local boards met at a national conference each year, to which a prominent international speaker was invited. Judith Hyslop, a member of the Dunedin Branch Board from 1993 and its president in 1995–96, recalls that this brought "some really key people" into the country "to help us in our thinking." She felt this helped generate "a groundswell around moving to the social model" of disability. Each region sent a representative to the national board, who provided a conduit for information about developments in thinking about disability. The practical changes that introduced the social model of disability were, however, led by the branch boards, not the national office; as Judith Hyslop recalls, "there were a lot of drivers—leaders—on the local board." The Crippled Children Society became the first of the long-established social charities to move into the new way of thinking.⁸⁰

An economic downturn meant the conservative National Government of 1975–84 was reluctant to fund social services generously. It was in any case suspicious of charities that appeared to have a political agenda, such as those dealing with child poverty or overseas aid. A "userpays" principle was applied to public services, and its influence was perceptible in the growing presence of commercialization in government policy relating to the disability service sector. The Labour Government of 1984–90 introduced many neoliberal economic reforms which were continued and intensified by its National Party successor in the early 1990s. Among these reforms was a fundamental change to the position of charities such as the Crippled Children Society. The state assumed a much greater role in the provision of social services, and the funding of nonprofit organizations was separated from the provision of services. It placed increased emphasis on individual choice on the part of what were now termed "consumers." Along with other charitable organizations, the Crippled Children Society was faced with commercial competition for the provision of services for people with disabilities. The Dunedin branch found that:

there was an insistent aura of the necessity of the Executive, Staff and registrants to realize the need to provide additional services and equipment to not only keep pace with advancing thought but also to be aware that an increasing number of kindred organizations are now becoming involved in the care of the disabled.⁸³

A wider range of social service organizations was competing for limited government funding and increasingly scarce private charitable donations.

In the course of the 1980s and 1990s the central government increasingly contracted out social services within the community. This had the effect of reducing the independence of charities by making them overwhelmingly dependent on state funding. Organizations that provided a range of services faced multiple and fragmented contracts that were enormously time consuming to deal with. By the late 1980s, the Dunedin branch still received only a "very small proportion" of its income from contracts. Its board had felt that the branch should remain a provider of services rather than contracting for them, which might have meant it could no longer act as an advocate for its clients. Many other charities similarly believed the freedom with which they could pursue their advocacy role would be constrained by the fear of losing contracts and state funding. However, a financial crisis obliged the Dunedin branch to become "proactive in getting contracts"; this was not something forced on them by the government but rather because the branch had been "living way beyond its means."

Nationally, the response of the Crippled Children Society to greater government intervention was to centralize its regional capital reserves and organization into a national executive. On a regional level this increased commercialization and centralization within what was essentially developing into the modern disability service quasi-industry. Competition replaced the previous cooperation among charities and agencies. 89 This development caused some frustration and uncertainty on the part of both the regional branches of the Crippled Children Society and their clients. In 1986 the society introduced a new set of aims, leaving behind what it saw as the old ethos of providing care and instead adopting the explicit goal of facilitating independence. In some ways, though, this was more a change in emphasis than in philosophy, as the Dunedin branch from the outset had sought to change public attitudes towards disability, not just to prepare disabled children for life in the wider community. The declared intention of the 1986 reforms was to "work with individuals and families to overcome or minimize [the] effects of disability [and] with disabled people to promote public education to remove interpersonal and physical barriers in the community." The society would "foster integration and independence of disabled people with the community," work with them "to advocate for the improvement of statutory provisions" and "to promote awareness of and access to welfare rights."90

One policy change that did entail a major change in the culture of the society was the increased emphasis placed on "empowering people with disabilities and inviting their involvement in the management of the Society." When the New Zealand Coordinating Council for the Disabled was formed in 1978 it encountered opposition from, among others, the Crippled Children Society. The society believed the new council should not be the New Zealand representative to the Rehabilitation International organization because it was "too much influenced by consumer interests." In line with the new policy, however, disabled "consumers" were invited for the first time in 1986 to attend the Annual General Meeting of the Crippled Children Society. Not all the branches moved as quickly as some would have liked: one board meeting of the Canterbury branch was stormed by a group of young disabled people to protest against their exclusion. They were supported by their social workers and clearly had been influenced by the Disability Rights Movement (DRM).

The DRM, utilising the experience of other human rights movements around the world during the 1960s and 1970s, developed its own analysis of disability as a way of freeing itself from the restrictions of service provider organizations and state intervention. In New Zealand, as well as internationally, the phrase "nothing about us without us" was used to establish a strong and united movement which would push for equal rights in society. The slogan's message was that policies could not be formulated without full consultation with those affected by them. This was so as to avoid making similar mistakes as other movements which allowed advocates speak on their behalf.⁹⁴ The International Year of Disabled Persons in 1981 was seen as a crucial impetus for the organization of disability groups in New Zealand. 95 However, early attempts by disabled people, disability advocacy groups and service organizations to work closely together soon brought their differences to the fore, creating conflict. For example, service providers, while accepting the participation of disabled people, still sought to retain the ability to decide strategic direction and determine important issues. 96 The central issues engaged by the DRM in New Zealand today are "the promotion of true de-institutionalisation, particularly for people with high and complex needs, guaranteed education and employment opportunities, and campaigns for individualised funding of disability services with greater control by disabled people. Attention to cultural diversity is another crucial component." A further important element is the monitoring of the UN Convention on the Rights of Persons with Disabilities by six New Zealand disabled people's organizations: Deaf Aotearoa, The Association of Blind Citizens, Disabled Persons Assembly, People First, Nga Hau E Wha, and Ngati Kapo.⁹⁷

The emphasis on the need for individual independence and integration into society infused the nationwide "services policy" adopted in 1986. It stressed the "need for more effective communication and information sharing to enable people with disabilities to become more independent, and have responsibility for determining solutions to their needs." The policy restated an aspect of the Dunedin branch's work that had been present since its beginning, the "need to advocate [provision for] special transport needs to be met throughout the community." Community-based services and facilities would, according to the services policy, need "to provide more flexibility in the provision of services and respond to the changing community needs." These services would include "the provision of long-term accommodation in the community and . . . short-term and transitional accommodation."98 A hostel for school-age children from out of town was set up in South Dunedin in the early 1980s. It provided longterm care for eight "clients" as well as a weekend relief service for local parents of disabled children. 99 In addition to this hostel, by the mid-1980s the Dunedin branch provided a kindergarten, an adult care centre and a family holiday home in rural Central Otago. 100 Sheltered workshops had been introduced nationally in the 1960s, ¹⁰¹ and the society was among the first to introduce a home support service in the 1970s. 102

Though much of the substance was little changed, the ideological emphasis of the 1980s was new. Gone were the references to the disabilities of the individual and the acts of charity by the society to help those individuals overcome their physical burden. The society now sought to minimize the effects of disability, both physical and interpersonal. It was no longer working *for* but rather working *with* people with disabilities, and was now clearly committed to the social model of disability. The legislative framework within which the society operated was also transformed. The social model was consciously advanced by, among other legislation and policy statements, the Health and Disability Consumer Act of 1994, the New Zealand Disability Strategy of 1995, and the Code of Health and Disability Services Consumers' Rights of 1996. ¹⁰³

The later 1980s and early 1990s were not just a time for radical change in policy and ethos but also saw dramatic administrative and bureaucratic restructuring of the entire organization of the Crippled Children Society. Over a short period most such traditional charitable organizations became, in response to changes in government policy, more streamlined "service providers" modelled on large commercial businesses. The national body of the society sought to bring itself and its branches into a sustainable position in relation to the increasingly commercial environment within which it operated. This did little to allay the apprehension that had been expressed at the regional level in the late 1980s, which continued into the next decade.

CCS Disability Action

Over the years the name Crippled Children Society had become increasingly irrelevant to much of the range of the association's activities, and it was felt the name was "disrespectful" towards the adults. 104 Suggestions were invited for a new name, 105 and in 1990 the national board adopted the acronym CCS, along with a new logo; this was elaborated to "CCS Disability Action" in 2007. The Dunedin branch explained that "Consumers have felt for some time, and rightly so, that the name Crippled Children Society, was demeaning and did not accurately relay to the public the nature of our work." 106 "Disability Action" was chosen to reflect the organization's "determination to work with, and support, all disabled people [to enable them] to have the same right to relationships, learning, recreation, work and community as everyone else." 107 For some time after the change of name, on the society's stationery it was felt necessary to explain that CCS was "formerly the Crippled Children Society"—otherwise it was felt that donations might suffer as the public might not realize what CCS signified. ¹⁰⁸ The new logo avoided any visual allusion to disability, dropping the image of a boy on crutches. The adoption of acronyms and new, more abstract logos was widespread among social service charities at this time. Also in the spirit of the times, the Dunedin branch adopted a new mission statement: that it was "Building a future for people with physical disabilities. As we move forward it is imperative that the future of CCS develops in partnership with consumers and care-givers." Two years later in 1992 the mission statement was re-expressed. The Dunedin branch declared it sought a "world in which people with disabilities participate fully in all decisions affecting their lives, on the basis of equality and respect for their dignity and rights."110

The Dunedin branch was the first in the country to undergo major restructuring in the 1990s, due to (as noted above) a financial crisis. Given the current state of the historiography, it is not clear to what extent this was typical of other branches. Over several years, the Dunedin branch had become accustomed to deficits, but these had become unsustainable. ¹¹¹ The branch undertook an extensive review of its services in 1991. The review team comprised a mixture of staff, board members, branch management, national office representatives and, significantly, "consumers," who until this point had had little active involvement in the governance of the branch. ¹¹² In some branches, more "consumers" became members of staff in this period, though they still often felt patronised and "the division between staff and consumers was strict." ¹¹³ Some aspects of the new approach reversed policies that were themselves recent. One of the "effects of mainstreaming," which entailed "a move away from institutional care," was the closure in 1991 of the branch's hostel for school-age children that had been set up barely a decade earlier. ¹¹⁴

In her anniversary history of CCS, Carol Atkinson emphasized the distance the society had come in sixty years. Initially providing helpful links between the medical profession and families, it had by 1995 shifted to placing emphasis "on ensuring that government agencies and boards make equipment available. CCS is totally committed to full consumer participation.

Today the organization's policy makers are frequently people with direct experience of disabilities—either their own or those of their children." ¹¹⁵ Beneath the positive gloss, however, there were tensions regarding the new direction imposed by government policy. Reductions in state funding from 1991 and the introduction of contracts for support services for the disabled made it difficult or impossible for the society to pursue these aims. ¹¹⁶

A further review of the branch—"a long and painful process"—was conducted in 1993–94. The priorities given to its services were reassessed. 117 "Consumer forums" were held to discuss these priorities; a consumer advocate explained that a "lot of these issues are emotional ones. And if people feel they're not being listened to or taken notice of, they get upset or angry." 118 The branch continued to eat into its financial reserves to fund its deficit; the Treasurer reported that "accumulated funds are being eroded at quite an alarming rate." 119 This led to the management consultants Deloitte being called in to conduct another review in 1996. 120 This was an unusual step for a charity, but the board felt it needed the perspective of "someone from the outside looking in." 121 Deloitte recommended "significant changes" to the branch's structure and strategy, and as a result six management positions were "re-defined." 122 Five of these six members of staff resigned rather than reapply for these "re-defined" jobs, and some of their friends and colleagues were "frustrated and angry" at seeing them being treated badly by the board. 123 The new operational model meant the Dunedin branch lost its autonomy, a move that was subsequently adopted by the other branches throughout the country. 124

A major restructuring of the New Zealand CCS was the adoption of the Millennium Charter in 1997 which defined the rules of engagement between individual branches and the National Society based on the premise that there should be a clear separation of management and governance and consistent standard to services on a national level. As a consequence of the charter the CCS was restructured into seven regions with sixteen branches. Whilst local branches remained legal entities, local boards were replaced by Local Advisory Committees (LAC), responsible for bolstering the involvement of disabled people locally and formulating original ideas for the way forward to branches, and Local Executive Committees (LEC), overseeing branch financial assets to ensure sufficient funding was available for services identifies by LACs. ¹²⁵

The society presented itself by the mid-1990s as a consumer-driven organization. It believed the "original concept of charity had long been outgrown. Today CCS is innovative and enterprising, supported by the community and acting as [a] lobby and conscience for those with disabilities." ¹²⁶ The Dunedin branch decided in 1994 to make financial membership compulsory for all its "consumers" so they would be legally entitled to a voice in how the society was organised. Until then, only about fifty of its approximately 250 users paid the annual membership fee of \$10. ¹²⁷ The CCS consumer representative approved, arguing "that people need to become involved because otherwise the organization is just bureaucratic structure." Many of CCS's clients were used to people doing things for them, but "they can directly influence things if they're involved. It's not so much to do with physical disability as a mind-set and [a case of] negative dependency." ¹²⁸

The branch president was confident in 1994 that her call for "more consumer involvement in decision-making processes" had produced positive results. ¹²⁹ The society's 1995 anniversary history quoted John Sexton, the father of a boy with spina bifida, agreeing with this view. He recalled that "over the last 25 years, CCS has changed from doing things for people—that was the community attitude back then—to work[ing] with people who have disabilities and empowering them and their families. The key issue (and this is why CCS is so effective an

organization) is to ensure people with disabilities and their families receive information, education and advocacy." ¹³⁰ Several "consumers" and volunteers at the Dunedin branch's annual meeting in 1996 strongly disagreed. Despite the rhetoric, one felt that "consumers" were still being listened to in a very "tokenistic" way: "This organization is supposed to be run for us and our voice is not being heard. It needs to be changed. A lot of consumers are afraid to speak out and that's wrong." Others "voiced their anger about the lack of consultation." One "wheelchair-bound consumer" complained about the lack of consultation by the local board. She "did not believe her needs were catered for any longer" and intended to leave the society. 131 In retrospect, Judith Hyslop wonders whether the people with disabilities on the board were given sufficient support: "we had to be careful about tokenism." She recalls that although the consumer advocacy group had a representative on the branch board, to an extent "selective hearing went on"; the board "didn't want to hear the bad news." A CCS National Policy Review Project in 2002 acknowledged these "deficiencies in the way the organization makes and implements policy . . . and the way it encourages consumer participation and involvement." Consumers and their families felt "they [were] not being listened to" in regard to the development of policy, and held the "perception nothing will come of it"; "People do not see CCS as relevant."133

The society had evolved dramatically by the mid-1990s and now saw itself as a "lobby and conscience" for people with disabilities, and stressed innovation and enterprise. Yet this was more a change of emphasis than a total change of direction. From the outset the society had professed to support innovation in the treatment and training of disabled children, in advance of what was provided by the state. 135 "It is the function and privilege of the voluntary organization to go ahead pioneering the unknown fields, testing and exploring in ways which the State controlled body hesitates, and rightly so, to attempt," the Crippled Children Society stated in 1939. The society's advocacy role also dated to its earliest years. At the original meeting founding the Dunedin branch in 1935, one of its aims was declared to be the forwarding of any legislation which had as its aim the condition of crippled children. Almost sixty years later this was still important: the society lobbied for the inclusion of discrimination on the grounds of disability in the Human Rights Act of 1993, for example. In the same year, when the Disabled Persons Community Welfare Act of 1975 was repealed, CCS lobbied against its replacement, the Health and Disability Act, on the grounds that it would lead to the "re-medicalisation of disability."

Conclusion

Over its lifetime, CCS Disability Action has evolved and reinvented itself considerably. Originally run for disabled people by the able-bodied, the society now holds itself up as a "progressive, strong, inclusive national organization... very much a partnership organization working with disabled people, their whanau and families and the wider community as well as with government and other NGO's [sic]." Lady Gillies, involved with the society since the 1950s, sees the change as one from a philanthropic "charity emphasising personal interest in crippled children" to something more like a corporation. To many who lived through them, the major changes of the 1980s and 1990s still loom large. To some, a well-established, successful operation appeared to have been turned upside down for largely ideological reasons. Yet the Crippled Children Society had always been a much more flexible organization than many recognized, and had deliberately been designed that way in 1935: "the founders of the society preferred, very wisely, to regard it as a living organism rather than as an unchanging structure. An organism must either grow or perish." It moved with changes in the attitudes of wider society, but could not afford to be too far in advance of them if it was to retain public support. The Crippled Children Society has moved from a paternalistic, philanthropic and

charity-based model to an activist model in CCS Disability Action, influenced by and influencing societal changes in New Zealand throughout its history. Three foundational documents—the Treaty of Waitangi, The New Zealand Disability Strategy (2001) and the UN Convention on the Rights of Persons with Disabilities (2006)—form the basis for the future of the organization, a future which encompasses biculturalism and multiculturalism under the strategic leadership of disabled people and their supporters.¹⁴²

The Crippled Children Society was, from the start, dependent on state funding, and so was obliged to follow changes in government policy. These constraints complicate the picture of the social model of disability simply supplanting the medical model. The Society's Dunedin branch adopted the social model of disability by adapting in a pragmatic fashion to changes in the needs of its "consumers" and the demands of the political and social environment. As the society's sixtieth anniversary history proclaimed, "flexibility . . . has always been its strength." ¹⁴³

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¹ J. Renfrew White, alluding to Isaiah 40:4 and Luke 3:5, at the first public meeting establishing the Dunedin Branch of the Crippled Children Society, as reported in the *Otago Daily Times*, 1 May 1935, 8.

² Annual Report of the NZ Crippled Children Society, 1939–40, as quoted in Mathilde Schorer, "From the New Zealand Crippled Children Society to CCS Disability Action: A Social and Political History of a Disability Organisation in Aotearoa New Zealand Moving from Charity to Social Action" (MPhil thesis, Massey University, 2012), 86.

³ Until the early 1970s. For its history, see Dorothy Page, *Anatomy of a Medical School: A History of Medicine at the University of Otago 1875–2000* (Dunedin: University of Otago Press, 2008).

⁴ Margaret Tennant, *The Fabric of Welfare: Voluntary Organisations, Government and Welfare in New Zealand, 1840–2005* (Wellington: Bridget Williams, 2007), 215.

⁵ Judith Hyslop, interview by Austin Gee, 12 August 2014, author's personal copy.

⁶ For a concise review and discussion of the history of disability in New Zealand, see Hilary Stace, "Some Aspects of New Zealand's Disability History," three parts (2014–15) at

http://publicaddress.net/access/some-aspects-of-new-zealands-disability-history/

⁷ Susan Burch and Ian Sutherland, "Who's Not Yet Here? American Disability History," *Radical History Review* 94 (Winter 2006): 129.

⁸ Burch and Sutherland, "Who's Not Yet Here," 129.

⁹ Piotr Miexejewski, "Consumer Inclusion Within CCS Disability Action New Zealand" (MA thesis, University of Otago, 2009), 55.

¹⁰ Burch and Sutherland, "Who's Not Yet Here," 128.

¹¹ Margaret Tennant, "Disability in New Zealand: An Historical Survey," *New Zealand Journal of Disability Studies* 2 (1996): 14.

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- ²⁰ Schorer, "From the NZCCS," 34–35.
- ²¹ Schorer, "From the NZCCS," 35.
- ²² Schorer, "From the NZCCS," 37.
- ²³ Schorer, "From the NZCCS," 38.
 ²⁴ Schorer, "From the NZCCS," 48.
- ²⁵ Mihi Ratima. "Kia uruuru mai a hauora: Being healthy being Māori, conceptualising Māori health promotion" (PhD thesis, Otago University, 2001), quoted in Keri Ratima and Mihi Ratima, "Māori Experience of Disability and Disability Support Services," in Haura: Māori Standards of Health IV. A Study of the Years 2000–2005, ed. B. Robson and R. Harris (Wellington: Te Ropu Rangahau Hauoria a Eru Pomare, 2007), 189.
- ²⁶ Schorer, "From the NZCCS," 151.
- ²⁷ Tennant, *Fabric of Welfare*, quoted in Schorer, "From the NZCCS," 42.
- ²⁸ In contrast, its Australian counterpart was named the Crippled Children's Society.
- ²⁹ Tennant, "Disability in New Zealand," 5, 19.
- ³⁰ Schorer, "From the NZCCS," 79, 80n.
- ³¹ Otago Daily Times, 1 May 1935, 8; Schorer, "From the NZCCS," 84.
- ³² Henry E. Carey, The History of the New Zealand Crippled Children Society's First Twenty-Five Years: 1935–1960 (New Plymouth: The Society, 1961), 6, 11.
- ³³ Edward G. A. Frost, *Rotary Club of Wellington: The First 25 Years 1921–1946* (Wellington: The Club, 1960), 83, quoted in Schorer, "From the NZCCS," 82.

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- ³⁶ Schorer, "From the NZCCS," 81.
- ³⁷ Minutes of the Public Meeting of Citizens for the Forming of a Crippled Children Society, Dunedin Branch (30 April 1935; all archival records relating to the Dunedin branch of the Crippled Children Society referenced in what follows [annual reports and minutes from meetings] are held at the CCS Disability Otago/Dunedin Branch, 514 King Street, North Dunedin).
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- ³⁹ Tennant, Fabric of Welfare, 115.
- ⁴⁰ Tennant, Fabric of Welfare, 101.
- ⁴¹ Schorer, "From the NZCCS," 83.
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- ⁴⁶ The 1935 Labour Government established the principle of state subsidies for private charities.
- ⁴⁷ Obituary, [James] Renfrew White, *British Medical Journal* (27 January 1962): 266; Page, *Anatomy* of a Medical School, 92–93; Seyed B. Mostofi, Who's Who in Orthopedics (London: Springer, 2005), 357.
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- ⁴⁹ Minutes of the Public Meeting of Citizens for the Forming of a Crippled Children Society, Dunedin Branch (30 April 1935; records held at the CCS Disability Otago/Dunedin Branch). 112
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- ⁵⁵ Tennant, Fabric of Welfare, 100.
- ⁵⁶ Tennant, "Disability in New Zealand," 5.
- ⁵⁷ Carey, First Twenty-Five Years, 3.
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- ⁶¹ J. Renfrew White, quoted in Otago Daily Times, 1 May 1935, 8.
- ⁶² Tennant, Fabric of Welfare, 101.
- ⁶³ Minutes of the Vocational Guidance Committee, Crippled Children Society, Dunedin Branch (28 August 1935; records held at the CCS Disability Otago/Dunedin Branch).
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- ⁶⁸ Otago Daily Times, 1 May 1935, 8.
- ⁶⁹ Annual Report for the Year Ended 31 March 1959 (Crippled Children Society, Dunedin Branch; records held at the CCS Disability Otago/Dunedin Branch).
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- ⁷² Schorer, "From the NZCCS," 92–93.
- ⁷³ Annual Report for the Year Ended 31 December 1981 (Crippled Children Society, Dunedin Branch; records held at the CCS Disability Otago/Dunedin Branch).
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- ⁸³ Annual Report for the Year Ended 31 December 1983 (Crippled Children Society, Dunedin Branch; records held at the CCS Disability Otago/Dunedin Branch).
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- ⁹⁵ For example, People First New Zealand (1984), the Disabled Persons Assembly (1983), Nga Hau E Wha, and Ngati Kapo O Aoteoroa Inc (1983).
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- ¹⁰⁸ Judith Hyslop, interview by Austin Gee, 12 August 2014.
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