MINISTRY OF HEALTH
MANATŪ HAUORA
New Zealand Government

Disability Respite Survey

2016

Summary of responses

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Purpose

1. During October and November 2016, Disability Support Services (DSS) within the Ministry of Health conducted two surveys to inform the development of a Respite Strategy: one survey for disabled people and their families/whānau, and one for providers of services for disabled people. This report presents the findings of these surveys.

Summary of main points

2. The survey for disabled people and their families/whānau attracted 1,268 responses. It achieved good geographical coverage, and engagement across all ethnic groups. Survey respondents were candid in giving insight into the struggles they face in their everyday lives, and in accessing respite in particular.

3. The key findings of the survey are as follows.
    - Sixty-two percent of respondents were satisfied or very satisfied with their current respite options.
    - Fifty-one percent were satisfied with the amount of respite they had been allocated.
    - People's ability to use their full respite allocation ranged from 31 percent to 66 percent, depending on the type of respite they had been allocated.
    - The main reason for not using respite allocations was an inability to find a suitable carer.
    - Forty-eight percent of respondents said they would like to access facility-based respite if it was available, while 40 percent said that they would not. The remaining 12 percent already used facility-based respite.
    - Families/whānau using facility-based respite reported higher levels of satisfaction with respite services overall, compared to those who were not using facility-based respite.
    - Respondents reported benefits of respite for families/whānau that included having a break to take the pressure off, protecting carers' mental health, enhancing the wellbeing of the family/whānau, sustaining the family/whānau in the caring role and providing new experiences for the disabled person.
    - Families/whānau reported that they want access to flexible respite funding; they wanted to be able to buy a range of respite options to meet their needs.
    - Families/whānau reported that they want assistance to learn about the range of respite options and how to access them.

4. We received 50 responses to our survey for providers, including from small community-based providers running successful activity-based programmes purchased using Carer Support or individualised funding (IF). These responses showed that community-based respite can be an effective option.

Background

5. Disability Support Services within the Ministry of Health is developing a respite strategy to improve the way we support disabled people and their families/whānau to achieve “respite” or a short break from the caring role.

6. As well as reducing stress for carers and sustaining the family unit, respite also provides a disabled person with a break from their usual routine. It can offer them the opportunity to have new experiences, develop independence, visit different places and make a broader range of friendships.

7. Greater choice and control, and improving outcomes for disabled people underpins DSS’ strategic direction. Trends in New Zealand and overseas indicate the need to move to more flexible options for respite. The respite strategy aims to bring greater choice, control and flexibility to respite.

8. The online surveys we developed to inform development of this strategy ran from 19 October until 30 November 2016.

9. Participants accessed the surveys through the Ministry’s website. We sent email invitations to complete the survey to existing respite stakeholders and providers, and asked them to distribute the survey to their clients and networks. Stakeholder groups and providers were supportive of the survey, and promoted it on social media, in their newsletters and through email.

10. We thank everyone who contributed to distributing the survey, and those who took the time to respond. The survey responses was used extensively to develop the DSS draft respite strategy.

Analysis of survey responses from disabled people and their families/whānau

Demographics

Number of responses

11. We received 1,268 responses to the family/whānau respite survey. Of these:
    - 99 (8 percent) were from people with disabilities
    - 1,067 (84 percent) were from parents and primary caregivers of disabled people
    - 114 (9 percent) were from 'others', including friends, extended family/whānau members and other interested parties
    - 905 were from people with a current respite allocation.

Responses by region

12. The survey asked 'What region do you live in?', and asked people to select the Needs Assessment and Service Coordination service (NASC) region where they lived.

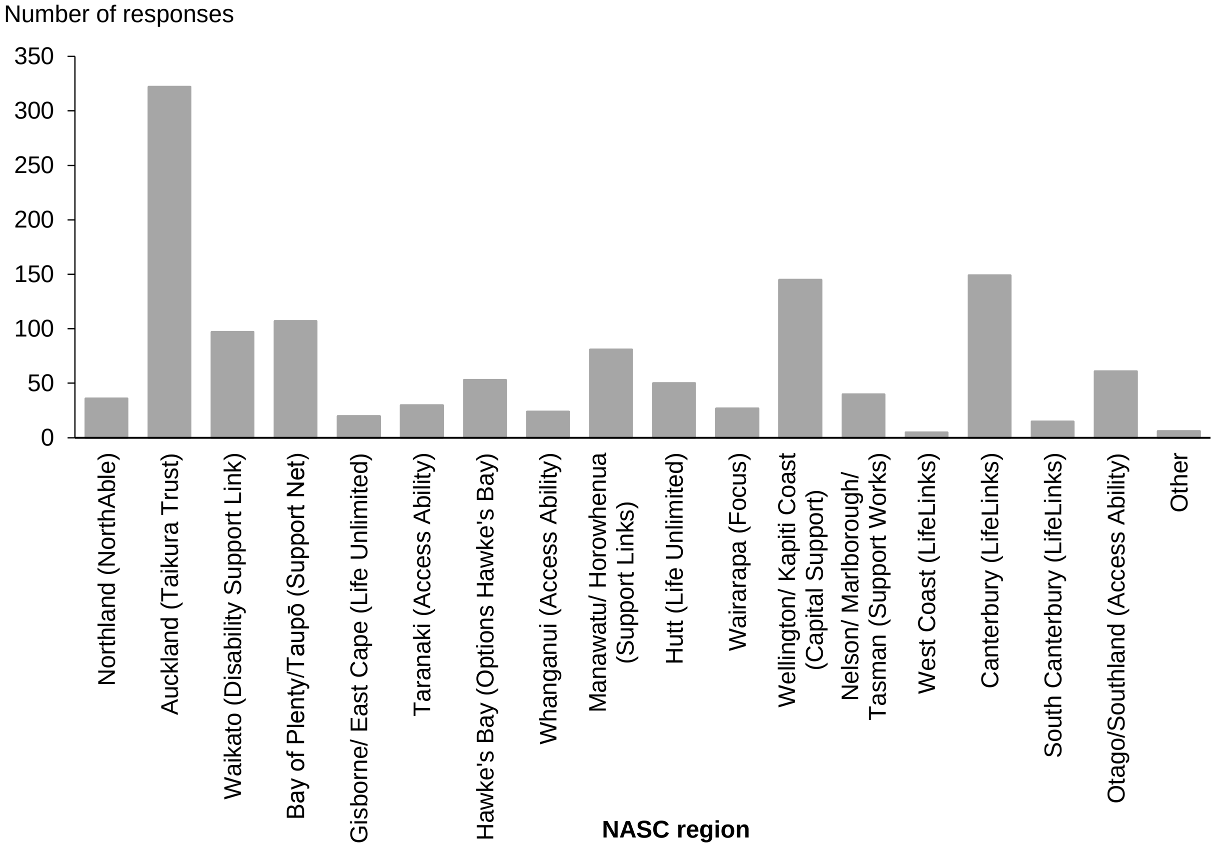
13. Responses to this question demonstrated good national coverage of the survey; we received responses from people in all regions relative to the population of the regions.

14. As might be expected, the greatest number of responses (322 people: 25 percent) were from the Auckland (Taikura Trust) region. The fewest number of responses (5 people: 0.4 percent) were from the West Coast (LifeLinks) region.

Table 1: Responses by region

Region	%	#
Northland (NorthAble)	3	36
Auckland (Taikura Trust)	25	322
Waikato (Disability Support Link)	8	97
Bay of Plenty/Tauranga/Rotorua/Taupō (Support Net)	8	107
Gisborne/East Cape (Life Unlimited)	2	20
Taranaki (Access Ability)	2	30
Hawke’s Bay (Options Hawke’s Bay)	4	53
Whanganui (Access Ability)	2	24
Palmerston North/Manawatu/Horowhenua (Support Link)	6	81
Hutt (Life Unlimited)	4	50
Wairarapa (Focus)	2	27
Wellington/Kapiti Coast (Capital Support)	11	145
Nelson/Marlborough/Tasman (Support Works)	3	40
West Coast (LifeLinks)	0	5
Canterbury (LifeLinks)	12	149
South Canterbury (LifeLinks)	1	15
Otago/Southland (Access Ability)	5	61
Other	1	6
Total	**100**	**1,268**

Figure 1: Responses by region



Responses by ethnicity

15. The survey asked 'Which ethnic groups do you identify with?'

16. This question elicited 1,211 responses. Respondents selected a total of 1,482 options, because some identified with more than one ethnic group. Fifty-seven people chose not to answer this question.

17. Of responses, 204 (14 percent) were from Māori, 68 (5 percent) were from Pasifika and 47 (3 percent) were from Asian people. We consider that that this level of response means that Māori, Pasifika and, to a lesser extent, Asian views were relatively well represented in the survey responses.

Table 2: Responses by ethnicity

Ethnic group	%	#
European	78	1,155
Māori	14	204
Pasifika	5	68
Asian	3	47
Other	1	8
Total		**1,482**

Responses by age

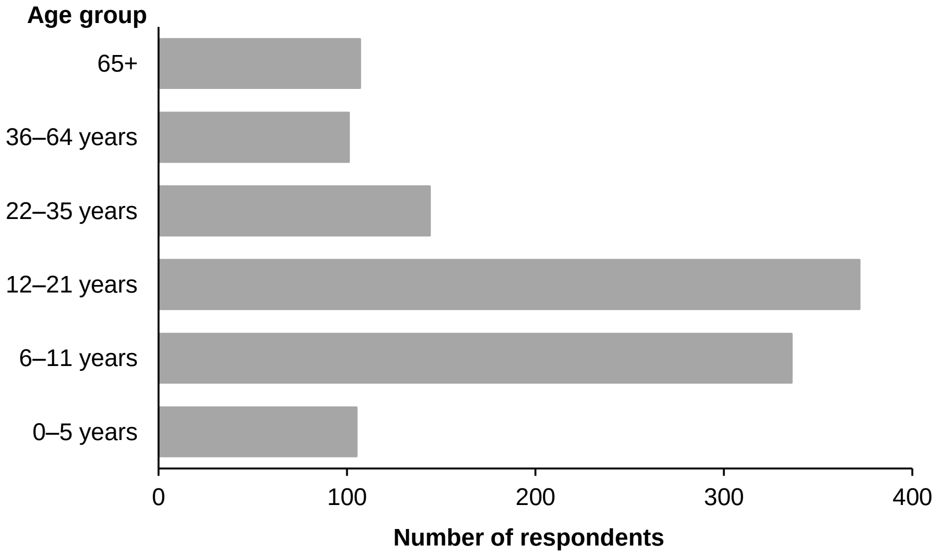
18. The survey asked participants 'What age is the person with the disability in your family?' This question elicited 1,165 responses.

19. Seventy percent of answers to this question represented age categories between 0 and 21 years. This shows that families/whānau with disabled children and young people are very engaged in the issue of respite. The survey provides us with a good level of information about what we need to do for younger people in the future in terms of respite.

Table 3: Responses by age

Age of person with disability	%	#
0–5 years	9	105
6–11 years	29	336
12–21 years	32	372
22–35 years	12	144
36–64 years	9	101
65+ years	9	107
Total	**100**	**1,165**

Figure 2: Responses by age



Responses by disability type

20. The survey asked participants to self-identify the type of disability they or their family/whānau member had, and the level of need they experienced as a result.

21. 1,163 people answered this question. Where a respondent experienced more than one disability type, the survey invited them to select as many options as required.

22. All disability types were represented in the survey responses. Specifically:
    - 779 respondents had a physical disability
    - 550 had a sensory disability (vision or hearing)
    - 711 had an intellectual disability
    - 569 had a neurological condition (such as Parkinson's disease)
    - 592 had autism spectrum disorder (ASD)
    - 270 people had 'other' types of disability.

23. More people considered that their level of need was 'high or very high', rather than 'moderate/medium' or 'mild/low'.

Table 4: Responses by disability type

Type of disability	Mild/very low or low needs	Moderate/medium needs	High or very high needs	Total
Physical	154	254	371	779
Sensory	179	194	177	550
Intellectual	94	246	371	711
Neurological	98	207	264	569
ASD	88	249	255	592
Other	23	101	146	270

24. A number of response in the ‘other’ category were outside the scope of DSS’ overview, such as:
    - mental illnesses
    - age-related fragility and disability
    - medical conditions.

Responses by type of respite allocated

25. The survey asked participants ‘Do you have an allocation for respite?’ 1,176 people answered this question.

26. Over 900 (77 percent) of the respondents reported that they had a current allocation for respite. Ninety-eight people (8 percent) said they did not have a current respite allocation but would like to.

Table 5: Responses by type of respite allocation

Do you have an allocation for respite?	%	#
Yes	77	905
No	11	128
No, but we would like a respite allocation	8	98
We used to have a respite allocation	4	45
Total	**100**	**1,176**

Quality of current service delivery

Satisfaction with current respite options

27. The survey asked participants ‘How satisfied are you with your current respite option(s)?’

28. This question elicited 846 responses. Of these, 62 percent of respondents were ‘satisfied’ or ‘very satisfied’ with their current respite options. Māori and Pasifika respondents reported very similar satisfaction rates.

Table 6: Responses by satisfaction with current respite options

Level of satisfaction with current respite options	%	#
Not at all satisfied	38	325
Satisfied	48	405
Very satisfied	14	116
Total	**100**	**846**

29. We need to keep this level of satisfaction in mind when developing changes to respite. It is worth noting that, although there are problems, the current arrangements do work for many. A number of survey respondents expressed their gratitude for the support.

> ‘Respite services have really improved my life and my ability to keep going during difficult times. Our family is really grateful for this service.’[1]
>
> ‘Our respite facility is fantastic. Staff are incredible, professional, hard-working and very caring to all the young people and their families. My son LOVES to go there.’

Satisfaction with amount of respite allocated

30. The survey asked participants ‘Are you satisfied with the amount of respite you have been allocated?’ This question elicited 853 responses. Half of respondents were satisfied with the amount of respite that had been allocated to them; this rate was similar among Māori and non-Māori.

31. About one-third of respondents reported that they were not satisfied with their respite allocation. The remaining 18 percent of respondents selected ‘other’ and opted to comment.

Table 7: Responses by satisfaction with amount of respite allocation

Are you satisfied with the amount of respite you have been allocated?	%	#
Not at all satisfied	51	435
Satisfied	31	263
Very satisfied	18	155
Total	**100**	**853**

32. Comments in relation to this question that included the following.
    - The allocation is redundant if it cannot be used.
    - The allocation for single parents should take into account their greater need for respite compared to two-parent families/whānau who can share the caring role on a daily basis.
    - Some families/whānau felt that they had to fight to get the allocation.
    - Some families/whānau feared the allocation being reduced in future, or that it would not increase as their need increased.

> ‘Hours get cut if you don’t use them, but if it doesn’t work for you, of course you don’t use them. It doesn’t mean there isn’t a need.’
>
> ‘15 days a year is not meeting my needs as a single mother to an autistic child. Working full time, caring full time, no family support.’

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[1] We have included quotes from survey respondents throughout this document.

Ability to use respite allocation

33. After asking participants which sort of respite they had been allocated, the survey asked them ‘Are you able to use your full respite allocation?’ This question elicited 850 responses.

34. Of respondents to this question, 66 percent stated that they were able to use their full Carer Support allocation. Interestingly, 76 percent of Māori respondents reported that they were able to use their full Carer Support allocation.

35. With regard to facility-based respite,[2] approximately 56 percent of respondents reported being able to use their allocation.

36. Of respondents allocated host-family respite, 31 percent reported being able to use it. This low rate is likely to be due to the difficulty in finding host families.

Table 8: Ability to use respite allocation

Type of respite	% of people able to use full allocation
Carer Support	66
Facility-based respite	56
In-home (buddy support) respite	42
Host-family respite	31
IF respite	65
Other	34

37. Overwhelmingly, the main reason respondents gave (across all age groups) for not being able to use their full respite allocation was a lack of available carers. Other reasons included a lack of suitable facilities in the area, the low rate of subsidy provided and the inflexible rules associated with respite funding.

Problems with current respite options

38. The survey asked participants ‘What are the main problems with your current respite options?’ This question elicited 682 responses.

39. Table 9 summarises issues raised by respondents. We devised the categories that appear in this table by identifying key themes; we assigned each narrative response to a category based on the main point it raised.

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[2] In facility-based respite, primary carers have a break while formal carers support a disabled person out of home; usually overnight in a dedicated respite house or other facility.

Table 9: Problems with current respite options

Main problem	#	%
Finding carers	231	34
Not enough hours/days	94	14
Lack of options	64	9
Rate of pay	58	9
Inflexibility	49	7
Quality of facilities	37	5
Administration	33	5
Travel	17	2
Access to information	9	1
Emergency/back-up respite	5	1
Uncertainty about the future	5	1
Other	63	9
No problem with respite	17	2
Total	**682**	**100**

40. As the table shows, approximately one-third of respondents considered that their main problem with respite was their inability to find suitable carers. This problem is exacerbated by the rate of the Carer Support subsidy, and an unwillingness on the behalf of carers to work with people with challenging behaviours.

41. Ninety-four people (14 percent) considered that they did not have enough breaks – primarily because they are not able to use their respite allocation due to lack of carers and a lack of suitable respite options.

42. People who identified 'lack of options' as their main problem often stated that there were few or no suitable respite services for the type of disability experienced; for example, that group or out-of-home options were not ideal for those with ASD or anxiety. Respondents frequently mentioned a lack of school holiday programmes for children and young people with disabilities.

43. In terms of the current respite options being 'inflexible' (the main problem for 49 respondents – 7 percent), the issues respondents raised included not being able to:

- work while using Carer Support
- get the type of break they wanted
- get a break at short notice
- get a break at a time that suited their family/whānau
- book a 2- to 3-week break.

44. Thirty-seven people (5 percent) made comments indicating that they were not satisfied with the quality of facility-based respite. Problems raised included:

- lack of outdoor areas
- lack of activities (in some places, television was the only activity)
- frequent staff turnover and understaffing

- disabled people being distressed while staying at the facility
- insufficient personal care.

> ‘We were offered out of home respite but I was horrified at what I saw. They could give me no answers as to how they would manage son’s poor eating, poor sleeping and hygiene needs since they had no bath (and he is scared of shower and incontinent). We really want out of home respite but it seemed there was no negotiation as to suitable times – we would just get allocated it. Also that the respite place was 45 [minutes’] drive (not traffic) from our house. Seemed very unsatisfactory. I want a respite that they can implement strategies to make our time at home better. The respite offered was just a sticking plaster without dealing with the huge mess of raising a high needs child.’

45. Respondents who reported that ‘administration’ was a problem mentioned the complexity of processing Carer Support forms, the time it took to find carers, the time it took to be reimbursed for Carer Support and lack of responsiveness from providers and NASCs.

46. Other feedback elicited by this question mentioned:

- lack of access to information about respite options and the rules about using each
- the need for emergency respite or back-up options
- concern about what might happen in a family/whānau’s future in terms of respite allocation, including the need to transition to other forms of respite as a disabled person or a primary carer ages
- excessive travel time involved in accessing respite.

> ‘We are struggling to fully utilise the funding we have been assigned. There is not enough funds to enable us flexibility and self-determination in how respite could look. We are desperately in need of a good respite option as we are exhausted and have little time for our other children, for our relationship or to take care of ourselves. Carer support is not enough of a financial incentive to attract a skilled carer. Our Individualised Funding for respite is very little and leaves us without enough to establish a regular stable and secure relationship for our child. There is no additional funding given to fund the transition and training our child requires to be safe.’

Benefits from respite

47. The survey asked participants ‘What are the main benefits to you and your family from respite?’ This question elicited 778 responses.

48. Many people responded emotionally to this question, expressing gratefulness for the respite they had received. Table 10 sets out the main benefits that people identified, and includes a quote that we felt was illustrative from a respondent for each category of benefit.

Table 10: Main benefits of respite

Benefit	Illustrative comment
The ability to have a break – rest, sleep, recharge batteries, take time for oneself – and to recuperate.	‘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 we all feel more relaxed. As parents it takes the pressure off us.’
Protection of mental health – stress reduction and prevention of burnout. Sustain the ability to perform the caring role.	‘Absolutely vital to enable me to keep going in caring for my loved one. It is both physically demanding, but also mentally and emotionally draining. Sometimes I feel as though one more day without a break will be too much.’
Opportunity for the disabled person to have new experiences.	‘My child learns to cope and learn that he can learn, have support/help and fun with other trusted adults. This helps to build confidence and independence in other environments. This also helps me as his mother to learn about how he copes and implement helpful strategies for his carer and for any future opportunities in his development. During this time apart, I am able to feel refreshed and happy that his needs are being met elsewhere.’
Protection of the wellbeing of the family/whānau – allowing couples to work on their marriage, parents to spend time with other children and the whole family/whānau to engage with extended family/whānau.	‘Our family would not be together if it wasn’t for our respite. It has been and continues to be an incredibly stressful time for us raising a child who is completely blind and extremely anxious. This provides an enormous amount of challenges and a huge amount of energy is needed so the breaks are essential. It is also saving our marriage!’

Future respite options

What disabled people and their families/whānau want in future

49. The survey asked participants ‘How would you like respite to be in future?’ This question elicited 773 responses. In summary, people reported that they want:
    - flexible funding
    - assistance to access services
    - a range of options
    - security for the future (eg, a guarantee of respite that will evolve over a person’s lifetime)
    - respite options suitable for the relevant disability type and age
    - an increased rate of pay for support workers
    - fewer administrative difficulties
    - more respite hours/days
    - access to quality respite facilities near their home.

More flexibility

50. Overwhelmingly, the message from disabled people and families/whānau we received through the survey was that they all have individual needs, and would like the funding available to provide them with the flexibility to meet these needs.

51. Some of the main barriers to using respite at present that respondents reported relate to the respite system being inflexible.

> ‘More flexible in [its] use, taking into account that I have autism and I need breaks away by myself to retreat and “recharge”.’
>
> ‘I would prefer to use my respite as a family together not to be forced to separate from my sons to have a break. The amount of preparation needed to send my sons on respite & the amount of anxiety it causes my sons makes it more stressful to have a break than to not have a break! If we were able to have a family holiday that was subsidised by our respite it would be of assistance to my sons & myself! This would be the best option for us.’
>
> ‘I think it should be block funded and the families choose what fits and is right for them: it’s such an individual circumstance.’
>
> ‘There should be significant flexibility for families in the future, with a budget made available for them to use as suits their needs, without excessive restrictions.’
>
> ‘I think funding could be handed in some cases to the families to decide what and where it would be best spent; eg, model of Enabling Good Lives. More community involvement and people being aware they can help and be paid, even if it is once a month.’

Navigation/coordination/assistance to access

52. A second theme in the comments people made about the future of respite related to the need for better information about what is available, early access to respite and help with accessing respite options.

> ‘More open and available – easier for people to find out about and access. If you don’t know the right questions to ask you don’t get the right answer!’
>
> ‘More assistance on how to use it, more options of where our children can go.’
>
> ‘Maybe [finding it] easier for parents that are struggling, being told about it sooner and explained a lot about help, as the parents may be confused and sleep deprived, maybe more information about help.’
>
> ‘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.’

Preference for various respite options by age

53. The survey asked participants ‘If you could choose from a wider range of respite options, what would you most like to have available?’ and invited them to rate a range of options in terms of their preferences. This question elicited 961 responses overall, although the number of responses for each option varied, from 773 to 882.

54. Table 11 breaks down responses to this question into age categories of the disabled person concerned. The number of people who responded in each age group ranged from an average of 56 (for over 65s) to an average of 286 (for 12–21-year olds). In interpreting this data, be aware that for age groups in which we received only a small number of responses, data is less reliable: be aware of using it as an authoritative indication of that age group’s general preferences.

Table 11: Preference for respite options by age of disabled person

	Percentage, by age group																	
	0-5			6-11			12-21 ▯			22-35			36-65			65+		
Respite option	No, thanks	That could be ok	Sounds great	No, thanks	That could be ok	Sounds great	No, thanks	That could be ok	Sounds great	No, thanks	That could be ok	Sounds great.	No, thanks	That could be ok	Sounds great	No, thanks	That could be ok	Sounds great
Day trips - support workers assist a group to go to the zoo or beach etc	30%	38%	35%	13%	35%	52%	16%	30%	54%	26%	31%	43%	43%	32%	25%	45%	27%	28%
Group activities - support workers assist groups of disabled people in activities at a fixed location	33%	43%	28%	16%	38%	46%	20%	33%	46%	24%	29%	48%	49%	30%	21%	35%	37%	28%
School holiday programmes	18%	22%	62%	5%	17%	77%	16%	23%	61%	51%	20%	30%	75%	14%	11%	88%	2%	10%
Holiday camps	30%	32%	32%	15%	33%	52%	22%	26%	52%	35%	25%	40%	69%	16%	15%	91%	0%	9%
Overnight stays in a house only used for respite	40%	32%	30%	35%	22%	43%	30%	24%	47%	23%	27%	50%	41%	31%	28%	38%	29%	33%
Overnight stays in a rest home (aged care facility)	84%	5%	6%	89%	6%	5%	89%	7%	4%	84%	7%	9%	76%	21%	3%	33%	36%	31%
Overnight stays in a group home where three or more people live permanently	83%	15%	2%	73%	17%	9%	53%	31%	16%	41%	35%	23%	72%	22%	6%	82%	12%	6%
A support worker assists the disabled person in their home (includes overnight while main carers are away)	18%	30%	55%	22%	37%	40%	25%	35%	40%	30%	30%	40%	18%	32%	49%	20%	36%	43%
A support worker takes the disabled person out for the day/half day	33%	32%	32%	30%	35%	34%	26%	30%	44%	22%	32%	46%	27%	41%	32%	46%	21%	32%
Overnight stay in another family home (foster or shared care)	59%	28%	13%	56%	22%	23%	50%	28%	22%	39%	35%	26%	71%	23%	6%	79%	6%	15%
Evenings out for the disabled person (eg, seeing a movie or having dinner)	43%	33%	26%	28%	39%	33%	17%	32%	51%	17%	30%	53%	36%	31%	33%	58%	19%	23%

55. Table 12 summarises information from Table 11. This information may help guide planners in their service development, but is not completely reliable, given the small numbers involved.

Table 12: Most popular respite options by age of disabled person

Age	Most popular respite options
0–5	Support worker coming to the family home to provide respite School holiday programmes Day trips Group activities
6–11	School holiday programmes Day trips Group activities Holiday camps
12–21	School holiday programmes Day trips Group activities Evenings out Holiday camps
22–35	Evenings out A support worker takes the disabled person out for the day/half day Overnight stays in a house only used for respite Group activities Day trips
36–64	Support worker coming to the family home to provide respite A support worker takes the disabled person out for the day/half day Evenings out Overnight stays in a house only used for respite
65+	Support worker coming to the family home to provide respite Overnight stays in an aged care facility Group activities Overnight stays in a house only used for respite

Demand for facility-based respite

56. The survey asked participants ‘If there was an option of a house you could use for overnight respite, would you like to use it?’ The question elicited 949 responses. Table 13 shows responses.

Table 13: Demand for facility-based respite

Would you like to use facility-based respite?	%	#
We already use a respite house/centre	12	112
Yes	48	455
No	40	382
Total	**100**	**949**

57. Almost half of the respondents (48 percent) to this question stated that they would like to use an overnight respite house if they could. This apparent level of unmet demand for facility-based respite is interesting to note alongside the fact that many facility-based respite houses are operating under capacity – some houses have occupancy rates as low as 30 percent.

58. Overall, levels of satisfaction with current respite options were much higher among people who already used a respite house – in this group, 78 percent stated they were either satisfied (53 percent) or very satisfied (25 percent) with their current respite options, while 22 percent were not at all satisfied.

59. In comparison, among respondents who said that they would like to use facility-based respite and did not currently have access, 52 percent said they were either satisfied (43 percent) or very satisfied (9 percent) with their current respite, and 48 percent were not at all satisfied with their current respite options.

60. Forty percent of respondents to this question said that they did not want access to facility based respite. The reasons respondents gave for not wanting access 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.

61. Some respondents expressed offence at the idea of facility-based respite, seeing it as old-fashioned and institution-like.

> ‘No outside facility available. All external care is institutionalised and [impersonal]. Respite needs a more caring home environment for a lot of people.’
>
> ‘I understand you mean sending our daughter to a facility; that sounds quite institutionalised and backwards.’

Analysis of survey responses from providers

62. We received 50 responses to our shorter survey for providers of respite.

63. The providers who responded covered the full range of the current contracted respite services, and some non-contracted services that families/whānau access through Carer Support and IF.

Types of providers

64. The survey asked providers 'What types of respite services do you provide?' This question elicited responses from 49 providers – many selected more than one type of service.

Table 14: Types of respite services offered by providers

Type of respite service provided	%	#
Carer Support	47	23
Facility-based respite (dedicated) – a house or other building used only for respite	16	8
Facility-based respite (shared) – a room or unit providing respite as part of a residential service	35	17
In-home respite (buddy support) – a support worker providing respite in a person's own home	16	8
Host-family respite – respite provided in the home of a host (or foster) family	14	7
IF respite – through which a person uses IF to purchase their own respite	25	12
None[3]	27	13
Other	11	11
Total		**99**

65. Those who answered 'other' to this question were providers of school holiday programmes, NASC services or providers of non-contracted services such as social activities for people with disabilities (funded by Carer Support or IF).

What works best for respite providers

66. The survey asked providers to 'Please tell us what works best about the respite services you provide'. This question elicited 37 responses.

67. For the most part, providers identified that respite worked well as part of an approach of holistic support for the family/whānau, and saw benefit in taking an investment approach to respite (in terms of starting early).

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[3] We have no further information about those who responded 'none' to this question.

> ‘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.’

68. While host-family respite currently makes up a small proportion of total respite services, and it can be difficult to recruit host families for this purpose, some provider comments mentioned particularly positive benefits of this type of respite.

> ‘The child we take care of so her family can have respite is like another member of our family, she has her own bed, toys, car seat and push chair and other stuff that she needs while she is with us. She comes where we go and has even gone away on holiday with us. We are great friends with her family and spend time with them as well even when we aren’t having their daughter for respite care.’

69. Three community residential providers stated that offering respite had the benefit of allowing them to fill an empty bed when there was no permanent resident allocated to it.

Challenges in providing respite services

70. The survey asked providers ‘What are your biggest challenges in providing respite services?’ This question elicited 37 responses. Table 15 sets our analysis of these responses.

Table 15: Most common challenges for providers

Challenge	Reasons
Funding	The low Carer Support subsidy The cost of activities for children and young people The fact that the contracted rate for facilities does not take into account all the extra administration required to manage a respite bed
Finding carers	Recruiting, training and retaining carers
Medication management	The transience of respite clients, meaning staff have to learn new medication management for each client, and work with different doctors and pharmacies
Inability to meet demand	Cannot meet demand for weekend beds Difficulties in accommodating acute or emergency placements
Challenging behaviours	Incompatibility of respite residents and permanent residents (eg, in terms of age, gender or disability-related need) Challenges involved in implementing behaviour management plans on a short-term basis
Administration/compliance	Time required to complete paper work
Trust of providers among Māori	Challenges in providing a culturally appropriate service, and recognising that Māori can be less likely to trust whānau with a lesser known carer
Low demand	The view that respite is not economically viable, due to low referrals and demand

Feedback from disabled people and their families/whānau to providers

71. The survey asked providers 'What feedback have disabled people and their families/whānau given you about the quality or effectiveness of respite services?' This question elicited 49 responses.

72. The comments providers gave reflected the feedback we received in the survey for disabled people and their families/whānau. They included the following consistent themes.
    - Families/whānau are grateful for respite, and say that they wouldn't cope without it.
    - There are problems with transport from school to respite.
    - Families/whānau are sometimes unable to find carers.
    - There is a lack of nationwide consistency in the way respite is allocated and provided.
    - Families/whānau sometimes do not know about or understand the options available.
    - Current options are too inflexible.

Providers' vision for the future

73. The survey asked providers 'How would you like to see respite provided in future?' This question elicited 46 responses. Generally, providers responded that respite should be:
    - geared to individuals
    - age-appropriate
    - easier to access than it currently is (eg, through online information on availability, and online booking)
    - supportive of community-based participation and networking
    - culturally appropriate
    - available in a wide range of options
    - geared to specific disabilities (eg, ASD-specific)
    - flexible
    - appropriately funded.

> 'Youth don't want to sit around an old nana's house and be minded while their families are living their lives without them, they want to go on the same adventures afforded to regular youth.'

Support for providers

74. The survey asked providers 'What do you think the Ministry of Health should do to support providers to make changes to how respite is offered?' This question elicited 46 responses.

75. Providers suggested that the Ministry should:

- ensure that funding for each disabled person reflects their need
- encourage transparency from providers on vacancies and capacity
- increase the Carer Support subsidy and relax rules about family/whānau not working while using Carer Support
- make housing modifications, so that respite can take place in other family homes
- work with training providers to build the student carer workforce
- focus on flexibility
- produce clear policy written in plain English, and nationwide guidelines
- provide appropriate training for assessors and carers
- ensure the uniformity of NASC services
- provide clear, accessible (eg, online) information for professionals and family/whānau.

> '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 "whānau-ised" 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.'