

Transforming Respite

Disability Support Services
Draft Respite Strategy
2017–2022

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Overview

Most parents would agree that parenting is hard. For families 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 is less likely to have access to the same types of natural supports as their peers – friends and extended family may not feel confident in having a child with a disability come to stay, and therefore do not offer. Parents can feel isolated from their communities and become stressed when leaving the family home requires significant planning and it is difficult to take a break.

For these reasons, the Ministry of Health supports families caring 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, and helps them to continue in the 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. There are also significant issues with provider sustainability, and families' ability to access services.

There is a case for bringing innovative and transformative change to the area of respite. These changes will be 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 so that both the family and the disabled person have access to a 'good life'. Respite itself is a means for carers to get a break and feel refreshed. 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 need to focus on outcomes rather than specific inputs. The outcome we 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 for disabled people. This requires a new way of thinking; in particular, to trust that families will access supports that meet their needs, whatever those needs are.

Respite support needs to be available early, before families start to feel that they cannot cope. Respite should be age appropriate, and a best match for the family as the child grows into a young person and adult. Respite is a lifelong investment in the wellbeing of the disabled person and their family.

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

- offers **choice, control and flexibility** about how disabled people and their families they take a break
- recognises the **value of respite** and takes a lifelong investment approach to allocation and funding
- **enhances the range of quality respite options** able to be accessed by the families who need them most
- is **easy to use** and to access.

There is a lot of work that needs to be done to transform the respite model. We don't yet have all the answers. This draft strategy is presented to you for your feedback. We need disabled people and their families, carers, providers and other government agencies to guide us through this transformative change and deliver the outcomes that families need.

How to have your say

There are a number of ways you can give us feedback on this draft strategy:

- using the submission form provided at the end of this document and on our website
- using the electronic submission form on our website (www.health.govt.nz)
- emailing or posting us your written comments
- attending a meeting in Auckland, Wellington or Christchurch
- requesting a telephone meeting with Ministry of Health staff.

Written submission

A submission form is included at the end of this document, and lists questions for your feedback. The submission form is also available on our website (www.health.govt.nz) in word format or an electronic questionnaire. You do not have to use the submission form to make a written submission.

You can send us your written submission by email respitestrategy@moh.govt.nz or by post.

Respite Strategy
Disability Support Services
Ministry of Health
PO Box 5013
Wellington 6140.

Sector meetings

You are invited to attend one of the following meetings in Auckland, Wellington or Christchurch during April 2017.

When: 6 April 2017
Time: 2pm to 5pm (providers); 6pm to 9pm (disabled people and their families)
Where: Helen Smith Room, Pataka, 17 Parumoana St, Porirua, Wellington.

When: 10 April 2017
Time: 2pm to 5pm (providers); 6pm to 9pm (disabled people and their families)
Where: Independent Living Service, 14 Erson Avenue, Royal Oak, Auckland.

When: 12 April 2017
Time: 2pm to 5pm (providers); 6pm to 9pm (disabled people and their families)
Where: Barcelona Room, St John of God, 26 Nash Road, Halswell, Christchurch.

Please email us (respitestrategy@moh.govt.nz) to let us know which meeting you will be attending.

Request a meeting

If you would like to talk to Ministry staff, please email us on respitestrategy@moh.govt.nz to arrange a time.

Introduction

What is ‘respite’?

1. 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, to help them to continue in the caring role. A break can be for a few hours, a day, overnight or longer, and may take place in or outside of the family home.
2. 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 break they need, in whatever form suits them.
3. 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 family/whānau.
4. 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.

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?

5. The Ministry of Health currently spends approximately \$61 million per year on respite. There are problems with all the types of respite that we currently fund. In general:
 - some current respite 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 of and rules of use for 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

¹ A respondent to the recent survey that Disability Support Services 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.

² A subsidy for carers of disabled people, reimbursing some of the costs of using a support person.

- some contracted respite options do not provide value for money – for example, some respite houses are underused
- there is inconsistency in services available throughout the country, and rates paid.

Scope of this strategy

6. Disability Support Services (DSS)' strategic direction prioritises greater choice, greater control and better outcomes for disabled people. The respite model need to align with this.
7. This strategy will set the direction for respite from this point on. 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 families, individualised funding (IF) and facility-based respite)
 - respite for disabled children, young people and adults, and their families/whānau and carers
 - increasing the capability of needs assessors and coordinators to support families/whānau to access respite
 - development of a range of respite options to suit individual families/whānau.
8. 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 or the Accident Compensation Corporation (ACC).³
9. In 2015/16, DSS allocated respite to approximately 18–20,000 clients. For most (18,331), this took the form of Carer Support. In addition, DSS allocated approximately 1,830 people with host family or facility-based respite, 1,924 with in-home support and approximately 700 are using IF respite.

Methodology and stakeholder engagement

10. 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.
11. 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 1268 responses to the online survey from disabled people and their families/whānau, and 50 responses to the provider survey. The information received through the survey was used extensively during development of this strategy.
12. 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 (a Māori advisory group), the Faiva Ora Leadership Group (a forum for Pasifika stakeholders), the Consumer Consortium (an

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

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 Individualised Funding 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).
13. In addition, in development of this strategy we took into account:
- a review of how respite is provided overseas
 - a literature review to identify best practice in respite
 - a cost-benefit analysis
 - consideration of the history of respite in New Zealand, and previous reviews
 - alignment with the new model,⁴ Enabling Good Lives (EGL), the New Zealand Health Strategy and the New Zealand Disability Strategy.
14. During the sector engagement period, we will run workshops with sector groups, providers, NASCs and service users in Auckland, Wellington and Christchurch.

Vision

15. This strategy will enable disabled people and their families:
- greater choice, control and flexibility over their respite options and how they are funded or purchased
 - access to respite at a time and in a way that suits their needs.

Principles

16. The principles of this strategy are based on those developed for EGL, and set out in the DSS Tier One Service Specification. 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 from caring that they need.
Beginning early	We take an investment approach to respite, and recognise that supporting families/whānau to have a break may prevent crisis and sustain the family unit.

⁴ 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 information on the Ministry of Health’s website: www.health.govt.nz/our-work/disability-services/disability-projects/new-model-supporting-disabled-people

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 into their communities.
Mainstream first	We support disabled people and their families/whānau to access mainstream services.
Mana-enhancing	We recognise and respect the abilities and contributions of disabled people and their families/whānau.
Easy to use	Disabled people supports are simple to use and flexible.
Relationship-building	Supports build and strengthen relationships between disabled people, their families/whānau and their communities.

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

Strategic context

18. This strategy supports government priorities. It is aligned with the United Nations Convention for Rights of Persons with Disabilities, the Disability Action Plan, the Treaty of Waitangi and He Korowai Oranga (the Māori Health Strategy), and contributes to delivery of the Ministry of Health Disability Support Services Strategy 2014–2018. This strategy is also linked at an operational level with a number of other government, Ministry of Health and DSS action plans, including those set out below.

The New Zealand Health Strategy

19. The New Zealand Health Strategy 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.

The New Zealand Disability Strategy

20. The vision of the New Zealand Disability Strategy is that New Zealand is a non-disabling society – a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen. The respite strategy 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

21. Work is underway to transform the New Zealand's disability support system, based on the Enabling Good Lives (EGL) vision and principles, and informed by evidence of 'what works'. This draft strategy is linked to that work.

New Zealand Carers' Strategy Action Plan for 2014 to 2018

22. The New Zealand Carers' Strategy Action Plan for 2014 to 2018 aims to improve support for families/whānau in their role of caring for someone with a health condition or disability.
23. Enabling carers to take a break is Objective one of the plan. This respite strategy contributes significantly to meeting this objective, and a further three objectives in the Carers' Strategy Action Plan: protecting the health and wellbeing of family/whānau and carers; providing information families/whānau and carers need; and improving pathways to employment for carers.

Whāia Te Ao Mārama

24. Whāia Te Ao Mārama is the Māori Disability Action Plan for Disability Support Services 2012 to 2017. 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.
25. We discussed the strategy with Te Ao Mārama, and invited the group to distribute our respite survey through their networks. We achieved a significant number responses from tangata whaikaha and their whānau to this survey – 204 responses (14 percent of the total) were from individuals who identified as Māori.

Faiva Ora 2016–2021: the National Pasifika Disability Plan

26. This respite strategy aligns with the vision of Faiva Ora 2016–2021: the National Pasifika Disability Plan: that Pasifika disabled people and their families are supported to live the lives they choose. We engaged with the Faiva Ora Leadership Group in developing the strategy.
27. This strategy recognises that Pasifika have a preference for Pasifika-specific disability services. They prefer respite services provided by Pasifika relief carers, who understand their language and their cultural needs.

The Health and Disability Kaiāwhina Workforce Action Plan

28. The Health and Disability Kaiāwhina Workforce Action Plan aims to achieve a kaiāwhina (helper) workforce that adds value to the health and wellbeing of New Zealanders by being competent and adaptable, and an integral part of service provision. One key problem with current respite service delivery is a lack of kaiāwhina with the right skills and attitudes.
29. The Ministry of Health is developing a new disability workforce action plan.

History of respite support

30. 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.
31. From the mid-1970s, government's approach to services for people with disabilities became increasingly community-based and rights-based. Increasingly, government recognised the need for people with disabilities to have access to a wide range of community-based support.
32. 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.
33. 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.
34. 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). This took place from 1993 to 1995.
35. 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. A national provider developed respite houses in the Central and Southern regions. The RHAs also funded one on one care 'in-home' or buddy support.
36. Further government reforms saw the Ministry of Health 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.
37. The Ministry of Health introduced IF respite in 2014.

The current state of respite

People supported, and funding

38. The current respite budget is approximately \$61 million per year. Around three-quarters of the people who receive a respite allocation are aged under 25 years. One in five is Māori, and around 8 percent are Pasifika.
39. Needs Assessment and Service Coordination services allocate respite support based on the needs of individual full-time carers, and the needs of the person being cared for.
40. The Ministry of Health currently supports respite through:
 - a) Carer Support – which reimburses 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-to-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 another family/whānau’s home. The host family receives payment through Carer Support, or through a provider contracted to the Ministry. Children and young people are more likely to receive respite with a host family.
41. 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 22 percent had a sensory, neurological or ‘other’ disability. Eighty-one percent of people receiving Carer Support had a ‘medium’ or ‘high’ disability-related need.
42. As at September 2016, the Ministry was allocating 2,977 people other types of respite (see list above). 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	\$16.8 m	1,830	28 (+ rest homes)
In-home support	\$11 m	1,924	4
Individualised funding – respite	\$1.3 m	731	5 hosts
Total	\$61 m	19,648⁵	

Current respite options: further details and current issues

Carer Support

43. A number of rules govern the use of Carer Support. Carers perceive many of these to be inflexible and out dated. The main areas of complaint are:
- the low rate of subsidy: \$76 for 8–24 hours of relief care
 - the rules preventing use of Carer Support while a full-time carer is working
 - inconsistency in the rules, compared to those that govern IF
 - inadequate allocation of respite hours, and inconsistency in allocation between regions
 - inability to use the funding flexibly.
44. There are many misconceptions about the Carer Support rules; families/whānau need clearer guidance.
45. Across the country, carers use approximately 75 percent of allocated Carer Support days each year. Carers tell us that finding relief carers in their area who have the right skills, experience and attitudes is very difficult, especially because of the low rate of the subsidy available.
46. 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 1 mistake on the forms they are sent back to me. I have to get carer to resign forms and send back! Takes another 2 weeks to get paid. I always pay my carers upfront 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!

⁵ Note that some clients are counted more than once.

Facility-based respite

47. 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 the families' stress levels and enabled them to continue in a caring role.
48. 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 he or she 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 his or her family/whānau, or may not be available on the days that they would like.
49. 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.

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.

Dedicated respite houses

50. The Ministry of Health 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 at various times. Demand is higher during weekends.
51. Dedicated respite houses carry the most financial risk for providers compared to 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.
52. It is difficult to get a clear picture of demand for dedicated respite houses. At present there are few alternatives. Our survey found that about half of 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 for leaving a disabled family 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.
53. Current evidence suggests that dedicated respite houses are 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.
 54. 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, despite it being financially unsustainable, because they see the need in the community and their organisational values support continuation of the service.
 55. Other providers report that they have waiting lists of people wanting to access their services. Individuals and community groups often contact the Ministry seeking to set up new respite houses in response to apparent demand for overnight respite within their communities.
 56. Most facility-based respite is located in cities, where there 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.

Child- or adult-specific facilities

57. 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) the rules require them to transfer to an adult facility.
58. Feedback through our survey 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

59. 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.
60. Some feedback from disabled people and 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 friendships to develop.
61. 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.

62. 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.
63. 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

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

66. Individualised funding enables a disabled person and/or their family/whānau to decide how and when they receive home and community supports (HCSS)⁶ or respite, who provides the support and how much they’re paid.
67. 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.
68. 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 of \$150 is too low; it 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.

⁶ Home and community supports services’ 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).

In-home support

69. The Ministry of Health currently allocates approximately 1,924 people with disabilities funding for in-home or buddy support, at an hourly rate of approximately \$25.
70. 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

71. Host-family respite has the benefit of widening the support network of a disabled person and his or her 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. The host family also benefits, from the satisfaction of providing support to a family/whānau in need, and from the opportunity to enrich the disabled person's experiences and quality of life.
72. It can be difficult to recruit host families to provide this service. In addition, it can be difficult to make a host family's home accessible for a person with a physical disability, or to provide them with the necessary equipment (eg, a hoist).
73. Responses to our survey showed that the host-family 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.

Challenges and opportunities

74. 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 of these areas.

The workforce

75. Finding suitable carers is the main barrier to families/whānau making use of their respite allocation. Finding carers in rural areas and smaller towns is a particular challenge.

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

76. A lack of carers is not unique to the disability sector. We need a cross-Ministry, cross-sector approach to attracting and retaining skilled carers. A number of other strategies (including the Healthy Aging Strategy, the Carers' Strategy and the Health and Disability Workforce Action Plan) are already seeking to improve access to carers.
77. Technology (such as the Mycare website: <https://www.mycare.co.nz/>) could improve families/whānau's ability to find carers and support workers.
78. Ensuring that a paid carer's work is purposeful and fulfilling would help with staff retention and provide a positive experience for the disabled person.

Provider sustainability

79. This strategy seeks to strike a balance between providing disabled people and their families/whānau with choice, control and flexibility and ensuring that providers have enough financial sustainability to design and operate their services to the greatest effect.
80. The Ministry of Health would like to move to an outcomes based approach respite model, and to move away from paying for respite beds regardless of whether they are used – this is not a good use of funding where the bed occupancy rate is low.

Respite allocation

81. Needs Assessment and Service Coordination services manage disability support services within an allocated budget. This encourages a culture of allocating the minimum supports, with a view to managing the allocated 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 the allocation. Single parents considered that their allocation should take into account their greater need for respite compared to two-parent families.
82. Analysis of DSS data shows that four out of five people who entered community residential housing during 2014/15 had not been allocated facility-based respite prior to 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 entry into adult residential facilities is delayed represents an average saving to the health system of around \$70,000 per person. Preventing or delaying residential care for children with very high needs represents a higher cost saving per child per year.
83. Children with disabilities are significantly over-represented within the Child, Youth and Family 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

84. Currently, some respite providers are non-government organisations with limited resources to fund capital projects or invest in service development. In addition, the Ministry of Health does not have a budget to fund providers who wish to develop new respite services (eg, new respite houses, school holiday programmes or activity-based programmes). As a result, there has been very limited respite service development in recent years.
85. Some smaller providers are running respite services on very minimal funding, using Carer Support payments and community grant funding. Even so, some of these providers are running the most popular and innovative respite options available. This shows what can be achieved with the right attitude and with community support – but it remains difficult for these providers to grow and expand without more investment.

Respite for people with high and complex needs and medical needs

86. The Ministry of Health 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 nursing staff, and receive more funding than most other respite options.

87. These specialist facilities are located in Auckland and the Waikato, and are available to people in neighbouring regions. However, out-of-region uptake is low. 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.
88. The specialist facilities are expensive to operate; it is likely that there are more cost-effective options for delivering this level of care, outside dedicated facilities.
89. In this context, we need to consider ways of using existing funding to better support families/whānau in need.

Respite for people with challenging behaviours

90. Family/whānau of disabled people with challenging behaviours often need respite, but find it very hard to find a suitable option.
91. 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 safely support the person or that the person's behaviour would negatively affect others using the facility. Finding carers using Carer Support or in-home (buddy) support funding can be similarly difficult.
92. The Ministry of Health funds specialist Behaviour Support Services for disabled people whose behaviour makes it difficult for them to engage in everyday routines, settings, activities and relationships. 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.
93. Where it may help, families should be supported to access behavioural support services so that the disabled person can participate in respite activities.

After school care, before school care and school holiday programmes

94. There is high demand for after school care, before school care and school holiday programmes ('out-of-school' programmes) that cater for children and young people with disabilities. Respondents to our survey showed a preference for out-of-school care as respite option for school-aged children and young people.
95. 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 such mainstream programmes. Some families currently use Carer Support to fund a support worker to attend a mainstream programme with their child. There is scope for teacher aides to similarly provide support in the out of school care environment, using respite funding.

96. Mainstream out-of-school care will not be suitable for all children with disabilities. The Ministry of Health contracts some providers to run school holiday programmes specific to children and young people with disabilities. Other school holiday programmes are funded through Carer Support or paid for privately.
97. If respite funding becomes more flexible, it is likely that more parents will opt to use respite funding for out-of-school care programmes. We may need to work with other agencies to support this.

Information provision and coordination/planning of services

98. The Ministry of Health invests in Disability Information and Advisory Services (DIAS). Its DIAS contracts aim to provide high-quality information to disabled people and their families/whānau, including on where to go for more information, the services available and access.
99. Under the new model, the Ministry funds local area coordinators (LACs), whose role is to support disabled people and their families/whānau to access the community. 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 a family/whānau’s support network in relation to respite.
100. Disability Information and Advisory Services, along with the LAC and independent facilitator roles, 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.
101. Our survey found that, for some families/whānau, lack of information about options and their governing rules 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.

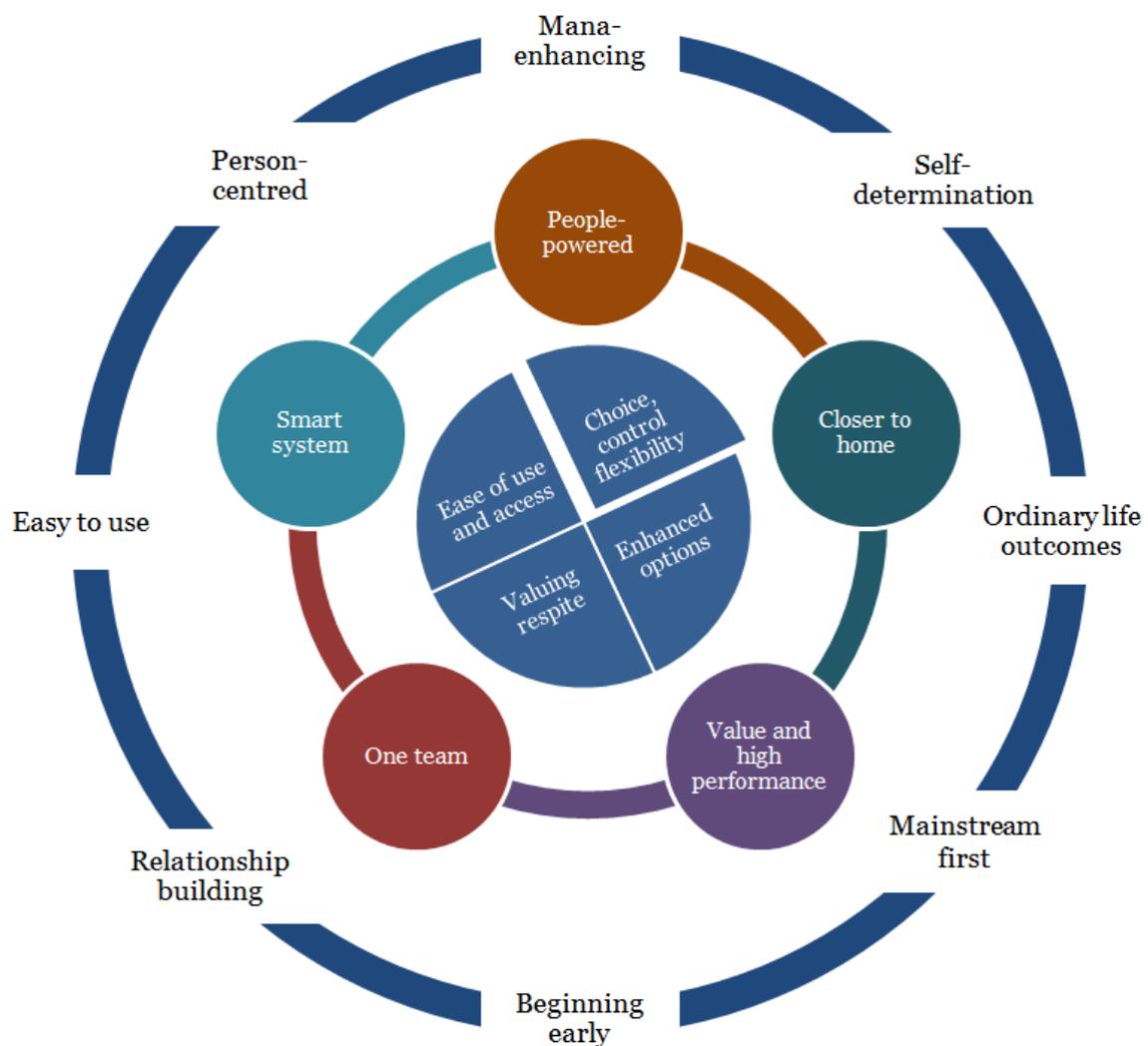
Better coordination and advertising of available services. Every parent I speak to knows of activities and services I have never come across, so a website where specific details can be posted with contact information would make life much easier for parents.

102. In 2016, the Ministry engaged Sapere Research Group to review DIAS and NASC services. The review recommended a culture and paradigm shift for some DIAS and all 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 families/whānau have access to clear information about respite options, and that we see respite as an investment in family/whānau resilience.

Future direction

103. We need to look at where we can improve existing services, and where we need to innovate.
104. The strategic framework for the future of respite encompasses the goals of the New Zealand Health Strategy and of EGL.
105. This section sets out a draft set of outcomes for this respite strategy, under headings that reflect our key aims – choice, control and flexibility, valuing respite, enhanced options, ease of use and access.

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



Choice, control and flexibility

Flexible respite budgets

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

106. In the context of respite, 'flexibility' will mean different things to different people, just as people's definitions of effective respite services will differ.
107. This strategy proposes to introduce flexible respite budgets that disabled people and their families/whānau can use to pay for the type of break that suits them best.
108. 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.⁷

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.

Outcome 2: Disabled people and their families/whānau have choice and flexibility to use respite funding in the way that suits them.

109. This strategy proposes to introduce a new set of flexible, permissive parameters for use of the funding. There would be few rules about what the respite budget could be used for, and the rules would allow families/whānau to define a 'break'.
110. Families/whānau may wish to buy 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

⁷ 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.

- activity-based programmes for the disabled person (such as day trips, evenings out or activities at a fixed location)
 - out-of-school care
 - holiday camps
 - overnight stays in respite homes or with another family/whānau.
111. To meet people’s diverse respite needs, we need to focus on outcomes rather than specific inputs. The main outcome we are seeking is primary carers who are not stressed, who are resilient, who have capacity to have ordinary life experiences and who feel able to continue to provide care. This requires a new way of thinking, involving, in particular, a trust that families/whānau will access supports that meet their needs, whatever those needs are.

Valuing respite

Taking an investment approach to respite

Outcome 3: Support for disabled people and their families/whānau to have a break from the caring role begins early, and evolves throughout their lives.

112. An investment approach is about recognising that up-front support will provide stress relief and assist families/whānau to stay together. An investment approach involves spending money early to improve outcomes and potentially save money 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
 - help people to become more independent.
113. The Ministry of Health’s recent review of NASCs⁸ 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.
114. This strategy proposes to introduce a paradigm shift for NASCs towards an investment approach, through which we allocate supports that will allow disabled people and their families/whānau to live more independently in future.
115. As we transform respite, we will update NASC allocation guidelines and training to reflect this investment approach. In future, support to access respite may include:
- teaching families/whānau about the importance of taking regular breaks from the caring role
 - encouraging families/whānau to build a support network of trusted friends and family and to ask them for help
 - allocating funding for respite where it is needed, at a time before the family/whānau becomes stressed and at risk of breakdown
 - enabling families/whānau to find and use respite options that work for them.

⁸ Sapere Research Group Ltd. 2017. *Disability Information and Advisory Services and Needs Assessment and Service Coordination Review – A Proposed Design and Framework*. Wellington: Ministry of Health.

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.

Value for money

116. We calculated a cost-benefit analysis using the Treasury's CBAX tool.⁹ The analysis was done conservatively, using the following inputs:

- people feeling more in control of their life
- delaying disabled adults entering residential care
- preventing/delaying children and young people entering residential care
- preventing/delaying families/whānau needing intensive wrap-around services.

117. The analysis predicted that ongoing investment in respite has a positive net present value (NPV). The five-year NPV at a 6 percent discount rate is \$2.2 million; the NPV at 50 years with a 3 percent discount rate is \$51 million.

118. The return on investment to society is \$30 per \$1 spent on respite (using a 6 percent discount rate). We expect the return on investment would be greater if we also took into account other factors, such as:

- better value for money for use of respite funds (eg, a reduced rate of underused facilities)
- prevention/ delay of children and young people entering Child, Youth and Family care
- savings from a decreased number of carers accessing mental health services
- increased ability for carers to participate in paid employment
- reduced administrative costs for the Ministry in processing and auditing Carer Support claims and responding to complaints and enquiries
- increased social capital, through more volunteer and koha-based support.

The ability to be able to recharge my batteries (and get some sleep) so I can continue to look after my daughter for longer in our home. Without this respite I would have burned out by now.

⁹ The Treasury. 2016. The Treasury's CBAX Tool. URL: www.treasury.govt.nz/publications/guidance/planning/costbenefitanalysis/cbax (accessed 6 March 2017).

Continuous quality improvement

Outcome 4: Ongoing investment in respite is supported by systematically measuring the effective achievement of outcomes.

119. We need to carry out effective data collection and analytics to inform our future planning and decision-making.
120. This strategy proposes to design a comprehensive framework for evaluating achievement of our outcomes. Our focus will be on measuring the extent to which families/whānau are getting the breaks they need.
121. The evaluation framework will identify and drive ongoing quality improvement.

Enhanced options

Outcome 5: Disabled people can access a range of respite options.

122. This strategy proposes to develop an expanded range of services in response to local demand. It will encourage disabled people, providers, families/whānau and groups of parents to work together to design innovative respite solutions.
123. This strategy proposes to focus on respite in the form of active, person-centred and community-based recreation that builds competency for disabled people, rather than in the form of additional passive leisure time.¹⁰
124. This strategy proposes to encourage 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 need.
125. The Ministry of Health proposes to set up a small contestable innovation fund for eligible providers – particularly not-for-profit organisations – for development of new and effective respite services.

Outcome 6: Families/whānau who care for disabled people with challenging behaviours or high and complex needs can experience a break from the caring role.

126. This strategy proposes co-design of 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.
127. 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.

¹⁰ Armstrong J, Shevellar L. 2009. Re-thinking Respite. *NADD Bulletin* XII(6) Article 3.

Outcome 7: Families/whānau who wish to access mainstream or disability-specific out-of-school care programmes are able to do so.

128. 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 8: Respite services provide a fulfilling work environment for support workers.

129. This strategy proposes to support 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.

Ease of use and access

Outcome 9: Respite support payments are easy to administer.

130. This strategy proposes to replace the current Carer Support claim and payment system with a flexible respite budget, administered electronically.
131. The strategy proposes an online platform, through which people could find carers or respite providers, pay for services from their flexible respite budget and to access volunteers or support, perhaps in exchange for koha.

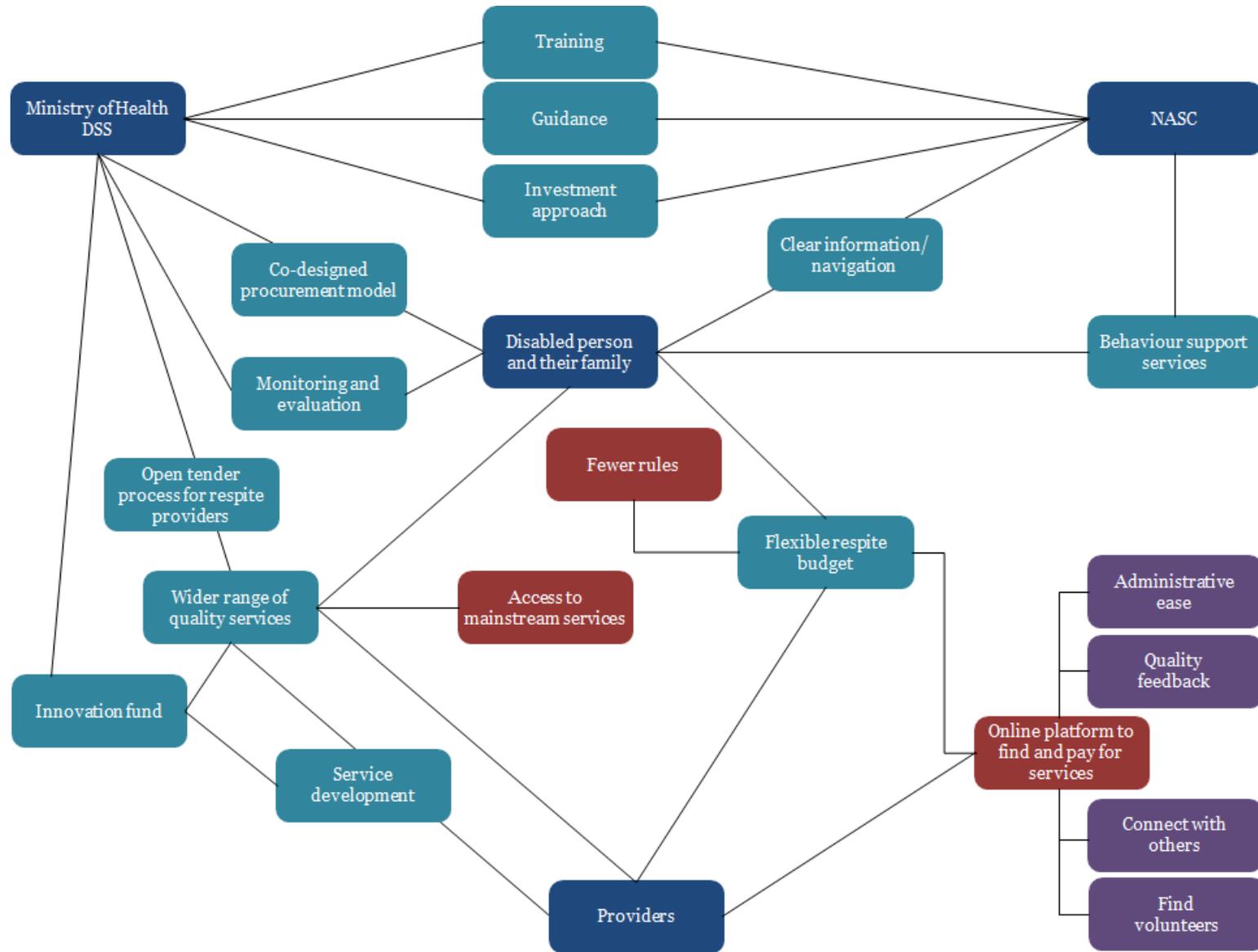
Outcome 10: Disabled people and their families/whānau can find and access respite options in their community.

132. This strategy proposes to set up comprehensive online resources to support families/whānau to find and engage carers or respite services.
133. 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.

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

134. This strategy proposes engaging with, training and mentoring NASC staff to support them in changing their practices towards an investment approach. This includes allocating supports, enabling 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.

Figure 2: Respite strategy linkages



Implementation roadmap

135. The following table sets out a proposed roadmap for implementing the respite strategy. A full implementation plan would be developed once the respite strategy is finalised.

Outcome	Suggested action	Within one or two years	Within three to five years
Choice, control and flexibility			
Outcome 1: Disabled people and their families/whānau have control of a flexible respite budget.	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).
Outcome 2: Disabled people and their families/whānau have choice and flexibility to use respite funding in the way that suits them.	Action 2: We develop clear guidelines for use of funding.	The market responds to the strategy, offering services that people want to buy.	
Valuing respite			
Outcome 3: Support for disabled people and their families/whānau to have a break from the caring role begins early, and evolves throughout their lives.	Action 3: We update NASC allocation guidelines and training to encourage an investment approach 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 4: Ongoing investment in respite is supported by systematically measuring the effective achievement of outcomes.	Action 4: The Ministry and stakeholders design a framework for measuring the level of investment in short breaks, and the outcomes achieved.	An outcomes measurement framework is in place, and necessary data is being collected.	Evaluation of outcomes shows that families/whānau are better able to access respite.
Enhanced options			
Outcome 5: Disabled people can access a range of respite options.	Action 5: We establish and administer a contestable funding pool to support provider investment in 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	Suggested action	Within one or two years	Within three to five years
Outcome 6: Families/whānau who care for disabled people with challenging behaviours or high and complex needs can experience a break from the caring role.	Action 6: The Ministry establish a stakeholder group to co-design a model for ensuring that respite services are available to those who need them most.	All agencies understand each other's position regarding access to facilities and other supports. Establish a work plan involving the operation of joint services where possible. A respite purchasing model is completed.	A joint approach to sharing of 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 7: Families/whānau who wish to access mainstream or disability-specific out-of-school care programmes are able to do so.	Action 7: We work with the Ministry of Social Development, the Ministry of Education, schools and out-of-school care providers to remove barriers to access.	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 and holiday programmes if they wish to.
Outcome 8: Respite services provide a fulfilling work environment for support workers.	Action 8: The Ministry of Health's Workforce Action Plan includes actions to address current difficulties in attracting and retaining support workers.	Families/whānau find it easier to find paid or volunteer carers.	Families/whānau can find paid or volunteer carers. Work as a carer is fulfilling, and is seen as adding value to the life of disabled people, and to the wider community.
Ease of use and access			
Outcome 9: Respite support payments are easy to administer.	Action 9: The Carer Support administration system is replaced with electronic processing.	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.	Action 10: We develop an easy-to-understand explanation of how families/whānau can use respite funding. Action 11: 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 DIASs have updated their information.	Comprehensive information on the range of respite options in each area is available online and through DIASs.

Outcome	Suggested action	Within one or two years	Within three to five years
Outcome 11: NASCs are supported to implement changes to respite.	<p>Action 12: We train NASC services on:</p> <ul style="list-style-type: none"> • taking an investment approach • using flexible respite funding • offering behavioural support services • supporting parents 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. 	<p>NASC services begin to take an investment approach to allocating supports.</p> <p>Families have advice on respite options and access.</p>	<p>Families/whānau feel supported by NASC services to access respite.</p> <p>Families who want it, have access to independent help to find and access services.</p>

Submission form

Your details

This submission was completed by: (name) _____

Address: (street/box number) _____

(town/city) _____

Email: _____

Organisation (if applicable): _____

Position (if applicable): _____

(Tick one box only in this section)

Are you submitting this:

- as an individual or individuals (not on behalf of an organisation)?
 on behalf of a group, organisation(s) or business?

(You may tick more than one box in this section)

Please indicate which sector(s) your submission represents:

- | | |
|--|--|
| <input type="checkbox"/> Disabled person or their family | <input type="checkbox"/> NASC |
| <input type="checkbox"/> Disabled Person's Organisation | <input type="checkbox"/> DIAS |
| <input type="checkbox"/> Current respite provider | <input type="checkbox"/> Other sector(s) (please specify): |
| <input type="checkbox"/> Potential new respite provider | |

Privacy

We may publish all submissions, or a summary of submissions on the Ministry's website. If you are submitting as an individual, we will automatically remove your personal details and any identifiable information.

If you do not want your submission published on the Ministry's website, please tick this box:

- Do not publish this submission.

Your submission will be subject to requests made under the Official Information Act. If you want your personal details removed from your submission, please tick this box:

- Remove my personal details from responses to Official Information Act requests.

If your submission contains commercially sensitive information, please tick this box:

- This submission contains commercially sensitive information.

Please send the submission in a Word document (not PDF please) by email to:

respitestategy@moh.govt.nz by **5 pm**, Wednesday 3 May 2017

Questions

Although this form provides blank spaces for your answers to questions, there is no limit to the length of your responses; you should take as much space as you need to answer or comment. Feel free to enlarge the boxes or attach additional pages.

Q1 Do you think that implementation of the strategy will make it easier for families to continue in the caring role?

Yes No

Reasons/additional comments:

Q2 Are there any parts of the draft respite strategy that you don't like?

Yes No

Reasons/additional comments:

Q3 Do you think there is anything missing from the draft respite strategy that you would like to have added?

Yes No

Reasons/additional comments:

Q4 Do you support the introduction of a flexible respite budget?

Yes No

Reasons/additional comments:

Q5 What barriers (if any) do you think there are for families with disabled children and young people using out-of-school care programmes?

Q6 What do you think should happen so that there are respite options for people with high and complex needs and challenging behaviours?

Q7 What additional information about respite do you think should be available for disabled people and their families, and in what format?

Q8 Do you think there is a need for families to have individual help to find a respite option that works for them?

Yes No

Reasons/additional comments:

Q9 Do you support changes to Carer Support administration?

Yes No

Reasons/additional comments:

Q10 Do you support the development of an online system (website) for managing flexible respite budgets?

Yes No

Reasons/additional comments:

Q11 Many people don't like the term "respite". What should we call it instead?

Q12 Are there any other comments you would like to make?