
Discussion Paper for Carers New Zealand and the NZ Carers Alliance

Paid Family Care Discussion: Funded Family Care and other schemes in New Zealand

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We thank everyone who contributed, whether it is was with talking with us, completing a survey and / or providing written information and copies of letters. We value your experience and time in responding. We also acknowledge there are varying, and at times competing, views on paying family carers and various components of policy, especially concerning the Ministry of Health's Funded Family Care policy. We have endeavoured to reflect the range of views we heard in this paper.

Carers New Zealand and the NZ Carers Alliance

Carers New Zealand is the peak body for family carers in New Zealand, assisting a large network of family, whānau and aiga carers who support someone who has health, disability, mental health, injury, and /or age-related care needs. It acts as the Secretariat for the NZ Carers Alliance.

The NZ Carers Alliance is an alliance of 45 national not for profit organisations which, with Carers NZ, commissioned this paper to inform decision-making about the issue of payment for family caregivers.

Executive summary

Background and purpose

Carers New Zealand and the NZ Carers Alliance commissioned this discussion paper relating to payment of family carers for the support they provide, including Funded Family Care (FFC) and other payments and policies, to a family member requiring assistance due to an injury, disability, chronic condition or illness, or in old age. This issue is relevant across government sectors and agencies, as well as ACC.

The scope was to canvass views on payment to family carers for home and community support type activities such as domestic assistance and personal cares, across all populations of family carers. Policies for paying family carers are held by Disability Support Services (DSS) in the Ministry of Health (the Ministry), the Accident Compensation Corporation (ACC) and District Health Boards (DHBs). DHB policies relate to the health of older people, those with long-term chronic conditions, complex paediatric / youth, and people with mental health and addiction needs. For ACC payment of family carers is mainly relevant for those who are covered by the Serious Injury part of the scheme.

While our scope covers payment of all family carers, it became clear it was necessary to consider linked and interdependent parts of the wider Health and Disability system and ACC to understand current paid family care systems.

Context

In 2010 a claim taken by families (known as the Atkinson Case) cited discrimination based on family status as the Ministry at that time would not pay family members for undertaking family care. The High Court and then the Court of Appeal (2012) both ruled in favour of the families and since then the Courts have decided more cases in favour of family carer plaintiffs. In 2013 Part 4A of the New Zealand Public Health and Disability Act 2000 was enacted under urgency. It outlaws any further Court cases on the topic.

ACC has and continues to pay some family members for home-based care, which it terms as attendant care. All cases of action to date that we are aware of have been against the Ministry of Health and ACC. 13 more plaintiffs have cases lodged with the Human Rights Commission to be heard in the future.

Historically New Zealand has relied on family to be the first line of support for people who need it. However, many of those who contributed to this paper highlighted a changing society with more economic pressures, especially if people have had to give up employment to care. There are increasing demands due to people with support needs living longer at home, so that more, and longer, periods of family care may be needed over time. Many mentioned the double disadvantage of losing a wage, and then not being able to receive other benefits such as KiwiSaver and / or not being able to plan for retirement.

'When a family life plan is disrupted like this, when caring long term for a loved one, it has significant long term impacts.'

This paper provides a summary of contemporary views on the issues of family care and how a fairer approach to payment for those in intensive caring situations could be achieved.

Views were sought in various ways

We canvassed views from a wide range of key stakeholders who are familiar with the legislation, policies and implementation of these policies. Most importantly, we sought the views of a sample of families who have ‘lived experience’ of the policies. Other stakeholders were involved such as lawyers, government officials, needs assessment and service coordination services, the Human Rights Commission, ACC and DHBs, as well as NGOs supporting people with care needs as a consequence of long term conditions, such as stroke and Alzheimer’s disease. Carers New Zealand was also interviewed as part of the process and the NZ Carers Alliance made comment as well. Interviewees were selected for their experience and knowledge rather than being a representative group.

The numbers of informants grew as the depth of concern and distrust of paid family care schemes became evident. The distrust was particularly focused on the Ministry and ACC policies and their administration. Informants were quiet on DHB family care payment policies with the exception that some thought spouses and partners should be able to be paid.

In total 36 people were interviewed and 406 replied to an online survey. The survey themes are included in the body of the report along with those from the interviews. A rapid literature scan was undertaken and key government papers and strategies as well as relevant Court judgements were considered.

Policies seen as unfair and unlawful

By far the majority of informants who had input into this paper believe government approaches to payment of family carers and current payment systems are unfair, discriminatory and need immediate remediation. Informants were vehement and frequently used terms such as ‘disgusting’, ‘discrimination’, ‘nonsense’ and, ‘appalling’. The fact that the Ministry policy is setting precedents for DHB family care payment policies, and some people believe potentially for ACC too, creates even more urgency for change.

A key theme reflected in a comment from carers was:

‘Carers are impatient after years of battling. They and their families require fairness and leadership across government. We urgently need to see progress with paid family care.’

The Ministry of Health’s FFC policy attracted most comment

The Ministry’s policy attracted most comment. As this policy appears to act as a precedent, DHBs’ policies are based on the Ministry of Health’s, and we can assume similar concerns arise (other than that, DHB policies allow families to negotiate an hourly rate which may be higher than the minimum wage). We also heard that the uptake of payment for families in DHBs is very low. Informants were not clear on reasons why.

A key concern by many is the low uptake of the Ministry’s FFC. We heard that only 354 families of the 1,600 expected are accessing the payment five years after inception. This significant underspend makes families and others spoken to very angry and sceptical about government’s commitment to paying families for care. There were various comments that people are not given information about the option of FFC and so real choice and equity issues arise.

ACC policy is broader and can pay spouses, de-facto and civil union partners, any age and covers a range of other factors. ACC has always had some form of payment for family carers, however concerns were reported around a change to how many hours ACC is willing to pay family carers and a stronger move to a task based assessment system. ACC confirmed it is not doing any active policy work in this area and that there have been no changes to how they approach paying families. Some strongly believe ACC is ‘retrenching’ how much they pay family carers and, similar to Health, there is variation in how assessments are done by ACC contracted assessors. We believe more work is required to understand any recent trends and resulting changes with ACC processes.

Questions of legality

Part 4A of the Act and policies were quoted as being unlawful. People strongly felt that the United Nations Convention on the Rights of Persons with Disabilities and the Human Rights legislation were being disregarded by government agency policies, and that the legislation governing ACC was also being contravened. For Health and Disability this been borne out by the Court decisions which have ruled in favour of the families. It is understood that eight more families (a total of 13 litigants) are currently proceeding to take the Ministry to the Human Rights Review Tribunal.

A change to Part 4A of the NZ Public Health and Disability Act 2000 (the Act) was passed under urgency and didn’t follow standard Cabinet and consultation processes. This amendment is believed by those spoken with to be discriminatory. The key point around the amendment is that it prevents families being able to take previous or new cases to the New Zealand Courts. Instead they are able to be heard by the Human Rights Review Tribunal.

Discrimination alleged

Key points of discrimination within Health and Disability policies were reported as:

- pay rates being inequitable, i.e. the Ministry pays family members a minimum hourly rate only whereas other services such as home care agencies and ACC operate pay parity and offer higher rates
- the number of hours family members can be paid per week is unfair, i.e. capped at 40 hours irrelevant of how many hours are needed to support the person
- inequities due to payment only being offered if the disabled person is age 18 or over; and
- discrimination on family status in that a spouse, de-facto partner or civil union partner cannot be paid like other family members. Note: ACC can pay any family member and does not exclude spouses, and age 18 for the person being supported or the paid family carer is not a limit.

Assessment systems seen to be inconsistent, inaccurate and unfair

Assessment systems and resulting allocation of the number of hours to be paid are seen to be unfair and linked to minutes per task rather than being based on a person’s needs or a carer’s work or responsibilities. This is seen to be inconsistent and discriminatory, as paid formal carers may get more time allowed in some circumstances. It is also seen as not supporting the person and family in a holistic manner.

The fact assessment processes are task based relating to transactional based ‘minutes per task’ was seen as demeaning and ‘nonsense’. There was a lot of comment on assessment processes being inconsistent and therefore inequitable. Some processes e.g. the Ministry (via NASC) do not consider tasks that are not ‘hands on’, i.e. activity such as ‘supervision’ of a person, time for coordination of care and administration of the family scheme and legal and accounting support if required. This exacerbates perceptions of unfairness and disregard of family carer roles.

The Ministry FFC system is complex and hard to understand

The Ministry FFC system is complicated and people find it very hard to understand, navigate and work with. The most common complaint is not being able to understand what was allowed, who was eligible, and we were told many people were not given the option of a family member being paid. Two other key issues raised here were:

- the onerous and expensive liabilities of being an employer e.g. IRD, ACC levies, understanding employment law, financial and legal advice; and
- some families having multiple funding streams to juggle with varying ‘rules’ and payment methods, for example all from DSS, such as Carer Support, home and community support, FFC, Individualised Funding etc.

Concern at the Ministry requiring the disabled person to be the employer

The Ministry policy requires the disabled person to be the employer of the family carer. However, eligibility criteria for disabled people needing high levels of care and support detailed in the Ministry’s policy, can’t communicate by traditional methods, and we were told many don’t read or write. By default, the carer ends up undertaking the employer tasks for themselves. Many saw the need for the disabled person to be the employer as ‘nonsense’. The Inland Revenue Department was also reported as challenging some families on why their offspring was their employer.

DHB policies reviewed require the family member to be employed by a formal home and community support agency. This takes away the need for the family member to be the employer and gives family carers the right to negotiate their wage rate with their employer based on skills and supports provided, i.e. it does not default to the minimum wage.

ACC leaves it to the person and their family member to decide about employment arrangements. For example, if the monies are paid into the person’s bank account, tax is deducted at source by ACC. If the monies go direct to the family carer’s account, the carer is deemed to be an independent contractor and arrangements are sorted between the family members.

Summary is that urgent change is needed

In summary, by far the majority of informants called for an immediate review of the family carer payment schemes and policies to make them fairer, and to align better with the United Nations Convention and with relevant legislation and national strategies (named by many informants as the NZ Carers’ Strategy and the NZ Disability Strategy). It is noted the Minister of Health has asked the Ministry to consider how the FFC policy might be changed.

Informant opinion is to not wait for the rollout of DSS Transformation work but to address the issues with urgency and across the system – including DHBs, ACC and Ministry policies. With any changes it will be important to acknowledge and consider how to support the wide diversity of family and disabled peoples’ needs and circumstances. Choice and flexibility, along with fairness and non-discrimination, are called for. Most people felt it is important for any consideration of change to any paid family care policy to have an overall government approach, not separated by one or more funder ‘silos’.

Key points of change called for are:

- legislation, strategies and policies need to be non-discriminatory, line up and connect to make one fair system
- open and transparent non transactional assessment processes and appeal processes so families can understand what is being allocated and why, discuss any fairness concerns and have the ability to appeal outcomes if required
‘Families shouldn’t have to use Courts and Tribunals to get a fair deal and get things sorted.’
- the DSS policy is setting precedents for other funders, and therefore needs to be addressed most urgently regarding discrimination, notably:
 - removing the age 18 restriction for the person needing support
 - paying a fair wage, including consideration of the recent Pay Equity decisions
 - not limiting the hours family can be paid to 40 hours per week, but based on need and family circumstances
 - providing choice and a more open and flexible process for paid family care payment processes, including consideration about who the employer is
 - removing the rule that spouses, de-facto partners and civil union partners can’t be a paid family carer; and
 - informing and promoting paid family care as an option across assessors and funders
- in addition, informants sought simplification of the system to give disabled people and families more choice, and unbundling and connecting of silos of support that have differing rules; and
- give families information and support to work with the new and simplified system, not just from one agency, i.e. the single current payment gateway for FFC.

Finally, and importantly, informants identified the need to have a streamlined system for task based assessment that can allocate in simple ‘packages’ or ‘bands’. This approach would help families to know and understand what funds they can get and use them in ways that reflect their daily and, at times, changing needs.

Informants acknowledge all changes must be sustainable and may not be able to be undertaken at one time. Our suggested prioritised order of change might be as follows. This suggested order of change is our view and would need to be further talked about with stakeholders.

Area of change	Aspect of change	Why this is a priority for informants	Other potential considerations
1. Operational policies	<ul style="list-style-type: none"> • Remove age 18 for the person requiring support • Enable spouses, de-facto partners and civil union partners to be paid • Ensure that family carers can be paid a fair wage, i.e. remove the minimum wage requirement • Enable a choice of who the employer of the family carer might be, and whether there is a need to have an employer at all, i.e. how payments can be made in a more simplified manner like the ACC arrangements and the upcoming expected Carer Support 'bulk' payment, enabling choice, i.e. one process might not suit all circumstances • Consideration of the age of the family carer who can be paid, i.e. what is the minimum age for 'young carers' • Allow flexibility in hours of care to be paid, e.g. in complex cases a carer may be paid for more than 40 hours per week 	<p>Fairness and removing major discrimination</p> <p>Choice over who is the most appropriate carer(s) for a person requiring support</p>	<p>How this impacts across Government – DHBs, ACC and DSS</p> <p>Tax and other legal implications such as effects on other benefits people or families might be eligible for</p>
2. Assessment and time allocation processes	<ul style="list-style-type: none"> • Take away the task based transactional assessment processes that consider minutes per task and move to allocation approach based on simplified 'bands' according to broad need e.g. low, medium and complex needs 	<p>Promote trust between parties and simplify the processes</p> <p>Remove the demeaning processes and look at the holistic needs of the those requiring support and</p>	<p>Consideration across all assessment processes: ACC, DHBs and DSS</p> <p>Simplify assessment tools and make relevant to the disabled person and family situation</p>

Area of change	Aspect of change	Why this is a priority for informants	Other potential considerations
		their families	
3. Supportive infrastructure including real and quality respite options	<ul style="list-style-type: none"> • Enable payments to be made without the need to go via a third party as currently happens with FFC payments for DSS • If a third party is required by government and at the choice of the family or person, provide choice rather than a single provider • Consider how procurement of supports and providers can help to simplify the system and support families to make real choices with quality paid carers and choice of respite options • Work with formal home and community support providers to support them to ‘employ’ family carers in a safe employment manner, if this is the family choice 	Simplify the system to enable choices and best access for people and their families	Respite is a major consideration in supporting family carers and quality options need to be developed at all ages
4. Legislation	<ul style="list-style-type: none"> • Repeal Part 4A of the NZ Public Health and Disability Act, using an open and inclusive process to ensure the Act is fair and in line with other Human Rights Legislation 	<p>Major concern over the original process of change and implications for previous cases not to be heard in Court</p> <p>Seen to be unfair and discriminatory</p>	How any change might fit with other legislative priorities

1. Scope and context

In this section, we set out what the intent and scope of this paper is and our approach to gathering the views of people. We also note key context concerns as an introduction to the rest of the paper.

1.1 Scope is payment to all groups of family carers

Carers NZ and the NZ Carers Alliance commissioned this discussion paper on paying family carers to promote policy discussion and subsequent ministerial debate. Other audiences include family carers, disabled people¹ and wider whānau, the Carers' Strategy Governance and Working Groups, the DSS Transformation Work Group, funders of Funded Family Care (FFC) and paid family care such as the Ministry of Health, DHBs and the Accident Compensation Commission (ACC), the legal fraternity, and other New Zealanders interested in this social policy area.

Carers NZ and the NZ Carers Alliance asked for a particular focus on identifying issues related to:

- Funded Family Care (FFC) from Disability Support Services (DSS) of the Ministry of Health (the Ministry) for families supporting disabled adults
- paid family care from District Health Boards for older people being supported and those supporting someone of any age with long-term chronic conditions, palliative, and mental health and addiction support needs; and
- paying family carers via ACC.

Payment for family care for all of the above is directly related to home and community type supports (e.g. domestic assistance and personal cares) in the home. There are links to other funded supports that support families, such as respite care, which will be mentioned in this paper too.

1.2 Our approach to seeking views

We canvassed views as follows:

- interviews, n=36
- e-survey of mainly family carers (n=406 responses)
- rapid literature scan
- review of key papers

¹ Although this paper is about paying family carers, it is acknowledged that a family unit includes family carers and disabled people, as well as wider networks of whānau and others. For the purposes of this paper that is the definition of who we are talking about.

- review of recent Court judgements regarding payment of family members
- review of relevant government agencies strategies; and
- consideration of related government and cross government strategies under development such as the new Carers' Strategy Action Plan, the NZ Disability Strategy and the DSS System Transformation work, including the Enabling Good Lives Principles
- interviewing of selected key stakeholders such as:
 - families in caring roles, including some who had been through the NZ Court process
 - government officials especially funders of family carers
 - selected Needs Assessment and Service Coordination (NASC) agencies, both for DSS and DHBs
 - key bodies such as Carers NZ, the NZ Carers Alliance and the Disabled Person's Assembly (DPA)
 - legal representatives, PSA Union, and others with a particular knowledge of the topic; and
 - Non-Government Organisations (NGOs).

All information received, including the survey results, was triangulated and analysis undertaken before drawing conclusions about paid family care, especially FFC, and possibilities for future thinking.

There may also be some areas that would merit future in-depth consideration and / or stakeholder input such as Māori, Pacific, mental health and addictions, foster carers, palliative end of life care, MSD (e.g. around benefits such as caring for someone with a health condition or injury) and youth.

1.3 Vigorous challenge to the current arrangements

This paper reflects the current issues and views from a number of key stakeholders (informants) we interviewed. The Ministry FFC policy is the guiding contract for DHBs' policies, setting precedent. In contrast to the health sector, ACC has an established precedent of paying family carers. However informants clearly believe ACC is "retrenching" on the amount they pay families, conversely to ACC saying they are not changing Policy.

'They are definitely trying to stop or reduce paying overnight time and cares.'

'ACC is changing what they do. Reassessments are based on a task based time allocation, like the Ministry process.'

'It depends on the assessor who is contracted to ACC. Some have more empathy to the real situation.'

The ability to pay family carers is believed to be a positive move forward, but not by all, especially with the current policy arrangements. Four families have taken the Ministry to Court to challenge its policies and to seek remedies. The causes of action have had a

particular focus on discrimination based on the family member status of carers and, also, assessment processes.

To date all families have been successful in these Court actions. We understand there are 13 other family members currently preparing for Court action. The most recent judgement against the Ministry was released on 7th February 2018 (CA460/2017 [2018] NZCA 8, generally known as the Chamberlain case). We understand there is a case against ACC pending release.

There has been recent activity and profile in the media about FFC (television, radio, print and online) highlighting the family and public interest in this issue.

Following are two quotes about the system and use of Courts to resolve these issues.

'Why should any parent have to go through that just to care for their family?'

'For any person litigation is very stressful ... and when caring full time as well. That is huge.'

1.4 Who funds and provides relevant support services

There are a variety of legislation and policies across government that influence paid family care.

The New Zealand Health and Disability System² and the ACC promote supporting people to live as independently as possible in their communities and places of choice. There are a range of supports and services in place with government and the ACC funding to support them to achieve this. However there are accounts where these do not meet the needs of individuals or families, leaving some struggling to provide care and to participate in life outside of the home (including paid employment and meaningful day activities, as well as respite options).

For some time, families who support disabled or injured adult family members with high needs have been calling for a stop to discriminating against them on the basis of family status, especially regarding who can be paid to provide these supports and the payment rate. Often the carers in question support family members who require very intensive, intimate and complex cares, and at times up to 24 hours a day care. Some require two people caring at one time where support and safety requirements are high. Some examples are those requiring a significant level of health care such as tube feeding, bowel cares and skin integrity consideration. The other level of complexity reported was supporting people with behavioural challenges both within the home and in the community.

For people with significant and / or complex needs traditionally most supports have either been provided by unpaid family members and / or a combination of unpaid family plus services purchased by the Ministry, ACC or DHBs through contracted providers. Access for these funded supports is via the contracted Needs Assessment and Service Coordination

² In this context Health and Disability includes those with mental health and addictions as well as older people.

(NASC) agencies (in DHBs for older people and for those with mental health and addiction and other support needs), or for ACC via contracted assessors.

1.5 Legislation and policy and combined with implementation and assessment processes, compound the impact on families

Legislation governing paying family carers sits in both Health (including disability) and ACC legislation. Policy surrounding and detailing FCC for the Ministry (DSS) sits in DSS; paid family care for older people and those with mental health or addictions and other support needs sits with DHBs; payment policy for ACC clients and their families sits with ACC.

As referred to in the judgement released from the Chamberlain Case, policy relating to FCC is not only the Ministry Operational Policy, but also includes all linked policies such as FCC, and Home and Community Support Services contracts and service specifications.

The operationalising of those policies is where families are impacted, as well as the legislation (for example with the assessment tools used, and the resulting allocation of hours). The Judge in the Chamberlain Case³ states:

'The fact that the service cannot be quantified discreetly or routinely by the Ministry's unit-based measurement model does not justify its [intermittent personal cares] exclusion. A formulaic approach to assessment is inconsistent with the spirit and purpose of the Policy.'

Source: Para [83].

Post the 2013 legislation change of Part 4A of the NZ Public Health and Disability Act 2000, Disability Support Services (DSS) of the Ministry implemented a Funded Family Care Operational Policy.

'... together with the Funded Family Care notice 2013 and other Ministry documents and practices, sets out the Ministry's policy under part 4A.'

Source: Page 1, the Ministry's Funded Family Care Operational Policy.

The DHB policies for Paid Family Care that we have evidenced are based on the DSS precedent with some amendments. One DHB interviewee noted that in 2014 DHBs were given just one month to design and implement a paid family care policy, hence the need to do so rapidly using the already drafted DSS one as a basis, even if they felt it would not necessarily meet their DHB's needs. The key difference in the FCC Ministry policy and the DHBs' is the mechanism for employment and therefore payments and responsibilities. The DHBs require the family carer to be an employee of a formal contracted home and community support agency. The family carer is subject to all employment rules of the provider.

³ Shane Chamberlain First Appellant and Diane Moody Second Appellant.

ACC policies allow the person and their family to determine the employment relationships and it can be via the family member, the family carer as an independent contractor and / or a formal agency. Whoever holds the funds from ACC can decide who to pay with them.

A list of the guiding legislation and documents for payment to family carers can be seen in the table below. Note: this list may not be exhaustive, for example there may be some individual organisational or DHB policies not included. In addition there are other legal documents that guide work relating to payment of family carers, such as the ACC Statement of Intent.

The table shows how various statutes and policies flow to impact on paid family care. Note the lists are not exhaustive but demonstrate the cross Government and statutory links.

Table 1 Cascade of statutory power and wider guiding policy

Type	List	Lead
United Nations Convention	<ul style="list-style-type: none"> Convention on the Rights of Persons with Disabilities 2006⁴ 	Government
Legislation	<ul style="list-style-type: none"> Human Rights Act 1993 NZ Bill of Rights Act 1990 Health and Disability Commissioner Act 1994⁵ NZ Public Health Act 2000 Accident Compensation Corporation Act 2001 Funded Family Care Notice 2013. 2013-g06248. Gazette.govt.nz 	Government

⁴ The UN has announced its latest review of New Zealand's implementation of the Convention ref: Press release Minister Sepuloni, 14 March 2018, Beehive.govt.nz

⁵ Including s 10(2) (a) of the Act, as noted in the Moody case. Source: Para 28

Type	List	Lead
National Strategies	<ul style="list-style-type: none"> • NZ Carers’ Strategy and Action Plan (currently being updated) • NZ Palliative Care Strategy and Palliative Care Action Plan 2017 • NZ Disability Strategy 2017 • NZ Health Strategy 2016 • Healthy Ageing Strategy 2016 • He Korowai Oranga: Māori Health Strategy 2014 • Ala Moúí: Pathways to Pacific Health and Wellbeing 2014 - 2018 • Whānau Ora 2010 to current • Pacific Health and Disability Action Plan 2002 • Primary Care Health Strategy 2001 	<p>Health</p> <p>Government Ministries and ACC (being involved in some cross-Government work)</p>
Policies and Service Specifications	<ul style="list-style-type: none"> • Funded Family Care Operational Policy 2016 (updated) • Various DHB⁶ Paid Family Care Policies (circa 2014) • Home and Community Support Services 	<p>Ministry of Health and DHBs</p> <p>ACC</p>
Assessment and allocation	<ul style="list-style-type: none"> • Contract with service specification – for both assessment and service allocation 	<p>Ministry of Health and DHBs⁷</p> <p>ACC</p>

Source: Sapere list for the purposes of this paper

⁶ Each DHB is required to have a policy to pay family carers.

⁷ Note: the NASC agencies for younger disabled and older people, as well as for those requiring mental health and addictions support, are typically separated from each other.

2. A system wide fair approach to paying family carers is needed

Family members have been seeking recognition and payment for a long time. For more than 20 years New Zealand families have actively pursued fair pay for their work caring for disabled, ill or injured family members. This work enables people requiring support to remain in their own homes and receive as required very intimate cares provided by a person they know.

'People should have the choice of a stranger or someone they know providing those very intimate cares that are often required.'

'For some people a family member is the most appropriate to provide the care. Take people with dementia for example – they often need someone they know.'

'Continuity of care and reliability is key. We can't rely on outside carers to turn up.'

In summary, the key rights that families continue to seek are:

- **Respect and recognition:** family members be respected and recognised and therefore paid as others are for the work they do, with fair allocation of hours and equitable pay rates.
- **Non-discrimination and fairness:** legislation and policy does not discriminate on the grounds of being a family member or age (18 years or over for the person with a disability). That policies and options do not contravene the Human Rights Act and other important legislation. That the two thirds of New Zealand family carers who are women are fairly recognised and paid for their work without discrimination on the basis of their gender.
- **Simplified, transparent and easy to understand systems:** that the system is simplified for assessment, access and ongoing management of cares and supports.
- **Who the employer is:** points as noted above. Indeed, questions regarding if there need to be an employer or can it be a simpler funding and transactional system were asked

2.1 There are many concerns, with some policy taking precedent

We document some of the concerns raised with us in this section. They are in order of how people saw the cascade of decisions required, yet we believe that there may be some earlier changes to consider, as per our conclusion section.

'How can a policy override legislation – something that is legal?'

'Why is it that the Courts have ruled in the families' favour and still policy has not changed? It doesn't make sense.'

How can it be I get funds from ACC and DSS and they don't marry up? I am so confused.'

2.1.1 FFC: legislation, policy and implementation are of particular concern to many people

In its pre-election manifesto, Labour indicated it would repeal the Act that governs paying family members. Many proponents of this change believe the 2013 changes to legislation governing FFC⁸ were pushed through under urgency, which people were not fairly consulted and various aspects of the legislation remain discriminatory based on family status.

Most notably, the main concerns about discrimination are as follows:

- the person with a disability having to be age 18 or over
- not being able to be paid if you are the disabled person's spouse, civil union or de-facto partner⁹ (i.e. still based on family status); and
- not being recognised for the level, type and amount of care needed over and above what family members would 'typically be required to provide'. Issues about the level of pay include hourly rates of payment as family members are remunerated (where they are remunerated) at the minimum wage rate irrelevant of the level of support given. There appears to be widespread disagreement on what is 'typical' for a family member to provide.

Another key issue is the system being very complex. In particular, there is especially a lack of transparency around the assessment process for disability and ACC, making it difficult for people to access payment. Current payment policies administered by DHBs are not well promoted or understood which is a barrier to access for carers of older people and others for whom payment might be an option.

2.1.2 Recognising and paying family carers has begun to improve, but much more work is needed; policies vary

Overall many acknowledged what is in place now is better than before and that consideration and supports of family carers will continue to evolve over time. Interviewees acknowledged FFC particularly needs to be seen as a strategic solution and part of a wider social and policy response to carer payment for government and communities. There were some concerns that any changes would mean even less support for families.

'It is not good and is discriminatory. But heck, don't throw the baby out with the bathwater. Make sure we build from where we are now.'

'Every time I have a reassessment – whether I ask for it or they require it – I seem to lose hours. Why is that? Our needs haven't changed, in fact at times have become more difficult. I hope any future changes to policies don't make it even worse.'

⁸ Part 4A of the New Zealand Public Health and Disability Act 2000

⁹ Source: page 4 FFC Operational Policy

‘At this stage, just tidy it up.’

Paying family carers has been in place longer for ACC than in the health system. For all payments to carers, an allocation of hours or funds by the Ministry, DHBs or ACC allows a person to choose whether a family member provides their care. The hours only relate to home and community support type services such as domestic assistance (e.g. cleaning and housework) and personal or attendant cares (e.g. showering, bathing, dressing, eating, personal hygiene, etc.). In some circumstances this may also include overnight type cares such as a sleepover or awake staff.

There are policies around what status of family member can provide the care (e.g. not spouses, de-facto or civil union couples) and how many hours per week can be allocated. For the Ministry it is limited up to 40 hours, although there are some exemptions. There are varying rules between policies around who the employer of the family member is, e.g. the person with a disability, the provider etc.

An important distinction between funders is who can be paid and who can act as the ‘employer’ of the family carer. Being an employer requires that people or an agency understand employment law including annual leave and statutory holiday requirements, hourly rates, ACC levies, IRD responsibilities, Kiwi Saver etc.

DSS requires the disabled person to be the employer of the family member. This can be very difficult, and in practical terms not possible for many people, when the criteria to access FFC payment are about the disabled person having high or very high needs. In many instances this means the disabled person does not have the ability to open bank accounts, or indeed act as an employer, undertaking all the legal and administration requirements this entails.

‘The disabled person being the employer is just nonsense; it is farcical.’

DHB and ACC paid family care processes differ from that of the Ministry. Less concern was voiced over the DHB policies while some concern was voiced over the ACC policy and process. DHB policies require the paid family member to be employed by a contracted home and community support service (HCSS) provider. The family member is subject to all employment requirements of the provider, the same as all other employees, including being able to negotiate rates of pay (i.e. not necessarily the minimum wage). The difference between family carers and other employees of the provider is the family member only has one client, i.e. their family member.

The ACC system is more flexible in who the family carer can be, i.e. anyone can be paid if the person chooses them, including spouses, de-facto partners and civil union partners. Who is required to be the employer is also up to client and family choice. Various other parts of the policy differ as well. However there were several examples from families and others where ACC is seen to be ‘retrenching’ their family funded supports and believed to be reducing overnight funded care and expecting families to pick up more supports unpaid. Also of note were reports of the variance of assessors contracted to ACC in how the assessment is done and the outcome for the injured person and families.

2.1.3 Main concerns with change to Part 4A of the Act

The NZ Public Health and Disability Act guides the policies in health and disability for paying family carers. There were two main concerns reported with the 2013 changes to Part 4A of the NZ Public Health and Disability Act 2000 (the Act) namely:

- **Process for change:** the method of change, being rushed through in urgency on Budget night, without full Cabinet process considerations.
- **Non ability to challenge in retrospect:** for those who already had issues before the date of legislative change, they can't now make a claim through the Courts.

There is varying opinion as to whether repealing the Act would result in better outcomes for families and disabled people, or whether it is actually the policy and implementation of this that makes the biggest difference. However as the Act does guide the policies, and some informants felt it was discriminatory in its own right, some were very strong that the Act does need to be changed.

A statement reported in the media¹⁰ by one of the lawyers acting for families says:

'In any situation it's completely wrong to have a law that prevents people accessing the courts,' Judd said. 'This law is wrong for that reason.'

2.1.4 Implementation of the Act and operational policies exacerbate complexity and hence discrimination

In summary, all but a few interviewed said that while Part 4A of the NZ Public Health and Disability Act and the policy discriminatory clauses cause significant issues, it is compounded by how implementation is undertaken. The operational detail really makes a difference to families' lives on a day to day basis of:

- implementation
- assessment
- allocation; and
- simplicity of processes.

'Having the disabled person as an employer, when by the nature of FFC they have high and complex needs, is farcical – a nonsense.'

'My daughter can't be an employer – she can't read or write. I do all the work and this causes me a lot of paperwork, talking with IRD, etc ... it is only more stressful.'

Several raised the issue of the new Support Workers (Pay Equity) Legislation (2017) and how it has made the hourly rate even more discriminatory for FFC.

'Some of the support workers in other agencies, due to their tenure, are getting up to \$10 an hour more than me. Tenure! I have been doing this for 50 years and that is not recognised. It is just not fair.'

While a few acknowledged the importance of FFC having been a beginning towards a fair paid family care system in New Zealand, an overhaul is overdue and needs to be urgently prioritised.

People are apprehensive that the Ministry, DHBs and ACC will not respond to the issues raised in this paper and that any national change may take years, while they work out policies and Prototype Transformational Change (for DSS).

¹⁰ Johnston, K. Family carers' heartfelt call on Government for law change. NZ Herald 6 March 2018

'We can't wait for all these other things to change. I think DSS are talking about a long development and implementation process. Families need this addressed now, not in 5 years!'

Other government agency work that may be occurring should not affect a timely review of the paid family care policies.

2.1.5 Human rights discrimination a major concern by majority

As mentioned, overwhelmingly people reported on the Ministry FFC operational policy contravening various laws and other strategies or policies. As DHB paid family care policies are based on the Ministry's FFC policy, discriminatory concerns flow across them all. The main concern voiced in relation to ACC's approach to paying family carers is its task based assessment process and the number of hours applied.

Although also covered in the Court judgements, in summary what the informants for this paper stated as their key discrimination concerns are:

- **Family status:** not allowing payment for family care of spouses, de-facto or civil union partnerships.
- **Age:** age of the person being cared for having to be age 18 years or over¹¹.
- **Limit of hours:** limiting maximum hours (without exemptions) to 40 for family carers when others can get longer hours.
- **Pay rate:** not in line with Pay Equity recent decisions. Only being able to be paid the minimum wage, as opposed to the commensurate wage of those working at the same level (applies to DSS only, other policies allow a range of pay rates).

The latter has been accentuated by the introduction of the Care and Support Worker (Pay Equity) Settlement Act 2017. This has meant that for the same work, family carers are potentially paid an amount with an even greater gap than before.

Many informants said they were shocked at the situation. Most were *'incensed'* at the impact on individuals and families as a whole. A sample of descriptive words about the FFC policy include:

- Staggered, appalled, disgusted, ridiculous, discriminatory, complex, non-transparent, mean, nonsense, offensive, outrageous.

'It is a dog's breakfast.'

'It allows for no dignity for the disabled person or the family. It is disgusting.'

'It shows disrespect to the families and carers of disabled people.'

'It shows no value for the role those families play in a lifetime of care for those disabled children who are now adults, who will be with them forever. That is the reality.'

¹¹ Some people even though under the age 18 have very complex care needs that families would not normally be undertaking

2.1.6 People and their families must traverse various layers of the system

For some families there is a range of other service streams to support the disabled person and the family. This is in addition to paying family carers if the person with the disability and their family is eligible. These can include:

- HCSS from formally contracted providers to funders
- Individualised Funding
- Carer Support
- respite care (having a break); and for some,
- day breaks, via activities outside the home.

All of these additional services have varying rules and policies about access, systems and who can be paid. Some families may be allocated all of these funding streams and supports and others not:

'It is very confusing about what I am allowed to do, or not. Some hours for this, and others for that, at different pay rates, with different rules. Some I can get paid for myself and others I can't. I really don't know how to do it.'

'For some services I am the employer, for some my daughter is, and for others it is external agencies. Others get paid a higher hourly rate than me for the same (work), and this is so unfair.'

The access and transactional parts of the system can be very confusing and are complex for many people. There are various parts of the system and layers that impact on families and disabled people. This includes getting information, assessment, allocation of hours, employment, through to managing payments and bank accounts. Some families also talked about some of the complexities outside of the system, but required for the funding to be managed correctly such as paying accountant and legal fees.

2.1.7 Very low uptake of DSS FFC for various reasons

A concern voiced by many is the low uptake of FFC by disabled people and their family / whānau carers. We didn't source quantitative data for this as it was a qualitative paper and out of scope in this instance.

The key example we do have is that for the Ministry cohort, budgeted and actual uptake is:

- budget volume: 1,600 people / families; uptake: 354 families
- budgeted expenditure from Treasury Allocation: \$23 million; actual spend: \$8.8 million (as reported at time of writing).

We heard that low uptake is due to various factors as detailed below.

'The system is so hard, I just can't do it.'

'They don't really want to pay families so they make it so hard we can't get it.'

'Many families and disabled people are not told this is an option. Where is the information on this?'

'I was told [about it] but it is too hard – I didn't understand what I needed to do.'

For:

- ACC and Ministry
 - too complex
 - dislike of the assessment transactional task based focus which is ‘invasive and demeaning’ for families
 - don’t want the person with a disability or the family carer to be an employer – as it is too onerous and too risky (employment law and other legal obligations), as well as onerous on time that is already busy with care
 - the discriminatory nature of the FFC policy and the precedents it sets for other policies
- Ministry and DHBs:
 - NASCs not informing people that paying family members may be an option

‘Well that’s one way of keeping families from being paid carers isn’t it? That is, making it so complex and invasive that people can’t, or don’t want to, do it.’

‘I am so cynical. Why is it so hard and so discriminatory? And why haven’t they [DSS] spent all the money they had allocated? Because they don’t want to let families be paid – that is why!’

‘Are they using that money they haven’t spent for something else?’

2.1.8 Parts of the system can work against each other

One issue that has arisen is that some of the older policies, service specifications and assessment tools can at times counteract or clash with the principles and intent of more recent policies or supports, such as Enabling Good Lives Principles, the DSS Transformation and indeed, assessment and paying family carers fairly.

An example repeatedly mentioned by informants was the ‘outdated and complex’ assessment process across government. Several said they couldn’t understand it. Some noted that assessors didn’t have the skills and depth of experience to understand, review, and allocate supports for people with the level of complex needs in question and therefore aligning the needs of their families / whānau.

Most commonly people also expressed concern about:

- what was included as in types and amount of care, such as counting minutes for tasks and activities like toileting and not considering the wider role of family commitment to caring e.g. often the person can’t be left alone. This can be termed a ‘supervisory’ role, but in effect is much more and can include changing care needs that aren’t listed in the assessment. Note: ACC does pay for this if it is outside of what is typical family care or the family care role.
- the allocation of hours post-assessment is often a ‘non-transparent’ process which people couldn’t understand; and
- DSS’s lack of an open and independent review process if the number of hours was to be challenged. It was perceived and stated variously that the review ‘DSS tribunal’ was made up of only internal Ministry people and the contracted person who reviews all FFC cases (i.e. the people who are reviewing your case are the ones who made it in the first place) and families have no opportunity to attend.

The following table highlights also the complexity of some packages which can be made up of a range of service and funding streams that can each have different rules of how they might be used.

Table 2 Various support streams a family may have at any one time

Support or Service	Allocated by....	Employer
FFC	Tasks and hours per week	Disabled person
Individualised Funding (IF)	Hours per week	Whoever the disabled person and family decide – e.g. self, provider, host agency (i.e. Manawanui in Charge for disabled people ¹²) Note: the family carer often does all the administration and coordination for the IF package and this can take considerable (unpaid) time. This is akin to FFC in terms of who can be paid, how it works etc.
Home and Community Support Services	Hours per week	A contracted agency (provider)
Respite care	Days per year	Varies, more like a contracted provider
Carer Support (respite but different rules than the Respite above)	Subsidy for days per year	Varies, more like IF, or the family member is the ‘employer’

For example, if a family is allocated some or all of the above, each funding type may have different rules about what it can be used for, resulting in a very complicated and stressful situation. Many stakeholders noted that not only may the employment status vary but if families wanted to flex between allocations then this was, at times, seen by officials as not meeting the rules. For example there were many reports given of families being prosecuted for ‘fraud’ by the Ministry for their choice of use of Carer Support funds when they were trying to work out which funding stream can be used for what. The same complexities can arise from DHB allocated supports but as the family carer is employed by a provider then there is less confusion.

¹² Contracted by the Ministry to provide a range of support services such as payroll, training for caregivers etc.

Many explicitly spoke of the need to move away from assuming each person requires the same time to have a shower, get dressed, toilet etc., when it is blatantly clear to many that not only will this vary by person, but can vary by individual person by day as well depending on health needs, changes in behaviours etc. Once again this also links in to time being available and recognised for supervisory and coordination functions. For those with extreme complex needs there is a duty of care for someone to be present to promote and oversee safety and the person's quality of life.

2.2 Policy development concerns for funders also identified

There were a range of stakeholder reports of actual, anecdotal or perceived concerns by those developing policy about their approach when considering paying family members. A mix of stakeholder views and our comment on these is summarised below.

Table 3 Policy risks and myths: actual or perceived as noted by stakeholders

Perceived risk	Stakeholder comment	Our comment
1. It will change family dynamics	<p>What does this mean?</p> <p>In one Court case the judge identified that after xx¹³ years, this certainly hadn't occurred.</p> <p>It may improve the family relationships as there are less financial pressures.</p>	<p>Family dynamics are reliant on many things and payment may or may not change this, for the positive or not so positive.</p>

¹³ Xx used to not identify the years and therefore potentially the family

Perceived risk	Stakeholder comment	Our comment
<p>2. Families / individuals will become dependent on the money and there may be perverse incentives for families to continue care when other options might be more appropriate for the person.</p>	<p>Feedback ranged from ‘this would mean family members wouldn’t want to withdraw care’ through to ‘one way or another family members need to earn’.</p> <p>If they can care for a loved one at the same time it is a ‘win win’.</p> <p>Some families have to give up paid employment to be available to care, so need some form of replacement income.</p>	<p>Most informants felt this was a minimal risk and that there is the ability to have checks and balances to work with the disabled person and their families / whānau over time.</p>
<p>3. Family carers will only do the care to take the money.</p>	<p>Not likely as this is not a role people tend to do just for income as payment rates are not high for the level of care provided.</p> <p>There can be abuse and this needs to be monitored.</p>	<p>Many family members are doing care anyway. Payment of some form to support them to do this is seen by stakeholders as fair.</p>

Perceived risk	Stakeholder comment	Our comment
<p>4. Families should care for their own anyway and not be paid – will create a huge demand of those already caring, and therefore impact fiscal risk.</p>	<p>A key question for NZ is, 'What is fair and reasonable for family to do?' What is normal for the 'age and stage' of the person needing care or support?</p> <p>Comments ranged from 'nonsense' to 'it can be managed via policy and prioritisation, if it was to occur'.</p> <p>Many feel they are highly qualified and experienced after years of providing care, perhaps more so than the 'professionals'.</p>	<p>With people living for longer at home with growing care and support needs, NZ also needs to think about what is 'fair and reasonable' for families to do. This needs to be considered in a range of ways, as not every family has the same circumstances and the answer may be different for different ages and stages of caring need e.g. the needs of a middle-aged profoundly disabled person with behavioural challenges and an ageing frail person with dementia and chronic health conditions might require distinct responses to this risk.</p> <p>Several informants commented on that if more appropriate support services were available in the community this may change some of the need for families to care.</p>

Perceived risk	Stakeholder comment	Our comment
<p>5. There could be an increased risk of family abuse to vulnerable disabled and / or older people.</p>	<p>Abuse types stated by some stakeholders as needing consideration and could be at increased risk by families being paid for care included:</p> <ul style="list-style-type: none"> • financial • physical • psychological • sexual • isolation • quality of life decline • neglect. <p>Many commented that we don't know what occurs within families anyway and this risk might already be there.</p>	<p>We are not aware of any evidence of increased abuse from paying family members.</p> <p>Put in place (non-invasive) systems to monitor this e.g. through the elder abuse response services for older disabled people, ongoing contact / advocate for younger disabled people with complex needs.</p>
<p>6. It is a challenge for families to be carers as they are not trained like external carers and there are no quality standards in place.</p>	<p>Many families are already providing care but may not be able to continue without adequate supports (including financial) around them.</p> <p>Many family members feel they are highly qualified and experienced after years of providing care.</p> <p>How to treat family members fairly with other employees when engaged by a formal home and community support provider raises discussion and concern for some providers.</p>	<p>Consideration of how to support family carers including 'training' or access to learning opportunities is important.</p>

Perceived risk	Stakeholder comment	Our comment
7. Costs will blow out as families who are already caring will want to be paid.	The exact numbers of families providing care at the level in question is not known.	For the Ministry there has been significant lower uptake than expected (about a quarter of Treasury allocation).

3. Our reflection on why there should be change

This report has already identified many aspects where improvements could occur. As noted in the scope, the purpose is to inform decision-making for the future and to improve policy and fairness. We have not had time to fully analyse the policies and therefore offer these comments as points of discussion rather than a firm direction. In particular, we note family carer payments in other countries are largely entitlement payments akin to an insurance payment for misadventure (see Appendix 1). There is a strong belief by stakeholders that paying families, especially the current FFC policy, should meet the intent of legislation and that the Ministry's Operational Policy does not. Most stakeholders had this sentiment as indicated by a sample of comments below.

'The system was made over-complicated to restrict access – as the Ministry didn't want it [FFC].'

'Everyone is doing work around rules to try and make the system work for families. It just doesn't.'

'People don't have the energy to deal with all these complexities.'

'The way is set up, it is ... nonsense.'

Media articles also have statements worth mentioning:

'Even the Ministry's own document on Funded Family Care acknowledges: "The requirements of the FFC arrangement are quite extensive and complex and understanding the obligations and responsibilities of being an employer in this arrangement can be quite daunting."'

'The disabled person first has to make an informed choice to use the scheme. But many of those most likely to benefit from the scheme are unable to make that choice.'

Source: Kathy Spencer. Article, 12 Years in Court and Still Fighting: Disabled Adults and their Carers Deserve Better. Dominion Post, February 27, 2018.

3.1 Key components for change

Although there were many aspects of the legislation, policy and need for system change commented on as part of the conversations with families and other stakeholders, the following are the key ones that we would like to highlight.

3.1.1 Real choice is important

Real choice should be fair and simple. Payment to family members should be one option for disabled people and family carers to choose from when planning their supports. Policies should sit within, not outside of, existing and future legislation and frameworks. The system should be seamless and easy to access and use across government for disabled people, injuries, chronic illnesses, mental health or addictions, older people, long-term palliative support needs, and their families, whānau, and aiga.

That also means for the future including consideration of paying family members in the DSS Transformation work and any policy changes ACC and DHBs are making. This includes around the Enabling Good Lives Principles. It is understood and respected that government

supports and services must remain financially sustainable but equally should be fair, well promoted, and easy to understand.

3.1.2 The policies and systems for paying family carers need change and improvement

The policies and systems have many layers, are not homogenous across funders, and do not have widespread agreement on them. For FFC especially there is universal dislike and disagreement about the policy and its implementation.

There is general agreed comment from those aware of the change to Section 4A of the Act, that it was not a fair process or outcome. However only some want it repealed. Others believe that changes to operational policies and how they are implemented is where key impacts, positive or negative, will occur for disabled people and their families. Some worry if the legislation is repealed then family carers will lose some of what they have now.

All people who were involved in the inputs for this paper want something better than the current system(s) for paying family carers, especially for FFC, even if their drivers are different.

Not everyone wanted the same changes, but there was consensus that there needs to be change for improvements and to reduce angst for families and those in the system alike.

Families deserve better than what they have to do to get through now in the system.'

We need to know where we are going with this policy in New Zealand for everyone's sakes.'

3.1.3 In addition to policies, the quality and inconsistency of assessments are key to equity and fairness

If NASCs were doing their job FFC would not be hard to access and the outcomes would be different.'

Assessment processes and allocation outcomes vary; inconsistencies are observed within and between assessment agencies. The fact that some assessment outcomes are challenged by families who then get a different assessment outcome and allocation is also seen that the process is not robust enough.

NASC – inconsistencies and unless you know about FFC they won't tell you.'

The whole assessment system is nonsense.'

ACC assessors vary so much in how they do the assessments and then the outcomes of how much support and rehabilitation can be paid for.'

We heard also that the inconsistency is also an issue for those covered by ACC. Most informants believe that ACC is 'retrenching' their ability to pay families and is expecting families to provide more unpaid care. The various changes in ACC legislation over the years also create differing abilities for ACC to pay families for care.

The debate on the two ends of the continuum range between a fully paid wage with no hourly limits but being based purely on 'assessed needs' through to no payment for families at all. No one interviewed believed a family member should be paid 24/7 as sustainability and support of the family is also a significant consideration. Neither did we hear that a family

member should not be paid. It is the detail of the policy that is causing dissent and dissatisfaction. What was said is that of most importance is a fair assessment, then discussion and agreement on what can be paid to a family member.

Many brought up the 'age and stage' discussion around what would normally or typically a family member be required to do for a person in their family at that age and stage of the person's life. Two frequent examples given were that typically parents can expect to not be undertaking full-time care for their adult offspring. Therefore this should be considered. The other was that if someone was injured or had a progressive disease, then caring became a new factor in that family, that they weren't expecting to do. That it disrupts a family's life plan.

3.1.4 Payment mechanisms and employment relationships a key consideration

The FFC scheme may be delivering choice and control for a relatively small group of disabled people who wish to, and can, deal with the requirements and obligations of being an employer. However, a system needs to work for a much wider group. Other options should be available to suit people with a range of disabilities and preferences, as well as family circumstances, about their care and options.

For example, some families may prefer to be paid funds direct in to their bank account (like one option in the ACC model). Others might prefer the traditional Individualised Funding model, where others would be happier being an employee of a contract home support agency. Irrelevant of hours available from the assessment, individual circumstances and families should be able to choose what mechanism works for them.

Currently the only payment gateway to administer FFC funding is via a single host agency contracted by the Ministry. Some felt this was cumbersome and requires reviewing after the five years it has been in place.

People asked 'what if no employment relationship was required, how could that work?' For example, how could a system pay family carers as a type of payment but also has with it all the recognition of being a paid carer, but without the complex employment relationship requirements? Previous carer consultations were mixed on being paid a wage for formal recognition versus another form of payment. However the current question is whether there is something in between that government could consider and design that would provide choice for family carers and those they support?

Another question was, could there be a choice of who the employer might be? As in, can there be more than one option for a disabled person and family to choose from?

'Who is the employer and who vets parents of family members is very fraught.'

'For DHBs the HCSS provider is the employer and that seems to work quite well and quite simply. I can imagine this would not work for family carers of younger disabled. But it should be a choice.'

3.1.5 There are dis-incentives for access

A range of disincentives for access for family carers include:

- complexity of the system
- potential impacts on some benefits people may be receiving
- having to take on the role of employer by people who potentially do not have the capacity, energy and / or time to do so; and
- fear about reassessment and losing hours.

3.1.6 Discrimination based on family status for Ministry and DHBs

A significant and repeated factor highlighted by informants was the discrimination based on family status. As is well known, that was the basis for the first Court challenge to the Ministry in 2012.

The inability still for spouses, de-facto and civil union partners to receive payment for their caring work is still seen to be discriminating on family status, and especially impacts women, as two thirds of New Zealand's family carers are female. A question that was raised was that if the cost to the Crown is no larger if paying a spouse etc., as opposed to another family member, then what is the barrier? However those concerned with policy were wondering if it was opened up to spouse, de-facto partners and civil union partners, what would the extra potential demand and therefore cost be.

There is a need to consider options for all status of family members being able to be paid. A cross government approach to look at what ACC is doing and the impact that it has had on their demand might inform the debate.

3.1.7 Payment rates at minimum wage for Ministry policy

It appears that the minimum wage set for family carers only applies to the Ministry Operational Policy. For DHB and ACC policies, hourly rates can vary. For those employed by HCSS providers the Pay Equity legislation will also now apply so their hourly rates will have risen, whilst the disparity has yet to be addressed for those covered by the Ministry's FFC policy.

There are questions as to fairness and equity of this. Some families interviewed spoke openly about the 'insult' of being paid less than employees of an agency when at times they are more experienced and have longer 'tenure' than paid carers. Also of note, in some instances family members are delivering what might be termed 'nursing' type cares such as bowel evacuations and wound management. Informants said there is no recognition evidenced of these higher levels of care in the Ministry's hourly rate paid to family carers. Many interviewed also noted that at times formal carers were unreliable and didn't turn up, and at times had been allocated to a family without any training or knowledge of the needs of the disabled person.

3.2 Respite care needs addressing for families who are caring, irrelevant of being paid or not

The topic of respite couldn't be adequately addressed in this paper as payment to family members was the scope, but needs to be considered to support family carers and disabled people across a system wide approach. Addressing respite gaps across government is part of the discussion of the revision of the Carers' Strategy and upcoming refreshed Action Plan for 2019-2024.

'All we want is to have a proper break. To know when we go away our daughter is cared for in a safe and quality way. If we don't have that then we don't have a break – we are on tenterhooks all the time.'

3.3 Summary table of possible changes

Informants acknowledge all changes must be sustainable and may not be able to be undertaken at one time. A suggested prioritised order of change by us might be as follows. This suggested order of change is our view and would need to be talked about with stakeholders.

Table 4 Suggested areas and priorities for change

Area of change	Aspect of change	Why this is a priority for informants	Other potential considerations
1. Operational policies	<ul style="list-style-type: none"> Remove age 18 for the person requiring support Enable spouses, de-facto partners and civil union partners to be paid Ensure that family carers can be paid a fair wage, i.e. remove the minimum wage requirement Enable a choice of who the employer of the family carer might be, and whether there is a need to have an employer at all, i.e. how payments can be made in a more simplified manner like the ACC arrangements and the upcoming expected Carer Support 'bulk' payment, enabling choice, i.e. one process might not 	<p>Fairness and removing major discrimination</p> <p>Choice over who is the most appropriate carer(s) for a person requiring support</p>	<p>How this impacts across Government – DHBs, ACC and DSS</p> <p>Tax and other legal implications such as effects on other benefits people or families might be eligible for</p>

Area of change	Aspect of change	Why this is a priority for informants	Other potential considerations
	<p>suit all circumstances</p> <ul style="list-style-type: none"> • Consideration of the age of the family carer who can be paid, i.e. what is the minimum age for 'young carers' • Allow flexibility in hours of care to be paid, e.g. in complex cases a carer may be paid for more than 40 hours per week 		
<p>2. Assessment and time allocation processes</p>	<ul style="list-style-type: none"> • Take away the task based transactional assessment processes that consider minutes per task and move to allocation approach based on simplified 'bands' according to broad need e.g. low, medium and complex needs 	<p>Promote trust between parties and simplify the processes</p> <p>Remove the demeaning processes and look at the holistic needs of the those requiring support and their families</p>	<p>Consideration across all assessment processes: ACC, DHBs and DSS</p> <p>Simplify tools</p>
<p>3. Supportive infrastructure including real and quality respite options</p>	<ul style="list-style-type: none"> • Enable payments to be made without the need to go via a third party as currently happens with FFC payments for DSS • If a third party is required by government and at the choice of the family or person, provide choice rather than a single provider • Consider how procurement of supports and providers can help to simplify the system and support families to make real choices with quality paid carers and choice of respite options • Work with formal home 	<p>Simplify the system to enable choices and best access for disabled people and their families</p>	<p>Respite is a major consideration in supporting family carers and quality options need to be developed at all ages</p>

Area of change	Aspect of change	Why this is a priority for informants	Other potential considerations
	<p>and community support providers to support them to 'employ' family carers in a safe employment manner, if this is the family choice</p>		
4. Legislation	<ul style="list-style-type: none"> Repeal Part 4A of the NZ Public Health and Disability Act, using an open and inclusive process to ensure the Act is fair and in line with other Human Rights Legislation 	<p>Major concern over the original process of change and implications for previous cases not to be heard in Court</p> <p>Seen to be unfair and discriminatory</p>	<p>How any change might fit with other legislative priorities</p>

Appendix 1 What other countries are doing

We undertook a rapid literature scan to see what other countries were doing in terms of carer payments. Key search terms were:

- carers
- caregivers
- payment for caregivers
- family caregiver payment
- funded family care
- Eurocarers
- caregiver compensation

A summary table of details by country is set out below.

Direct compensation programs are a common aspect of caregiving policy in a number of countries. Australia, the United Kingdom, France, Germany, the Netherlands, Sweden and Norway all maintain some kind of program that can be accessed by family caregivers.

The programs vary significantly in terms of the monetary value of the payment, the eligibility requirement for benefits, and the framework within which they are situated.

Some programs are framed as social assistance and income security measures; others are aspects of health and home care policy (the latter is usually the case with payments to care recipients for caregiving services which may be used to fund informal family care or professional assistance).

We didn't have the ability to interview those receiving these assistances so cannot determine what is working well or otherwise for families.

Jurisdiction & responsible entity	Support available	Payment rate
<p>United Kingdom</p> <p>Department for Work & Pensions</p>	<p>Carer's Allowance: You could receive the allowance if you care for someone at least 35 hours a week and they get certain benefits.</p> <p>For each week you get Carer's Allowance you'll automatically get National Insurance credits.</p> <p>The person you care for must already get a particular benefit.</p>	<p>Up to £62.70 a week</p> <p>https://www.gov.uk/carers-allowance</p>
<p>Local authorities</p>	<p>Carer's credit: You could get Carer's Credit if you're caring for someone for at least 20 hours a week.</p> <p>Carer's Credit is a National Insurance credit that helps with gaps in your National Insurance record.</p> <p>If you're eligible for Carer's Credit, you can get credits to help fill gaps in your National Insurance record.</p> <p>This means you can take on caring responsibilities without affecting your ability to qualify for the State Pension.</p>	

	<p>Direct payments A direct payment is the amount of money that the local council/trust has to pay to meet the needs of you or the person you are looking after, and which is given to enable you/them to purchase services that will meet your/their needs (as assessed by the local council/trust).</p>	<p>This payment is *generally* not available for family members providing care.</p> <p>It is an ‘employer-employee’ (cared for-caregiver) arrangement.</p>
<p>Canada</p> <p>Department of Employment and Social Development</p>	<p>Financial assistance from the government for caregivers in Canada is mainly in the form of federal tax credits and insurance benefits.</p> <p>NB: For 2017 and subsequent taxation years, the budget proposes to consolidate the infirm dependant credit, the caregiver credit (for in-home care of a relative) and the family caregiver credit as part of the new Canada caregiver credit (CCC).</p> <p>Federal tax credits and insurance benefits:</p> <p>Compassionate care Benefit (CCB) program. Employment Insurance benefits and job protection are provided to eligible family members for up to twenty-eight weeks while caring for someone.</p>	<p>Employment Insurance Compassionate care benefits The basic benefit rate is 55 percent of your average insurable earnings, up to a yearly maximum insurable amount (\$51,700 in 2018). This means that, in 2018, you can receive a maximum payment of \$547 per week. Your EI payment is taxable income, meaning federal and provincial or territorial taxes, if they apply, will be deducted.</p> <p>You could have a higher benefit rate if your family includes children, and if you earn a low family income—less than \$25,921 per year. If you or your spouse receives the Canada Child Tax Benefit, you may then be entitled to the Family Supplement, which means a higher benefit rate. However, the benefit payments will never be more than \$547 per week.</p>
	<p>Canada Caregiver Credit.</p>	

	<p>Disability Tax Credit. A person with a “severe and prolonged” impairment in physical or mental function may claim the disability amount once they are eligible. Caregivers of dependents or spouses/common law partners may be eligible to have the disability tax credit amount transferred to their own tax return.</p>																										
<p>Canada</p> <p>Nova Scotia Department of Health & Wellness</p>	<p>Currently, Nova Scotia is the only province in Canada that has a monthly income or allowance available (known as The Caregiver Benefit Program).</p>	<p>If the caregiver and the care recipient both qualify for the program, the caregiver will receive \$400 per month.</p>																									
<p>Australia</p> <p>Department of Human Services</p>	<p>Carer Payment supports you if you can’t work in substantial paid employment. This can be providing full time daily care to:</p> <ul style="list-style-type: none"> • someone with severe disability or medical condition, or • someone who is frail aged 	<table border="1"> <thead> <tr> <th>Pension rates per fortnight</th> <th>Single</th> <th>Couple each</th> <th>Couple combined</th> <th>Couple each separated due to ill health</th> </tr> </thead> <tbody> <tr> <td>Maximum basic rate</td> <td>\$814.00</td> <td>\$613.30</td> <td>\$1,227.20</td> <td>\$814.00</td> </tr> <tr> <td>Maximum <u>Pension Supplement</u></td> <td>\$66.30</td> <td>\$50.00</td> <td>\$100.00</td> <td>\$66.30</td> </tr> <tr> <td><u>Energy Supplement</u></td> <td>\$14.10</td> <td>\$10.60</td> <td>\$21.20</td> <td>\$14.10</td> </tr> <tr> <td>TOTAL</td> <td>\$894.40</td> <td>\$674.20</td> <td>\$1,348.40</td> <td>\$894.40</td> </tr> </tbody> </table> <p>https://www.humanservices.gov.au/individuals/enablers/how-much-carer-payment-you-can-get</p>	Pension rates per fortnight	Single	Couple each	Couple combined	Couple each separated due to ill health	Maximum basic rate	\$814.00	\$613.30	\$1,227.20	\$814.00	Maximum <u>Pension Supplement</u>	\$66.30	\$50.00	\$100.00	\$66.30	<u>Energy Supplement</u>	\$14.10	\$10.60	\$21.20	\$14.10	TOTAL	\$894.40	\$674.20	\$1,348.40	\$894.40
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	<p>Carer Allowance is an income supplement for parents or carers. You need to provide daily care for someone:</p> <ul style="list-style-type: none"> • with disability • with a medical condition, or • who is frail aged <p>There's no income or assets test for Carer Allowance. We pay the same rate no matter what you earn or own.</p>	<p>If you are providing care to someone who is aged 16 or older Carer Allowance is \$127.10 each fortnight.</p> <p>If you are providing care for a child aged under 16 Carer Allowance is either:</p> <ul style="list-style-type: none"> - for a child with higher needs – \$127.10 every fortnight and a Health Care Card for the child - for a child with lower needs – a Health Care Card for the child <p>https://www.humanservices.gov.au/individuals/enablers/how-much-carer-allowance-you-can-get</p>
	<p>Carer Adjustment Payment is a one off payment. It helps families when a child up to 6 years of age is diagnosed with:</p> <p>a severe illness medical condition, or major disability</p>	<p>The most any family can get is \$10,000 for each child for one catastrophic event. How much you get depends on your family’s circumstances. You won’t pay tax on this payment.</p>
	<p>Child Disability Assistance Payment is a yearly payment to help parents with the costs of caring for a child with disability.</p>	<p>Each year you can get up to \$1,000 for each child who qualifies for Carer Allowance. If you are getting Carer Allowance for 2 children, you will get 2 payments.</p>
	<p>Essential Medical Equipment Payment is a yearly payment to help with increases to home energy costs. This can be from the use of essential medical equipment to help manage disability or a medical</p>	<p>The most you can get is \$154 each year.</p>

	condition.	
	<p>The National Disability Insurance Scheme aims to support people with a permanent and significant disability and will pay for some aids and equipment.</p> <p>Each state and territory has its own equipment schemes.</p>	Provides support to people with disability, their families and carers. Supports may be funded in areas such as education, employment, social participation, independence, living arrangements and health and wellbeing.
USA	<p>In 15 states, Medicaid offers a Cash & Counselling program (see cashandcounseling.org) that provides an allowance that can be used for various services, including paying family members for care.</p> <p>In some communities across the U.S., veterans who are at risk of nursing home placement can enrol in the Veteran-Directed Home and Community Based Services program that allows veterans to manage their own care, including hiring and paying their own caregivers.</p> <p>Also available to wartime veterans and their spouses is a benefit called Aid and Attendance that helps pay for in-home care, as well as assisted living and nursing home care. This benefit can also be used to pay family caregivers (means tested).</p>	Medicaid eligibility criteria apply.
Sweden	<p>The Swedish Care for the Elderly law, entitles caregivers to an allowance and social security protection comparable to what exists for care personnel in the formal caregiving sector.</p> <p>The municipality reimburses the caregiver of an elderly dependent with a salary equal to that of municipal formal home care worker. This salary is subject to income taxes. In addition, the Attendance Allowance is an untaxed cash payment to a care recipient to compensate a family caregiver.</p>	The maximum charge for home help, daytime activities and certain other kinds of care is SEK 1,772 per month (2016).

	<p>Eligibility is usually based on level of dependence/amount of caregiving (calculated care hours/week) and payment is around kr. 5000/month (~550 Euro).³²⁰ Each municipality has authority over the Attendance Allowance and whether and how it is offered is within their discretion – there is no federal or state regulation – and availability, payments, eligibility criteria, and maximum payment vary by municipality. https://www.bcli.org/sites/default/files/Family%20Caregiving%20-%20Chapter%206.pdf</p>	
<p>Norway</p>	<p>The Care Wage is a taxable wage available to caregivers who are providing extraordinarily burdensome care to severely disabled persons. The amount of the wage is based on care needs but the average pay is kr. 4600/month. However, this salary would purchase one month’s groceries plus seven train tickets in Oslo but is not adequate to cover the cost of rent in Norway. https://www.bcli.org/sites/default/files/Family%20Caregiving%20-%20Chapter%206.pdf</p>	

Appendix 2 Survey results

Following is the analysis of the survey responses. These have been integrated in the full findings for this paper.

The survey response rate of 406 is a finding in its own right, in that so many people took the time to respond so quickly, with around half responding in the first two days.

In our analysis we have concluded that overall the survey respondents wish to see urgent changes to current policies to fairly pay family carers. Their views reflect those of the stakeholders interviewed across age ranges and types of disabilities for this paper.

The views of those responding to the survey reflect those of the stakeholders interviewed, therefore the conclusions are not repeated here but are included throughout the paper.

Method and purpose of the survey

This was a brief easy to complete survey to encourage people to respond and to get the greatest response rate in the week the survey was open. It was a seven question survey using Survey Monkey to canvas views on paying family members who provide care. The survey ran for seven days from 16 March to 23 March 2018 and was electronic only.

The survey was independent (i.e. from any carer organisations or groups) and all responses came direct to us. An url link was sent via three key carer platforms¹⁴ for loading via social media. We understand it was shared far more broadly than that. Expectations were that there would be 60 to 80 responses; to receive more than 400 in such a brief period was noteworthy.

Throughout the analysis direct quotes from respondents (in italics for identification) have been used to show a sample of responses.

Respondents could tick more than one response in each question therefore some add up to over 100%. Of the 406, 71 (17%) responses were incomplete, but the majority of questions had been answered.

The purpose of the survey was to gather a wider response rate and voice from people who are family carers or support them, than we could during the interview process, about specific questions that arose from interview feedback from other family carers and key stakeholders. The survey analysis informs and feeds into this paper.

The full analysis of the survey is included in the body of this paper to give a full analysis.

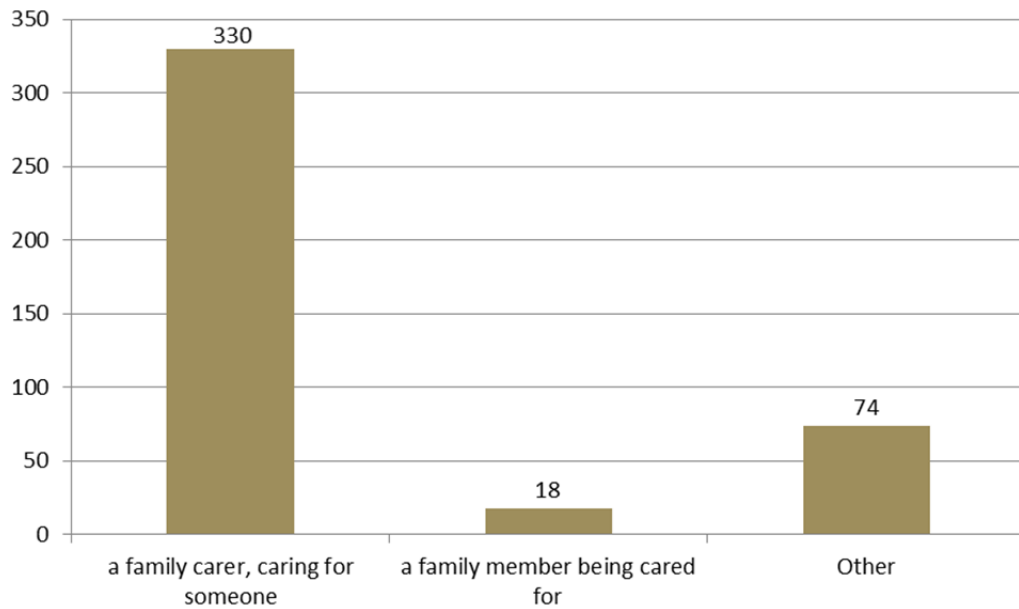
The respondents

We received 406 responses, with the majority (81 percent) being family carers. There were also responses from someone being cared for (4 percent), and 'others' (18 percent). 'Others'

¹⁴ Complex Carers Group, Carers NZ and a private Facebook group for carers receiving Funded Family Care.

included those who had cared for someone in the past, a friend to someone who was cared for, or cared, and support or other workers in a similar field.

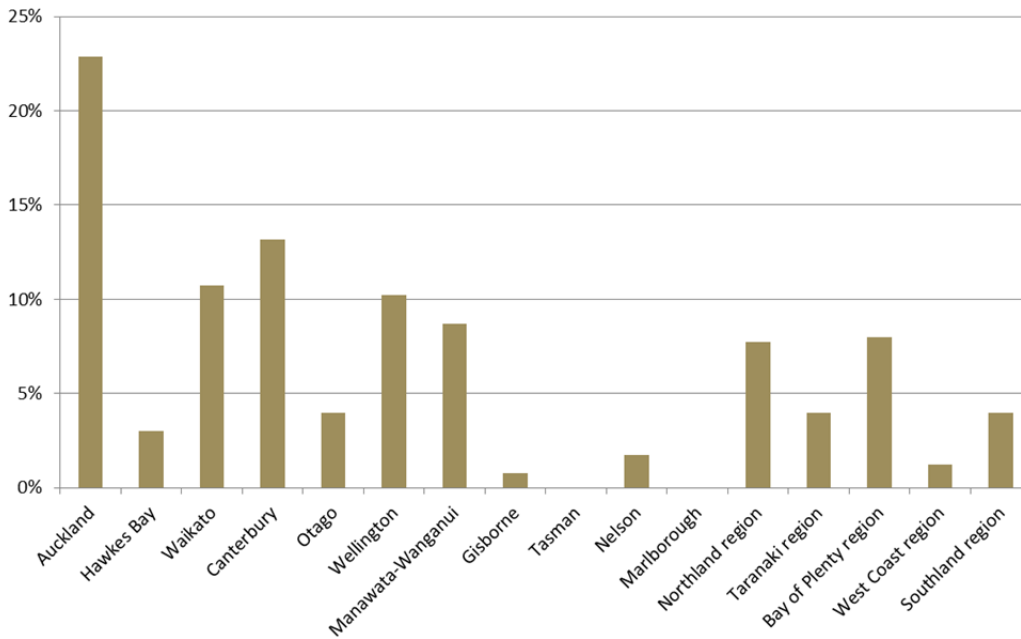
Figure 1 Please tell us a bit about yourself (n=406)



Source: Sapere analysis

Responses represented a good spread across the country. The majority of respondents came from Auckland, Canterbury, Waikato and Wellington. This was followed by Manawatu / Whanganui, Northland and Bay of Plenty.

Figure 2 What part of New Zealand do you live in? (n=402)

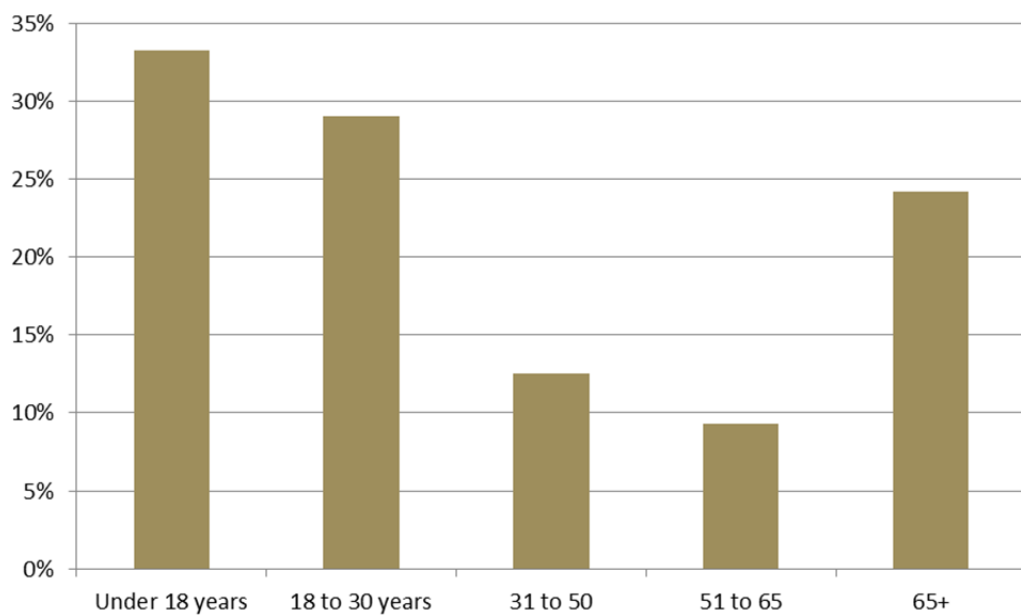


Source: Sapere analysis

The person being cared for

A third of respondents care for someone under 18 years of age (33 percent). Fifty-one percent are caring for someone aged between 18 and 65.

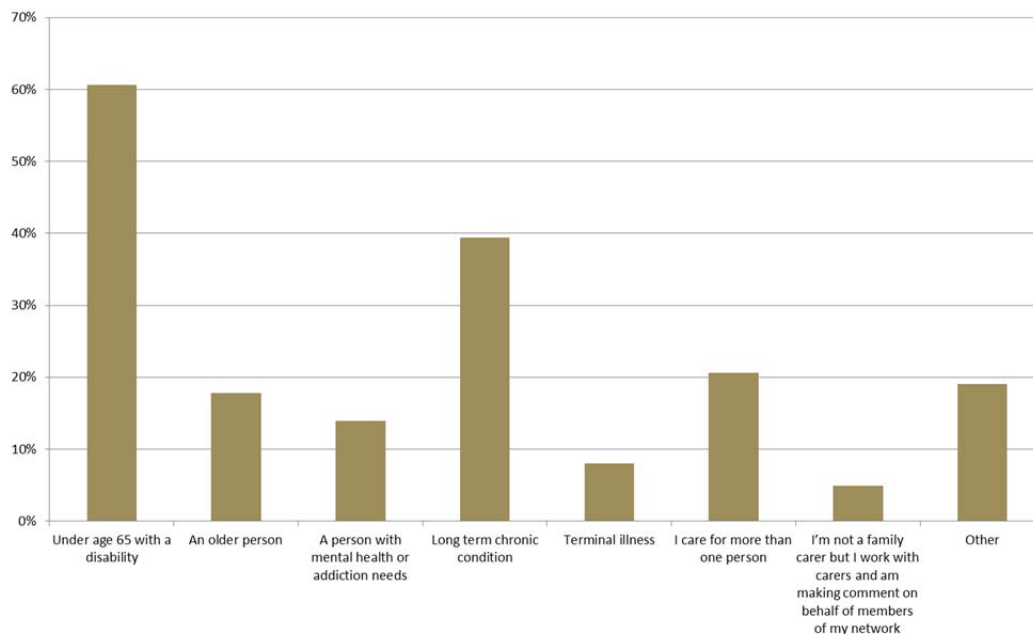
Figure 3 If a carer, what is the age of the person(s) you are caring for? (n=376)



Source: Sapere analysis

When asked about the type of care the person needs, the majority of respondents are caring for someone aged under 65 years with a disability (61 percent). Forty percent were caring for someone with a long term chronic condition. Just over 20% are caring for more than one person.

Figure 4 What type of needs/disability does the person(s) you are caring for have? (n=388)



Source: Sapere analysis

Note: Respondents could tick more than one type of need/disability, therefore the responses will add up to more than 100 percent.

Respondent views on paying family members for care

A range of commonly heard views on paying family carers was presented for respondents to state whether they agreed or not with them. Note: these were based on a mix of specific parts of current policies for paying family carers and feedback to date from carer and stakeholder interviews.

- most people disagreed (26%) or strongly disagreed (45%) that the person being cared for should be over 18. That is a total of 71% who disagreed or strongly disagreed.
- there was much stronger disagreement that partners and spouses should not be paid (66%). This was a double negative question (disagreement should not be paid) based on the policy, therefore the interpretation is that 66% thought partners and spouses should be able to be paid (there are more examples in the free text later in this analysis).
- most responses strongly agreed that the pay should be at the same rate as other paid carers e.g. support workers (68%).
- there were views as to whether the disabled person must be the employer of the family carer. Twenty one percent strongly disagreed the disabled person should be the employer and 26% disagreed. That is a total of 47% who disagreed in some way. A

further 32% were neutral, with 21% agreeing or strongly agreeing the disabled person must be the employer.

Table 5 Survey respondent views of paying family members

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
The person being cared for should be age 18 or over	45%	26%	9%	12%	8%
Spouses, de-facto partners or civil union partners should NOT be able to be paid as carers	66%	20%	9%	2%	3%
Family members should be paid at the same rate as other carers who might come into the home	4%	3%	4%	21%	68%
The disabled person must be the employer of the family carer	21%	26%	32%	15%	6%
A home and community services provider can be the employer of the family carer	12%	10%	39%	33%	7%

Source: Sapere analysis

Respondent views about the needs assessment process

Respondents were allowed to comment narratively (free text) on the needs assessment process. There were 267 responses. While a small number of these found the process to be OK, the majority of these comments were related to the overall process which they found to be unfair, stressful, over-complicated and intrusive.

'Too complicated and tangled in red tape.'

'Complex. Subjective. Challenging.'

'Too intensive and too long.'

'Parents should not have to be made to feel as though they are not worthy of caring for their loved ones. My assessment was terrible. I had to account for every single thing I do and even then it was not all considered caring. I think the definition of caring needs to be extremely broad and not narrow focused to home help.'

The nature of home assessment is an issue

Assessment processes using a comparative time measure for basic tasks was found by many to be ‘unrealistic’ and ‘humiliating’. There were also many responses that found the assessment process as not being thorough enough in terms of the importance of the decision for them, while a one-off visit may not reflect the realities of that person’s needs on a daily basis.

‘It is TERRIBLE! People assessing you that have never walked a day in your shoes and have 1 hour or so to make a decision that will affect your family in a major way!’

‘Someone who comes in for 5 minutes cannot judge your situation. Yet they do. And most don't get it their assessment right because you only see the tip of the iceberg in 5 minutes.’

‘This can be stressful for the client applying, and two hours is not long enough for the needs assessment to be completed correctly.’

Issues raised about the competency of assessors

There were also a number of specific issues raised as to the competency of assessors and the process which does not take into account medical opinion and is reliant on a non-qualified opinion of the assessor.

‘The assessor needs to be experienced in the requirements of the client.’

‘Confusion by the assessors doesn’t help. They need training and to really know their stuff.’

‘Should be completed by someone qualified e.g. nurse or carer.’

Respondents felt the assessment approach is not suitable and needs to be more flexible

People found it to be a deficit-based approach, and felt it was designed to be obstructive, with to the intention of fixing costs rather than providing help. They found the model to be inflexible, and not responsive if a person’s needs change.

‘It is currently a deficit-based model disguised as a strengths-based approach. If you have managed to be resilient for a time, you generally won't receive the funded support you may actually require long-term.’

‘Not empowering to families. It’s very deficit and negative.’

‘I think it is reductionist and also tries to put needs into a box. Lacks flexibility.’

‘Limited and not flexible enough. Had time taken away that was used for exercises and two years down the track it's harder to transfer Mum as her strength has diminished so makes lifts etc., harder. Quick to take time away and hard to get support back.’

The process varies between regions and assessors

There were a number of responses that were related to the variability of the assessment process between regions, and between assessors.

‘Inconsistent varying not just from one NASC to another but also within the same NASC. It is unfair. It is aimed at personal and household management but what about guidance for the person, keeping them supported and safe in their community. It is time the system was updated and actually served the true needs of people with disabilities.’

'It's not very consistent at present! People with the same needs get such a wide variance of help, some lots some little.'

'There is no transparency in how the needs are accessed or measured, the outcome of the assessment seems to vary depending on who is doing the assessment, as a carer I would like to be able to see the rationales behind the needs assessment outcome.'

Family carers should be paid, regardless of their relationship to the person receiving support

When asked an open question for any other feedback on the topic, 260 responses were entered. The overwhelming majority stated that carers should be paid, regardless of relationship to those being cared for, i.e. child, sibling or partner.

'The need to care for someone should not come at the financial cost of the carer. Work is work and should be paid fairly. A family member giving up work to look after a loved one deserves the financial support of earning just as much as a non-related caregiver.'

Most of the feedback is centred around the implications and costs that would be incurred if the family member required residential or outside paid carers. Many pointed out that they already incur substantial, non-recoverable costs such as travel for medical and other appointments which payment for their caring role would help to offset.

A few responses also indicated how the current model perpetuates poverty.

'Families should not be discriminated against if they would rather do the caring; many have had to give up their jobs to care for their child and been forced into benefits and poverty.'

'Financial impact of disability is huge. Families need to be supported to be as financially stable as they would have been if there wasn't a disabled family member. This is truly valuing disabled people and their carers. People should not be living in poverty because they have a disabled member in the household.'

'In my view it is essential. Let's face it, the work is arduous, unappealing and thankless, and that is when it is done as a paid job! Very often the family member is the only one that is actually able or willing to look after the person. It can lead to severe distress for the patient if they have to have someone unsuitable. Families who care for a family member are almost always severely financially disadvantaged anyway - in our case in addition to having to drop to one income, we also pay for many other interventions out of our own pocket.'

'Currently there is no transition to caring, you can go from being fully employed to caring for your family member in a blink, there is no support to rearrange budgets. On the flip side, there are no opportunities to gain professional accreditation for being a carer. If the person you are caring for dies, you are expected to return to paid employment, you have hands-on skills, but not qualifications, so you are competing with immigrants and school leavers.'

A few also equated being paid with being valued and recognised for what they do:

'We need recognition.'

'That they should receive the same respect and recognition from the community for doing an amazing job.'

'It values their contribution. It recognises that families have a vested interest in the (person's) wellbeing and is contributing to our community. It is open to abuse. Accountability is going to be a challenge especially for stressed out families and those who are not highly capable themselves. They also need support. Because of exhaustion I made an error in my Carer Support claiming from the wrong pot of money. Why can't it all be combined?'

Some comments highlighted that some respondents are near breaking point, and without help and support may not be able to continue caring, which has implications for the whole family:

'I am forced to work overnights because I am required to care for my mum 24/7. I have three young children under 5 and I have had two days off in three years. I don't receive help from my family, but they do just enough to prevent me from accessing respite care. I think it's gutting that I'm at the point of considering residential care for Mum because I'm just so desperate to have one day that I don't have to look after someone. Talk about set up to fail with zero supports.'

'The time has come for the role of a full-time carer to be recognised. Not only are we totally exhausted because of the lack of respite, but we are also restricted in our own quality of life. We are unable to pursue vital self-care and are restricted in time with our friends (if we still have any). All of these issues need to be addressed as well as paying us for our time which is usually all night, every night.'

'Although I am caring for two elderly parents my downtime doesn't exist. My day can start from 5am - 1am sometimes. I am frequently exhausted but I have a ton of patience to do what must be done because they are ... my parents.'

'While being paid as a family carer I think respite and other options should be available to give the disabled person a break from the carer. There needs to be an independent accountability process to ensure the person being looked after is living a "good life" and has opportunity for growth. Also the carer needs a break from caring to look after mental and physical wellbeing. While they may be the best person for the role there is a danger of not letting others help and becoming overwhelmed. The majority of families with a disabled member are on one income, it is hard to find employment while a member needs constant care. Many carers struggle financially and it would lead to a better quality of life if some of that pressure was taken away by allowing them to be paid an equal wage for the work they do over and above natural support.'

Appendix 3 EGL Principles

1. **Self-determination**

Disabled people are in control of their lives.

2. **Beginning early**

Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.

3. **Person-centred**

Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.

4. **Ordinary life outcomes**

Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.

5. **Mainstream first**

Disabled people are supported to access mainstream services before specialist disability services.

6. **Mana enhancing**

The abilities and contributions of disabled people and their families are recognised and respected.

7. **Easy to use**

Disabled people have supports that are simple to use and flexible.

8. **Relationship building**

Supports build and strengthen relationships between disabled people, their whānau and community.

Long term change direction

Significant redesign and change will be needed on multiple fronts:

- Building knowledge and skills of disabled people: to ensure disabled people understand the direction for change, and can exercise more choice and control over their supports.
- Investment in families/whānau: to assist them to support their disabled family member to have a good life and help them develop aspirations about what can be achieved.
- Investment to build inclusive communities: to ensure communities, including businesses, workplaces, schools, and cultural, sport and recreational activities, are accessible, welcoming and recognise the contribution of disabled people.
- Changing government systems and processes: to support the system redesign e.g.

integrated, outcomes-focussed contracting, individualised funding, funding pooled from across Votes and involving disabled people and families in governance, system and service design and monitoring.

- Changes to service provision: to align service governance, delivery models, workforce capability, accountability measures, monitoring and evaluation with the vision and principles of the transformed system.

Appendix 4 Key stakeholders interviewed

All interviews were agreed to be non-identifiable in the report. No comments are attributed to an individual in this report. It was our role to analyse the comments and draw themes. It was important to hear from stakeholders from a range of parts of the system including families, disabled people, policy makers, funders, Judicial experts involved in previous and potentially future Court cases, government officials and representative groups e.g. Complex Carers, NASCs, etc.

The following is a summary of the numbers interviewed or involved by group.

Families, n=9

Ministry of Health, n=5

ACC, n=2

DHBs, n=3 (with one being on behalf of several DHBs)

MSD, n=1

Carers NZ and the NZ Carers Alliance, n=2 plus a round table meeting of n=14

Disabled Persons Assembly, n=1

NASCs, n=3

Other NGOs and providers, n=4

Journalist, n=1

Legal counsel, n=5

Total: 36 interviews

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