

Where I Live; How I Live

Disability Support Services Community Residential Support Services Strategy, 2018 to 2020

Citation: Ministry of Health. 2018. *Where I Live; How I Live: Disability Support Services Community Residential Support Services Strategy, 2018 to 2020*. Wellington: Ministry of Health.

Published in March 2018
by the Ministry of Health
PO Box 5013, Wellington 6140, New Zealand

ISBN: 098-1-98-853941-6 (online)
HP 6766

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Foreword

It is an exciting time in the disability community – the transformation of the disability support system will improve the lives of people with disabilities and their families/whānau by offering more choice and control over the supports disabled people receive.

This strategy, *Where I Live; How I Live*, is about providing disabled people with choice, control and flexibility around where and how they live. It supports both the transformation of the disability support system and the Government’s commitment to the Enabling Good Lives (EGL) approach of empowering disabled people to make their own decisions about the supports they receive to live everyday lives.

This strategy also increases options for disabled people, their families/whānau/aiga to have opportunities that allow the greatest degree of freedom possible to meet their needs and have a good life. The strategy encourages access to information and support to enable disabled people to make choices.

Where I Live; How I Live draws heavily on feedback from disabled people, their families/whānau, disability organisations, advisory groups and providers about how community residential supports can be improved. We have considered this feedback and appreciate the time and effort taken to provide it. I now look forward to seeing disabled people being better able to exercise their self-determination and independence when deciding where to live and how to live.

Hon Julie Anne Genter
Associate Minister of Health

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Introduction

Families/whānau provide most of the living arrangements for their disabled family members. But what happens when the family/whānau experiences problems? Family/whānau relationships can break down; people providing support become older or their circumstances change; disabled people can't access the supports they need to remain in the family home? the disabled person might want to experience a more independent life and try living with their friends.

Community residential support services

For those who need non-family residential supports; small, community-based, family-like homes are now the norm. The Ministry of Health's Disability Support Services (DSS) funds community residential support services that provide eligible disabled people access to 24-hour support to enable them to live in a community environment. Generally, 'eligible disabled people' are those under the age of 65 years who have a long-term physical, intellectual and/or sensory impairment that requires ongoing support.

Residential support services provide a necessary level of support to enable eligible disabled people to experience a safe and satisfying home life. The provider organisations vary in size from a single residence with fewer than five people to large homes and groups of small homes or flats to organisations that coordinate multiple residences across the country. Larger facilities can also operate a number of specialist services, particularly supporting people with significant physical and medical needs.

The disability support system is in the process of transforming (System Transformation). Work is under way to ensure disabled people have more choice and control in the supports they receive and the lives they lead. This work is based on the Enabling Good Lives (EGL) vision and principles and is informed by evidence of 'what works'. The community residential support services strategy for 2018 to 2020, *Where I Live; How I Live*, is linked to System Transformation.

The transformation is in its early stages, and the new system will take several years to design, implement and embed. In the meantime, some changes are needed to community residential support services to provide disabled people with more choice (and flexibility) in the current system and more control over where they live and how they live.

The Community Residential Support Services Strategy

The vision of *Where I Live; How I Live* is to optimise the independence and self-determination of disabled people, in line with the Enabling Good Lives (EGL) principles.

It seeks to achieve the following high-level outcomes for adult disabled people and their families/whānau.

- Greater choice, control and flexibility over where and how disabled people live.
- Opportunities that allow the greatest freedom possible to meet day-to-day disability needs and to lead good lives.
- Access to information and support to enable well-considered choices about where and how disabled people live and receive support.
- Increasing independence and choice fostered by service providers.

The strategy also aims to improve options for disabled people whose complex support requirements present challenges to current services.

DSS's strategic direction prioritises greater choice, greater control and better outcomes for disabled people. *Where I Live; How I Live* seeks to align with these priorities.

In many cases, disabled people requiring access to 24-hour support have some choice about where they live and from whom they receive supports, but this choice is limited by a range of barriers, including:

- limited service options in some parts of the country
- providers being contracted to offer only one service option rather than a continuum of independent support options
- limited understanding of a full range of possible choices, with many families/whānau opting for the current residential support model due to its perceived increased safety (eg, staff are available 24/7).

Services are also limited and are being increasingly stretched as they seek to meet the needs of a growing number of disabled people with complex medical, physical, environmental and behavioural needs. In many cases, when existing placements become available disabled people may be required to move to alternative placements sometimes beyond their local area and at significant cost to all parties. Providers are delivering highly individualised support packages that require high levels of staffing to manage risks. At times, this can result in restrictive arrangements that are unsustainable and potentially undermine the disabled person's independence and freedom.

The disability support sector has been discussing alternative ways of supporting this group that focuses on safeguarding individuals, defining appropriate service models that provide value for money and developing services and workforce capacity and capability. Further development of these concepts along with the wider intent of the strategy will form part of the next steps of the community residential support services strategy.

Scope of the strategy

Where I Live; How I Live encompasses:

- community residential support services that are currently funded by the Ministry, including, but not limited to, services provided to eligible disabled adults with complex support requirements (ie, people with complex medical, physical, environmental and behavioural needs)
- workforce capacity and capability requirements.

The strategy does not cover residential support services for people who are primarily clients of:

- mental health services
- health of older people services
- palliative care
- services for children or young people in aged residential care.

It also does not deal with DSS eligibility criteria, Behaviour Support Services, services provided under the High and Complex Framework and the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, or funding levels.

The strategy does not seek to identify any single right way to provide residential care, nor does it seek to justify alternatives. In designing and developing a residential support system/model of residential care or accommodation support for disabled people, it takes into account the following considerations.

- International evidence indicates that currently most people enter residential care in early adulthood and remain in residential care for their life.
- Most disabled people with the highest disability needs are supported in residential care.
- Currently those with the highest need may not have any options but to remain in residential care, in which case the key challenge is to ensure they have as much choice and control as possible.
- A residential support option is important for some disabled people who are unable to remain living at home.
- Trends indicate a move towards supported independent living in the community.
- People who have lived in residential facilities for many years may need more intensive support to make their own choices.
- The Ministry has an important role in funding residential care for disabled people.
- There will be key policy and commissioning issues and challenges for the future of residential care that need to be identified and considered as part of System Transformation.
- There are significant differences in providing services for adults as opposed to children or young people.

Principles

The principles of *Where I Live; How I Live* are based on those developed for EGL and the DSS Tier One Service Specification. The EGL principles are as follows.

- **Self-determination** – disabled people are in control of their lives.
- **Beginning early** – invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.
- **Person-centred** – disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.
- **Ordinary life outcomes** – disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation – like others at similar stages of life.
- **Mainstream first** – disabled people are supported to access mainstream services before specialist disability services.
- **Mana enhancing** – the abilities and contributions of disabled people and their families are recognised and respected.
- **Easy to use** - disabled people have supports that are simple to use and flexible.
- **Relationship building** – support, build and strengthen relationships between disabled people, their whānau and community.

In addition to the above, there are currently principles within DSS provider contracts which state that people:

- are individuals who have the inherent right to respect for their human worth and dignity
- have the right to live in and be part of their community
- have the right to realise their individual capacities for physical, social, emotional and intellectual development
- have the same rights as other members of society to services, which support their attaining a reasonable quality of life
- have the right to make choices affecting their lives and to have access to information and services in a manner appropriate to their ability and culture
- have the same rights as other members of society to participate in decisions which affect their lives
- have the same rights as other members of society to receive services in a manner which results in the least restriction of their rights and opportunities
- have the right to pursue any grievance in relation to services without fear of the services being discontinued or any form of recrimination.

Strategic context

Where I Live; How I Live aligns with the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the Treaty of Waitangi. Its strategic framework embraces the New Zealand Health Strategy,¹ He Korowai Oranga (the Māori Health Strategy),² the New Zealand Disability Strategy 2016–2026,³ the vision and principles of Enabling Good Lives⁴, and the work programme of System Transformation.⁵

It is also linked at an operational level with a number of other Ministry, DSS and other government department action plans, including:

- Whāia Te Ao Mārama 2018–2022: The Māori Disability Action Plan
- Faiva Ora 2016–2021: National Pasifika Disability Plan⁶
- Disability Action Plan 2014–2018: Update 2015⁷
- The Health and Disability Kaiāwhina Workforce Action Plan⁸
- Transforming Respite: Disability Support Services Respite Strategy 2018 to 2022.⁹

1 See: www.health.govt.nz/system/files/documents/publications/new-zealand-health-strategy-futuredirection-2016-apr16.pdf

2 See: www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga

3 See: www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/pdf-nz-disability-strategy-2016.pdf

4 See: www.enablinggoodlives.co.nz/about-egl/egl-approach/

5 See: www.health.govt.nz/our-work/disability-services/disability-projects/disability-support-system-transformation

6 See: <http://www.health.govt.nz/publication/faiva-ora-2016-2021-national-pasifika-disability-plan>

7 See: www.odi.govt.nz/assets/Disability-action-plan-files/disability-action-plan-2014-2018-update-2015.pdf

8 See: www.workforceinaction.org.nz/wp-content/uploads/sites/2/2016/05/Kaiawhina-Workforce-Action-Plan.pdf

9 See: www.health.govt.nz/publication/transforming-respite-disability-support-services-respite-strategy-2017-2022

Stakeholder engagement

This strategy has been developed with engagement from key stakeholders. Methods for engaging with the stakeholders have included:

- meetings with disabled people and key providers to inform the strategy scope of change
- presentations and workshops with providers
- information on the Ministry's website about the objectives and scope of the proposed development work
- meetings with other government agencies to explore areas of joint interest
- targeted consultation on a draft strategy
- communication with other teams within the wider Ministry.

The development also included:

- a review of how community residential support services are provided overseas
- a literature review to identify best practices in providing community residential support services
- ensuring alignment with the New Model, EGL and work already completed in System Transformation.

Background to the strategy's development

Over the last 50 years, there has been a significant change in the services provided to and attitudes towards people with disabilities. New Zealand has moved from a 'medical model' to a 'social model' of disability support. Disabled people are no longer seen as having an illness or disease that requires medical services (including institutions). Instead they are respected as having rights equal to those of all other members of society, including the right to live in the community and live lives that are free from attitudinal and environmental barriers.

The New Zealand Disability Strategy was first published in 2001 (and updated in 2016) with an aim of eliminating such barriers, increasing the value of disabled people's lives and encouraging communities that enhance participation for all members. It recognised the discrimination and marginalisation that exists for people with intellectual disability.

As a result of changing attitudes, large-scale institutional care for people with intellectual disabilities came to an end in 2006 with the closure of the Kimberley Centre.¹⁰ Institutions were replaced by a range of community-based residential options; largely group homes, where people with a range of disabilities shared facilities and resources and could access 24-hour support. However, submitters to the 2008 Social Services Committee's Inquiry into the Quality of Care and Service Provision for People with Disabilities, were concerned that many people with disabilities living in residential facilities had limited choice in and control over their lives.¹¹

In 2009, in response to this concern, DSS developed a New Model for supporting disabled people. This model resulted in a range of actions focused on providing disabled people with greater choice, control and flexibility and developing new models of individualised funding (Enhanced Individualised Funding – EIF) and initiatives such as Local Area Coordination and Choice in Community Living (CiCL).

System transformation

In July 2017, a group of disabled people, families/whānau, service organisations and officials completed a high-level design of a transformed disability support system. The design reflects the wide diversity among disabled people and their families/whānau and for this reason, is more likely to be effective.

The new system builds on what we have learned from EGL demonstrations in Waikato and Christchurch and innovative practices from within New Zealand and overseas. We have learnt a lot about what works and what doesn't. The new system will differ from what's gone before.

- Disabled people and whānau will have more choices and opportunities, and control over their support and their lives.

¹⁰ See: www.health.govt.nz/system/files/documents/publications/resettlement-of-kimberley-residents.pdf

¹¹ Social Services Committee. 2008. *Inquiry into the Quality of Care and Service Provision for People with Disabilities: Report of the Social Services Committee*. Wellington: New Zealand House of Representatives. URL: www.parliament.nz/en/pb/sc/reports/document/48DBSCH_SCR4194_1/inquiry-into-the-quality-of-care-and-service-provision (accessed 26 October 2017). Note: These concerns were also reported in: National Advisory Committee on Health and Disability. 2003. *To Have and 'Ordinary' Life: Kia wha oranga 'noa'*. Wellington: Ministry of Health.

- It will transform the existing system rather than adding a new layer. The EGL demonstrations and other initiatives targeted small groups operating in parallel or as add-ons, contributing layers and at times, complexity. The transformation will replace what currently exists in a whole of system change.
- It is cross-government and will enable disabled people and whānau to receive seamless government disability support. The transformation is about identifying and offering an ideal experience that government agencies will seek to deliver for disabled people and their families and whānau.

However, the transformation of the system is in the early stages, and it will take several years to refine the detailed design and implement and embed that design across the country. In the meantime, some changes are needed to community residential support services to increase options so that disabled people can exercise more choice (and have more flexibility) in the current system and have more control of where they live and how they live.

For more information, see the EGL website: www.enablinggoodlives.co.nz/system-transformation/

Current state of community residential support services

Trends in residential care

Families/whānau continue to provide most of the living arrangements for their disabled family members. For those who need non-family residential supports, small, community-based, family-like homes are now the norm. The Ministry has seen a number of important trends, including:

- an increasing emphasis on community presence and participation
- a greater proportion of people with higher and more complex needs requiring higher levels of support
- young people transitioning to residential support services due to a lack of alternative support options
- disabled people and their families/whānau demanding more choice, control and flexibility over residential supports
- disabled people having a better quality of life.

Profile of people living in community residential support services

The Ministry currently spends over \$520 million per annum in purchasing community residential support services. Nationwide, there are currently 97 providers who hold community residential contracts and 13 providers who offer residential support services for children and young people.

In the Ministry demographic report on client's allocated DSS services as at September 2016,¹² there are approximately 6,600 people living in community residential support services with a further group of less than 1,000 living in hospitals or rest homes. Of the disabled people in residential care, 77 percent are New Zealand European/other and 15 percent are Māori. The Pacific and Asian populations are significantly underrepresented in residential care settings compared with the general population (3% and 2% respectively).

People with learning/intellectual disabilities account for around 82 percent of the people in residential services (see Appendix 1: Current community residential care options in New Zealand).

¹² Ministry of Health. 2017. *Demographic Report on Clients Allocated the Ministry of Health's Disability Support Services as at September 2016*. Wellington: Ministry of Health.

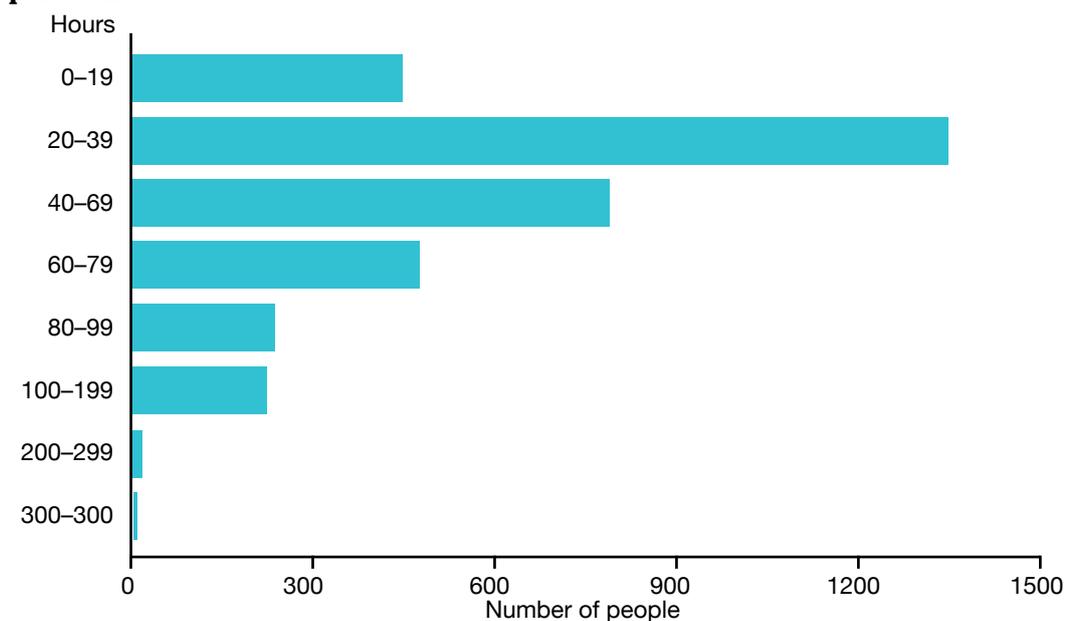
Other key observations

- The median age of community residential clients is currently 48 years, one year older than the median age in 2014.
- There are significantly more males than females using community residential support services, although this imbalance has reduced from 59 percent males in 2013 to 57 percent in 2016.
- The largest group using community residential support services is people in the 45–54 years age group for both males and females.
- The proportion of people aged under 30 years living in community residential support services has reduced from 20 percent (of the entire population of people accessing community residential support services) in 2013 to 14 percent in 2016.

People currently in community residential support services by assessed hours of support

Figure 1 shows the profile of users currently in community residential support services by assessed hours of support, (broken down into ranges/service streams).¹³ Further investigation and analysis needs to be done for each of the streams to better understand what opportunities there would be to support a move to greater independence.

Figure 1: Number of community residential support service users by assessed hours of disability support per week



Hours	0-19	20-39	40-69	60-79	80-99	100-199	200-299	300-400
People	446	1,349	789	475	235	222	16	5

Note: People requiring more than 168 hours of support per week are those who for part of the day need more than one staff member allocated.

¹³ Derived from Ministry of Health Disability Support Client Database (Socrates) 2017.

Services provided

Service providers work to ensure that people with disabilities:

- have a range of opportunities to foster relationships and to maximise their inclusion and participation in the community, both within and beyond the service
- are supported to achieve their goals, engage in life-enhancing activities (including those that may involve a degree of risk), have opportunities for learning and employment and participate in family/whānau and social life – just like other people who are at similar stages of their lives. This requires the support of skilled staff who respect people’s individuality, dignity and privacy and are sensitive and supportive of their aspirations, wellbeing and needs.
- are supported by staff who understand the person’s means of communicating and can communicate effectively with that person.

Providers work flexibly with the people they support to determine how support can best be provided in the home and community using the available funding, community resources and recognising the individual’s aspirations, strengths and abilities. Putting people at the centre of support allows them to have greater choice and control over their home and environment. This person-centred approach should enable people to receive quality supports within a safe environment and reflect skilled and experienced staff and effective and efficient management of resources.

Satisfaction with current services

In 2014, the New Zealand Disabled Person’s Organisation Report¹⁴ to the United Nations Committee on the Rights of Persons with Disabilities stated that:

- disabled people in group residential homes say they continue to experience oppressive living arrangements
- there is a lack of age-appropriate residential facilities that severely restricts residential choices.

Similar issues were identified in the Putting People First review of 2013,¹⁵ which highlighted that poor residential or supported living placements and services tend to come about following:

- poor assessment of an individual’s needs that make either the service or the level of support inappropriate resulting in negative outcomes
- placement choice driven by funding considerations
- a difficult mix of individuals, which can put even a good service into crisis
- wrong support staff for a particular individual
- lack of sufficient or appropriate training for staff
- poorly motivated staff or a poor care culture
- a ‘warehousing’ approach to individuals instead of supporting them to live a good life
- the inability of services to evolve alongside individuals
- putting the organisation before the individual.

14 New Zealand Disabled Person’s Organisation Report: To the United Nations Committee on the Rights of Persons with Disabilities, on New Zealand’s Implementation of the Convention on the Rights of Persons with Disabilities, 31 July 2014. Page 24. <http://www.dpa.org.nz/resources/sector-resources/the-united-nations-convention-on-rights-of-persons-with-disabilities/dpo-shadow-report>

15 See: www.health.govt.nz/our-work/disability-services/disability-projects/putting-people-first-quality-review

In the 2015/16 year, the Working Group Review of Safety Regulation in Disability Support noted several concerns about the current regulation relating to safety in disability supports. The regulations:

- do not cover all disability residences, applying only to facilities with five or more beds
- are not always effective in keeping disabled people safe or responding promptly when issues arise
- are not fit for the purpose of ensuring that disability consumers experience good outcomes that enable them to live everyday lives
- are out of date with the current direction of the disability sector towards person-centred and self-directed models of support.

Survey results

In 2015, the Ministry commissioned the research and evaluation company Malatest International to survey disabled people who used Ministry-funded community residential support services. The aim was to gather statistically valid data focusing on outcomes for people living in residential support services to inform both the Ministry, residential service providers and disabled people and their families/whānau. Service users across four locations and 20 providers were interviewed or completed the survey online. Valid survey responses were received from 356 service users and 35 proxies.

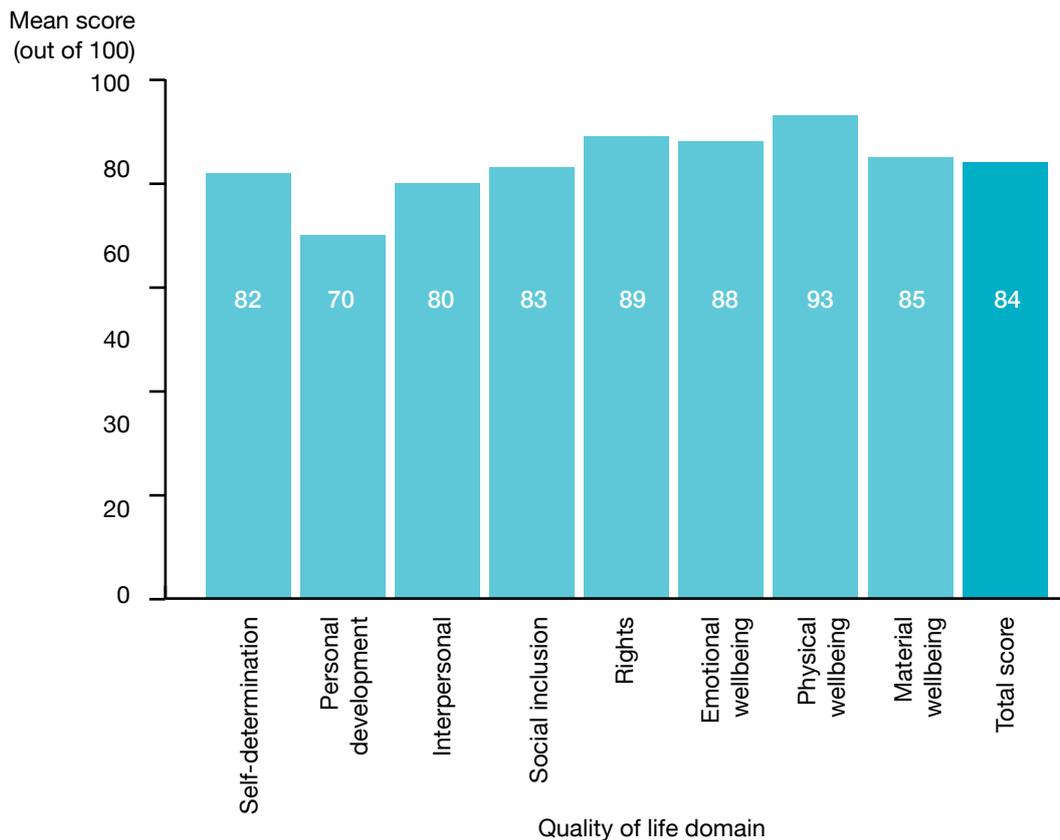
The survey¹⁶ found that:

- 88 percent of service users liked the residence or home where they lived
- staff were an important factor in whether service users liked their homes (staff who engaged with residents, talking with and getting to know them, were very important to the residents)
- the majority of services users who provided feedback were positive about their quality of life (the overall mean quality of life score was 84 out of a possible 100, with 37 percent of service users having scores between 90 and 100).

Figure 2 shows how interviewees scored the various domains. Scores were high but consistent with the results of similar surveys. The highest mean score was for physical wellbeing and the lowest was for personal development.

¹⁶ Malatest International, September 2016. www.health.govt.nz/publication/feedback-people-living-ministry-health-funded-residential-services-people-disabilities. The survey did not include children in residential support services.

Figure 2: Percentage of community residential support service users scoring positive outcomes from their support experience



Service users who had consistently higher quality-of-life scores were more likely to be younger (less than 40 years old) and to have an intellectual/learning disability rather than a physical disability. People with physical disabilities were more negative about social inclusion. This relates in particular to access to transport and the community. Overall, the quality-of-life scores did not vary between genders or ethnic groups.

Perspectives of the state of residential care

Service users' perspective

During Ministry-led workshops and meetings about the proposed changes to community residential support services held in December 2016, service users suggested that:

- the Ministry should continue to support the principle of achieving an ordinary life
- living arrangements can sometimes be cumbersome – homes did not always feel homely due to the compliance constraints and disability standards
- disabled people want to lead lives like their peers – including having pets, friends and parties – and want:
 - to keep their own hours and select their own staff
 - transition planning for a real future
 - ready access to specialist help as and when required
 - the information that is available about them to be relevant, up to date and accurate

- flexible and tailored respite care made available for them as and when required
- people to be involved in their support who ‘know me well and can support me’ effectively to manage any emerging or presenting difficulties that might negatively impact on wellbeing
- there should be more spot checks to ensure services are operating as they should be in the person’s best interest
- there should be more options for support outside of residential models and where residential models are used, then greater choice and control
- disabled people should have access to a competent workforce and choice over who is involved in ‘my life’ – with staff who are well trained and well paid.

Providers’ perspective

Providers were asked about the quality of service delivery. They suggested that:

- transitions need to be improved in order to ensure better service delivery
- disabled people need opportunities to trial different types of living situations and to be supported throughout the process of trialling and choosing
- services need to be marketed effectively so disabled people and their families/whānau know all the choices available to them
- contracting under separate service lines can inhibit real choice as one provider may not be able to support the disabled person as that person becomes more independent
- staff training and workforce development must be supported at all times
- a whole person approach is needed, including supporting relationships of choice
- providers need to be able to support people across the spectrum of supports, depending on the person’s needs at the time.

Choice in Community Living

Choice in Community Living (CiCL) is an alternative to current residential support services that increases disabled people’s independence. The Ministry contracts providers to deliver a flexible range of supports that enables people to live independently in a home of their own and choose the people they live with. This enables people with disabilities who would otherwise live in residential support services to:

- have the same range of housing options as other people
- have increased choice about which provider supports them and how they are supported
- access a more flexible range of funded and unfunded supports.

The implementation of CiCL was evaluated in 2013, providing some useful insights into how this initiative is working and identifying issues for further consideration. Many disabled people participating in the evaluation reported significant benefits to ‘their sense of freedom to live their lives as individuals’ as a result of the increased independence.

CiCL has also enabled participants to develop skills and capabilities with more opportunities for relationships and accessing and participating in the community.

Challenges and opportunities

Some new models are evolving that aim to support disabled people to live more independently in their local communities with people of their own choosing. International experience confirms this trend.

Innovative options, including use of assistive technology to minimise reliance on staff, are widening the choices available to disabled people and enabling people with complex needs to become more independent.

However, the investment required to achieve the best outcomes for disabled people must be balanced against affordability.

Workforce capability

While estimates of the disability workforce in Ministry-funded residential care are not currently available, the Business and Economic Research Limited (BERL) report *Health and Disability Kaiāwhina Worker Workforce: 2013 Profile*¹⁷ provides an in-depth profile of the disability kaiāwhina workforce, with insights on the size and nature of the residential care sector.

Compared with the total New Zealand workforce, the disability workforce in 2013:

- had an older age profile
- was female dominated
- was more ethnically diverse (more Māori and Pacific and Asian populations)
- had slightly more migrants (overseas born)
- had lower qualification levels
- had lower incomes.

Specific roles with the largest number of workers in 2013 were:

- personal care assistant – 29,860 people (47 percent of the disability workforce)
- community worker – 7,200 people (11 percent of the disability workforce)
- aged or disabled carer – 5,770 people (9 percent of the disability workforce)
- welfare worker – 4,940 (8 percent of the disability workforce).

¹⁷ Twaddle S, Masrur K. 2014. *Health and Disability Kaiāwhina Worker Workforce, 2013 Profile: April 2014*. Wellington: Business and Economic Research Limited. URL: www.nzcmhn.org.nz/files/file/703/2013-Health-and-Disability-Kaiawhina-Worker-Workforce-Profile.pdf (accessed 27 October 2017).

The residential care services industry was the largest employer of the 2013 disability workforce, followed by medical and other health care services:

- around one-third of the disability workforce (31.4 percent or 19,290 people) was employed in the residential care sector, including the aged care sector.
- just over one-fifth of the workforce (22.8 percent or 13,970 people) was employed in the medical and other health care services industries. This industry includes general practitioner services, allied health services and pathology and diagnostic imaging services.
- around one-quarter of the workforce was employed in the other social assistance services industry (13.3 percent or 8,130 people). This industry is primarily engaged in providing a wide variety of social support services.

The success of *Where I Live; How I Live* depends on developing and maintaining a resilient and competent workforce. For example, there is a need to further develop workforce capability in the area of responding to people with complex support requirements. We need a cross-Ministry, cross-sector approach to attract and retain skilled workers.

A number of other strategies (including the Healthy Ageing Strategy and The New Zealand Carers' Strategy Action Plan for 2014 to 2018) are also seeking to improve the current and future capability and capacity of the health and disability workforce. For the high and complex group of disabled people, we need skilled support workers and providers who are responsive to the needs of this community and who can invest in improvements.

On 1 July 2017, the Care and Support Workers (Pay Equity) Settlement Act came into effect increasing the remuneration of those employed in the sector. The settlement also makes provision for relevant qualifications and/or experience. This will go a long way to recognising the value of the support workforce.

Assistive technology

Assistive technology is any item, piece of equipment, software, product or system that is used to maintain or improve the functional capabilities of individuals with a disability. The rapid pace of advances and growing availability of affordable assistive technologies provides opportunities to improve the support disabled people can receive and increase their independence. Assistive technology has a large role to play in enabling disabled people to take full advantage of their potential in a number of areas, such as education and employment.

Future desired state

Where I Live; How I Live aims to provide disabled people and their families/whānau with greater choice, control and flexibility, while acknowledging that people's own experiences will contribute to their level of desire to explore different living choices. The following description of the desired future state complements the direction of the transformation of the disability system.

- A range of alternative community-based options will be offered to disabled people entering a community residential support service and to disabled people already living in community residential support services, which allows the person to be as independent as possible, without necessarily having to rely on residential supports.
- The disabled person may choose to:
 - live on their own
 - share a home with others who do not have a disability
 - share a home with other people who have a disability
 - opt for other arrangements.
- Children and young people will be supported to express their views on where and how they want to live in the future.
- Community residential support services that provide access to 24/7 supports will be specialist services for disabled people who require more intensive support.
- The community residential support workforce will be skilled in supporting people whose complex support requirements challenge services and in providing supports to clients who are self-determining.
- DSS community residential support service providers and their staff will have the foundation skills in managing challenging behaviours that may emerge from time to time.
- Access to specialist services will be available to disabled people whose complex support requirements present challenges to services and those supporting them, including behaviour support and mental, primary and secondary health care services.
- Community residential service providers will be governed by boards that will include disabled people.
- The rights of disabled people living in community residential support services will be upheld, including the rights to:
 - security of housing tenure
 - safety, security and freedom from abuse
 - access to the full range of health services available to the non-disabled
 - age-appropriate living arrangements
 - disability-appropriate living arrangements
 - employment and education
 - fulfilling relationships
 - well-supported transitions between different levels of support for their disability needs for as long as they need them.

- Disabled people in residential care live a full life at home and in the community, which reflects their interest in recreation and leisure as well as education and learning etc.
- Contracts with disability services providers will be more flexible to allow the provision of a range of disability supports across the spectrum of need.
- There will be a range of community residential providers available to give people the option to live in any geographic region.
- Community residential service providers will be measured in accordance with the outcomes achieved for the disabled people they serve.

Desired outcomes

In line with the system transformation work, the goals and objectives of *Where I Live; How I Live* are to provide greater choice, control and flexibility for disabled people and their families/whānau. With a focus on these components, a range of initiatives have already begun such as:

- CiCL (see Choice in Community Living)
- Local Area Coordination (LAC)
- EIF
- supported self-assessment.

Once people enter residential care, it becomes much harder for them to transition into other independent options. Understanding the rationale for decisions that lead people to access residential support is important for designing services that are fit for purpose.

However, setting a defined threshold based solely on assessed need raises a range of complicating factors, such as cost of housing, provider behaviour, expectations of families/whānau and wider social pressures. In other words, there is no simple single solution to ensuring that the right people are accessing the right service at the right time.

The future of community residential support services

Disabled people

In line with Enabling Good Lives principles, disabled people will have greater choice, control and flexibility over the services they access. People's individual experiences contribute to their level of desire to explore different living options and they need to be supported to make decisions that maximise their independence.

Providers

Disabled people and their families/whānau or nominated agents will have the choice to manage a flexible budget and be able to direct how they spend that budget. If providers do not offer services that appeal to the disabled person and their family/whānau, the person can choose to purchase alternatives.

Providers will need to be open to working with disabled people and their families/whānau to provide innovative solutions.

DSS and NASCs

In the current landscape, DSS aims to improve its framework for monitoring and evaluating community residential support services. It will also do some work to better understand the contractual landscape.

The Ministry will engage with, train and provide ongoing mentoring for Needs Assessment Service Coordination (NASC) staff to support them in developing their practices to:

- invest now when allocating supports to ensure wellbeing over time while reducing costs to society
- enable early access to Behaviour Support Services

- help disabled people and their families/whānau determine what options are available (including residential support)
- best support disabled people and family/whānau decision making.

Under the EGL principles, disabled people and their families/whānau will have the option of working with someone who can help them envisage and plan a future that will improve their independence and their lives and will work alongside the NASC to deliver on decisions made.

Safeguarding the rights and needs of disabled people

The Ministry, alongside the health and disability sector, is currently considering how best to safeguard disabled people living in community residential support services, including reviewing relevant standards. Safeguarding aims to provide a good quality of life for disabled people while ensuring that disabled people are able to take the same risks as people without a disability. Safeguarding is a component of the system transformation work. The focus of that component is to have disabled people and their whānau at the centre of the system with a continuum of responses and activities to support safeguarding. These supports aim to protect, enhance and promote disabled people's human rights, health, safety and wellbeing.

Proposed roadmap

Table 1 sets out a proposed roadmap for implementing *Where I Live; How I Live*. A full implementation plan will be developed once the strategy is finalised.

Table 1: Community residential support services strategy roadmap

Outcome	Suggested action	Within two years
<p>Outcome 1 Disabled people and their families/whānau have the option to manage a flexible budget.</p> <p>Outcome 2 Disabled people and their families/whānau have the choice and flexibility to use funding in the way that suits them.</p>	<p>Action 1 The health and disability sector will explore options to enable disabled people and their family/whānau to use funding more flexibly.</p>	<p>System transformation officials work with representatives from the disability sector to explore options to improve disabled people's choice, control and flexibility over their funding.</p>
<p>Outcome 3 Disabled people live free from exploitation, neglect and abuse.</p>	<p>Action 2 The Ministry will ensure that the recently established guidelines on preventing and managing abuse are used effectively.</p>	<p>Providers follow clear and demonstrable processes to prevent abuse.</p> <p>There is evidence of a mature complaints culture among all providers.</p>
Workforce capability		
<p>Outcome 4 Community residential support services provide a fulfilling work environment for staff.</p>	<p>Action 3 The Ministry will work with the health and disability sector to improve options for attracting and retaining skilled support workers.</p>	<p>Disabled people and their families/whānau can easily find paid or volunteer carers.</p> <p>Work for support staff is fulfilling and is seen as adding value to the life of disabled people, and to the wider community.</p> <p>The Ministry is able to determine a pathway for implementing the pay equity settlement.</p> <p>The Ministry supports professional development where there are obvious gaps in workforce capability, eg, health and safety training when working with disabled people with challenging support needs.</p>
Ease of use and access		
<p>Outcome 5 Disabled people and their families/whānau can best utilise current residential supports and find and access alternatives to residential supports in their community.</p>	<p>Action 4 The Ministry will develop an easy-to-understand guideline for how to use funding and access supports.</p>	<p>Guidelines for using funding and accessing supports are in place.</p> <p>Comprehensive information on the range of options in each area is available online.</p>

Outcome	Suggested action	Within two years
	<p>Action 5 The Ministry will develop options for families/whānau that better support children and young people to live at home, in order to broaden and create future living options.</p> <p>Action 6 There will be cross-agency collaboration to ensure appropriate access to supports, including education and health services.</p>	<p>The Ministry supports choices that are available everywhere.</p> <p>The Ministry has contracts that enable providers to offer a full range/continuum of services appropriate to a person's needs.</p>
<p>Outcome 6 NASCs are supported to work better with disabled people to maximise their independence.</p>	<p>Action 7 NASCs will be supported to:</p> <ul style="list-style-type: none"> • invest now to ensure wellbeing over time while reducing costs to society • promote the use of flexible funding • offer early interventions, such as behavioural support services. 	<p>Disabled people and their families/whānau feel better supported by NASCs, through the provision of more options.</p> <p>The health and disability sector is clear about what investing now means when allocating supports.</p> <p>Disabled people and their families/whānau are offered access to independent help to find and access services when they want it.</p> <p>LAC's are available more widely to help families/whānau make better plans.</p>
Better support for people with complex support requirements		
<p>Outcome 7 Disabled people are supported to live well in the presence or absence of complex support needs that challenge services.</p>	<p>Action 8 The Ministry supports the development and expansion of providers' capacity to assist disabled people whose complex support needs challenge services.</p> <p>Action 9 Disabled people will engage early with specialist services.</p>	<p>Develop and expand the capacity of services to understand and respond to those whose complex support needs challenge services.</p> <p>Provide specialist services locally, which can support good mainstream practices as well as directly serve a small number of disabled people who have the most challenging needs.</p> <p>Crisis support options are available when needed.</p>
Assistive Technology		
<p>Outcome 8 Disabled people will have increased access to assistive technologies to support positive outcomes.</p>	<p>Action 10 The Ministry supports further development around improving access to and integrating assistive technologies in community residential support services, eg, using virtual technology or augmentative communication devices.</p>	<p>The Ministry will investigate ways to utilise assistive technology for both disabled people and providers.</p>

Monitoring the strategy

Any changes made to community residential support services need to be measured to ensure they are resulting in improvements. We need to design a comprehensive framework for evaluating how the outcomes set out in this strategy are being achieved.

The evaluation framework will:

- enable us to identify and implement further quality improvement initiatives
- set out what data needs to be collected and how that data can be used to inform future planning and decision-making
- be linked to the evaluation framework for the disability support services system transformation
- incorporate feedback and complaints from people who use community residential support services, support workers and providers.

An important part of measuring the quality of service delivery is enabling people to make complaints or suggestions for ways to improve the services they are using. The Ministry encourages providers of disability support services to develop a culture that supports people to speak out and provides those people with the opportunity to give regular feedback.

In addition, the Ministry has a team of people who investigate and respond to complaints made about disability services. More information on how to make a complaint about a disability service can be found on the Ministry's webpage, Complaints about a health and disability service, at: health.govt.nz/about-ministry/contact-us/complaints-about-health-and-disability-service

Appendix 1:

Current community residential care options

Residential care refers to long-term care given to adults or children who stay in a residential setting rather than in their own home or family home. The facility is registered and managed and run by a care provider who is responsible for all aspects of the disabled people's daily needs and wellbeing. Residential care may be required if home-based care is not available or not appropriate for an individual. Care options will depend on the needs of the individual.

Residential care may be necessary for adults who:

- are disabled and require lifetime care and support
- have age-related health conditions, for example, Alzheimer's and other forms of dementia
- are older and frail and are often cared for at home by paid or voluntary caregivers, such as family/whānau and friends, with additional support from home-care agencies
- have long-term mental health problems.

The purpose of Oranga Tamariki, the Ministry for Children, is 'to ensure that all tamariki are in loving whānau and communities where oranga tamariki can be realised'.¹⁸ When a child or young person has to access a residential service, there needs to be a time-limited plan in place to support their return home or to being cared for by a foster family. Residential support services should be provided in 'family-like settings that are local, therapeutic and time-limited'.¹⁹

Types of residential support

The Ministry supports the living arrangements of its disability clients in the following categories.

- Community Residential Support Services are provided in establishments where adults with disabilities live and are cared for. These adults typically will have a lifelong physical disability or lifelong learning/intellectual disability. Residences are places where residents can enjoy a good quality of life and live in a place that feels like home; one that upholds personal dignity, independence and respects privacy. This service provides access to 24-hour support at the level necessary for people to have a safe and satisfying home life. This includes being responsible for any disabled person who has to remain at home during the day for any reason.^{20, 21}

18 www.mvcot.govt.nz/about-us/who-we-are/

19 Ministry of Social Development. 2016. Expert Panel Final Report: Investing in New Zealand's children and their families, December 2015. Wellington: Ministry of Social Development. www.msd.govt.nz/documents/about-msd-and-our-work/work-programmes/investing-in-children/investing-in-children-report.pdf

20 See: www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/community-residential-support-services

21 See: www.health.govt.nz/our-work/disability-services/contracting-and-working-disability-support-services/contracts-and-service-specifications#t2cids

- Out-of-family residential support services for children and young people with disabilities from seven to sixteen years of age²² are services for people who have continuous, long-term support needs. Support can be accessed 24/7 at levels necessary for children and young people to have safe and satisfying home lives. This includes 24-hour responsibility for children or young people who may need to remain home during the day for any reason.
- Community residential support services within aged care facilities are 24/7 services provided for people with a lifelong learning/intellectual, physical or sensory disability aged between 16 and 65 years old.
- Community care is provided to people in their own homes, allowing disabled people to receive home help and personal care.
- Within community care, supported living supports can be tailored to fit people's specific needs. These arrangements offer many people more flexibility and independence than residential support services.
- Choice in Community Living (CiCL) is an alternative to residential support services for people with significant disabilities who might otherwise need residential support services, to plan for and live more independently in a home of their choice. A provider delivering CiCL will work with each disabled person independently to purchase and/or provide supports that are directed by the disabled person (and their representative or family/whānau) to enable that person to live as independently as they desire.²³
- The Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (IDCC&R Act) provides for two different levels of care, Secure Care (hospital level or community based) or Supervised Care in the Community. Care is delivered in designated secure or supervised facilities respectively, and the care recipient is required to remain in the designated facility other than for periods of approved leave.²⁴ At July 2014, there were 127 clients in supported accommodation receiving hospital-level care or in secure care.

Residential Support Subsidy

People receiving the Residential Support Subsidy from Work and Income are not income and asset tested but need to contribute towards the cost of their care from any benefit they may be receiving. A certain proportion of their benefit is generally paid directly to the residential support services provider, with the disabled person's consent.

Residential waiting list

For a number of reasons, there is usually a waiting list for residential care. At August 2017, there were 148 people on the waiting list.

Residential support funding

In the 2016/17 financial year, the Ministry spent \$1,188 million on disability support services, including:

- \$528 million (44.4 percent) was allocated to residential care for an estimated 7,500 clients at an average cost of \$70,400 per client²⁵

22 Under certain guardianship arrangements as notified by the Ministry, the age range may extend to 20 years. However, under typical circumstances, young people will receive adult services from 17 years of age.

23 See: www.health.govt.nz/our-work/disability-services/contracting-and-working-disability-support-services/contracts-and-service-specifications#choice

24 See: www.health.govt.nz/our-work/disability-services/about-disability-support-services/intellectual-disability-compulsory-care-and-rehabilitation-act-2003

25 Actual DSS spend on Community Residential Services for 2016/17.

- \$74.7 million (6.3 percent) was spent on 127 disabled people under the High and Complex Framework
- \$52.3 million (4.4 percent) was spent on clients in supported living arrangements
- 82 percent of clients were in community care compared with 18 percent in rest homes, hospitals or rental accommodation.

Respite in residential care

Community residential houses may also be used as a respite option when there is a spare bed available. Some feedback from disabled people and their families/whānau and providers suggests that such a practice is not ideal, because it can be unsettling for a community residential home's permanent residents to experience various people coming and going throughout the week. In contrast, some people believe there are benefits to having respite clients visit a residential home – providing variety for permanent residents and allowing new friendships to develop.

From a provider perspective, it is more cost-effective for residential homes to cater for permanent residents rather than respite residents. There are administration costs involved with providing respite within a community residential home. In addition, where a respite resident visits a community residential house, support workers often need to become familiar with additional medication, or behavioural or other support plans.

Some community residential house providers may accept a respite client only until they can fill the bed with a permanent client, which disrupts the respite client's routines.

One benefit for providers is that the practice allows them to show disabled people and their families/whānau what they can offer. A disabled person may later choose to move into the home permanently. Thus respite care in a community residential home offers an easier transition for the disabled person; an opportunity to 'try before they buy', allowing them to learn to trust the provider before they commit to that provider's care.

Appendix 2: Emerging trends

The disability demographic is likely to grow, following other trends, such as:

- ageing, which is accompanied by increases in chronic diseases, leading to more age-related disability
- disabled people living longer because of medical advances and improved health care
- increased disability due to emerging and new conditions requiring disability support or established conditions that appear to be growing in prevalence²⁶
- growing numbers of individuals with a significant acquired disability and a range of clinical and other needs that are beyond the support capacity of the existing disability system
- behavioural changes, including increased recognition of some risks through people being allowed more choice and control over their lives
- international social trends towards more inclusive societies, which call for additional social policies, tools and assessments to improve the visibility and recognition of people with disabilities and their rights, etc
- growing diversity of the disability population, often with few needs in common and from widely varying age groups.

Implications of change

Changes in the disability demographic have significant implications, including increased pressures from rising costs and an expanding burden of care. The increasing pressures will impact on the Ministry's disability support services system, requiring system transformation to prepare for and respond to the changing needs of the disability population.

Client experience of residential care

The 2008 report of the Social Services Committee, *Inquiry into the Quality of Care and Service Provision for People with Disabilities* observed that:

- some people with disabilities who would prefer to live in their own homes have to live in residential facilities with others because they require a higher level of support than existing home-based services will provide or than can be funded
- some people who choose to live at home do not receive adequate care for their degree of disability
- as a result, families/whānau sometimes provide some or all of the necessary additional support, which can place considerable strain on them

²⁶ A common point of dispute is whether reported increases represent growth in actual incidence, greater awareness and better surveillance and access to improved treatment options or simply the reduction of stigma in reporting.

- institutional attitudes are pervasive even in community-based homes – deinstitutionalisation had led to the establishment of hundreds of miniature institutions, where people with disabilities still have little say over their daily lives and where they live with people not of their own choosing
- while personal care is widely available to people with disabilities, funded support for tasks such as housework is restricted to those below a certain income (usually those with a Community Services Card).

Abuse, neglect and violence in residential care

A recent New Zealand study explored the kinds of abuse experienced by disabled people who require high levels of support in their day-to-day care and identifies the range of people who are abusers.²⁷

The study aimed to:

- increase understanding of the multidimensional nature in which abuse manifests in relation to disabled people
- identify the individual and structural barriers that prevent disabled people from voicing and extracting themselves from abusive environments.

Structural issues that were identified as maintaining the status quo include:

- a low level of societal awareness of disability abuse
- a variety of silencing processes
- a lack of appropriate monitoring
- poor management practice of a variety of disability-related residences and services.

²⁷ Roguski M. 2013. The hidden abuse of disabled people residing in the community: an exploratory study. Gisborne: Tairāwhiti Community Voice. URL: www.communityresearch.org.nz/research/the-hidden-abuse-of-disabled-people-residing-in-the-community-an-exploratory-study/ (accessed 27 October 2017).