

Summary of Submissions on *Transforming Respite*

Disability Support Services
Draft Respite Strategy
2017 to 2022

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Contents

Purpose	1
Summary of main points	1
Introduction	3
Sector engagement on the draft strategy	4
Stakeholder feedback	5
Choice, control and flexibility	5
Enhanced options	6
Ease of use and access	9
Valuing respite	11
A new name for respite	12
Priorities for implementation	12
The youth voice	12

Purpose

From 30 March to 3 May 2017, the Ministry of Health (the Ministry) invited the disability sector to give feedback on *Transforming Respite: Disability Support Services Draft Respite Strategy 2017–2022* (the strategy). This report presents our analysis of the messages we received from the disability sector about the strategy and from children and young people with disabilities about their respite experiences.

Summary of main points

Overall, there was strong support for the future direction proposed in the strategy. People commented that it was positive and forward thinking. They welcomed the concept of flexible respite budgets and changes to Carer Support rules and administration.

They were keen for more detail on how the strategy would be implemented and were eager for the actions to be implemented as soon as possible.

In their feedback, people expressed the importance of:

- providing clear guidance on how flexible respite budgets could be used appropriately
- ensuring there is assistance for people to find and access respite options and to manage their flexible respite budget
- having enough suitably trained people to provide relief care
- having safe and meaningful respite options available, including activities during business hours for adults with disabilities who live in their family home.

People also commented on the need to ensure:

- equity of access to respite services for people living in rural locations
- that there are both online and other ways of sharing information about respite options
- providers of respite care are able to remain financially sustainable
- quality service delivery and robust quality feedback systems.

As well as expressions of overall support, we also received some suggestions for changes that could be made to the strategy. Of note was the need to communicate more clearly that respite for disabled adults who live in their family home is included in scope, as well as respite options for carers of children and young people. Support for carers who are the spouse or child of the disabled person is also in scope.

People welcomed the opportunity for a co-design process to determine how to provide respite for people with high and complex needs.

There were mixed views on the proposal to find a new term for the word ‘respite’. ‘Family/whānau support’ or ‘short breaks’ were favoured options.

Feedback we received from children and young people with disabilities found that their current experiences of respite are for the most part positive, with some room for improvement. With some exceptions, most young people said they felt safe at respite.

The children and young people had intellectual disability, physical disability, autism or multiple and profound disability. The activities they want to do while at respite are the same as most people of their age are likely to want to do (eg, go to movies, play computer games, go to the park or beach).

The children and young people gave perspectives that had not been captured in our discussions with adults. Their new perspectives showed their desire to:

- establish a supportive community around their respite services
- ensure that their parents are well supported and welcomed within the respite service
- have more of a say about the types of activities on offer at respite and about how the service is run.

Introduction

In August 2016, the Ministry began developing a disability respite strategy. This strategy responds to requests by the disability sector to improve how respite supports are provided for disabled people and their family/whānau.

The aim of the strategy is to bring more choice, control and flexibility to the way disabled people and their families/whānau are supported to have a break from the caring role.

Sector engagement on the draft strategy

The draft strategy was released for feedback on the Ministry's website from 30 March 2017 to 3 May 2017 (a five-week period). Submissions were accepted until 8 May 2017 and have been included in this analysis.

Effort was made to reach a wide disability audience. The web link to the strategy and submission form was emailed to a large number of disability stakeholders, including providers, individuals and disability organisations. All stakeholders were asked to distribute the strategy, the submission form and a workshop invitation to their networks.

Six workshops were held in Auckland, Wellington and Christchurch, with a total of around 160 people attending across all the workshops. The majority of workshop attendees represented providers, disability organisations, or were health or disability sector professionals.

We received 114 submissions; 51 were by email or by phone, and 63 people used an online survey option. Two-thirds of the submissions that were made using the online survey were incomplete. Three-quarters of the submissions were from individuals, and one-quarter were made on behalf of a group or organisation.

The Ministry also held several meetings with interested parties to discuss the strategy. This included meeting with approximately 90 parents of children and young people with high and complex needs. We gave presentations on the draft strategy to the Consumer Consortium,¹ Te Ao Mārama Group,² the Needs Assessment Service Coordination Association (NASCA)³ and the National Needs Assessment Service Coordination Services Managers Meeting.

Because children and young people with disabilities make up 70 percent of respite users, we also sought feedback from them to ensure that their voice would be heard in the process. A summary of the findings of our youth engagement is included in this document.

¹ An advisory group of people representing national disability organisations.

² A group of external Māori advisors that support the implementation of Whāia Te Ao Mārama: The Māori Disability Action Plan and provides advice to the Ministry on issues that affect tāngata whaikaha (Māori with disabilities).

³ NASCA is the national association for Needs Assessment Services Coordination (NASC) agency managers and other senior NASC team members within the disability and health sectors.

Stakeholder feedback

Overall, most workshop participants and submitters considered that the strategy would make it easier for carers to have a break. A number of people made positive comments, such as describing the future direction proposed in the strategy as ‘manna from heaven’. People said:

- they felt heartened and excited about the future
- the increased ease of access and flexibility would better meet the varied needs of people
- they appreciated that there had been a good process of engagement with stakeholders.

Some people were unsure of the proposed future direction and wanted more detail about how it would work. Very few submissions opposed implementing the strategy.

One overarching criticism of the strategy was that it took a ‘silo’ approach to respite. People considered that the Ministry should be dealing with all types of respite together (that is, the strategy should also include respite for mental health, aged care and palliative care). One submitter said ‘This type of siloed thinking and funding currently causes issues across the system with gaps and duplication in services and will continue to do so unless addressed.’

People also commented that the strategy appeared to focus more on supporting families with children and young people who were born with a disability than on supporting adults who acquire a disability later in life (eg, as a result of a stroke).

Choice, control and flexibility

People’s ability to manage a budget

People welcomed the concept of being able to use the value of their existing respite supports flexibly to meet their individual needs. However, people also said that they didn’t want an additional administrative burden or challenges associated with employing staff directly. They said that the flexible respite budget would need to be much easier to administer than Individualised Funding (IF).

Providers, disabled people and parents voiced a concern that some families may not have the necessary skills to manage a flexible respite budget and would find it difficult to ensure that the funding lasted over the full budget period.

Other submitters considered that if people had a flexible respite budget in the form of a cash deposit into a bank account, they might use that fund for other pressing needs (such as groceries) rather than for achieving a break from the caring role.

People suggested that:

- people could use an IF host to help manage the budget
- access to a budget advisor or broker or other support could ensure that the budget was used appropriately
- the Ministry could continue to pay providers directly rather than making cash available to families

- there could be different ways to manage the budgets depending on how much money was involved and how each family wanted to manage their respite budget
- people could access volunteer budget support organisations or a broker to help them manage their flexible respite budget.

People were also concerned that having a flexible respite budget paid directly into their bank accounts might be seen as ‘income’ and as such could affect payment of any benefit that the family might also receive.

Accountability

A number of submissions and workshop participants (disabled people, their families and providers) thought it was important for people receiving a flexible respite budget to be held accountable for how they spent the money. They thought that the Ministry should have a mechanism for checking that people were using the money for respite (rather than other things). People felt strongly that this was needed, even for relatively small respite budgets.

To mitigate the risk of people misusing the respite budget, people suggested having the money paid into a bank account used only for respite, which could be audited by the Ministry. People also liked the concept of using an IF host to support people with larger respite budgets.

The workshop participants also discussed the idea of providers who had a contract with the Ministry being paid directly by the Ministry, with the choice of how to use the budget remaining with the disabled person or their family/whānau.

Clarifying how flexible respite budgets could be used

There were a number of questions about what people would be able to purchase or subsidise with the flexible respite budget. People wanted clear guidance, so they could be sure that they were using the budget appropriately.

In particular, people questioned whether the budget could be used to pay for:

- activity based programmes that operate during normal business hours and day programmes
- therapy type activities
- training carers
- volunteers and informal supports.

People also wanted to know how the flexible respite budget differed from IF. It was suggested that we need a process for review and arbitration.

Enhanced options

Facility-based respite

Some people and providers raised concerns about whether their current service would or could continue once the strategy was implemented. There were particular concerns for the sustainability of facility-based respite. This concern arises from the reduced certainty of funding for providers that could result if the strategy were implemented. People said that if existing providers do not have certainty of income, they may wind up their respite service, leaving a major gap.

On balance, it appears that most providers have accepted that Disability Support Services' future direction is towards an environment of greater choice, control and flexibility for disabled people. Providers understand that they need to ensure their services are appealing for disabled people and their families if they wish to continue to provide them.

Providers commented that it costs more to operate a respite bed than a residential bed. Costs result from transitioning new clients to the service and the administration involved with managing bookings, payments and entry and exit of clients.

People told us that it was unrealistic to expect providers to operate facility-based respite without direct funding from the Ministry. Submitters said that the amount of facility use was not the only measure of value for money, and we should also consider consumer's views about how much they appreciate the service.

Comments were also made that people coming into facility-based respite often have other issues (such as skin integrity problems or equipment that needs updating). Respite providers work to resolve these issues during the respite period. This is an additional benefit of respite that could prevent worsening health issues and contribute to the disabled person being able to continue living in the community.

Impact on price of respite services

People commented that the price of respite services (particularly overnight respite) could increase if there were no longer a specified rate in a provider's contract with the Ministry.

Disabled people and their families wanted assurance that they would be able to continue to purchase the same services once the strategy was implemented (ie, the overnight rate would not be reduced when converted to a flexible respite budget).

Out-of-school care

People and providers welcomed the inclusion of school holiday programmes and before/after school care in the strategy. People noted that this was an essential service with few (or no) options currently available for many families with a disabled child.

Providers commented on the financial challenges of operating out-of-school care programmes, particularly those reliant on Carer Support alone. One submitter said that Out of School Care and Recreation (OSCAR) funding⁴ needs higher rates for disabled children.

Barriers to operating out-of-school care included the current Carer Support rules (needing to operate an eight-hour programme to access a full day of Carer Support subsidy), transport and attracting skilled staff.

Barriers for families included Carer Support rules (specifically not being allowed to work while using Carer Support) and finding an appropriate programme (especially for children and young people over 14 years of age).

⁴ OSCAR programmes that are approved as meeting the OSCAR standards can apply for government funding. See <https://www.msd.govt.nz/what-we-can-do/providers/oscar/index.html>

Parents said that mainstream school holiday programme staff needed better training to be able to recognise and manage different behaviours.

People noted a need for Government departments to work together better in this area.

Options for people with high and complex needs and challenging behaviour

People welcomed the opportunity to address the future of facility-based respite and providing respite for those with high and complex needs through a co-design process that would involve all stakeholder groups working together to address this difficult issue. The comment was made that the strategy did not consider children with very high disability combined with high health needs.

People supported the opportunity for greater collaboration and coordination across the disability sector to make better use of existing facilities.

One submitter suggested setting up specialist respite beds in several locations throughout the country that could also be used for assessing and addressing challenging behaviours and serious aggression.

A lot of feedback about future options for supporting people with high and complex needs related to the need for additional training for support staff. People said that this work is demanding and highly skilled.

People felt there should be more investment in supporting people with high and complex needs – commenting that parents/carers of disabled people with high and complex needs deserved an appropriate level of support.

They also commented that the strategy appeared to be ‘anti-residential care’ and set an expectation that aging parents would continue to care for their adult children with disabilities until the end of their own lives.

People supported use of Behavioural Support Services (BSS) as a means of enabling access to respite. They also commented that access to BSS is only a small part of the challenge for people in accessing respite services. They mentioned that as long as there are wait lists to enter BSS, it would take time for this action to become effective in ensuring that people with challenging behaviours can access respite services.

Creating new respite options

One submission commented that additional respite services needed to be set up as a matter of urgency before the strategy could have any positive effect for families/whānau.

People also questioned whether there would be any increase in services in rural communities and felt that the government would need to intervene to ensure equitable access to services across the country. Some suggested that a specific focus of the strategy should be ensuring the provision of services in rural locations.

People said that the strategy could be successful but not if families were left with a budget and nothing to spend it on. Conversely, one submitter said that the worst outcome would be to have families end up with a lot of options that do not meet their needs and less access to the options they really need.

Families commented that they did not have the time or energy to set up new services themselves.

Innovation fund

Providers welcomed the concept of an innovation fund to support development and expansion of new respite options in new locations. One suggestion was that the innovation fund provide business mentorship to small non-governmental organisations (NGOs) running disability services.

Workforce

Submitters considered that finding trustworthy, competent carers is the main problem for many families. They said that this issue is not well addressed in the strategy and needed more consideration.

Some submitters spoke from the point of view of a support worker and the challenges of making a career as a carer. Comments were made about the need for training, career pathways, qualifications, peer mentoring and supervision in a team environment. People also mentioned health and safety considerations for support workers.

There was a call for support workers to be involved in the planned co-design process and in developing a national workforce development plan for the respite workforce.

While submitters recognised the value and dedication shown by people who volunteer their time to support people with a disability and their families, they were concerned about volunteers and their payment by koha becoming a substitute for dedicated services and trained professional staff.

Ease of use and access

Changes to Carer Support administration

Replacing Carer Support with an electronic payment system was a very popular proposal; many said this was long overdue.

People told us that we need to ensure there is a backup option for support workers, disabled people and their families who do not use computers or have internet access.

The need for information

Providers and families alike agreed that significant improvements were needed in the information provided for families on the types of respite available, where they are located and how to access them. People supported the development of a comprehensive website that shared all this information.

People commented that:

- some people have low health literacy, and any information needs to be in an easy-to-read format and in a number of languages
- a number of people do not have ready access to the internet, and information needs to be able to be shared in other ways (eg, brochures available in the community or an 0800 number that is accessible for cell phone users)
- general practitioners (GPs), nurses and Plunket nurses need access to good information so that they can provide good advice to families
- NASCs need comprehensive information about all the options available in each region.

Some disability information advisory services mentioned that they were nervous of sharing information about a service as it could be seen as an endorsement of that service, and they didn't feel they could endorse the service without knowing more about it.

The types of information that disabled people and their families want included:

- details on all the services they can access
- how to get access to the services
- how to safely engage a support worker; interview a carer; access credentials, police vetting, tax and health and safety compliance issues; understand qualifications and negotiate rates
- other service users' reviews on the quality of services.

Individual help to achieve a break

People strongly agreed that having a local area coordinator/ navigator/ facilitator/ broker to help families manage their respite budget and ensure that those families can find and access services or engage carers was an important part of the strategy. This option may not be relevant to everyone, but it was felt that it is important to have it available for those who need that level of support.

People suggested that NASCs, IF coaches, local area coordinators or a self-funded respite coordinator could all fulfil this role.

One submitter said that families need a personal coordinator to help them navigate all supports, including those funded by the Ministry of Social Development and the Ministry of Education – not just those funded by the Ministry of Health or just for disability respite.

Needs Assessment and Service Coordination services (NASCs)

A number of people commented that NASC operations would need to change significantly for the strategy implementation to be successful. People said that NASC staff need better skills at assessing the holistic support needs of the family.

A comment was made that the Ministry's proposed training for NASCs should be delivered to providers at the same time, so that everyone hears the same messages and has access to the same resources.

There was a call for nurse practitioners to be able to allocate respite to their patients and for supporting families who need respite, but are not accessing it, to get a respite referral.

People thought that we needed to put effort into improving the timeliness of response to individuals requiring respite.

Valuing respite

Measuring outcomes

Part of the strategy development process includes setting up a comprehensive monitoring framework so that we can check that the changes we are making are having the desired outcome (eg, making it easier for carers to have a break). We asked people to tell us what was important to them, so we could form outcome measures that are meaningful for the sector.

Suggestions included measuring:

- achievement of the principles/outcomes set out in the strategy
- the number of emergency unplanned or additional respite days needed now compared with after the strategy has been implemented
- consistency of service delivery across the country (and between NASCs)
- any unintended consequences of strategy implementation
- the number of children and young people with disabilities entering out-of-home placements
- school attendance for children with disabilities
- availability of services in rural areas
- outcomes from a child / young person's perspective
- financial sustainability of providers
- timeliness of people being assessed for respite and accessing services once a budget is allocated
- the number and nature of respite-related complaints now and after the strategy has been implemented
- respite staff turnover; sick-leave usage and qualifications of the workforce.

People also suggested using our 2016 disability respite survey as baseline data and repeating the survey to measure changes in satisfaction. There was also a suggestion to do a more intensive entry survey for a cohort, then retest that cohort at a later date to evaluate outcomes.

Ensuring quality and safety of services

People thought that the Ministry should continue to ensure that providers meet quality and safety standards.

With regard to safety, people said that:

- it needs to be clear what is needed to meet the requirements of the Vulnerable Children Act 2014
- we need a way to ensure it is safe to use volunteers
- families need guidance on how to do a background check on potential support workers.

One submitter commented about the need for greater transparency from both the Ministry and families on provider performance. Families could use this information to make a more informed choice about which services to access, and this transparency would serve as a driver of continuous quality improvement.

Making complaints

People also commented that they sometimes feel unsafe making a complaint directly to their current provider – they worried that there would be repercussions for the disabled person using the respite service. They also felt that other options for making complaints (eg, directly to the Ministry or to the Health and Disability Commissioner) were ineffective and took too long to be processed.

People also wanted the option to provide feedback to the Ministry on NASC service provision.

A new name for respite

There were a range of views on changing the term ‘respite’ to a name that has more positive connotations.

Those against a change said that changing the name would create confusion, is a waste of resource and would not change any aspect of service delivery (which is more important).

Disabled people supported a name change – they felt the term ‘respite’ implies that they are a burden. Some people preferred terms that gave impressions of caring, support, relaxation, stress relief, recharging batteries, time off.

‘Family/whānau support’, ‘short break’ and ‘time off’ were included in suggestions for a new name.

Priorities for implementation

People saw changing the rules for using Carer Support as a priority. They also suggested that it is very important to be provided with comprehensive information about what services are available and what the changes to respite mean for them.

Other priorities identified by submitters included training for professionals so they can advise disabled people on their options and workforce development for support workers.

The youth voice

In addition to the formal submission process, we also asked groups of children and young people to give use feedback on their respite experiences and their aspirations for the future. We did this in three different ways.

1. Teacher-assisted interviews with young people with high and complex needs.
2. An online survey for children and young people with autism.
3. Getting feedback from the Cerebral Palsy Society Youth Alliance Working Group.

The information provided by children and young people will be used to:

- tell providers what children and young people tell us about respite
- inform quality improvement of current respite services
- help develop a respite outcomes evaluation framework.

Teacher-assisted interviews with young people with high and complex needs

Teachers at a special school in Auckland interviewed 12 students aged between 15 and 21 years. All 12 students used respite in some form and had high and complex needs.

The students were asked if they had fun when they go to respite. Their answers were positive – they enjoyed activities like going to the park and hanging out with their friends. Students said they felt safe while at respite and were happy to go there. One student who spent time with a host family for respite said that the host family was like their second family.

Less positive aspects of respite reported by the students were that it was sometimes noisy and there were too many people there.

The students were asked what activities they like to do at respite. Their responses were typical of many teens and included:

- bowling
- shopping
- learning to cook
- going to the beach or park
- playing games
- going for walks
- going to the movies
- playing music.

Results of our survey for children and young people with autism

In consultation with Altogether Autism⁵ we designed an online survey for children and young people with autism. It was shared on social media from 1 to 9 June 2017.

We received 49 responses from people aged 4 to 19 years;⁶ 27 of whom said that they use respite or got looked after by someone who is not their parent or guardian. The most common types of respite was to be cared for by an extended family member or family friend.

The survey asked ‘Do you enjoy respite?’ There were 35 people who answered this question. Most (85%) said that they enjoyed respite or enjoyed it sometimes. Two young people said they did not enjoy respite and three were not sure.

⁵ A nationwide autism spectrum information and advisory service.

⁶ We did not include survey responses submitted by adults in our analysis of the survey results.

We asked whether the children and young people felt safe at respite. From the 34 responses to this question, 70 percent answered 'yes'. Three people said they sometimes felt safe: reasons included that the staff were not trained to understand autism. Three people said they did not feel safe. Four people were unsure.

The survey asked: 'Please tell me three activities you would enjoy doing at respite'. The responses are listed in order of popularity:

- watching movies
- playing Xbox or Playstation
- swimming
- going to the park, for a walk, bush walk, beach
- sports, dancing
- horse riding, cycling, go karts
- Lego, puzzles, games
- iPad, computers
- playing, hanging out with other kids
- cooking, baking
- art
- helping (with tasks around the house or garden)
- maths
- shopping
- music
- going out for a meal.

The survey asked: 'What would make respite better for you?'. Improvements that children and young people would like included:

- respite being located closer to home
- being able to interact more with their peer group – being with people they know and like
- having better activities on offer and being able to choose what to do
- having support workers they know, and who are caring and understand autism.

Feedback from the Cerebral Palsy Society Youth Alliance Working Group

The Cerebral Palsy Society established a youth advisory group which met to discuss youth perspectives on respite.

The group considers that the current problems with respite included:

- that it can be a negative experience with no access to the natural environment, no activities and no say in how the service is run (including what time you are put to bed)
- that it is not designed for youth, it's sterile, not a warm environment
- support workers need better training.

The group's vision for the future is that:

- children and young people have a say in what they do while at respite
- lots of activities are available
- respite is a community of good friends, a place you want to go
- the respite community is also a support network for parents
- the people working there love what they are doing and are empathetic
- respite is a place to build independence and transition to living away from the family home.

The group supports changing the term 'respite' to something more welcoming.