

Story: Care and carers

Page 4. Care of people with disabilities

In the mid-19th century, the care of children and adults with physical disabilities such as cerebral palsy, intellectual disabilities or mental illnesses was considered the responsibility of family. Those who were not seriously impaired often went to school or work, or helped at home. Because medical treatments of coexisting conditions such as epilepsy were rudimentary or non-existent, many people with serious disability had short life expectancies.

Care of people with intellectual disabilities

Psychiatric illness and intellectual disabilities were not officially acknowledged to be different conditions until 1911. From the 1860s affected people were often 'put away' permanently in asylums, which were deliberately built in remote areas. In the early 20th century, when the pseudo-science of eugenics became fashionable, the belief that intellectual disability was hereditary was common. It became government policy to segregate those defined as 'intellectually handicapped', to prevent them having children and to control disruptive behaviour.

Far from home

Conditions in hospitals for the people with intellectual disability were anything but home-like. One resident of Templeton from the late 1920s remembers, 'There were 106 in the dormitory and they only had four windows, just that much open so you couldn't climb out ... I didn't have any clothes of my own, not even underclothes. I didn't have anything of my own.'¹

Residential schools were established to teach work skills to children with mild disability, such as a boys' school at Ōtekaieke near Ōamaru which opened in 1908, and a girls' school at Richmond near Nelson which opened in 1916. For more serious cases, psychopaedic units were set up, notably Stoke Villas at Nelson Mental Hospital in 1922, Templeton near Christchurch in 1929 and Levin Training Farm and Colony in 1945. Parents were pressured to put their children into residential care, on the grounds that this was better both for them and for other family members. Those who chose to keep children with intellectual disabilities at home received no support services. Adults with intellectual disabilities who had grown up at home were often sent to mental or psychopaedic hospitals after one or both parents died or became incapable of looking after them.

Care for those with physical disabilities

In the 19th century adults with serious disability who were without family support were often admitted to benevolent institutions for the elderly poor. Later, a few homes were established specifically for this group, such as the Elizabeth Knox Home and Hospital in Auckland, which opened in 1914.

There was greater community acceptance of physically disabled people. If the disability had occurred as the result of an accident or infectious disease, both of which were common in the 19th century, it tended to be viewed sympathetically. Large-scale events such as the [First World War](#), which permanently injured many young men, and the polio epidemics of the 1920s, 1930s and 1940s, which afflicted children in particular, heightened public awareness.

Laura Fergusson Trust

In the 1960s the governor-general's wife was shocked to see many young disabled people in geriatric wards. She initiated the Laura Fergusson Trust in 1967. In the following decade, trust homes were founded in Auckland, Wellington and Christchurch. In the 21st century the trust continued to provide residential facilities, but also supported-living options, with a strong emphasis on rehabilitation.

Some institutions concentrated on integrating people into everyday life. Residential schools were established for blind and deaf children in the late 19th century to teach them literacy and occupational skills. After the First World War there was state-funded medical treatment and rehabilitation for injured soldiers in convalescent homes and hospitals.

Home care services

The Crippled Children's Society (now CCS Disability Action), set up in 1935 to support physically disabled children, established the Wilson residential home in Auckland. From 1940 it focused on providing services to children in their own homes. From the 1950s local IHC branches established day-care centres, and hostels for short- or long-term care for intellectually handicapped people.

Apart from these initiatives, there were few support services for disabled people living at home before the 1970s. The Disabled Persons Community Welfare Act 1975 was a landmark piece of legislation, giving practical assistance to disabled people and those looking after them, including loans for motor vehicles and home alterations. From that time, hospital boards began providing a wider range of home aids.

Supported living

Growing opposition to large institutions amongst professionals and consumer groups led to a policy of deinstitutionalisation. Between the 1980s and early 21st century, nearly all mental hospitals and psychopaedic units such as Templeton and Kimberley (formerly the Levin Training Centre) closed. Some former patients went to live with family. Others lived together as flatmates with support from community organisations and trusts. Seriously physically disabled people were provided with supported-living options by organisations such as the Laura Fergusson Trust.

Home and community support

People with disabilities can receive funding for paid services they need in order to continue living in their own homes through the Home and Community Support programme. People are paid an hourly rate to provide personal services such as showering, dressing, and assistance with eating. These people work for home and community support service organisations that are contracted to provide these services by the Ministry of Health.

In support of supported living

Although some families were apprehensive about community care for their intellectually disabled children, the reality was often a pleasant surprise. One parent recalled, ‘On our first visit to the group home we went to the front door and instead of having somebody go to the office and sign in and then phone over, and somebody else opening the door, we just went up to the door and rang the doorbell... opened the door and said: “May we come in?” and someone said, “The kettle is on.”’²

Funded Family Care

In 2013 the government introduced funding for care by parents or other **whānau**/family members (but not spouses, or civil union or de facto partners) for people aged over 18 with high or very high disability needs who require assistance with things like eating, showering, dressing, cleaning and cooking.

This policy was introduced after the Human Rights Commission argued that prohibiting family members from receiving payments to care for disabled family members was discrimination on the basis of family status, and illegal under the Human Rights Act 1993.

The family member with disabilities is assessed and a service plan is developed for the assistance that is required. Under this scheme, people with disabilities become the employer of family members in their home. The person with the disability is funded to pay the caregiver the minimum wage for their work and also meet the costs of Accident Compensation payments, Kiwisaver contributions and the wages of a substitute carer when family members take leave.

Disputes about Funded Family Care

Parents who care at home for adult children with severe physical and intellectual disabilities have contested decisions by the Ministry of Health about the hours for which they are eligible to receive funding. In February 2018 the Court of Appeal ruled that the Ministry of Health should make it easier for parents to apply for funding to care at home for disabled adult children with high or very high needs.³ The court upheld an appeal by a parent and her severely disabled son who argued that the Ministry of Health should fund her, not only for the personal care and household management she provided, but also for the intermittent care her son required 24 hours a day.

Those caring for adult children at home have also asked why the 2017 pay equity settlement for aged-care workers did not apply to parents caring for adult children with severe disabilities. Their rates of pay remained at the minimum wage, while paid carers in rest homes received wage increases.⁴

Footnotes:

1. Julia Millen, *Breaking barriers: IHC's first 50 years*, Wellington: IHC New Zealand Inc/Bridget Williams Books, 1999, p. 5.

2. *Breaking barriers*, p. 92.
 3. *Shane Barry Chamberlain & Diane Moody v Minister of Health* [2018] NZCA 8, (last accessed 21 March 2018).
 4. 'Anger at exclusion from new caregiver pay rise', *Radio New Zealand*, 19 April 2017, (last accessed 21 March 2018).
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