
Report for the Ministry of Health

Targeted engagement on Funded Family Care and Paid Family Care

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'Government should consider what does payment to family carers actually mean and need to be; not just try and make what we have got better.'

About Sapere Research Group Limited

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Glossary

ACC	Accident Compensation Corporation <p>ACC is a New Zealand crown entity responsible for administering the country's universal no-fault accidental injury scheme.</p> <p>ACC has a paid family care scheme for family carers of people affected by injury-related disabilities.</p>
Carer Support	<p>Carer Support is a subsidy to help full-time carers take time out from caring (respite). It provides reimbursement of some of the costs of using a support person to care and support a disabled person while the carer has a break.</p>
DHB	District Health Board <p>New Zealand's 20 DHBs are responsible for ensuring the provision of health and disability services to populations within their geographical areas. DHBs have paid family care schemes for family carers of: people aged 65 years and over, people of any age with mental health and addiction support needs, and people of any age with long-term chronic health conditions. These services are accessed via DHB-funded Needs Assessment and Service Coordination services.</p>
DSS	Disability Support Services <p>DSS is a Ministry of Health directorate responsible for the planning and funding of disability support services. Responsibilities include purchasing disability support services for people (generally under 65 years of age) with a long-term physical, intellectual and/or sensory impairment that will require on-going support.</p> <p>These services are accessed via a Ministry of Health-funded Needs Assessment & Service Coordination service in each DHB area.</p>
FFC	Funded Family Care <p>Funded Family Care is Ministry of Health funding for some eligible disabled people to employ their parents or family members over 18 who they live with to provide them with their personal care and/or household management supports. It is sometimes called paid family care.</p>
HCSS	Home and Community Support Services <p>Funded HCSS are services to help disabled people live at home. They can help with both household management (e.g. meal preparation, laundry, cleaning) and personal care (e.g. eating and drinking, getting in and out of bed, dressing, showering and going to the toilet, moving around home).</p>
IF	Individualised Funding <p>Ministry of Health IF is available for eligible people who have either a HCSS or respite allocation. IF gives disabled people increased choice and control to choose who provides this support, and how and when they use</p>

it, with options ranging from engaging support workers and planning how supports will be used, to employing care providers and managing all aspects of service delivery.

Ministry (the) Ministry of Health

The Ministry of Health (the Ministry) is the public service department of New Zealand responsible for healthcare in New Zealand.

MSD Ministry of Social Development

MSD is the public service department of New Zealand charged with advising the government on social policy, and providing social services. It provides income support including payments, entitlements and New Zealand superannuation.

NASC Needs Assessment and Service Coordination services

NASCs are organisations contracted by the Ministry of Health, and/or DHBs, to work with individuals and their family or carers to: identify their strengths and support needs, and determine their eligibility for funded support services.

NASCs are contracted by the Ministry of Health for disability support services and by DHBs for health of older people services and mental health & addiction services.

NASCs allocate Ministry-funded disability support services and help with accessing other supports. These services are then delivered by their respective service providers. In DHB funded health of older people services, allocation responsibilities are sometimes shared between NASCs and HCSS providers.

Part 4A The Government included Part 4A in the New Zealand Public Health and Disability Act 2000 (the Act) in 2013 to enable payment to family carers. Part 4A also sought to prevent any legal claims against the former policy preventing payment and the new policy enabling payment.

Respite Respite is having a break from caring responsibilities. Funded respite options can include Carer Support, Individualised Funding, or the disabled person spending time during the day or overnight in a facility (respite house or other facility).

Supported Living Payment Supported Living Payment is a weekly payment from the Ministry of Social Development to help people that have, or are caring full-time for someone with, a health condition, injury or disability.
Carers can receive the payment if they care for someone at home who isn't their partner, and would otherwise need to receive hospital or residential care.

Executive summary

This report details the methodology, question and a summary of the themes emerging as priorities from the e-survey and the targeted engagement (meetings) on Funded Family Care. It summarises the views of some families and organisations on options to improve what we know to be the key issues in the Disability Support Services Funded Family Care and District Health Boards paid family carer policies. Alongside this paper sits the e-survey report as a companion paper that informed this report. Key themes from the e-survey and the targeted engagement have been integrated into this report. It is advisable to read the two reports in conjunction for the full detail of what people said.

A strong response to the e-survey and interview requests

Overall feedback from the e-survey and the targeted engagement meetings was overwhelmingly consistent in most matters. Most people could answer the priority question very well, spouses, and partners being able to care was really important, as was being paid a fair rate.

We received 911 e-survey responses and interviewed 22 individuals and group representatives. Some represented wider groups, such as Non-Government Organisations (NGOs) concerned with family carers. We believe that the high level of response shows the level of commitment to these policies being changed. We have heard that people will be wanting feedback on their input and urge the Ministry to carefully consider how and when this is communicated.

Due to the very tight target engagement timeframe not all people or groups we wanted to talk to, have been yet. We look forward to working with the Ministry to see how this might be resolved moving forward.

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

Widespread dissatisfaction with the assessment and allocation process and a 40 hour a week cap

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

A wider system change may be required

In some of the meetings there was a very strong feeling that it is time to look at whether paying family carers should sit in a wider system model than just in Health. Options people felt would be simpler and better were for example, the Ministry of Social Development, the Payment for Working Families model or even the Accident Compensation Corporation model. Two points made in particular were:

- Not having employer employee relationships in a family.
- Being able to flexibly use your funds as your family would like or need, without being judged or prevented from doing that.

A number of other points were made

- People want a system that values the contribution of family carers: A common thread, running throughout responses of the survey and the meetings, was the need for a system based on principles of respect, valued family contributions, dignity, and listening.
- Ageing carers: A number of people raised the question of what happens to their family member if they become unable to care, particularly as carers themselves are ageing.
- Spouses and partners should be included and considered family members caring for children: An overwhelming majority of people in both the e-survey and the meetings believe that spouses, partners and civil union partners should be eligible for Funded Family Care for a variety of reasons including that they are trusted and provide safe care.
- Fair pay and ensuring a living income for full-time carers: Carers talked about the financial strain of caring and the need to ensure a living income for full-time carers, who are unable to undertake other employment.
- Ensuring the wellbeing of the whole family: There is a need to look after and ensure the wellbeing and safety of all family members—disabled people and family carers. With regard to disabled people this means ensuring they are receiving good quality care.

There is general agreement that no one should be paid caring 24/7 and they should be supported in other ways, but access to quality and safe community supports and respite is often not available. People felt that currently the Funded Family Care policy dis-incentivises multiple carers, and the inflexibility of the policy makes it more difficult.

Characteristics of the solution

In some of the meetings the following characteristics of what they would want in an improved system came up. These follow:

- Applicable across all policy and age settings; make it for all people
- Be practical and pragmatic so change can begin but plan out what else needs to happen, and when
- Flexible and gives real choices and options
- A clear message is not one size fits all (linked to flexibility and choice)
- Recognition of the wider system for families as a whole unit (e.g. a whānau ora approach), not just Disability Support Services and Funded Family Care.

We dwell further on two aspects:

- A system that is culturally responsive and appreciates diversity: Ensure Funded Family Care works for all people from all ethnicities and cultures. We asked if there are any specific aspects that should be considered for Funded Family Care for their culture, family, whānau or aiga. The majority of people said they did not have any other aspects to be considered. People talked about both practical aspects of administering a system,

such as documents in other languages and access to interpreters, but also a general theme of appreciating diversity and ensuring services are mana enhancing.

- Arrangements should be sensible, simple and flexible: Generally people felt employment relationships should be a choice. Many people talked about the impracticalities of the employment arrangement they find themselves in. People would like to receive their payments direct into a nominated family carer’s account and direct into the disabled person’s bank account. Other agencies’ systems and processes are reported to work better for them or others they know, where payment processes are simpler and allow flexibility in how the funds are spent.

Top themes for change

As already known, overwhelmingly people believe the current policies and legislation (Part 4A of the Act) to be unfair, unlawful and discriminatory. There were a variety of solutions posed to resolve this and the following are those where there was the most consensus.

Table 1 System top themes for change: from the meetings only

Theme	Description	Majority consensus?
Have one Government Policy for supporting families across Government Departments and Ministries	Departments and Ministries refer to examples given by participants such as Education, IRD, MSD and Work and Income Some people also referred to ACC processes	Mainly only came up near the end of targeted engagement (meetings) Suspect not full agreement on this due to previous Carers Strategy Consultations feedback Be good to consider this in line with emerging Carers Strategy Consultation and Disability Strategy Consultation themes
If the Health Ministry and DHBs are constrained by their contract and payment policies and processes what is the “appetite” to move these funds for family carers to another Ministry or Government Department	When discussing FFC payment options for the future other current precedents for a simpler and more flexible process for payment came up.	Mainly only came up near the end of targeted engagement (meetings)

Table 2 Top eligibility and policy themes for change: joint from the e-survey and meetings

Theme	Description	Majority consensus?
Repeal of Part 4A	Repeal of the Act, Part 4A	Mainly. But there was varied opinion on this. Some concern over what it could mean
Spouse, partner or civil union partner being paid	Currently excluded. General consensus the relationship status of your carer should be irrelevant	Yes
Age of paid family carer	The current age is 18 years or older to be a paid family carer. Some thought it could be more linked to other NZ law e.g. children can care if they can still go to school, etc. No statement on an older age for caring, except for concern about the carer's health	Some – mainly linked to not wanting child carers
Age of disabled person	The current age is age 18 years. Many people commented that it should be more based on need and could be age 16 years, or even younger in some circumstances	Yes – mainly (A few thought it could be older and some thought it could stay at age 18)
Terms of engagement: status of employer	Most thought the disabled person with complex and high needs should not be expected to be the employer – concern for mental capacity But also many thought it should be a choice as to who the employer is – for both the disabled person and the carer	Yes
Pay rates and 40 hour cap	Most wanted a fair wage, in line with other carers and that the 40 hour cap is not fair Less agreement on what an upper limit cap would be, but not one person wanted someone to be paid 24/7 as they need a break too	Yes

Theme	Description	Majority consensus?
	Safety and supervision needs should be taken in to account	
Assessment and allocation of hours by NASCs	<p>General consensus that this process is difficult, not accurate re actual need and flawed (for many reasons)</p> <p>Suggestions including taking it away and making a banding system not a task based hourly number</p>	Yes
Natural family supports	<p>This doesn't have a clear and transparent definition yet NASCs are required to consider them when assessing and allocating hours</p> <p>Needs a clear definition</p>	Yes

1. About this report

In the Health and Disability system in New Zealand there are two key policies and methods that govern paying family carers to undertake care for family members in their home. These policies are from Disability Support Services (DSS) of the Ministry of Health (the Ministry) Funded Family Care (FFC) policy and the district health board's (DHBs) Paid Family Care policies for older people, people with long term chronic health conditions and people with mental health and or addictions. There is governing legislation¹ that guides both policies. In this paper we refer to both policies as FFC for simplicity.

ACC payment to family carers' policy, also a public system payment mechanism for carers, is out of scope for this paper.

All FFC is limited to undertaking care and support for home and community type care, such as personal cares and domestic assistance. Any support needs outside of the home are currently excluded such as day activities, shopping and such like.

There have been five years of litigious activity and challenges about the DSS FFC policy and the governing legislation. The main challenges have been around discrimination in the legislation and policy, as well as some unfair and complicated and difficult to use parts of the policy. The DHB's Paid Family Care policies for older people's needs, people with long term chronic health conditions and people with mental health and/or addictions have not received as much public profile or challenge, to date.

On 27 September 2018 the Hon Dr David Clark and Hon James Shaw announced the Government's plans to change FFC policy and their intention to repeal Part 4A of the New Zealand Public Health and Disability Act (2000) (The Act). This is the relevant part of the Act that governs paying family members for care.

Advice is underway from the Ministry to Ministers regarding future options for these Health policies. As an input for their advice to Ministers, the Ministry engaged Sapere Research Group (Sapere) to provide guidance and services for targeted engagement with a range of family carers, disabled people and other key sector organisations. The key focus on this engagement is about solutions to the issues, as the issues have already been well canvassed.

The purpose of this paper is to detail what we did, how and who we engaged with, and what we found. This includes both from people and organisations we met with and from the e-survey we ran. There is a full paper on the e-survey *Survey on future options for Funded Family Care in New Zealand* which is a companion paper to this findings paper. It is advisable the two papers are read in conjunction for the full detail of what people said.

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

1.1 What we asked people

Previous work and a significant amount of input from family carers and their advocates (where applicable), along with the judgements of several Court cases between families and the Crown, have highlighted and recorded the issues with the current legislation and especially the DSS policy. The issues with the DHB policies, at this stage, appear to relate more to lack of awareness of FFC as an option and that it is not routinely being offered.

As noted, due to the issues being widely documented, the focus for this targeted engagement was on solutions and options for the future. However, many people in both the e-survey and meetings did want to reinforce their issues and the impacts this has on them as families, and the disabled family members they care for.

The questions generally related to specific parts of legislation, eligibility and policy where issues had been identified, but in summary we were asking:

1. From the issues already raised what options, changes or solutions would you see for the future?
2. Are there any challenges for these changes that you can identify?
3. Of the issues and solutions for change are there any priorities for change?
4. Is there anything else you want to raise with regard to paying family members for care?

1.2 What we did: our approach

We undertook a limited number of in depth qualitative interviews and two focus groups. We also ran an e-survey. With severely constrained timeframes, due to Ministry requirements and processes, we undertook this engagement in a practical and pragmatic way during October 2018. Planning for this commenced in September and analysis was undertaken in late October and early November 2018.

As already noted we provide both this primary report and a full analysis of the e-survey as a companion paper.

For both the interviews and e-survey we recorded inputs and undertook a thematic analysis to identify the key themes and highlight priorities. The following sections give more detail of each of the processes.

1.2.1 Individual meetings and forums

From our wide knowledge of the disability and health sector we identified a number of individuals and groups to engage with. We look forward to working with the Ministry to see how this might be resolved moving forward.

We met or spoke by phone with representatives (most of whom are family carers themselves) from:

- Carers New Zealand (the peak body for family carers in New Zealand)
- The NZ Carers Alliance (two focus groups, one in Auckland and one in Wellington—total of 11 NGOs were represented, including one specific Pacifica NGO)

- Complex Carers Group
- The Human Rights Commission
- Three family members and/or the disabled people they care for (they approached us)
- A family advocate (they approached us)
- Needs Assessment and Service Co-ordination Association (NASCA)
- The manager of the Disability System Transformation.

Others that were identified and approached, requiring following up, or can be approached include additional representatives from or for:

- Māori
- Pacific
- National Enabling Good Lives Leadership Group
- New Zealand Home & Community Health Association
- Disabled Persons Organisation Coalition
- DSS Consumer Consortium.

1.2.2 E-survey for broader input

We developed and tested an e-survey, finalised and loaded it live. Anyone could respond to the e-survey although we were targeting family carers. The e-survey ran from Tuesday 16 October to midnight Sunday 28 October 2018.

We received 911 responses, at least 300 (50%) more than expected based on previous experiences of between 400 and 600 survey responses. In the e-survey family carers were asked to provide information about their demographics and caring status and all survey respondents were asked about their views on the legislation, eligibility and policy issues that have already been raised over previous years.

The interview and e-survey questions reflected the same topics.

2. What we found: responses were consistent

There was consistency in the information gathered across the interviews, focus groups and the e-survey.

There are three clear themes in the feedback:

- Health and Disability system-wide issues
- How families are supported overall by Government
- Possible legislative and FFC policy specific responses.

For the purposes of this paper, based on the FFC policy, we note the person's disability needs are complex and the person has high or very high needs.

2.1 Themes from the meetings

There was a lot of discussion on how people felt the Government should consider wider Government policy frameworks and precedents for how they already support families. They suggested Government consider payment to family carers as part of this; not to continue to silo this support within Vote: Health. The key principles sought are flexibility and simplicity.

This flexibility and simplicity included considering how families are supported over and above what families normally do, for additional demands or extenuating situations due to supporting a disabled person in a caring role.

2.1.1 Paid support should be one part of a much wider Government policy system

There was robust discussion and the principles of simplicity, choice and flexibility for support were very clear.

A simpler payment method is called for with some examples of other precedents

In the interviews and some of the focus groups particularly, there was a lot of discussion and feedback on how FFC and other payment to family members for care should fit within a wider Government approach and framework for supporting families. People gave examples of Government policy and payment precedents for supporting families over and above what families are expected to do, or can do for themselves. These examples were reported as all having a simple approach that allows flexibility and doesn't necessitate:

- Requirements to be an employer
- Tax and other legal associations of being an employer, such as IRD, ACC levies, KiwiSaver etc.

Discussions were on the mechanisms for how payments or supports were given. Examples of precedents given for supporting families with various payment mechanisms were:

- Working for Families Tax Credits
<https://www.ird.govt.nz/wff-tax-credits/working-for-families-tax-credits.html>
- Work and Income Benefits
<https://www.workandincome.govt.nz/eligibility/>
- Education supports like the Ongoing Resourcing Scheme
<https://www.education.govt.nz/school/student-support/special-education/ors/criteria-for-ors/>
- Winter Energy Payment
<http://www.superseniors.ms.govt.nz/news-events/news/2017/winter-energy-payment.html>
- Childcare Subsidy
<https://www.workandincome.govt.nz/products/a-z-benefits/childcare-subsidy.html>

A key principle being drawn on was that already there are precedents where Government assists families with relatively simple and established mechanisms, without the extensive rules, assessments and barriers like people currently experience in FFC. Also importantly, that there is no restrictions on, or monitoring of, how those funds are spent and by whom, unlike FFC. People felt very strongly that disabled people and families should be able to determine how and when they spent the allocated funds for FFC and to not have the myriad of rules around it like there are now—from eligibility, through to assessment, allocation and then payment.

This created discussion and debate as to, perceived irrelevance of the FFC policy about and what could be paid for, the benefits and disadvantages of different payment mechanisms. Specifically the terms ‘allowance’, ‘benefit’, ‘tax free payment’ through to employment and employer relationships were all debated.

The role of a family member being an independent contractor was also raised as an option, however plenty of debate ensued due to the fact a contractor still has to have self-employment requirements such as legal, tax, ACC obligations and relationships continuing the burden of these administrative and legal processes for families.

The landing on the discussions was that various options should be in place so people can choose to be an employer if they wish, who their employer might be through to they don’t have to have an employment relationship, to receive funds.

2.1.2 Should payment to families remain in Vote: Health

Along with this was a call for Government to test if payment for families for disability and other health financial payments and supports should remain within Vote: Health or become part of a wider Government strategy for supporting families (e.g. as mentioned above, direct tax free payment type arrangement that is not scrutinised on how it is used) just like other benefits.

A clear message from one group was to ensure clarity on what legal responsibilities and payment policies and intent the Government has with families.

Does Government actually have an appetite for moving paying families out of the small and inflexible silo of DSS and actually commit to caring as a valuable part of society, like they proclaim to mean?

Along the lines of the quote above, following from this was a key question around what is the Government's inclination and ability to move all disability supports into a benefit type system and therefore change all the payment mechanism options, and not just consider options within current DSS, Ministry and DHB legal and funding mechanism constraints.

A secondary, but very important, principle in this discussion was that an assessment and allocation of 'hours' is not appropriate and does not reflect needs. If different payment paradigms and mechanisms were possible, as above, then it would be possible to move from a task based allocation and hours approach to a banding or 'entitlement' approach. This banding approach was also noted as already being a precedent in disability residential care and aged residential care.

2.1.3 The DSS FFC package approval and review processes are inherently flawed

In addition at the meetings we had feedback that for DSS FFC packages the process is that the package needs to go from NASC for consideration and approval by a third party.

This process is reported as being closed and flawed as packages appear to be unilaterally changed based on the documentation given, without meeting the family in question. People feel that if the assessment wasn't accurate in the first place this second step in the process compounds the issues.

Then the package is required to go via an organisation called Manawanui in Charge.² There is a perception from some people that this process was inherently flawed as well and didn't give any objective choices to families. In the future a variety of choices and transparent flexible processes, that are much simpler are called for.

The current review process is criminal. The person who approves the packages is the person who reviews it if there is a challenge. That is criminal.

Why does everything have to go via one organisation? Why does it need to anyway? Do they take any of our family funds for that? We are not sure and don't really understand what they do and how they get paid.

In general people felt that if the assessment and allocation system was significantly changed then the review process would not be needed in this form. However there should always be some form of redress, but it needs to be independent and not part of the original process.

² <https://manawanui.org.nz/>

2.1.4 Flexibility and real choices are vital

Families reported feeling that the current rules and systems, including employment requirements and payment systems in DSS³, leave them with no choices and no flexibility to use the allocated supports as they need to. At times, due to changing family circumstances, this might mean wanting to use hours allocated in different ways than the NASC had originally intended. This does not mean requiring more funds, but rather being able to use them in a meaningful way that supports the disabled person and the family carer the best.

Two repeated examples given were ability to pay others for some of the care at times and/or using more funds in one period and less in another (flexibility).

Just give us the money and let us get on with it. Get rid of all the red tape.

These systems create undue and unnecessary stress for people already under stress.

Each family circumstance is different and needs can change and flex over time. The reality of this and the choices people may need to make to meet their needs should be recognised.

Currently for both DSS and DHB systems this is reported by families to not be the situation. Sometimes this was thought to be due to the policies and other times due to the payment cycles e.g. fortnightly.

We note also that in the survey a lack of flexibility was noted as an issue.

2.1.5 Some cynicism towards the Ministry not wanting to pay families and managing risk, affecting sensible policy

There was a lot of cynicism towards this targeted engagement actually being open and the Ministry truly wanting to hear from and listen to families, and Government being open to making changes that will really make a difference. In general people felt that the Ministry was keen to ‘tinker’ at the edges of the policy and put a ‘band aid’ on FFC, as opposed to actually considering what should be done.

Let's do it differently. Do you think the Ministry will listen?

If the same people who designed the first policy and currently implement and manage it, are doing this [current process], then we will get more of the same. Government needs to be bold and make changes that will really make a difference!

People thought that to make the changes needed Government needs new people—not the current Ministry people. This is a major Government wide system change that is needed.

³ For DHB FFC, the employment relationship is via a contracted home and community support services provider, so some of the DSS constraints and family frustrations, e.g. at the amount of risk and paperwork of being an employer, do not apply.

2.1.6 What ‘natural supports’ are needs to be clearer and less subjective for everyone

This topic was raised repeatedly as an issue from the meetings. Not so much in the survey.

Currently, especially in DSS NASC processes, NASCs are required by the Ministry to identify and determine what the level and type of typical ‘natural supports’ a family might be expected in New Zealand as norms to do for their family member. That is, before any funded supports can be considered. There has been, and continues to be, an exceptional challenge to the lack of objectivity and consistency of the determination of how much ‘natural supports’ should be in any individual family circumstance. It was reported that this doesn’t take in to account individual family circumstances and/or their ability to do other ‘natural supports’.

There may be different family norms for different cultures in what or how ‘natural supports’ get done. This may also be the same if the family member is in paid employment or has other such commitments.

It was also reported that the definition of ‘natural supports’ from DSS⁴ is not clear, it changes, and therefore, how NASCs determine what this means. It is seen as subjective and is difficult for NASCs as well, as this is the first part of where challenges to assessment might begin. People also reported their perception that DSS uses their increasing expectations of what natural supports are, and how much families can do, to manage DSS budgets.

Natural supports..... ha! All that is, is DSS using it as a rationing thing for their budgets. It is nothing to do with what families actually can do and disabled people need.

What do natural supports actually mean? DSS keeps changing their thoughts on this and telling NASCs what to do. But it seems to be different across the country and sometimes even within NASCs. This is a very unclear and unfair part of the process.

The discussion around ‘natural supports’ relates directly back also to the assessment process, but merited a section on its own due to the significant impact this has on supports a disabled person and their family might be allocated.

If the disabled person and family supports was to move from a needs based system to a more flexible simple system, the underlying premise of what families should be and can be expected to do in certain circumstances needs clarification and consistency across the Government system.

2.1.7 Other legal considerations fed back to us

In addition to employer and employee status, there were other legal considerations noted for going forward, if the system was to change. However, as already stated, some are within the current system. These included:

- Mental capacity to be an employer

⁴ In fact it is not clear how much of this is a requirement of DHB funded NASCs and processes.

- Ensuring employment law and related aspects are upheld — notably IRD, tax law, ACC levies, Kiwi Saver
- Guardianship requirements
- Substitute decision making and role of advocates
- Potential impact on other personal or household income streams and benefits (e.g. MSD benefits); means tested or not.

We will work with the Ministry to discuss these and if required make further comment on them.

2.1.8 Transparent communication is key

From the interviews in particular there was significant cynicism that there will be an open and transparent process resulting in changes that would make real and significant differences and choices for disabled people with profound disabilities, and their families. To help mitigate or alleviate this there was a call for open and ongoing communication of:

- Advice and change processes — internal to the Ministry, DHBs and with Ministers (e.g. dates, options, rationale)
- Full feedback on this targeted engagement process and what people said
- What changes are being advised to Ministers by the Ministry
- Financial modelling assumptions and potential impacts (to help inform people’s advice on priorities for change)
- Any constraints or challenges to getting changes made.

2.2 Common themes across the survey and interviews

Here we highlight themes that were common across the survey, interviews and focus groups. They relate more directly to specific aspects of the FFC policy than the discussion in the above section.

2.2.1 Spouse or partners to be paid

The current FFC policies state that spouses, partners and civil union partners cannot be paid under FFC. We asked if people thought a spouse/partner/civil union partner should be able to be paid. Of the 680 people who answered the question, an overwhelming majority (92% or 624) answered ‘yes’.

In the meetings people were very clear that paying a carer should be irrelevant of their relationship to the person being cared for. Explicitly it was stated that definitely spouses, partners and civil union partners should be included in who could be paid; but it should still be a choice about who does the care. This should be the choice of the person being cared for and if they don’t have the ability to communicate, their advocate or spokesperson. Also the spouse or partner should have a choice and be able to say no to family caring if they want or need to.

2.2.2 A whole of family approach is needed

There has been a move over recent years to strengthen the disabled person's voice and roles within the NGO and disability sectors. Families report that at times this has meant that disabled people and family carers have been seen by policy makers and others as individuals and/or adversarial to each other. Quite rightly the Ministry also promotes strong principle based stances on the rights of disabled people. However the way this has worked compounds family carers believing they are being marginalised and not valued for their input as part of the wider caring workforce, with their own rights and wellbeing needs. They feel they are a valuable and important part of the caring workforce and this should be demonstrated by Government.

For many people with very complex disability needs the family unit can be vital in their support networks and circles.

The Ministry's rhetoric and principle based approaches are not the reality for many of our families. It is just not working out there in homes and in the community.

The disability community is not all the same. Our people with these very high needs...many of them rely on the families.

Therefore there was a desire from many at the meetings to see a holistic whānau ora approach to considering the rights and support needs of both the disabled person and family carers. Being considered together this makes for a better solution and outcome for both as well as a more long term sustainable funding path.

2.2.3 Varied opinion on the need to repeal Part 4A of the Act

Ministers have already announced their intention to repeal Part 4A of the Act.

In the survey we asked if people agreed with this intention and it was completed by 581 people. Of those, the vast majority (82%, 476) agreed that Part 4A should be repealed.

Families at meetings were not united in the need to repeal all or some of Part 4A of the Act. A lot of this appeared to be due to a lack of surety about what repeal might mean and if it would be a full or partial repeal.

However people were united in the need to continue to be able to pay family carers.

What if they repeal it and things get worse for families? How will we know?

I am not sure about repealing the Act and if it will achieve what we as families need. I think it is the DSS policy that needs getting rid of. Let's start again and make it a real choice for families and the people they love.

2.2.4 The age the person being cared for and of the carer; more consistent on the level of need of the disabled person

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

In the survey 653 respondents expressed an opinion as to whether a paid family carer should be aged 18 years or over—three-quarters (75%) agreed. In both the survey and the meetings generally people felt that age 18 or 16 years for the disabled person being cared for, was appropriate but with the ability to have exceptions, based on need.

Age depends. If a family member is caring for a person younger than 16, but they have significant 24/7 needs then that is over and above what families would normally do. It may also impact on their employment options.

No upper age limit was reflected in feedback. Exceptions included things like the wellbeing and health status of the carer and the needs of the younger person with disabilities. Practical examples included such things as the size and weight of the person, the need for the family carer to give up paid employment to care (when typically this would not be required of a family member) and specific needs of the disabled person (e.g. behaviour management, health management, safety and risk).

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

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

From the meetings in general the consensus was that the age should at least fit with other New Zealand law, for example a person needs to be age 14 to be left alone and/or to 'babysit' others. Some felt age 18 years was appropriate and others age 16 (generally linked to other New Zealand laws and norms, like ability to vote, get married and/or receive certain types of benefits).

On the topic of an upper age of being a paid family carer, feedback was more linked to the wellness and physical capabilities of the carer.

I'd worry about very old people looking after another very old person. What about their [carer's] health? What if they had to lift the person?

It is more about the needs of the person and the person caring for them. Sometimes progressive diseases sneak up on you and there is one more thing to care for one after another and then it is too late. The person caring has an injury or worse.

On the topic of the person being cared for, there was general consensus that they should have high or very high needs.

I think though that the person with a disability should have high or very high needs. This is not just for everyone.

I agree the person [being cared for] should have high needs. It isn't for everyone. Isn't it like band 4 and 5 for residential?

2.2.5 There should be choice about the employment relationship

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

There was some discussion at the meetings over if the disabled person was non-verbal and had no communication options, there was potential for 'capture' by the family member who might be paid and that they use their own voice and not reflect the true choice and rights of the disabled person.

Some of the disabled people we are referring to in this cohort are the most vulnerable. We need to make sure they have an advocate to support them if they don't have their own voice to say who they do want doing their cares.

I think spouses should be included but also they have the choice NOT to be the carer. It is a choice to be made together by the two people. It is important to preserve the family relationships and for some that [the paid caring role] may change it.

This was accompanied by a call for pay rates to be based on equity and parity with other carers doing the same job, levels of skill and experience.

Lastly, having the activities limited to personal cares and domestic assistance is unfair as it should be about an amount families can be paid in total and then be flexible and be able to be used for the needs of the person and/or the family carer (i.e. to have a break and pay another carer; go out in to the community, etc.).

Overall the discussion on employment and roles and responsibilities eventually linked back to the choices and flexibility families are seeking in terms of:

- Assessment (how the process works and not linking it to minute based task functions)
- Allocation processes, moving from hours to bands (or some other form of more flexible arrangements)
- Choice (people should be able to choose if there should be an employment arrangement with the disabled person, an agent or a contracted provider, or not).

Some people in the meetings noted the precedent of the carer support payment not being a wage and just being able to be paid to a person, carer or family. However others noted their concern in linking this with FFC as carer support is clearly a subsidy that pays for a small part of the care required for the disabled person, especially when considering the level of complex needs in question.

Just take the burden away from us of all the legal things, paperwork, tax and administration. Even though [name] is meant to be my employer I am the one who does all that. In effect I am my own employer – it is nonsense!

2.2.6 Payment mechanisms complicated

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

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

The answers in the meetings were the same.

2.2.7 The assessment and allocation process is flawed

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

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

Allocation of hours

The e-survey asked if people agreed with the number of hours allocated to them to care for their caring. Of the 298 people who answered that they had experienced an assessment, 75 per cent (224) did not agree with the number of hours allocated.

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

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

In the meetings only one person said they were happy with their allocation of hours. Most people expressed dissatisfaction with the assessment process and felt that it underestimates the time required to provide good care. There was strong feedback that the assessment process (i.e. via NASC) is now outdated and that there needs to be a significant change to be truly needs based and in line with the Enabling Good Lives (EGL) principles, if FFC stays within Vote: Health.

The assessment process is just awful. A stranger comes to your house, judges you and then ticks a few boxes. It is so humiliating – and they don't listen to your needs anyway.

What can I say about the assessment process! It is so degrading and they don't listen to you.

Allocation of tasks by minutes just doesn't work for this group of people with high and changing needs. Just give a sum of money and let's stop all this argy bargy over minutes. We don't need this stress.

Maximum hours

Overall people felt that 40 hours per week cap, irrelevant of need, was very unfair. This linked to the perception of the unfair assessment and allocation process as much as to the FFC policy and the approval payment mechanism processes.

In the e-survey we asked whether people agree with this cap. 589 people answered this question, 68 per cent (404) disagreed that 40 hours should be the maximum number of paid hours a week.

At the meetings there was a very strong call to move away from task based minute assessment and allocations (e.g. 'x' number of minutes for task (a) and 'y' number of minutes for task (b)). This included the need for many families to be present, or on call, 24/7. Sometimes this is known as supervision or oversight, although there is some dissension on that term.

The solutions people promulgated for removing the 40 hour cap and making a fair wage included:

- Move away from hours to a package, using 'banding' similar to that of the DSS and aged care residential pricing linked to levels of need but not task focussed.
- Have a minimum number of set hours (e.g. 40 hours per week which can then be built on depending on need).
- In the e-survey one suggestion was a minimum of 60 hours per week as this would give a living wage based across seven days of care a week (seven days being the reality for many people and families at this level of need), not five.

2.2.8 General agreement that no one should be paid for caring 24/7

Even though it was reported and acknowledged that many families do care 24/7 for disabled people with high and complex levels of need we did not identify anyone that thought a single family member should be paid for this level of care. More importantly was the wellbeing and support required of the 'primary' family carer and subsequent other supports to support them.

This might be other family members and/or a mix of more 'traditional' supports purchased by funders (e.g. contracted Home and Community Support Providers, respite care, day services, etc.).

2.2.9 Ensuring safety at home and in other services

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

In the e-survey we asked people how they think safety should be considered or checked in the home when a family carer is receiving a FFC payment. 597 people answered this question. The majority of people agreed that some system or oversight is needed but that it

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

From the meetings a significant concern for many people is that community based quality and safe supports for disabled people with this level of need are not in place. Specific examples, repeatedly given, included people with a combination of profound disability, chronic health and progressive needs, including such things as feeding, oxygen saturation monitoring, prevention and management of escalating behaviours and/or seizures, could not access services. Services would say they don't deliver to that level of need. Respite, including emergency respite, was also commonly stated as a gap, even in some of the bigger centres.

Services or supports that had previously been tried and found to be unsafe, or where there are significant gaps in service options for this cohort, included home and community support services, respite care, day services and/or residential care. Families reported not being able to trust these services based on previous experiences of abuse, significant medication errors, inappropriate supports etc.

Therefore even though they may be allocated some hours and access to these services they were either not available, wouldn't take disabled people with this level of care needs and/or they didn't trust them (usually based on previous experience) so couldn't safely leave their loved one there.

I actually don't want to be a family carer. But there are just no other safe choices.

No one will take her for care, even for respite and yet I am expected to do all those health cares myself. I've had no training.

3. References

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