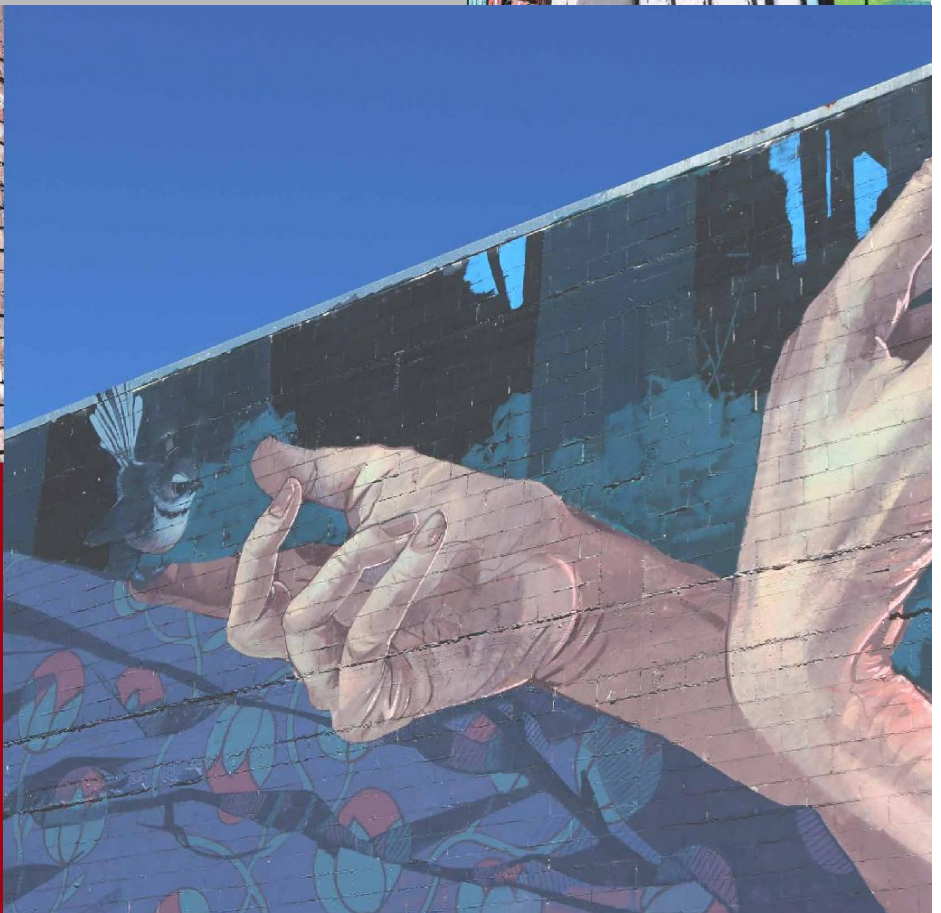
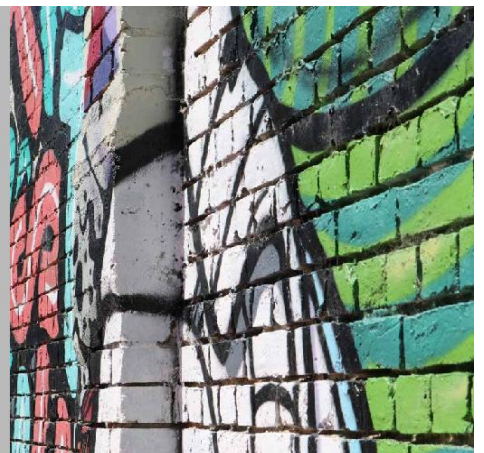


“You care for me when you care about my son.”

An exploration of the  
respite experiences of  
New Zealand carers





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## EXECUTIVE SUMMARY

Despite a growing emphasis on the need to care for carers, delivering respite that responds to the lives of disabled people and those who support them has proved difficult to achieve.

The aim of this research was to generate information that could be used by those interested in responding to the respite needs of New Zealand carers that aligns with current respite policy and best practice models of support.

Three methodological strands informed this research:

1. An integrative literature review that located New Zealand policy and respite service provision within the context of available research that had a specific focus on respite support and services. Information for the literature review was collected through a systematic search of a number of relevant databases and "grey literature" accessed through the Ministry of Health and Ministry of Social Development websites.
2. An online survey designed to generate quantitative data about New Zealand carers understanding of the purpose of respite, respite allocation and use and assessment of value of a range of different respite models. The "*Responding to Respite Needs Survey*" was hosted on the SurveyMonkey platform between 5 November – 15 December, 2015. Ninety female and 14 male carers contributed to the research as Survey respondents (see Appendix 1).
3. In-depth qualitative interviews, principally with a purposive sample of carers who indicated an interest in providing an interview at the conclusion of the *Responding to Respite Needs Survey*. Five male and thirteen female carers contributed to the research by providing a semi-structured interview. The research team also spoke to a range of key informants who provided additional contextual information (see Appendix 2).

This Report is titled "*You care for me by caring about my son*" because the findings strongly align with previous studies that assert contemporary understandings of respite need to include a focus on the role short-term breaks can play in the lives of those receiving care. Moreover, this research takes this conversation a step further by suggesting that the health and wellbeing of carers and the disabled family member they support are indivisible and that the future design of respite planning needs to begin with this as its guiding principle.

Findings from this study confirm the high incidence of poorer health and wellbeing outcomes experienced by carers reported elsewhere in international and other New Zealand studies. For example:

- Six out of every ten survey respondents said they had felt close to breaking point.
- Half of the carers who responded to the survey did not feel they were able to access sufficient respite, suggesting that the issues of funding and respite access are likely to underscore poorer health and wellbeing outcomes experienced by New Zealand carers.
- Feeling as if you received sufficient respite was found to be protective of carer health and wellbeing (as measured by the likelihood they would report having felt close to breaking point).
- The way carers experienced respite was found to have an impact on carer wellbeing too, with the attributes of reliability and service quality being to the fore.

Respite options provided by a Disability Service and in particular, facility based respite and holiday programmes were rated least likely to have the attributes that respite carers valued. A pre-eminent concern of carers was that respite should also enhance the health and wellbeing of their family member. Respondents who used facility based respite and/or a Holiday Programme were significantly more likely to say they experienced care that did not meet the needs of their family member. Six out of every ten respondents who used facility based respite and eight out of every ten carers who used a Holiday Programme determined these to be contexts that fell short of meeting their family member's needs

When we spoke to carers about their respite experiences, a number of carers reported incidents of physical assault and some expressed concerns for the physical safety of their family member when in facility based or other service led respite contexts.

Respite facilities also tended to be characterised as seldom going beyond attending to more instrumental care needs with the social practices of service delivery failing to personalise support in ways that made it possible for a carer's family member to access a range of attributes they identified as being indicative of a positive respite experience. By dislocating people with a learning disability from their community and the ordinary routines and relationships of home and community life, respite facilities in particular were read as social contexts that were "disabling."

Low staff to family member ratios, lack of training and the social construction of carer's family member as a "client" rather than a valued and vital community member were identified as contributing to the hiatus of facility based respite.

Carers who supported a family member with an autistic spectrum disorder (ASD) were most likely to feel that a facility based environment was inappropriate, foregrounding the development of respite tailored to the support needs of people with ASD as an important arena for future respite service provision.

When we asked carers about the usefulness of particular respite contexts, slightly more carers reported that they would find in-home respite highly useful. Consistent with findings reported in another study of the respite needs of New Zealand carers, forty-seven percent of survey respondents said they would find in-home respite highly useful.

What carers said they valued about in-home respite was that it:

- Was flexible enough to respond to the changing circumstances of the wider family, including alternative carers assimilated within an expanded "field of care".
- Enabled the carer to participate in conversations, mentor and support alternative carers to tailor respite to the needs and preferences of their family member.
- Facilitated the development of relationships of social knowing and trust that could be taken outside of the family home.
- Enabled a carer's family member to continue to access attributes of homeliness including; an insiders sense of psychological safety; an influence over the routines and rhythms of the household; a repository of significant and affirming social relationships; an expectation that they contribute to the household economy and somewhere they felt safe to invite others to.

Rather than displacing out-of-home respite, evidence suggested that carers preference for in-home respite was in part driven by their failure to find similar attributes in out-of-home respite contexts. This report reached this conclusion based on the following:

- Forty-two percent of carers said facility based respite would be "highly useful" to them and their family and an additional twenty-two percent said it would be "useful."
- Facility based respite was used and highly valued by carers who: were in full-time employment; supported a family member with a behavioural disorder; and older carers who tended to have a smaller informal network to draw support from and who were mindful of the transition their family member would eventually make beyond their care.
- The only significant predictor of whether a carer would use in-home support was whether or not they received Facility Based Respite Care funding. Carers who had Facility Based funding were significantly less likely to use in-home support and significantly less likely to rate in-home support as highly useful

- Further evidence on the way respite care was funded, and its difficulties for carers in finding out-of-home respite experiences they may otherwise have preferred, might also be inferred by the finding that carers who used facility based respite were significantly more likely to report feeling as if they had a choice about the type of respite they received.

Common to the narrative of carers who used in-home support was a shared belief that managing respite within the more naturalistic setting of their home represented the best way to ensure respite was a positive experience for their family member too. In doing so, however, carer's homes often ceased to be places of respite and refuge and rather than moderating the demands of the carer role, assuming the role of respite provider simply added to those demands. Carers who took on the role of organising respite described:

- Homes that could be populated by professionals, alternative carers and strangers.
- The stress of forever having to find, train, and orientate new carers to their family member.
- Of continually being an "on-call" expert and organiser of activity.
- And carers using Individualised Funding also noted that they were required to take on the additional responsibilities that followed employing staff.

Whilst a clearer picture is starting to emerge of a range of elements that are critical to quality respite support and service delivery, what has eluded articulation and evaluation are examples of respite care that have succeeded in translating existing research into support practice.

Although the limited scope of this research and the diversity of carer experiences we were exposed to conducting it made it impossible to advance specific model(s) of respite support, the findings do point to three design principles that ought to guide the development of future respite strategies.

Carer participants consistently applied the same set of indicators to determine the usefulness of respite contexts irrespective of whether they were evaluating in-home, out-of-home or examples of more innovative respite options currently unavailable to them. Carers described to the DBI research team the important aspects of respite care for their family member, including that it:

- Contributed to the development of an expanding network of trusted relationships.
- Supported the development and expression of an autonomous self-identity.
- Promoted people's connections with their community.
- Assisted the transition to greater independence.

- Supported life-long learning in a planned and integrated way.

Carers also indicated that the allocation and use of respite funding in isolation may do little to enhance their health and wellbeing as carers. In New Zealand, the Needs Assessment Process disentangles the carer and care recipient, limiting the scope of the assessment to an identification of care recipient support need. Systems of respite service delivery have also developed in ways that do not take adequate account of the context in which the care act is transacted, including an array of other factors known to undermine a carer's capacity to support their disabled family member. Subsequently, this study concludes that future service delivery needs to take a "**whole of family**" approach to the provision of respite support, including supporting carers to identify and remediate a range of factors known to have an impact on carer resilience, including:

- Social isolation and the loss of community.
- Poor mental health and especially depression and anxiety.
- Carer dislocation from an ordinary life trajectory, including separation from the worlds of employment and education.
- The demands of multiple caring roles.
- Carer attention to the needs of siblings.
- Structural and environmental contexts, including having to navigate a fractured health and disability support landscape.
- A higher prevalence of relationship breakdown.

Carers indicated that the design and delivery of more responsive respite models needed both to be conceptualised as a collaboration between Service Providers, carers and disabled people and best conducted within regular cycles of ongoing dialogue and action. When carers spoke of the missing elements to respite support, they tended to identify the absence of conversation rather than what was missing from the landscape of Disability Service Provision. One of the more important motifs to emerge from the discussions the research team had with carers was that respite was as likely to be found in relationships as it was in buildings. What carers said would be useful, was having the ability to transcend the immediacy of the carer role by talking to and planning with people who could help them to "*see the bigger picture*," leading to the conclusion that carers would benefit greatly need from a dedicated respite coordination (coaching) role that supported them to integrate supports within a "**whole of family**" respite plan.

The ability of Service Providers to respond to findings presented in this report will also be determined by changes in the policy and funding environments within which they are embedded.



Required changes at the policy level foregrounded by this research might include:

- Acknowledging the value of alternative care as a way of keeping disabled people connected to their community and out of more expensive forms of institutional care. Adjusting the Carer Support Day subsidy so that it aligned with the Minimum Wage Act 1983 may not only be required following a recent decision in the Employment Court, it would also have a range of additional advantages including; enabling carers to employ staff directly, avoiding disadvantaging carers who had taken on the responsibilities associated with Individualised Funding, the creation of a market for new and innovate respite options precluded by current funding levels, and assisting the National Carer Matching Service to become more viable.
- To be consistent with the objectives of the Carer Strategy and other New Zealand social policy, carers should not be excluded from using Carer Support while at work.

Changes to the Needs Assessment Process that would support the development of more responsive respite services might include:

- Incorporating the identification of carer support needs in the needs assessment and service co-ordination process. Failure to collect information related to the caring context made it difficult for services to respond to circumstances that undermined carer resilience. The insensitivity of the Needs Assessment Process to carers' support needs appeared to disadvantage carers who needed the most support, including those providing support to younger children or a family member with continuous or high and complex support needs.
- The needs of siblings should be included in a ***“whole of family”*** approach to the provision of respite support.
- The right of carers to seek and/or remain in employment needs to be acknowledged in the assessment and coordination process.

The first objective of the Carers Action Plan (2013 – 2018) issues an invitation to all those engaged in the conduct of respite care to collaborate in trialing new respite options that respond to the diversity of carer needs. To do that successfully will require all stakeholders to expand their vision of *“how to care for (all) those who care.”*

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# INTRODUCTION

Despite a growing emphasis on the need to care for carers (New Zealand Carers Strategy, New Zealand Carers Action Plan) delivering support that is responsive to both individuals who are cared for and those who provide it is difficult to achieve (Mansell and Wilson, 2009, p.55). Barriers to effective respite care are myriad and occur at the individual, family, service and policy and funding levels. This report details findings of a scoping study designed to comprehensively explore respite care, primarily from the perspectives of family (and a small number of non-family) primary carers of disabled children and adults. The research was conducted to gain a deeper understanding of what users of respite services identified as key attributes of responsive respite support.

In the following section we provide a brief outline of the method we used and an abridged summary of the literature review conducted in Phase One of the project.

# METHOD

The purpose of this study was to learn more about the respite care experiences, needs and aspirations of family and non-family carers receiving respite support in the New Zealand context. A key aim of the project was to generate evidence that might be useful to providers of respite support thinking about developing service and social practices that respond to the diverse needs of New Zealanders meeting the support needs of disabled family and non-family members on a daily basis. To do this we employed a three-phase, mixed-method approach in which each methodological element sequentially informed the design, data collection and analysis strategies adopted in subsequent research phases.

## Phase One – Literature Review

In Phase One of the research, a literature review was undertaken to identify national and international respite models, current policies and practices that influence the delivery of respite support in New Zealand. An integrative review methodology was used to carry out the literature search. An integrative approach was appropriate for this work as it allows a wide range of evidence to be drawn on including quantitative, qualitative, and other "grey" literature such as unpublished reports and policy documents (Wittemore & Knaft, 2005).

Information for the literature review was collected through a systematic search of a number of relevant electronic library databases accessed through the University of Otago library, and through two specialist disability libraries, the IHC National Library, and the CCS-Disability Action National Library. The literature search was (largely) confined to literature published during the period 2005-2015, and included research specifically focused on respite support and services. A range of other terms were employed in the search, most notably the term "short breaks," to ensure that international research on this topic was captured. Relevant "grey" literature was accessed through the Ministry of Health and Ministry of Social Development websites, and from specific agencies and organisations that were known to have undertaken work on this topic. In keeping with an integrative review methodology, literature was analysed thematically to identify and illustrate key findings related to the reception and provision of respite support.



## Phase Two – Responding to Respite Needs Survey

Phase Two of the study involved the administration of an online survey designed to generate quantitative data about perceived need, funded respite hours and respite use.

The *Responding to Respite Needs Survey* (the Survey) was a 43-item on-line survey specifically developed for this study, which incorporated a mix of forced choice and open-ended questions. The Survey was designed to provide a snap shot of respite care use, carer experiences and carer's thoughts about the type of respite arrangements they felt might respond to their family's support needs.

The Survey contained five sections that sampled for:

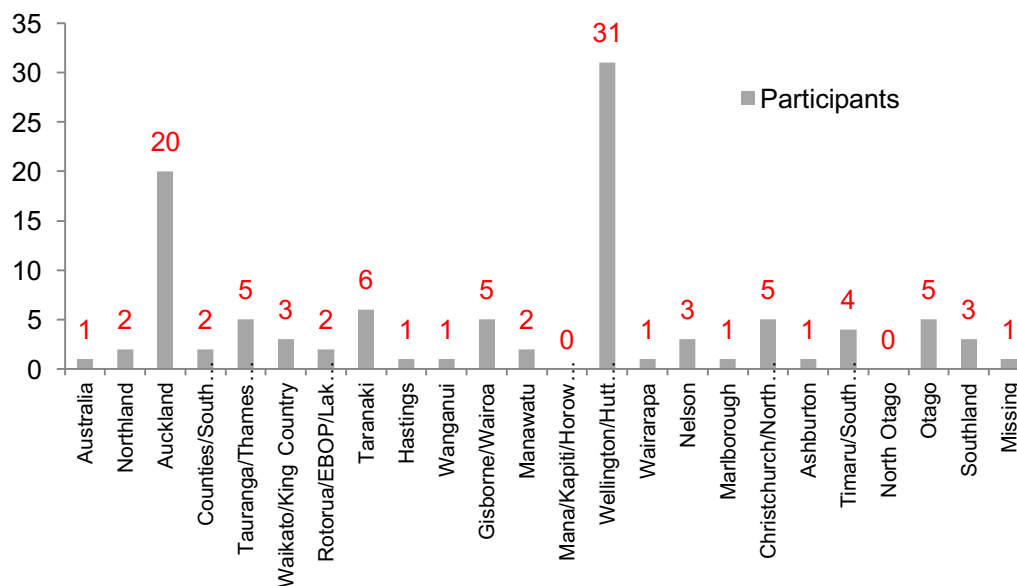
<b>1. "Tell us about yourself"</b>	Carer attributes
<b>2. "Tell us about the person you provide care for"</b>	Family member attributes
<b>3. "Do you use respite care?"</b>	Whether carers used respite care support, including the reasons for not seeking or using respite care
<b>4. "The respite care you receive"</b>	The type of respite care support carers received, reasons for seeking respite care and carers experiences of the respite care they received.
<b>5. "Designing more responsive respite care arrangements"</b>	What attributes of respite care carers prioritized and their assessment of the usefulness of a range of innovate respite care options identified in the literature review.

A sixth section invited survey respondents to indicate whether they would be interested in participating in a telephone interview. The use of questions that sampled for the personal attributes of carers and/or their family member(s) allowed the research team to explore whether it was possible to detect statistically significant patterns of responding (associations) between identifiable groups and their experiences of respite care or the types of respite services they felt best responded to their family's respite care needs.

## Survey respondents

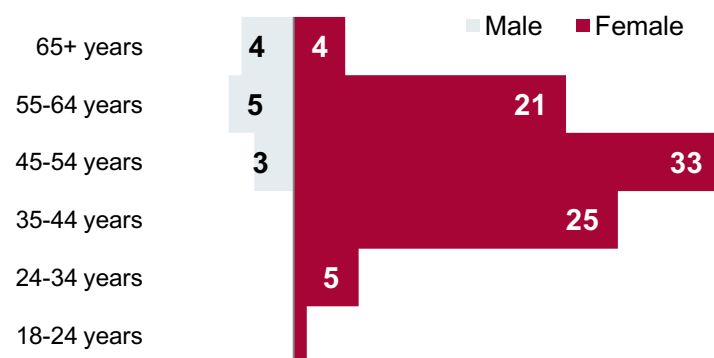
The Survey was hosted on the SurveyMonkey® platform and ran from 5 November – 15 December 2015. One hundred and four carers responded to the survey. Approximately half of the survey respondents were from the Wellington/Hutt Valley (n=31; 29.5%) and Auckland (n= 20; 19.1%) regions.

**Figure 1 The number of survey respondents by region**



Ninety female (85.7%) and 14 male (13.3%) carers responded to the survey. The gender skewing of the survey respondents is consistent with the commonly reported finding that the role of primary carer for disabled children tends to be overwhelmingly occupied by women.

**Figure 2 The age and sex of carer survey respondents**



Approximately three out of every four respondents described themselves as being of New Zealand European ethnicity (n= 77; 23.3%). Ten respondents were Māori (9.5%), and three respondents self-reported being of either Pacific people (2.9%), Chinese (2.9%), or Indian (2.9%) ethnicity.

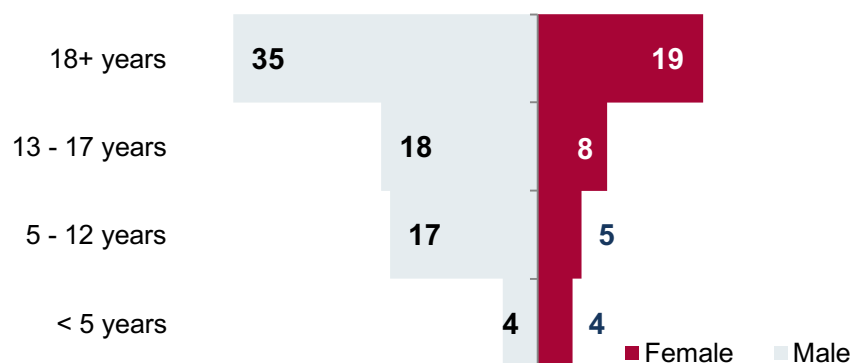
Seven out of every ten respondents were in a parental relationship with a care recipient (n= 74; 70.5%). Three siblings and three other family members responded as carers (2.9%). Twenty-one respondents reported being either a non-relative (n=16; 15.2%) or in another relationship (n= 5; 4.8%).

The majority of carers said they provided disability related care for one person (n=89; 84.8%). Ten carers said they provided care for two people (9.5%) and one respondent provided care for three people.

## Care recipients

The ratio of male to female care recipients was the reverse of the gender skewing found for care provider respondents. Two out of every three family members being cared for were male (n=74; 67.3%) with a similar sex ratio existing across all age categories for care recipients older than five years.

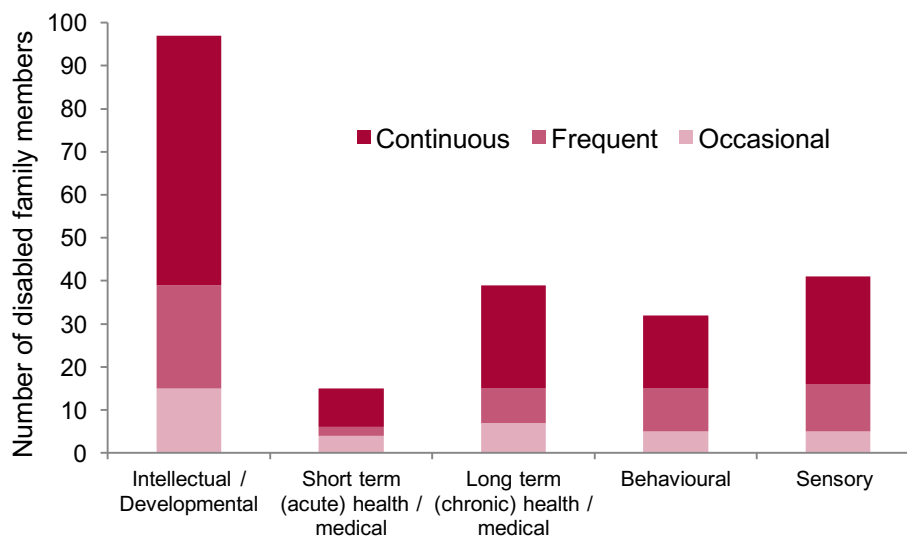
**Figure 3 The sex and age of disabled family members**



Almost all disabled family members were described as having an intellectual or developmental disability by their carer (n= 97; 92.4%). Forty-one care recipients were also said to have a sensory impairment, thirty-nine a long term (chronic) health or medical condition, thirty-two a behavioural disorder and fifteen a short-term (acute) health or medical condition.

Carers were also asked to indicate the level of care they felt they were required to provide. Six out of every ten carers assessed themselves as providing continuous (twenty-four hours, seven days a week) support to their family member across four of the five categories of impairment sampled for. Carers of children or adults whose impairment included a behaviour disorder were slightly less likely to report needing to provide continuous care (53.1%).

**Figure 4 Carer's assessment of support intensity by type of disability**



## Coding and analysis

Survey information was entered as data and managed using IBM®SPSS® Statistics 19 statistical software. Descriptive statistics, augmented by binary logistical regression modeling were the primary modes of analysis used. Within the regression models a range of carer attributes (sex, age, relationship status, employment status, relationship with care recipient) and care recipient attributes (sex, age, type of impairment, intensity of support need) were employed as potential predictors of respite care related outcomes described by survey participants.

## Phase Three – Qualitative Interviews

The final phase of the research involved the conduct of in-depth qualitative interviews with a sample of carers who responded to the *Responding to Respite Needs Survey*.

Survey respondents were asked at the conclusion of the questionnaire whether they would be willing to participate in a qualitative telephone interview. In total, forty-two survey respondents indicated that they would be willing to do so. The scope of the study only allowed for approximately twenty qualitative interviews to be conducted. A process of

purposive sampling occurred to ensure that those eventually selected reflected the diversity of carer demographics seen within the wider survey.

Eighteen carer interviews, five with male and thirteen with female carers were undertaken in February 2016.

The research team also spoke to a range of key informants who provided contextual information, including Needs Assessment and Coordination (NASC) Service Managers and Managers from the Ministry of Health.

The interviews were transcribed, coded and analysed thematically before being integrated with the quantitative survey results in order to provide a deeper understanding of the experiences, needs and aspirations of carers within the context of respite support.

## Terms used in the report

The meaning of the following used throughout this report are

<b>Carer</b>	For the purposes of the report the New Zealand Ministry of Health's definition of a fulltime carer was adopted. A carer was therefore defined as a person who provided more than 4 hours per day unpaid care to a disabled person.
<b>Family member</b>	Family member was used as the referent for a disabled person receiving support regardless of whether the carer was the custodial parent or not.
<b>Respite</b>	Short-term break from the carer role enabled by the use of an informal or paid alternative carer, facility based respite, or use of an organised Holiday or After School Programme.
<b>In-home respite</b>	Respite in which the family home represented the epicentre of support. In-home support included support provided by an alternative carer coming to a family members home to enable the carer to leave or participation in the community that involved a return migration to and from the family home.
<b>Out-of-home respite</b>	Respite involving a family member leaving the family home to provide the carer with a short-term break. Out-of-home respite included the use of a respite facility or residential setting, organised Holiday or After School Programme or use of a Matched Carer Placement to provide a

short-term break.

**Carer Support Day**

Funding allocated by the NASC designed to make a contribution towards the costs incurred by an alternative carer providing respite.

**Facility Based Respite**

Funding allocated by the NASC designed to provide a short-term break for a carer through the use of a respite facility or respite bed provided by a disability provider contracted to the Ministry of Health or regional District Health Board. In this report, the noun "Facility Based Respite" in proper caps refers to the funding stream within the context of the Ministry of Health only, whereas "facility based respite" in lower case describes the provision of respite care in a facility-based format generally.

**Person with a learning disability**

'Person with a learning disability' has been adopted as a collective referent consistent with the preference of national self-advocacy disabled person's organisation, People First New Zealand, except where "intellectual disability" is used as a diagnostic referent or the more generic "disabled person" is more appropriate.

# LITERATURE REVIEW

## Respite from a research perspective

The first phase of this scoping project involved an exploration of the research and policy landscape relating to respite care, both nationally and internationally. The aim of the literature review was to provide an evidence-based context for the subsequent phases of the research. Specifically, the review delivered information about: the purpose of respite care; the role of respite care; current trends in respite use; the characteristics of disabled people who receive respite services and support; the characteristics of carers; barriers to access; and the features of effective and responsive services and support. An additional aim of the literature review was to identify any new or innovative models of support that had the potential to be implemented in the New Zealand support landscape. This last objective was difficult to achieve due to the fact that, while a significant amount of research has focused on the areas outlined above, we were unable to locate evidence-based, innovative and transferable respite models in the available literature suggesting that more innovative respite models had either not been widely implemented and/or evaluated.

### What is respite care?

The term respite care has been defined and redefined in a multiplicity of ways over an extended period of time. Despite subtle differences, all definitions tend to characterise respite as an opportunity for those who care for disabled people to have “short breaks” from caring. Australian researchers Chan, Merriman, Parmenter & Stancliffe (2012) reported that the original purpose of respite care was to provide carers with *“a break from the pressure and responsibility of caring, whilst allowing those that they provide care for to stay at home.”* While the New Zealand policy context will be considered later in this introductory chapter, it is important to note here that the development of respite services nationally has been informed by the Ministry of Health, which promotes the purpose of respite care as being *“designed to provide short-term breaks for the carers of a disabled person, while also providing a positive, stimulating and worthwhile experience for the disabled person”* (“Respite Services | Ministry of Health NZ,” n.d.).

This policy statement reflects a more current understanding of respite which has shifted, at least in part, to include a focus on both the needs of carers and the role that respite can have in the lives of those receiving care (Mansell & Wilson, 2009). A wider interpretation of what type or models of support constitute respite care has also occurred. Contrary to earlier definitions, which assumed that a disabled child or adult would “stay in place” while their

carer sought respite away from home, there is now an acknowledgement that respite can (and in some circumstances, should) occur in a range of locations and contexts.

In addition to these extended understandings of respite, there has also been debate over the terminology that is used in research, policy and practice in the field of respite. The term respite can be loosely translated as meaning relief from something that is difficult or unpleasant. The implication that caring is a burden has been contested, particularly in the United Kingdom (see for example Collins, Langer, Welch, Hatton, Robertson & Emerson, 2014; Mencap, 2013; Robertson, Hatton, Wells, Collins, Langer, Welch & Emerson, 2011) and has influenced the emergence of the alternative term short breaks. A similar change in vocabulary has not yet taken hold in New Zealand, and respite care remains the term most commonly used and understood amongst policy makers, funders, service providers and carers, and was therefore used for the purpose of this study.

## Outcomes for carers

Internationally, respite care is the most prevalent form of family support (Freedman et al., 1999 quoted in Caples & Sweeney, 2010). Deinstitutionalisation and the associated development of community-based support and services provided the original impetus for respite care, with provision for respite care beginning to appear in policy in the 1980's. An ongoing commitment to disabled children and (in some cases) adults remaining at home has seen families increasingly involved in all aspects of their disabled family member's care (Caples & Sweeney, 2010). Because of this emphasis on parental care, there has been a significant amount of research examining the emotional and physical demands now being placed on parent carers. Most significantly, there has been a considerable amount of research that has confirmed family carers are at high risk for stress. In the UK, the poor mental health of carers was highlighted by a Mencap study reported that 8 out of 10 family carers of disabled people with high and complex needs had self-assessed as experiencing high levels of stress (Mencap 2003). A follow up to this study occurred a decade later and no improvement in self-reported carer stress was found; 8 out of every 10 respondents reported still being at "breaking point" (Mencap, 2013). In the New Zealand context Carpinter, Irwin and Rogers (2000) reported that primary carers experienced poor physical and mental health. In a study of parent carers of children and adults with high and complex needs, Bray et al. (2005) found that 20% of carers had *never* experienced a night away from their disabled family member. Finally, in a large national study of family carers Jorgensen, Parsons & Jacobs (2009) reported that 85% of participants indicated some level of stress, and two-thirds as suffering from depression.



One consequence of these, consistently negative research findings, has been to focus on respite as an important way to assist family (and non-family) primary carers to maintain positive physical and mental health (Chan et al., 2012; Kyzar, Turnbull, Summers, & Gómez, 2012). At the most basic level, respite provides carers with the opportunity to stay connected with some of the ordinary rhythms of community life, including catching up on every-day, essential tasks such as bill payment, household chores and attending to their own medical care (Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009; Carpinter et al., 2000; Doig, McLennan & Urichuk, 2009; MacDonald & Callery, 2004; Welsh et al., 2014). Effective respite care also has been identified through the literature as having the potential to:

- Ameliorate carer stress, anxiety and exhaustion (Jorgenson et al., 2009; Nankervis, Rosewarne & Vassos, 2011; Harper et al., 2013)
- Reduce feelings of being overwhelmed (Collins et al., 2014)
- Increase family quality of life (Caples & Sweeny, 2010; Kyzar, Turnbull & Summers, 2012)
- Increase family resilience (Chan et al., 2012)
- Enable parents to spend uninterrupted time with their other children (Wilkie & Barr, 2008)
- Provide an opportunity for carers to plan for when they can no longer provide care (Collins et al., 2014)
- Achieve improved health and wellbeing through social contact, social relationships, skill development (employment and study) and improved family relationships (NEF consulting, 2009; Collins et al., 2014; Welsh et al., 2014)
- Maintain and improve both marital quality and family relationships (Autism New Zealand, 2011; Harper et al., 2013).

The other outcome emphasized in the research literature is the critical role respite can play as an intervention to prevent relinquishment or the breakdown of family integrity. Respite is frequently framed as a strategy, funded to avoid families reaching breaking point and seeking permanent out of home placement for their family members (Chan et al., 2012; Mencap, 2003; Robertson et al., 2011). In the New Zealand context, there is wide recognition that (most) children are best served by being with their families, that out-of-home placement of disabled children should only occur in very extreme situations, and that all steps should be taken to avoid this action. There is a significant imperative, therefore, to continue to explore ways to deliver high quality respite that is responsive to the needs of both carers and the individuals they care for to avoid the harmful and more expensive consequences of "out of home" family member placements.

## Outcomes for disabled children and adults

Although the ability of respite to meet the multiple needs of carers (and parents in particular) has remained a primary research focus, studies are beginning to emerge that detail the actual and desired outcomes for children and adults who receive respite care. The unifying theme within those studies is that respite also needs to meet the needs of disabled children and adults and most especially in ways that respond to their impairment, life stage, interests and aspirations. Outcomes identified in the literature as indicative of quality respite experiences for disabled children and adults include;

- Access to an enjoyable and enriched environment (Burton-Smith et al., 2009; Doig et al., 2009; NEF consulting, 2009; Wilkie & Barr, 2008).
- Support that is well matched to the needs and interests of the individual (Autism New Zealand, 2011; Robertson et al., 2011; Welsh et al., 2014).
- Opportunities to participate in leisure activities (Autism New Zealand, 2011; Wilkie & Barr, 2008).
- Stimulating environments that teach a range of social and physical skills (Doig et al., 2009; NEF consulting, 2009)
- Increased health and wellbeing (Jeon, Brodaty, O'Neill, & Chesterson, 2005; NEF consulting, 2009).
- Assistance with developmental goals (Doig et al., 2009).
- Opportunities to develop social skills (Autism New Zealand, 2011; Doig et al., 2009; NEF consulting, 2009; Robertson et al., 2011; Wilkie & Barr, 2008).
- Opportunities to form and maintain relationships with children outside of their own family or school environment (Wilkie & Barr, 2008).
- Support to develop independence from their parents and participate in activities when their parents are not around (2009; Welsh et al., 2014)

## Outcomes for siblings

Given parent carers frequently cite concern for their other children as a reason for needing to access respite, it is relevant to include here what is known about the impact of respite on non-disabled siblings. Respite care has been reported to provide parents with more time to focus on other siblings, and to attend events and activities that they participate in (Hatton & Greig, 2011; Mencap, 2013; Welsh et al., 2014; Wilkie & Barr, 2008). However, some conflicting evidence exists that suggests that some siblings do not like the separation that respite care creates and experience feelings of anxiety and miss their siblings while they are apart (Robertson et al., 2011). It has been suggested that providing in-home support is particularly

beneficial for siblings, as it allows them to stay with their brother or sister and to develop a relationship with the respite care provider (Welsh et al., 2014).

## Care recipient attributes

Research that has explored the age of respite care recipients has indicated that respite support is utilised most significantly for adults over twenty years of age (Chan, 2008; MacDonald & Callery, 2004; McConkey et al., 2011, 2010). A study that explored three Irish national health databases reported that more adults than children were receiving respite care (McConkey et al., 2010). Consistent with the previous findings, infants and toddlers appear to be the lowest users of respite services (Chan, 2008), which various authors attributed to an inability to find suitable carers, that they were new parents/carers and had not yet experienced significant burnout/stress, or that complex behaviours develop with age. MacDonald & Callery (2004) found that the uptake and duration of respite services developed with age. In infancy short, informal breaks were sufficient, whereas if more complex behaviours developed as the child aged, parents looked for more frequent breaks of longer duration (MacDonald & Callery, 2004). Interestingly, this pattern does not appear to be repeated in New Zealand data, with statistics reported by the Ministry of Health (2015) estimating that around 70% of respite care users were under the age of 25 with the highest users aged between 10 to 14 and the second highest users 15 to 19 years of age.

The care recipient's level of impairment has been found to be another significant predictor of respite use. McConkey et al. (2010) found that it was in fact the highest predictor of respite use within the Irish context. Following their analysis of the Irish national database McConkey et al (2011) estimated that those caring for children or adults with profound disabilities were up to five times more likely to seek respite. Other individual characteristics studies have reported as correlated with respite use include; communication ability, multiple limitations of function and a family member's level of dependence (Nankervis et al., 2011a; 2011b).

Conversely, Mac Donald, Fitzsimons & Walsh (2007) found no evidence of a relationship between the disabled child's level of independence and children's respite care use and that fewer children with challenging behaviours than expected used respite care in the Irish context. (Mac Donald et al., 2007). To the authors knowledge, this scoping study is the first to explore any association between care recipient attributes and the use of respite care reported by a small group of New Zealand carers.

## Carer attributes

A smaller body of research has considered whether carer attributes influence respite use. Like care recipients, a relationship between the age of carers and respite use has been identified. Vecchio, (2008), for example, reported an association between the (increasing) age of carers and respite care use after analysing data from the Australian Survey of Disability, Ageing and Carers (2003).

It has also been suggested that carers' income and employment influences respite care use. Carers who are currently working, (whether in full or part-time employment) have been found to be more likely to use respite care than those who are unemployed (Vecchio, 2008). In an American study Dougherty et al. (2009) found that family income was also associated with respite use, and the majority of those receiving funded respite support were in low to lower- middle income ranges.

Geographical location also appears to influence respite use in families. Chan (2008) reported finding that carers living in rural areas were significantly less likely to use respite care in New South Wales, Australia, where only 13% of respite users lived in remote areas. In relation to this issue, McConkey et al. (2010) have challenged the inequity in access to respite care, arguing that it should be accessible for all families, regardless of where they live (McConkey et al., 2010).

Several other carer characteristics have emerged in research seeking to understand respite service use. Contact with a social worker within the past year was identified as a significant factor in predicting respite use in Ireland (McConkey et al., 2011). Interestingly, single carers were found to be no more likely to receive breaks than those with two parents/carers (McConkey et al., 2011). Furthermore, Mac Donald et al., (2007) found no obvious correlation between family size and use of respite services.

## Barriers to access: What stops carers using respite care?

A concern of many studies in the area of respite support has been to identify the factors that impede or facilitate access to respite support. An array of, sometimes interrelated factors have been identified in the research literature as creating barriers to respite services and support, including:

- Repeated inability to access services and support when carers need or wish to use it (Jeon et al., 2006).
- Previous negative experiences of respite facilities or individual carers (Jeon et al., 2006).
- When the child or adult receiving respite support does not enjoy respite care and is therefore reluctant to leave their primary carer (Bray et al., 2005; Power, 2009).
- An absence of age appropriate respite support (Jorgensen et al., 2009).
- Inflexible respite services (Autism New Zealand, 2011; Canavan & Merriman, 2007; Dougherty et al., 2009; Jorgensen et al., 2009; Mencap, 2013).
- Services that demonstrate an unwillingness to be responsive to individual need (Autism New Zealand, 2011; Canavan & Merriman, 2007; Dougherty et al., 2009; Jorgensen et al., 2009; Mencap, 2013).
- Limited availability of crisis respite care is another issue of concern, where the majority of providers provide planned respite, rather than crisis care (Dougherty et al., 2009).
- Lack of accessible information about what respite support is, how to find it, and how to use it care they are entitled to, what respite is available or how they can access it (Autism New Zealand, 2011; Canavan & Merriman, 2007; Doig et al., 2009; Jeon et al., 2006; Mencap, 2013).
- Lack of trust in the competence of respite service providers and individual respite care workers (Carpinter, et al., 2000).
- Unmotivated, dispassionate providers (Welsh, et al., 2014).
- Respite carers who lack empathy and understanding of the disabled child or adult (Thompson and Emira, 2011).
- A difficulty in trusting strangers to provide care (Autism New Zealand, 2011).
- Frequent staff change and turnover across all forms of respite service provision (Welsh et al., 2014).
- Restricted eligibility for and inadequate levels of respite funding (Welsh, et al., 2014; Chan, 2008; Jorgensen et al., 2009).
- Disabled children or adults being excluded from respite services on the basis of challenging behaviour (McGill, Papachristoforou & Cooper, 2006).
- Disabled children or adults being excluded from respite services on the basis of healthcare needs and requirements. (Chan, 2008).
- Lack of confidence in the ability for respite services or individual respite carers to detect changes in health when a disabled child or adult also has complex health needs (Welsh et al., 2014).

- Respite services and support being unavailable to younger children (Dougherty et al., 2009; Jorgensen et al., 2010).
- Lack of access to respite services and support after school and during school holidays (Bray et al, 2005).

Were the lack of access to respite is extreme the lack of suitable or appropriate respite options has continued to contribute to New Zealand families contemplating permanent out of home placement and the breakdown of family integrity (Bray et al, 2005). As noted in the New Zealand Carer's Strategy Action Plan (Ministry of Social Development, 2014), out of home placement is an expensive outcome for the state, with the financial benefits of maintaining disabled peoples connection's with their family and community including; remaining out of more expensive, state funded care options, improved health outcomes for families and primary carers, and an ability to attend to the needs and wellbeing of siblings, reducing education and social-related costs (NEF Consulting, 2009).

## What are the features of effective respite support and services?

The definitions and classifications of respite care vary considerably throughout the literature. Most of the definitions, however, can be included in a four-fold taxonomy of respite or short-term care options; informal support from friends and family, formal respite care delivered in the home of the disabled child or adult, support delivered through facility based respite services, or respite delivered through Recreation or Holiday Programmes (Jeon, Brodaty, & Chesterson, 2005). Primary carers and the disabled children and adults they support typically draw on one or more of these support or service options depending on the availability of support, the support needs of a disabled family member and/or the perceived demands on carer and their wider family. Regardless of the model of delivery, a number of features have been identified as being critical to quality respite service and support, including:

- Services and supports offered in a range of formats (Chan et al., 2012).
- Services and supports that are available during school holidays and over weekends (Burton-Smith et al., 2009; Wilkie & Barr, 2008).
- Greater flexibility about where, when and for how long respite support is provided (Chan et al., 2012; Welsh et al., 2014).
- Respite support that is responsive to both the needs of the primary carer and the disabled child or adult (Chan, 2008; Jorgensen et al., 2009).
- Respite services and support that is focused on the family unit as a whole (Jorgensen et al., 2009), Canavan & Merriman, 2007; Elton Consulting, 2014; Staley, 2008).

- Consistent and reliable respite services and support (Autism New Zealand, 2011; Doig et al., 2009).
- Stimulating, innovative and educational models of respite care (Staley, 2008; Burton-Smith et al., 2009; Mansell & Wilson, 2009).
- Services and support underpinned by trusting relationships (Autism NZ, 2011).
- Support that is focused on building family resilience (Chan et al., 2012; Hatton & Greig, 2011).
- Services that consider and incorporate the views of primary carers and disabled children (and adults) in the development and implementation of services (Canavan & Merriman, 2007; Hatton & Greig, 2011).
- Services and support that are responsive to changing individual and family needs and circumstances (Elton Consulting, 2014; Hatton & Greig, 2011; Staley, 2008).
- Culturally sensitive services and support (Chan et al., 2012; Carpinter et al., 2000).
- Respite services and support that are integrated with other models and forms of support, including informal and community supports (Elton Consulting, 2014).

Missing from the corpus of research that informed this review, however, were studies intended to compare or evaluate outcomes associated with any particular form of respite care or support. In the literature, we reviewed, the research inquiry had continued to focus on; defining what respite was and exploring the impact short-term breaks had parent(s) and primary carers, the factors that impeded access to respite, and the set of discrete elements that parent/primary carers perceived to be integral to quality respite services and support. Significantly less evident in the literature were specific examples of respite models that have attempted to weave available evidence together to develop and implement responsive respite services and support. This brief review of the literature has confirmed that both nationally and internationally, there appears to be a long-standing difficulty in translating research into policy and practice in the area of respite services and supports.

Importantly, during the course of this scoping project another New Zealand study of respite requirements for children and young people with high level, complex, health related support needs was made available to the research team (Prilesky et al., 2015). A model for responding to the respite needs of children and young people with complex needs was advanced. The model, and its potential utility is discussed more fully in the final chapter of this report.

# RESPIRE FROM A NEW ZEALAND POLICY PERSPECTIVE

It has been estimated that over 400,000, or one in 10, New Zealanders act as a primary carer for someone who needs help with everyday tasks because of a health condition or disability. Carers, therefore, represent *"New Zealand's largest health and social service workforce,"* (Ministry of Social Development, 2014) with the number and proportion of New Zealanders acting in a carer role expected to expand rapidly as the New Zealand population in general and disabled people in particular, age demographically.

At the same time, families caring for disabled people have found themselves positioned at the centre of "New Models" of disability support as they and their informal support networks are increasingly being seen as critical to advancing the kind of community participation imagined as pre-requisite to living "valued lives" within New Zealand social policy (Minister for Disability Issues, 2001) and the United Nations Convention on the Rights of Person with Disabilities (UNCRPD).

In the New Zealand Carer's Strategy, carers role in both *"helping to reduce [our] dependence on long-term paid care systems, such as residential care"* and in *"enabling disabled people to participate more fully in their whānau, aiga and communities,"* is acknowledged amongst the more important contributions carers make to New Zealand society.

In a way that mirrors the vision articulated for disabled people in the New Zealand Disability Strategy, the destination envisaged by the New Zealand Government in the Carers' Strategy is that *"New Zealand Aotearoa is a society that values individuals, families, whānau or aiga who support others who need help with their everyday living."* A further aspiration is that caring should be a role performed with pride. Aligned with Objective 15 of the New Zealand Disability Strategy, the New New Zealand Carers Action Plan articulates that caring should be a "valued" social role and that this vision will have been reached when:

- Carers have choices and opportunities to participate in family life, social activities, employment and education.
- Carers' voices are heard in decision-making that affects them, (Ministry of Social Development, 2014).

Furthermore, providing opportunities for carers to exercise control over the ways in which they are supported and ensuring that the act of "caring" doesn't marginalise those who provide it from the same array of choices and opportunities that define citizenship for other New Zealanders is also seen as a key determinant of the health and wellbeing of people in a



carer role. Valuing and supporting carers in these ways will, the New Zealand Carers Strategy argues, lead to the development of *“strong, healthy families able to assist (disabled) family members to reach their full potential as participating members of society.”*

Within the social policy framework, therefore, a clear linkage is made between the ability of service providers to recognise and respond well to the array of factors that may compromise the health and wellbeing of carers and the human rights status of people being cared for.

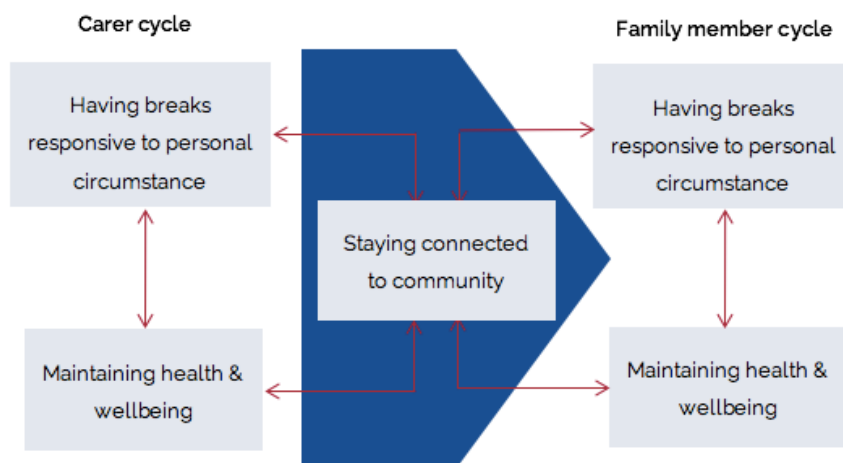
In their submission to Ministry of Social Development, the New Zealand Carers' Alliance affirmed this view by stating that the Carers' Strategy needed to:

*...commit to [...] Supporting carers succeed in their important role (by) considering the impact of their role on carers' lives, the lives of those they support if carer's wellbeing is compromised, and their participation in paid work and the wider economy.*

(cited: Ministry of Social Development, 2014, p.8)

The health and wellbeing of both carer and disabled family member are, therefore, seen as intimately connected in two ways. Firstly that “valued lives” are experienced through a shared ability to stay connected to those community contexts that define and support participatory citizenship. Personally responsive respite is framed as supporting family integrity, not just by providing a short-term break from the demands of caring, but by enhancing carers' ability to participate in their community. The second way that the health and wellbeing of carers and disabled people are seen as connected, is that strong and healthy families are acknowledged as providing the most effective conduit to disabled people experiencing an unbroken participatory presence within the whānau, aiga and communities that also enhance their health and wellbeing.

**Figure 5. The interconnected cycles of carer and disabled family member wellbeing**



## What New Zealand carers said was important in the New Zealand Carers' Strategy Action Plan

Recognising the diversity of carers changing needs and developing support systems that proactively respond to them are two of the four guiding principles of the New Zealand Carers' Strategy. Acknowledgement of the central role carers views and perspectives will have in achieving the vision of a greater societal valuing of the role can be found in that previous two Carer's Action Plans (2008-2012 and 2013-2018) were informed by consultation rounds that engaged New Zealand Carers and the New Zealand Carers Alliance.

Following their most recent consultation, the Ministry of Social Development amended the 2013-2018 Action Plan, including re-arranging the set of objectives to better reflect the priorities of carers that emerged during the consultation. Within the Action Plan, the Ministry of Social Development noted that, whilst all of the objectives were important, the *"consultation made it clear that the top priorities (for Carers) are practical support for taking a break and Carers' health and wellbeing."* (Ministry of Social Development, 2014, p12).

Objective One of the Action Plan 2013-2018 (*"Enable whānau, aiga, family and carers to take a break"*) responds to carer feedback by identifying the development of a range of respite options that better meet carers needs as its first priority. Actions under this objective are intended to provide whānau, aiga, families and disabled people access to *"respite care at a time and in a way that suits their personal needs, giving families greater choice, control and flexibility over the services they receive."*

As lead agency, the New Zealand Ministry of Health has responsibility for developing a range of respite options by:

- Trialing different types of respite options for families that give greater choice, control and flexibility over the services they receive.
- Exploring the development of an online carer matching service.

Objective two of the Action Plan 2013-2018 (*Protect the health and wellbeing of whānau, aiga, family and carers*) responds to the second priority identified by carers.

Whereas providing a break from the demands of caring and most especially, making sure carers have the opportunity to participate in family life, social activities, employment and education are identified as contributing to the health and wellbeing of carers in the Carers' Strategy, the Action Plan narrows the scope of this objective by focusing on the development and delivery of learning resources and best-practice guidelines.

As a result of this policy emphasis expressed in these two outcomes:

- **A window of opportunity exists to contribute to the Objective 1.1 of the Carers' Action Plan 2013-2018 by trialing respite options that respond to the diversity of carer need.**
- **The Ministry of Health has assisted the design process by identifying, greater carer choice, control and flexibility as key attributes of respite responses, services and support.**

In the following sections of this report, we detail our findings following combined analysis of the Online Survey and Key Informant Interviews. The chapters are organized in a way that responds to four thematic questions that emerged from the analysis, with findings clustered into carer's perceptions of;

- What is the purpose of respite care?
- How accessible is respite care?
- How do carer's assess the range of current respite options?
- What is missing from the respite care landscape?

# WHAT IS THE PURPOSE OF RESPITE CARE?

## Meeting New Zealand carer's need for short breaks

Before presenting the specific results generated through this scoping project, it is important to take a brief look at what is known about carer support and facility based respite at a national level.

In New Zealand, carers ability to access short-term breaks occurs through the allocation of Carer Support Days and/or facility based respite services. Both services are funded by the New Zealand Ministry of Health and are accessed by carers through regional Needs Assessment Service Coordination services (NASCs), subcontracted by the Ministry to determine carer eligibility and funding allocation. NASCs are also responsible for detailing service and support options available to carers and other DSS clients. Carers managing their own support through an Individualised Funding arrangement can also purchase either Facility Based respite and/or In-home support (IF Respite) by using their Individualised Funding allocation.

As presently configured, Carer Support and Facility Based Respite are funded to meet slightly different objectives.

## The intended purpose of Carer Support

Carers who provide more than four hours unpaid care to a Disabled people each day are eligible to receive a Carer Support subsidy. Funded by the Ministry of Health or a District Health Board (DHB), the subsidy is intended to provide an opportunity for a Carer *"to take a break"* by contributing to costs that may be incurred by an alternative carer.

Carer Support is funded at seventy-six dollars per day and is intended to provide carers with the *flexibility* they need *to chose and organise their own relief care*. By providing an opportunity to organise either formal or informal support in ways that respond to carers' particular family and/or care context, the Carer Support subsidy is promoted as *"enabling the full-time carer to continue to provide the required support that (will) allow the person with a disability to continue to live in the community as long as is practical."*

Carer Support is intended to draw on the collective resources of a carer's informal support network to provide carers' with a break. The largely "unspoken rationale," however, is that

framing the subsidy as a "reimbursement" reinforces the principle that caring is an ordinary act most correctly transacted within a disabled person's community of informal support.

Carer Support can be used in a variety of ways including claiming full or half days to fund; out-of-home respite in residential care facilities, in-home care provided by a service provider or friends and family who are not full-time carers and who do not live at the same address, participation in an After School and/or Holiday Programme, (typically run by a service provider).

The number of Carer Support Days allocated is determined through the Needs Assessment Process and orientated towards identifying the support needs of the disabled family member. Although the Needs Assessment is care-recipient focussed, the purpose of the funding is framed as providing the carer with a break, with the expectation that respite care also meets the needs and aspirations of the disabled person seen as a carer responsibility.

## The intended purpose of Facility Based Respite

Facility Based Respite provides short term relief support to Carers in a residential service setting. Like Carer Support, Facility Based Respite is intended to address the sustainability of family and other non-service caring contexts as a way of supporting disabled people to remain in the community as a way of avoiding more expensive residential care alternatives. The purpose of Facility Based Respite, as expressed by the New Zealand Ministry of Health (2016) is to *"provide a break for the person's carer(s) **in order to sustain their longer term support for the person to live in the community**"* (emphasis added).

Facility Based Respite is also intended to provide carers with an opportunity to include planned and predictable respite support elements, although the DSS Service Specifications for facility based respite providers includes an expectation that services also provide opportunities for "unplanned" respite use when carers *"are in urgent and immediate need of respite due to a family emergency, crisis or unforeseen event."*

Unlike Carer Support, facility based respite Service Specifications make explicit that respite support needs to respond to the needs of the Care recipient too by providing *"positive, stimulating and worthwhile experiences"* that *"replicate the 'out of family' experiences of people who do not have disabilities and who commonly stay with school friends, extended family relatives and friends"* (Ministry of Health | Tier Two Facility Based Respite, n.d.)

Facility based respite is also intended to contribute to a carer's existing "network" of support by building relationships of trust and support. To facilitate this relationship, facility based

providers are required to collaborate with carers and the disabled person in the design and orientation of support to meet outcomes expressed, with a person's support needs, preferences and respite aspirations recorded in their Personal (Respite) Plan. Facility based providers are also expected to engage in timely and appropriate communication prior to and at the conclusion of a respite placement.

## Determining carers' respite path

Communication with New Zealand NASC agencies conducted in the course of scoping this project suggested that the allocation of either Carer Support Days or Facility Based Respite as a funding option tended to not be determined by any fixed service guideline. Rather, allocations were determined by service coordinators' attentiveness to a range of factors drawn out in the Needs Assessment interview, including a carer's preference for a particular model of respite support and the type of support needs they described.

NASC managers also said the allocation of respite was moderated by the range of respite service options available in their region. Marked regional differences were said to exist in a carer's ability to access facility based (and other) respite options and that this was often reflected in their allocation of respite funding.

NASC managers told us that Needs Assessment Coordinators were trained to question and expected to inform themselves of the care context during the Needs Assessment interview. A key focus of the interview was, they said, to learn more about a carer's wellbeing and the size and configuration of the support network from which they could draw "informal" support.

## Carers allocated Carer Support Days

In 2013, 15,890 Disability Support Services (DSS) clients were allocated a Carer Support subsidy (Ministry of Health, 2015).

Forty-three percent of carers allocated Carer Support were meeting the day-to-day support needs of a family member with a primary diagnosis of intellectual disability (n= 6772). When combined with carers who were supporting a family member whose primary diagnosis included intellectual disability (Physical & Intellectual, n= 410; Neurological/Intellectual/Physical, n=300; and Intellectual/Neurological/Physical, n= 48), approaching half of the carers allocated a Carer Support subsidy were caring for a family member whose impairment included intellectual disability (n= 7530, 47.4%). Carers providing support to a family member whose primary diagnosis was an Autistic Spectrum Disorder

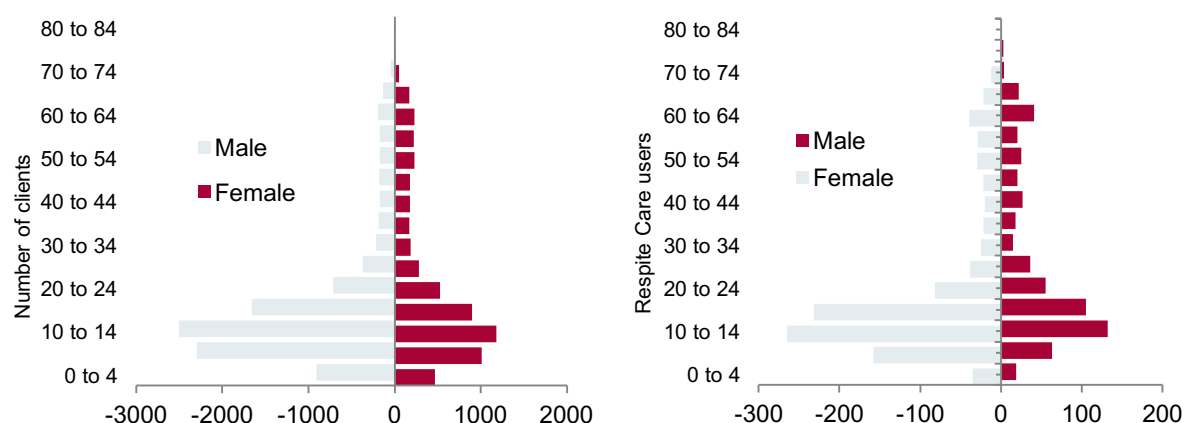
(ASD) were the second largest group of Carer Support Day recipients. Twenty-six percent of DSS clients who received an allocation of Carer Support Days provided support for a family member with ASD (n= 4139) and 15.9% of carers allocated Carer Support Days were caring for a family member whose primary diagnosis was a physical impairment.

**Table 1 Carer support clients by sex and principal disability (Ministry of Health, 2015)**

Disability	Male	Female	Total	%
Intellectual	2799	3973	6772	42.6%
ASD	805	3334	4139	26.0%
Physical	1196	1326	2522	15.9%
Not DSS	250	348	598	3.8%
Sensory	264	297	561	3.5%
Physical and intellectual	201	209	410	2.6%
Physical/neurological	248	151	399	2.5%
Neurological/intellectual/physical	140	160	300	1.9%
Neurological	46	85	131	0.8%
Intellectual/neurological/physical	18	30	48	0.3%
Neurological and physical	3	7	10	0.1%
<b>Total</b>	<b>5970</b>	<b>9920</b>	<b>15,890</b>	

Six out of every ten carers who received a Carer Support Day allocation were supporting a family member aged between 5 – 19 years (9545, 60.1%). Although heavily represented in the DSS support population, the carers of young men were over-represented within the profile of carers receiving Carer Support Days. Conversely, carers supporting children under the age of 5 years were under-represented, perhaps indicative of a, seemingly pervasive understanding that very young children's support needs are not dissimilar to their age peers. Carers supporting adults over the age of 25 years were also under-represented compared to the DSS support population, indicative of their transition to adult residential or supported living contexts.

**Figure 6 The number of DSS clients receiving (a) Carer Support & (b) Facility Based Respite by age and sex**



The majority of Carer Support Day clients lived in the Auckland (n= 5960, 37.5%) and Canterbury (n=2082; 13.1%) regions. The Ministry of Health compared the regional allocation of Carer Support Days to the DSS support population. They found that carers in Auckland were disproportionately more likely to receive a Carer Support Day allocation relative to the proportion of DSS clients living in Auckland (7.1% difference). Conversely, carers in the Manawatu-Wanganui (-1.62% difference), Otago (-1.36 difference) and Nelson (-1.4% difference) regions were less likely to receive a Carer Support Day allocation relative to the proportion of DSS clients living within those administrative regions.

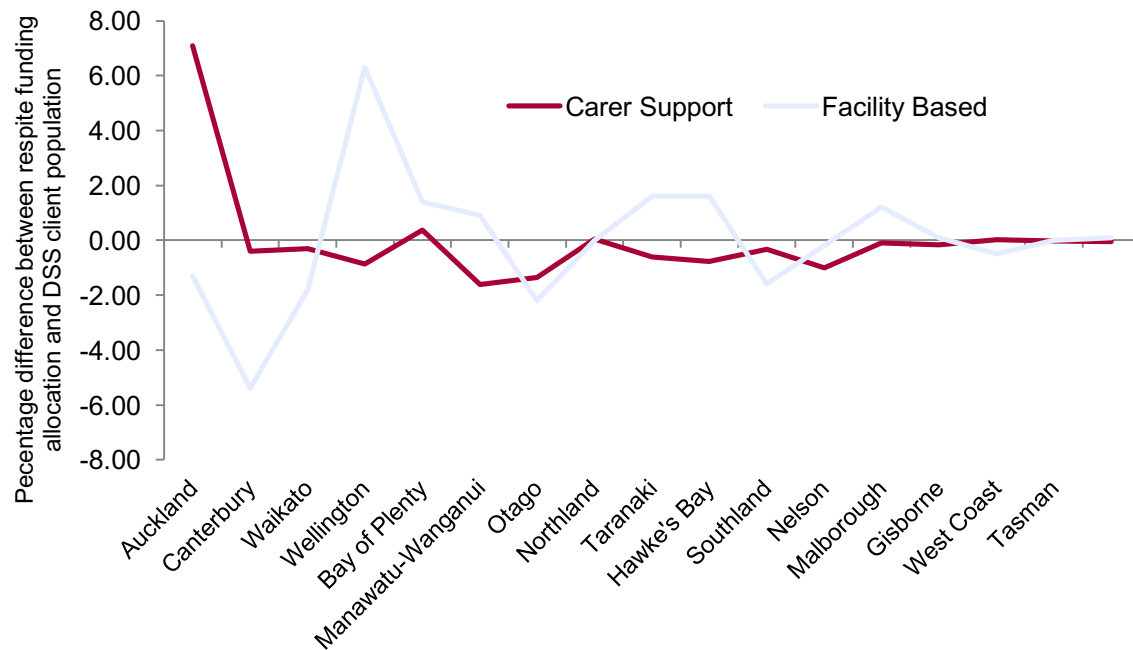
## Carers allocated Facility Based Respite

The number of carers who used facility based respite was much lower than those who received Carer Support Days. In 2013, 1,637 clients accessed facility based respite, although it is important to note that given the way Facility Based Funding is contracted, it was only possible to determine how many clients used a facility in that calendar year and not the number of Facility Bases Respite Days/Nights allocated.

The age-sex profile of facility based respite care users was very similar to the those allocated Carer Support Days. One in six disabled people whose carers used facility based respite were aged between 5 – 19 years (n= , 58.3%), although the proportion of children aged less than ten years was lower in comparison to the higher proportion of adults aged 20 – 29 years.



**Figure 7 The percentage difference between Carer Support and Facility Based Respite allocation and the DSS client population by region**



The Ministry of Health noted that there were marked disparities in the regional use of Facility Based Respite. Auckland (n= 477, 29.1%) and Wellington (n= 252, 15.4%) were the regions associated with the highest use of Facility Based Respite. The Ministry suggested that carers in Wellington were over-represented as users of Facility Based Respite, with 9.1% of DSS clients living in that region but 15.4% of those clients using Facility Based Respite. Using the same formula, the Canterbury region was under-represented, with 13.5% of DSS clients living in that region and only 8.1% of those clients using facility based respite.

A general trend was observed for the percentage difference between Carer Support allocation and the DSS population to be lower in regions where facility based respite use was higher relative to the DSS population in that region. It was not possible to determine the extent to which this may be reflective of;

- NASC agencies responding to the absence of Facility Based Respite options within their region with a higher allocation of Carer Support funding (or vice versa).
- Regional differences in carers ability to access facility based respite even when they had Facility Based Funding.
- Fiscal pressure on NASC agencies to manage funding budgets.
- Regional differences in the distribution of support need or demography of care recipients.
- Other factors that may contribute to the overall pattern.

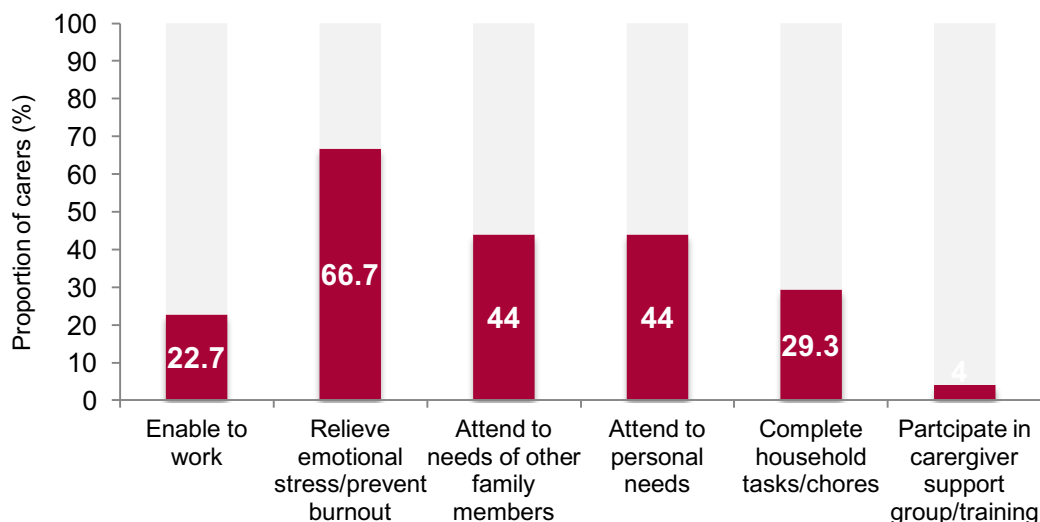
South Island regions were more likely to be under-represented in both Carer Support Day allocation and Facility Based Respite use relative to their respective DSS client population. As a proportion of their respective regional DSS client populations, carers from Canterbury, Otago and Southland were less likely to receive Carer Support Days or use Facility Based Respite.

## What did carers think the purpose of respite care was?

In the *Responding to Respite Care Needs Survey*, carers were asked why they had most recently sought respite care. The question was intended to provide insight into what carers thought the purpose of respite was, including how respite support responded to their particular family's needs.

The responses of carers mirrored those of carers consulted during the development of the New Zealand Carer Action Plan 2013 – 2018, in that they emphasised the need to take a break and, in particular, the need to relieve emotional stress as their pre-eminent reason for seeking respite.

**Figure 8 The reason carers named for seeking their most recent use of respite care**



## Having the opportunity to relieve the emotional stress of caring

Two out of every three carers reported seeking respite most recently for reasons of preventing carer burnout (n= 51; 66.7%).

All carers characterised the process of providing support as stressful - and periodically so in ways that had an impact on their health and wellbeing. For some, caring included the struggle to understand and respond to unpredictable behaviour, but most carers reported that caring was an unrelenting vocation. Carers described themselves as *"forever listening"* and explained that the accumulation of needing to remain vigilant and responsive to needs that were "out of sync" with other children was stressful in ways that undermined wellbeing and their capacity to care well.

*C      The only reason we haven't reached breaking point is because of respite. That's been a lifeline for both of us. Just being able to have a break. You have no idea how important it is. It's vital for both of us. For our sanity and for our mental health and for our physical health – just to be able to have that break to recharge and regroup. To carry on basically.*

Having an opportunity to *"pull back from the daily grind"* of caring was described by many as providing the space they needed to recharge their batteries. Carers repeatedly reported that taking a break enhanced their capacity to care by providing the distance they sometimes required to *"think about new ways of doing things"* or to look at things with an objectivity that was sometimes difficult when meeting the multiple demands of the carer role.

In the absence of many other forms of acknowledgment, some carers read the allocation of respite funding as indicative of a valuing of a role what could otherwise be socially isolating and/or stressful. For others, simply having funding available provided a sense of psychological safety that made caring easier.

*I      You said you weren't using (respite) because it would be unfair to dump him in such a place. Could you expand on that?*

*C      Well I just wanted somewhere where he would be going in an emergency so they gave me the days and that was it. And I thought well there is no point in using them unnecessarily, well just keep them in the back of our mind and we've got them there to use.*

However, what was more typical was that most carers felt vulnerable to the loss of Carer Support or Facility Based Respite funding. As a consequence, most described worrying about the Needs Assessment Process and of being fearful that without either drawing attention to all of the negative aspects of caring for a family member, or of not using their allocated respite funding, that respite support would diminish.

Almost all carers described being able to take a short break as elemental to their wellbeing able to "carry on." Respite was "the light at the end of the tunnel" whereas providing care without interruption, was described as wearing a person down in ways that "inevitably led to the point where you can't cope".

- **Carers identify the interruptions provided by respite as a possible window of opportunity for rethinking and reframing support in ways that enhance family resilience**
- **Feeling that respite is available contributes to carers sense of wellbeing regardless of whether it is used, provided capacity existed for them to use it in the case of emergencies or changed circumstance.**

## Reaching breaking point

Six out of every ten carers who answered the *Responding to Respite Needs Survey* reported they had felt close to breaking point as a consequence of not getting sufficient respite care (n= 44; 58.7%)

## Who were most likely to report having felt close to breaking point

To explore whether it was possible to identify carers most at risk of describing themselves as having felt close to breaking point we modeled the association between a range of care provider and care recipient attributes and the likelihood carers' would report experiencing moments of extremely poor mental health.

A statistically significant association was found between the **intensity of support** carers said they provided and the likelihood they would report having felt close to breaking point. Carers who assessed themselves as having to provide continuous (n= 29; 60.4%) or frequent (n= 9; 64.3%) assistance were more likely to describe themselves as having felt close to breaking

point as a consequence of not getting sufficient respite. The odds that a carer who provided continuous assistance would report having felt close to breaking point were 16.9 (95% CI= 1.43 – 200.0) times higher than carers who provided occasional support (n= 1; 14.3%).

**Parents** were also at significantly greater risk of self-reporting having felt close to breaking point. Whereas more than six out of every ten parents said they had previously felt close to breaking point as a consequence of not getting enough respite (n= 30; 62.5%), non-relative (n= 5; 35.7%) and sibling or other relative (n= 2; 50.0%) carers were less likely to report having felt close to breaking point. The odds that a parent would report having felt close to breaking point were 4.0 (95% CI= 1.1 - 14.9) times higher than non-relative carers.

The most significant predictor, however, was carer's assessment of whether they **received sufficient respite care**. Feeling as if you didn't receive enough support was strongly associated with the likelihood a carer would report having felt close to breaking point ( $\chi^2= 22.4$ ;  $p < 0.001$ ), supportive of carers assertion that providing practical support for them to take a break was protective of their health and wellbeing.

Conversely, carers who identified themselves as most vulnerable to experiencing a breakdown (parents and carers who provided continuous support) were also most likely to report difficulty accessing the kind of respite they felt they needed.

## Receiving the respite carers felt they needed

Half of the carers who completed the *Responding to Respite Needs Survey* reported feeling that they did not receive enough respite care (n= 38; 50.7%).

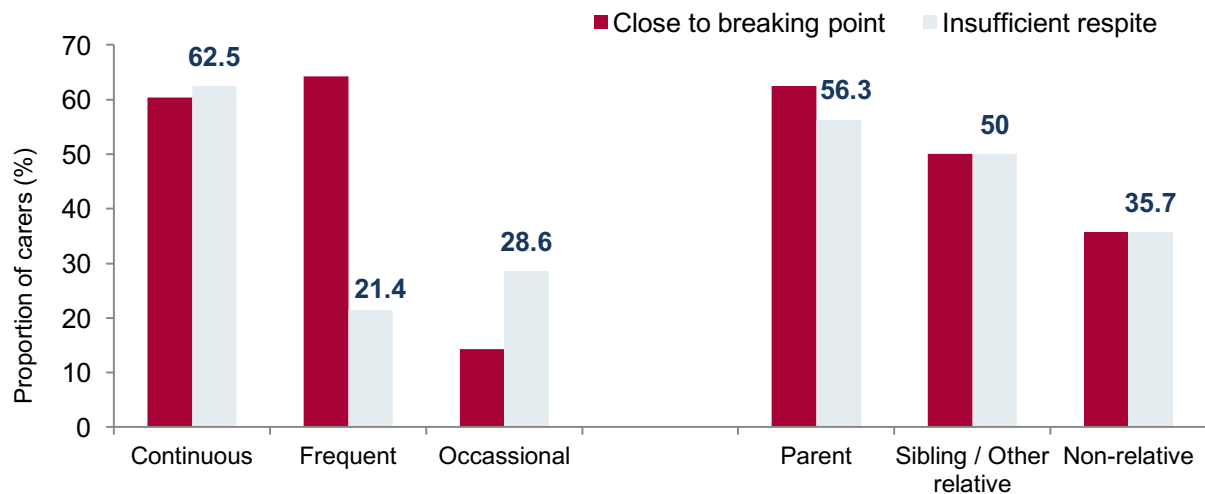
## Who were most likely to report not receiving sufficient respite?

As would be expected by the strength of association between carer health and wellbeing and the feeling that sufficient respite was provided, the intensity of support provided by carers and whether a carer was a parent or not also predicted whether respondents would say they received sufficient respite.

Carers providing **continuous support** were most likely to feel as if they did not receive sufficient respite (n= 30; 62.5%) and were 6.4 (95% CI= 0.9 – 43.5) times more likely to report not receiving enough respite than carers who reported providing occasional support.

Similarly, **parents** providing support were most likely to report not receiving enough respite care (n= 27; 56.3%) than sibling or other relative (n= 2; 50.0%) or non-relative (n= 5; 35.7%) carers - although the association was not found to be statistically significant.

**Figure 9 The proportion of carers who reported having felt close to breaking point and who felt they received insufficient respite by intensity of support and support relationship**



- Consistent with international research, a high incidence of poor health and wellbeing as measured by the likelihood of having felt close to breaking point among carers was reported with six out of every ten survey respondents saying they had felt close to breaking point.
- The feeling that respite received was sufficient was found to be protective of carer health and wellbeing on the basis of a strong association found between carers feeling like they had sufficient breaks and the likelihood they would report having felt close to breaking point.
- Half of the carers who responded to the survey did not feel they were able to access sufficient respite.
- Parents and carers providing continuous support were identified as at greatest risk of receiving insufficient respite, and thus, experiencing poorer health and wellbeing.

## Was it the same carer group who said they used respite care to address emotional stress?

For some carers, having an opportunity to relieve the emotional stress of caring for a family member appeared to be more important than others.

Carers **providing care to three or more** other children or young adults living in the same households were significantly more likely report seeking respite to relieve emotional stress (n= 13; 86.7%) than other carers (n=36; 62.1%). The odds that a carer with three or more dependents living in the same household would report most recently seeking respite to relieve emotional stress were 8.8 (95% CI= 0.966-79.956) times higher than carers with fewer dependent children or adults. In addition to an increased care responsibilities, this finding is consistent with previous research that has found that carers can experience feelings of guilt associated with the difficulty they often have in balancing the needs of their disabled and non-disabled children. As is outlined in more detail later in the report, some carers said that became difficult to attend to their children's increasingly different needs and aspirations as the life trajectories of their children diverged. Carers who had two or more children repeatedly told us that respite afforded an opportunity to attend to the relationships they had with their non-disabled children by doing things they might not otherwise have the chance to do.

Carers who were **single** (n=17; 85.0%) were more likely to report most recently seeking respite to relieve emotional stress than carers with a partner (n= 33; 60.0%), although the amount of variance explained by the relationship status of carers fell short of statistical significance when other variables were controlled for. It is not unreasonable to speculate, however, that not having a partner may have denied single carers access to moments of respite that can come with sharing the responsibilities of caring and the support of someone similarly invested in the wellbeing of their family.

Carers supporting a disabled **male family member** were also significantly more likely to say they had most recently sought respite care to relieve emotional stress (n= 73.5%) than carers providing support to a female family member (n=13; 52.0%). The odds that the carer of a male family member would report seeking respite to protect their mental health and wellbeing were 3.4 (95% CI= 1.03-11.24) times higher than the carer of a female family member.

Finally, respondents caring for **teenage children** were also more likely to report most recently seeking respite to relieve emotional stress. Three out of every four carers supporting children aged between 13 – 17 years most recent sought respite care for this reason (n= 16; 76.2%) compared to 66.7% of carers who provided support to a family member

aged 18 years or over and 60.0% of carers providing support to a family member aged between 5 – 12 years.

Previously we noted that young male disabled people tended to be over-represented in the population of DSS clients allocated Carer Support Days and Facility Based Respite. As we will discover later in the report, the carers of teenage male family members were also more likely to report finding it difficult to access appropriate respite care.

## Having the opportunity to attend to personal needs and the needs of other family members

Although carers were most likely to say that the reason they had most recently sought respite was to take a break from the emotional demands of the carer role, in excess of four out of every ten carers identified their need to attend to personal matters (n= 33; 43.4%) or the needs of another family member (n=34, 44.7%) as the reason for seeking a short-term break.

Caring for a disabled family member was described by most carers as contributing to a sense of dislocation from the people, places and activities associated with ordinary participatory citizenship for other New Zealanders. Most described the role as socially isolating, interrupting the ordinary trajectory of adult lives in ways that made it difficult to work, pursue leisure or recreational interests, visit friends or sustain relationships or to participate in other forms of civic or community activity. Respite, many said, provided moments of personal freedom, even if as simple as providing an opportunity *“just to do things,”* or *“to go out and about so that I don't become too narrow.”*

*C It's absolutely essential. It makes me feel like we actually have a life. You know, a real life. For a long time I felt like I was pretending to be normal. I would go to work and pretend to be normal but what I was dealing with at home was so difficult and relentless that I would get to work on Monday morning and be literally speechless. If anyone spoke to me I would be basically breaking down in tears.*

Others valued the recalibrating effect of respite, attributing moments like having the *“chance to eat meals together,”* or of *“going for a coffee”* as *“almost bringing (them) back to a normal family.”* Included in carers' narratives were stories of couples who only ever attended weddings without their partner or carers who wouldn't have a holiday or do other activities as a family for years.

Carers also valued the opportunity respite provided them to redress the deficit of attention they said was often experienced by their non-disabled children. All carers described the everyday rhythms and routines of the household being shaped by the needs of their



disabled family member and that other family members typically “missed out” as a consequence. Family activities were often said to be limited to the places their disabled member might cope and almost all carers described associated feelings of guilt about the unequal draw on their resources and atypical family life that was the day-to-day reality for siblings. Short-term breaks provided carers with an opportunity to go beyond the life-spaces and relational boundaries defined by their disabled family member by allowing carers to attend to the needs of other siblings.

*C My other son misses out on a lot because we can't do a lot of things with him either. [Family member] doesn't cope with the things they are into like sports or anything like that. So we try to do things that we can't do because [Family member] is at home in those (respite) days and he kind of gets our undivided attention.*

For some, however, not being able to access respite carried with it the threat of missing major life events.

*C I'm in a new place and I've got no one. My daughter gets married in a few months and I'm already starting to worry that I am not going to be able to make it.*

Many carers also had multiple care roles and worried too about their ability to respond to the unanticipated but none-the-less ordinary life events that pulled on their time and energy, like medical or health related emergencies, appointments, school visits and all the other ordinary incidents that became extraordinarily difficult without the ability to temporarily step outside caring for their disabled son or daughter.

- **Maintaining an ability to participate within the community is not acknowledged in the Needs Assessment Process or respite planning, in spite of its influence on carer health and wellbeing.**
- **Although carers report that their non-disabled sons' and daughters' lives are significantly affected by the support needs of their sibling, the impact of caring on “other” family members is largely unacknowledged in the Needs Assessment Process or respite planning**

## Having an opportunity to complete household chores

Three out of every ten carers said that their reason for most recently seeking respite care was to complete household tasks or chores (n= 22; 28.9%).

For many carers "respite" was a misnomer. Rather than taking a break, carers frequently described using respite to "catch up" on tasks that couldn't otherwise be done.

*C I do find I use it to get things done that I sort of can't do with [Family member] in tow because we get severely behind. That's the reality. However I still feel it's worthwhile because it relieves a stress load on me. I know there are things that need to be done and it's nice to know I have two hours that I can do them. It's not so stressful.*

For others, the orderliness of their life-spaces had a wider symbolic importance, communicative of a family's resilience and capacity to approach normality. *"Having a break,"* one carer told us, *"allow(ed them) the mental energy to create a nice, stable, comfortable home. You know it's so important to us."*

## Having an opportunity to work

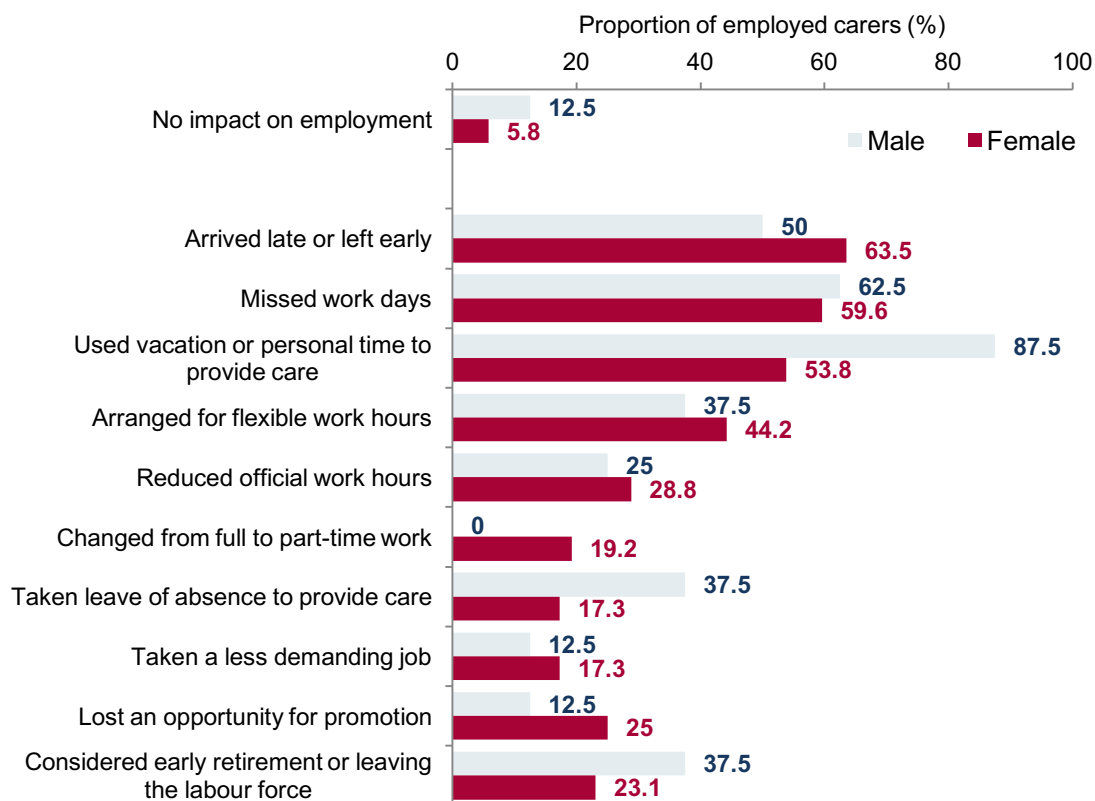
Objective 4 of the New Zealand Carers Action Plan 2013 – 2018 (*"Improving pathways to paid employment for carers and support for whānau, aiga, family and carers to balance their work, life and caring roles"*) responds directly a desire many carers expressed to continue to participate in employment. (Ministry of Social Development, 2014). Within the Carer Action Plan, employment is promoted as advancing a range of positive outcomes for carers including; permitting carers to remain productively engaged in their community, providing intellectual stimulation, broadening one's social network whilst also defraying the financial costs of providing care. Employment was also seen as providing an opportunity for carers to experience a natural break from caring within an ordinary community context. The carers who talked to the research team and who worked spoke of their employment as providing similar outcomes. Conversely, caring for a disabled family member made their working lives more difficult.

In the *Responding to Respite Care Needs Survey*, we asked working carers in what way(s) their role as carer had affected their employment in the previous twelve months. Nine out of every ten carers in part or full-time employment named one or more different ways that providing care had had an impact on their employment (n= 56; 93.3%). Arriving late or leaving early (n= 37; 61.7%) and missing work days (n= 36; 60.0%) were the most commonly named impacts with six out of every ten carers indicating that caring for a disabled family member

had affected their employment in these ways. Having to use vacation or personal time to provide care was also cited by six out of ten carers as one of the impacts that the care role had had on their employment (n= 35; 58.3%).

Difficulty balancing the demands of caring with the demands of employment also contributed to women, in particular, reducing their participation in the workforce. Approximately three out of every ten female carers said they had reduced their work hours in the previous twelve months (n= 15; 28.8%) and an additional 19.2% of female carers described changing from full to part-time employment (n=11). Overall, female carers were more likely to report that caring had an impact on their employment (n=49; 94.2%) than male carers (n=7; 87.5%). The way caring was described as having an impact on employment appeared to be slightly different for male and female carers too. Male carers were more likely to identify the need to use vacation or personal time to provide care (n=7; 87.5%) or more likely to describe having to take a leave of absence from work in the previous 12 months (n= 3; 37.5%) than female carers. Female carers, were more likely to identify arriving late or having to leave work early (n= 33; 63.5%) or as having to change from full to part-time work (n= 11; 19.2%) as work related impacts.

**Figure 10 The ways carers indicated the care role had had an impact on their employment in the previous 12 months**



Not captured in the statistics, however, was the impact that caring had had on the employment trajectory of carers and the related sense of self of those who felt marginalised from the ordinary world of employment.

*C On the one hand we're saving the state money, but we can't have a career. I would have loved to be a midwife but unfortunately it didn't work out. I don't know. I just accepted that that's the way it is.*

*I Perhaps. I wonder if we could get respite right it might have been possible for you to be a midwife.*

*C Yeah. A nurse or a midwife. That's what I would have loved to have done. And everybody said, 'Oh mum. You would have been a great nurse.' They call me doctor mum (laughs). But you know...*

For a significant number of carers, the demands of caring for a disabled son or daughter meant that employment was not seen as a viable option.

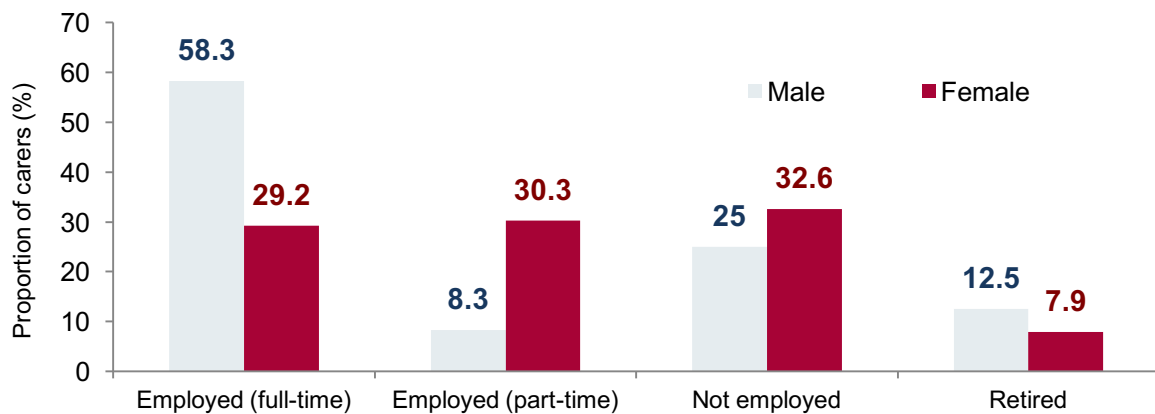
*C My wife is at home full-time. It's impossible for her to work. [Son] gets sent home from school all the time because of his seizures and things. It's always been that way.*

## Was it possible to identify carers who were not working?

Six out of every ten carers who completed the *Responding to Respite Care Needs Survey* said they were employed (n= 61; 59.8%) although only one out of every three carers said they were currently in full-time employment (n=33; 32.4%). An almost equivalent number of carers described themselves as being in part-time employment (n= 28; 27.5%) or not currently employed (n= 33; 32.4%). Eight respondents had retired from work (7.8%).

**Female carers** were significantly less likely to be in full time employment (n= 26; 29.2%) and more likely to be in part-time employment (n= 27; 30.3%) than male carers (full-time n= 7; 58.3%. part-time n=1 8.3%). New Zealand research has consistently identified women as overwhelming acting in a caring role for disabled family members. Indicative of the gender skewing of the carer role, the odds that a male would report being in full-time employment were 3.8 (95% CI= 1.01-14.49) times higher than for female respondents.

**Figure 11 The employment status of male and female carers**



Whether a carer was **single or not** was also found to have a significant impact on the likelihood they would report being in full-time employment. Female carers were more likely to be single (n=23; 26.1%) than male carers (n=1; 4.2%). Perhaps contrary to expectations, carers who were single were significantly more likely to describe themselves as in full-time employment (n= 11; 45.8%) than carers who lived with a partner (n= 22; 28.6%). Female carers who worked told us how important their work was to them. Employment, they said, represented their only way of improving their material wellbeing, but work was also highly valued as a way of stepping beyond the narrow social role and experiences of full-time care and an important conduit to relationship in the absence of a partner. What this meant was for approximately half of the women who cared without the assistance of a partner, was that they had to balance the demands of the carer role with the obligations of full-time employment. For these and for many other carers in full and part-time employment, working was only possible by either (illegitimately) drawing on their respite allocation or by paying for alternative care themselves.

## What impact did employment have on carers ability to provide support?

Approximately one out of every four carers who responded to the *Responding to Respite Needs Survey* said they most recently sought respite care to enable them to work (n=17, 22.7%). This represented 33.3% of carers in part or full-time employment and half of all carers in full-time employment (n=10; 50.0%). For a small number of carers, using their respite allocation was the only way they felt that they could remain in the workforce.

*I        What is the impact of the way you currently use your allocation? What does it allow you to do?*

*C        It allows me to have a full-time job. That's all it allows. It allows us, I work like every other New Zealander is entitled to do.*

At present, the New Zealand Carers Action Plan 2013 – 2018's only response to the calls from carers to remain engaged in employment is to provide information on flexible working arrangements entitled under the Employment Relations Act 2000 (Action 4.1) and to provide information for employers on supporting staff with caring responsibilities (Action 4.2). Whilst progressing these actions might, in time, assist the 16.7% of carers who said they had had to reduce their work hours and 10.8% of carers who said they had changed from full to part-time employment, it does not address the lack of Holiday and After School and/or After Vocational Centre Programmes, or alternative forms of support offered by Disability Support Services that some carers described experiencing in their region.

Moreover, contrary to the Objective 4 of the New Zealand Carers Action Plan 2013 – 2018, as-well-as the known practices of both carers and Disability Providers, New Zealand carers are not permitted to use their Carer Support Day allocation while at work. ([www.health.govt.nz/system/files/.../pages/how-to-claim-carer-support-09.pdf](http://www.health.govt.nz/system/files/.../pages/how-to-claim-carer-support-09.pdf)).

For carers, the inequity of caring for a family member aged fourteen years or older who would otherwise legally be able to be by themselves was obvious, but as carers pointed out, often the care needs of their son or daughter required competencies beyond those of ordinary carer contexts - leaving them with little option other than to purchase trained alternative carers. Similarly, whereas other New Zealanders can leave younger siblings in the care of a fourteen-year-old, carers in receipt of Carer Support Days were not only unable to leave their disabled son or daughter in the care of a young person, they were also unable to use their funding to reimburse care provided by someone else living in the same household.

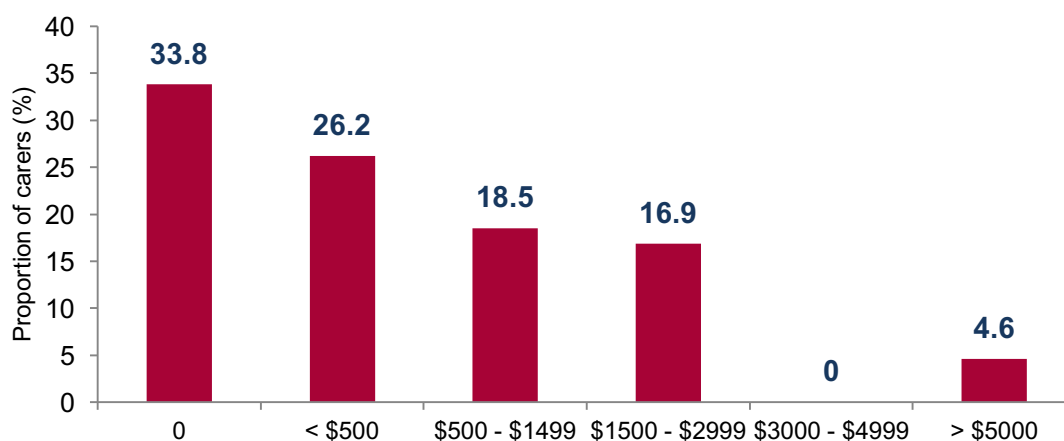
Framed the other way, one impact that employment had on carers' capacity to care was that, not only did employment leave and other work-related entitlements tend to get used-up trying to provide support for their family member, drawing on Carer Support meant that working carers were doubly disadvantaged by not being able to access to the benefits that other's described experiencing from respite care. Sometimes, the costs of not acknowledging this reality of many carer's lives were borne by others.

*C Not only do I have to pay for a person to look after [Family member] from when she gets dropped off by the taxi, from 2.30 and 3.00. It's never consistent. From then until I finish work and get home. I have to use .... all of my respite gets used-up during the school holidays. My other daughter is sick at the moment and I don't have any leave because it has been taken up caring for [Family member].*

The alternative for working carers was that they paid for respite. A number of the carers we spoke to said they used their own financial resources to pay alternative carers or to "make up" the difference between Carer Support Day funding and the cost of service-led respite.

Two out of every three carers who completed the survey said they used their own money to purchase respite care (n=43; 66.2%) with one in five respondents estimating they spent in excess of \$1,500 per year to purchase respite care (n= 14; 21.5%).

**Figure 12 The proportion of carers who used their own money to purchase respite**



For these carers, paying for respite represented an additional demand on the resources of families already materially disadvantaged by medical and other support-related costs associated with supporting a disabled family member. For a number of families, and for single parents in particular, balancing the need to provide for a family through employment whilst also meeting the emotional and financial cost of providing good attendant care was emotionally and financially draining.

## Respite as a positive experience for disabled children and adults

Within New Zealand social policy and the Needs Assessment process, respite is more typically read as a “carer-centric” support need, the purpose of which is usually described as giving the primary carer a break from the demands of a role with acknowledged psychosocial risks. Yet carers themselves were more likely report seeking respite support to attend to other family member’s needs. Nearly half of the carers who answered the question said they most recently sought respite care as a way of responding to the needs of other family members (n=34; 44.7%).

As has been discussed previously, many carers had multiple caring roles, including responding to the social, emotional and physical needs of a spouse, parents and/or the day-to-day needs of their other non-disabled children.

Missing from the array of questions the research team asked in the *Responding to Respite Needs Survey* was the way carers considered respite as a way of responding to the needs of their disabled family member. Carers’ contemplation of the purpose of respite occurred during the interviews and largely focused on the potential of respite to add meaning and value to the lives of their disabled family member.

*I        What is the purpose of your respite?*

*C        First and foremost it’s about [Family member] having time with other people and learning to be with other people and planning for her future, because we are not always going to be around. So she needs to start preparing for that. It also helps us manage.*

Five themes emerged from the data generated by the interviews we conducted with carers as central to their vision of the potential respite care could hold for their disabled family member. These included ideas that that respite care might offer; an expanding network of social relationships; the kind of connections with their community that communicated “having a place(s)” beyond family; the opportunity to develop their own identity; a chance to learn new things and a “stepping stone” toward adulthood and/or more independent lives.

Carers vision for what respite might mean for their family member remained the same regardless of the model of respite care they chose and as such represent generalizable set of indicators to the quality of disabled people’s respite experiences. The five outcomes envisioned by carers are discussed in more detail in the sections that follow.



## Contributing to an expanding social network

Carers said that their children could be socially disadvantaged in two ways. Firstly, because, as their family member grew up, their lives began to deviate from the life trajectory of their age peers. In addition to the everyday moments of social "othering" disabled people often experience, carers said that their disabled sons and daughters didn't have the same opportunities to meet other people and/or to sustain social relationships by doing things together. *"The kids his own age,"* they told us, *"are pretty much all gone."* Secondly, many carers suggested that, because of the shrinkage of their own social world and the (almost constant) feelings of being tired that were the inevitable consequences of caring, their children also tended to be exposed to fewer people and places than their non-disabled age peers.

For many carers, the opportunity respite afforded their family member to do things and to be in places with others beyond their care was highly valued. Their hope was that sharing experiences with others during respite might help to build relationships of trust and personal knowing. *"Spending time with others,"* they told us, *"was huge."*

Furthermore, most carers saw the development of trusting and valued relationships as key to unlocking a cascade of other positive consequences. The relationships they had in mind were not necessarily restricted to peers in their age group or potential sources of informal support. Staff and paid alternative carers were also included as potentially "important others." Many carers told stories of how respite relationships had flourished and become the conduit to a range of community experiences and connections that their sons or daughters wouldn't ordinarily have experienced.

## Staying connected to the community

Respite was also viewed by carers as another way for their family member to participate in the life of their community and to "get out and do the stuff that [their age peers] would be doing." One carer spoke for others by expressing the hope that, *"They could be outside riding bikes, swimming, or going for walks, playing pool going places, you know. That kind of ordinary stuff."*

Participating in the community in these ways was read by some carers as providing their family member with an opportunity to begin to explore and also to develop a sense of who they were and what they liked beyond parental surveillance. Embedded in that expectation was the hope that their family member might also develop a sense of themselves as a

contributing member of their community that was not just through their presence but by adding value in other ways.

Participating in the community in these ways was read by some carers as providing their family member with an opportunity to begin to explore and also to develop a sense of who they were and what they liked beyond parental surveillance. Embedded in that expectation was the hope that their family member might also develop a sense of themselves as a contributing member of their community.

*C The capacity for him to widen his relationships or develop his own identity. No they don't do much of that. But wouldn't it be great if there was some opportunity for him to be part of a young group of people doing things. Like picking up trash in the park as a conservation exercise, you know, something like that would be fantastic.*

The important caveat for carers, however, was that their family member was present in their community in self-authored ways and that their respite experience responded to their needs and preferences, including the need to feel a sense of psychological safety.

*C This is the place he feels safe and secure and is not stressed. Now, he is getting someone that takes him out and is focused on him rather than being lumped in with a whole of other people with disabilities. And so that's what you ideally want. Something that's catered to them, that meets their needs, on their terms.*

## Transitioning to more independent lives

Spending time with others" was seen by carers as a necessary pre-requisite for a longer-term need to support their family member's transition to a life beyond their immediate care.

As can be seen in the comment above "learning to be with people," and "future planning" were often presented as interlaced support needs. Carers emphasised the importance of their family member developing trusting relationships as a way of seeding confidence and of assisting what, for some, seemed like an inevitable transition into residential support and, for others, the ordinary adult transition out of the family home and into more independent lives.

*C For [Family member] it's about helping him to adjust to being out of our care... He is almost 16 now. He has always had mum and dad at home, so we are just trying to get him... very very slowly transitioning, to eventually being capable of being away from home, with different carers to the ultimate move which will come when he is older.*

A number of carers pointed out that, without having many of the ordinary experiences that contribute to greater independence, quality respite could be a critical determinant of the success or otherwise of their son's or daughter's aspirations to transition to ordinary lives of their own.

*C Even the word (respite) is, for [Family member] a bit insulting. I mean it's like 'oh my parents need a break from me. It's respite for them – not for me.' The whole thing should be about providing a nurturing supportive and social environment for the young person. Where they are continuing to learn and grow. Probably because he doesn't have ... He doesn't get invited to sleepovers, he doesn't go on camps, so this is the place where he goes, you know. And you explain to him that it's part of normal growing up. You learn to stay in other places, away from home.*

## Supporting life-long learning

Through the comment above, this carer's covert hope that respite care replicate the ordinary life experiences that her son had been marginalised from finds expression in the New Zealand Facility Based Respite Service Specifications. Nowadays, Respite Provider contracts make explicit an expectation that care recipients experience *"positive, stimulating and worthwhile experiences"* that *"replicate the 'out of family' experiences of people who do not have disabilities and who commonly stay with school friends, extended family relatives and friends."* (Ministry of Health, 2016). Central to this expectation is an assumption that, embedded within these experiences, are opportunities to "learn and grow" in ways that expand the range of possibility for disabled people. Carers insisted that respite care should contribute to a process of life-long learning.

Some spoke of respite as potentially providing their family with "adventures" and experiences beyond their day-to-day family life. Some saw it as an opportunity to tailor support in ways that responded to the preferences of their family member in terms of the things they would like to do or try. This, in carers' minds, might include, but is not limited to, supporting their family member to participate in the sporting, arts and cultural, civic and recreational and leisure activities enjoyed by other New Zealanders. Almost everyone recognised that respite provided a different kind of opportunity for their family member to acquire skills and to develop new competences. As we describe in more detail in the final chapter, carers expressed a strong preference for innovative respite options that included a vocational orientation.

*C You could paint a really narrow view that respite is to give a rest. But I see it as, if you are going to work with a child to give the family a rest, why not use that time productively by giving them some skills or, you know, helping them out that way. It just seems silly to have someone come and hang around with them.*

Facility based respite in particular was seen as offering the chance to learn life skills and to contribute within that settings in ways that might seed a sense of being "at home" rather than "out of place."

*C At home, he would help with the preparation of his food. He would take the trash out and he would help carry the groceries. (The alternative is to) treat him like a patient rather than a lovely young man who is working on his social skills.*

As part of the new Service Specifications, facility based providers are required to collaborate with carers and the disabled person to develop a Personal Respite Plan. The aim of the Plan is to articulate a person's support needs, preferences and respite aspirations. During our interviews with carers, no-one mentioned having a Personal Respite Plan. Carers also said they had not had the kinds of conversation with their provider that framed respite as a support element to be considered alongside the goals and objectives of the other types of disability support they received nor as part of a longer-term vision for their son's or daughter's future.

- **Carers pre-eminent concern was that respite should also enhance the health and wellbeing of their family member.**
- **Carers identified five outcomes as instructive of the quality of the respite experience for their family member. Carer vision for respite was that it should:**
  - **Contribute to the development of an expanding network of trusted relationships.**
  - **Support the development and expression of an autonomous self-identity.**
  - **Promote people's connections with their community.**
  - **Assist the transition to greater independence.**
  - **Support life-long learning in a planned and integrated way.**
- **To fully realise the potential of respite, planning needs to incorporate a longer-term vision of a disabled person's future and how the respite experience might be tailored to promote that vision.**

- **Respite care should be considered alongside other forms of disability support as part of a holistic approach for a disabled person and their family.**
- **Changes in the funding landscape embedded in the “New Models” of disability support offer carers the potential to combine funding streams (from Ministry of Health, Ministry of Social Development, ACC and hopefully the Ministry of Education) to purchase respite, vocational and educational support needs that intersect simultaneously.**
- **Carers should be integral to respite planning in order to “tap” into the resources and resourcefulness of their existing informal networks.**

# CARER'S ABILITY TO ACCESS RESPITE CARE

## The type of respite funding allocated to carers

People who provide full-time care to a disabled person may be eligible for three different types of respite funding, including: Facility Based Respite Care, Carer Support Days and Individualised Respite Funding.

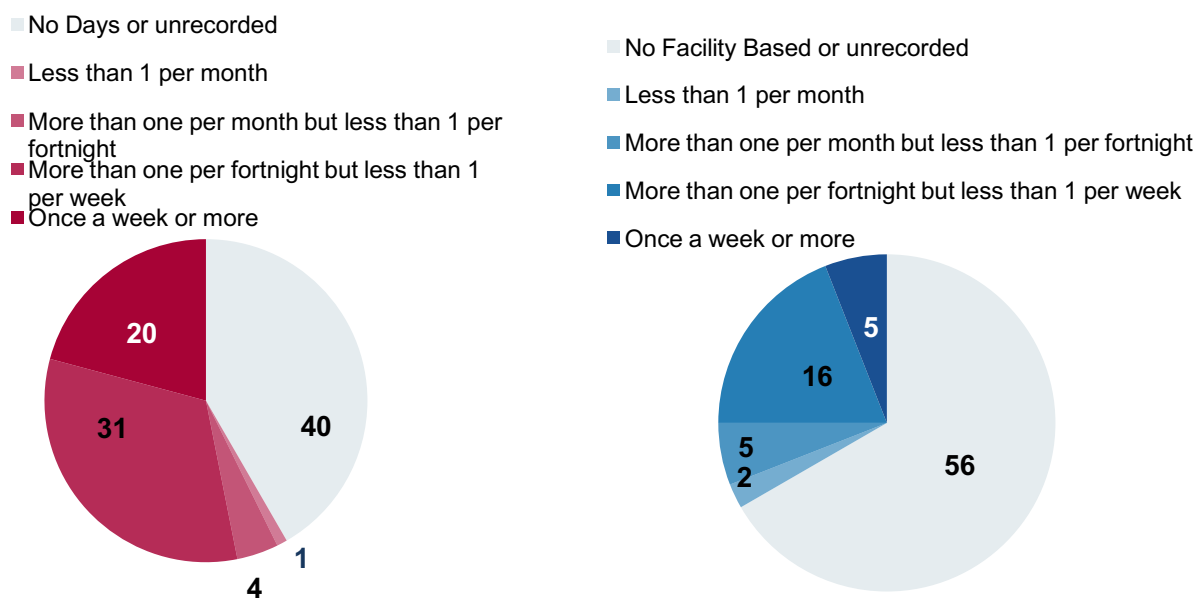
By asking respondents which type of funding they received, analysis of the *Responding to Respite Care Needs* allowed the research team to explore whether it was possible to identify particular carers or care recipients who were more likely to receive different types of respite funding. Some caution needs to be taken in interpreting the findings. Carer interviews revealed that carers were often confused about the type of funding they received. The survey also asked carers whether they received "Respite Nights" as the alternative to Carer Support Days and it is probable that some carers may have misinterpreted this as a descriptor for Facility Based Respite Care.

Of the three different types respite care funding, the pattern of respite funding did, however, approximate the national funding allocation reported by the New Zealand Ministry of Health as described previously.

Carers were more likely to report being allocated Carer Support Days than other respite funding options. Nearly six out of every ten respondents reported being allocated Respite Care Days (n= 56; 58.3%), the majority of whom said they received, on average, the equivalent of at least one respite day per fortnight (n=51; 46.9%).

One out of every three carers reported receiving Facility Based Respite Care funding (n= 28; 33.3%). Only one in four Carers had an allocation that enabled them to access Facility Based Respite Care at an annual average of at least one Day/Night per fortnight.

**Figure 13 The proportion of carers allocated (a) Carer Support Days & (b) Facility Based Respite**



## Who were most likely to receive respite funding?

To explore whether it was possible to identify whether particular carers were more or less likely to receive respite funding, the research team tested the strength of association between a range of carer and care-recipient attributes and the likelihood carers would receive either Carer Support and/or Facility Based Respite Care funding.

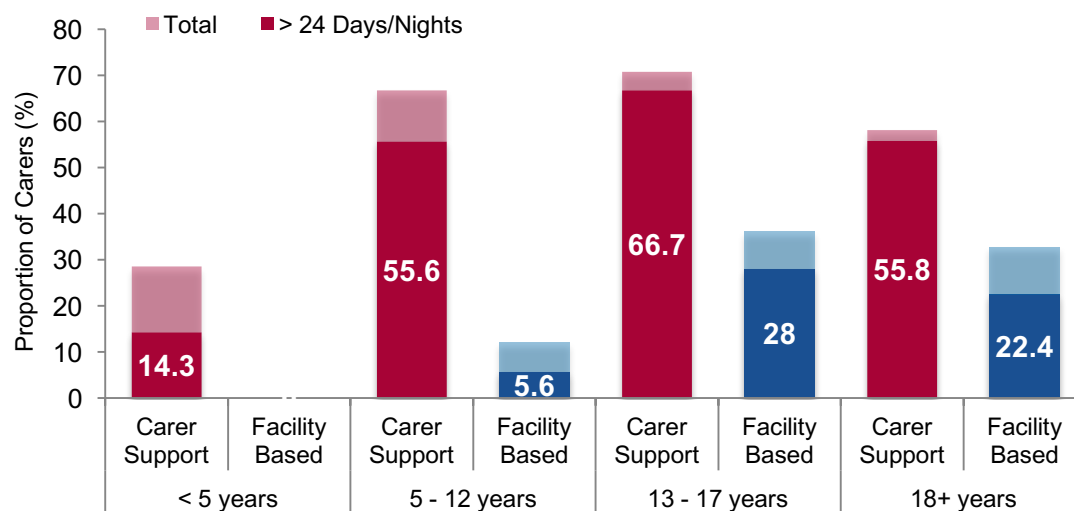
Of all of the potential predictors tested the **age of the family member** was the only attribute to explain variation in funding allocation.

Carers providing day to day support to teenage children (13-17 years) were more likely to receive an allocation of 24 or more Carer Support Days per year (n=16; 66.7) than other carers. Consistent with the national trend for the carers of children aged between 5 – 19 years to be over-represented as recipients of respite care, carers who provided day to day support to teenage children (13-17 years) were also significantly more likely to receive a Facility Based Respite Care allocation of 24 or more days/nights (n=7; 28%) than carers supporting others.

Conversely, carers providing support to children under 5 years were least likely to receive Carer Support Days (n= 2; 28.6%) and no parent with a disabled child under 5 years reported being allocated Facility Based Respite Care.

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**Figure 14 The proportion of carers who received 24 or more days/nights of Carer Support or Facility Based Respite per year by age category**



The assumption that appeared to underscore the more limited access parents of younger children had to respite was that the support needs of young children were not dissimilar to their non-disabled age peers. This reading was consistent with the narrative of many parents who described the exhaustion they experienced as not dissimilar to the exhaustion all parents experience and most carers described not receiving respite until their family member had reached the age of about eight or nine years.

*C It's different when they're little, you know when they are like 3 or 4, you're kind of used to high level of support anyway because its part of the whole infant period. So you know respite ... it's a funny thing because you feel like 'oh no, I don't want anyone else taking care of my kid'.*

For a number of parent carers, however, the first seven years of their son's or daughter's lives were described as being the most stressful. For these parent, the carer role at this time was made more demanding by the lack of an adequate diagnosis, absence of co-ordinated support and/or intervention and the inability to take a break.

*C Between 18 months until he was 8 years old was a crisis time for us. It was really frightening, especially when you realise there is no one to help you. You know, like the paediatrician, she doesn't know (laughs). Everyone is happy to give advice, nobody is happy to come over at 2am to stop the tantrum. You've got to do it by yourself. And so I*



*figured out how to do it by myself over time. I knew there were things driving the behaviour, but it had to stop. Because we were all, you know, there were so many times I thought we were going to die. Somebody is going to die in this situation. The screaming and banging in the middle of the night is terrifying. We took out a mortgage to do ABA therapy and spent tens of thousands on that just to get through the days. It was unbelievable how long it took to stop.*

Having other children's needs to attend to, including at times the need for protection, simply added to the seemingly unrelenting stresses of caring for these parents.

Beyond the age of care recipients, the Needs Assessment Process appeared largely insensitive to other attributes likely to have had an impact on the health and wellbeing of carers.

Perhaps most importantly, the self-reported intensity of support carers provided made no difference to the likelihood they would be allocated either Carer Support Days or Facility Based Respite Care. Carers who said they provided continuous assistance were, for example, only slightly more likely to receive more than 24 Carer Support Days per year (n= 31; 59.6%) than carers who provided frequent (n= 11; 50.0%) or occasional (n= 6; 50.0%) assistance. Similarly, no association was found between the intensity of support carers provided and the likelihood they would be allocated more than 24 Facility Based Respite days/nights per year. The proportion of carers who provided continuous assistance who received such 24 or more Facility Based Respite Care days/nights per year (n= 12; 21.1%) differed little from carers providing frequent (n= 4; 18.2%) or occasional assistance (n= 2; 15.4%).

Parents were the other group who were statistically more likely to report having felt close to breaking point. Parents were also more likely to say they did not receive sufficient respite care. Whilst parents were slightly more likely to report receiving more than 24 Carer Support Days, they were less likely to have been allocated more than 24 Facility Based Respite Care days/nights (n= 11; 16.4%) than either sibling (n= 1; 20.0%) or non-relative (n= 5; 29.4%) carers.

Whether a carer was supporting a person with more complex support needs appeared to make no difference to the a carer's respite allocation either. For example, although caring for a someone with a behavioural disorder is a known risk factor for carer stress, carers providing support to a family member with a behavioural disorder were typically less likely to receive more than 24 Respite Care Days (n=11; 42.3%) or Facility Based Respite Care (n=5; 17.9%) than carers providing support for a family member without a behavioural disorder (n= 40; 58.8% and n= 14; 19.2% respectively). Similarly, carers providing support to a family member who also had a sensory impairment (n=17; 47.2%) or short-term chronic health condition (n= 8; 53.3%) were slightly less likely to report receiving more than 24 Carer Support

Days than carers supporting a family member without these impairments (n= 34; 58.6% and n= 43; 54.4% respectively).

Other attributes of the care context that the allocation of respite care appeared insensitive to included the number of children or young adults a carer also provided support to within the household and the employment status of carers. Carers who were employed part-time were most likely to report being allocated more than 24 Carer Support Days (n= 16; 64.0%) and carers employed full-time were more likely to report receiving more than 24 Facility Based Respite Care days/nights per year, although no statistically significant association was found between the number of other family members a carer provided support for or the employment status of carers and the likelihood they would report being able to take a break from the carer role at least once a fortnight.

Although no statistically significant association was found between carers relationship status and the likelihood they would report being able to take a break from the carer role either, carers who were single (n= 14; 66.7%) were more likely to receive more than 24 Carer Support Days than carers who had a partner (n= 37; 49.3%) but were no more likely to receive more than 24 Facility Based Respite Care days/nights (n= 5; 20.8%) than carers who had a partner (n= 14; 17.7%).

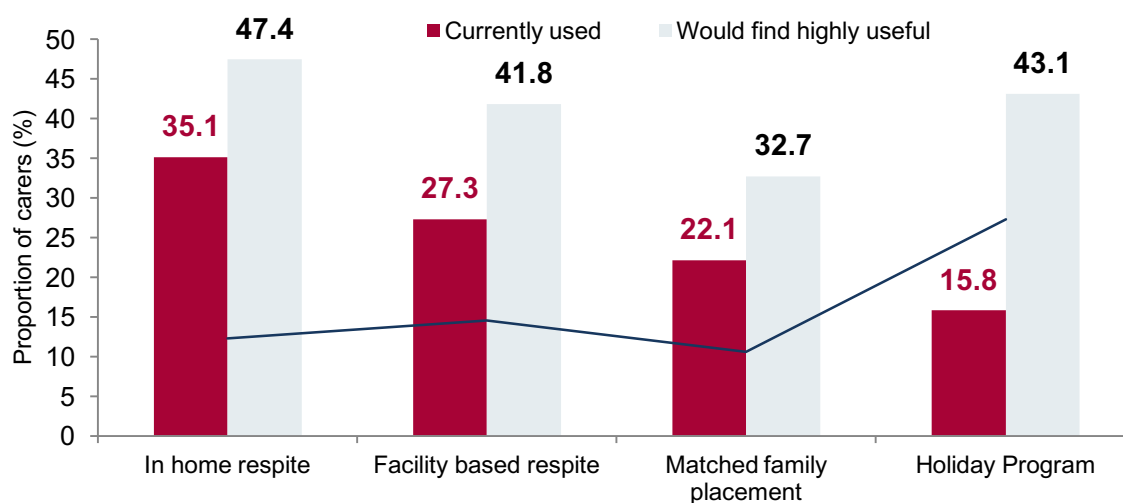
- **The Needs Assessment Process and in particular its failure to collect information about the caring context can contribute to carers who are most at risk of not receiving respite commensurate with their family circumstance.**
- **Carers providing support to young children and children with more intensive and/or more complex support needs emerged as groups who were most likely to be disadvantaged by the failure to collect contextual information.**
- **Carers expressed an interest in having someone to assist them during the Needs Assessment Process to make transparent circumstances that undermined their health and wellbeing, and their resultant need for appropriate short-term breaks.**

## What type of respite did carers use?

In the *Responding to Respite Needs Survey*, carers were asked, out of a range of different types of respite, which support they currently used. Rather than representing a simple expression of carer preference, the pattern of respite use was also shaped by factors that constrained carers' abilities to make choices. Pre-eminent amongst an array of external factors that explained the pattern of respite use were:

- The allocation of respite care funding (whether carers were allocated Facility Based Respite Care or Carer Support Days).
- The availability of specific services. Regional differences in out-of-home respite services appeared to influence the allocation of respite funding as-well-as carers ability access particular respite care options.
- Attributes of the caring context that influenced the size and configuration of carers' informal support network.

**Figure 15** The proportion of carers who currently used different types of respite care and the proportion who indicated they would find them highly useful



Slightly more than one in three carers reported using In-home respite (n= 27; 35.1%). In-home respite was the most commonly reported type of respite support used. Carers use of In-home support is consistent with a more general reorientation of disability support towards drawing on the resources of natural community. It also aligns with previous New Zealand research that suggested a mismatch exists between the preferences of parents with high and complex support needs for "respite solutions delivered in their own home or in a 'home-like' environment" (Prileszky et al, 2015) and the provision of facility based respite care as a respite solution.

## Who used In-home respite?

No statistically significant association was found between any of the carer and care recipient attributes tested for, however two groups did appear more likely to use In-home respite.

Four out of every ten **parent carers** reported using in-home respite (n= 20; 40.0%) whereas the use of in-home respite was less prevalent for sibling (n= 4; 28.6%) and non-relative carers (n=0; 0.0%). Carers providing daily support to **children aged 5 – 12** years were also more likely to report using in-home support (n= 8; 53.3%) than carers supporting people in other age groups including carers supporting children under 5 years (n= 1; 33.3%) and adults over 18 years (n= 9; 25.0%).

On the other hand, carers who said they provided support to a family member with a **behavioural disorder** (n= 5; 22.7%) or a **sensory condition** (n= 8; 26.7%) were less likely to access in-home respite than other carers (n=19; 40.0% and n= 19; 40.4% respectively). Therefore, contrary to findings reported by Prileszky et al, (2015), carers who provided support to people with more complex support needs tended to access in-home support at a lower rate than other carers.

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Of all of the variables tested, the only factor to emerge as predictive of carers use of in-home respite was whether or not carers **received Facility Based Respite** funding. Carers who did not receive Facility Based Respite Care funding were more than twice as likely to report using in-home respite (n= 21; 42.9%), than carers who had the option of also seeking Facility Based Respite Care (n= 6; 21.4%). Only two out of every five carers who received an allocation of Facility Based Respite Care days/nights said they also accessed in-home respite.

A range of factors may have contributed to this finding, including that people who used in-home respite were less inclined towards facility based care and/or had the kind of informal support networks that more easily allowed them to seek alternatives to the traditional facility based respite. However, included in the array of possible explanations is that the current allocation of respite funding, and in particular the lower level of funding for Carer Support Days, precluded carers from considering or achieving the kind of "out of home" respite they might otherwise have preferred. Corroborative evidence for this possibility was found following a closer examination of carers perceived ability to exercise choice over their respite decisions.

- **Carers who supported a family member with more complex support needs were least likely to use in-home respite.**
- **Carers who received Facility Based Respite were significantly less likely to use in-home support, introducing the possibility that the lower rate of Carer Support funding precluded carers from achieving the out-of-home respite they might otherwise have preferred.**

## Who used facility based respite?

Only one in three carers who completed the survey reported being allocated Facility Based Respite Care funding and yet 23.3% (n= 21) of carers surveyed said they used some form of facility based respite care.

Carers in **full-time employment** were more likely to receive Facility Based Respite Care Funding, and therefore, not surprisingly, were more likely to report using facility based respite (n= 8; 38.1%) than carers employed part-time (n= 5; 20.0%) or who were not employed (n=4; 16.7%). The odds that a carer in full-time employment would report using facility based respite were 8.7 (95% CI= 1.13-66.67) times higher than carers not in employment.

**Retired carers** were the group most likely to report using facility based respite. Although small in number, two out of every three carers who said they were retired reported using facility based respite (n=4; 66.7%).

**Older carers** tended to see residential support in a Community Group Home as the most likely future for their family member and a number of carers saw their use of a respite facility as a *"way of keeping (their) foot in the door"* of residential care and/or of acculturating their

family member to a service setting. They worried too about becoming unwell or of what would happen if they needed hospitalisation and, of course, what their sons or daughters future would be once they could no longer provide support. For these carers, facility based respite looked like the obvious stepping stone along an inevitable path towards a more permanent residential placement.

Older carers also tended to be more sensitised to what they saw as "the burden" of caring, and many expressed a preference for professional, and therefore paid, facility based care rather than having to ask others to look after their family member. This was especially true for those with a more geographically dispersed family. Some retired carers told us there was "*no one else to do it,*" having both a smaller and older informal support network upon which to draw from as a source of alternative care.

The other statistically significant predictor of the likelihood a carer would report using facility based respite was whether respondents described the person they supported as having a **behavioural disorder**. Four out of every ten carers who supported a person with a behaviour disorder said they used facility based respite (n=9; 40.9%) compared to 21.8% of carers who provided support for someone without a behaviour disorder (n=12). The odds that someone caring for a family member with a behavioural disorder would describe using facility based respite care were 3.2 (95% CI= 0.685-14.896) times higher than other carers

The **age of care recipients** also appeared to influence the likelihood a carer would report using facility based respite care. Research has identified that caring for disabled children during their adolescent years can be a potentially stressful time for carers as a consequence of a range of factors including: young disabled people's aspiration to develop their own identity; an increasing awareness of disability as a marker of difference; and as a period frequently characterised by the shrinkage of people's social network.

Carers supporting young adults aged between 13 – 17 years were, however, least likely to report using facility based respite care (n=4; 26.7%). This finding is at odds with both the pattern of facility based respite care funding nationally and within the population of survey respondents given that survey respondents caring for young adults were significantly more likely to receive Facility Based Respite Care allocation of 24 or more days/nights (n=7; 28%) than other carers. More than half of the carers who said they had received Facility Based Respite Care days/nights said they currently used facility based support (n= 15; 53.6%).

Talking to the carers of teenage children suggested two possible explanations. Firstly, a number of carers described finding it difficult to access facility based respite options for this age cohort. Parents in particular described difficulty identifying service-based options for teenage sons or daughters who were described as falling between service concerns with

regard to placing teenagers with younger children, on the one hand, and their own concerns about the safety of their family member being in a facility with adults on the other. We noted too, that carers described marked regional differences in the provision of facility based respite, including many who said facility based respite was not an option as there were either no facilities in their region or none that would take their family member.

*C It took a long time to be honest. I think it took about 18 months to get back into care. And we went through local management here who just...I never heard from them for a long time. And when I chased it up we had a meeting and we were just told that they didn't think it would be an appropriate place for [Family member]. So we said 'why?' and they ran through everything, about how he was five years previously .... And we said that this is a different kid and we asked them to talk to his school.*

Carers also said that it was difficult to find facility based respite care that was appropriate to the needs and life preferences of their teenage sons or daughters. As noted previously, Service Specifications for Facility Based Respite Care make explicit an expectation that respite support is required to provide a "positive, stimulating and worthwhile experience" for the care recipient that "replicate(s) the 'out of family' experiences of people who do not have disabilities and who commonly stay with school friends, extended family relatives and friends." As is discussed in more detail later in this report, a number of carers described being met by service practices that dislocated their family member from the ordinary routines, activity and preferences of their teenage sons and daughters and it is not possible to know what impact that this had on carers use of facility based care.

- **Older carers may become an expanding carer population as women have children later, people with a learning disability continue to live longer and new service models promote familial support and independent living as alternatives to the traditional residential model.**
- **Older carers said they had no one to talk to about their family member's future and how respite support might assist them to plan for the future**
- **Whereas teenagers are typically over-represented as a cohort in receipt of Facility Based Respite Care Funding, they were significantly under-represented in the pool of people who reported using facility based respite services.**
- **The gap between funding allocation and respite use suggests that the support needs of carers in receipt of a facility based respite care are likely to have an unmet respite support need and/or that facilities do not cater well for a population most at risk of both compromised health and wellbeing and most likely to benefit from a positive respite experience.**

## Who used a Holiday Programme?

Although a few carers told us they were able to use Carer Support Days to purchase emergency respite (at the Carer Support rate), if a residential service or a bed was available, most said it was difficult to use Carer Support Day funding to access facility based respite. By way of contrast, carers were able to use Carer Support Day funding to access respite through service-led Holiday Programmes.

Only twelve carers said they used a Holiday Programme, however, with the small proportion of respondents who reported accessing a programme (15.6% of respondents) seeming to suggest that this form of respite was also difficult to access for carers who used IDEA services.

Difficulty in accessing a preferred form of respite might also be inferred by a comparison between the proportion of carers who described using a Holiday Programme and those who reported they would find it useful. Although only 15.6% of respondents said they used a Holiday Programme, being able to access a Holiday Programme was the second most highly rated form of respite with more than one in four respondents saying they would find a programme highly useful (n= 23; 43.1%) and an additional 32.1% saying they would find it useful (n=17). The blue line in Figure 15 plots the difference between the proportion of carers who described using a particular type of respite support and the proportion who said they would find it highly useful. As such it represents a very simplistic indicator of potential unmet demand for a particular type of respite support.

Despite being able to use Carer Support Days to purchase this form of respite, a very similar pattern of (non)use emerged. Carers who were **employed full-time** were more likely to report using a Holiday Programme (n=7; 33.3%) than carers who were employed part-time (n= 3; 12.0%) or were not employed (n=2; 8.3%) or retired (n= 0; 0.0%). Moreover, as was outlined previously, carers frequently described having to leave full-time employment or interrupting their career progression to support their disabled children because finding alternative carers during the school holidays and after school was so difficult.



## How much choice did carers feel they had about the type of respite they received?

Providing respite “*at a time and in a way that suits their personal needs, giving families greater choice, control and flexibility over the services they receive,*” is identified as a key outcome within the New Zealand Carers Action Plan 2013-2018.

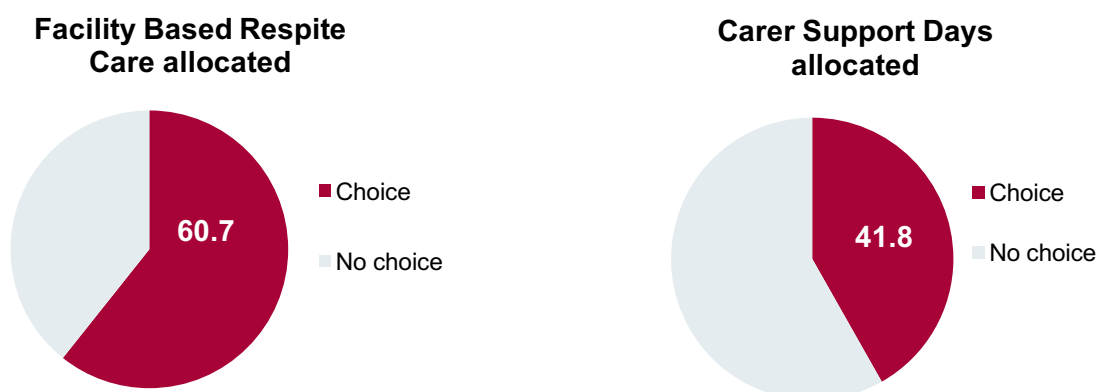
Within the array of respite options, the Ministry of Health advances Carer Support as providing the choice, control and flexibility imagined by the Action Plan.

When asked, more than half of the carers who responded to the *Responding to Respite Needs Survey* said that they were given no choice about the type of respite care they received (n= 42; 55.3%), but more interestingly, the type of funding allocation carers reported being given and the type of respite care they were able to access had a significant impact on the degree of agency carers said they experienced.

Contrary to public policy and previously published research, Carers who were able to access **facility based respite** through a Facility Based Respite Care allocation were more likely to report having a choice about the type of respite care they received and were significantly more likely to report having a choice (n= 17; 60.7%) than carers who did not receive Facility Based Respite Care funding (n= 17; 35.4%).

Conversely, carers who received Carers Support Days were less likely to report having a choice about the type of respite care they received (n= 23; 41.8%) than carers who did not receive a Carer Support Allocation (n=10; 58.8%).

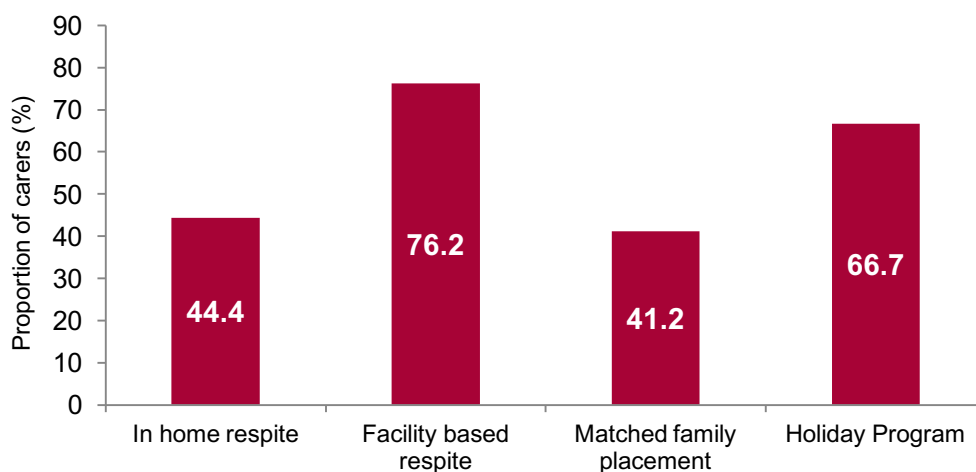
**Figure 16** The proportion of carers who reported feeling they had a choice about the type of respite they received



Further evidence that having an ability to access out-of-home care was, for many carers, equated with having greater choice was found when the proportion of carers who expressed a degree of agency about the type of respite care they received was calculated for those using different types of respite care.

Whereas less than half of carers who used in-home respite said they were given a choice about the type of respite care they received (n= 12; 44.4%), three out of every four carers who used facility based respite felt they had a choice about the respite they received (n= 16; 76.2%). Moreover, despite many expressing grave reservations about the support their family member received in respite facilities, a statistically significant association was found between carers who did and did not use facility based respite (n= 18; 32.7%) and the likelihood they would report being given a choice about the respite care they received.

**Figure 17**The proportion of carers who felt they were given a choice about the type of respite they received by the type of respite support they received



Carers who were able to access a Holiday Programme were also, on average, more likely to report being given a choice about the type of respite care they received (n= 8; 66.7%) although the proportion of carers who said they had access to either a Holiday Programme (n= 12; 15.6% of respondents) or an After School Programme (n=1; 1.3% of respondents) was extremely small and no association was found between being able to access either respite option and the likelihood carers would report having any choice about the type of respite they received.

## Who were most likely to feel as if they had a choice about the type of respite they received?

Two carer attributes predicted whether carers were likely to report having a choice about the respite support they received.

Carers who remained in **full-time employment** were most likely to say they were given a choice (n= 13; 61.9%), whereas carers who were not employed were least likely (n= 6; 25.0%). The odds that a carer in full-time employment would describe themselves as being given a choice about the respite care they received were 5.7 (95% CI= 1.10-29.26) times higher than a carer who was not employed. As noted previously, carers who were employed full-time were also most likely to receive a Facility Based Respite Care allocation (n=10; 30.3%) whereas carers who were not employed were less likely to receive similar funding (n=4; 12.1%). For carers in employment it appeared as if providing respite support that enabled them to "*participate in family life, social activities, employment and education*" was also experienced as having greater control over their respite options.

However, the corollary of this observation is that carers who were less likely to achieve the kind of respite that enabled them to continue participating in work and other community roles were also less likely to access out-of-home respite or feel as if they had any choice about the support they received.

The other cohort who felt significantly disadvantaged in terms of their ability to exercise choice about the type of respite care they received were **non-relative carers**. The majority of non-relative carers who responded to the *Responding to Respite Needs Survey* were either providing or had begun their support of a person through a contract board arrangement. Although non-relative carers told the research team that they considered the person for whom they provided support to be part of their family, only one out of every ten non-family carers said they felt they were given a choice about the type of respite they received (n= 2; 14.3%). By way of comparison, almost six out of every ten parent carers reported feeling that they had a choice about the respite they received. (n=57.1%). The odds that a non-relative carer would report not having a choice about the type of respite they received were 12.6 (95% CI= 1.73-91.64) times higher than parent carers.

- Carers who had access to facility based and other types of out-of-home respite were significantly **more likely** to feel as if they had a choice about their respite care, indicative of the important role out-of-home respite played for a cohort of carers.
- Carers who were not participating in the workforce were least likely to report having a choice about the type of respite they received.

## The experiences of carers supporting non-relative children through contract board

Carers supporting people through contract board said that, as non-custodial carers, they had little choice (and more often, no choice) about where or who cared for the person they had assimilated within their own family. Carers reported that the timing and choice of alternative carer provider was decided by IDEA Services with little information exchanged between care contexts.

*C [Family member] will come back from the weekend and, if we don't ask the caregivers, we would have no idea what she's been up to. You know what I mean, it feels strange. One day she ended up in A&E with a suspected broken leg and it was only by chance we found out about it.*

Rather than acknowledging the affection and commitment they expressed to someone who had become an equivalently important member of their family, non-relative carers characterised their respite experience as “being treated like a contractor” with the requirement to relinquish the person they cared for without having any significant input into the organisation of the out-of-home placement contributing to this impression.

*I And so your experience of respite. I was thinking about when and where it occurs. It sounds to me as if you are locked into those three nights rather than being able to think about the myriad of different ways you might use a respite allocation?*

*C Well on one level that's true ...*

*I I was thinking about meeting other kinds of needs. Whether you had to take a whole night or whether you could use it for a whole range of different ... you know young people's clubs, recreational respite...*

*C No no. I've never done it, or I've never been offered that.*

*I So that's become part of [Family member's] package and she goes for three nights?*

*C Yeah.*

Whilst the location in which respite took place was important to carers, what mattered most was how they and their family member experienced respite. Carer's assessments of their respite experience varied in ways that reflected differences in service and support practice and in their particular family circumstance. How carers felt about forms of in and out of home respite had a significant impact on the degree of choice they felt they had and their capacity to mould respite in ways that responded to their families support need. Understanding more about variation in the way people assessed the quality of their respite care is the focus of the chapter that follows

# WHAT DID CARERS THINK OF THEIR PRESENT RESPITE OPTIONS?

Broadly speaking, carers chose one or a combination of two different types of respite care in seeking a short-term break. *In-home respite* is where paid staff or members of a person's informal support network provided alternate care in, or radiating out from, a family member's own home. The other option was to use out-of-home care, which is where a family member received alternate care within a range of service contexts including facility based respite care or participating in a Holiday or After School Programme or, alternatively, through a Matched Family Placement.

In the following sections, we report on feedback from carers who used each type of respite option either through the *Responding to Respite Needs Survey* or semi-structured telephone interviews.

## What carers felt about in-home respite

Carers who used in-home support accessed respite by either an alternate carer coming to the family home to enable the carer to leave while their family member stayed in place, or an alternate carer would support the family member to participate in a community activity that provided a short-term break between their journey to and from the family home.

In-home support could be provided by a member of the carer's informal support network or by a carer either employed by a Disability Support Provider or the family. If using the Carer Support Day subsidy (funded at \$76.00 per day), carers had the option of contributing to costs incurred by an alternative carer or pay the equivalent of a wage by "topping up" the subsidy or by discretionary use of Individualised Funding.

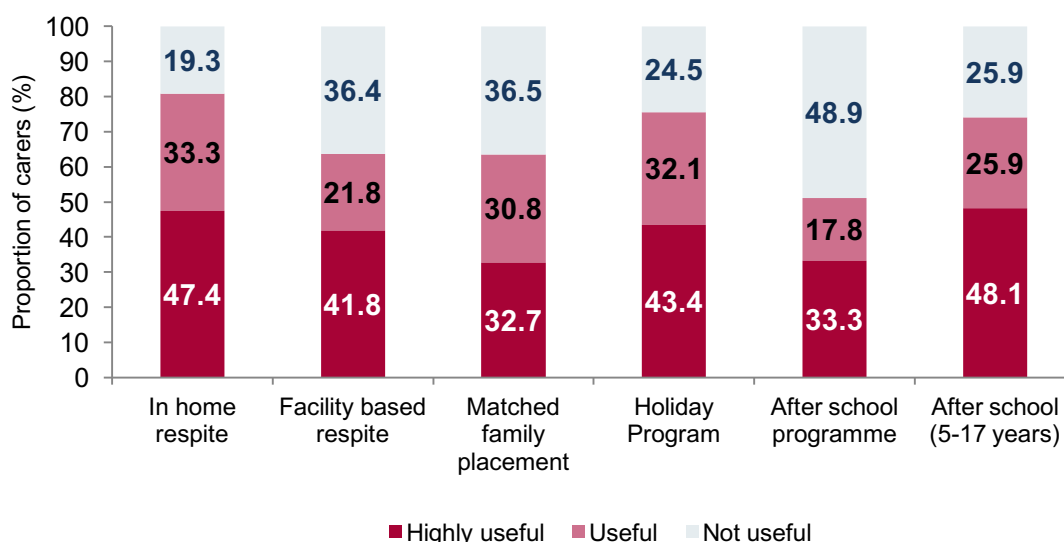
Recent research identified in-home support as the preferred respite option of New Zealand carers supporting a family member with high and complex support needs (Prileszky et al, 2015), and the New Zealand Ministry of Health currently promotes Carer Support Day funding as the best means of providing carers with the *flexibility* they said they needed in that study *to chose and organise their own relief care*.

In the *Responding to Respite Care Needs Survey*, carers were asked to rate how useful to them and their family they felt the range of respite options currently available were or would be. Previous chapters in this report described how respite was predominantly funded through the allocation of Carer Support Days and that in-home respite was the most commonly named type of respite care used by survey respondents (n=27; 35.1%). Further

analysis revealed that in-home respite was also rated by carers as the type of respite their family would find most useful.

**Figure 18 Carer ratings of the usefulness of different types of respite care**

At first reading, this would seem to provide good evidence to support Prileskzy et al.'s (2015)



finding that in-home support best met carers respite needs and that Carer Support Day funding advanced carers preferred respite outcome. A deeper analysis of the data, however, revealed a more complex picture, confounded both by the type of respite carers could (and could not) access and their experiences of the support their family member received within in and-out-of home contexts.

## Who rated in-home respite highly useful?

Perhaps not surprisingly, carers who **accessed in-home respite** were significantly more likely to rate in-home respite highly useful (n= 19; 70.4%) than carers who did not (n= 8; 26.7%).

As noted previously, however, the use of in-home respite was in some ways obligated by the differential funding of Carer Support Days and Facility Based Respite Care. Previously we learnt, for example, that the only predictor of carers use of in-home respite was whether or not they had received Facility Based Respite Care funding. Carers who did not receive Facility Based Respite Care funding were more than twice as likely to report using in-home respite than carers who had the option of also seeking out-of-home facility care and only two out of every five carers who received an allocation of Facility Based Respite Care said they also accessed in-home respite.

Furthermore, it was noted earlier that carers who received an allocation of Facility Based Respite Care were significantly more likely to say they were able to make choices about their

respite care but when the research team looked at how carers who received facility based respite rated in-home respite, only one in four carers rated this type of respite as highly useful (n=3; 25.0%).

Two factors appeared to underpin carers' preference for in-home support. Firstly, their inability to access out-of-home respite options and, secondly, their inability to access the outcomes they identified as indicative of the quality of the respite experience for their family member in the service-led out-of-home respite options they had used. The ratings provided by carers who used Matched Family Placement for respite are further evidence that an absence of the kind of out-of-home experience carers were looking for may have contributed to carer' ratings of the usefulness of in-home respite.

## How did carers who used Matched Family Placements rate the usefulness of in-home support?

Matched Family Placements were the non-service alternative for out-of-home respite. They were also rated as the least useful respite option (n= 19; 36.5% of carers rated as "Not useful"), but whilst this was true for carers overall, receiving respite through care provided by another family was a preferred option for both sibling and non-relative carers. Whereas only 12% of parent carers accessed respite this way (n=6), half of the sibling (n=2; 50.0%) and non-relative (n=7; 50.0%) carers who responded to the *Responding to Respite Care Needs Survey* reported receiving respite from a Matched Family Placement. Moreover, the proportion of siblings and non-relative carers that rated Matched Family Placements as highly useful were both significantly higher than the average ratings they gave for any other type of respite support (n=2; 66.7% and n= 7; 50.0% respectively) and significantly higher than ratings given by parent carers (n=8; 23.5%).

Parents and siblings and/or non-relative carers took very different paths to the carer role, which might, in part, account for the reticence parents expressed for using and rating Matched Family Placement highly.

As is discussed in more detail later in this report, carers who used facility based respite or a service-led programme often expressed concern that the social practices that their family member tended to be met in a way that communicated a sense of them being a "client" or "service-user." Furthermore, carers attributed many of the problems they perceived with provider-led respite, including concerns for their family member's personal safety or inability to feel either "at home," or to flourish, to this understanding of their son or daughter and the attributes of relationship that followed. Put simply, carers did not feel as if staff saw their family member in the way they did nor cared for them in the same way they could.



C *It was a really big step to even drop him off at the facility*

I *Why was that?*

C *It was really emotional. Like you know, I take him to a place with people that we didn't know, that were caring for him. There were a whole lot of kids with different disabilities, with their own challenging behaviour (laughs). Like one kid kept coming up and sticking his hands down the back of your neck, which is fine but quite upsetting for [Family member]. So we dropped him off there and oh, it was just, I mean, both my husband and I just cried. It was just so hard.*

Sibling and non-relative carers, on the other hand, had made their decision to step into a carer role by coming to love someone else. As a consequence, non-parental carers' contemplation of respite options was informed by an embodied knowledge that you could care and commit to the future of a disabled person beyond parental love.

C *She is living with us permanently ..... You know we have grandchildren now. We are as committed to [Family member] as much as we are to our own grandchildren.*

I *But, [Family member] clearly loves you and your wife. I would have thought that would have been to the forefront of everyone's thinking about her wellbeing, her quality of life.*

C *You see even when she moved into services, the language stayed the same, you know, 'service user'. I think [Family] member is seen as a service user. And by definition we're seen as service users. And when you do that, this case management thing goes on.*

I *Missing the human element?*

C *Yeah.*

Interestingly, carers who received respite from a Matched Family Placement were significantly less likely to rate in-home respite highly useful (n= 2; 12.6%) when compared to carers who didn't use this type of respite (n=25; 55.6%). The odds that a non-relative carer would rate in-home respite highly useful were 4.9 (95% CI= 0.814-29.412) times lower than other carers. Pre-eminent in the minds of non-family carers, as-well-as carers who expressed a preference for in-home placement, was that familial-like relationships made it more likely that their family member might be exposed to the relational attributes that would make respite a positive experience for them.

## What carers valued about in-home respite

Funded through a Carer Support Day allocation or Individualised Funding, respite care centred on the family home tends to be promoted as the way carers choose and organise relief care in ways that best respond to their family's needs. Carers who organised their own in-home respite and who spoke to the research team identified the **flexibility** that in-home respite afforded to be one of the more significant advantages of this type of respite care. Where the carer exercised control over the timing of support, it also meant they and their family member could make full use of their respite allocation.

*C The pro (of Individualised Funding) obviously is that it is more flexible, so I can bring people on as I want to and change hours as I want to. Whereas with the home support hours we had through services, he had to have 5 hours at a fixed time. And if you didn't use those 5 hours for some reason, or that person was away, they just seemed to disappear.*

Carers who organised their in-home respite support typically saw this as an advantage to the people they employed and/or engaged with, given that it permitted a similar capacity to respond to the changing lives of those with whom they shared the care of their family member.

Having the ability to choose and organise relief care had other advantages. Firstly carers were able exercise a degree of control over the people who entered their family member's lives. The carers who contributed to this scoping project described valuing the opportunity respite care provided them to both **monitor and mentor alternative carers**. Carers explained that, in order to experience short-term breaks through respite, it was important to have confidence and trust in the people who were caring for their son or daughter. It was, they said, *"especially important if they are coming into your home."*

Having an ability to **tailor respite to the needs and preferences of their family member** was the second major advantage carers identified as following the ability in-home respite afforded them to organise their own relief care.

*C Well with [Family member] there was never anyone around, except for people I cultivated as friends or paid. Like, I have got a fantastic caregiver. She taught him to swim. She couldn't find anyone to help her so she just figured it out herself. And now what he needs are social opportunities. I can construct that. I can make a place where on Friday evenings he can go out – that is going to be suitable for him or outings with his peers where he will get the social interaction that he really craves. You know you need*

*people that are sensitive and subtle and let him feel its ok to be a teenager and not a client. Yes they are being paid, but they are actually there because they enjoy each other's company.*

Carers said they felt most confident about alternative care when it was delivered within relationships of reciprocated trust and liking. For some, *"enjoying each other's company,"* was enhanced by doing things together beyond the home, and yet for others, the most important attribute of in-home respite was the chance it gave them to continue to remain within the sacred space of "home".

A number of carers told us that their preference for in-home support was that they could take short term breaks without their family member having to leave the **people, places and routines that made them feel safe**. This was especially true for people for whom the "noise" and unpredictability of service settings and/or people they didn't know was threatening and disorientating.

*I Is [Family member] able to express what he likes or doesn't like about his support?*

*C I know that he was relieved not to go back to the base. Occasionally he will bring it up and say he's "a home man now." I wonder if he has been a bit traumatised, you know, has got bad memories.*

*I Well that's one way he can tell you, "I'm a home man now." Maybe we should be listening to [Family member]?*

*C Yes. Yes. Yes, that's it. Because this is the place that he feels safe and secure and is not stressed.*

This carer went on to say how since leaving the base, her family member's home had become a place from which he now pushed out from. *"He is getting someone that takes him out and is focused on him now,"* she explained, *"rather than him being lumped in with other people with disabilities".*

Other carers noted that in-home support had enabled their home to become a safe space in which their family member and alternative carer could develop a **more intimate knowing of each other**. Through this process, the alternative carer themselves could also become a "safe place" for their family member as trust in the relationship grew and their family member was increasingly able to participate in community activity as a form of respite care.

C *I think the thread underlying all of this is just seeing a beautiful child, not the condition. And so she just absolutely has bonded with [Family member]. They're a team, she pushes him and they do interesting things together. They go swimming, hiking, go to town. She is helping him with his iPad. Like I say. They're a team.*

At times the field of reciprocated care extended beyond disabled the family member. Sharing the more intimate social space of the family home seemed to make it more likely that carers might also become part of an **expanded family of care** in which all those whose lives intersected through respite care might respond in ways that were protective of the health and wellbeing of each other.

C *Now the last carer we had, she not only looked after [Family member], she looked after me as well. She became like a friend. And she sort of... cause she was an older woman and a nurse. I'm a nurse so it was kind of instinctual.*

## In-home as the antithesis of respite

Common to the narrative of carers who used in-home support was a shared belief that managing respite within the more naturalistic setting of their home represented the best way of ensuring that respite was a positive experience for their family member too. In their minds, the care needs of their son or daughter and their own need for respite were inseparable. Knowing that their family member was safe and that respite contributed to their health and wellbeing *"took the pressure off [them] too."* As one participant articulated, *"To take care of me, you need to care for my son".*

In doing so, however, their own home often ceased to be a place of respite and refuge for carers.

Where carers had more limited control over the entrances and exits of staff, carers said their homes often became populated by strangers. Furthermore, in the absence of sustained relationships, carers also said they could be caught on a treadmill of repeatedly training and orientating new carers to their family member, or of continually having to make suggestions about what to do with shared (respite) time or to be on call to provide a lifetime's worth of expert advice should things go wrong: *"To be frank, with respite in the home you are feeling like you've got to be catering to the person giving it."*

The following comment also speaks to the difficulty of accommodating an unfamiliar person within carer's homes.

*C At that time it was someone coming here to our house and that wasn't very helpful. It meant another stranger in our home. What we really needed was [Family member] to go out somewhere and do things and not to have somebody here who, you know, they're young people. They don't know what they are doing. They're in your house. They're uncomfortable. You always knew better than them. And I just wanted four hours of peace basically. I would sleep or do something with our younger son. Just do essential things.*

When in-home respite wasn't provided by a member of a carer's informal network, like family or a trusted friend, respite could be the opposite of restful and a carer's house sometimes no longer felt like a home.

*C But the great thing is, we can take him there and drop him off and come home and he's not here. Which sounds pretty awful but we get to have a real proper rest in our own home.*

In discussing what they were looking for in out-of home respite, the carers we spoke to tended to describe the attributes of homeliness outlined above, but without finding them in out-of-home respite care contexts, many carers had come to provide the service they sought inside of their own homes. The most obvious consequence of this decision was that, rather than moderating the demands of the carer role, respite for some carers simply added to the demands.

- **In-home support was more likely to be rated as “highly useful” than other types of respite care. By attending to the attributes of in-home support carers value, disability providers can also make an contribution to supporting the health and wellbeing of carers.**
- **Carers who used in-home respite were significantly more likely to rate it as highly useful and only one in four carers who received facility based respite rated in-home support highly useful.**
- **Carers' assessment of the usefulness of in-home respite appeared to reflect variation in their ability to access the attributes of respite they identified as elemental to their family member having a positive respite experience within the range of existing out-of-home respite alternatives.**
- **Having the flexibility to respond to the changing circumstances of the wider family, for example having an alternative carer, was identified as major advantage of in-home respite.**

- **A significant number of carers chose and valued in-home respite because they felt able to mentor and support alternative carers to tailor the respite experience towards the needs and preferences of their family member. Carers said they had limited opportunity to engage in an ongoing dialogue within out-of-home providers.**
- **The development of relationships of trust and social knowing were seen as the conduit to positive outcomes for carer's family member. Alternative carers could become relational points of safety for disabled care recipients.**
- **Disability providers could improve the transition to out-of-home care by allowing people to take trusting relationships into respite settings and/or establishing and sustaining relationships of trust with an identified staff member prior to and during out-of-home respite care.**
- **Carers who used in-home respite said they were looking for experiential attributes that transform service contexts into home-like settings, including: an insider's sense of psychological safety; an influence over the routines and rhythms of the household; that the house become a repository of significant and affirming social relationships; and being in place carried with it an expectation that the contribute to the household economy**
- **Carer's felt a home was somewhere that their family member felt safe and/or wanted to invite others into.**
- **Having to provide those experiential attributes in the family home increased the demands of caring in ways that undermined many carers' abilities to benefit from respite.**

Carers using in-home care faced other challenges too, including the difficulty they experienced accessing alternative care as a consequence of having shrinking informal support networks and the difficulty of affording paid carers.

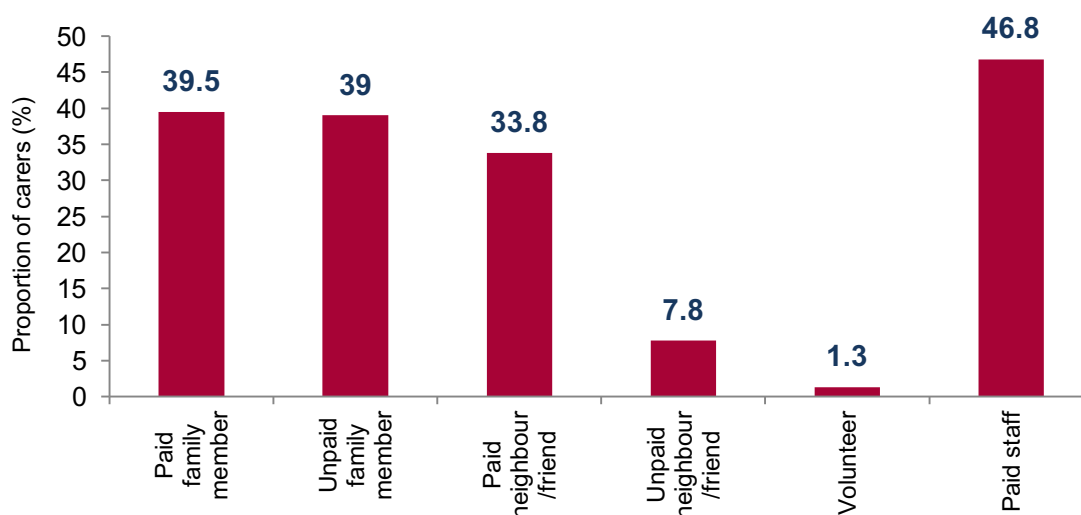
## The shrinking pool of informal carers

Framed as a contribution towards the cost of alternative care, Carer Support Day funding assumes carers will draw on their informal support network to access in-home respite. None of the ways Carer Support Day funding is provided, for example, allows carers to pay someone the minimum wage.

Seven out of every ten carers who completed the *Responding to Respite Needs Survey* described receiving paid or unpaid support from neighbour(s) friend(s) and/or a family member(s) (n= 54; 71.1%) and just over half of all carers sampled drew exclusively on their informal network to provide either paid or unpaid respite support (n=41; 53.2%).

Family represented carers most commonly cited source of informal respite care either in a paid (30; 39.5%) or unpaid paid (n= 30; 39.0%) capacity. Four out of every ten carers said that the respite they received by a family members was unpaid, although people's definition of what constituted respite may have varied between respondents in ways that probably underestimated the informal respite other family members provided. One in three carers said they occasionally paid a friend or neighbour to provide respite but unpaid respite was much less commonly reported. Only eight percent of carers said they received unpaid respite from friends and neighbours. Only eight percent of carers said they received unpaid respite from friends and neighbours.

**Figure 19 The source of carer's informal respite care**



For most carers, therefore, their ability to access In-home respite was determined by their ability to access alternative care from within their informal support network.

All carers spoke of the difficulty they had finding people to step into an alternative carer role. Most attributed the difficulty they experienced to a wider shift in society that went unrecognised in respite funding. People today, they said, live much busier and more disconnected lives, pointing out that whereas a decade ago it was common to find women who didn't work and/or were more community oriented, today both partners, including their sons and daughters needed (or were required) to work in order to maintain a reasonable standard of living.

*C They're [NASC] very um, forthcoming in offering assistance like that, their allocation of hours and that. But I guess in this day and age, with society living, you know everybody working and busy, there's not as many people around.*

Three groups were particularly disadvantaged by the shrinkage in people's informal networks.

Parents who were **dislocated from their sons and daughters** or other family members, experienced great difficulty accessing informal respite care. As a funding model, Carer Support Days assumes geographic proximity and, communities of place have increasingly been replaced by communities of interest and increased mobility. Families have become increasingly dispersed and carers equivalently mobile. Geographic separation from the most common source of informal care made it extremely difficult for some carers to take a break.

*C ... so eventually if you had some carers support, I guess you could actually have a break. But ... I'm in a new place and I have no one. I've got a daughter who has recently got engaged who isn't going to be available and my other daughter lives in the South Island.*

By not following the ordinary life trajectory of their age peers, disabled children and their families tended to be absented from the sleepovers and sporting and recreational clubs and other institutions that pulled other adults into common community. Carers also said it was increasingly difficult to find social contexts within which they could build relationships - meaning that the "communities it took to raise a (non-disabled) child" were harder to find for the parents of disabled children. Even when carers found communities of place, they were reticent to change the nature of relationships they encountered by asking for help.

*C There are a lot of people at our church. Um yeah, you just don't want to sort of... you know, it's not that your afraid to ask for help, you just don't want to put your sort of burdens onto other people. It would be different if someone offered, but then it's hard but then you would have to .... It's hard you know [Interviewer]. People with Autism are so different*

Relatedly, one of the ways that carers described finding alternative care was by using the networks of other carers. Carers who had the opportunity to meet other carers recommended alternative carers, gave each other advice about where to go for support and informed each other about their eligibility for services and assistance. Those carers who were most likely to report drawing on the collective resources of other parents were carers whose children attended Specialist Schools.



The second group of carers that appeared to experience great difficulty accessing informal support were those **supporting teenage children**. Tacit acknowledgement of both the demands on carers that can follow their family member approaching adulthood and the difficulty many carers experience finding suitable respite options for can be found over-representation of this cohort within the population of people allocated Carer Support Days. The carers of young adults told us that when their son or daughter was younger, their siblings found it much easier to look after the disabled brother or sister, but that as they became older, support became more difficult and siblings sometimes questioned their competence.

*C Our families do love us and care about [Family member] and we both come from big families, but we have never had any of them offer to take [Family member] and give us a break. But then in saying that, they might feel daunted or they might not feel they have the ability to do it.*

At an age at which parental responsibilities and the life-spaces of other families were changing as a consequence of their sons and daughters increasing independence, carer's lives were taking an altogether different trajectory.

And finally, the last group who appeared to experience difficulty accessing informal support were **older carers**, whose families were most likely to have migrated, whose friends were least likely to feel confident and who were least likely to be able to pay for alternative care.

*C We don't have family nearby, so we cant use family as regular..... well, if they are down visiting. But you want somebody whose right And if you can't afford to pay more that what the rate is, well.....*

## The (un)affordability of paid alternative care

Carers who experienced difficulty accessing informal support and who preferred or were obliged to use in-home respite had little option other than to rely on formal support accessed through a Disability Provider. Whilst carers almost always appreciated the support, most also reported that this form of in-home respite was highly problematic.

Whereas having the opportunity organise relief care in a way that responded to family (and alternative carer) circumstances was identified as the major advantage of in-home support, the opposite was true when alternate care was sourced through a Disability Provider. Services were said to "gate-keep" the provision of support in ways that were perceived to undermine the usefulness of in-home respite.

*C We get Carer Support Days. Frankly, they're barely worth the trouble. He can only spend an hour or two out there. Everything seems to revolve around the carers, or they dictate the hours. They dictate when. They change it when they want to. Don't get the impression that I'm not glad to be having it, but it's a very one-sided relationship. There is no flexibility for us, but we are expected to be very flexible the other way around. They won't change nappies, so we can only stay around two hours max.*

In the narrative above, this carer expresses dissatisfaction, not just with the inflexibility of her support, but that the skill set and preferences of the staff member limited the way she could use her Carer Support allocation. Other carers also described a level of dissatisfaction with staff whose support they perceived they had to accept. For some, concerns about the quality of support had, paradoxically, led them to contemplate disengaging with respite as a way of maintaining their health and wellbeing.

*C Most mums I've talked to have had the same issue, just getting really inappropriate carers. And then you'd go to the point of just safeguarding yourself from it .... where you just don't engage in it anymore because after having to deal with carers that are not adequately trained or too elderly. I have a child who does have a tendency to get violent. You just .... There's no peace of mind at all.*

The discretionary use of Carer Support Funding was, for some carers, similarly undermined by seemingly inflexible service practices.

*C I put in for an hour and a half (between 3.30-5.00pm) for [Family member] to be looked after and they say no one is going to want to do that because of the wages we pay, you won't get anyone to do the hour. I already had the hours approved by [NASC] and they just said we are not going to give it to you. When it comes across my desk I'm not going to send it back saying no one wants to work an hour a day. So they won't even look after her. They won't do it. You have to find someone else. So then I found someone else who said she would.*

*I So you find the buddy, but it has to be administrated through the service?*

*C Yep! I find the buddy because they won't find them. They say no one wants to work only an hour a day. That's ridiculous!*

In addition to not being able to decide when and for how long to use in-home support from service providers, other carers spoke of how slow employment processes could be and how the failure to communicate well contributed to the problem of finding alternative care.

C I wanted it to start on the 4th of June so I put it in way back at the beginning of the term. So anyway, it was 13, 14, 15 weeks for them to actually hire someone. They say that they can't do it and their hiring process takes that long. So, I went to the manager to make the process quicker. And it still took three months to get. It's like you're kidding me! Who wants to wait that long for a stinking job that you only get so much.

Carers who had contacted services to seek alternative carers repeatedly told us that they didn't consider it to be *"their job to find these people"* and that being *"busy running the house, looking after children, taking care of an autistic son, and a baby meant that you just didn't get there. That (was) the reality."*

Without informal support, however, carers who could not afford to "top up" their Carer Support Day funding had little choice but to rely on Provider Contracts to access paid support. At a Half Day remuneration rate of \$38.00 and Full Day remuneration rate of \$76.00, carers were required to top up Half Day funding by between \$23.00 (4 hours) - \$70.75 (7 hours) to achieve the minimum wage and between \$46.00 (8 hours) - \$290.00 (24 hours) should they wish to employ their own staff by drawing on their Carer Support allocation (calculated at a minimum wage rate of \$15.25 per hour).

**Table 2 The difference between half and full day Carer Support Funding and the minimum wage**

Half Day Carer Support rate		Full Day Carer Support rate	
Hours	Deficit (\$)	Hours	Deficit (\$)
4	23.00	8	46.00
5	38.25	10	76.50
6	53.50	12	107.00
7	70.75	24	290.00

Carers employing alternative care through an Individualised Funding arrangement were most disadvantaged.

*C [Family member] does get a few overnights with his grandparents, which works really well. But for a carer to do it now, they have to be paid the minimum wage for the whole 24 hours which is just too expensive.*

Most carers simply could not afford the pay the difference. Furthermore, those who valued their support struggled with the ethics of not paying alternative carers commensurate with their worth or of using their Carer Support Day funding in ways that were not permitted.

*C [Carer] is exceptional. I pay her just over 19 dollars an hour and she is worth all of it.*

*I Gosh. If you weren't doubling up your funding, it would be hard to get someone wouldn't it?*

*C Yeah. Yeah I almost wish that it was a .... You know, that they gave you. Oh I know it's difficult because you don't want people just paying whatever they want, but sort of an option to do that legitimately because I think I am breaking the rules by doing that.*

The rationale articulated for the New Zealand Ministry of Health (and District Health Boards) to provide carers with an opportunity to take short-term breaks, is that supporting carer health and wellbeing represents an investment, the return of which is to uphold disabled peoples human right to live in the community, beyond Residential Facilities currently contracted to provide respite care at \$150.00 a bed night.

A recent decision by the Employment Court that people providing relief care may be considered as having the status of "homeworker" as defined by the Employment Relations Act 2000, may ultimately require the Ministry of Health to comply with the Minimum Wage Act 1983 and Holidays Act 2003. The Court found that the Ministry had statutory responsibility to provide health and disability services, requiring them to "engage" relief carers so that they might discharge those responsibilities (See *Lowe v Director-General of Health, Ministry of Health and Chief Executive, Capital & Coast District Health Board*; [2015] NZEmpC 24 WRC 11/14). They also concluded that, whilst the Ministry described Carer Support as a "subsidy" in the sense that it was a contribution made to supplement an unpaid carers efforts, such a term did not reflect the reality of an arrangement in which payments for service were made on the basis of an invoice and on terms and conditions as defined by the Ministry. Such terms included the right of the Ministry to investigate false claims, conduct random audit checks, investigate complaints and contractually oblige relief care to be

delivered in a supportive manner that respected the dignity, rights, needs abilities and cultural values of the disabled person and their family.

Adjusting the Carer Support Day contribution so that it aligns with employment rights as defined in the Minimum Wage Act 1983 and Holidays Act 2003, would facilitate a number of positive outcomes. Such benefits might include, but not be restricted to:

- Allow carers to circumvent the infrastructure of service provision by “engaging” alternative carers directly.
- Avoid materially disadvantaging carers who have embraced Individualised Funding and taken responsibility for employing, training and managing their own staff compliant with existing employment legislation.
- Create a market for new and innovative respite support models currently unaffordable through Carer Support Day funding.
- Provide carers with the opportunity to pay alternative carers commensurate with their skills without having to “*break the rules*,”
- Assist the new National Carer Matching Service to become a more viable conduit to flexible respite care.

## The National Carer Matching Service

From October 2015, DSS clients in receipt of Carer Support Day and Individualised (Respite) Funding have been able to access the “MyCare” carer-matching portal. The initiative responds to Objective One of the New Zealand Carers’ Action Plan 2013-2018 (“Enable whānau, aiga, family and carers to take a break”) in which the Ministry of Health was identified as the lead agency tasked with developing a national online carer matching service.

The intended purpose of the service is to “*increase the range of respite options*” available to carers by linking those seeking and offering In-home respite. To establish the Service, the Ministry of Health dissolved regional carer matching contracts to establish a national pool of carers seeking paid or voluntary employment. Carers post their profile and contact details and carers can similarly post details of the respite they are seeking. Unlike previous contracts, however, contacting alternative carers and negotiating and making pay arrangements are the responsibility of the carer, as is the decision about whether to seek a background (police) check. The National Carer Matching Service also does not offer emergency relief care.

Only one of the carers spoken to by the Research Team said they had heard of the National Carer Matching Service and no carer had either sought or received a referral from their NASC to access the portal. When informed of the service, carers typically recognised its value in terms of exposing them to a wider pool of carers and liked the idea of being able to exercise some choice about who they selected as an alternative carer.

Feedback provided to the research team during the conduct of the project included, however, that marked regional differences in the size of the pool of potential carers existed and that most of the postings were from carers seeking employment, putting them beyond the Carer Support Day subsidy.

NASC agencies also reported sometimes needing to make a Service Provider referral to support carers to log on and use the MyCare portal.

- **Carer's ability to access respite was often determined by their ability to access alternative care from a member of their informal support network.**
- **Seven out of every ten carers drew on informal support for respite and just over half drew exclusively on their informal support network.**
- **All carers expressed difficulty finding people to act as alternative carers, attributing this to wider societal changes in patterns of employment and mobility.**
- **Families who were geographically separated, supporting a teenage disabled family member, and older carers were most disadvantaged by the shrinkage in their pool of alternative carers.**
- **A number of carers expressed dissatisfaction at the quality of staff and employment practices of Services that provided staff.**
- **Carers who relied on formal support services for alternative carers purchased with Carer Support were between \$23.00 - \$70.75 in deficit of the minimum wage for Half Day funding and between \$44.00 - \$290.00 for Full Day funding.**
- **Carers wanted to pay alternative carers commensurate with the value of their support.**

- **Adjusting the Carer Support Day subsidy so that it aligns with the Minimum Wage Act 1983 would have a range of additional advantages including; enabling carers to employ staff directly, avoid disadvantaging carers who had taken on the responsibilities associated with Individualised Funding, create a market for new and innovate respite options precluded by current funding levels, and assist the National Carer Matching Service to become more viable.**
- **Few carers knew of the National Carer Matching Service and users of the service report regional differences in the pool of available carers, problems of accessibility and that most (alternative) carer postings were made by people seeking employment.**

## What carers felt about facility based respite

Carers said they accessed facility based respite in one of two ways, either through the use of a staffed facility established specifically for the provision of out-of-home respite, or less commonly at a residential home that had a respite bed vacancy or was unoccupied for periods of the day.

Facility based respite was funded by carers through their use of a Facility Based Respite Care allocation (\$150.00 per Day/Night) although occasionally carers could use their Carer Support Day funding at the Provider's discretion.

Approximately one out of every four carers who completed the *Responding to Respite Needs Survey* said they currently received facility based respite (n=21; 27.3%).

As noted previously, carers were asked to rate how useful they felt the range of respite options currently available would be to them and their family in the *Responding to Respite Care Needs Survey*. Four out of every ten carers felt that facility-based respite would be highly useful (n=23; 41.8%) and an additional 21.8% said that they felt facility based respite would be useful. More than one out of every three carers therefore described facility based respite as not useful to them or their family (n=20; 36.4%).

## Who rated facility based respite highly useful?

Two groups of carers were significantly more likely to rate facility based respite as highly useful.

Seven out of every ten carers who described themselves as **employed full-time** felt facility based respite would be highly useful (n=10; 71.4%). The odds that a carer employed full-time would rate facility based respite as highly useful were 11.6 (95% CI= 1.65-83.33) times higher than carers who were not employed (n=4; 23.5%).

Previously, we described how many carers described experiencing difficulty balancing the, sometimes conflicting demands of employment and care. The research team also found that carers in full-time employment were significantly more likely to be single women and noted that annual leave and other opportunities for respite for these women tended to get used up during the school holidays or to provide care during less predictable events like health or medical emergencies.

*“Respite care,”* several participants reported, *“was the only way (they) could keep their job,”* and in the Survey, 22.7% of all carers (n=17) and 50.0% of carers in full-time employment (n=10) described most recently using respite care to enable them to work. Facility based respite care provided people working full-time with an opportunity to work or recover without having to balance their work and care obligations. Moreover, carers were not permitted to use allocated Carer Support Days when they were at work.

Although small in number, half of the carers who described themselves as **retired** rated facility based respite highly useful (n=3; 50.0%). As has also been described previously, facility based respite represented the only viable respite option for some older carers following the dispersal of their family and the more limited number of age peers they felt comfortable asking to support their family members. Most retired carers had also begun to think about a future beyond their ability to care and had come to see facility based care as a way of getting their family member used to the model of the support they anticipated would eventually replace their care.

Carers who supported a family member with a **behavioural disorder** were also significantly more likely to rate facility based care as highly useful (n= 12; 50.0%) when compared to other carers (n=31; 35.5%). Many expressed the view that their son or daughter was “their responsibility” and appeared more reluctant to transfer that responsibility to friends and family by asking them to temporarily support a family member they knew could be



challenging. Carers who supported a family member with a behaviour disorder often expressed a preference to seek respite from trained and supported facility based staff.

## What carers valued about facility based respite

Whereas carers who expressed a preference for in-home respite emphasised its flexibility as an important quality, carers who liked facility based respite were more likely to identify **certainty** as one of the most important attributes of facility based respite. A number of carers suggested that facilities tended to prefer families able to timetable their facility use and those who were locked into regular respite times valued the chance it gave them to plan with confidence.

Those carers whose family member liked the facility commonly spoke of valuing the way out-of-home respite took their son or daughter **beyond the geography and relationships of their everyday lives**. Facility based respite had the potential to expose their family member to new people and activities that at times they didn't have the energy to create. In doing so, they said facility based respite provided an, albeit brief, opportunity for their family member to do and experience things beyond parental surveillance and authorship. *"It provides him"* one carer said, with *"the chance to have a break from us."*

*C Well, I think it exposes him to more leisure activities. Because if it was left to us, we're that bloody tired. There's a tendency for us to just stay at home and be isolated. So for [Family member], it's about getting him out of the house and doing leisure activities with people who aren't so stressed out and tired. It's a new environment. It's new people. I think the worst thing you can do is closet them away and only have the family work with them. It's good to have lots of people in their lives.*

People who attended a facility regularly also had an opportunity to **build relationships of place**. Carers mostly mentioned their family member's liking for familiar staff but one carer noted that the facility was one of the few overlapping social contexts her son had as a consequence of sharing the respite home with people he knew from school.

*C Oh he loves it. He knows his life by his routine. So he knows on Friday he has one sleep in [Facility name]. And he has a roster of carers. So the same carers in the house rotated around. And he knows a lot of the children there. A lot of them would go to the same school. He's really happy there.*

For perhaps the majority of carers, however, facility based care represented a lost opportunity, neither replicating the home-like attributes they hoped for nor the five outcomes carers identified as instructive of a positive respite experience for their family member

## Out-of-home care as the antithesis of respite

For many the journey to facility based respite was fraught, having, on one hand, come to depend on the break out-of-home respite provided to recover resilience and to maintain their health and wellbeing and, on the other, carrying grave reservations about the suitability of facility based respite as a destination for their son or daughter. The journey was especially hard for carers who knew their family member didn't like going, like this mum who was picking her son up after a three-day break.

*C I am dreading what I am going to find and I feel guilty dropping him there because I knew he was unhappy... That he's not happy there. He doesn't enjoy it and he feels a bit sad about it, but he kind of knows it's because I need a break from him, or that we need a break from him.*

## When home doesn't offer a sense of respite and refuge

Parents worried not just that the place they were taking their family member was experienced in an adverse way, but also about the impact growing up with the knowledge that in order for your family to be ok you needed to go somewhere you didn't like. Parents worried about the impact this knowledge might be having on their son's or daughter's often fragile sense of self. As described previously, the noise and complexity of the facility was often most difficult for children with autism.

*C Well, as far as he is able to communicate what I understand is that he definitely doesn't like to go there. Um, and that makes him feel sad and he feels lonely. "Lonely" is the word he used. And as I said. It's more about the behaviour that speaks volumes, you know. [Family member] having toilet accidents. What's that about? It's when he feels hopeless to fix something ... and so he does things he would never do here. He got upset the other day and I asked him why he was crying and he types, 'I am autistic'.*

In an open-ended survey question about the quality of respite care their family member received, a number of carers expressed concern about the appropriateness of the facility as a support context for people with an autistic spectrum disorder. Included in their comments were concerns about how what they perceived to be a lack of staff training shaped the way that staff responded to their family member. Some carers worried about the failure of staff to moderate support practices or the way that they interpreted and/or responded to their family member's behaviour. In the survey different carers wrote that their son or daughter was met by staff who *"didn't understand Austistic Spectrum Disorders"* or had a *"lack lofl understanding of complex support needs"* and/or had *"no empathy for my child."* High staff turnover and the need to continually relate their family members support needs were also identified by a number of carers as interrupting respite care in ways that undermined the development of trusting and responsive relationships.

Others expressed concern about the physical safety of their family member, or of issues of compatibility between the people they shared the facility with. A number of carers, albeit small, wrote of their family member *"(getting) pinched and scratched by another service user and staff are unable to prevent this"* or of the *"home (being) unsafe"* and of concerns they had about the level of surveillance and/or attendant care.

These experiences were elaborated on in a number of participant interviews. Carers described, for example, their family member *"coming home with a huge bite mark on her face (that) nobody could explain"* or of witnessing moments of physical abuse and intimidation. Other stories evoked those that that had brought the issues of staff ratios and adequate care in respite facilities into sharp relief.

*C [Family member] has high needs. He has two carers assigned to him because he would go missing. Five years ago, he went missing for over an hour. It was late, in the middle of winter and we were really angry because we knew exactly where he would have gone but nobody called us. We ended up pulling [Family member] out because it was the third time he went missing there. They just weren't taking his safety seriously enough.*

*I But he is back at [Facility name] now?*

*C Yes he is. There is only one house.*

And another carer:

*I Do you worry about [Family member] You said something before about the skill-set of the staff.*

*C Yeah. No it's a concern. He has had some really bad seizures while he has been in care. One time [Family member] had one in the bath. He needs people with him all the time. But I know that's not always easy.*

Concern about their family member's safety had led a number of carers to stop using facility based respite. One carer who supported a family member with challenging behaviour told us that forever feeling anxious because *"every time he went away, that, whether we would get a police phone call – because it had happened a few times"* had led them to conclusion that *"look, this isn't actually respite."* The carers of victims of abuse sometimes took an equivalently long time to give up on out-of-home respite too.

*C When he did go he would isolate himself, because the, um acoustics of the place. It was just terrible. I mean you know for someone with autism and acute hearing, it was just too much. In a way when he was the victim of abuse again (the carer had made complaints about three other incidents), in a way that was the catalyst for changing things a bit. Because I hadn't been happy with that for a while.*

## When home doesn't contribute to an expanding network of social relationships

Like many service settings, when carers spoke of their family member having rewarding social relationships of place, they almost invariably meant the relationships that they had with regular staff. Facility based respite tended not to be perceived as an opportunity to start or expand the network of social relationships disabled people might have with each other. Similarly, facilities tended not to be thought of as a conduit to the kind of shared activity that might contribute to the ongoing development of interpersonal intimacy, and as a consequence, more socially orientated care recipients were described as gravitating towards the staff who moderated the rhythms and routines of their stay.

*I What about widening [Family member]'s relationships or giving him the chance to develop his own identity?*

*C No they don't do any of that. Wouldn't that be great. If there was some opportunity for him to be part of a group of young people who were picking up trash in the park as a conservation exercise, you know. Something like that would be fantastic.*

As is articulated in the narratives above, for less socially orientated family members, the facility could become a place in which they experienced a sense of feeling “lonely” and estranged or “isolated” from affirming relationships.

And finally, in addition to the respite facility tending not to act as a repository of rewarding social relationship between people who shared the space, they tended also not to be seen as a context that offered disabled people the gifts of invitation or hospitality. As a consequence, care recipients typically remained dislocated from their most important social relationships whilst there.

## When a home doesn't connect people to their community

That facility based respite offered their family member an opportunity to step beyond the geography and relationships of their everyday was one of attributes of out-of-home care that carers said they valued. Yet the majority of carers the research team spoke to felt that facility based respite care tended to dislocate, rather than locate people with their community. In contrast to their more expansive aspirations, carers described social practices of facility based care as a “minding” culture in which disabled people were “shepherded” through their stay.

*C They don't do anything with these children. They're just minding them in a house. And it's like. It's making them more disabled. Any person, and especially teenagers need stimulation. They need exercise. They need stuff to do. They're just shepherding them around the house and stopping them from getting into trouble. Which would be out of absolute boredom.*

The shepherding appeared to occur beyond the house too. Some carers described staff as not confident enough to take disabled people – whom they saw only episodically – into the ordinary spaces and places of their community or to attempt more adventurous ways of being in the community. These included: going for a swim or watching the rugby, biking, going out at night or doing any of the other things their age peers were likely to be doing. As a consequence, the community was most often experienced by the family member from the back of a van.

*C [Family member] goes in the weekend. So, they might go for a van ride. But you know that's not very exciting. Basically, they are just based around the house, which is a very nice house and they are very nice people, you know. But they are not interactive with the community.*

## When a home doesn't contribute to lifelong learning or a transition to new lives

Carers were generally of the view that their family member using facility based respite had limited opportunities to shape the rhythms or activities of the house, and as a consequence, none of the ways they participated in the community were reflective of their passions, interests or unrealized aspirations.

Carers felt that an absence of expectation that their family member contribute to the household economy was equally disabling. Staff performed all the tasks associated with "home-making" thus distancing care recipients from attributes likely to engender a sense of homeliness. Not participating in these ways was also perceived as simultaneously squandering the opportunity for people to acquire the skills they might need to live more independent lives. Rather than engaging their family member in the patterns of ordinary life, respite support tended to be characterised as instrumentally-focused care.

*I        If you were to suggest that [Family member] emulate the routines, you know the sorts of things that were happening in day to day life in the house, could they respond to that?*

*C        I just don't think they have the conception. I mean when you see the people there, they're cooking dinner... you know they've got these different ages. The ratios are sometimes three children to one staff member, who is trying to do the washing, trying to get the beds made, cooking, signing people in and out. And they are not people who are thinking about the bigger picture. They're just trying to get through the shift. And so depressing things like... Sometimes when I pick [Family member] up at 5(pm) those kids, even teenagers are in their pyjamas. At 5(pm)! So they are just waiting to get them in bed.*

## When a person becomes a client

Most carers attributed the hiatus of facility based respite to the facility based staffing ratios and the tasks staff were expected to accomplish whilst supporting people who they didn't know well and who only met periodically. *"When I drop [Family member]," a carer told us, "the staff often look more exhausted than we do."*

Others, however, saw the problem as one of social construction, whereby both carer and care recipient had to make the relational transition from being mother and son/daughter to occupation of the socially-defined roles of "service-provider" and "client." For some, the transition was easy and simply an inevitable reality of living with a learning disability. For

others, it was difficult, undermining as it did, their sense of their son or daughter's personhood.

*C I'll have to go this afternoon .... and they will tell me all the bad things that have happened, which will be the behaviours that do not happen here. Wandering in the night. Toilet accidents, you know, all those sorts of things that make my heart sink. [My son will] be sort of out of his mind because they won't have done anything with him. And then they will give me these notes that they have written 'oh he used the toilet'. It's just... it's literally like they are observing (non-persons).*

- **One in four survey respondents said they currently received facility based respite, more than would be expected from DSS funding allocation data.**
- **Carers who used facility based respite valued the ability regular out-of-home respite afforded the to plan their lives with certainty. They also liked the way facility based respite could take their family member beyond the activities and relationships that populated their everyday lives, including the prospect of developing trusting and affirming place-based relationships.**
- **Carers in full-time employment and who supported a family member with a behavioural disorder were significantly more likely to rate facility based respite highly useful.**
- **Carers who supported a family member with an autistic spectrum disorder typically felt the facility based environment they experienced to be inappropriate for their family member and other carers reported incidents of physical abuse and/or where the physical safety of their family member was compromised.**
- **Respite facilities were characterised as mostly meeting instrumental care needs with the social practices of service delivery failing to personalise support in ways that made it possible for their family member to: expand their network of social relationships; connect to their community; and develop new skills or transition to new lives.**
- **Carers attributed the hiatus of facility based respite to low staff to family member ratios, lack of training and the social construction of family members as “clients” rather than valued and vital community members.**

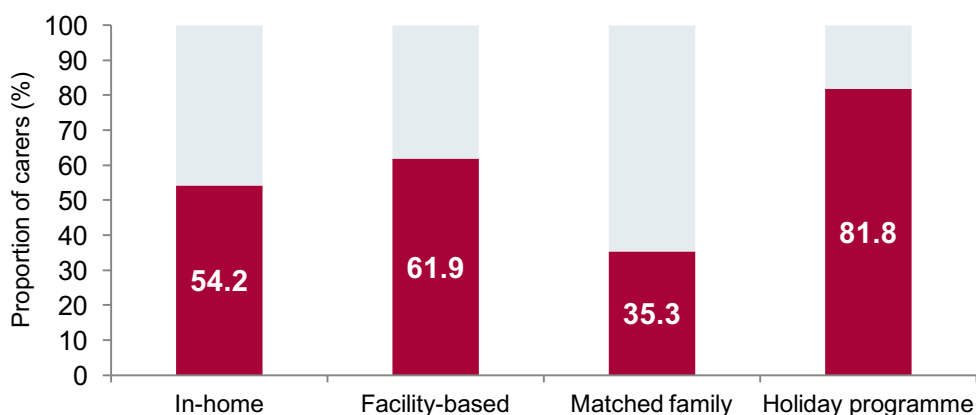
## Carers' assessments of whether respite did(not) meet the needs of their family member

Within the discourses of both research and social policy, the advantages of respite for disabled people have typically been linked to benefits assumed to follow from providing the people who care for them a break from the demands of the carer role. Attending to the health and wellbeing of a disabled person's primary carer, it is argued, improves the carer's capacity to care well in ways that, on the one hand, keep them engaged in the life of their family and community and, on the other, live beyond more institutional forms of care.

This research adds to a much smaller body of research has begun to describe the impact of respite care on those who receive care, including documenting the kind of potential personal benefits that respite can provide disabled people. The kinds of possible benefits carers identified were that respite; broaden their family member's network of relationships or expand personal experiences, contribute to the development of a social identity independent of a person's family, promoting greater community participation and assist the process of transitioning to new lives.

To explore whether carers felt the type of respite support they received also responded well to their family member, we asked whether they had received respite care that did not or could not meet the needs of their family member. Four out of every ten carers who completed the *Responding to Respite Care Needs Survey* said they had received respite care that did not or could not meet the needs of their family member (n= 31; 42.5%).

**Figure 20 The proportion of carers who reported receiving care that did not meet their family member's needs by respite type**



Least likely to report receiving respite that did not meet their family member's needs were carers who received respite from a Matched Family (n= 6; 35.3%). Most likely to report



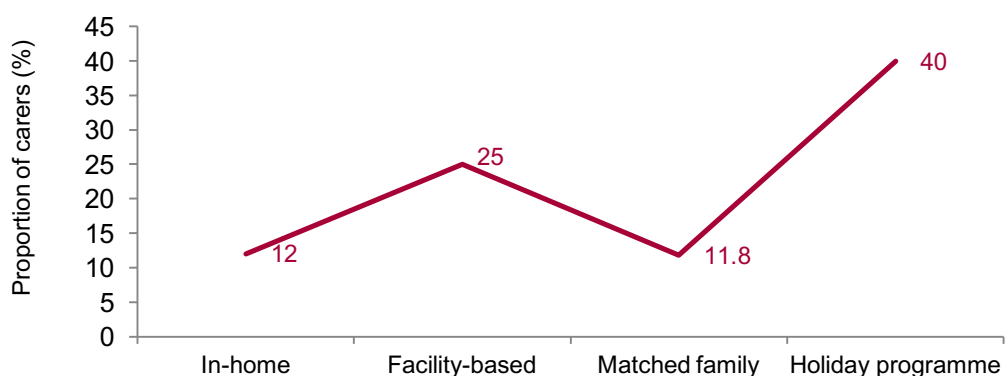
receiving respite care that did not meet their family member's needs were carers whose respite included support from a Disability Service Provider.

Six out of every ten carers who received **facility based respite** said they experienced care that did not or could not meet the needs of their family member compared to 34.6% of carers who did not receive facility based respite (n= 18). The odds that someone receiving facility based respite would report care that did not meet their family members needs were 3.1 times higher than carers who did not use facility based respite (95% CI= 1.07-8.77).

A strong association was found between the likelihood of reporting that care had not met the needs of a family member and whether carers used the other type of service-led respite option. Eight out of every ten carers who accessed respite care through a **Holiday Programme** (n= 9; 81.8%) compared to 35.5% of carers who did not (n= 22) said that they had received respite care that did not or could not meet the needs of their family member. The odds that someone who used a Holiday Programme as part of their respite care would report support that did not meet their family member's needs were 8.2 times higher than carers who did not use a Holiday Programme. (95% CI= 1.62-41.26).

Within the survey respondents were also asked how satisfied they were with the quality of the respite care they received.

**Figure 21 the proportion of carers who reported not being satisfied with the quality of their respite care by respite type**

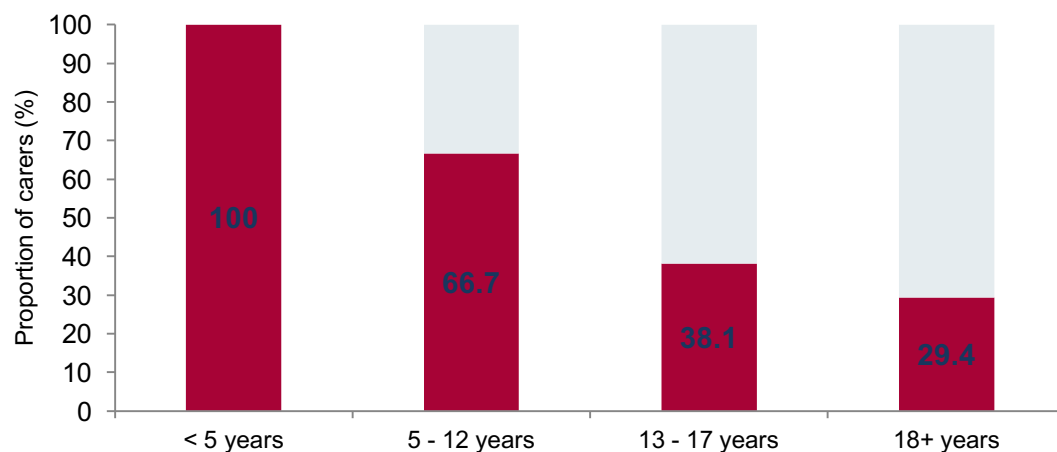


Although eight out of every ten carers indicated they were satisfied with the quality of their respite care, carers who used service settings for respite were also significantly more likely to report not receiving good quality respite care than carers who did not. Four out of every ten carers who accessed respite through a Holiday Programme (n= 4; 40.0%) and one in four carers who accessed facility based respite (n= 5; 25.0%) felt that the support they received was not good quality.

## Which carers were most likely to say respite did not meet the needs of their family member?

Analysis of the responses carers gave revealed a strong association between the **age of care recipients** and the likelihood they would report receiving respite care that did not or could not meet the needs of their family member. Only two carers of children under five years completed this question, but both reported experiencing respite care that did not meet the needs of their children. Approaching seven out of every ten carers of children aged between 5 - 12 years also reported experiencing respite care that did not meet their children's needs (n= 10; 66.7%). The odds that a person caring for a child aged between 5 -12 years would report receiving respite care that did not meet their family member's needs were 4.8 (95% CI= 1.31-17.66) times higher than for carers supporting adults aged over 18 years.

**Figure 22** The proportion of carers who said respite care did not meet the needs of their family member by care recipient age



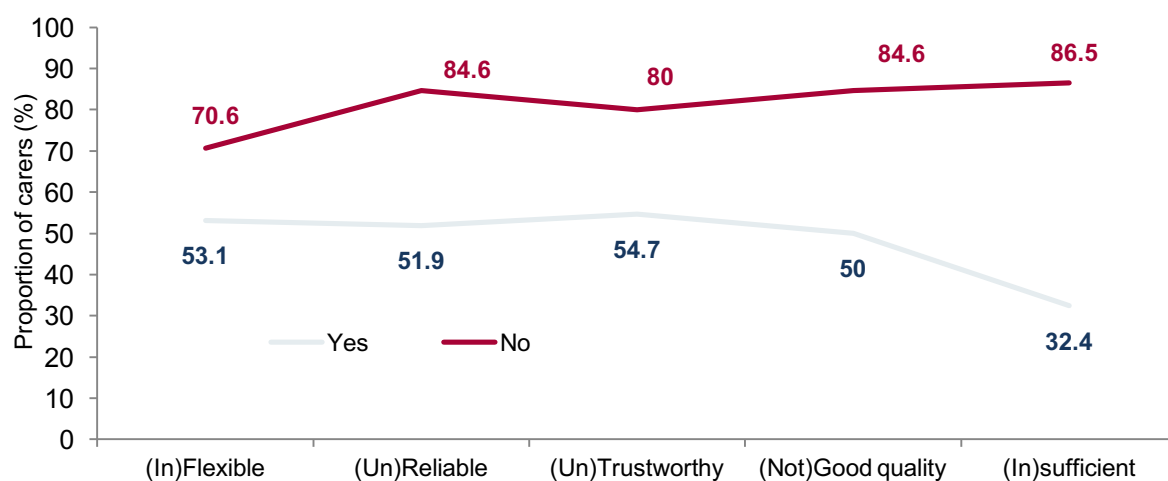
## Did carer's respite experiences affect their self-reported health and wellbeing?

An assumption that providing responsive respite care contributes to the health and wellbeing of carers in ways that enhance their ability to care is central to the Carer's Strategy and disability related social policy. To test carers' assertion (that how respite is experienced influences their health and wellbeing), we tested for the strength of association between carers assessment of the four attributes of respite sampled for in the *Responding to Respite Care Needs Survey* (Flexibility, Reliability, Trustworthiness, Quality) and the likelihood carers would report having felt close to breaking point.

As described previously, feeling as if you had sufficient respite was a key determinant of health and wellbeing as measured by the likelihood carers would report having felt close to breaking point.

Approximately nine out of every ten carers who felt they received **insufficient respite care** (n= 32; 86.5%) described having felt close to breaking point compared to 32% of carers who felt they got sufficient respite (n= 12; 32.4%). Carers who did not feel they received sufficient respite care were 13.3 (95% CI= 4.15-43.48) times more likely to also say they had felt close to breaking point than carers who were satisfied with the amount of respite they received.

**Figure 23 The difference between the proportion of carers who said they felt close to breaking point and who did or did not rate their respite experience has having four key support attributes**



The **reliability of respite** was found to have had a significant impact on the likelihood carers would report having felt close to breakdown too. Eight out of every ten carers who characterised their respite care as unreliable (n= 11; 84.6%) said they had felt close to breaking point compared to approximately half of the carers who reported experiencing reliable respite care (n= 28; 51.9%). The odds that someone who the respite care they received was unreliable would also say they had felt close to breaking point were 5.1 (95% CI= 1.03-25.0) times higher than carers who experienced the respite care they received to be reliable.

A statistically significant association was also found between carers' feelings about the **quality of the respite** support and the likelihood they would report having felt close to breaking point. More than eight out of every ten carers who felt the respite care they received was not good quality (n= 11; 84.6%) said they had previously felt close to breaking point, compared to a little over half of carers who felt they received good quality respite (n= 26; 50.0%). The odds that someone who felt the respite care they received was not good

quality would say they had felt close to breaking point were 5.5 (95% CI= 1.10-27.03) times higher than carers who felt they experienced good quality respite care.

- **Four out of every ten survey respondents said they received respite care that didn't meet the needs of their family member.**
- **Carers who accessed service provider led respite support were most likely to report receiving respite that did not meet the needs of their family member, and most especially those who used facility based respite or a Holiday Programme.**
- **Carers supporting younger children were most likely to say they received respite that did not meet the needs of their family member.**
- **How carers felt about the respite experience was found to be predictive of their health and wellbeing, as measured by the likelihood they would report having felt close to breaking point.**
- **A strong association was found between carer's assessment of the reliability and perceived quality of respite care and their mental health and wellbeing. Not experiencing these attributes in respite care, therefore, has the potential to undermine rather than enhance carer' health and wellbeing.**

# WHAT'S MISSING?

## Beyond the allocation of respite hours

When carers were asked about what they perceived to be the missing elements of respite support, they tended to talk about the absence of conversation rather than what was missing from the landscape of Disability Service provision. What they perceived to be missing was an opportunity to collaborate with service providers to promote the health and wellbeing both of themselves as carers and of people who simultaneously were at the centre of their labour and their love.

Silences at either end of respite provision spectrum prevented this conversation. Carers told us they had few opportunities to contribute to conversations about what they wanted from respite care at the time respite need was acknowledged and having very little opportunity to refashion respite care after it had been experienced. Both omissions meant that respite couldn't be moulded or modified in ways that responded to changes in the lives of those intimately connected through care.

*C Umm. I think the missing bit would be more advice and support around the respite. It's sort of like, you've been given the respite and then a service provider signs you up, and that's it. It's like there is a missing bit where they come along and say 'oh, you've been given five hours a week, this is what some other families do. Or, these are some of the things that carer support workers might do with your child.' Just coaching them along a little bit. And then maybe coming back. That's one thing that has really surprised me. I've never had anyone from the respite service contact me and ask, 'oh how is respite going. Am I happy with the quality of the respite?' Yeah. I have never had a chance for feedback. Apart from now (laughs) So I'll grab that opportunity.*

Carers repeatedly told us that they often felt alone in caring for their family member and that this isolation was occurring against the backdrop of their lives having taken a very different trajectory to their friends and a pool of support that had shrunk as their children grew up.

For carers, this sense of insular responsibility has the potential to become further entrenched by changes in terrain of disability support. Included in the disability "turn" is a shift away from the legislated obligations of Ministries and Provider Contracts towards the "unpaid," informal community of disabled people and their family and friends. For some of the carers seeking the greater flexibility offered by Individualised Funding, this had meant adding the roles of recruitment, training and staff management to the demands of the carer role. For others it meant exchanging their relationship with a trusted respite coordinator, to become personally

responsible for contacting, security checking and orientating prospective carers on the National Carer Matching Portal, following the dissolution of regional respite contracts similarly promoted as enhancing flexible support.

Common to all, however, was a narrative that highlighted carers' inability to access the kinds of dialogue with providers that was likely to lead to the flexible and responsive respite care that both public policy and carers were seeking.

*I So you have never had a conversation with the NASC or your Provider about the demands of caring for [Family member]?*

*C Not really, perhaps something in the review we had in March. Last year.*

*I You've never had a chance to say, well this is how it would be the best for my family. For [Family member] and my family.*

*C Not as such. No.*

*I Umm. What about assistance to plan and to think about how to use respite support?*

*C No*

For carers, the lack of dialogue carried with it the risk of undermining the health and wellbeing of the family member whom they supported.

## You take care of me when you care about my son

All contracted respite providers are required to provide a secure and safe environment for disabled people. As noted earlier, however, a number of the carers we spoke to reported that their family member had not been safe in service settings. A number of factors appeared to have contributed to the hazardousness of those contexts, with carers identifying staff training and the ratio and/or workload of staff who worked as issues of particular concern. Carers felt that an inability to have in-depth and regular conversations with service providers contributed to a real or perceived threat to the safety of their family member.

Embedded in the DSS Tier Two Facility Based Service Specifications is an expectation that the provider and recipient of disability support build a relationship of trust by collaborating in the design and orientation of a Personal (Respite) Plan. The aim of the Plan is to ensure that the personal support needs and aspirations of the disabled person are articulated in a such a way that might instruct support practice. Some carers told us the planning process left many of the things that were important to say about their son or daughter unsaid.

*C When you walk into an organisation and you are handing over your child, at the barest minimum you should have a sheet to fill in. An up to date sheet of what their needs are.*

*I And what they like to do and what they don't.*

*C It's like, well are we going to do an update? One had been done a year or two ago with some of her basic details and that was it. ... I think they must be breaking the law to be honest. I think they would go for a skate if someone came and had a look at their processes. It's a bit like Russian roulette really. Taking her down and thinking - how are they going to respond when they don't have enough information? No one has asked me.*

Including carer's reciprocal right to know more about the people to whom they were entrusting the care of their family member.

*C [Alternative carer] put up her hand to look after [Family member] and [Family member] knew her but she didn't know her routines... And she was great with [Family member] but it was organised that [Family member] would go there the next weekend and we asked if she would meet us at home and just talk about her behaviour support needs and the eating stuff and the strategies we use. We asked the support worker several times and it never happened. It's that kind of functional stuff*

Many carers had a much wider vision for respite though, identifying a cluster of attributes they felt transcended "*mind*ing" and "*shepherd*ing" by adding value to the lives of their family member. As has been described previously, their aspiration was that out-of-home care might augment their families network of support (rather than replace it) by representing a context in which their son or daughter might experience:

- An expanding network of social relationships;
- The kind of connections with their community that communicated "having a place(s)" beyond family;
- The opportunity to develop their own identity;
- A chance to learn new things;
- A key element within the larger process of transitioning to adulthood and/or more independent lives.

They also felt it important that their family experience the kind of attributes of being in place that were likely to transform a "facility" or the social construction of "client" into a "home" or a place of "belonging." Included in that set of attributes were that their family member experience:

- An insiders sense of psychological safety;
- An influence over the routines and rhythms of the household;
- A repository of significant and affirming social relationships;
- An expectation that they contribute to the household economy and;
- A place they felt safe to invite others to.

Previously in this report we described how carers felt their inability to communicate and/or contribute to the advancement of this alternative vision tended to distance their family member from the attributes they advanced as indicative of a positive respite experience.

Interestingly, the same set of attributes carers were articulating as indicative of a positive respite experience for their family member find expression within the service and support values that underscore the delivery of other service contracts. Feedback by carers suggested that what they hoped for in respite care were experiences that reflected the kind of ordinary participatory activities available to people with a learning disability accessing **vocational support**. Options included within the array of experiences already offered by vocational service providers are as wide as people's interests and could include; theatre and art groups, walking, sport and other recreational or interest groups, community linking and employment-related training. The vocational space is also currently in flux, with a number of service providers remaking themselves by using "**community development**" as an alternative framework for seeding inclusive forms of community participation. Within this framework, new imaginings of inclusive forms of community participation are emerging, such as disabled and non-disabled people collaborating in the design and delivery projects like community bicycle workshops and libraries, men's sheds, themed art installations, public performance and community events, environmental or public service projects and community gardens and allotments

At present, vocational service delivery usually occurs between 9.00am – 3.00pm. Configured to replicate the "ordinary" migration from home to work, one of the consequences of this, seemingly socially normative migration, has been to dislocate disabled people from the ordinary cadence of (non-disabled) community participation. Most New Zealanders recreate and/or contribute to their community outside of "vocational hours" and therefore partnering disabled people and their families and other service providers in the design and conduct of non-facility based respite would, for some, require a realignment of the vocational support timetable.

Designing respite in ways that disabled people might recognise themselves in day-to-day rhythms and activity that define their respite experience obligates an attentiveness to their voices. Some, however, experienced great difficulty in contributing to conversations likely to



bend support practice in ways that might allow them to “do some of the things (they) normally liked doing”.

*C We have been using AAC (Alternative & Augmentative Communication) with [Family member] ... (but) there's no one on site who has a depth of understanding. Who you could talk to and who you could expect to be there in another month. Or someone who was already familiar with AAC and you just had to bring them up to speed with how [Family member] does it. That would be the key thing. To be able to get a communication system in place so that he could make choices and he could have some control over it. And yeah, I think he would choose to be able to do some of the things he normally likes.*

Although carers were unequivocal that a short-term break was only respite when they felt confident they were entrusting the care of their family member to people who were similarly committed to the health and wellbeing of the son or daughter, parents too expressed the feeling of being marginalised from conversations likely to communicate shared love.

*I You were saying before, 'I'll tell you how to look after my respite needs, you can look after [Family member] well.'*

*C Mmm. It's as simple as that. That's exactly right. I wouldn't know who to talk to. Nobody at the service would ever ask me 'what do you want out of respite?' What are the activities that [Family member] might like to do? There's nothing like that. It's not how they are thinking.*

*I Well do you ever get the chance to say how you are experiencing it? And how people might adapt or change it?*

*C No. They did have a meeting last year with a whole bunch of other parents*

*I No. What I was really meaning was a degree of curiosity about whether it is working for you and for [Family member].*

*C No, no, no, no. There's none of that.*

- **Although required under the DSS Tier Two Facility Based Service Specifications, none of the carers we spoke to described having a Personal (Respite) Plan.**
- **An opportunity exists for a wider contemplation of respite “outcomes,” including long-term (transitional objectives) through the use of the Quality of Life or similar organising frameworks.**
- **Personal (Respite) Plans can be integrated with other disability support elements, including a closer collaboration with providers offering “vocationally orientated” experiences to promote attributes of respite support many carers identified as indicative of good quality respite care.**
- **A respite website and App could alert family and alternative carers to the range of ordinary participatory experiences that might also provide carers with a regular short-term break.**
- **A respite website might be used to profile staff and/or a pool of alternative carers - in a way that is similar to the National Carer Matching portal. It could also be used to alert carers to vacancies that exist within respite and/or residential facilities to help carers and relief staff plan more effectively.**
- **Carers and disabled people would like to be included in an ongoing dialogue with their provider to assist in the process of developing respite experiences that respond to changes in their needs and personal circumstance. Respite services might, therefore, consider providing respite in ways that connect with and empower disabled people and their wider network of relational and material resources to design their own respite care.**

## “You care about my son when you care about me”

In the quote above, this carer begins by steering her conversation towards her son and how best to meet his needs. Her concern is that she hasn't been able to make her son and his preferences visible enough to make his experience of out-of-home respite a break from the limitations of familial care or an affirming experience. In this sense she tethers his wellbeing to hers. “In order to take care of me,” she told us, “you need to take care of my son.”

As true as that may have been for her, the reverse was also true for her son. His health and wellbeing was also inextricably interlaced with those who loved and supported him every other day of his life. It is a curious omission, therefore, that whilst funding for respite care is predicated on the assumption that short-breaks are required to support the resilience of

carers, nothing is done to moderate the, now well-known risk factors that can undermine carer wellbeing.

A systemic unresponsiveness to the context in which carers cared emerged as a common theme within the narrative of carers who described the relationship they had with respite care providers. NASCs key informants noted that the narrative of Needs Assessment did include trying to get a clearer picture of a carer's family circumstances and of trying to accommodate them within their allocation of respite funding, the process was, however, primarily focussed on identifying a disabled person's support needs, not the things that made caring difficult or demanding.

*C There are a number of things that don't work well. The hours that you're allocated do not take the personal circumstances into account, as the carer. So, like, um it doesn't matter that I went through a divorce, I had a nervous breakdown, I was very ill with pancreatitis, [Family member's] needs haven't changed so the fact that, you know, my father died, my mother moved out, my husband and I separated ten days after my father died, I became a single working mother. All those sort of things, although it was huge change, made no difference to how much I could get because [Family member] her needs were no different.*

*I I have been thinking about that too. You were brave enough to say, 'I am struggling with my mental health' but didn't have any way of saying, 'well, these are the things that are impinging on my ability to take good care of [Family member]'. It all depends on parents having to articulate the support needs of their son or daughter.*

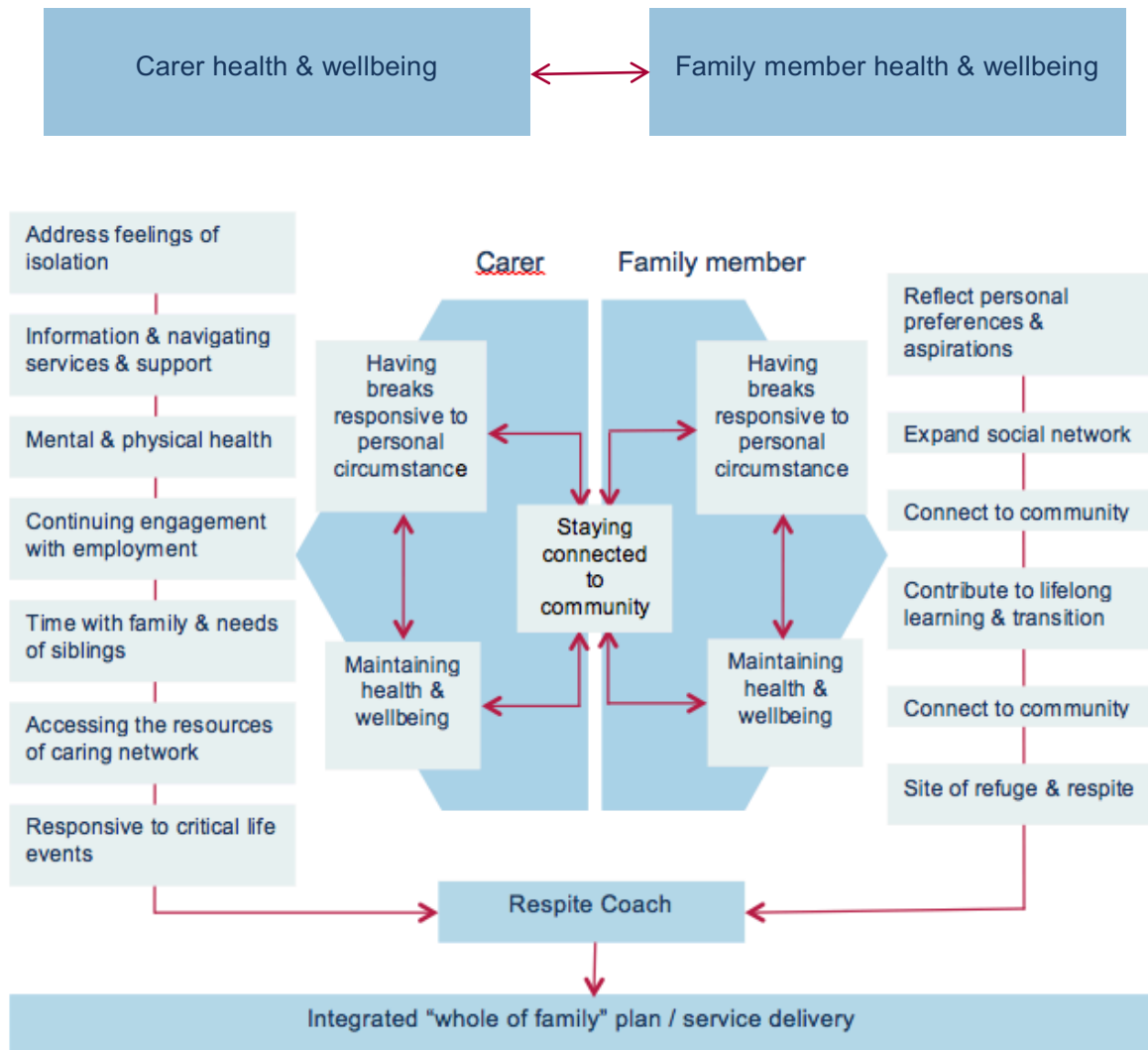
*C That's right. Nobody gives a s\*\*\* about me. I mean excuse the language, but that's the truth.*

As was outlined in the literature review, and has been affirmed by findings presented throughout this report, carer fatigue is only one of a number of contextual factors known to have an impact on carer resilience. Associations between carer breakdown and/or out of home family placement and the following set of predictors are now commonly assumed:

- Social isolation and the loss of community.
- Poor mental health and, most especially, depression and anxiety.
- Becoming dislocated from the ordinary life trajectory including separation from the worlds of employment and education.
- Multiple caring roles and parental guilt that a disabled person's siblings don't get the attention or opportunities they deserve.
- The lack of diagnosis and/or planned intervention.
- Having to navigate a fractured health and disability support landscape.

- A higher prevalence of relationship breakdown.
- Other critical life events that can overwhelm carer resilience.

**Figure 24 (Re)considering the interconnected cycles of carer and family member wellbeing**



Even if consideration of carer context was to make a difference to the allocation of Carer Support Days or facility based respite care, “respite” in and of itself does little to support carers to address the array of other factors that can threaten their health and wellbeing or, similarly, might impinge upon their ability to provide care. Another of the missing pieces, therefore, might be to develop ways of responding to the entire spectrum of carer need, rather than simply providing carers with a temporary escape. In the section that follows, the report suggests that, rather than contributing to the fragmentation of Health and Disability support services, Respite Providers might, through “*whole of family*” planning and “*coaching*,” offer a useful point of intersection for responding to the very different but interlaced support needs of carers and their families.

Not all of the interviews the research team had with carers took the same course, but within those that did discuss whether it would be useful to carers to have someone to assist them to identify and help remediate some of the things that were having an impact on their carer role, the team detected strong support.

*I One of the things that interested us was that the rationale for respite is to address the risk to carer's wellbeing, like the risk of the breakdown in family integrity, or feeling like you're on the edge of breaking down ... that might be contributed to by things like stress or anxiety and depression, or feelings of being isolated, or of having to care for other people too. But it seems like no one is having the conversations or seeking to address those risk factors. Do you think that's a fair observation [Carer]?*

*C I think you are pretty much on the spot there. I've caught up with a lot of other parents with disabled children. And yeah, that's what they are saying too.*

Attending to carer as well as care recipient support need requires two kinds of responsiveness. Firstly, as described above, there is a need for *"a degree of curiosity about whether respite was working for a carer and their family member."* Doing so, carers said, would allow them to partner with alternate carers to refine and tailor their respite experience. And secondly, an ongoing dialogue that invited a more complete conversation about the way both respite and familial care were being transacted. The absence of either tended to be interpreted by carers as a lack of professional empathy.

*C They don't provide anything. I mean they don't even check on us or anything. They provide us with nothing.*

If an overarching theme was identified within the carer narratives, it would be that, in addition to seeing respite as a physical destination (temporarily separating them from the demands of the carer role), what most carers said they would find useful was respite within relationship(s) that provided a light in the sometimes darker times.

*C It wears you down. There is no light at the end of the tunnel. And a lot of it is that ... I'm still doing the same things for [Family member] that I was doing when she was four.*

## Relational respite

During this scoping project, we interviewed carers from throughout New Zealand whose particular circumstances were as divergent as their individual stories. Common to all, however, was the narrative that caring was often a tiring vocation that drew on all of a family's material and emotional resources. Caring was a role that demanded an immediacy

that made it difficult to “*see the bigger picture.*” Carers tended to be forever “*dealing with the stuff that’s important right there and then.*” What most carers said was missing was an attentive and responsive ally. Someone who might help them see a more integrated picture of where they were, and from there, navigate where they might like to go.

*C Um, I think this person would be an overall coach. Someone who has the overall picture how things are going at school how things are going disability wise. Yeah someone like that would be really cool.*

Where carer’s lives intersect with service provision, a space is opened for exactly this sort of dialogue. Under the new DSS Service Specifications, carers and providers of Facility Based Respite Care are required to collaborate in the design of a respite plan. We recommend that a similar opportunity to engage in planning be offered to all carers who seek disability-related support and that the purpose of the plan (and subsequent dialogue) expand beyond the provision of more instrumental duty of care obligations.

Five attributes of respite planning and facilitation emerged as important to carers.

From the perspective of carers, it appeared that for respite planning to be useful the needs of the entire family were indivisible and recognition of this needed to be a guiding principle of future respite development. **Whole of family planning** need not necessarily be deficit-focused, but might also include the resources and connectivity families brought to the support relationship. What was pre-requisite, however, was that planning and facilitation needed to be grounded in a more intimate knowledge of the carer context.

*C You need to go, this is not [Family member], this is [Surname] family. This is who is looking after [Family member] at the moment. Now the family consists of a husband and wife, who have been married for so long, their other children. These are the troubles they are having, you know what I mean. One person works and the other person can’t. And it covers the whole spectrum so you get a really good picture. Who their support networks are. How far away you know. Do they belong to a church. What groups they have you know.*

Siblings and their needs were also to be included as an important element within a responsive respite plan.

*C She was a single mother, and the siblings were clearly traumatised by the behaviour of this child. These parents need intensive support. But that’s what can happen with autism. It is serious. It can absolutely ruin everyone’s lives. And the people themselves. The children are suffering and they need a lot of help.*

It was also seen as important that the plan not only accommodate, but assist carers to **respond to changes in their life circumstance**. Whilst this would necessarily include changes in the health and wellbeing of a carer, it would also include the capacity to respond to other critical life events with the potential to undermine carer' resilience. Such events might, for example, include the illness of another family member, changing behavioural or educational needs, advocacy related to service provision or the infringement of their family member's rights and/or other accommodation issues.

Carers also saw planning and facilitation as an opportunity to think and plan respite in ways that stretched beyond the immediacy of day-to-day care. Older carers communicated their need to think and to work towards an eventual transition to support arrangements beyond their capacity to care, whilst younger carers recognized the potential for respite to assist them to support their family member towards greater independence.

**Incorporating, long-term goals and objectives** in respite planning might also act as a useful conduit to the better **integration of the range of health and disability services**. In the conversations we had with carers, we learnt that many family members were in receipt of a range of disability supports, sometimes within the umbrella of support offered by the same service provider. Incorporating a wider vision of the aims and objectives of respite within the totality of a person's support would permit disabled people and their families a wider canvas for achieving personal goals and ambitions.

Having a **foci for communication** might also assist carers who, in the face of constant staff turnover, described themselves as "giving up" on having to continually re-orientate alternative carers to their son's or daughter's life narrative, preferences and their ever changing needs.

*C Things will change. There will be some kind of toileting programme, or something like the holidays and things have gone backwards and right, we've got a new programme. I've got to tell everyone what it is. We have to go through it. Yeah. It's just constant. And sometimes I wish I had like a human resources person, you know, someone else that could do all that (laughs).*

Perhaps most importantly though, was that carers identified the need for **assistance to navigate the complex and fragmentary worlds of disability support and service provision**. Carers described that having a disabled son or daughter obliged them to engage with multiple agencies, all of whom were originally unknown and unfamiliar to them and all of whom had idiosyncratic service aims and social practices.

*C It's just trying to get through the bureaucracy of it all. You know. If they had a simplification of what's available to people, then people could look at it and say, 'I don't need that' or 'that's something I've been looking for, but where the hell has it been'. Because we don't know where a lot of things are.*

*I Including, I guess, stories of some of the more creative and innovative ways people are using respite. Would that be helpful?*

*C It would be very helpful for people. Especially when you start at the very beginning, you know absolutely nothing.*

In New Zealand, a number of different support arrangements accommodated within the rubric of the "New Model" are currently being trialed. Whilst the role of individualised service coordination or "navigation," is a common element of all four different models, "Enabling Good Lives," "Choices in Community Living," "Local Area Coordination" and the "Enhanced NASC" all locate the role differently.

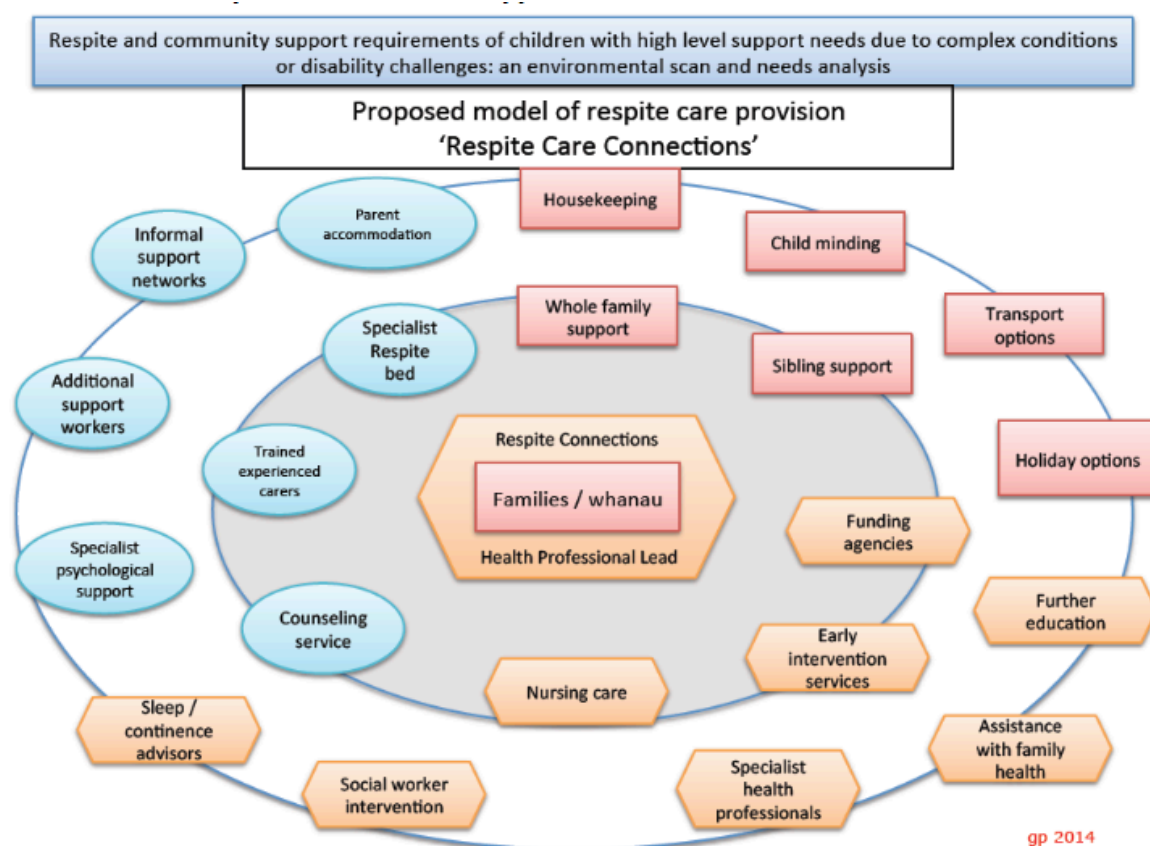
The discussions with carers that occurred as a part of this scoping project, however, suggested the need for dedicated respite coordination, and that, rather than adding to the mix of separate providers, it might be more usefully to integrate supports within a "whole of family," respite plan.

In a report commissioned by "Nurse Maude," Prileszky et al (2015) reached a similar conclusion after talking to carers providing day-to-day support to children with high-level, complex health related care needs in the Canterbury (New Zealand) region. They too advanced a "whole of life model," centred on the relationship between a family / whanau and an identified health professional.

Like the present authors, Prileszky et al (2015) argued that children with high and complex support needs would *"significantly benefit from an individualized respite plan,"* (p11) and that *"poor cross-sector coordination of both information and support,"* (p11) underscored the limited access to appropriate respite that Canterbury families' experienced. Their recommendation was for improved collaboration and coordination across the sector, promoting, what they described as a the "Respite Care Connections" model as a way of mobilising the range of supports required to provide responsive respite services.



Figure 25 The Respite Care Connections model (Prileszky et al, 2015; p12)



Whilst not all participants would have found an expanded respite plan and/or “coaching” or “navigating” useful, many would have. Whilst we did not ask directly, it can be assumed that many will have had a clear understanding of their eligibility and the range of service and supports available to them. Some may also have unimpeded access to the respite they require.

There was sufficient evidence in our findings to suggest, however, that many would have welcomed the chance to reimagine respite for themselves and their family member, including having access to someone who held the “*bigger picture*” when it was at times difficult to see.

Six out of every ten survey respondents reported having almost reached breaking point as a consequence of not receiving responsive respite care, with the prevalence much higher amongst an identifiable carer population, including carers; providing constant support, care to three or more family members and who were single. Furthermore, nearly seven out of every ten carers who answered the survey said they last used respite to relieve emotional

stress without much more than the relief provided by a short-break from the role to mitigate other factors known to undermine carer health and wellbeing.

Finally, the demography of a carer support population in which young people are over-represented and our finding that carers experienced great difficulty finding appropriate in and out-of-home respite for young people approaching their transition to adulthood would seem to indicate a much wider utility to more comprehensive respite planning and co-ordination.

As the "New Model" of support moves increasingly towards self-directed funding, it seems appropriate that the approved uses for carer support might also include the "purchase" of respite planning and co-ordination in much the same way as will be permitted by Enhanced Individualised Funding.

Furthermore, what is imagined by the "coaching" and facilitation role, is that not that it act as gateway to a fixed array of existing services but that in partnership with disabled people and their families, new and more tailored responses to respite need might emerge from a more dynamic planning and facilitation process.

As was described in the literature review, although a growing body of research now paints a fairly comprehensive picture both of the demands of the carer role and of the difficulties carers are experiencing finding appropriate respite care, this knowledge hasn't been met by the emergence of new and innovative respite models.

Carers highlighted that their central preoccupations tended to be with issues of eligibility and of retaining their respite allocation, the struggle to access available services or to find alternative carers and of coping with the daily realities of providing support to a disabled family member. Services, on the other hand, told us of being constrained by Service Contracts, the limited supply of appropriate alternate carers and by funding levels that made it difficult to staff facilities in ways that meet even the most perfunctory duty of care obligations. Without speaking to each other it became hard think beyond what was already in place

*C It's hard to think outside of the box sometimes. You get so embedded and don't don't realise what you are doing.*

*I Well it's hard in two ways isn't it. It's not just hard for you to think of alternatives. It's hard also for services and your needs assessor to think beyond their boxes too isn't it?*

*C Yeah that's right. Sometimes you just have to come at things from a different angle*

## Coming at things from a different angle

At the conclusion of the *Responding to Respite Needs Survey*, carers were asked how useful they might find a range of respite options the research team had become aware of, but remained untested in the literature.

Most of the support contexts were not available within the current repertoire of respite options available in New Zealand, but we did also include out-of-home respite with a care arrangement with another family or special respite facility given as possible examples.

Consistent with the themes that emerged from carer narratives, out-of-home respite emerged as the most preferred alternative respite option. Two out of every three carers rated out-of-home respite as highly useful (n= 49; 66.2%), with an additional 20.3% rating it as useful. Only 12.2% of carers rated out-of-home respite as not personally useful. The age of the family member being cared for had a significant impact on carer ratings. When the data was disaggregated, three out of every four carers who supported a young adult aged 13 – 17 years (n= 16; 76.2%) or family member aged 18 years or older (n=26; 76.5%) described out-of-home respite as *highly useful*, compared to one in three carers supporting a child less than 12 years (n= 6; 33.3%).

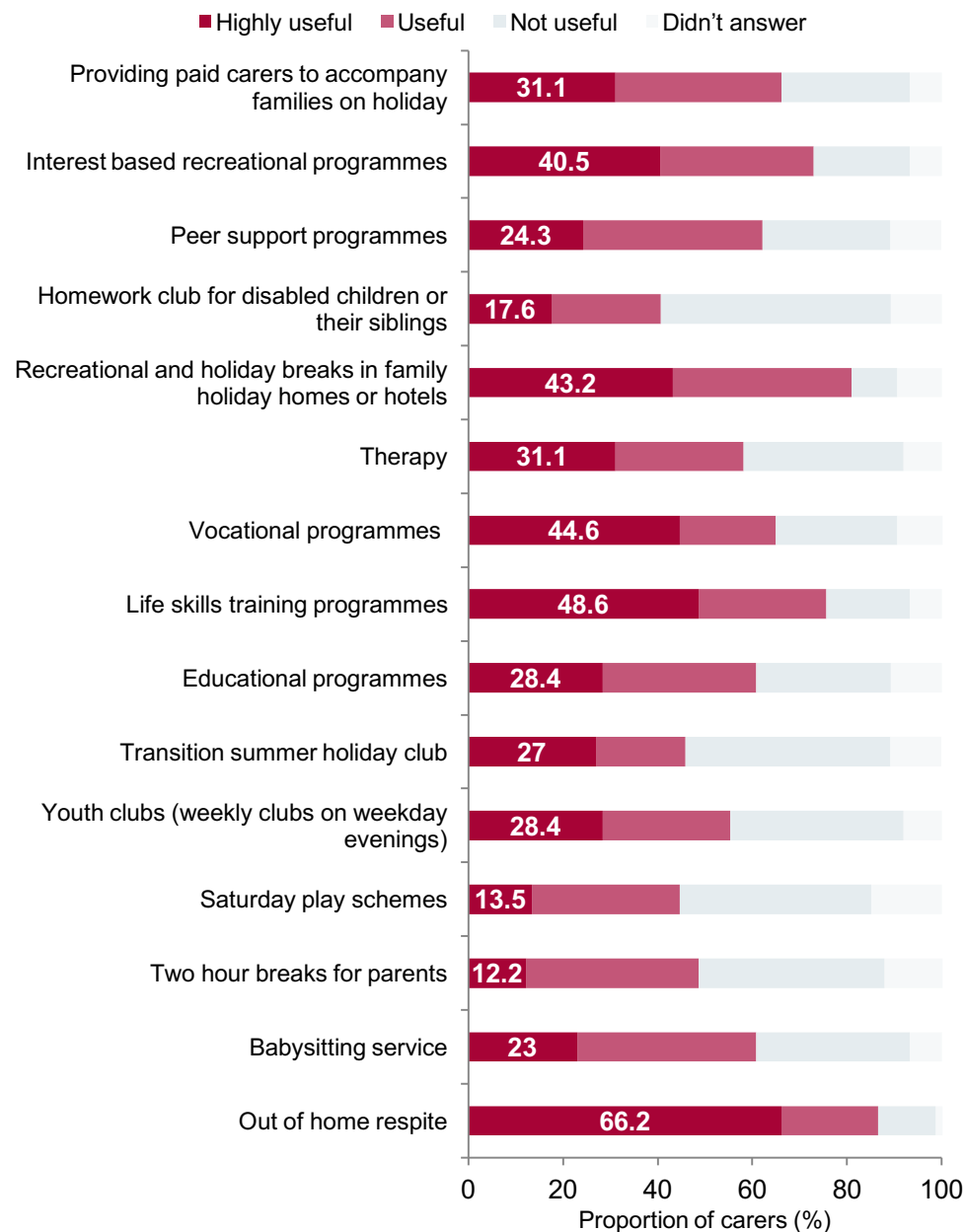
Closer examination of the respite options carers rated most highly revealed a preference for four types of respite experience.

Firstly, carers tended to rate respite that provided the whole family with an **opportunity to recreate together** as a preferred option. Rather than thinking of respite as necessarily taking a break from a family member, a significant number of carers appeared to value having the chance to reimagine and reinforce existing familial relationships by doing new things together. Supporting families to recreate together also answered the concerns many carers expressed about their son or daughter having to grow up thinking that family integrity depended on them being periodically absent. More than one third of carers felt providing an alternative carer to accompany them on a family holiday would be useful (n=26; 24.8%) and an additional 31.1% felt it would be highly useful (n=23). Similarly, 37.8% of carers described feeling recreational and holiday breaks in family holiday homes or hotels would be useful (n= 28) and an additional 43.2% felt this type of respite would be highly useful.

Respite options that acknowledged and supported the **viability of a disabled family member as a life-long learner** also appeared to be highly valued by carers. A cluster of vocationally orientated respite experiences that promoted skill development were rated highly. Approaching half of the carers who responded to the survey said they would find respite

options that trained life skills highly useful (n= 36; 48.6%) with an additional 27.0% describing this option as useful (n= 20).

**Figure 26 Carer's ratings of the usefulness of a range of alternative respite options**



A similar proportion of carers also rated their family member's participation in a vocational programme to be highly useful (n= 33; 44.6%) with an additional 20.3% rating a vocational training or support as a useful respite experience.

Carers also liked respite options that with the potential to link their family member to the community by providing **interest-based recreational programmes**. Four out of every ten carers rated their family member's participation in an interest based recreational programme

as highly useful (n= 30; 40.5%) with an additional 32.4% describing this option as useful (n= 24; 32.4%).

Not surprisingly, an association was found between carer's preference for vocationally-orientated respite options and the age of the person they provided support for. Carers who provided support to a family member aged over 12 years were significantly more likely to rate vocationally-orientated training programmes highly in comparison to carers of a family member aged 12 years or younger. When considered as discrete cohorts the preference for this type of respite expressed by carers of older family members became even more explicit. For example, approaching six out of every ten carers of young adults aged between 13 – 17 years rated life skills training as highly useful (n= 12; 57.1) and 55.9% of carers of a family member aged 18 years or older rated vocational support as highly useful (n= 19; 55.9%).

The final cluster of more innovative respite options reflected carers' aspirations for their son family people to **meet and build friendships** through shared activity. In addition to expressing a liking for interest-based recreation programmes, carers were also interested in peer support and "out-of-hours" youth clubs as possible respite options. One in four carers felt that respite that engaged their family member within a network of supportive peers would be highly useful (n=18; 24.3%) with an additional 37.8% rating this option as useful (n= 28). Similarly, 28.4% of carers felt that youth clubs on a weekday evening would be highly useful (n= 21) with an additional 27.0% feeling that this would be useful as a respite option (n=24).

Carers of children aged under 12 years were more likely to express an interest in **therapy-based respite** and **in-home baby-sitting**.

Six out of every ten carers with a child aged 12 years or younger felt that respite received through their child receiving some form of therapy would be highly useful (n= 11; 61.1%) and an additional carer felt this form of respite would be useful (n=1; 5.6%). As was noted previously in the report, some carers described the earlier years of their child's life as particularly stressful, including the struggle to learn more and to improve their prognoses or moderate challenging behaviour.

Carers of children aged 0 - 12 years and young adults aged 13 – 17 years also rated the possibility of receiving respite from an in-home baby-sitting service highly. Only 16.7% of carers supporting children aged 12 or younger said they would not find baby-sitting useful with 33.3% indicating they would find it highly useful (n=6) and an additional 50.0% reporting feeling it would be a useful option (n=9). Similarly, 28.6% of carers providing support for young adults aged 13 – 17 years indicated they would find an in-home baby-sitting service highly useful (n=6) and an additional 42.9% describing it as a useful option (n= 9).

Analysis of carer ratings of less traditional forms of respite care reveals a remarkable degree of concurrence between what carers told us were the important attributes of respite care in the interviews we conducted and the kinds of respite options they felt might be useful. In both carers clearly indicated that out-of-home respite ought to remain as a possible option on the support landscape.

More interestingly, however, they applied a very similar metric to assess the usefulness of both in and out-of-home respite models. What carers looked for, were respite experiences that communicated a commitment to health and wellbeing of their sons and daughters and sought expressions of that commitment within the "places" of their home or facility and the "placelessness" of more ordinary forms of community participation.

## Drawing the strands together

This report is titled "You care for me by caring about my son" because this research strongly aligns with previous studies that assert an understanding of respite needs to include a focus on the role short-term breaks can play in the lives of those receiving care (Mansell & Wilson, 2009). Moreover, this research takes the conversation a step further by suggesting that the health and wellbeing of carers and the disabled family member they support are indivisible and that the future design of respite planning needs to begin with this as its guiding principle.

On a more positive note, whilst this research confirms the high incidence of poorer health and wellbeing outcomes experienced by New Zealand carers reported elsewhere in international (Mencap, 2013) and other [New Zealand](#) studies (Carpinter, Erwin & Rogers, 2000; Bray et al, 2005; Jorgensen, Parsons & Jacobs, 2009), respite was found to be protective of carer resilience, as measured by the likelihood they would report having felt close to breaking point.

At the conclusion of the literature review, the report noted that whilst a clearer picture is starting to emerge of a range of elements that are critical to quality respite support and service delivery, what has eluded articulation and evaluation are examples of respite care that have succeeded in translating existing research into support practice.

Whilst the limited scope of this research and the diversity of carer experiences the research team was exposed to make it impossible for this report to advance a specific respite model(s), the findings do point to three design principles that ought to guide the development of future respite strategies.

- That the design and evaluation of future respite care adopt the five attributes carers consistently identified as indicative of a positive respite experience for their family member.
- Future service delivery needs to take a “whole of family” approach to the provision of respite support, including supporting carers to identify and remediate a range of factors known to have an impact on carer resilience.
- That caring and the design and delivery of more responsive respite models is conceived of as a collaboration between service providers, carers and disabled people conducted within cycles of ongoing dialogue and action.

The report also noted in the literature review, that barriers to effective care are myriad and occur across a number of different levels. This research contributes to a growing body of research literature that identifies a mix of individual, family, service policy and funding barriers to responsive respite, including carers reporting:

- Difficulty accessing respite at times that suit and/or respond to changes in family circumstances.
- Regional differences in the availability of appropriate respite support services, particularly for younger adults, children with high and complex support needs and people with an autistic spectrum disorder.
- Exclusions from out-of-home respite support because of reported difficulty in staffing facilities or respite programmes at a safe level.
- The shrinkage of carer's informal support networks and difficulty finding alternative carers.
- Negative experiences of respite facilities, and especially a perceived failure of providers to tailor support to the needs and preferences of disabled family members.
- Failure to capture or respond to carer circumstance, and most especially to issues known to undermine resilience.
- A lack of trust in the training and/or competence of alternative carers.
- A perceived inability to replicate the attributes of relationship that communicate affect and a commitment to the future of carer's family member.
- Frequent staff turnover and an erosion of carer motivation to retell the stories that humanise their family member and keep them safe.
- A lack of After School and Holiday Programmes or other forms of alternative care that can support carers continued engagement with the worlds of work and ongoing education.

If there is another "missing" element to the aim of re-fashioning respite care, it could be seen to be the failure of stakeholders at different levels to act in a coordinated way to address the now commonly agreed barriers to effective and responsive respite care. That said, the ability of respite providers to respond to the findings presented in this report will also be determined by changes in the policy and funding environment within which they are embedded.

Required changes at the policy level foregrounded by this research might include:

- Acknowledging the value of alternative care as a way of keeping disabled people connected to their community and out of more expensive forms of institutional care. Adjusting the Carer Support Day subsidy so that it aligned with the Minimum Wage Act 1983 may not only be required following a recent decision in the Employment Court, it would also have a range of additional advantages including; enabling carers to employ staff directly, avoiding disadvantaging carers who had taken on the responsibilities associated with Individualised Funding, the creation of a market for new and innovate respite options precluded by current funding levels, and assist the National Carer Matching Service to become more viable.
- To be consistent with the objectives of the Carer Strategy and other New Zealand social policy, carers should not be excluded from using Carer Support Day funding while at work.

And changes to the Needs Assessment Process that would support the development of more responsive respite services might include;

- Incorporating the identification of carer support needs in the needs assessment *and* service co-ordination process. Failure to collect information related the caring context made it difficult for services to respond to circumstances that undermined carer resilience. The insensitivity of the Needs Assessment Process to carer's support needs appeared to disadvantage carers who needed the most support including those providing support to younger children or a family member with continuous or high and complex support needs.
- The needs of siblings should be included in a "whole of family" approach to the provision of respite support.
- The right of carers to seek and/or remain in employment needs to be acknowledged in the assessment and coordination process.



The vision at the heart of the New Zealand Carers Strategy is *that "New Zealand Aotearoa is a society that values individuals, families, whānau or aiga who support others who need help with everyday living"* (Ministry of Social Development, 2014). This vision is benchmarked against carers having the same opportunities to participate in the lives of their families and communities and their voices being heard in the decision-making that affects them.

This research represents an attempt to capture the voices of New Zealand carers and it concludes by emphasising the need to incorporate those voices within cycles of dialogue and action. These conversations need to happen within the intimate relationships that will foster better ways of planning and responding to individual respite need, in the development of new and innovative respite support models and the wider discourses that shape the experience of providing care within New Zealand society.

The first objective of the Carers Action Plan (2013 – 2018) issues an invitation to all those engaged in the conduct of respite care to collaborate in trialing new respite options that better respond to the diversity of carer's needs. To do that successfully will require all stakeholders to expand their vision of "how to care for (all) those who care."

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