Disability and disability organisations by Martin Sullivan

In the past, many people with disability were excluded from participation in education, employment, sport and many leisure activities. Since the 1970s attitudes to disability have been changing. Disabled people have increasingly advocated for themselves and run their own organisations. They now represent their country in sport and succeed in many fields. About 24% of New Zealanders have some form of disability.

Care until the early 20th century

Until the 20th century disabled people were usually cared for by their families. Those with severe conditions might receive hospital care, while those with psychiatric disabilities often ended up in asylums. A few people with disability were reduced to making their living on the streets, doing things such as busking.

Accidents

During the 19th century accidents and injuries were a leading cause of disability. Some industries like forestry and mining were very dangerous, and loss of limbs or senses from events such as falling trees or rocks, or mine explosions, were relatively common.

First organisations

Slowly organisations were formed to care for people with disabilities. These included the Sumner Deaf and Dumb Institution in Christchurch (now the Van Asch Deaf Education Centre). Founded in 1880, it was the world's first government-funded residential school for the training of deaf people who could not speak. In 1890 the Jubilee Institute for the Blind was opened in Auckland. It was a residential home built and maintained by private interests using public funds.

Although attitudes to residents were sometimes oppressive – for example sign language was banned at Sumner – these two institutions were important in providing sites where deaf and blind people could develop their own cultures. It was from these beginnings

that two important organisations of people with disabilities developed – Deaf Aotearoa New Zealand and the Association of Blind Citizens.

Home of Compassion

Some organisations were church-based. In 1899 Mother Mary Joseph Aubert and her Sisters of Compassion moved to Wellington, from their previous base at Jerusalem, on the Whanganui River, and founded the St Joseph Home for Incurables (the chronically and terminally ill) at Island Bay. This was followed in 1907 by the Home of Compassion, which cared for children with a variety of disabilities, including spina bifida, Down syndrome and cerebral palsy.

State care

The state followed in 1910, when hospital and charitable aid boards were amalgamated, and old people's homes became convenient dumping grounds for physically disabled people of all ages.

War

The state also became heavily involved in providing care for those disabled by war. The issue came to the fore during the South African War (1899–1902), to which New Zealand sent forces. Premier Richard Seddon declared that the state would employ those able to work and a state pension would be available to those who could not. During the First World War more than 1,000 New Zealand men had their limbs amputated. Artificial limbs were expensive: wooden legs cost £22 each at a time when the average skilled wage was £2 per week.

War wounded

In 1919 there were 39 men receiving permanent pensions for total disablement resulting from war injuries. In Christchurch they included 'two single men who have suffered the amputation of both legs ... [Another] has lost the left eye, the left leg and the right thumb, and has a shell wound in the right hand.' By 1924 the number of servicemen on permanent pensions had risen to 1,078.

Convalescence

The state took the main role in caring for men disabled by war. In 1919 part of Trentham Army Camp was converted into an orthopaedic hospital capable of caring for 700 patients. Convalescent homes were opened in Rotorua and Hanmer. Smaller homes for patients with severe disabilities operated in Wellington and Auckland. A number of returned soldiers suffering from shell shock (post-traumatic stress disorder) were sent to asylums.

Some servicemen with disabilities made an important contribution to national life, including John A. Lee, a writer and influential Labour politician, who lost an arm in the First World War.

Footnotes

Poverty Bay Herald, 5 December 1919, p. 8. Back

Ideas about disability care

Benevolence

Disability organisations were shaped by ideas of their day. In the 19th century responses to disability were based on charity and benevolence. Organisations such as the Sumner Deaf and Dumb Institution provided services and care to those with severe disabilities.

Medicalisation

During the 20th century the approach to disability was medicalised, reflecting the growing power of doctors and welfare professionals in the sector. Disability was seen as something that might be cured through medical intervention. If the cure was only partial, then rehabilitation experts stepped in to help the individual operate within mainstream society. If the disability could not be cured, then the individual was very often sent to be cared for in specialised institutions apart from society.

Disability organisations that formed during this period – such as the Intellectually Handicapped Children's Parents Association (which became IHC) – often began as feisty organisations fighting for the rights of people with disability. But by the late 1950s they had become professionalised, medicalised, controlled by people without disabilities and seen by some as autocratic and paternalistic.

Social model

From the 1970s disabled people developed their own model of disability: the social model. It argued that individuals had impairments rather than disabilities and redefined disability as the negative social response to impairment. The model argued that 'disablist' attitudes restricted people with impairments from fully participating in society. Disability could be eliminated by creating a non-disabling society.

Deinstitutionalisation

Impairments not disabilities

In the late 20th century people with disabilities redefined the term disability. According to a 2001 government report: 'Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments.

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Such thinking led to the deinstitutionalisation of disabled care. Specialist institutions were closed and residents placed back with families or put in small residential-care facilities in existing communities. Students with a disability were integrated into mainstream schools. Support was provided by specialist service providers, who visited homes and worked in schools.

Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have.'

21st-century reforms

In the early 21st century the government introduced a minister and an Office for Disability Issues, which engaged people with disabilities and their organisations in making public policy. The Office of Disability Issues has the goal of creating a 'non-disabling society' – a place where people with disabilities have equal opportunity. It has the responsibility to guide the work of other government agencies on disability issues between 2016 and 2026. It also works with employers and businesses to achieve goals of the United Nations Convention on the Rights of Persons with Disabilities (2007). This government agency liaises with community organisations supporting people with disabilities.

Other new initiatives included:

- The New Zealand disability strategy, which aimed to create a non-disabling society
- the passing of the New Zealand Sign Language Act 2006, making sign language an official language in New Zealand
- the repeal of the Disabled Persons Employment Promotion Act 1960, which had created sheltered workshops and low pay rates for workers with disabilities
- the 2006 closure of the Kimberley Centre near Levin, the last remaining institution for people with disabilities in New Zealand.

Footnotes

• The New Zealand disability strategy: making a world of difference. Wellington: Ministry of Health, 2001, p. 1. Back

Organisations for people with disabilities

Organisations for people with disabilities have been typically organised and controlled by non-disabled people, although many now have disabled people in leadership and governance roles.

Royal New Zealand Foundation of the Blind (RNZFB)

Beginning as the Jubilee Institute for the Blind in Auckland in 1890, the RNZFB provided services to blind, blind and deaf, and vision-impaired people. Its Parnell home provided sheltered workshops where blind people were employed and housed. The late-20th-century fashion for deinstutionalisation led to the home's closure. In 2002 new legislation made the organisation more accountable to its nearly 12,000 members. In 2019 its name changed to Blind and Low Vision NZ.

All in the name

Under the Royal New Zealand
Foundation of the Blind Act 2002,
full members (who had to be blind
or vision-impaired) would elect
eight out of the 11 board directors.
It also changed the organisations
name from 'for the Blind' to 'of the
Blind' which for many 'symbolise[d]
a move from paternalism to selfgovernance in the blind world.' 1

National Foundation for the Deaf (NFD)

Formed in 1978, the NFD is an umbrella organisation for groups representing the interests of nearly half a million deaf and hearing-impaired people. It tries to break down barriers faced by people with hearing loss.

CCS Disability Action

Until the discovery of a vaccine for poliomyelitis (polio) in 1952, periodic polio epidemics left thousands of children with paralysed or weakened limbs. Frustrated by the lack of support services, orthopaedic surgeon Alexander Gillies founded the Crippled Children Society in 1935. Branches provided home support, vocational training and financial help. After polio was eradicated from New Zealand, the Society cared for and supported people with cerebral palsy. It was privately funded through an annual appeal which used images of waif-like crippled children. Other funding came from lottery grants, membership subscriptions and legacies.

In the 1970s the society was criticised for its medicalised and paternalistic approach to disability. This changed in the 1980s when people with disability were elected to governance boards. In 1989 the CCS officially recognised the Treaty of Waitangi, entered into a partnership with Māori, and changed its name to New Zealand CCS. In the 21st century disabled people were more influential in the organisation and there was an increased focus on advocacy. This was reflected in its new name – CCS Disability Action.

IHC New Zealand

The Intellectually Handicapped Children's Parents Association (IHCPA) was founded in 1949 by Harold and Margaret Anyon. Their son Keith had Down syndrome, but they

had refused to institutionalise him. The barriers to his education in mainstream schooling led to children's rights being a central concern of IHCPA.

The IHCPA was against institutionalisation, promoting short-term residential care instead. But the government was reluctant to support community-based care, and the number of places in institutions for intellectually disabled people increased from 550 to over 2,000 between 1952 and 1969. IHC continued to push for community-based services and in 1989 it helped to win the right for all children to be locally schooled.

In 1994 the organisation became IHC New Zealand and an advocacy advisory committee was established in 2000 to coordinate its advocacy functions. IHC was restructured in 2005 into IDEA Services (needs assessment, residential and respite care) and Timata Hou (crisis respite services as well as living and work support).

Autism New Zealand

Autism New Zealand was started in 1969 as a support group for parents of children with autism. It was originally part of IHC but became an independent society in 1995. Autism was considered a rare condition in the 1960s, affecting about one in 10,000 children. By the 21st century autism was associated with a wide spectrum of psychological conditions affecting about one in 100 people. Autism New Zealand runs social-skills and music-therapy workshops, and has a network of regional branches.

Footnotes

 Peter Beatson, The disability revolution in New Zealand: a social model. 3rd ed. Palmerston North, School of Sociology, Social Policy and Social Work, Massey University, 2004, pp. 503–504. Back

Sports organisations

Paralympics New Zealand

Paralympics New Zealand is the national sports organisation for athletes with disabilities. It began in 1965 and encourages athletes with disabilities to compete at the international Paralympic Games. It provides a coaching development and accreditation scheme, organises national and international sport meets, and has a schools programme.

Special Olympics New Zealand

This organisation was founded in 1983 for athletes with intellectual disability to boost their skills and confidence. In that year a team from New Zealand competed for the first time in the Special Olympics at Baton Rouge, in the US. The first national games were held in Lower Hutt in 1985. Athletes regularly compete at national and world summer games. In the 2010s there were about 7,000 athletes with intellectual disabilities training and competing throughout New Zealand.

Winning gold

At the 2010 Vancouver Winter
Paralympics New Zealand skier
Adam Hall – born with spina bifida
– recovered from a mid-race fall to
win gold in the standup slalom.

Deaf Sport Federation of New Zealand

The Deaf Amateur Sports Association was formed in 1963 and became the Deaf Sport Federation of New Zealand in 2001. It is an affiliated member of the International Committee of Sports for the Deaf, and operates as an umbrella organisation for deaf sport associations including cricket, netball, golf, darts, indoor and lawn bowls, basketball and tenpin bowling. The annual New Zealand Deaf Games is the largest part of the Deaf Sport Federation of New Zealand. New Zealand hosted the 16th Deaflympics (World Games for the Deaf) in Christchurch in 1989.

Disabled peoples organisations

Disabled peoples organisations are organised for and by disabled people.

Disabled Persons Assembly (DPA)

Formed in 1983, DPA is an umbrella organisation representing disabled people. In the 2010s it advocated on behalf of its 300 organisational and 1,200 individual members, and offered them advice. Most members on the national executive were disabled.

DPA has led negotiations on disability issues with government. It influenced the Human Rights Act 1993 and the Disabled Persons Employment Promotion Repeal Act 2007 – which abolished sheltered employment and gave people with disabilities the same employment conditions, rights and entitlements as other workers.

Ngāti Kāpo o Aotearoa

This Māori health and disability organisation for Māori disabled (kāpo Māori) was founded in 1983. In the 2010s it had over 15 regional Ngāti Kāpo rōpu (groups) and provided support 'by kāpo Māori and their whānau for kāpo Māori and their whānau.' Ngāti Kāpu activities include peer support,

Gaining representation

A central aim of ABC was the promotion of blind people into Royal New Zealand Foundation for the Blind management, long dominated by sighted people. An

policy advice, advocacy, public awareness, workforce development, research and training.

Blind Citizens New Zealand

Blind Citizens NZ was founded in 1945 (as the Dominion Association of the Blind) to advance the interests of blind people. Only blind people could be members. In contrast to the 1950s paternalism of the Royal New Zealand Foundation for the Blind, Blind Citizens NZ was about 'blind people speaking for ourselves'. Its achievements have included:

acrimonious debate between management and reformers in 1978 led to a protest march along Auckland's Queen Street and strident calls for the government to intervene. In 1980 the government appointed Don McKenzie and Michael Turner as blind representatives to the foundation's board.

- the 1958 abolition of the means test for blind people applying for the invalid's benefit
- beginning talking-book services, radio for the blind, and magazine taping
- training members to use speech and Braille programmes on computers.

Aotearoa Network of Psychiatric Survivors

This network was created in 1990 to support users of mental health services and improve the mental health system. It lobbied for deinstitutionalisation of care and community-based housing for former patients. Changes in government funding in the early 1990s led to its decentralisation into four regional networks.

Deaf Aotearoa New Zealand (DANZ)

Formed in 1977, DANZ promotes deaf culture, New Zealand Sign Language and the interests of deaf people. It withdrew from the National Foundation for the Deaf in 1998 because it did not believe the foundation was adequately representing deaf interests or identity. DANZ's governing body is elected from the deaf community by deaf people.

People First

People First (PF) is the self-advocacy organisation of people with learning disabilities. Originally the organisation was under the wing of IHC, but in 2003 PF declared its independence and established a separate office. IHC was still heavily involved in supporting a national network of PF groups, but these were controlled by PF, not IHC.

Footnotes

Free as a butterfly

In 2009 the Deaf Association of New Zealand changed its name to Deaf Aotearoa New Zealand and adopted a new logo incorporating a butterfly. Butterflies are seen as free, independent and liberated - as the association believes deaf people are when they have sign language.

Disability and disability organisations

- 'About us Mo Matou Ra.' Ngāti Kāpo o Aotearoa, (last accessed 26 May 2010). Back
- 'About Blind Citizens NZ.' Blind Citizens New Zealand, (last accessed 12 July 2018). Back

Patterns of disability

Although a child with intellectual disability or a blind adult with a seeing-eye dog are often the public face of disability, those with severe disabilities are a relatively small proportion of people with disability – around 12%. A more representative image would be someone on a mobility scooter or an elderly person receiving help with heavy housework from a paid caregiver. 2013 research identified that about 24% of New Zealanders lived with disability.

Disability rates

A 2013 disability survey provided a snapshot of disability in New Zealand.

Age

The proportion of the population with disability increased with age: 11% of children (aged 0-14) had a disability, compared to 59% of adults aged over 65. One-third of people with a disability were over 65.

Gender

Overall, males and females had the same disability rate (24%), but the difference between boys and girls was pronounced (13% of boys compared to 9% of girls).

Ethnicity

Māori had the highest rate of disability (24%), followed by Europeans (18%) and Pacific people (17%). The rate for Asian and other ethnicities was 13%.

Adult disabilities

The most common disabilities in adults were:

Footpath hazard?

Between 2005 and 2010, 10 elderly people were killed and 19 seriously injured in mobility scooter crashes and accidents, leading some to argue for a form of driver assessment. Nelson transport official Margaret Parfitt said it was 'a little intriguing to see somebody with a white cane on a mobility scooter.' The Ministry of Transport acknowledged mobility scooters were an 'emerging focus for road safety'. ¹

Disability and disability organisations

- mobility difficulty walking 350 metres (16% of the total population)
- hearing inability to hear a conversation (10%)
- agility inability to pick something up from the floor (9%)
- difficulty communicating and doing everyday activities due to a psychiatric or psychological condition (6%)
- difficulty remembering things (5%).

Apart from psychiatric or psychological disabilities, these disabilities were most common in older age groups. Multiple disabilities increased with age.

Child disabilities

In children the most common disabilities were:

- learning disabilities (such as dyslexia) that required use of special education (6% of all children)
- speaking disabilities (4%)
- psychiatric or psychological disabilities (4%).

Causes of disability

Disease and illness were the most common causes of disability in adults (42%), followed by accident or injury (34%) and then natural ageing (31%). In children, conditions present at birth were the most common causes of disability (49%), followed by disease or illness (25%).

Employment

Disabled people had a lower rate of employment than people without disability. In 2013, 50% of people aged 15 and over with a disability were in the labour force, compared to 76% of people without a disability.

Support needs

84% of adults and 86% of children with disability had low or medium support needs, such as for help with housework, meal preparation and shopping. Most people with disability lived in private homes; only 4% lived in residential care.

Workplace prejudice

While educational qualifications improved the chance of disabled people getting work, their participation rate was lower than that for equally qualified people without disability. People with psychiatric or psychological disability had a relatively low rate of labour-force participation, while those with sensory disability (seeing, hearing) had participation

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Accessible housing is often a struggle for those with mobility

rates close to those of people
disabilities. People disabled by accident can apply for funding
to modify their homes so that they are more accessible. Those
disabled through illness or congenital disabilities, or their
parents, can apply to the Ministry of Health for funding to make their homes more
accessible. This requires assessment by an occupational therapist. As housing costs
increase, disabled people needing accessible homes are finding it more difficult to meet
their housing needs, especially because they often have lower incomes than nondisabled people.

Footnotes

 Quoted in Lois Cairns, 'Mobility scooter rules stay despite death toll.' (last accessed 18 May 2010) Back

External links and sources

More suggestions and sources

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The New Zealand disability strategy: making a world of difference. Wellington: Ministry of Health, 2001.

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