
Report prepared for the Ministry of Health

Survey on future options for Funded Family Care in New Zealand

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15 November 2018

About Sapere Research Group Limited

Sapere Research Group is one of the largest expert consulting firms in Australasia and a leader in provision of independent economic, forensic accounting and public policy services. Sapere provides independent expert testimony, strategic advisory services, data analytics and other advice to Australasia's private sector corporate clients, major law firms, government agencies, and regulatory bodies.

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Acknowledgement

We sincerely thank the large number of people who gave their time to complete the online questionnaire. This report endeavours to faithfully reflect the range of views expressed through this process.

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Glossary

- Aiga** Aiga is a word in the Samoan language which means ‘family’. The ‘aiga is the family unit of Samoan society and differs from the Western sense in that it consists of more than just a mother, father and children.
- ACC** **Accident Compensation Corporation**
ACC is a New Zealand crown entity responsible for administering the country’s universal no-fault accidental injury scheme.
ACC has a paid family care scheme for family carers of people affected by injury-related disabilities.
- Carer Support** Carer Support is a subsidy to help full-time carers take time out from caring (respite). It provides reimbursement of some of the costs of using a support person to care and support a disabled person while the carer has a break.
- DHB** **District Health Board**
New Zealand’s 20 DHBs are responsible for ensuring the provision of health and disability services to populations within their geographical areas. DHBs have paid family care schemes for family carers of: people aged 65 years and over, people of any age with mental health and addiction support needs, and people of any age with long-term chronic health conditions. These services are accessed via DHB-funded needs assessment and service coordination services.
- DSS** **Disability Support Services**
DSS is a Ministry of Health directorate responsible for the planning and funding of disability support services. Responsibilities include purchasing disability support services for people (generally under 65 years of age) with a long-term physical, intellectual and/or sensory impairment that will require on-going support.
These services are accessed via a Ministry of Health-funded needs assessment & service coordination service in each DHB area.
- FFC** **Funded Family Care**
Funded Family Care is Ministry of Health funding for some eligible disabled people to employ their parents or family members over 18 who they live with to provide them with their personal care and/or household management supports. It is sometimes called paid family care.
- HCSS** **Home and Community Support Services**
Funded HCSS are services to help disabled people live at home. They can help with both household management (e.g. meal preparation, laundry, cleaning) and personal care (e.g. eating and drinking, getting in and out of bed, dressing, showering and going to the toilet, moving around home).

IF	<p>Individualised Funding</p> <p>Ministry of Health IF is available for eligible people who have either a HCSS or respite allocation. IF gives disabled people increased choice and control to choose who provides this support, and how and when they use it, with options ranging from engaging support workers and planning how supports will be used, to employing care providers and managing all aspects of service delivery.</p>
Ministry (the)	<p>Ministry of Health</p> <p>The Ministry of Health (the Ministry) is the public service department of New Zealand responsible for healthcare in New Zealand.</p>
MSD	<p>Ministry of Social Development</p> <p>MSD is the public service department of New Zealand charged with advising the government on social policy, and providing social services. It provides income support including payments, entitlements and New Zealand superannuation.</p>
NASC	<p>Needs Assessment and Service Coordination services</p> <p>NASCs are organisations contracted by the Ministry of Health and/or DHBs to work with individuals and their family or carers to: identify their strengths and support needs, and determine their eligibility for funded support services.</p> <p>NASCs are contracted by the Ministry of Health for disability support services and by DHBs for health of older people services and mental health & addiction services.</p> <p>NASCs allocate Ministry-funded disability support services and help with accessing other supports. These services are then delivered by their respective service providers. In DHB funded health of older people services, allocation responsibilities are sometimes shared between NASCs and HCSS providers.</p>
Part 4A	<p>The Government included Part 4A in the New Zealand Public Health and Disability Act 2000 (the Act) in 2013 to enable payment to family carers. Part 4A also sought to prevent any legal claims against the former policy preventing payment and the new policy enabling payment.</p>
Respite	<p>Respite is having a break from caring responsibilities. Funded respite options can include Carer Support, Individualised Funding, or the disabled person spending time during the day or overnight in a facility (respite house or other facility).</p>
Supported Living Payment	<p>Supported Living Payment is a weekly payment from the Ministry of Social Development to help people that have, or are caring full-time for someone with, a health condition, injury or disability.</p> <p>Carers can receive the payment if they care for someone at home who isn't their partner, and would otherwise need to receive hospital or residential care.</p>

Executive summary

This report is a reference paper detailing the methodology, analysis of each question and a summary of the themes emerging as priorities from the e-survey. It summarises the views from the family input on options to improve what we know to be the key issues in the Funded Family Care (FFC) and district health boards' paid family carer policies. The report is a companion paper that informs our primary report *Targeted engagement of Funded Family Care and Paid Family Care*. Key themes from the survey have been integrated into the primary report and it is advisable to read the two reports in conjunction for the full detail of what people said.

The number of survey responses was higher than we expected—based on responses to previous surveys. We believe this was due to the depth of feeling in the disability community, regarding the need for change in Funded Family Care policies.

The majority of people agree with the Government's intention to repeal Part 4A of the New Zealand Public Health and Disability Act 2000 but people still want a way for family carers to be paid.

People want a system that values the contribution of family carers

A common thread, running throughout survey responses, was the need for a system based on principles of respect, valued family contributions, dignity, and listening. As one respondent pointed out, *'Often a loving family member provides the most cost-effective, efficient and consistent care with the best outcome...and supporting those carers keeps the disabled person out of the costly healthcare system'*.

Family carers highlighted the 'discrimination' they face and the inequity between the pay that family members and other carers receive.

A number of people raised the question of what happens to their family member if they become unable to care, particularly as carers themselves are ageing.

Partners should be included and consider family members caring for children

An overwhelming majority of people believe that spouses, partners and civil union partners should be eligible for Funded Family Care for a variety of reasons including that they are trusted and provide safe care.

Most people agree with the current policy that a paid family carer should be aged 18 years or older.

Over half of people disagreed with the age limit of the person being cared for (currently 18 years). Most of these people thought it should be younger than 16 years. There was little consensus around what the exact eligibility age should be but a general feeling that eligibility should be based on the level of need/care required by the person being cared for.

Arrangements should be sensible, simple and flexible

There was a mixed response to whether the person being cared for should be the employer of a paid family carer with a small majority agreeing that they should but only in some circumstances. Employment relationships should be a choice. Many people talked about the impracticalities of the employment arrangement they find themselves in.

There are a variety of ways payment could work. When we asked how people would like to receive their Funded Family Care payments the preferred methods were direct into a nominated family carer's account and direct into the disabled person's bank account. Although, having the choice of different options to suit individual circumstances is important.

People also talked about other agencies' systems and processes that work better for them or others they know.

Widespread dissatisfaction with the assessment and allocation process

Many people expressed dissatisfaction with the assessment process and felt that it underestimates the time required to provide good care. The dominant theme was that the allocation of up to 40 hours of paid care does not reflect the reality of, what is sometimes 24/7, supervision and care. The requirement for (constant) supervision of some disabled people has a significant impact on family carers and there needs to be some recompense for this in policy.

People felt the standard 'timed task' approach is inappropriate—the assumption that tasks take the same time for everyone whereas it can vary greatly dependent on the complexity and situation of the individual, or at any given point in time.

The majority of people disagreed that 40 hours should be the maximum number of paid hours a week, and that there should at least be some ability to flex up in times of higher need. Most people were reluctant to suggest an alternative 'cap' and felt it should be based on individual need. A smaller number suggested that 8 hours for 7 days a week would be fairer recognition of full time caring.

Fair pay and ensuring a living income for full-time carers

Carers talked about the financial strain of caring and the need to ensure a living income for full-time carers, who are unable to undertake other employment. There was a mixed response about whether a paid family carer should be paid a variable hourly rate based on factors like experience, length of time caring or relevant qualifications. However, there was a general feeling that the work of paid family carers needs to be valued, respected, treated equitably with non-family carers and that there should be a way of recompensing those that are caring 'full-time' and/or intermittently.

Ensuring the wellbeing of the whole family

In responses to a number of survey questions, a strong theme emerged around the need to look after and ensure the wellbeing and safety of all family members—disabled people and family carers.

With regard to disabled people this means ensuring they are receiving good quality care. Many people acknowledged the need for some oversight by an external party, but that it needs to be respectful of individual circumstances. What came through strongly that the FFC system should reflect the principles of Enabling Good Lives and support disabled people to participate in their communities.

There is general agreement that no one should be caring 24/7 and not be supported in other ways, but access to quality and safe support and respite is not always available. People felt that current FFC policy dis-incentivises multiple carers. Many people called for more proactive information on available services and entitlements. People thought that training options for family carers was helpful, on topics such as de-escalating behaviours, safe lifting, etc.

A system that is culturally responsive and appreciates diversity

To ensure that Funded Family Care works for all people from all ethnicities and cultures we asked if there are any specific aspects that should be considered for Funded Family Care for their culture, family, whānau or aiga. The majority of people said they did not have any other aspects to be considered. Of those that did have aspects to be considered, culture and spirituality or religion was the most common consideration identified. People talked about both practical aspects of administering a system, such as documents in other languages and access to interpreters, but also a general theme of appreciating diversity and ensuring services are mana enhancing. There was general agreement that there is no one size fits all solution as people have individualised needs and circumstances.

1. Introduction

1.1 Purpose

The purpose of this report is to reflect and summarise the views from the e-survey of family input to options to improve what we know to be the key issues in the Ministry of Health Funded Family Care (FFC) policy and the district health boards (DHB) paid family carer policies. An e-survey was used to get broad input in an efficient way. It considers people's priorities for change, risks and how they think these can be managed; as well as providing an opportunity for people to have their say on anything else that is important to them regarding FFC and payment to family carers.

1.2 Background and context

The Ministry of Health (the Ministry) asked Sapere Research Group (Sapere) to develop and run an independent and anonymous survey on FFC. Funded Family Care is when family members can be paid to provide care for another family member. The Ministry, DHBs, and Accident Compensation Corporation (ACC) each operate their own family care policies. Our survey was concerned with the FFC operated by the Ministry and DHBs. ACC's payment to family carers policy is out of scope for this report.

In the Health and Disability System in New Zealand there are two key policies and methods that govern paying family carers to undertake care for family members in their home. The two key policies are from Disability Support Services (DSS) of the Ministry of Health (the Ministry) Funded Family Care policy and the DHBs Paid Family Care policies for older people, people with long term chronic health conditions and people with mental health and or addictions. In this paper we refer to both policies as FFC for simplicity. There is governing legislation ¹ that guides both policies.

1.3 About this report

This report is a reference paper detailing survey methodology, responses and analysis of each survey question. We also discuss cross-cutting themes emerging as priorities from the survey.

This is a companion paper that informs our primary report *Targeted engagement of Funded Family Care and Paid Family Care*. The primary report explores and discusses options for changes to FFC. Key themes from the survey have been integrated into the primary report. It is advisable the two papers are read in conjunction for the full detail of what people said.

¹ Part 4A of the NZ Public Health and Disability Act 2000.

2. Survey design and methodology

The aim of the survey was to get broad input from and hear the views of family carers and those that support them about the ideas and solutions they see for FFC and payments to family carers.

2.1 Questionnaire design

We developed an anonymous electronic survey made up of a mix questions that allowed either single or multiple option selections (closed questions) and free text (open questions).

Development of the e-survey included:

- discussion and liaison with the Ministry to develop and agree the survey questions
- drafting and testing with those above
- updating and amending the survey
- loading and testing the survey with several parties (internal and external to Sapere)
- finalising and running the survey.

2.2 Participant recruitment and survey deployment

The voluntary survey was primarily targeted at family, whānau or aiga carers that care for a family member with a disabling condition. However, the survey was open to anyone to complete as it was equally important that we heard the views of other people, who support these carers (e.g. another family member, provider of home and community support services) or be the person being cared for.

A link to the e-survey (implemented via Survey Monkey) was emailed to Carers New Zealand, Complex Carers Group, NZ Carers Alliance, Needs Assessment and Service Co-ordination Association and Disabled Persons Organisation Coalition for distribution via their networks. It was also sent to the DSS Consumer Consortium and a closed FFC face book page.

The survey ran from Tuesday 16 October to midnight Sunday 28 October 2018, and a reminder email was sent in the second week.

2.3 Analysis

We produced simple descriptive statistics (percentages) where people answered questions by selecting one (or more) of the options given. We reviewed free-text responses to identify common themes and assigned category 'codes' each time a response related to a theme. Common themes are detailed in this report, with a range of quotes (*italicised*) from respondents included as supporting examples.

3. Survey respondents

We received a total of 911 responses to the survey. This was at least 300 (50%) more than expected based on previous experiences of between 400 and 600 survey responses. We believe this reflects the depth of feeling in the disability community, regarding the need for change in FFC policies.

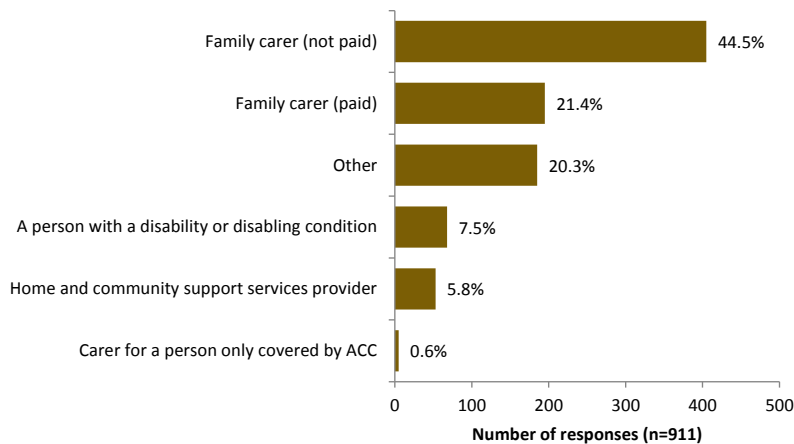
Of 911 respondents, 137 only completed the first, compulsory, question that described them-self.

3.1 Description of survey respondents

All respondents (911) were required to answer this question. Of those, 66 percent (600) were family carers (405 unpaid and 195 paid) (Figure 1).

There were a wide variety of descriptions given by those that selected ‘Other’ (20%, 185) the most common were health or other professional, another family member, a former family carer, an interested party and a parent of a disabled person.

Figure 1 Description of survey respondents

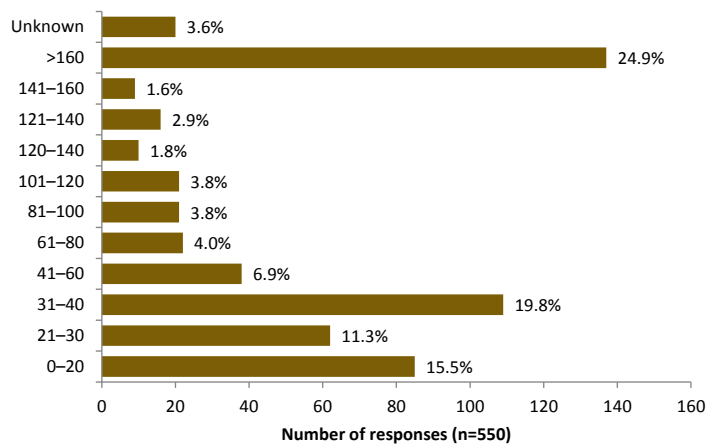


Source: Sapere survey analysis

3.2 Description of family carers

Of the 600 family carers that responded to the survey, 550 answered the question about the typical number of hours of family care they provide a week. More than 40 hours care a week was provided by 54% (294) with 25% (137) providing more than 160 hours of care a week (Figure 2).

Figure 2 Hours of care provided per week by family carers (paid and unpaid)

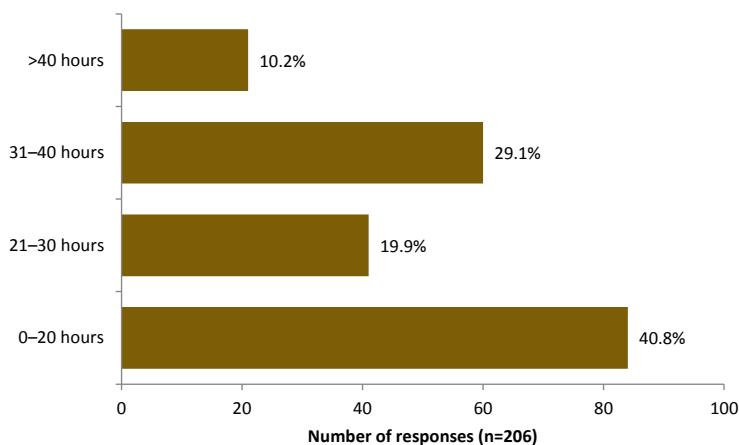


Source: Sapere survey analysis

We asked those who are family carers if they receive a payment from the Government or a home and community support provider for some or all of the care they provided. Of the 540 family carers that responded to the question, 61 percent (328) did not receive a payment.

For those who indicated they did receive a payment (39%, 212), we asked them how many hours a week they are paid for under FFC or from the Government in another way. 206 respondents answered the question with 41 percent (84) being paid for 20 hours or less (Figure 3).

Figure 3 Paid hours per week for family carers that receive a payment



Source: Sapere survey analysis

Of the 212 respondents that said they received a payment from the Government or a home and community support provider, 198 completed both questions about how many hours of care they provide and how many hours caring they are paid for. Table 1 compares how many hours of care a family carer provided with how many hours the family carer is paid for.

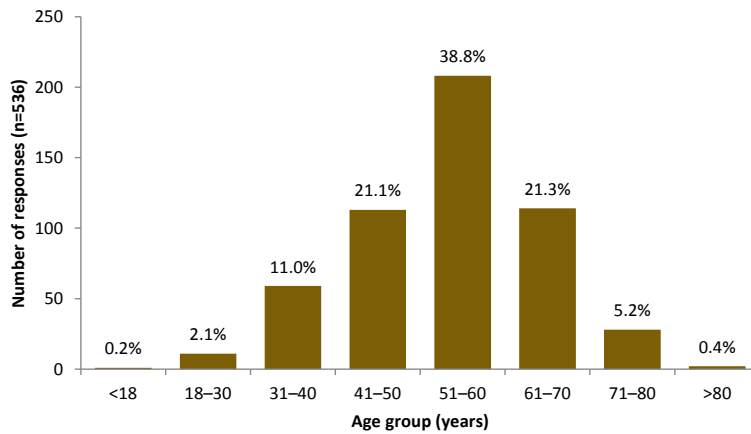
Table 1 Comparison of the number of hours of care provided by family carer with the number of hours family carers are paid

Hours provided	Hours paid						Total
	0–20	21–30	31–40	>40	Respite only	Unknown	
0–20	17	0	0	0	0	0	17
21–30	8	10	1	0	0	1	20
31–40	20	10	10	0	0	0	40
>40	42	20	47	8	1	3	121
Total	87	40	58	8	0	4	198

Source: Sapere survey analysis

Of the 536 respondents that answered this question about their age, the largest proportion (39%, 208) were aged 51–60 years (Figure 4).

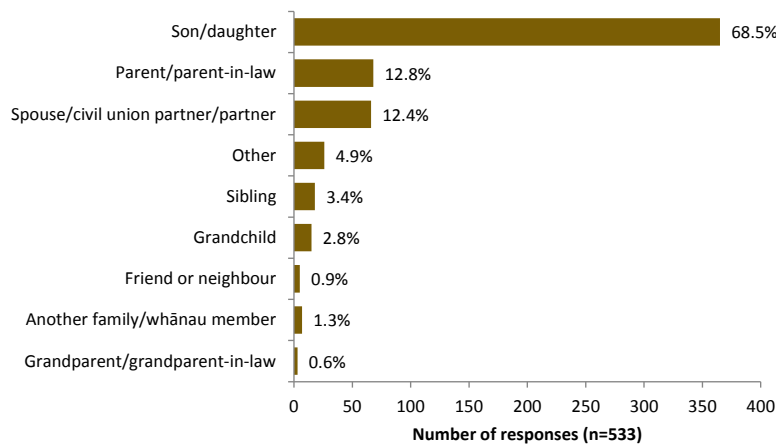
Figure 4 Age of family carers (paid and unpaid)



Source: Sapere survey analysis

Of the 533 respondents that answered this question about their relationship to the disabled person, the majority (68.5%, 365) care for their son or daughter (Figure 5).

Figure 5 Relationship of disabled person to family carer (paid and unpaid)



Source: Sapere survey analysis

There were 530 family carer respondents that completed both questions about their age and their relationship to the person they care for. Table 2 shows the family carers by their age and who they care for.

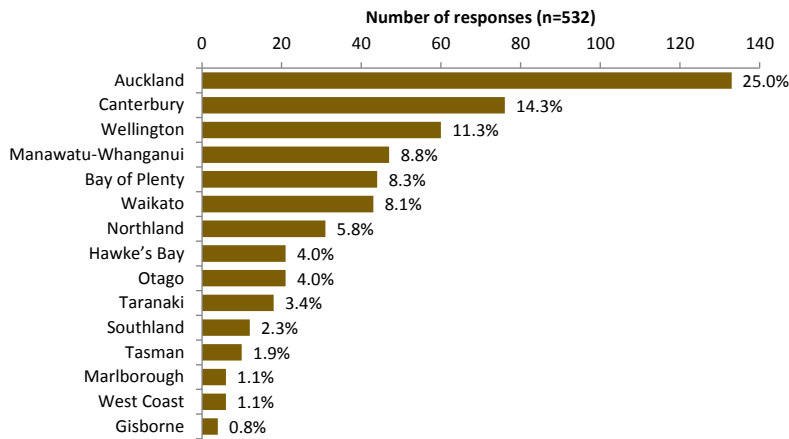
Table 2 Family carers by their age and who they care for

Relationship to person cared for to the family carer	Age of family carer (years)								Total
	<18	18–30	31–40	41–50	51–60	61–70	71–80	>80	
Son/daughter	0	3	44	88	138	63	7	1	344
Parent/parent-in-law	0	2	6	13	35	12	0	0	68
Spouse/civil union partner/partner	0	0	1	6	16	24	16	1	64
Sibling	0	3	2	1	6	3	0	0	15
Other	1	1	3	3	0	6	0	0	14
Grandchild	0	0	0	1	9	2	2	0	14
Friend or neighbour	0	0	1	0	1	1	0	0	3
Another family/whānau member	0	0	1	1	1	2	1	0	6
Grandparent/grandparent-in-law	0	2	0	0	0	0	0	0	2
Total	1	11	58	113	206	113	26	2	530

Source: Sapere survey analysis

We asked what region the family carers live in. Of the 532 respondents to this question, there were respondents from all regions of New Zealand. As expected the largest number were from the Auckland region (25%, 133) (Figure 6).

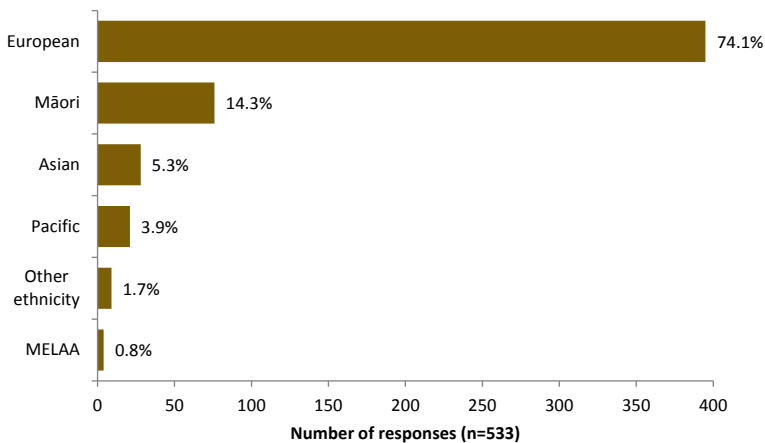
Figure 6 Home region of family carers (paid and unpaid)



Source: Sapere survey analysis

Of the 600 family carer respondents, 533 answered this question about their ethnicity. The majority of respondents were European (74%, 395) (Figure 7).

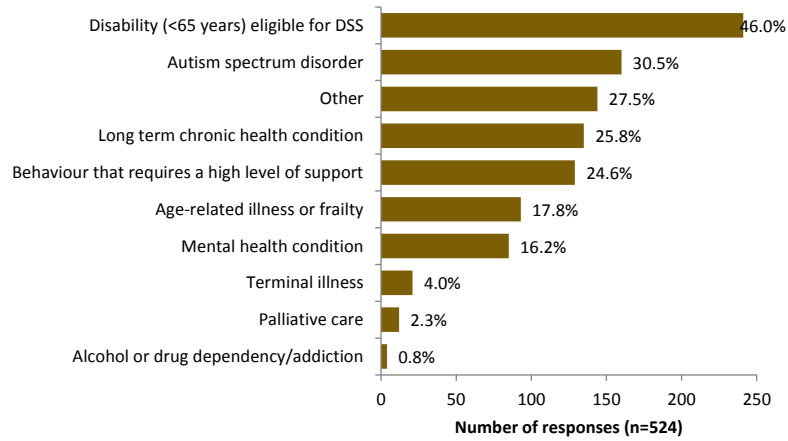
Figure 7 Ethnicity (prioritised) of family carers (paid and unpaid)



Source: Sapere survey analysis

Of the 524 respondents answered this question about the type of impairment or disability, 46 percent (241) selected that the person cared for was someone with a disability that was aged <65 years and eligible for DSS (Figure 8).

Figure 8 Type of impairment or disability for people cared for by a family member (paid and unpaid)



Source: Sapere survey response

1. Responses add to more than 524 as respondents could select multiple disability types.

4. Question responses

4.1 Part 4A of the Act

The Government included Part 4A in the Act in 2013 to enable payment to family carers. Part 4A also sought to prevent any legal claims against the former policy preventing payment and the new policy enabling payment. The current Government has now stated they intend to repeal Part 4A to fix some of the issues that families have experienced with it.

We asked if people agreed with the Government's intention to repeal Part 4A. This question was completed by 581 respondents. Of those, the vast majority (82%, 476) agreed that Part 4A should be repealed.

We then asked if people wanted to see any of Part 4A retained 508 respondents expressed a view, with two-thirds (68%, 346) answering 'no'. Of the 162 who answered 'yes', 50 respondents were unsure about the contents of Part 4A. The most common part people wanted to see retained was the part that enables family carer payments (68 respondents). Ten respondents wished to see all of Part 4A retained.

4.2 Eligibility to receive FFC

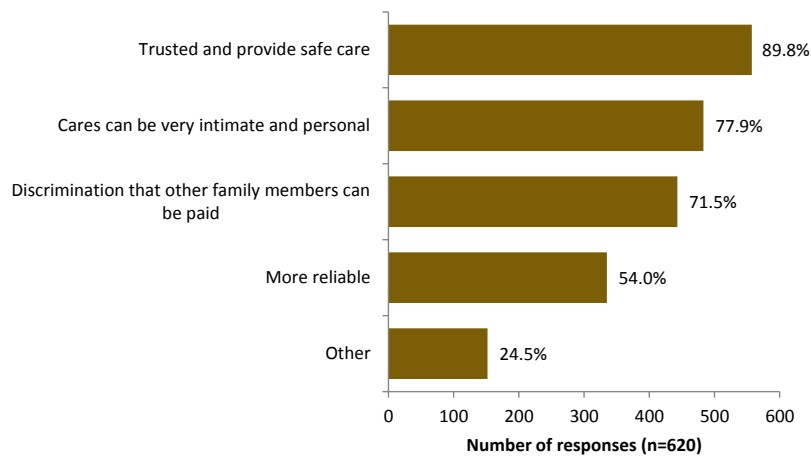
4.2.1 Spouse or partner

The current FFC policies state that spouses, partners and civil union partners cannot be paid under FFC. We asked if people thought a spouse/partner/civil union partner should be able to be paid. 680 people answered this question. An overwhelming majority (92%, 624) answered 'yes'. Of those, 620 went on to say why they thought partners should be able to be paid. Figure 9 shows the range of reasons for paying partners that people agreed with.

Of the 8 percent (56) of respondents that did not think a spouse/partner/civil union partner should be able to be paid their reasons for disagreeing included a spouse receives other support, there is a risk of neglect or abuse, the cost of alternative care would be too high, they would prefer to use funded help, it is the spouse's obligation.

We then went on to ask why those that agreed thought a spouse/partner/civil union partner should be paid. From the options we provided the most commonly selected was because they are trusted and provide safe care (90%, 557/620) (Figure 9).

Figure 9 Reasons spouses/partners/civil union partners should be paid



Source: Sapere survey analysis

1. Responses add to more than 620 as respondents could select more than one reason

Of the 152 respondents that selected ‘Other’, the more common reasons why people thought partners should be paid were because the partner as a carer:

- is unable to work another job

I need to be paid for caring for my husband because I can't go out and get a paid job somewhere because he can't be left alone for very long.

They may give up other work to provide care which is outside what a spouse etc. usually does.

If they have to give up their paying career or reduce hours then they should be financially compensated as someone else would have to be paid to undertake the care anyway.

- knows the person's need the best

They care ABOUT the person not just FOR them.

Spouse is generally in the same place as myself (the disabled) and can attend to immediate needs. If my wife wasn't there I feel it would be ridiculous to pay an outsider who cannot be available all the time to come in and attend to the same needs.

...caring for their loved ones encompasses love and an understanding born of years of being together and knowing each other's little idiosyncrasies.

With communication issues they are often the method of communication to the world.

- because it should be the individual's choice

The person with the disability should have the choice to choose who cares for them. Often a loving family member provides the most cost effective, efficient and consistent care with the best outcome for the person with a disability and supporting those carers keeps the disabled person out of the costly healthcare system.

...it is about situation and choice. If you are a spouse/partner of someone who needs care, if you decide that you are the best person to care for your loved one then you should be able to and not suffer financially as a result.

Have a choice to do so if appropriate culturally and there are safeguards to avoid exploitation of human rights use of monitoring mechanisms based on high trust.

- the cost of alternative care would be far more

Not paying partners leaves them in a position where their options may be limited to placing the person in full time care or living in poverty. Paying partners is surely better and cheaper than the state paying for institutional care.

They deserve to be funded for duties that other public funded organisations would/could otherwise receive.

- they are often already the back stop for when a non-family carer is unavailable

When agency staff fail to turn up for their shift, it is the unpaid spouse/parent who does the cares. The agency has never provided a back up person in my experience.

*Finding suitable and available backup support workers is next-to-impossible. My wife often fills in with my personal cares for days or weeks at a time when my staff are unavailable, or if they have resigned and I haven't yet found a replacement. It's devastating that I can't, in some way, acknowledge this work she does financially. It puts a huge strain on me - and our relationship - that she has to do this work for free, and makes me feel like I owe her in a way I can never make up for. I don't *want* to be paying my wife to look after me, but currently she does it for free, and I feel awful about it, and it's not sustainable for our relationship.*

Providers cannot always provide staff to assist because of location, timing, gaps in what support they can provide so needs are not met.

- there should be equity

Prohibiting payments to some family carers based on marital or family status, who would otherwise be paid for the work that they do, contravenes the Human Rights Act 1993. Discrimination on these grounds forces couples to choose between living in poverty and having people who would not be their first choice provide support and care. It prevents disabled people from exercising their right to choose who provides them with care.

4.2.2 Age of a paid family carer

There has been some discussion about how old a person must be to be a paid family carer. The current policy states the carer must be aged 18 years or over.

653 respondents expressed an opinion as to whether a paid family carer should be aged 18 years or over—three-quarters (75%) agreed.

4.2.3 Age of the disabled person

The current policy states that the person being cared for has to be aged 18 years or over. We asked if people agreed with this and 673 respondents answered this question. The majority disagreed (58%), 32 percent agreed and 10 percent didn't know.

Where respondents disagreed that the person being cared for should be 18 years or over (390 people), we asked what age they think is appropriate. Nearly all answered this follow-on question (373). Most (342 or 92%) thought the age should be younger than 18 years however a small proportion (8%) thought the age should be older.

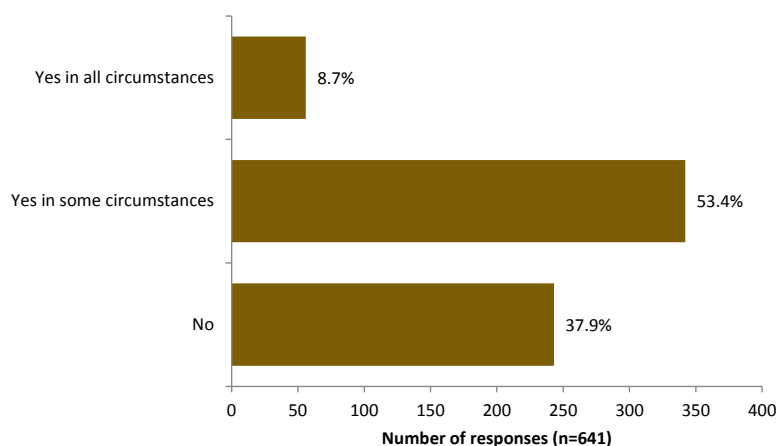
We asked respondents who thought a lower age should apply, if they thought 16 years, or younger, should apply. Almost all (340) answered this question. The vast majority (73%) thought that the age should be younger than 16 years and 27 percent thought that 16 years or older was appropriate.

4.3 Terms of engagement

Employment relationships between the paid family carer and the person being cared for have caused a lot of concerns for many. For Disability Support Services (DSS) the legal employer has to be the disabled person whereas for the DHB Paid Family Care the family member has to be employed by a Home and Community Support Services provider that is contracted to the DHB. Being an employer comes with various legal responsibilities like managing sick leave, annual leave, ACC levies, Kiwi Saver and tax, etc.

We asked if the person being cared for should be the employer of the paid family carer, 641 respondents answered this question. Almost forty percent (243) of people said no. Of the 398 people that responded yes to this question, only 9% (56) thought they should be the employer in all circumstances. The majority (53%, 342) of people responded yes in some circumstances (Figure 10).

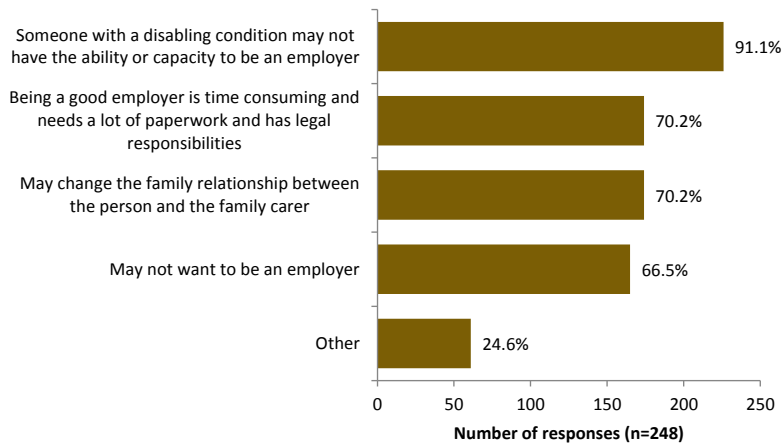
Figure 10 Views on whether the person being cared for should be the employer or not



Source: Sapere survey analysis

If respondents disagreed with the disabled person being the employer, we asked them why. Respondents were able to make multiple selections or provide another reason. Of the 248 people that responded to this question, 91percent (226) thought that someone with a disabling condition may not have the ability or capacity to be an employer (Figure 11).

Figure 11 Reasons given for why the person being cared for should not be the employer of the paid family carer



Source: Sapere survey analysis

1. Responses add to more than 248 as respondents could select more than one reason.

Of the 61 respondents that selected ‘Other’, the more common reasons why people thought the person being cared for should not be the employer were that:

- they may not have the ability or capacity

My brother is my employer - he does not understand anything about money. He knows I look after him and that is that.

In my son’s case it is absolutely ridiculous that he is the employer as he has no capacity to undertake that role, so I do it instead, otherwise no FFC option is available to us. In some situations I can see that it could be open to manipulation by family members who may exert power and influence over someone who may not actually want them as a carer but who lacks the intellectual capacity to manage the situation for themselves.

- it should be an independent agent

There’s a difficult balance to find in these relationships. Some carers sometimes need to be firm with the person which is difficult if you are able to be fired by that person. Some carers could exploit the relationship and not do their job. A third party can monitor all aspects of the relationship fairly.

There needs to be formal oversight from an agency to ensure no abuse. Also it could be isolating for the carer. Being part of a team could help this. Also easier access to training and H&S support etc.

- it is an extra burden for the family and can change relationships

It would be totally ridiculous to put the responsibility of paperwork and responsibility on someone who is already struggling with a disability!!!! Or, in our case, another responsibility for me - the mother.

It changes the power dynamic and has the capacity to create complications in an already fraught situation.

I have found this part to be very stressful having to act on my disability daughter's behalf, etc. ACC, Tax department, and every time I would have to explain what FFC was because they were not informed about it. So they never knew what I was talking about.

- it is unrealistic

Bringing the term 'employer' into this situation is a nonsensical farce. Just because a disabled person/their agent wants to have a choice in selecting their own support workers and make their own rosters, does not equate to them wanting to be 'an employer'. Forcing disabled folk to become pretend 'employers' just because they want some autonomy from providers and the choice to select their own support worker and rosters, is illogical and abusive. The current system is flawed - it steals the free time of the 'agent', adding more pressure and stress to an already difficult situation.

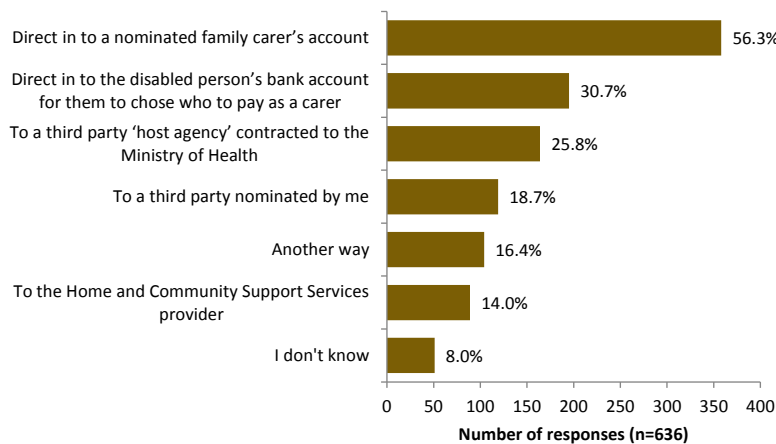
It simply defies reason and logic.

4.4 Pay

There are a variety of ways payment could work. We asked about the mechanisms people have talked to us about previously. Being a contractor means the carer receiving the payment is responsible for all tax, sick leave, etc., themselves as individuals. Some people have told us they may or may not engage an accountant or someone else to help them with that.

We asked how people would like to receive their FFC payments. 636 people responded to this question and were able to make multiple selections or provide another suggestion. The most common way people selected to be paid was direct into a nominated family carer's account (56%, 358), followed by direct into the disabled person's bank account (31%, 195) (Figure 12).

Figure 12 Ways people would like to receive FFC funds



Source: Sapere survey analysis

1. Responses add to more than 636 as respondents could select more than one option.

Of the 104 respondents that answered 'another way' to this question the most common responses were:

- to be able to choose from any of the options mentioned as it is situation dependent

All of these options should be made available in order to provide as much flexibility as possible. Any system should be monitored and audited from time to time by a third party, i.e. someone other than the disabled person, their carer, host agency, etc.

Carers are all individuals with one size not fitting all. Therefore this needs to be flexible with multiple ways of families selecting what works best for them, also depending on the age of the person with a disability etc.

- via third party

The current system where the funds go to the disabled person and a service agency takes care of pay and tax is ok, BUT this agency should automatically take care of ALL payments, (ACC, public holiday adjustments, and sick leave adjustments when notified,) without the carer having to call in and ask, (except for sick leave and annual leave of course). Rates should also be indexed to the cost of living or tied to all other carer groups' rate changes.

I support third party host agencies, however the option for the family or client to source a preferred third party agency could be an option as opposed to a MOH contracted agency.

The problem with the current way is that all the administration is worn by the carer who may or may not understand employment law. Having an agency deal with all of that is helpful especially for covering sick leave and holidays, ACC payments, etc.

- direct to carer with tax already deducted

It should come directly from the MOH to the carers account. We have absolutely no trust in third party arrangement. Everyone wants to clip the ticket.

Not the disabled person in my opinion. It is great to give people that kind of respect and options, but ridiculous to assume many disabled can work through all the issues. As a family carer, I would like to be employed by another person, and have the wages appear in my account regularly. So the employer takes care of tax, super, holiday pay etc.

It should be taxed at source, the same as every other benefit, then paid to the carer for the amount of funding they are entitled to.

- as or similar to a benefit/allowance

Schedular payments would be one option, where the carer can determine the deduction rate. This mechanism has the advantage of having being used by ACC for many years. The option to be supported by a Host etc. would resolve any issues regarding the submission of yearly Tax Returns. I can't see why a person/family shouldn't be able to choose the mechanism of payment as currently happens under Individualized Funding arrangements. Alternatively, they could opt for the kind of arrangement currently

It could be just another benefit and paid through the benefit system directly to the carer. Or it could be a system like the System Transformation allows - a variety of possibilities.

Currently there are two systems for payment, those paid under the:

- Disability Support Services (DSS) system where there is a minimum adult wage hourly rate with no ability for this to change over time
- DHB system where there is an hourly rate for home and community support services provider, as the employer will pay, based on their systems. The hourly rate may vary based on experience and skills, etc.

We asked if respondents think paid family carers should be paid a range of hourly rates based on factors like experience, length of time caring and relevant qualifications. 613 respondents answered this question, the responses were fairly evenly split with 52 percent (319) responding 'yes' and 48 percent (294) responding 'no'.

Respondents that answered 'yes' (319) were asked to specify why they thought paid family carer hourly rates should vary. The most commonly suggested reasons were:

- to recognise experience and skills

Because I am a long term carer I have had a lot of experience probably more experience than other carers we have had.

It should not just be the minimum adult wage hourly rate if you are caring for a family member. As a family member you have better skills and knowledge than someone who may be qualified. There is nothing more valuable than experience with the family member's exact requirements. It takes a long time to train even a qualified carer. Currently many hours are spent not only caring for the family member but also training carers. With someone with very high needs there are multiple carers and with staff turnover there is always training. It would be less strain for the family member often if they could be paid for the caring instead of trying to juggle work and looking

after staff and training whilst still having to provide care and be there to overlook the care and well-being of the person being cared for.

- equity (with other carers and other occupations)

I believe all family carers need to be paid the rate that other carers receive. A family carer may not have a piece of paper that says they have trained as a professional carer but in fact they may have more caring experience than the so call[ed] professional carer. A piece of paper does not mean you are better than another. In my case I have had 40 years' experience looking after my daughter and have learnt many caring skills. And at the end of a day I can't get up and leave to go home. As so called professional carers can. I'm on duty twenty four seven.

Because it's discrimination not to pay what an HCA or equivalent carer would be getting paid to provide the same care, if the family wasn't providing the care then the patient would either need to be in a hospital rest home or care facility where the workers are being paid well above minimum wage and not providing the extent of care a family carer provides.

- level of care required

The variety and complexity of the care provided to family members demands variability in payment.

Every disabled person has a unique set of care and support requirements. Some disabled persons will require a higher level of expertise, i.e., performing specialised medical procedures, which should be paid at a higher hourly rate than the minimum adult wage. Experience dealing with the disabled persons specific needs and length of time caring should be taken into account as well.

Definitely, some people will require a higher degree of care than others. In these cases, the Carer has considerably less time for themselves, restricting their ability to either take time to relax, and/or seek employment. Earning capacity is affected.

- they are unable to work another job

Because they sacrifice work opportunities to be caring for family with disability instead of govt helping them with expenses. It becomes another burden not able to work due to the needs.

- hours of caring

As looking after a child or adult with a disability is a full time career and has no days off 365 days a year 24 hours a day and it is the hardest job out looking after a disabled child or young adult.

Pay according to time caring. I don't know any family carers who have relevant qualifications. I certainly have never had the time or funds to do relevant qualifications!!! Beside I still have to train and educate ALL carers that have been employed to care for my son....not one of those with qualifications has known what to do!!! Yet they all get paid way more than minimum wage.

- to recognise qualifications

Qualifications should be reflected in pay scale.

Some careers have qualifications that if they were caring for a private client they would receive a higher wage. It shouldn't be less just because it's a family member.

4.5 Assessment and allocation of hours

To receive FFC there is an assessment process for eligibility and to determine the number of hours a week a family carer can be paid. The process looks at: tasks a carer might need to undertake, the needs of the person being cared for, and a range of other factors.

There has been a lot of criticism that the assessment process is not realistic in how they assess and/or allocate time to a task (e.g. how long it takes to toilet a person, feed a person their meals, watch over them if they have medical conditions that need supervision, etc.).

4.5.1 Allocation of hours

We asked if people agreed with the number of hours allocated to them to care for their family member. Of the 298 people who answered that they had experienced an assessment, 75 percent (224) did not agree with the number of hours allocated. We asked these people to say why and make suggestions for improving the process.

Often disagreement with allocated hours

Many people expressed dissatisfaction with the assessment process and felt that it underestimates the time required to provide good care.

The process is deeply flawed and unrealistic. The philosophy of only looking at unmet need should be dumped. Actual disability support need should be genuinely assessed and funded.

The assessment process is too rigid, demeaning and fails to fully recognise individual needs and extra work FFC has created dealing with IRD, ACC etc.

The dominant theme was that the allocation of up to 40 hours of paid care does not reflect the reality of, what is sometimes 24/7, supervision and care.

My life is totally focussed on caring for my daughter. I struggle with the concept of assessment of hours.

Any time over 40 hours becomes unpaid, which is discriminatory.

There was much disagreement with the restriction of paid hours to personal care and household management, when a large part of caring comprises other activity such as transport, safety, supervision, paperwork and advocacy. A number of people felt that the allocation of paid hours is not aligned to the principles of Enabling Good Lives. That is, that family carers cannot be paid for other activity that helps a disabled person connect with and participate in their community; and the receipt of FFC limits their ability to have this support funded via other providers.

There also must be provision for hours for community participation, getting FFC hours should not stop [the] client from getting hours through [a] provider for community participation, inclusiveness and towards leading an ordinary life.

Needs assessment is based on minimal care required to keep a person safe and well at home, but offers no real flexibility to accommodate what is required for an individual and their family to 'have a normal life', and this goes beyond the front door...

The requirement for constant supervision of some disabled people has a significant impact on family carers and there is no provision for this in the FFC policy.

The process is not actually aligned with reality. Over and above his needs, I have to supervise my son all the time and there is no provision for this in the assessment.

Further, the intermittent nature of providing personal care means that family carers may be unable to find other employment. And if they did, it could reduce the hours of FFC they receive.

It does not take into account the fact that I cannot find alternative employment due to the broken up nature of caring across 24 hours.

People felt the standard 'timed task' approach is inappropriate—the assumption that tasks take the same time for everyone whereas it can vary greatly dependent on the complexity and situation of the individual, or at any given point in time.

The assessment seemed to be a matrix with predetermined values for tasks and was not flexible for the needs of the person cared for.

As a NASC worker noted themselves, "it is very hard to determine this when we are not there every day completing these tasks, it is impersonal and could depend on a number of factors". A number of people commented that allocations did not allow for paid hours to 'flex up' when required.

...personal care can take longer than assessed due to poor health, product faults, equipment faults acute health changes.

Finally, a number of process issues were highlighted, including:

- the inability to gain a true understanding of people's reality in a one-off, two hour assessment
- inconsistent allocations between NASCs
- a perceived inability to dispute or have allocations modified
- final allocated hours being reduced from what the assessor recommended.

Suggestions for an improved process

It was difficult to identify 'repeating themes' relating to solutions but a few suggestions were put forward by individuals:

- a broader definition of paid 'care', that is not limited to personal care and household management. If other activity types are not included in FFC, then some people felt they should be able to have it funded from other providers without affecting their FFC entitlement.
- in situations where carers live with a family member with high and complex needs, 40 hours should be provided as standard.

- If a disabled person would otherwise be in residential care, then the MSD process could be used and the family carer paid 40 hours.

4.5.2 Maximum hours

Currently the maximum number of hours a week a paid family carer can be paid is 40 hours. We asked whether people agree with this cap. 589 people answered this question, 68 percent (404) disagreed that 40 hours should be the maximum number of paid hours a week.

We asked these people to tell us what they think the limit should be and why.

Alternatives to the 40 hour per week limit

Unsurprisingly, it was difficult for people to give an alternative number of hours for a maximum funded allocation. The most frequent responses were those suggesting allocations should be entirely based on individual need and either stating or implying there should be no limit to funded hours. One person noted the requirement for robust assessment tools under such a system.

Balancing this view were a (smaller) number of people who acknowledged that it is unrealistic to fund unlimited care.

I understand why it can't have no limit even if the carer is working 24/7.

Other people considered 40 hours to be a benchmark, but that it should be flexible in situations where needs are higher for a period of time; or that there is a robust, fair and transparent exception process for people with high and complex needs.

I think the person's assessed need should be true reflection of their requirements and if exceeds 40 hours consideration should be given as to how this need is met and if additional staffing is required. I think it is unreasonable to expect an individual to provide up to 168 hours care for 40 hours payment - how would they ever get a break.

Needs change, so hours should be flexible for times when more care is required.

A number of people felt that 40 hours would be acceptable only if other funded carers (including other family members) were available to cover care required over and above that.

I would agree to 40 hours per week if allocations of funding are provided so that carers can be employed to cover the remaining 128 hours in a week. Otherwise if the family member is expected to provide the remaining 128 hours per week of extremely high and complex care then absolutely 40 hours per week does not reflect the care and services the family will be exploited and pushed into forced labour.

A small number of people suggested for full-time family carers, ensuring a living wage is more important than the actual number of funded hours.

Yes, I'm not 'hands-on' for 24 hours a day but I also can't go elsewhere to earn money. I don't want to be paid a full hourly rate for being here but the total for the week needs to be a living wage amount, however that is calculated.

Around ten percent of people who disagreed with the 40 hour maximum suggested an alternative number. Half of these suggested 56–60 hours as a possible number,

acknowledging seven day a week care (at around 8 hours a day). Around a third of them suggested 80 hours or more would be more appropriate.

If the carer has some respite then 40 hours is fair. However, if the carer cares 7 days per week with no respite it should be increased to at least 56 hours. The whānau could choose. Full time carer or carer + respite options.

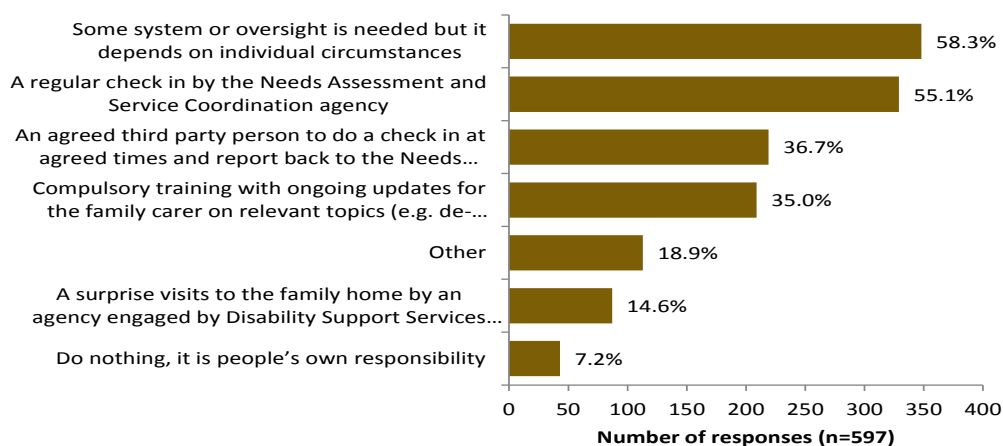
100 hours, as this is the reality especially in cases of severely intellectually handicapped persons with behavioural difficulties. And where physical conditions also have to be monitored to keep them safe, the work is in reality 24/7.

4.6 Ensuring safety

There has been some discussion about how to ensure people are safe, over time, in a family care situation. Safety applies to both the person being cared for and the family carer too (e.g. mental wellness, fatigue, and other health conditions). Some people being cared for may not be able to speak for themselves, or the family carer may not have enough supports (e.g. other people or support or health services around them).

We asked people how they think safety should be considered or checked in the home when a family carer is receiving a FFC payment. 597 people answered this question and were able to make multiple selections.

Figure 13 Ways safety should be considered or checked in the home when a family carer is receiving a FFC payment



Source: Sapere survey analysis

1. Responses add to more than 597 as respondents could select more than one option

A majority of people agreed that some system or oversight is needed but that it depends on individual circumstances (58%, 348), and that there should be a regular check in by the NASC (55%, 329). Others thought that an agreed third party should do a check in at agreed times, reporting back to the NASC (37%, 219). Just over one-third of people thought that training should be compulsory with on-going updates for family carers on relevant topics (e.g. de-escalating behaviours, safe lifting, etc.).

I had no idea on how to lift my dad from the wheelchair to the bed, how to assist moving him in the bed, toileting procedures, bathing procedures etc...I did not want to injure myself or stress myself over things that seemed simple to hospital staff...So ensuring good quality training is provided to the carers and respite support for the carers.

Many other people thought that training was helpful but that it should not be compulsory as it may not always be relevant or appropriate. Some suggested training and support could be provided in a variety of ways, such as online or video resources.

Non-compulsory training with on-going updates for the family Carer. Internet chat site, for Carers providing practical tips, and emotional support. This could either be with other Carers, a professional capacity, or both.

People highlighted the need to support and look after the wellbeing of families and carers, ranging from informal or peer support groups to therapy and counselling if required; and ensuring access to other services such as social work, navigation and occupational therapy. Respite and access to other funded care was highlighted as an important safety requirement.

Some people talked about the need to have monitoring in place to keep people safe from neglect and/or abuse.

Need to keep the person being cared for safe. At risk of abuse. Similar to what happens in Elder Abuse-family members can be perpetrators.

The system needs some authority with Discretion to prevent Fraud and abuse of people being cared for.

A number of people wanted to ensure consistency with other policies regarding oversight and safety.

Similar alert checks to those in small group homes or IF funded employees. Treat family carers like all other carers. Stop discriminating.

Same as applies (I hope) for ACC carers.

4.7 Other aspects

4.7.1 Specific considerations for families including culture

The system for FFC should work for all people from all ethnicities and cultures. We asked if there are any specific aspects that should be considered for FFC for their culture, family, whānau or aiga. 556 people answered this question, of these, 69 percent (385) of respondents said they did not have any other aspects to be considered.

31 percent (171) of people identified specific cultural, family/whānau/aiga aspects that should be considered. A greater proportion of Māori (35%), Pacific (36%), and Asian (44%) identified specific considerations, compared to European (23%). More than one-quarter of people answering this question did not give their ethnicity and the number of Asian and Pacific is small.

Culture and spirituality or religion was the most common consideration identified. This was true for all ethnic groups however it was raised more often amongst Māori and Asian people compared to European. People talked about both practical aspects of administering a system, such as documents in other languages and access to interpreters, but also a general theme of appreciating diversity and ensuring services are mana enhancing. Some useful examples were given relating to family caring arrangements.

Pasifika people and families sacred relational orientation needs to be considered. For example, in the Tongan and Samoan cultures and most Pacific ethnic cultures, sisters and brothers cannot wash or toilet each-other therefore the responsibility may need to be assigned to others that are considered appropriate by the family. Similarly, it is not appropriate that sons are given these responsibilities in the care for their mothers.

A number of people mentioned privacy in general, having different carers for different tasks. For example, a disabled person might want a family carer for some things but prefer non-family for some personal cares.

A general principle of respect for family carers, acknowledging and valuing the work they do was reiterated by a number of people. Hand-in-hand with this is respect for family decisions and different ways of doing things that work for individual families, with individual needs.

Respect us as family carers, believe it or not most of us know what we are doing.

Many people talked about differing family constructs and how the system does not work for them. Some people have good extended family networks and would like flexibility to pay multiple family carers.

We have very good extended family networks so carers need to be interchangeable and any payment made accordingly.

Not restricting policy to a single carer, but supporting any 'it takes a village' like approaches to family and kinship.

Other families have very little natural support and need a different combination of funded supports.

We are Asian and [have] no other family around and we need more help...We tend to do [it] all by ourselves.

I care for a disabled son with very little extended family support. Currently, it is difficult for me to take breaks and have respite due to the limited funding and limited access to support workers. When I was allocated FFC funding my son's IF was cut out and instead he received reduced hours of respite.

Some people talked about the complexity of systems and barriers to accessing information and support.

Funding services in the disability sector should be user-friendly and easily accessible. The current supports from the Ministry are surprisingly complex, often times contradictory and always difficult to access.

4.7.2 Final words

At the end of the survey, we gave people an opportunity to tell us anything else they thought we should know, or anything else they wanted to say about FFC or paid family care for the future (e.g. other changes that need to be made to make it simple and better for FFC and paying family carers). 328 respondents completed this question. Many of these comments reiterated the themes identified under previous questions; in particular, reference to inappropriate employment arrangements, a mismatch between the hours paid and hours spent caring, extension of eligibility to partners and multiple carers, and fair recompense for supervision.

In general, people wanted FFC to be easier, fairer and more flexible.

People encouraged more proactive communication about what is available and how to get it, including help with equipment and transport. Some people noted that it can often be difficult to find carers to provide back-up or additional support. A number of people highlighted the need for better respite options and other support for carers. People also mentioned their concerns about who will do the caring if they are not able to, particularly as they themselves (the carer) get older.

A number of people pointed out that the system relies on family carers, but that often puts families under financial strain. Family carers give love and attention to their family members that is not the reality of residential or other care, but they are not treated equitably with respect to pay and conditions. People felt the system should be based on principles of respect, valued family contributions, dignity and listening. Some people considered that this would require culture change within the Ministry and NASCs.

People talked about the need to empower families to make choices that work best for their loved ones and family circumstances. A number of people acknowledged that checks and balances are required in the system to ensure disabled people are kept safe, and that reassessment is important as needs change at different times. One size does not fit all.

A number of people suggested there should be the ability to access and/or combine multiple funding streams, for example combining FFC and individualised funding. Some people suggested that there should be one agency or at least a reduction in the number of agencies involved in paid care. Others felt there should be more sharing of information between government departments.

Some people provided their views on what FFC could look like.

I believe it should be streamlined...new division of MSD distributing and taxing and home matching and when other carers needed they have access to people wanting jobs. MOH assess hours and give money to WINZ to deal with. MOH to run the checks on carer and patients and to arrange relevant training and inform. MSD to match clients to relevant HNZ housing....hoist ramps wet showers etc. WINZ can make sure people on [supported living payment] who should qualify apply to be assessed and those with enough hours approved will be off the benefit. WINZ and MSD to encourage kiwisaver as we are poor and need it and that will save future taxpayer dollars. MSD and MOH can share medical notes info and this saves a lot of dollars spent getting doctors to fill in and write duplicate things at top dollar to the taxpayer who subsidise our visits or at hospital paying for a specialist time to fill in another form. ACC could share the medical info as well.

Make simple; easy payment systems; not too [much] paper work with the I.R.D and A.C.C. If the disabled person was not the employer I would not need to pay I.R.D or A.C.C. More option with the funding, e.g. Transport (petrol) from A - B. and B - A. If it is a business I should also be able to claim expenses, phone, internet, petrol for activities during the day etc. At the moment it is only to pay wages. Restriction on going overseas at present is only 28 days max. (for the disabled person) Because if I am overseas with the person. The person still need cares regardless where they are.

I SUGGEST THIS...For example, my son would go through the NASC process and receive his package of care, as happens now. Our family makes a decision re his funded family carer(s) and they are nominated to, for e.g., MSD or MOH. His funds are held by either MSD or MOH and I, as his welfare guardian, have access to them to fund his carers. I electronically access the funds using a login/password arrangement and use a designated unique code for each family carer (to identify them) and enter the number of hours they are getting paid for that fortnight. When I enter the designated code and hours, the funds are automatically transferred to the family carers designated bank account with the family carer receiving the net amount. At the same time tax is paid automatically, so the gross amount is deducted from the funds held by MSD or MOH, a running total, year-to-date and weekly spend etc. details are available through the MSD or MOH portal. THIS SYTEM REQUIRES NO BANKS, NO BANK FEES, NO 'MIDDLE-MANAGERS/EXTERNAL AGENCIES TO MANAGE FUNDS, NO DRAMA TO SET UP FOR THE PERSON WITH A DISABILITY... I can't overspend as the total amount available to me within the package doesn't increase. This is a much more efficient system that the current one I believe.

An allowance paid by the Ministry, with tax deducted as appropriate, or an ACC-type option should be among the options. If there is a demand from some disabled people to be the employer, that option should be included, but in a simplified form. Discrimination between family and non-family carers needs to be removed in the following areas: rate of pay; family relationship; level of need required to be funded; number of hours for which care is needed.

Keep it simple. Use Needs Assessors because that is what they are there for. Have one independent arbitrator whose decision is final. This allows for the myriad of varieties of needs. The law cannot bundle all disabled into one pigeon-hole and expect to be all things to all men. Give carers some respect and credit. Not everyone is a greedy cheat.