

Transforming Respite

Disability Support Services Respite Strategy 2017 to 2022



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Foreword

It is an exciting time to be the Minister for Disability Issues – the disability system transformation will improve the lives of people with disabilities and their families/whānau by offering more choice and control over the supports they use.

This strategy, *Transforming Respite*, brings choice, control and flexibility to respite supports. It supports both the disability system transformation work 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 choose to live everyday lives.

This strategy also takes a social investment approach to respite supports – it recognises the important role that family/whānau carers play in supporting people with disabilities to live a fulfilling life within their communities, iwi and hapū. It invests in family/whānau resilience to continue in that caring role and makes it easier for carers of disabled people to take a break.

Transforming Respite draws heavily on the feedback provided by disabled people, their families/whānau, disability organisations, advisory groups and providers about how respite supports can be improved. We have listened to your feedback, and we are very grateful for the time you took out of your busy lives to tell us your stories. Your insight has been invaluable.

Hon Nicky Wagner
Minister for Disability Issues

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Overview

Most parents would agree that parenting is hard. For families/whānau with developmentally typical children, the parenting journey gets easier as their children learn to take care of themselves and help around the house. For these parents, it's natural and relatively easy to get a break from the caring role when their child is invited to a play date, has a holiday with their grandparents or attends a school holiday programme.

For parents of a child with a disability, the caring role may not get easier as the child grows – everyday activities can be challenging and time consuming and may in fact become harder as the child develops toward adulthood. The family/whānau is less likely to have access to the same types of natural supports as their peers – friends and extended family/whānau may not feel confident in having a child with a disability come to stay and therefore do not offer to take them. Parents can feel isolated from their communities and become stressed if leaving the family home requires significant planning and it is difficult to take a break.

For other families/whānau, disability comes later in life (eg, as a result of a stroke or a neurological condition), and spouses, aging parents or children can find themselves in a caring role on top of their other work, parenting or social commitments. Feelings of fear, loneliness, anxiety and grief are typical for carers, and taking a break from caring can be key to a carer's ongoing wellbeing.

For these reasons, the Ministry of Health (the Ministry) supports families/whānau who care for a disabled person by funding 'respite', or a 'short break', for carers. Respite is an investment in protecting the health and wellbeing of the family/whānau and helps them to continue in their caring role.

There are a number of areas for improvement within the existing respite model. Respite needs to align with the Disability Support Services (DSS) strategic direction to give greater choice, control and flexibility to disabled people and their families/whānau. There are also issues with the current funding model, provider availability and the ability of families/whānau to access services.

There is a case for bringing innovative and transformative change to the area of respite. These changes are linked to the wider work programme to transform the disability support system.

When reconsidering how respite is delivered in New Zealand, we need to ask what is required to ensure that both the family/whānau and the disabled person have access to a 'good life'. Respite itself is a means for carers to get a break and refresh themselves. Rather than focusing on what hours or placements someone needs, we need to think about what it takes to enable carers to get the breaks they need.

Ultimately, to meet people's diverse range of respite needs, we must focus on outcomes rather than specific inputs. The outcome we are seeking is to ensure carers are not stressed, are resilient, have capacity to have ordinary life experiences and feel able to continue to provide

care. This requires a new way of thinking; in particular, to trust that families/whānau will access supports that meet their needs, whatever those needs are and in ways that may be unique to them.

Respite support needs to be available early, before families/whānau start to feel that they cannot cope. Respite should be age appropriate and a best match for the family/whānau. Respite needs will change throughout the stages of life. Respite is a lifelong investment in the wellbeing of the disabled person and their family/whānau.

The high-level outcomes we seek through this strategy are to ensure that the respite model:

- offers **choice, control and flexibility** about how disabled people and their families/whānau take a break – this includes offering disabled people and their families/whānau a flexible respite budget that allows them to take breaks in the ways that suit them best
- **enhances the range of quality respite options** that families/whānau who need them most can access – this includes developing new and expanded respite services, in line with what people want
- recognises the **value of respite** and takes a lifelong approach to respite allocation and funding
- is **easy to use** and to access – this includes easier administration and payment methods, better access to information about the respite options available and support to find and use these options.

Introduction

What is ‘respite’?

Respite literally means a period of rest or relief. In the context of disability support, respite aims to provide families/whānau or carers with a planned, temporary break from caring for a person with disability. The primary purpose of respite is to relieve carer stress as a way of supporting them to continue in their caring role. A break can be for a few hours, a day, overnight or longer and may take place in or away from the family home.

Carers need the opportunity to rest, recover and re-energise. Each carer will have their own idea about how best to do this: they may want to maintain social connections with their community, to catch up on sleep, to exercise or to spend time with other family/whānau. We need to design our respite services so that carers can get the breaks they need, in whatever form suits them.

Respite is an essential part of the overall support that a family/whānau needs. When we support respite for carers, we invest in protecting the health and wellbeing of the whole family/whānau.

Respite also gives a disabled person a break from their normal routine. It can provide them with new experiences, chances to develop their independence or opportunities to visit different places or make new friends. Most importantly, respite options for the disabled person must be something they look forward to.

A rest, a break, a breather!
A chance to re-energise and
‘come up for air’ from the, at
times, gruelling and exhausting
job of caring for a child with
special needs. Patience is not
infinite – but with a regular break,
you can replenish the supply!¹

Why a respite strategy?

The Ministry currently spends approximately \$61 million per year on disability respite. There are problems with all the types of disability respite that we currently purchase. In general:

- some current options are inflexible, and do not meet the needs of families/whānau
- finding relief carers who have the right skills, experience and attitudes is very difficult
- the administration and conditions of use of Carer Support² are outdated
- some families/whānau do not want to use facility-based respite, and sometimes those who need it most cannot access it
- some contracted respite options do not provide value for money – for example, some of the available options are underused
- there is inconsistency in services available throughout the country.

1 A respondent to the 2016 survey that DSS conducted of disabled people, their families/whānau and providers on the topic of respite. We have included quotes from respondents to this survey throughout this document. A report on the results of the Disability Respite Survey 2016 can be found at: www.health.govt.nz/publication/disability-respite-survey-2016

2 A subsidy for carers of disabled people, reimbursing some of the costs of using a support person to help them take a break from their caring role.

Scope of this strategy

DSS's strategic direction prioritises greater choice, greater control and better outcomes for disabled people. The respite model needs to align with this.

This strategy will set the direction for respite from 2017 to 2022. It will enable a wider range of quality options, funded through flexible budgets. Its scope is:

- respite funded through all current mechanisms (Carer Support, in-home support, host-family respite, Individualised Funding (IF) and facility-based respite)
- respite for disabled children, young people and adults, and their families/whānau and carers
- increasing the ability of the Needs Assessment Service Coordination (NASC) agencies to support families/whānau to access respite
- developing a range of respite options to suit individual families/whānau.

This strategy does not cover respite for people who live permanently in community residential houses or who are primarily clients of mental health services, health of older people services, palliative care or the Accident Compensation Corporation (ACC).³ We are collaborating with these services where it is efficient and effective to do so.

Vision

This strategy will enable disabled people and their families/whānau:

- greater choice, control and flexibility over their respite options and how those options are funded or purchased
- access to respite at a time and in a way that best suits their needs.

Principles

The principles of this strategy are based on those developed for Enabling Good Lives (EGL) (Enabling Good Lives 2017). They are as follows.

Self-determination	Disabled people are in control of their lives. In the respite context, families/whānau feel empowered and able to take the breaks that they need from caring.
Beginning early	We take an investment approach to respite and recognise that supporting families/whānau to have a break may prevent a crisis and sustain the family unit.
Person-centred	Disabled people and their families/whānau use respite supports that are tailored to their individual needs and goals and that take a whole-life approach.
Ordinary life outcomes	We offer respite options that support disabled people and their families/whānau to access everyday life, learn, grow social networks, increase independence and integrate with their communities.

³ However, we are working with the relevant teams to enable sharing of facilities or other improvements for the purpose of respite, where this is mutually beneficial.

Mainstream first	Everybody experiences full participation and inclusion within their community (people, places, assets, infrastructure and supports) as of right and can choose funded supports to enhance and facilitate this ⁴ .
Mana-enhancing	We recognise and respect the abilities and contributions of disabled people and their families/whānau.
Easy to use	Supports are simple to use and flexible.
Relationship building	Supports build and strengthen relationships between disabled people, their families/whānau and their communities.

In addition, it is essential that disabled people feel safe while accessing respite services.

Strategic context

This strategy is aligned with the United Nations’ Convention on the Rights of Persons with Disabilities (United Nations 2006) and our own Treaty of Waitangi. The strategic framework includes the New Zealand Health Strategy (Ministry of Health 2016a and b), He Korowai Oranga (Ministry of Health 2014c), the New Zealand Disability Strategy (Office for Disability Issues 2016) and the disability system transformation work programme.

This strategy is also linked at an operational level with a number of other Ministry, DSS and broader-government action plans, including those set out in Appendix 1: Strategic framework.

History of respite support

The formal concept of respite was developed in response to deinstitutionalisation (a focus on allowing people to remain in their natural homes rather than in long-term care facilities) during the 1960s and 1970s.

From the mid-1970s, government’s approach to services for people with disabilities became increasingly community- and rights-based. Increasingly, government recognised the need for people with disabilities to have access to a wide range of community-based support.

The Disabled Persons Community Welfare Act 1975 introduced into New Zealand legislation the concept of ‘relief’ from the responsibility of caring for disabled children who lived with their parent(s) or guardians. The Act set out a responsibility on the part of the government to fund a relief period of up to four weeks per year.

During the 1980s and 1990s, government introduced a formal contracting system to purchase disability services – this replaced government grants to charitable organisations for this purpose.

In 1992, the Government announced a ‘new deal’ for people with disabilities. Responsibility for services for people with disabilities (with the exception of vocational services) transferred to the Regional Health Authorities (RHAs).

⁴ This is the working definition of the EGL principle ‘Mainstream first’ that was agreed by the National EGL Leadership Group and some system transformation co-design group members in April 2017. The principle may evolve further during the disability system transformation process.

During the late 1990s, RHAs purchased respite support. This took the form of overnight respite in dedicated houses (ie, 'facility-based respite') and was primarily available only for children. The respective RHAs established specialised respite support for children with high and complex needs in Auckland and Waikato. The RHAs also funded one-on-one care 'in-home' or buddy support.

Further government reforms saw the Ministry taking responsibility for disability support funding. Respite has been centrally funded since 2001.

In 2006, the Ministry tendered for more respite support to be provided in dedicated facilities, and, in 2014, it introduced IF respite to try to increase the flexibility of existing respite options.

The current state of respite

People supported and funding

The current respite budget is approximately \$61 million per year. Around 70 percent of the people who receive a respite allocation are aged under 25 years. Eighteen percent are Māori, 10 percent are Asian and 7 percent are Pacific peoples.

NASC services allocate respite support based on the needs of individual full-time carers and the needs of the disabled person.

The Ministry currently supports respite through:

- a) Carer Support – which contributes to some of the costs of a break for carers (paid on a half-day or daily rate)
- b) facility-based respite – which provides care for a disabled person out of their home (usually overnight in a dedicated respite house or other facility, which provides care for a group of about five people at one time)
- c) IF respite – through which disabled people or their families/whānau directly purchase their own respite supports
- d) in-home support or one-on-one ‘buddy’ support – which may be provided in the home, in the community or through after-school, before-school or holiday programmes (paid at an hourly rate)
- e) host-family respite – which provides an overnight break in the home of another family/whānau. The host family/whānau receives payment through Carer Support or through a provider contracted to the Ministry. Children and young people are more likely to receive host-family respite.

As at September 2016, the Ministry was allocating Carer Support to 18,331 people: 76 percent were aged under 25 years; 46 percent had an intellectual disability; 32 percent had autism spectrum disorder (ASD); 18 percent had a physical disability and 4 percent had a sensory, neurological or ‘other’ disability. Eighty-one percent of people receiving Carer Support had a ‘medium’ or ‘high’ disability-related need.

Also at September 2016, the Ministry was allocating 2,977 people other types of respite. Of these people, 70 percent were aged under 25 years; 49 percent had intellectual disability; 24 percent had ASD and 89 percent had a ‘high’ or ‘very high’ disability-related need.

Table 1: Summary of current respite funding, clients and providers

Type of respite funding	2016/17 budget	Number of clients	Number of providers
Carer Support	\$32 m	18,331	19,000
Facility-based/host-family respite	\$17 m	1,830	28 (+ rest homes)
In-home support	\$11 m	1,924	4
IF respite	\$1 m	731	5 hosts
Total	\$61 m	19,648*	

* Note that some people are counted more than once.

Current respite options: further details and current issues

Carer Support

A number of conditions govern the use of Carer Support. Carers perceive many of these conditions to be inflexible and outdated. The main areas of complaint are:

- the low rate of subsidy: \$76 for 8–24 hours of relief care
- the conditions preventing use of Carer Support while a full-time carer is working
- inconsistency and inflexibility in the conditions, compared with those that govern IF
- inadequate allocation of respite hours, and inconsistency in allocation between regions
- inability to use the funding flexibly.

There are many misconceptions about the Carer Support conditions, and families/whānau need clearer guidance.

Across the country, carers use approximately 75 percent of allocated Carer Support days each year. Carers tell us that it is very difficult to find relief carers in their area who have the right skills, experience and attitudes, especially because of the low subsidy rate.

The system of claiming Carer Support is based on paper forms and conventional mail. This is seen as frustrating, old-fashioned and time consuming. Mistakes in completing forms can lead to delays for families/whānau being reimbursed for care they have already subsidised.

The paper work! In this day and age, you would think it would be able to be done online. If I make one mistake on the forms they are sent back to me. I have to get the carer to resign the forms and send them back! It takes another two weeks to get paid. I always pay my carers up front and have a reasonably tight budget of my own, so this always creates a hassle for me. Time wasting and time consuming! I spend my whole life filling out forms for all sorts of things, and it is never ending. An online system would be much quicker and more efficient for everyone concerned, and I am sure hundreds of parents would agree with me. From a parent who is very time poor!

Facility-based respite

Our respite survey found that families/whānau that had access to facility-based respite appeared to be among the most satisfied. The break from caring has reduced their stress levels and enabled them to continue in a caring role.

However, families/whānau who receive an allocation for facility-based respite cannot always access this service. Barriers include the following.

- Respite houses are not available in all parts of the country; some families/whānau may need to travel for several hours to access a respite house.
- Some respite houses are at capacity and cannot accept any new referrals.
- Some respite houses may not be able to accept a particular disabled person because that person is not a 'good match' with the other people in the house (in terms of age, gender, disability type, level of support needed or challenging behaviour).

- Available respite houses may not be appealing to a disabled person or their family/whānau or may not be available on the days that they would like.

A person may receive facility-based respite in a range of settings, including dedicated respite houses, child- or adult-specific facilities, community residential houses and aged care facilities (rest homes). The remainder of this section discusses each of these in turn.

Dedicated respite houses

The Ministry currently contracts for dedicated respite houses for children and adults. ‘Dedicated’ respite houses are generally not used for anything other than providing overnight respite. The occupancy of dedicated respite facilities varies significantly between houses and times – demand is higher during weekends.

Dedicated respite houses carry the most financial risk for providers compared with other respite options as they require investment in leasing or purchasing a property, modifying and furnishing the property and staffing the service. There is currently variability in the rates paid for facility-based respite, which is not necessarily related to the extent of support provided at the service.

It is difficult to get a clear picture of demand for dedicated respite houses. At present there are few alternatives. Our survey found that 48 percent of the respondents would like to use a respite house, and 40 percent said they would not (the remaining respondents were already using a respite house). Reasons people gave for not wanting to use a respite house included:

- fear of and guilt at leaving a disabled family/whānau member with strangers in an unfamiliar environment
- fear for the safety of the disabled person (specific fears included abuse, escape, falls and medical needs not being attended to)
- worry that the disabled person’s behaviour would deteriorate and/or trigger anxiety
- belief that a disabled child was too young for overnight respite
- a preference for other options.

Current evidence suggests that dedicated respite houses are an outdated and institutional model of care and that parents in particular would like respite facilities to be more homely and less institutionalised, with more activities and outings available. Younger children can find residential care especially difficult.

Under the current model, some respite houses are closing or in danger of closing due to low occupancy. Some providers tell us that they continue to offer a respite bed because they see the need in the community and their organisational values support the service being continued.

Other providers report that they have waiting lists of people wanting to access their services. Individuals and community groups have sometimes contacted the Ministry seeking to set up new respite houses in response to apparent demand for overnight respite within their communities.

Most facility-based respite is located in cities, where there is higher demand for the service. As a result, people who live rurally or in smaller towns generally have to travel to a larger centre to access a respite house.

During respite times it gives our family the chance to have a break from each other and our busy life. Our son comes back home happy and like a new person [and] we all feel more relaxed. As parents it takes the pressure off us.

The availability and funding model for current facility-based respite is difficult to manage as occupancy rates vary considerably. Trying to find the balance between compatibility of people using the service (eg, not mixing children with adults), their level of need and days that work best for the family/whānau (eg, weekends rather than week days) has resulted in providers struggling to fully utilise available respite beds.

Child- or adult-specific facilities

The current facility-based respite contracts specify a maximum age for children and young people. When a young person turns 16 (or 21 for some facilities), they are required to transfer to an adult facility.

Survey feedback from providers, disabled people and their families/whānau often expressed a desire to remove the age cap from the children's respite house contracts so that people could remain in a respite house they were used to visiting and 'grow with it'.

Community residential houses

Disabled people may be able to access respite where there is a spare bed in a community residential house in which other people with disabilities live permanently. This option is generally available for adults only.

Some feedback from disabled people, their families/whānau and providers expressed the belief that this option is not ideal because it can be unsettling for a home's permanent residents to experience various people coming and going throughout the week. In contrast, some feedback stated that there were potential benefits in some situations: having respite residents to stay could provide some variety for permanent residents and allow for new friendships to develop.

From a provider perspective, it is more cost-effective for residential houses to cater for permanent residents rather than respite residents. There are administration costs involved with providing respite. 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. This causes disruption for the respite client at that point.

One benefit for providers in having respite clients in community residential houses is that it 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. Respite thus provides an easy transition for the disabled person; an opportunity to 'try before they buy'.

Aged care facilities

Aged care facilities are not ideal for people under the age of 65, but they have the benefit of being available in all parts of the country and able to provide hospital-level care.

Our survey found that overnight stays in an aged care facility was the least popular option of all those presented. People aged over 65 were more willing to receive respite in an aged care facility, compared with those aged under 65.

Individualised Funding (IF) respite

IF enables a disabled person and/or their family/whānau to decide how and when they receive home and community supports services (HCSS)⁵ or respite, who provides the support and how much they're paid.

Of respondents to our survey, 193 people were using IF respite. Many noted that the benefits of this system included increased flexibility and the ability to choose their own carers.

However, IF users and disability service providers also report that:

- disabled people are sometimes unable to use their full allocation of IF respite (usually because they are unable to find relief carers)
- the IF respite overnight rate is too low and is a barrier to purchasing facility-based respite
- the Ministry requirement for IF users to account for their use of IF respite separately from their use of HCSS is onerous and overly bureaucratic.

In terms of IF respite – feedback is great because people make their own choices and are in charge of quality and effectiveness themselves.

Feedback is universally about the low rate being insufficient and the hassle therefore of keeping the two budgets separate. Delivery and supports are not the issue.

In-home support

The Ministry currently allocates approximately 1,924 people with disabilities funding for in-home or buddy support.

People using this type of respite have reported problems with finding support workers or buddies, lack of consistency in the buddy who provides the service and lack of reliability and back-up when buddies are not available.

We can't find a buddy that wants to work with my son because of our rural location.

Host-family respite

Host-family respite has the benefit of widening the support network of a disabled person and their family/whānau – in this way, a disabled person comes to know and trust the host family, who may also extend their care in a more informal way. Host-family respite can be an option for people with all types of disability, including high and complex needs. The host family can feel like a second family for the disabled person.

It can be difficult to recruit host families to provide this service. In addition, it can be difficult to make their home accessible for a person with a physical disability or to provide them with the necessary equipment (eg, a hoist).

Responses to our survey showed that the host-family respite option works very well for some.

Having it in our home works best for us as we have young kids too, and they love it when the other kids come to stay.

5 HCSS help disabled people live at home and access the community. They include services supporting household management (eg, meal preparation or household chores) and personal care (eg, eating and drinking, dressing and showering).

Challenges and opportunities

To offer successful respite services, we need skilled support workers and providers who are responsive to what the community wants and who can invest in continuous improvement.

We need to ensure equity of service delivery across the country, for all disability types and all ages. Disabled people and their families/whānau need to know what services are available and how to access them. There is room for improvement in all these areas.

The workforce

Finding suitable support workers or respite services is the main barrier to families/whānau making use of their respite allocation. Finding support workers in rural areas and smaller towns is a particular challenge. Electronic resources (such as the Mycare website: www.mycare.co.nz) could improve the ability of families/whānau to find carers and support workers.

Hard to find staff, hard to find family, it's just all hard.

A lack of support workers is not unique to the disability sector. We need a cross-Ministry, cross-sector approach to attracting and retaining skilled support workers.

A number of other strategies and action plans, including the *Healthy Aging Strategy* (Associate Minister of Health 2016), *The Health and Disability Kaiāwhina Workforce Action Plan* (HWNZ and Careerforce 2014), the *Mental Health and Addiction Workforce Action Plan 2017–2021* (Ministry of Health 2017d) and *The Disability Workforce Action Plan 2013–2016* (Ministry of Health 2013b), are already seeking to increase the availability of a competent, qualified, adaptable, person-centred workforce. Improving the availability of a skilled respite workforce is linked to actions within these other strategies and action plans.

The Ministry is also working with Te Pou o te Whakaaro Nui to progress development and leadership in the disability workforce (see Te Pou 2014). This work includes research and evaluation, workforce innovations, career promotion and planning, and sector collaboration and integration. Training and leadership grants are available to the disability workforce. More information about our work with Te Pou o te Whakaaro Nui can be found at www.tepou.co.nz

The care and support workers' pay equity settlement means that, from 1 July 2017, support workers will receive an increase in the hourly rate of pay of between 15 and 50 percent depending on their qualifications and/or experience. The settlement means that, over the next five years, the workforce will see their wages increase to between \$19 and \$27 per hour.

The settlement also creates incentives to help care and support workers gain formal qualifications and reduce staff turnover in the sector.⁶ The settlement is expected to make support work more appealing as a career.

⁶ For more information about the care and support worker pay equity settlement, see Ministry of Health 2017a.

In addition, the types of respite options promoted in *Transforming Respite* would provide a framework for purposeful, fulfilling, valued and supported work, which would help with staff retention and provide a positive experience for both the disabled person and the support worker.

Managing the market

This strategy seeks to offer disabled people and their families/whānau choice, control and flexibility in their respite options. To do this, we need to consider carefully how we can best support providers to enter and remain in the business of offering flexible respite.

The Ministry would like to move to outcomes-based respite models. This will require reconsideration of the current funding model so that we can move away from paying for respite beds that may not be used and focus the available funding on providing choice for families/whānau that deliver value for money. Such a model needs to work for all parts of the system – disabled people and their families, providers and funders.

Respite allocation

NASC organisations manage disability support services through the allocation of varying types of support or, under IF, an annual budget. Our respite survey found that about one-third of people were not satisfied with their respite allocation. People mentioned having to fight to get the allocation and living in fear of losing it. Single parents considered that their allocation should take into account their greater need for respite compared with two-parent families.

Analysis of Ministry data shows that four out of five people who entered community residential housing during 2014/15 had not been allocated facility-based respite before moving out of their family home. We do not know whether a respite allocation may have prevented or delayed the entry of these people into community residential homes, but we do know that every year that entry into adult residential facilities is delayed represents an average saving to the health system of around \$70,000 per person.

Children with disabilities are significantly over represented within the Ministry for Vulnerable Children, Oranga Tamariki care system, and are some of our most vulnerable children. Investment in respite, along with other services to support their family/whānau carers may prevent children from entering out-of-family care.

Investment in service development

Currently, some respite providers have limited resources to fund capital projects or invest in service development. There has been very limited respite service development in recent years, partially because of the lack of attractiveness to providers of the current respite models.

Some smaller providers are running popular and innovative respite services using Carer Support payments and community grant funding. This shows what can be achieved with the right attitude and with community support.

Respite for people with high and complex needs and medical needs

The Ministry currently contracts for a small number of specialist respite facilities that cater for children with high and complex needs who also have co-existing medical conditions (eg, a high

risk of epileptic seizure or a need for suctioning or oxygen use). These facilities have trained nursing staff and therefore receive more funding than other respite options.

The specialist respite facilities are very highly valued by the people who use them. For many of the families/whānau, there are no alternative respite supports that could cater for the level of care needed. The specialist respite facilities provide a level of support to the family/whānau that is essential to their ongoing ability to care for the disabled person in the family home.

These specialist facilities are located in Auckland and the Waikato, and are available to people in neighbouring regions. Out-of-region uptake is low, and occupancy rates are variable – some facilities are continuously full or near full, but others are underused. There are no specialist respite facilities available in the rest of the country, and consideration needs to be given as to whether such services need to be established in other regions.

People with high and complex needs also use other facility-based respite services (that are disability specific but less specialised). A one-on-one support worker may be required so that people can access these services. These services are also highly valued by the families/whānau who use them and often struggle to find any other suitable respite options.

Some young people with high and complex needs told us that they enjoyed respite and hanging out with friends there.

People with high and complex needs are usually well linked with child development services and the wider health and education systems. However, even with access to these other services, they are not always given information about respite supports that may also be available to them.

Respite for people with challenging behaviours

Family/whānau of disabled people with challenging behaviours often need respite but find it very hard to find a suitable option.

Providers of facility-based respite may decline to accept a referral for people with challenging behaviours. The provider may consider that they are unable to support the person safely or that the person's behaviour would negatively affect others using the facility. It can also be difficult to find carers through Carer Support or in-home (buddy) support funding.

The Ministry funds specialist Behaviour Support Services for disabled people whose behaviour makes it difficult for them to engage in everyday routines, settings, activities and relationships.⁷ These services work with the disabled person and their support network to make it easier for the disabled person to be independent and involved in the community.

Where it may help, families/whānau should be supported to access Behaviour Support Services so that the disabled person can participate in respite activities.

A highly skilled and supported workforce is needed to provide respite support for people with challenging behaviours.

⁷ For more details, see the Ministry's webpage: www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/behaviour-support-services

After-school care, before-school care and school holiday programmes

There is high demand for after-school care, before-school care and school holiday programmes ('out-of-school' care programmes) that cater for children and young people with disabilities. When respite funding becomes more flexible, it is likely that more parents will opt to use it for out-of-school care programmes.

Some mainstream out-of-school care providers we spoke with are eager to run inclusive programmes, and support children and young people with disabilities to attend. A current barrier is a lack of funding for additional staff to support children with disabilities within the programmes.

Some families/whānau currently use Carer Support to fund a support worker to attend a mainstream programme with their child. There is scope for teacher aides to provide similar support in the out-of-school care environment, using respite funding.

Mainstream out-of-school care programmes will not be suitable for all children with disabilities. The Ministry currently funds some providers to run school holiday programmes specifically for children and young people with disabilities, and other school holiday programmes are funded through Carer Support or paid for privately.

Information provision and coordination/ planning of services

The Ministry invests in Disability Information and Advisory Services (DIAS). Its DIAS providers aim to provide high-quality information to disabled people and their families/whānau, including details on where to go for more information, the services available and how to access them.

Under the new model for disability support (the New Model), the Ministry funds local area coordinators (LACs) to support disabled people and their families/whānau to access the community.⁸ As part of EGL, the Ministry has also established independent facilitators, who assist disabled people and their families/whānau to 'dream big', make plans for the future and connect with their local community. Each of these roles can play a part in providing disabled people and their families/whānau with information about respite options and widening the respite support networks available to families/whānau.

DIAS, along with the LACs and independent facilitators, came about through a realisation that it is not sufficient to allocate funding for disabled people and their families/whānau – there is also a need to help people work out how to access support in the community and use their funding allocations effectively.

Our survey found that, for some families/whānau, a lack of information about options and their governing conditions was the main barrier to accessing respite. When we asked people how they would like respite delivered in future, they said they needed better information about what is available, early access to respite and help with accessing respite options.

8 The New Model is a new way of supporting disabled people to achieve their goals. It gives people more choice and control over support and funding in their everyday lives. For more information, see the Ministry's webpage New Model for Supporting Disabled People at: www.health.govt.nz/our-work/disability-services/disability-projects/new-model-supporting-disabled-people

In 2016, the Ministry engaged Sapere Research Group to review DIAS and NASC services. The review (Sapere Research Group 2017) recommended a cultural and paradigm shift for some DIAS and NASC functions to simplify and streamline them. It recommended an investment approach: aiming to meet people's needs early and, where possible, reduce the necessity for long-term disability supports, in line with LAC and EGL principles. That finding is consistent with the aims of this strategy: to ensure that families/whānau have access to clear information about respite options and that we see respite as an investment in family/whānau resilience.

Better coordination and advertising of available services. Every parent I speak to knows of activities and services I have never come across, so a website where specific details can be posted with contact information would make life much easier for parents.

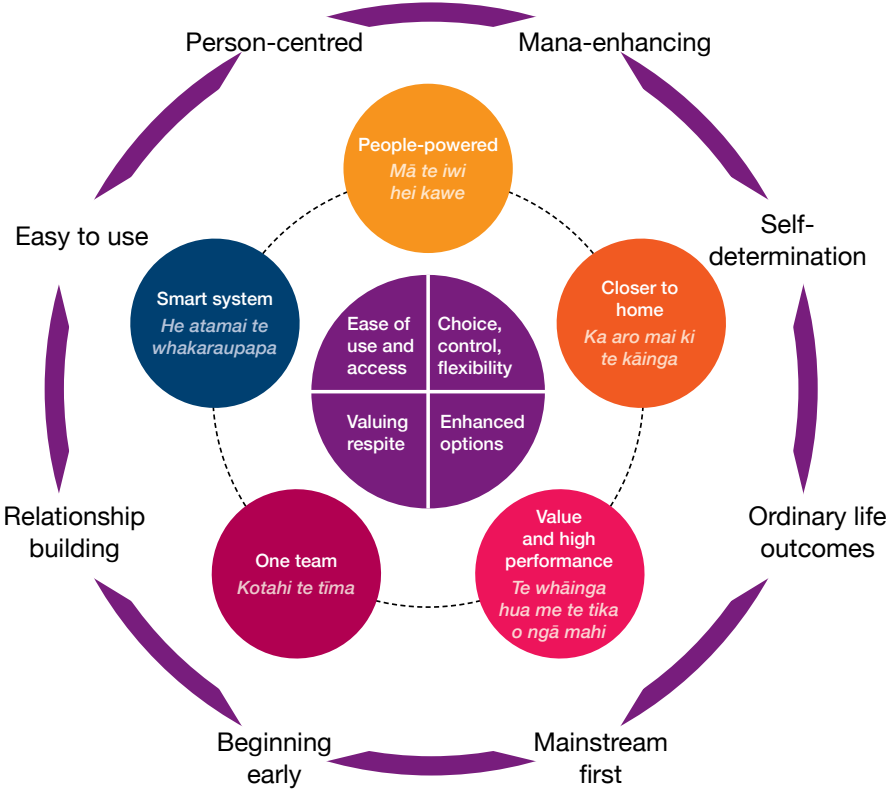
In feedback on the draft DSS respite strategy, people told us that provision of better information on the respite options available and how to access them was a priority. People also told us that they needed both online and other options for receiving information about respite options.

Future direction

The strategic framework for the future of respite encompasses the goals of both the New Zealand Health Strategy and EGL (Ministry of Health 2016a and b; Enabling Good Lives 2017). In the future, we will be focused on where we can improve existing services and where we need to innovate.

This section identifies some outcomes for this respite strategy, listed under headings that reflect our key aims – choice, control and flexibility; enhanced options; valuing respite; and ease of use and access.

Figure 1: The strategic framework for the future direction of respite



Choice, control and flexibility

Outcome 1: Disabled people and their families/whānau have control of a flexible respite budget.

In the context of respite, 'flexibility' means different things to different people, just as people's definitions of effective respite services will differ.

This strategy proposes to introduce flexible respite budgets that disabled people and their families/whānau can use to pay for or subsidise the type of break that suits them best.

Recent research shows that personal budgets can have a positive impact on the life of disabled people and their carers alike. For disabled people, the benefits include feeling in control of their support, improved physical and mental wellbeing and better relationships with family/whānau members. For carers, the benefits include improved quality of life, improved physical and mental wellbeing and support to continue caring (Hamilton et al 2016).

Outcome 2: Disabled people and their families/whānau have choice and flexibility to use respite funding in ways that meet their respite needs.

The Ministry's *Purchasing Guidelines for the New Model for Supporting Disabled People* (Ministry of Health 2013a), will be used to set guidelines for the use of flexible respite budgets. These guidelines are currently used for other types of flexible disability supports, such as Enhanced Individualised Funding (EIF). The guidelines are at www.health.govt.nz/publication/purchasing-guidelines-new-model-supporting-disabled-people

Families/whānau will be able to define what a 'break' means for them. People will have clear guidance on the use of respite funding.

Families/whānau may wish to buy or subsidise respite in the following forms (this list is not exhaustive).

- A support worker coming to the family home to assist the disabled person while the family/whānau have a break outside the home, or in the home if they wish.
- Sleepovers/holidays for the disabled person with friends and family/whānau.
- Funding for transport costs for a family/whānau member or friend to come to the family home (or elsewhere) to care for the disabled person.
- A support worker to assist the disabled person while the family/whānau are all on holiday together.
- Activity-based programmes for the disabled person (such as day trips, evenings out or activities at a fixed location).
- Out-of-school care programmes.
- Holiday camps.
- Overnight stays in facility-based respite homes or with another family/whānau.

To meet people's diverse respite needs, we need to focus on outcomes. The main outcome we

The Ministry should give everyone who requires it a respite budget and let them determine who they purchase services from and/or how they want to use the budget to suit them. We need to make the 'how' and 'what' you can purchase with the respite budget more flexible and less restrictive. Respite is 'a break', and that is defined differently by everyone – this needs to be recognised and supported so that however the person wants to spend their budget to achieve that is fine. Less residential respite and more individually tailored situations.

are seeking is primary carers who: are not stressed, are resilient, have capacity to have ordinary life experiences and feel able to continue to provide care. This requires a new way of thinking, involving, in particular, support for families/whānau that meet their needs, whatever those needs are.

Enhanced options

Outcome 3: Disabled people can access a range of respite options.

Implementing this strategy will see an expanded range of respite services in response to local demand. We encourage disabled people, providers, families/whānau and groups of parents to work together to design innovative respite solutions.

This strategy will focus on respite that takes the form of active, person-centred and community-based recreation that builds disabled people's competencies rather than additional passive leisure time (Armstrong and Shevellar 2009).

This strategy encourages providers to respond to the changing and evolving desires of disabled people and their families/whānau and develop a new range of services to meet changing needs. Feedback included the need for more meaningful activities programmes available for disabled adults during business hours and for more out-of-school care options for school-aged people with disabilities.

Outcome 4: Families/whānau who care for disabled people with challenging behaviours or high and complex needs can experience a break from the caring role.

This strategy proposes co-designing an appropriate model for ensuring respite services are available to those who need them most. The focus would be on determining how to deliver respite services for those with challenging behaviours, services that cater for high and complex or medical needs and a sustainable model for dedicated facility-based respite.

To achieve this outcome, the Ministry would engage with providers, stakeholders, other agencies and other parts of the health and disability sector to explore how we can share resources and achieve joint outcomes.

Outcome 5: Families/whānau who wish to access mainstream or disability-specific out-of-school care programmes are able to do so.

This strategy proposes to work with out-of-school care providers, alongside other agencies, to reduce barriers to disabled children and young people accessing mainstream and disability-specific programmes.

Outcome 6: Respite services provide a fulfilling work environment for support workers.

This strategy proposes to support the development of a range of respite options that are empowering for disabled people, support workers and providers alike. Where respite options work well, support workers act with initiative and purposefully work to enhance the competencies of disabled people. Both the support worker and the disabled person grow, and the support worker's job is meaningful and fulfilling. An effective workforce also brings benefits to providers.

Valuing respite

Outcome 7: Support for disabled people and their families/whānau to have a break from the caring role begins early and evolves throughout their lives.

An investment approach is about recognising that up-front support will provide stress relief and assist families/whānau to stay together. It involves providing support early to improve outcomes and potentially make savings later. Early investment can:

- reduce future need or escalation of need
- reduce the total cost of support over the lifetime of a person with a disability
- achieve better long-term outcomes
- support people to become more independent.

The Ministry's recent review of NASC organisations (Sapere Research Group 2017) found that a reduction in the costs of care over a disabled person's lifetime should arise from administrative streamlining, more innovative allocations with an investment approach and additional flexibility.

This strategy proposes to introduce a paradigm shift towards an investment approach, through which we allocate supports that will enable disabled people and their families/whānau to live more independently in future.

As we transform respite, we will update NASC allocation guidelines to reflect this investment approach. In future, support to access respite may include:

- working with families/whānau on the importance of taking regular breaks from the caring role
- encouraging families/whānau to build a support network of trusted friends and family/whānau and to ask them for help
- allocating funding for respite where it is needed, *before* the family/whānau becomes stressed and at risk of breakdown
- enabling families/whānau to find and use respite options that work for them.

With children and young people, we find starting early with their family/whānau is important as it allows us to help them build their connection to their community and natural supports from the beginning. We also find using ordinary terms such as babysitting, sleepovers and holiday programmes, rather than the term 'respite' is helpful. In general, it is important that families/whānau do not see respite as something punitive or about sending their family member away but part of everyday life.

Outcome 8: Ongoing improvements to respite supports are identified through measuring the effective achievement of outcomes.

We need a way to measure whether the changes we are making to respite are achieving the improvements that we expect. 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 it will be used to inform our future planning and decision-making
- be linked to the evaluation framework for the disability system transformation
- incorporate feedback and complaints from people using respite 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 have a culture that supports people to speak out and provides those people with the opportunity to give feedback regularly. In addition, DSS has a team of people who investigates and responds 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 Health and Disability Services](http://www.health.govt.nz/about-ministry/contact-us/complaints-about-health-and-disability-service) at: www.health.govt.nz/about-ministry/contact-us/complaints-about-health-and-disability-service

Ease of use and access

Outcome 9: Respite support payments are easy to administer.

This strategy proposes looking at options for replacing the current Carer Support claim and payment system with a flexible respite budget, administered electronically. This may result in an online platform, through which people could find volunteer carers, support workers or respite providers and offer koha or subsidise or pay for services from their flexible respite budget.

Outcome 10: Disabled people and their families/whānau can find and access respite options in their community.

This strategy proposes setting up comprehensive online resources to support families/whānau to find and engage carers or respite services. Printed versions of the resources would be available from NASCs, DIAS and in the community for people who do not have access to computers or the internet.

The strategy proposes setting up a mechanism for providing help to families/whānau who need support to find out what respite options are available and how to access them. This help would include access to LACs, where available, or alternative support through DIAS and/or NASC.

Outcome 11: NASCs are supported to implement changes to respite.

This strategy proposes engaging with NASC staff to support them in moving towards an investment approach. This includes allocating supports, access to Behavioural Support Services (where challenging behaviour is a barrier to accessing respite) and ensuring that families/whānau have help to determine what options are available and how to access them.

Implementation roadmap

The following table sets out a proposed roadmap for implementing the respite strategy.

Choice, control and flexibility		
Outcome 1: Disabled people and their families/whānau have control of a flexible respite budget. Outcome 2: Disabled people and their families/whānau have choice and flexibility to use respite funding in ways that meet their respite needs.		
Actions	Within one or two years	Within three to five years
Action 1: We convert existing respite funding for each family/whānau to a flexible budget with fewer restrictions for its use.	Disabled people and their families/whānau can access and pay for supports online.	Disabled people and their families/whānau can use respite budgets flexibly alongside other support funding they receive (such as funding for personal care, household management and supported/independent living).
Action 2: We develop clear guidelines for funding use.	The market responds to the strategy, offering services that people want to buy.	
Enhanced options		
Outcome 3: Disabled people can access a range of respite options.		
Actions	Within one or two years	Within one or two years
Action 3: We investigate innovative ways to enable respite service development.	Providers connect with local communities to determine the respite services required in each region. More respite options are available.	A wide range of quality respite options are readily available throughout the country.
Outcome 4: Families/whānau who care for disabled people with challenging behaviours or high and complex needs can experience a break from the caring role.		
Actions	Within one or two years	Within one or two years
Action 4: The Ministry looks at ways of co-designing new models for respite that include input from across the health sector as well as other agencies.	All agencies understand each other's position regarding access to facilities and other supports. A work plan is established that involves the operation of joint services where possible. A respite purchasing model is completed.	A joint approach to sharing facilities or other supports for disabled people with challenging behaviours or high and complex needs is in place where possible. We are equitably supporting all families/whānau to access respite.

Outcome 5: Families/whānau who wish to access mainstream or disability-specific out-of-school care programmes are able to do so.

Actions	Within one or two years	Within three to five years
Action 5: We work with the Ministry of Social Development, the Ministry of Education, schools and out-of-school care providers to remove barriers to access to out-of-school care programmes.	No policy or operational barriers to accessing out-of-school care remain. Out-of-school care providers are responsive to the needs of disabled children and young people.	Children and young people with disabilities can access mainstream out-of-school care programmes if they wish to.

Outcome 6: Respite services provide a fulfilling work environment for support workers.

Actions	Within one or two years	Within three to five years
Action 6: The Ministry's Disability Workforce Action Plan includes actions to address current difficulties in attracting and retaining support workers.	Families/whānau find it easier to find paid support workers or volunteer carers.	Families/whānau can find paid support workers or volunteer carers. Work as a support worker is fulfilling and is seen as adding value to the life of disabled people, and to the wider community.

Valuing respite

Outcome 7: Support for disabled people and their families/whānau to have a break from the caring role begins early and evolves throughout their lives.

Actions	Within one or two years	Within three to five years
Action 7: We update NASC allocation guidelines and training to encourage an investment approach and more flexibility to allocating respite.	NASC services have access to updated information and training to support them in taking an investment approach to allocating respite.	NASC services are able to provide families/whānau with certainty and confidence that they can take a break through all stages of their lives.

Outcome 8: Ongoing improvements to respite supports are identified through measuring the effective achievement of outcomes.

Actions	Within one or two years	Within three to five years
Action 8: The Ministry and stakeholders design a framework for measuring achievement of the outcomes.	An outcomes measurement framework is in place, and necessary data is being collected. People are aware of how to make a complaint if they are unhappy with a service.	Evaluation of outcomes shows that families/whānau are better able to access respite.

Ease of use and access

Outcome 9: Respite support payments are easy to administer.

Actions	Within one or two years	Within three to five years
Action 9: Work is undertaken to improve the current Carer Support administration system with an electronic processing option.	Some people can access their flexible respite budget online and pay for respite supports online. An alternative system for administering respite supports exists for those who wish to use it.	Most people can access their flexible respite budget online and pay for respite supports online.

Outcome 10: Disabled people and their families/whānau can find and access respite options in their community.

Actions	Within one or two years	Within three to five years
Action 10: LAC, NASCs and DIAS have comprehensive information about all available respite options in each region in an easily accessible format and are knowledgeable about changes to respite.	Guidelines are in place, and DIAS have updated their information.	Comprehensive information on the range of respite options in each area is available online and through LAC, NASC and DIAS.

Outcome 11: NASCs are supported to implement changes to respite.

Actions	Within one or two years	Within three to five years
Action 11: We work with NASC services on: <ul style="list-style-type: none"> • taking an investment approach • using flexible respite funding • offering behavioural support services • supporting families/whānau to understand the need to take a break and how to build a community of support • ensuring families/whānau have help to identify and access respite options. 	NASC services begin to take an investment approach to allocating supports. Families/whānau have advice on respite options and access.	Families/whānau feel supported by NASC services to access respite. Families/whānau who want it, have access to independent help to find and access services.

Glossary

Carer: A person assisting a family/whānau member or friend who has a disability to do everyday activities.

Carer Support: A subsidy to cover some of the costs of using a support person to help a carer take a break from the caring role.

Disability Information and Advisory Services (DIAS): Organisations who share information and connect people with disability services and other disability related resources.

Disability Support Services (DSS): The group within the Ministry of Health that is responsible for the planning and funding of disability support services.

Enabling Good Lives (EGL): An approach to supporting disabled people that aims to make it easier for disabled people and their families/whānau to create good lives for themselves by offering them greater choice and control over the supports they receive.

Facility-based respite: Care provided for a disabled person out of their home, usually overnight in a dedicated respite house or other facility, which provides care for a group of about five people at one time.

Individualised Funding/Enhanced Individualised Funding (IF/EIF): Mechanisms that enable disabled people to manage their disability supports directly. IF gives disabled people more choice in how they are supported and includes an option to employ their own support worker directly.

Kaiāwhina: The over-arching term to describe non-regulated roles in the health and disability sector. The term does not replace the specific role titles, for example: health care assistant, orderly, mental health support worker.

Local area coordinator (LAC): A person working in the disability sector to assist disabled people and their families/whānau to live good, everyday lives within welcoming communities, hapū and iwi.

Ministry of Health: The government's principal advisor on health and disability: improving, promoting and protecting the health of all New Zealanders.

Needs Assessment Service Coordination Services (NASCs): Organisations contracted by the Ministry of Health to work with a disabled person and their family/whānau or carers to identify the disabled person's strengths and support needs, outline what disability support services are available and determine their eligibility for Ministry of Health-funded support services.

Respite: Short-term breaks for the carers of a disabled person that also provide a positive, stimulating and worthwhile experience for the disabled person.

Support worker: An individual employed or contracted to perform respite support tasks for the disabled person and their family/whānau. This term also includes volunteers.

References

- Armstrong J, Shevellar L. 2009. Re-thinking respite. *NADD Bulletin* XII(6) Article 3.
- Associate Minister of Health. 2016. *Healthy Ageing Strategy*. Wellington: Ministry of Health.
- Enabling Good Lives. 2017. URL: www.enablinggoodlives.co.nz (accessed 20 June 2017).
- Hamilton M, Giuntoli G, Johnson K, et al. 2016. *Transitioning Australian Respite* (SPRC Report 04/16). Sydney: Social Policy Research Centre, University of New South Wales.
- Health Workforce New Zealand (HWNZ), Careerforce. 2014. *The Health and Disability Kaiāwhina Workforce Action Plan*. URL: www.workforceinaction.org.nz (accessed 20 June 2017).
- Minister of Health. 2016a. *New Zealand Health Strategy: Future direction*. Wellington: Ministry of Health.
- Minister of Health. 2016b. *New Zealand Health Strategy: Roadmap of actions 2016*. Wellington: Ministry of Health.
- Ministry of Health. 2012. *Whāia Te Ao Mārama: The Maori Disability Action Plan for Disability Support Services 2012 to 2017*. Wellington: Ministry of Health.
- Ministry of Health. 2013a. *Purchasing Guidelines for the New Model for Supporting Disabled People*. Wellington: Ministry of Health.
- Ministry of Health. 2013b. *The Disability Workforce Action Plan 2013–2016*. Wellington: Ministry of Health.
- Ministry of Health. 2014a. *The Guide to He Korowai Oranga: Māori Health Strategy 2014*. Wellington: Ministry of Health.
- Ministry of Health. 2017a. Care and support workers pay equity settlement. URL: www.health.govt.nz/new-zealand-health-system/care-and-support-workers-pay-equity-settlement (accessed 20 June 2017).
- Ministry of Health. 2017b. *Disability Respite Survey 2016: Summary of responses*. Wellington: Ministry of Health.
- Ministry of Health. 2017c. *Faiva Ora 2016–2021: National Pasifika Disability Plan*. Wellington: Ministry of Health.
- Ministry of Health. 2017d. *Mental Health and Addiction Workforce Action Plan 2017–22*. Wellington: Ministry of Health.
- Ministry of Health. 2017e. *Transforming Respite: Disability Support Services Draft Respite Strategy 2017–2022*. Wellington: Ministry of Health.
- Ministry of Social Development. 2014. *The New Zealand Carers' Strategy Action Plan for 2014 to 2018*. Wellington: Ministry of Social Development. URL: www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy (accessed 20 June 2017).
- Office for Disability Issues. 2016. *New Zealand Disability Strategy 2016–2026*. Wellington: Ministry of Social Development. URL: www.odi.govt.nz/nz-disability-strategy/about-the-

strategy/new-zealand-disability-strategy-2016-2026/read-the-new-disability-strategy (accessed 20 June 2017).

Office for Disability Issues. 2014. *Disability Action Plan 2014–2018: Update 2015*. Wellington: Office for Disability Issues. URL: <https://www.odi.govt.nz/nz-disability-strategy/disability-action-plan/#access> (accessed 20 June 2017).

Sapere Research Group. 2017. *Disability Information and Advisory Services and Needs Assessment and Service Coordination Review – A proposed design and framework*. Wellington: Ministry of Health.

Te Pou. 2014. *Let's Get Real: Disability*. Auckland: Te Pou o te Whakaaro Nui. URL: www.tepou.co.nz/resources/lets-get-real-disability-a-framework/530 (accessed 20 June 2017).

United Nations. 2006. Convention on the Rights of Persons with Disabilities (CRPD) URL: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (accessed 20 June 2017).

Appendix 1: Strategic framework

The New Zealand Health Strategy

The New Zealand Health Strategy (see Minister of Health 2016a) provides the overarching framework for our country's health system. The central concept is that 'all New Zealanders live well, stay well, get well, in a system that is people-powered, provides services closer to home, is designed for value and high performance, and works as one team in a smart system'. The concept of a 'people-powered' system is particularly relevant to this respite strategy.

He Korowai Oranga

New Zealand's Māori Health Strategy, He Korowai Oranga (see Ministry of Health 2014a) sets the overarching framework that guides the government and the health and disability sector to achieve the best health outcomes for Māori.

New Zealand Disability Strategy

The vision of the New Zealand Disability Strategy (see Office for Disability Issues 2016) is to have New Zealand become a non-disabling society – a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all New Zealanders works together to make this happen. *Transforming Respite* particularly reflects the New Zealand Disability Strategy's principles of choice and control, investing in our whole lives, ensuring disabled people are part of the decision-making process and developing specific and mainstream support and services.

Disability Support System Transformation

Work is under way to transform New Zealand's disability support system, based on the Enabling Good Lives (EGL) vision and principles and informed by evidence of 'what works'. *Transforming Respite* is linked to this transformation work.

Whāia Te Ao Mārama

Whāia Te Ao Mārama (see Ministry of Health 2012) is the Māori Disability Action Plan for Disability Support Services from 2012 to 2017. A refreshed Whāia Te Ao Mārama for 2017 to 2022 will be released in late 2017 on the Ministry's website. This respite strategy contributes to the vision of Whāia Te Ao Mārama; in particular, it supports tangata whaikaha (disabled people) and their whānau to achieve a good quality of life and wellbeing and to participate in their communities as other New Zealanders do.

We discussed *Transforming Respite* with Te Ao Mārama, and invited the group to distribute our respite survey through their networks. We received a significant number of responses from tangata whaikaha and their whānau – 204 responses (14 percent) were from individuals who identified as Māori.

Faiva Ora 2016–2021: the National Pasifika Disability Plan

Faiva Ora 2016–2021, the National Pasifika Disability Plan (see Ministry of Health 2017c) outlines the vision that Pacific disabled people and their families/whānau are supported to live the lives they choose. We engaged with the Faiva Ora Leadership Group in developing this strategy.

This strategy recognises that Pacific peoples have a preference for Pacific-specific disability services. They prefer respite services provided by Pacific relief carers, who understand their language and their cultural needs.

Disability Action Plan 2014–2018 (Update 2015)

The Disability Action Plan 2014–2018 (see Office for Disability Issues 2014) sets out priorities for actions that promote disabled people’s participation and contribution in society. It advances implementation of the United Nations’ Convention on the Rights of Persons with Disabilities (United Nations 2006) and New Zealand’s Disability Strategy (Office for Disability Issues 2016).

Priorities that align with *Transforming Respite* include disabled people having choice and control over their supports/services, making more efficient use of disability support funding and reducing barriers to disabled people making decisions to determine their own lives.

New Zealand Carers’ Strategy Action Plan for 2014 to 2018

The New Zealand Carers’ Strategy Action Plan for 2014 to 2018 (see Ministry of Social Development 2014) aims to improve support for families/whānau in their role of caring for someone with a health condition or disability.

Enabling carers to take a break is objective 1 of the plan. *Transforming Respite* contributes significantly to meeting this objective, as well as three objectives from the plan: protecting the health and wellbeing of family/whānau and carers; providing information that families/whānau and carers need and improving pathways to employment for carers.

The Health and Disability Kaiāwhina Workforce Action Plan

The Health and Disability Kaiāwhina Workforce Action Plan (see HWNZ and Careerforce 2014) aims to build a kaiāwhina workforce (people who hold unregulated roles in the health and disability sector) that adds value to the health and wellbeing of New Zealanders by being competent and adaptable, as well as an integral part of service provision.

The Disability Workforce Action Plan 2013–2016

This action plan is led by the Ministry, with advice from the disability workforce reference groups. The action plan’s aims include increasing the skills of the disability workforce, increasing the skills of people with disabilities and improving the learning options for carers.

Appendix 2: Methodology and stakeholder engagement

We developed this strategy by openly engaging with key stakeholders. We implemented a stakeholder engagement plan to ensure all stakeholders had an opportunity to be involved. We shared information about the objectives and scope of the strategy on the Ministry's website.

We conducted an online survey for disabled people and their families/whānau, and a separate survey for providers, about current and future respite options. We thank those who responded to our survey. We received 1,268 responses to the online survey from disabled people and their families/whānau and 50 responses to the provider survey. We used the information received through the survey extensively during development of this strategy. The results of the survey have been published on the Ministry's website (see Ministry of Health 2017b).

We also engaged stakeholders through:

- meetings with key providers and consumer groups (face to face and by telephone) to inform them of the strategy scope and the impact of potential changes
- presentations and workshops with Te Ao Mārama Group (a Māori advisory group), the Faiva Ora Leadership Group (a forum for Pacific stakeholders), the Consumer Consortium (an advisory group of people representing national disability organisations), Needs Assessment and Service Coordination services (NASCs), the Cerebral Palsy Society and at provider forums and the IF conference
- meetings with other government agencies (including ACC, the Ministry of Social Development and the Ministry of Education) to explore areas of joint interest
- communication with other teams within DSS and the Ministry (Health of Older People, Mental Health, Audit and Compliance, Policy and Payments and Purchasing), to identify areas of potential collaboration and joint service improvement
- email and phone contact with stakeholders who wished to get in touch with us (we provided contact details on the Ministry's website for this purpose).

In addition, in developing this strategy, we took into account:

- a review of how respite is provided overseas
- a literature review to identify best practices in respite
- a cost-benefit analysis
- consideration of the history of respite in New Zealand and previous reviews
- alignment with the New Model, EGL, the New Zealand Health Strategy and the New Zealand Disability Strategy.

The draft strategy (Ministry of Health 2017e) was released for feedback from 31 March to 3 May 2017. During the sector engagement period, around 160 people attended workshops in Auckland, Wellington and Christchurch. We received 114 written and telephone submissions on the draft strategy. A summary of submissions document is available on the Ministry's website (www.health.govt.nz).

We met with approximately 90 parents of children and young people with high and complex needs and attended a public meeting in Dunedin with around 50 attendees. We also discussed the strategy with sector groups, such as the Consumer Consortium, Te Ao Mārama Group and NASC governance groups.

We engaged specifically with youth with disabilities to ensure that we heard what children and young people wanted in a respite service.