

**Disability Support Services
Ministry of Health**

Evaluation of Funded Family Care



Judy Paulin, Sue Carswell & Nicolette Edgar

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Judy Paulin & Nicolette Edgar, Artemis Research NZ Ltd
Sue Carswell, Carswell Consultancy

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Executive Summary

The Funded Family Care (FFC) policy was introduced on 1st October 2013.

The Ministry commissioned an evaluation to assess the impact and effectiveness of Funded Family Care and the reasons influencing its uptake in its first year of operation.

Evaluation participants who contributed their perspectives of FFC were:

- 45 disabled persons and/or family/whānau carers (40 who were accessing FFC and five who were not);
- 13 Needs Assessment and Service Coordination (NASC) representatives;
- five organisations representative of disabled people and family/whānau carers and
- one manager from the Funding Advisory and Support Service (FASS).

In almost all of the 45 interviews with disabled persons and/or family/whānau carers, it was the family/whānau carer who did most of the talking. Many of the disabled persons were profoundly intellectually disabled which severely limited their ability to participate in the interview process.

Positive impacts

Nearly nine in every ten FFC funded families spoken with said that FFC funding had impacted positively on them in one or more ways.

Almost two-thirds said FFC had put their household on a better financial footing and nearly one half mentioned improvements to the health of the disabled person or family carer. The formal recognition of family carers as members of the paid workforce added to their sense of well-being.

Almost all FFC funded families would recommend uptake of FFC to others in similar circumstances. About three-quarters would do so without hesitation.

Effectiveness

There is no doubt the FFC policy is effective for some, but its overall effectiveness is constrained by its limited uptake by those who could potentially benefit from it. As at 1 April 2015, only 191 adult disabled persons nationwide were accessing FFC (compared with 1,600 forecast).

Reasons influencing uptake

The most common (and related) barriers to FFC uptake identified were:

- the requirement of the disabled person to make an informed decision about FFC. A substantial proportion of disabled people for whom the policy is intended to support are severely intellectually disabled and do not have the mental capacity to make an informed decision
- the disabled person as employer
- accessing the funding is too complicated and bureaucratic
- a lack of awareness of FFC among those disabled persons or family carers who had not been involved in, or had not closely followed the associated court cases, and some misinformation about FFC

- the restriction of funded support hours to 'personal care' and 'household management'
- the family carer payment set at the minimum wage.

The concluding Chapter offers some solutions to increasing uptake.

1 Introduction

1.1 Background

The New Zealand government needs to make difficult decisions about the types and amount of health services and supports it provides for its people. Vote Health accounts for more than a fifth of core Crown expenditure, and spending has been increasing faster than national income for most of the last 60 years.¹ In GDP terms, the increase has risen from 3.1% in 1950 to 6.9% in 2011. This reflects an increase in both the volume of services and the benefits provided, as well as higher unit costs.

The *Disability Support Services Strategic Plan 2010–2014*² sets out the Ministry of Health's (the Ministry's) overall purchasing strategy and actions for providing disability support services to New Zealanders. The Ministry's strategies for achieving its vision '*Disabled people can live in their homes and take part in their community in the same way other New Zealanders do*' are to:

- give disabled people and their families more control, choice and flexibility
- modernize and streamline supports
- manage risks to the sustainability of the support system
- give disabled people equitable and quality services, including implementing *Whāia te Ao Mārama* (the Māori Disability Action Plan), and a National Pasifika Disability Plan.

The Ministry currently provides services to approximately 30,000 disabled persons living in New Zealand. Most are aged less than 65 years, and have a physical, sensory or intellectual disability, or a combination of them. Other support is funded through District Health Boards and the Accident Compensation Corporation.

Until a group of nine parents of adult disabled children and two of their adult disabled children successfully challenged the Ministry's position (Ministry of Health v Atkinson [2012] NZCA 184; [2012] 3 NZLR 456 (14 May 2012)), the Ministry had excluded parents and resident family members from payment for the provision of various disability support services to their children.

The nine respondents claimed that the exclusion amounted to unlawful discrimination against them on the basis of their family status. Parents were providing services for their disabled children but were not being paid, and their adult children were denied their choice of caregiver.

The Ministry's position had been that funding of disability services was designed to complement or supplement services provided by the disabled person's natural supports that included family members. Further, that its determination of the level of funded support related to a disabled person's unmet need rather than his/her level of disability.

Following the Court of Appeal decision in the respondents' favour, the Ministry devised a series of options for the payment of family carers. Its preferred option for Funded Family

¹ Mays N, Marney J, King E. (2013). *Fiscal Challenges and Changing Patterns of need for Health and Long-Term Care in New Zealand*. Policy Quarterly Volume 9, Issue 4, November 2013 Pages 35-46.

² Ministry of Health (2012) *Disability Support Services Strategic Plan 2010 to 2014*. Wellington: Ministry of Health. <http://www.health.govt.nz/system/files/documents/publications/dss-strategic-plan-2010-2014.pdf>

Care (or FFC) – and the option that was implemented – was to make funding available in two specific situations:

- in very high need situations where a disabled person's ability to remain living at home is under threat because their family situation is fragile
- in high need situations where a disabled person has such high support needs that meeting those needs means that a family carer who wishes to work full time in another job outside the home is unable to do so.

The FFC scheme fits with Māori disabled people's desire to have their whānau valued as their primary support system.³ Disability is a significant issue for Māori, with one in five reporting having a disability.

The Ministry's estimated annual costings for FFC were based on an assumption that there were 1,600 disabled people living in very high or high need situations who would be eligible for and take it up (Cabinet paper. Paid Family Carers Case: Proposed response, 11 December 2012).

1.2 The evaluation

The Ministry commissioned an evaluation to assess the impact and effectiveness of Funded Family Care (FFC) and the reasons influencing its uptake in its first year of operation.

Evaluation participants who contributed their perspectives of FFC were: 45 disabled persons and/or family carers (40 who were accessing FFC and five who were not); 13 Needs Assessment and Service Coordination (NASC) representatives; five organisations representative of disabled people and family/whānau carers and one manager from the Funding Advisory and Support Service (FASS).

The evaluation methodology is included in Appendix 1. In almost all of the 45 interviews with disabled persons and/or family/whānau carers, it was the family/whānau carer who did most of the talking. However, the carers spoke in a way that was considerate and inclusive of their disabled family member. Many of the disabled persons were profoundly intellectually disabled which severely limited their ability to participate in the interview process.

1.3 Content of this report

Drawing heavily on the responses of evaluation participants, the remainder of this report is organised as follows:

- **Chapter 2** presents evaluation participants' perceptions of the positive impacts of the FFC policy in its first year of operation
- **Chapter 3** takes a closer look at the processes connected with the functioning of the FFC policy with a view to finding clues as to why uptake of FFC has not been as high as anticipated
- **Chapter 4** identifies factors influencing FFC uptake

3 Ministry of Health. (2012) *Whāia te Ao Mārama*: The Māori Disability Action Plan for Disability Support Services: 2012 to 2017. <http://www.health.govt.nz/system/files/documents/publications/whaia-te-ao-marama-maori-disability-action-plan.pdf>

- **Chapter 5** offers some solutions to increasing uptake of FFC among those it is intended to support.

2 Positive impacts: What aspects of the FFC policy are working well?

2.1 Introduction

One of the main aims of the evaluation is to assess the impact and effectiveness of the FFC policy.

This Chapter draws on the responses of FFC funded families and some NASC staff to questions about what they perceived the positive impacts of the FFC policy to be.

2.2 FFC funded families' experiences, recommendations & advice

FFC funded families were asked how the FFC arrangement was working out, and what had changed for the better.⁴

Nearly nine in every ten FFC funded families spoken with said that FFC funding had impacted positively on them in one or more ways. The benefits these families most frequently reported were:

- FFC had put their household on a better financial footing (mentioned by almost two-thirds)
- improvements in the health of the disabled person and/or the family carer (mentioned by nearly one half)

Almost two-thirds of families who reported any change for the better were very grateful for the difference the government support had made. For example:

'It has made a monumental difference to how our family unit runs. ... We run a tight ship any way but we can eat properly, [disabled daughter] is kept warm and comfortable. ... We can get on with dealing with the things that need dealing with, the really important things, like [disabled daughter]'s care and looking after ourselves because if either of us go under the ship stops sailing. So we can look after ourselves better and [disabled daughter] stays healthy and well and that is good for everyone.'

These FFC employed family carers mentioned the funding had enabled them and their families to eat more healthily, pay utility and car bills, replace broken appliances, pay optician and dental bills, save a little (for example, for holidays), and start saving for retirement.

One family carer said the FFC payments had made the difference between being able to keep the family house or not. The bank had recognised the FFC payments to the family carer as income.

'It's taken the noose off. We have been able to keep our house. [Accessing FFC funding] made all the difference because I had no income and because of the earthquake ... We are still fighting insurance companies ... Circumstances were at the worst but when the bank found out I would be paid their attitude changed.'

4 They were also asked about any downsides. Their responses to the latter question are incorporated elsewhere in the report.

Nearly one-half of families who reported any change for the better mentioned improvements to the health of either the disabled family member, the family carer, or both.

The following quote illustrates a FFC funded mother's observations to improvements in the health of her disabled son:

'There are lots of benefits. First and foremost the benefit for [disabled son] was his health. He just blossomed having Mum home. ... He has not had a day sick with illness since we started on the scheme which is huge, absolutely.... He just laughs 24/7. He goes to bed laughing and he wakes up laughing and he's far happier, far more settled ... It's just been huge. It was so the right thing to do.'

This mother attributed this to the high quality of the care she could wrap around her disabled son at a time when it best suited or was needed. For example:

'Since I took over his health has been a lot better because the carers weren't giving him his meds on time. I would come home and he would have a seizure. Or they had overdosed him.'

Family carers could provide the care as and when disabled family members needed it and were not tied to a precise schedule as external caregivers were. This flexibility within a 'routine' meant, for example, the disabled family member could sleep in, which in turn, could result in less seizures. For example:

'We're not tied to [external] caregivers coming in and working with her [according to their schedule. She was the first one on the list. She had to be up at 6.45am regardless and now ... she is able to sleep in. ... If she has had a really rough night, then I can just let [community provider] know she is coming in a bit later and let her sleep in. ... She is having less seizures so that is always a bonus.'

The disabled family members were said to be less exposed to illness too since they were spending more time in the comfort of their home and had the need for fewer outside appointments, and the outside appointments they needed could be arranged at a more convenient time.

'It is less stressful not having to leave the home [so much] and juggle appointments outside the home. And thinking god is she going to be sick again...She can go and lie down if she is not well. The appointments can be organised for after she is up and had all her cares done. So that side of things has been brilliant.'

One mother living in a small rural town mentioned that FFC funding had enabled her disabled daughter to have a better quality of life by getting out and about.

'I think for [disabled daughter] being able to get out and about, it's a plus. We did Christmas in the Park. We've gone to [larger town] shopping. Days like that shows her the bigger, wider world is a reasonably friendly place for people with disabilities.'

Access to FFC was reported to have health benefits for family carers too. Those who had left paid work outside the home to become FFC employed carers were the most likely to mention that this had reduced tension for themselves and among family members.

'The tension is not there as it was. The pressure is not there as it was. Before we went on the scheme I had run out of sick leave. It meant if [disabled son] was sick one of us had to stay home. Up until then we had juggled it around ... but there was nothing left to juggle.'

'If she gets sick - like she is not well at the moment – I don't have to stress about taking time off, you know. I can just chill, do what we need to do. ... If she's sick I don't have to stress to try to find someone to come in and sit with her. I can attend to her needs a lot better than what I could ...'

At least two FFC funded families mentioned that formal recognition of carers – usually mothers – in a paid role had improved their sense of wellbeing.

'Mum is now employed. She is not doing any more or any less than she was doing before, but she has a status boost of being an employed person rather than a filthy scrounging beneficiary.'

'The money is great, obviously, it's been fantastic. I feel like finally we are being recognised as being carers. ... From a well-being point of view, I feel like that what I am doing is recognised and worthwhile. What a huge difference that makes.'

Other benefits of accessing FFC mentioned by a FFC recipient or FFC employed family carer included:

- Government savings that the government would otherwise need to spend on residential care services (mentioned by 1)
- The ability under FFC to employ a family member as a replacement carer (1)
- The possibility for a retired carer to have sufficient funds to continue with the care of a disabled family member (1)
- A greater sense of financial security (1)
- Pressure from former involvement with Work and Income had gone (1)
- The ability to support a disabled son at home who might otherwise be in compulsory care (and with poorer quality of care). (1)

When prompted, none of the FFC funded families responded that the employer-employee arrangement under FFC had a negative impact on family dynamics, though it could generate some banter. The following example illustrates this:

'We have jokes about it. She was in the bedroom one day and she yelled out "Mum, would you mind going and getting me some chocolate milk down the road?" and I'm like, "Later, you know" just winding her up, "Actually I don't know if you've been good enough to have chocolate milk." And she yells out back down from her bedroom, "If you don't go and get me my chocolate milk I'm going to give you a written warning", and it was like, "Yeah, rightio. Here we go." So, it's never created any friction. We can joke about it.'

Three FFC funded family carers said that while FFC had improved their situation, the impact could have been greater if they had been allocated more hours than they had wanted or paid at a higher rate.

Recommend uptake of FFC to others in similar circumstances?

Families receiving FFC were asked whether they would recommend uptake of FFC to other families in similar circumstances.

All except one of the families receiving FFC said they would. About three-quarters would unreservedly recommend FFC. For example:

‘Yes, absolutely. ... It’s been an absolute game changer for us.’

‘Absolutely. I think that everybody that needs it should take it.’

About one-third of these families had gone ahead and recommended it to other families in similar circumstances.

About one-quarter put a rider on their recommendation of FFC. For example:

‘Yes, but only if it suits them. They have to work out the funds and everything to see if it’s beneficial. If I had still been on a benefit, I wouldn’t have taken it up.’

One family carer said s/he would not recommend FFC until her right to make a complaint of unlawful discrimination about family care policy to the Human Rights Commission was restored.

Advice to others in similar circumstances

Those who recommended FFC to others in similar circumstances were asked what advice they would give others considering whether to apply for it.

In order of decreasing frequency, disabled persons and/or their family carers advised others in similar circumstances to:

- seek information, advice and assistance from others – from FFC-funded families, organisations representing disabled people and their families, and the local NASC (mentioned by 7)

‘Find people who can help you to cut through the red tape.’

‘I think the best advice would be to go and talk to different people [FFC families] and maybe organisations ... to get that support until the policy is clear.’

- approach the assessment process with perseverance and patience, and not be intimidated (mentioned by 7)

‘You just have to sort of bite your lip and do what they want to do and then wait for it to grind through the organisation and eventually it will come out.’

‘It’s a bit like John Kirwan’s thing. If you get someone who doesn’t get it just keep going until you find someone who does and then say “This is not right.” Or “I think, you know, we need to have another look at this because things have changed” and with children with disabilities things can change relatively quickly.’

- be open and honest with the NASC assessor and expect that the assessment process or follow-up monitoring visits may feel intrusive (4)

‘You should be open to having your job scrutinised to a certain level to make sure that you are doing the job you are paid for like you would in any paid sector.’

- opt for SmartPayroll to manage fortnightly payments to family carers (4)
- do their homework thoroughly in order to fully understand the implications of FFC in their particular circumstances - whether the FFC payments to the family carer would incur secondary tax, for example (3)
- factor in community-based activities to counter any feelings of isolation (2)
- set up a separate bank account for the employer for the sole purpose of managing FFC funding (2)
- hone their computer or accountancy skills (2).

2.3 Perspectives of NASC representatives

Formal recognition of family carers for the work they do to support disabled family members was by far the most frequently mentioned response of NASC survey participants to the question of what aspects of the FFC policy had been most beneficial for their clients. Eight of the ten survey participants who responded to this question mentioned this.

Families who had typically been providing unpaid support for their disabled family member for years now had some financial support. For example:

'Families ... now feel recognised and valued that what they do is worthwhile.'

'[FFC] provides a formal role for a previously under acknowledged group.'

The financial support was perceived by NASC representatives as alleviating – at least partially – financial pressures on some families who had experienced financial hardship because of their choice to care for a disabled family member at home. For example, they wrote:

'Being able to access FFC has changed some families' lives significantly and ensured the disabled person can remain in their home for longer.'

'Some families have foregone paid employment elsewhere ... This had created financial hardship in those families which FFC was able to partially alleviate.'

Two NASC representatives relayed instances of family members resigning from paid work outside the home or coming off benefits to take up family carer roles funded through FFC. As one NASC put it:

'Most families want their disabled person to remain in the home for as long as possible to ensure not just safe and effective care is provided but also in a loving nurturing environment. Who better to do that than family?'

The only other benefit mentioned by one NASC participant was that some families seemed to be appreciative of the monitoring visits especially the first one or two.

2.4 Chapter Summary

- Nearly nine in every ten FFC funded families spoken with said that FFC funding had impacted positively on them in one or more ways.
- Almost two-thirds said FFC had put their household on a better financial footing and nearly one half mentioned improvements to the health or wellbeing of the disabled person, family carer or both of them.
- When prompted, none of the FFC funded families responded that the employer-employee arrangement under FFC had a negative impact on family dynamics.
- Almost all FFC funded families would recommend uptake of FFC to others in similar circumstances. About three-quarters would unreservedly do so.
- Families spoken with would most commonly advise others in similar circumstances who were considering whether to apply for FFC to first seek information, advice and assistance from others, and if they decided to investigate it further to approach the NASC assessment process with determination and patience.
- Eight of ten NASC survey participants thought formal recognition of family carers for the work they do to support disabled family members was the aspect of the FFC policy that had been most beneficial for their clients.

3 The FFC policy in detail

3.1 Introduction

This Chapter takes a closer look at the FFC policy, starting with applying the eligibility criteria for FFC. It then moves more or less sequentially through the processes connected with the functioning of the policy.

Its purpose is to start looking for clues as to why uptake of FFC has not been as high as anticipated. As at 1 April 2015, only 191 disabled persons were accessing FFC (and for an average of 29.4 hours each.)

Like Chapter 2 it draws on the responses of FFC funded families and NASC survey participants as well as those from some representatives of disabled persons' or carers' organisations.

3.2 Applying the eligibility criteria for FFC

A disabled person's eligibility for FFC requires them to meet all the primary eligibility requirements and at least one of the secondary requirements.⁵ As a starting point, the disabled person must be assessed as having high or very high disability-related needs.

The primary criteria require the disabled person to:

- be aged 18 years or over and to have been assessed by a NASC organisation as eligible for HCSS funding **and**
- confirm to the NASC facilitator their preference to employ a resident family/whānau member to provide them with the personal care and household management supports within their HCSS allocation **and**
- choose to employ a family/whānau carer who is aged 18 years or over and not the disabled person's spouse or partner.

The secondary criteria require that:

- the disabled person cannot remain living at home if they cannot employ a family/whānau carer to provide them with their personal care⁶ and household management⁷ supports **and/or**
- their chosen family/whānau carer is prevented from working in alternative full-time employment because of the disabled person's disability-related needs.

3.2.1 Perspectives of FFC funded families

FFC funded families were asked whether they thought the eligibility criteria were fair or unfair. Nearly six in ten who answered this question thought the eligibility criteria were fair, nearly four in ten that they were not, and one family carer thought the criteria were both fair and unfair at the same time.

5 For the exact wording see section 3.1 & 3.2 of the policy.

6 Personal care is not defined in the Policy. It includes assistance with showering and consuming food or assistance with night support in some cases.

7 Household management is not defined in the Policy. It includes assistance with cleaning and cooking.

The question did not evoke much further comment. Those who did expand on their rating were supportive of either broadening the criteria or the interpretation of the criteria in some way. For example, one family carer expressed concern that s/he did not know the basis on which disabled persons were being grouped as 'very high needs' or 'high needs' and in any case thought all intellectually disabled persons were 'high needs.' Another suggested the wording of the secondary criteria be broadened to provide for the situation where any adult disabled person who wanted to remain living at home could do so with their support needs provided by a family member.

3.2.2 Perspectives of NASC representatives

NASC survey participants had found it more testing to apply the secondary criteria than the primary criteria to determine whether a disabled person was eligible for FFC.

Half of the 14 NASC survey participants had found it either 'very easy' (3) or 'easy' (4) to apply the primary criteria and six had found it 'neither easy nor difficult.' Only one had found it 'difficult.'

In comparison, four of 13 NASC survey participants had found it 'difficult' to apply the secondary criteria. Five had found it to have been 'neither easy nor difficult' and four either 'easy' (3) or 'very easy' (1).

Seven of the survey participants provided comments related to the eligibility criteria.

- Three commented that they had found the eligibility criteria confusing, with two adding that their confusion had diminished over time as they had become more familiar with it.
- Another two commented specifically on disabled people and/or family/whānau carers excluded by the criteria: one on the exclusion of some disabled persons with medium disability-related with limited access to external support); the other on the exclusion of partners as carers.
- One commented on the time required by the NASC to gather together the information with which to make the decision about a disabled person's eligibility for FFC.
- Lastly, one passed on two sets of feedback from NASC service facilitators. The first was about the challenge of interpreting the secondary criteria in light of different cultural norms around the care of disabled family members. The second was the observation that the NASCs' different use of the Support Package Allocation (SPA) tool to determine the level of support a disabled person required could create inconsistencies in FFC decision-making among the NASCs.

3.2.3 Perspectives of organisations

A representative from one organisation for disabled people and carers spoke of feedback s/he had had from disabled persons or family carers about inconsistencies among NASCs in the application of the eligibility criteria. This meant the same person in different parts of the country may or may not qualify for FFC. If the policy was not consistently applied, this had significant impacts on typically very high needs people and their families who were making difficult choices, often facing a whole barrage of extra costs, and struggling to keep it all going.

A representative from another organisation expressed concern that people who did not use the 'right words' could miss out on FFC funding even if they did in fact meet the criteria. S/he explained the issue this way:

'It's a constant in this advocacy work with stuff with the Ministry of Health. There gets to be this sort of underground network of people who say "If I use these words to describe my situation I won't get it. But if I use these words I will pass the hurdle." That's not a response to genuine need. That's a response to learning to say the right words and I find that silly. And the people who don't learn to say the right words, they miss out.'

3.2.4 Summary

- Nearly six in every ten FFC funded families asked thought the eligibility criteria were fair and nearly four in every ten that they were not.
- NASC survey participants had found it more testing to apply the secondary criteria than the primary criteria to determine whether a disabled person was eligible for FFC.
- One representative from a disabled persons' or carers' organisation expressed concern about apparent inconsistencies among the NASCs in the application of the eligibility criteria. Another that the way the eligibility criteria were worded left room for different interpretation or application.

3.3 Assessment & allocation of FFC funded hours

Under FFC, a NASC can allocate an eligible disabled person no more than 40 hours/week of personal care and household management supports. If a disabled person's combined personal care and household management need is over 40 hours/week, the additional hours can be provided either through Ministry contracted service providers or providers contracted through Individualised Funding (IF).⁸

Other supports provided under Home and Community Support Services (HCSS) such as supporting the disabled person to access community activities are not included within FFC, but may be funded through other Ministry (Disability Support Services) funded services.

3.3.1 Perspectives of FFC funded families

Assessment process

The assessment process determines the extent of a disabled person's disability-related needs which includes what their family or natural supports are able and willing to provide to meet these needs. Because these needs may change (now that under FFC the family could potentially be paid for some of these supports) a disabled person may need to be reassessed if they or their family want to be considered for FFC eligibility.

FFC funded families we interviewed were asked to reflect on how well the assessment process had gone from their point of view.

Just over half of these families thought that the assessment process had gone well and just under half that it had not gone so well.

⁸ Individualised funding is funding that enables the disabled individual to contract their own disability supports other than, or in addition to Ministry contracted service providers.

Those FFC funded families who thought the assessment process had gone well mostly put this down to a positive long standing relationship with a NASC staff member. For example:

'They [NASC] know X well because of having ongoing contact since she was a baby and the person we deal with we have been dealing with for years. It makes it really easy because she knows X's case so well.'

The personal qualities of NASC personnel were consistently described in positive terms, regardless of the outcome of the FFC assessment. (*'The needs assessor is a thoroughly experienced man, a lovely guy, got lots of common sense ...*).

Nearly two in every ten FFC funded families mentioned that the person they had dealt with at local NASC had not been fully conversant with the FFC policy in the beginning. (*'Z NASC was very good but was obviously confused about what was happening and that was understandable. It was just coming on board at that point in time.'*)

Two common themes mentioned by just under half the families for whom the assessment process had not gone so well related to:

- the outcome of the assessment process - most frequently that the number of hours allocated under FFC were less than they had expected (also see next section)
'There's nothing wrong with the NASC assessment but it's transferring what's in the NASC assessment to getting the hours for it. That's where the system turns to custard.'
- the frequency of assessments and timing of the FFC assessment relative to other ones
'Well, I thought it was ridiculous actually because they had already done an assessment and knew his needs. I didn't think there was a need to do another one because they were the same assessment really.'

Some other criticisms mentioned by one or two families for whom the assessment process had not gone so well included:

- the conflicting signals they had received from the NASC as to eligibility for FFC and the battles that had ensued as a result. (*'We have enough battles just in daily life ... the agencies that are meant to be supporting you are making it more difficult.'*)
- that the assessment form was not specifically designed for FFC, it assumed the disabled person had the intellectual capacity to answer questions, and that in relation to specific activities there was no option of 'fully dependent'. (The options are 'independent', 'supported' or 'assisted'.)
- the long time it could take from applying to the FFC payments starting. In one case it was reported as taking 10 months
- the limited or poor quality of communications with the NASC (*'The NASC person will ring up and they will say: "Oh, we're allocating this and this and this." That's it. That's our interaction with the NASC.'*)
- that the FFC assessment had been undertaken without meeting face-to-face with the disabled person concerned.

Allocation of hours

Under the current FFC policy, funding is only available to support a disabled person's personal care and household management needs. (However a person with a disability can access supports in addition to FFC.)

Just under half of FFC funded families were allocated the hours they wanted and just over half were not.

Those in the 'just over half' group who were allocated less FFC hours than they wanted tended to the view that the allocation of hours was being applied 'very rigidly' or 'in a really miserly fashion.' To illustrate:

'If R is showering it's one of those activities where you can't go and do something else ... because he needs help with the shower head, then he will need help shampooing his hair ... having his feet washed ... To say that while he is in the shower the clock stops is I thought, if it is true, a dreadful way of measuring.'

'I just feel that the funding is so restrictive that it doesn't really do justice to the spirit of the whole scheme. In my view, it's actually not natural to have to turn the television on for a 30 year old, you know?'

Defining which activities were funded and which were not under FFC was a source of frustration for about one third of the families who were allocated less hours than they had wanted.

- Five families wanted FFC extended to cover supervision in the day or night.
'X doesn't understand the consequences of actions and things like that so you have got to really watch her very carefully. She can't be left by herself.'
'W has sleep apnoea. We have got baby monitors on her. We lie in bed at night listening to her breathing and if she stops breathing. Even though she is sleeping ... you often walk around and do other things.'
- A couple of families queried why there needed to be a distinction made between "personal care" and household management" within the policy. One put it this way:
'Why the distinction? The fact of the matter is you're caring for a person. It's neither here nor there if that caring involves making him cream buns or brushing his teeth after he's eaten the cream bun. It's all caring.'
- A couple of families were unhappy about the loss of pre-existing conditions or entitlements which they understood would not be affected under FFC.
'What I discovered is that if you are receiving home help it comes off your FFC entitlement. I had the choice I could take the 40 hours and lose two hours' home help or take 38 hours and keep my two hours' home help.'
- A couple of families expressed having little faith in the way the allocated hours were decided. (*'It's completely capricious. It's arbitrary. I don't think there can possibly be any sensible rationale...'*) At least one family referred to apparent inconsistencies across NASCs in this regard.

Just under one half of the families were allocated the hours they wanted. This group tended to have lower expectations. One said, for example:

'They were reluctant to give us the full care package... We're three quarters of the way ...so there's room to expand if I need more ... so that's quite nice to have.'

3.3.2 Perspectives of NASC representatives

Twelve NASC survey participants responded to the question: How easy or difficult has it been for staff to allocate funded support hours for people eligible for FFC? From five options ranging from 'very easy' to 'very difficult', five chose 'difficult', five 'neither easy nor difficult' and two 'easy'.

NASC survey participants commented that discussions with families regarding the allocation of FFC hours could be challenging for a variety of reasons including:

- Families are expecting the maximum allocation of 40 hours under FFC or their expectations exceed the NASC's allocation (3 comments)
- Families take a holistic view of care and do not differentiate, for example, between 'personal care' and 'household management' activities (2)
- Families are requesting allocation of hours for activities not covered under FFC – supervision (2), safety and oversight (1), social and emotional support (1) of the disabled family member
- Families and NASCs may disagree on the length of time a specific task takes (with the NASC using as a benchmark the time they would allocate to another provider to complete the task) (2)
- Families and the NASC staff may have differing views on which activities fall into 'natural support' and which activities do not (1)
- Families and the NASC staff may have differing views on which activities comprise 'hands on support' (and are funded under FFC) and which are 'supervision' (and are not funded under FFC) (1)
- A family member may need to be 'on call' overnight for a disabled family member but that is not classified as 'hands on' support and therefore not funded by FFC (1).

Two participants commented on processes they had put in place to support consistency of decision-making related to the allocation of FFC hours. In one NASC only one coordinator allocated the hours. Another used the ICare tool to support the process.

One participant described the allocation of hours as being a 'lengthy' process requiring two levels of approval (internal NASC approval and NASC national review/Ministry of Health approval) prior to referral to the FASS.

3.3.3 Perspectives of organisations

Under the current FFC policy, funding is only available to support a disabled person's personal care and household management needs. Three representatives interviewed from different organisations for disabled people and carers took issue with this on the basis that no allocation can be made for supervision. To quote them:

'It doesn't take into account supervision, the constant attention that the [disabled] people require. ... I have heard of families who just thought this was an insult and just gave up.'

'The NASC can't allocate personal care hours to supervision and supervision is the sort of care that people with significant autism spectrum disorders mostly require. So what you end up with is people who require 24/7 supervision, intensive supervision, with five hours allocated under Funded Family Care.'

'An assessor might say "Well, how many minutes does it take you to help someone actually brush their teeth? We will pay you for that, but we won't pay you for the supervision, the cleaning up before and after, the getting things ready because that's natural support."

According to these representatives the failure to include 'supervision' could act as a barrier to uptake, compromise a disabled person's safety - especially a person with a significant autism spectrum disorder - or lead to situations that were not viable or unsustainable.

One of these representatives explained the difficulty of allocating FFC hours by reference to a mother's constant care for her disabled son.

'[The allocation of hours] didn't take into account the constant demand on her to be orally engaged [with her son]. It was that constant ... the stuff that can really wear you down ... but it didn't fit neatly into any of those boxes. The fact that he got really stressed if she went out meant she actually had to take him everywhere with her. So if she went to the bowls he went to bowls. If she went to the movies he went to the movies ... It was an all-encompassing constant. It wasn't 'household management' or 'personal cares' but it sure was a job. A non-stop job and it never ended.'

The number of hours that had been allocated under FFC was criticised by one representative. S/he relayed feedback from three staff members from three different NASCS to the effect that the staff had wanted to allocate eligible disabled persons more hours under FFC than they had but their *'riding instructions were so tight.'*

Another criticism related to the way the interview process was usually conducted, with both the disabled person and family carer present, to determine the disabled person's support needs. It could be demeaning to the disabled person in some situations. For example, where a disabled person overstates their capability to undertake a task (such as 'I can hang out the washing') and the family carer needs to step in to qualify their response (such as by saying 'Yes, he can hang out the washing, but, my god, it will never dry because it's all curled in a bundle.')

Impact on the allocation of other funded support

A disabled person may also be allocated funded support to meet support needs other than their needs for 'personal care' or 'household management' which are funded under FFC. For example, a NASC may allocate funded support for a disabled person to access community activities. In addition, a disabled person receiving FFC funding may also be allocated funded carer support and respite care.

One representative relayed instances where receipt of the FFC funding had negatively impacted on other allocated funding (such as carer support hours). S/he said this had resulted in families not necessarily being any better off financially. S/he put it this way:

'You go through the assessment process. You qualify for the payment. You go through all the hoops. You start receiving payment but other things are taken away from you like IF (individualised funding) hours or respite. ... Some people have said they are having to use their Funded Family Care to pay for extra support hours because they are not getting enough support. It's a three ring circus. It actually hasn't improved people's lives in those cases.'

3.3.4 Summary

- Just over half of FFC funded families interviewed thought that the assessment process had gone well and just under half that it had not gone so well.
- Just under half of FFC funded families were allocated the hours they wanted and just over half were not.
- In response to the question: 'How easy or difficult has it been for [NASC] staff to allocate funded support hours for people eligible for FFC?' five NASC survey participants rated it 'difficult', five 'neither easy nor difficult' and two 'easy'.
- Nearly two in every ten FFC funded families mentioned that the person they had dealt with at local NASC had not been fully conversant with the FFC policy in the beginning.
- Defining which activities were funded and which were not under FFC was a source of frustration for about one third of the families who were allocated less hours than they had wanted.
- Three representatives interviewed from different disabled persons' or carers' organisations took issue with only 'personal care' and 'household management' needs being supported under FFC. The failure to include 'supervision' could act as a barrier to uptake, compromise a disabled's person's safety - especially a person with a significant autism spectrum disorder - or lead to situations that were not viable or unsustainable.

3.4 FASS involvement

Under FFC, a facilitator from a host provider called Funding Advisory and Support Services (or FASS) assists with the set-up of FFC (including with the development of an Individual Service Plan (or ISP)) and provides initial advice to the disabled person, their advocate, and their family/whānau carer about the employment relationship.

The FASS manager explained that FASS had extended its role to include assistance with some FFC-related issues that could otherwise be barriers to accessing FFC - such as meeting the bank's requirement for a person's proof of identity in connection with operating a bank account or IRD's requirement to speak only with the person concerned about their personal tax matters.

To illustrate: Banks need photographic ID to confirm the identity of an employer. Many very disabled people do not have existing photographic ID because they do not have a passport or a driver's licence and for them to go out and get photographic ID is very difficult from a practical point of view. FASS has found a workaround solution to this potential barrier. With agreement of the family concerned, FASS provides the bank with an official document

associated with an individual FFC referral and the bank accepts this in lieu of photographic ID.

As a rule, IRD will speak only with the person concerned about their personal tax matters. This means that IRD will not supply a disabled family member's IRD number to another family member who may phone requesting it on their behalf. Again, FASS has found a practical way around this. IRD has a form that can give another family member authority to act on the disabled person's behalf. It does still require the disabled person's signature – which can be another challenge since many cannot even make a mark. In any case it provides a solution. (The only other avenue is to get a court authorisation which can be costly and time consuming.)

3.4.1 Perspectives of FFC funded families

Almost all FFC funded families were very complimentary about the FASS facilitators who had met with them in their homes to set up the FFC arrangement - which included developing an individual service plan (or ISP), explaining responsibilities of the parties to the employment contract, and supporting families' decisions as to arrangements for payment of family carers' wages (for example, through SmartPayroll).

Four typical quotes from these families about their positive experiences with FASS personnel include:

'They were really nice and they spent as much time as was needed [for us] to get a grip on things.'

'She was brilliant. She talked pretty much nonstop for two hours just to get through the process of how the payments worked.'

'[There were] two of them. They were very easy to get along with, very easy to communicate with. I mean, the process was quite long winded but they were trying their best to really speed it up. They weren't trying to make it long winded. It was just so much paperwork that they had to get through ...'

'This lady was very, very supportive and approachable and I felt she related to our situation because she had a disabled son of her own.'

The four main related issues (in order of decreasing frequency of being mentioned) that the FFC funded families identified with these aspects of the process were:

- the disabled person's mental capacity to understand their responsibilities as employer (see section 3.4)
- the development of the individual service plan (ISP). At least one participant complained the ISP almost duplicated the disabled person's NASC-developed support plan.

'To me, it was a waste of time because the needs assessment says it all. And she copied off what was on that. ... There was a lot of repetition in the paperwork.'

Another, that the jargon that was apparently a necessary feature of the ISP had the potential to introduce errors.

'The part about the disabled person being supported to write a service plan was nonsense as far as I was concerned. Nobody was interested in letting me write a plain English service plan. ... There were things like I said: "I need Mum to clean my mask every morning" and that became "One-to-one assistance is needed to maintain the hygienic quality of the mask." Well, why did that need to change? ... We were being told by the [NASC] co-ordinator that the Ministry won't accept this unless it's been rewritten. And I thought, well, if it needs to be in jargon, you should have given me a guideline to the expected jargon so I could have incorporated it. Instead, I've got this person constantly rewriting my words and introducing errors and every iteration is another delay.'

- FASS added another layer of bureaucracy and cost

'It was just another layer of bureaucracy in between the NASC and us, you know? It was just another cost.'

- FASS was not a locally based provider

'It's just another service. Why couldn't they use an original service that was in town? ... They should use a service that's in your local town instead of paying another agency to do all this work when the money could be going back to us, you know?'

3.4.2 Perspectives of organisations

Two representatives from organisations for disabled people and carers passed on positive feedback they had received from FFC funded families about FASS. To quote one representative:

'[FASS] have tried very hard for people to actually be able to manage [FFC], administer it, and get advice and help.'

3.4.3 Summary

- Almost all FFC funded families were very complimentary about their interactions with the FASS facilitators.
- The issues arising from this part of the process that FFC funded families most frequently mentioned included the disabled person's mental capacity to understand their responsibilities as employer, developing of the individual service plan (ISP), and the inherent bureaucracy and cost.

3.5 Informed decision-making

Under Section 6.1 of the policy 'If the NASC is concerned that a disabled person lacks the capacity to fully understand the terms of FFC then the NASC can recommend that the disabled person obtains an advocate to assist with explaining the terms of the FFC arrangement. The advocate would also be expected to assist the disabled person with understanding the employment requirements under the FFC arrangement⁹ and support them with their decision to proceed with FFC or not.'¹⁰

9 See section 3.5 of this report for participants' perspectives on adult disabled persons' ability to understand their responsibilities as employer under the FFC arrangement.

10 The roles and responsibilities of the advocate are not included in Section 12 which sets out the roles and responsibilities of the various parties under FFC.

Under the policy, 'the NASC must ensure that the person is able to make an informed decision whether to choose this service option or not.' (Section 6, page 10). The disabled person may make the decision with or without the assistance of an advocate (Section 6.1, page 10). An advocate can be someone from their support network, as long as the advocate is someone other than the family member they are considering as paid family carer. Either way, 'the NASC must still be satisfied that the disabled person has made an **informed** and willing choice about the FFC option.'¹¹

3.5.1 Perspectives of FFC funded families

A commonly recurring theme from the feedback from FFC funded families was related to the disabled person's mental capacity to make an informed choice about the FFC option.

The fact that many disabled people most likely to benefit from the FFC funding were unable to make an informed choice strongly suggested to these participants that the policy needed revisiting. For example:

'[The policy is] written so that that person can say "I would like this person to be my carer" or whatever. The first question that I asked [the Ministry] was "Did you take into account people like my son [with severe autism] when you were making up this whole thing because I don't think you did?"'

'He doesn't talk. He can point with a finger ... if he wants some food or watch a DVD, but as far as making any decisions [about whether or not to take up FFC] he doesn't understand. His disability is such that he couldn't make any choices himself in regards to things like that.'

'C was not involved in the decision because C is incapable of being involved in the decision.'

'Under FFC we don't care how profoundly intellectually disabled they are. [The Ministry or the Ministry's agent] will accept that they have consented.'

Feedback from FFC funded families and advocates on the use of advocates was quite mixed. A positive quote from one advocate first, followed by a negative quote from a family carer.

'Being an advocate has been fine doing the meetings and things like that. That's all been very smooth. The meetings were made at times that matched both our needs.'

'We have got welfare guardianship. We still had to have somebody as an advocate for her which, for me, is a bit stupid really considering we have the legal process to be able to make those decisions for her ... That was a bit senseless in my opinion because there is no way that I would make decisions for her that weren't going to be suitable anyway.'

One advocate mentioned that severely intellectually disabled persons were incapable of choosing who they wanted to represent them.

'I'm not going to pretend for a moment that [disabled person] and me have had a heart to heart about me being an advocate for him. We might chuck in the monkeys and a free set of steak knives if he's lucky. It's just ridiculous.'

11 This requirement is not listed among the NASC's responsibilities set out under 23. Page 23.

One expressed concern that the policy needed to be more clearly written to reflect current practice.

'If the Ministry were willing to accept an advocate making a decision for somebody who couldn't make it then they should have said so.'

3.5.2 Perspectives of organisations

Four representatives from organisations for disabled people and carers commented on the role or responsibilities of the advocate under FFC.

A couple of them questioned the role or status of the advocate. The role did not come with any legal authority. One wondered aloud about the role and the lack of merits they saw in it:

'What's meant by advocate? If the role is to ensure that the disabled person is giving informed consent that's silly because in most cases the disabled person does not have the mental capacity to give their informed consent. If the point is to serve as a protective mechanism to see that the disabled person's concerns are being represented, just identifying another family member who has no specific training or legal authority is pointless.'

Two favoured broadening the FFC policy such that the disabled person supported by family (to the extent required) could make the choice whether to take up FFC.

One of the two thought that through the adoption of supported decision making principles common sense solutions could generally be found to enable a person even with significant intellectual disability to make their own decision about who cares for them.

'A husband becomes the advocate for their son or daughter and employs the wife. It's just silly stuff. Let's just adopt the principles of supported decision making and say "Does this person want mum or dad to be their caregiver, or brother or sister or whoever? How have we established that? Is that by listening to the people who know this [disabled] person well, who [knows what] their preferences are, who they like being part of their lives ...?'"

This representative thought the option to involve an advocate could present an additional barrier to uptake since no public advocacy service exists.

The other thought NASC staff should also have some discretion to make the call as to whether FFC was the appropriate care option for a disabled person on a case by case basis.

'Surely the NASCs should be able to pragmatically resolve whether someone is eligible for FFC or not ... Where you have an adult disabled person who has the mental capability to make these choices and appoint a family carer and so on, well, of course, they should be supported to do that. A lot of this comes down to NASC knowledge. They deal with people in all kinds of situations all the time. They should be able to make some calls.'

3.5.3 Summary

- A commonly recurring theme from the feedback from FFC funded families was related to the disabled person's mental capacity to make an informed choice about the FFC option. The fact that many disabled people most likely to benefit from the

FFC funding were unable to make an informed choice strongly suggested to these participants that this aspect of the policy needed revisiting. FFC funded families gave quite mixed feedback on the use of advocates.

- Four representatives of disabled persons and their carers commented on the role or responsibilities of the advocate under FFC. At least one representative observed the advocate role did not come with any legal authority and at least one thought the option to involve an advocate could present an additional barrier to uptake since no public advocacy service exists.
- Two representatives of disabled persons and their carers favoured broadening the FFC policy to provide for supported decision making within the family (in place of a specific advocate role). Another thought NASC staff should also have some discretion to make the call on a case by case basis as to whether FFC was the appropriate care option for a disabled person.

3.6 Disabled person's responsibilities under the FFC arrangement

Under the FFC arrangement the disabled person is the employer of the family carer.

The responsibilities of the disabled person as employer are set out in paragraph 20 (pages 21-22). The list of their responsibilities is the longest of any of the parties to the agreement. It includes responsibilities related to compliance with employment requirements such as complying with all laws as an employer, ensuring that payments relating to employment obligations are made, and resolving any employment problems.

3.6.1 Perspectives of FFC funded families

A frequent theme among the feedback from FFC funded families (including advocates) was related to the disabled person's mental capacity to carry out their responsibilities as employer of the family carer under the FFC arrangement.

For example:

'I question why the Ministry has done what they have done, it doesn't make sense. Disabled people who are very high needs and severely disabled don't have the ability to be an employer. It's not in their psyche. It's not something they can get their heads around, you know?'

'I mean it's farcical for [disabled son] to employ somebody. Strike me pink, you know, he doesn't know what day of the week it is. I mean a 44 year old man and he can't wipe his bottom properly. It's farcical, it's like something out of a Gilbert and Sullivan opera, isn't it?'

One advocate questioned whether an employment relationship could be said to exist if the disabled person lacked the capacity to carry out his/her responsibilities as an employer, the government made the decision as to the number of hours for which s/he could employ his family carer, and the government determined the host provider. To quote:

'The one that really bugs me is the complete legal fiction that D [disabled person] is effectively the employer of his mother, with all the responsibilities of the employer, yet there is no employment relationship. D doesn't have control over the employment relationship, the government tells D how many hours his employee can have ... They

tell D who his host providers are going to be. There's no standard employment relationship happening here. Yet, we're using this legal fiction that D has the mental capacity to have that relationship with his mother.'

3.6.2 Perspectives of organisations

Four representatives of organisations for disabled people and carers commented about the disabled person in the employer role. According to these representatives the requirement of the disabled person to be in the employer role created significant challenges and barriers to accessing FFC since the majority of those most likely to benefit from FFC lacked the intellectual capacity to exercise their employer responsibilities.¹²

They argued that it was wrong for the policy to have placed the employer role onto the disabled person. One of these thought that the Ministry should have had the foresight to know that many families would need to find a way around that requirement if their eligible disabled family member was to access the FFC funding. As one said:

'It's simply wrong. ... It's just stupid because they must have known that this will not happen.'

It was said by one representative to add insult to injury to expect people with a significant intellectual disability to be placed in an employer role. The employer needed to have the capacity to engage with government agencies such as Inland Revenue (IRD) and more often than not the disabled person at the centre of the policy was unable to do so.

For example, IRD has the expectation that anyone who is registered as an employer will have a business entity and will therefore be required to submit a tax return each year. Because there is no business activity as such, it requires the FFC employer to contact IRD to request an exemption from filing a return. IRD will not speak with anyone other than the employer unless that person has clear legal authority, usually attained through the court granting them a property management order. (The advocate did not necessarily have sufficient legal authority.)

A related point mentioned by two representatives was that the 'rigid insistence' of the disabled person as the employer went against the philosophical direction of giving disabled people more choice and flexibility.

'We think the rigid insistence ... has a lot of fish hooks. ... People's choice and flexibility, all those things we were supposedly moving toward in disability have actually been removed. So we would like to see that fixed.'

'[The Ministry] wants to give people more choice and control, more flexible services ... but then at a NASC level and operational level it gets dragged into these sort of short term issues ... about cost blowouts. [FFC] really came out of that really convoluted and conflicting goals and the fact that they had to do it.'

In addition to creating significant challenges for disabled persons, the employment arrangement set up under FFC was demeaning and marginalising of family carers (according to two representatives).

'Payment to carers is done in a way which demeans them, devalues them, dishonours them and insults them. ... These are carefully chosen words.'

12 The NASC or host facilitator (FASS) can suggest or recommend that the disabled person set up a 'circle of support' to assist them with administering all or some of their responsibilities within the FCC arrangement.

'It is disenfranchising family carers who in all the language used and in the structure of the policy are bit players in their own very important role in all of this and it's unfair and it's mad.'

For one representative the solution was to be found in re-directing the role and responsibilities of the employer away from the disabled person to the local NASC agency that was much closer to the ground. This representative thought there was *'absolutely no reason why that was not a reasonable and feasible approach to take.'*

3.6.3 Summary

- A frequent theme among the feedback from FFC funded families (including advocates) was related to the disabled person's mental capacity to carry out their responsibilities as employer of the family carer under the FFC arrangement. The fact that many disabled people were unable to carry out such responsibilities strongly suggested to these participants that the FFC arrangement needed revisiting.
- Four representatives of organisations commented about the disabled person in the employer role. According to these representatives the requirement of the disabled person to be in the employer role created significant challenges and barriers to accessing FFC since the majority of those most likely to benefit from FFC lacked the intellectual capacity to exercise their employer responsibilities. In addition, two representatives argued that the employment arrangement set up under FFC was demeaning and marginalising of family carers. For one representative the solution was to be found in re-directing the role and responsibilities of the employer away from the disabled person to the local NASC agency.

3.7 Payment under FFC

FFC payments are paid directly by the Ministry into the disabled person's bank account and it is the disabled person's responsibility to pay their employed family/whānau carer.

The FFC payments enable the disabled person to employ their approved family/whānau carer for no less than the adult minimum wage.

The current adult minimum wage rate (before tax) for employees aged 16 or over is \$14.75 per hour. This means that the maximum annual salary (before tax) of a FFC funded family carer at the minimum wage is \$30,680.

Based on an average of 29.4 FFC carer hours/week, the average annual salary (before tax) of a FFC funded family carer is approximately \$22,550.

3.7.1 Perspectives of FFC funded families

Almost all FCC funded families made the decision to use FASS-recommended SmartPayroll to assist them with the payment of family carers' wages.

Over four in every five FFC funded families reported that FFC payments to family carers were going well and they had no particular issues. The use of, and helpline back-up from SmartPayroll was credited with easing FFC payments to family carers. For example:

'I log on to SmartPayroll and I just need to click about three buttons. I just have to put in the right dates for the fortnight and it's just a drop down thing.'

Just under one in every five FFC funded families reported one or more issues with FFC payments to family carers. The issues identified by at least one interview participant from this group included:

- not knowing what to do with unused money accumulating in the employer's account. The funds may have accrued for various reasons, for example, because there had been no need to pay a replacement carer since the family carer had not taken (or been able to take) annual leave or sick leave or the employer's contribution to Kiwisaver was not required (since the family carer had chosen not to join Kiwisaver). They had not received a satisfactory response from the Ministry to their queries as to how to manage the accumulating funds.

An associated concern they expressed was what to do with the FFC funds left in a disabled person's bank account if s/he died. (Disabled persons who are FFC recipients are at increased risk of death due to their high levels of disability-related needs.)

Some of these families said not knowing what to do with unused money left them (and FASS) vulnerable to claims of misuse of the money.

- an employer's apparent inability to pay an employee bereavement leave in the period shortly after FFC payments commence (since there is not sufficient funds accumulated to provide for the leave)
- the Ministry's apparent lack of foresight to anticipate employer-related issues with IRD and ACC and to have not dealt with these in advance of the FFC roll-out
- a lack of clarity in the FFC policy as to the ability of an employer to reimburse their family carer for expenses (such as for latex gloves)
- a strong preference of an advocate not to have to handle the payroll side of things
- lack of flexibility around the exact timing of fortnightly payments to FFC funded family carers. For example, they could not be paid slightly early ahead of statutory holidays, something that Income Support did.
- the wait for the first payment (that one FFC funded family carer had earmarked to pay a power bill).

FFC funded family carers' level of payment

About two-thirds of FFC funded families viewed the funding for minimum wage payments to employed family carers under FFC as unfair and about one third viewed it as fair.

Some of those who viewed it as unfair thought the hourly pay rate insulting given the high level of skill some family carers required. A couple of typical responses from this group follow:

'Well, it's too low. ... Some of the stuff that Mum does and has been trained to do is basically nursing level care. You can't get a nurse for the minimum wage. I think it's bordering on an insult. ... I need 110 hours of care a week and they're paying Mum

40. *They're still expecting Mum to do upwards of 40 hours a week unpaid. The unpaid work is of the same quality and of the same importance as the paid work so from our point of view she's getting less than half the minimum wage per hour that she actually works.'* (FFC recipient)

'I think it stinks. ... I think we are being degraded. We are treated like second rate citizens when my sons or my grandsons can go to work at McDonalds and get the same rate of pay ... They're not doing nursing care. They're not doing feed pumps, suctioning, tube feeding. They're not putting in CPACs, VPACs on them at night. They're not changing nappies. They're not using a hoist bath bed, giving medication. It's disgusting.' (FFC employed family carer)

Some from this group found it particularly galling that non-family carers were being paid at a higher rate to do the same work.

Those FFC funded carers who viewed the current hourly pay rate under FFC as fair tended to the view that some payment was better than none. For example:

'I think when we've gone from nothing to anything it's fantastic.'

'I'm happy enough with it because it's better than not getting anything at all, yeah. I would say we are worth more than that definitely but that's fine.'

FFC funded family carers' experiences of annual leave and sick leave

Nearly four in every five FFC funded family carers had not taken any paid annual leave or sick leave at the time of the interview.

They gave a number of reasons for not taking leave. In decreasing order of frequency they mentioned:

- a lack of knowledge about managing the mechanics of leave in the payroll system:

'I haven't figured out how the hell I do that. Until I know someone who has done it ... I mean who do I ask how I do it? It's just another whole can of worms. I've just avoided it.'

'There is nobody to really talk you through it. I just wish somebody would, like with EIF. Nobody is giving us guidance. We're just stuck with this payroll.'

- the difficulty of finding a replacement carer, especially one who would work for the same low pay and conditions.

'I can't pay someone to care for him 24/7 and only get paid \$14.25 for 30 hours.'

One carer who said s/he could not find a suitable replacement carer willing to work for the same rate of pay and conditions said s/he might need to sue his/her disabled son/daughter under the Holidays Act 2003 so that s/he could take the annual leave to which s/he was entitled.

- a parent of a disabled daughter/son stated they could not take a holiday without them.

'As a parent you don't. You just don't. I think holidays for parents with children with disabilities are a joke. Well, they are in our case.'

- a replacement carer in paid work thought it would be much simpler just to provide the care on a voluntary basis rather than deal with the 'nightmare' of working out the secondary tax.

Just over one in five FFC funded carers had taken annual leave or sick leave whilst on FFC wages. None reported any issues managing the leave with SmartPayroll. However, about half had used part of their respite care allocation to fund the leave rather than through FFC. As one carer explained:

'I used my respite to pay me because I didn't want to touch [D's] account.'

3.7.2 Perspectives of FASS and organisations

FASS had recommended the use of SmartPayroll to manage payment of FFC employed family carers' fortnightly wages. (With SmartPayroll there is a small monthly fee.)

Majority feedback from representatives of organisations for disabled people and carers was that SmartPayroll had been a good choice since was relatively cheap, easy to administer, and had a phone helpline.

One representative thought that the Thankyou Payroll was a better option since it was free.

FFC funded family carers' level of payment

Four representatives from four organisations for disabled people and carers commented on FFC funded family carers' level of payment.

Three of the four representatives thought family carers deserved to be better financially supported under FFC. One described the current level of payment as 'offensive', arguing that the minimum wage did not enable family carers – many of whom are women – to make proper provision for their retirement.

One representative pointed out that a failure to recognise the value of family carers had repercussions for future generations who might not make the choice to care for family members at home. Yet, according to two representatives family carers had the potential to make savings for the government since it was less costly to care for family members at home than to place them in residential care at a much higher cost.

One representative pointed out the inequity attached to non-family carers getting paid at a higher rate than family carers for the same work.

Some other comments

Feedback from the FASS manager was that the Ministry payments branch sector services was doing a very good job of managing payments to FFC recipients. He said:

'They liaise with us closely ... Where they might have been rigid they have proven to be flexible. ... I found them very constructive to work with and they help the families where they can.'

One of the representatives passed on concerns s/he had received from FFC funded families about what to do with apparent surpluses accruing in the employers' accounts.

'We have heard about the surpluses in employer accounts and issues around sick leave and annual leave and so on. I think once again that probably needs a good look at. How simply can those things be made easier and better?'

Only in exceptional circumstances can an employed family carer work more than 40 hours weekly under FFC. One representative commented that this aspect of the FFC policy differed from the equivalent at ACC whose policy had not placed such a cap on family carer hours (of accident victims).

3.7.3 Summary

- Over four in every five FFC funded families reported that FFC payments to family carers were going well and they had no particular issues.
- Just under one in every five FFC funded families reported one or more issues with FFC payments to family carers. One of the issues identified was not knowing what to do with unused money accumulating in the employer's account.
- About two-thirds of FFC funded families viewed the hourly pay rate of \$14.75/hour to family carers under FFC as unfair and about one third viewed it as fair.
- Some of the FFC funded families who viewed the hourly rate as unfair thought it insulting given the high level of skill some family carers required. Some found it particularly galling that non-family carers were being paid at a higher rate to do the same work.
- Three representatives from disabled persons' or carers' organisations thought family carers deserved to be better financially supported under FFC. One described the current level of payment as 'offensive', arguing that the minimum wage did not enable family carers – many of whom are women – to make proper provision for their retirement. One representative pointed out the inequity attached to non-family carers getting paid at a higher rate than family carers for the same work.
- Nearly four in every five FFC funded family carers had not taken any paid annual leave or sick leave at the time of the interview. Reasons carers gave included: a lack of knowledge about managing the mechanics of leave in the payroll system; the difficulty of finding a replacement carer, especially one who would work for the same low pay and conditions; and not wanting or not being able to take a holiday apart from their disabled daughter/son.
- Just over one in five FFC funded carers had taken annual leave or sick leave whilst on FFC wages. None reported any issues managing the leave within the payroll system. However, about half had used part of their respite care allocation to fund the leave rather than through FFC.

3.8 Review processes

A disabled person, or a person acting on their behalf, can seek a review from the local NASC of their FFC eligibility assessment or the number of support hours which they have been allocated under FFC. According to section 3.4 of the FFC policy there are four levels

to the review process that a NASC must follow. (These are described in the NASC Managers' Manual.)

3.8.1 Perspectives of FFC funded families

Over nine in ten of the FFC funded families had been assessed as eligible for FFC at their first assessment and had not sought a review of support hours allocated under FFC.

Less than one in ten of the FFC funded families had sought a review, either of eligibility for FFC, or more commonly the support hours allocated under FFC.

All those who had sought a review had complaints about the process. Mostly, these related to what they perceived as a lack of transparency of decision-making and/or poor communications around the review processes and outcomes of it.

'We have got a situation where we don't know how they make their calls. There is nothing open or transparent about the whole process. ... Seriously, it's not much more scientific than a fairy at the bottom of the garden made the decision.'

'I'm not quite sure who the mediator ... moderator was. But when I said to the local office: "Seriously! They've knocked us back?" and she said: "Oh, you know, you will have another chance to reapply next year, so don't jump up and down yet." But it still rankles.'

3.8.2 Perspectives of NASC representatives

NASC representatives were asked whether any potential or actual FFC recipients in their region had sought a review. Eight of the 12 NASC survey participants who answered this question reported that a disabled person (or another person acting on their behalf) had sought a review of a NASC decision related to the FFC eligibility assessment or of the number of support hours allocated under FFC.

These participants had different interpretations of what a 'review' comprised.

Eight participants – six who had experience of a review process and two who had not - provided some comments on this aspect.

- Two participants who had some knowledge of the National Review Panel (NRP) process were complimentary of it. For example, one wrote: *'NRP appears to use good common sense thinking.'*
- One participant described their review process as having consisted of meetings between the NASC regional manager, the advocate for the disabled person, and the family carer to reach an agreement on the allocation of FFC funded support hours. Another participant described their review process as comprising an in-house reassessment of an application on an 'as required' basis.

Two participants described cases that were the subject of a review. One participant described a case in which the disabled person (or another person acting on their behalf) applied for a review throughout every step of the FFC process and this had required high involvement at Ministry level. The person had ultimately been unsuccessful in securing the additional hours of FFC s/he had sought. The other case involved an expectation within the family that FFC would fund a family carer for the provision of replacement care if an external support worker did not turn up.

Of the remaining two participants who had no experience of a review process, one thought the current process of having to get approval from the NASC National Review (NNR) before discussion or confirmation with the family effectively acted as a 'roadblock.' The other attributed their lack of experience of a review to their use of the ICare tool in their decision-making related to the allocation of FFC funded support hours.

3.8.3 Perspectives of organisations

Only one of the representatives of organisations for disabled people and carers interviewed commented on review processes.

S/he expressed concern that the introduction of the NNR process could result in more delays and frustrations for the families applying. S/he was of the view that the individual NASCs should be entrusted with applying the eligibility criteria and allocating hours under FFC, and to add the NNR process served to undermine that.

'There comes a point you have to trust the NASCs if they have been trained to implement the policy. It seems kind of crazy that you would have highly paid people micromanaging NASC decisions for a few hours here and there.'

3.8.4 Summary

- Over nine in ten of the FFC funded families had been assessed as eligible for FFC at their first assessment and had not sought a review of support hours allocated under FFC.
- Less than one in ten of the FFC funded families had sought a review, either of eligibility for FFC, or more commonly the support hours allocated under FFC. All of those who had sought a review had complaints about the process. Mostly, these related to what they perceived as a lack of transparency of decision-making and/or poor communications around the review processes and outcomes of it.
- NASC representatives were asked whether any potential or actual FFC recipients in their region had sought a review. Eight of the 12 NASC survey participants who answered this question reported that a disabled person (or another person acting on their behalf) had sought a review of a NASC decision related to the FFC eligibility assessment or of the number of support hours allocated under FFC.

3.9 Follow-up monitoring visits

The local NASC assists with monitoring the delivery, safety and quality of FFC arrangements by undertaking follow-up visits with FFC funded families. For at least the first six months of FFC the NASC is expected to undertake a follow-up visit each month.

3.9.1 Perspectives of FFC funded families

All FFC funded families had had follow-up contact from the local NASC. Mostly, this took the form of a home visit. The nature of the home visits varied from informal ('a flying visit') to something more substantive ('The nurse coordinator came in and religiously sat down with her forms and ticked the boxes and made sure I wasn't abusing X.'). A couple of the families mentioned that the follow-up had been by phone.

Over two-thirds of the FFC funded families said that the follow-up visits had gone well with the NASC staff member. They understood that the visits were part of FFC. Invariably these families already had a good pre-existing relationship with the NASC staff member and they had welcomed the visits at least from a social point of view. (*'It just felt like a friend dropping in for a cup of coffee. She was awesome.'*)

For under one-third of the FFC funded families the follow-up visits had not gone so well, largely because they were opposed to these visits in the first place, invariably perceiving them to be *'intrusive'* or *'invasive.'* Some of this group likened the follow-up visits to Police-like inspections.

Regardless of whether the follow-up visits had gone well or not, about one-quarter of the FFC funded families questioned their purpose or value. For example:

'It's kind of a bit of a joke, really. ... It's wasting money, wasting time.'

'The questions are just ridiculous. "Is Y happy with his mother looking after his cares?" Well, if you've got a child who can't even speak, how does that question come across? I know the advocate could speak, but the advocate could say anything. ... There's no feedback to anybody with that reporting, so why do it?'

3.9.2 Perspectives of NASC representatives

NASC survey participants were asked to rate on a five point scale how easy or difficult it was for them to monitor delivery of FFC. Half of the 12 NASC survey participants who answered this question reported that it was either 'very difficult' (1) or 'difficult' (5) for staff to monitor delivery of FFC. Two reported it as 'neither easy nor difficult' and four as 'easy'.

The NASC participant who reported the monitoring process as 'very difficult' went on to describe the process as *'flawed.'* Another reported the process as 'difficult' on the basis that staff felt strongly that the monitoring was *'inequitable and distrustful of families.'* Another described the process as *'quite invasive and time consuming for families.'*

Three mentioned that monitoring added to their workloads. In NASCs covering larger areas this was more pronounced since travel associated with the follow-up visits took longer.

Two participants mentioned how difficult it was to ascertain during the visits whether there were any issues for the FFC recipient or among the family.

One mentioned that a family carer had used the follow-up visit as an opportunity to re-litigate their allocation of FFC-funded support hours.

Another relayed feedback from some families who had asked why the monitoring was not being completed with the host provider (FASS).

Those participants who rated the monitoring process as 'easy' did so on the basis that the visits had generally been welcomed by the families. Two of these NASCs had a dedicated person who conducted all the monitoring visits.

One commented that the visits has assisted the NASC to get a better insight into what other community supports might benefit their clients.

One suggested reducing the frequency of monitoring visits to monthly for the first three months, then at six, nine and 12 months, then annually after that.

3.9.3 Perspectives of organisations

Four representatives interviewed from four different organisations for disabled people and carers commented on NASC monitoring of FFC delivery.

None was opposed to follow-up visits. They thought it was important, however, that the visits were fair and supportive of the disabled person and their family carer, rather than judgemental and punitive of the family carer. For example, one said:

'Keeping vulnerable people safe. Of course, that's important ... but not at the expense of bludgeoning carers so that they feel that they have to be checked on.'

Three compared the little or no scrutiny of family carers who undertook the care of disabled family members without payment with the follow-up visits imposed on them once they were paid under FFC. For one representative the monitoring was disproportionate to need and represented Ministry mistrust of paid family carers. (*'Suddenly you're a greedy, grasping potential fraudster.'*) Another imagined the visits could be quite insulting for some families.

One observed that the monitoring required by NASC staff was 'way outside' their current capabilities. This representative wondered whether the NASCs would have the time to do the follow-up visits.

Two other comments or suggestions from representatives were that:

- the monitoring should include monitoring for family carer burn out
- the frequency of monitoring was not sufficient to safeguard the disabled person from abuse by the family carer.

3.9.4 Summary

- All FFC funded families interviewed had had follow-up contact from the local NASC.
- Over two-thirds of the FFC funded families said that the follow-up visits had gone well with the NASC staff member.
- For under one-third of the FFC funded families the follow-up visits had not gone so well, largely because they were opposed to these visits in the first place.
- Regardless of whether the follow-up visits had gone well or not, about one-quarter of the FFC funded families questioned their purpose or value.
- NASC survey participants were asked to rate on a five point scale how easy or difficult it was for them to monitor delivery of FFC. Half of the 12 NASC survey participants who answered this question reported that it was either 'very difficult' (1) or 'difficult' (5) for staff to monitor delivery of FFC. Two reported it as 'neither easy nor difficult' and four as 'easy'.
- Four representatives interviewed from disabled persons' or carers' organisations commented on NASC monitoring of FFC delivery. None was opposed to follow-up visits. They were of the view that it was important that the visits were fair and supportive of the disabled person and their family carer, rather than judgemental and punitive of the family carer.

3.10 Some other aspects

3.10.1 Perspectives of NASC representatives

NASC survey participants were asked 'In your opinion, what aspects of the FFC policy have impacted the most on your NASC?'

The time required to familiarise themselves with the FFC policy was the most frequently mentioned response. Five of 12 NASC representatives mentioned this, with some reporting that the time required to apply the FFC policy to a specific case had reduced over time as they had become more familiar with it. For example, one responded:

'[The] time taken checking and rechecking the policy was followed correctly [was the aspect of the FFC policy that impacted the most]. As the uptake numbers were low this meant this took a long time to become business as usual.'

One mentioned that having a few coordinators with specific knowledge of the FFC criteria had helped staff apply the policy to specific cases.

Three participants mentioned the impact of the FFC policy had impacted little on their workload since few clients had expressed an interest in it or taken it up.

The monitoring requirement was identified by another three participants as the aspect of the FFC policy having the most impact on their NASC reputation-wise or time-wise. To illustrate:

'Monitoring has been a huge issue as it compromised NASC roles in the eyes of families. The travel and scheduling of regular monitoring visits impacted on workloads and workflow for the team.'

One participant thought that while assessment and service co-ordination was central to the NASC's role, monitoring was outside it.

Other aspects of the FFC policy mentioned by a single participant as having impacted the most included:

- managing queries about the host providers and their role, payment issues and arranging visits from the host providers to the region
- acquiring the skill level required to interact with these families and allocate supports within this new service to ensure that the person was well-supported and their voice heard
- the introduction about six months ago of the NASC national review (NNR) process, a process that involves peer review of applications prior to approval.

Ministry support to NASCs

NASC survey participants were asked to rate the extent to which they were supported by the Ministry of Health (the Ministry) in relation to raising awareness among disabled people and their families/whānau about the availability of FFC, training for NASC staff about FFC and responding to NASC queries about FFC.

Participants rated the Ministry more highly on responding to NASC queries about FFC than on the training the Ministry had provided for NASC staff or on raising awareness among disabled people and their families/whānau about the availability of FFC.

Four NASC representatives commented that while they had experienced some difficulty interpreting and applying the FFC policy in the initial months following its implementation, they were now more familiar with it and more confident handling applications.

One commented more generally that the Ministry had not recognised nor resourced the significant increase in workload of senior NASC staff brought about by implementation of the FFC policy – from the initial screening and allocation process, then responding to ongoing issues from families, monitoring the packages, and reporting. Implementation of FFC was reported to have added another layer of intensity to the NASC Service Facilitator role.

Ministry's response to queries

Two thirds of the NASC representatives reported being 'very well' (1) or 'well' (7) supported by the Ministry in regards to responding to their queries about FFC. Three reported being 'neither well nor poorly' supported and one 'poorly' supported.

Two commented that Ministry staff had been 'very good' or 'very responsive' when dealing with their queries.

In relation to review processes, one viewed as 'great' the introduction of the NASC National Review's (NNR's) process of peer reviewing all applications for consistency, while another expressed concern about the 'shifting sands as to who could appeal and who not.'

Ministry's delivery of training

Half of the NASC representatives reported being 'well' supported by the Ministry in regards to training for NASC staff about FFC. Five reported being 'neither well nor poorly' supported and one 'poorly' supported.

One NASC participant who described the Ministry training as 'valuable' had gone on to develop a checklist for their FFC coordinators to run through with FFC applications to correct 'a lot of misinterpretation' of the training and the material supplied. Another NASC supported ongoing training as a means of ensuring staff had a full grasp of FFC.

Ministry's support with dissemination of information about FFC

Half of the 12 NASC survey participants reported being 'neither well nor poorly' supported by the Ministry of Health in relation to raising awareness among disabled people and their families/whānau about the availability of FFC. Three reported being 'well' supported, two 'poorly' supported, and one 'very poorly' supported.

One NASC participant was of the view that the website information about FFC was 'not particularly helpful' since families were interpreting the content about the allocation of FFC-funded hours/week as being entitled to 40 hours/week rather than up to 40 hours/week.

3.10.2 Summary

- NASC survey participants reported that the aspect of the FFC policy that had impacted the most on their NASC was the time required to familiarise themselves with the FFC policy.
- NASC representatives rated the Ministry more highly on responding to NASC queries about FFC than on the training the Ministry had provided for NASC staff or on raising

awareness among disabled people and their families/whānau about the availability of FFC.

- Two thirds of the NASC representatives reported being ‘very well’ (1) or ‘well’ (7) supported by the Ministry in regards to responding to their queries about FFC. Three reported being ‘neither well nor poorly’ supported and one ‘poorly’ supported.
- Half of the NASC representatives reported being ‘well’ supported by the Ministry in regards to training for NASC staff about FFC. Five reported being ‘neither well nor poorly’ supported and one ‘poorly’ supported.
- Half of the 12 NASC survey participants reported being ‘neither well nor poorly’ supported by the Ministry of Health in relation to raising awareness among disabled people and their families/whānau about the availability of FFC. Three reported being ‘well’ supported, two ‘poorly’ supported, and one ‘very poorly’ supported.

3.11 Chapter Summary

- From the perspective of FFC funded families and some organisations representative of disabled people and carers, the requirements of the disabled person to give their informed consent to take up FFC and manage employer responsibilities created significant challenges and barriers to accessing FFC. The majority of those most likely to benefit from FFC lacked the intellectual capacity to comply with these requirements.
- Nearly six in every ten FFC funded families interviewed thought the eligibility criteria were fair. They were about equally divided on whether the assessment process had gone well or not, and whether they were allocated the FFC funded hours they wanted or not.
- The restriction of funded support hours to ‘personal care’ and ‘household management’ was a source of frustration for about one third of the FFC funded families who were allocated less hours than they had wanted and three organisations representative of disabled people and carers (who also wanted ‘supervision’ included). Over one third of NASC survey participants reported it being difficult to allocate funded support hours.
- Almost all FFC funded families interviewed were very complimentary of their interactions with FASS. Over four in every five FFC funded families reported that FFC payments to family carers were going well and they had no particular issues. One of issues mentioned was about not knowing what to do with unused money accumulating in the employer’s account.
- About two-thirds of FFC funded families viewed the funding for minimum wage payments to employed family carers under FFC as unfair – some because of the high level of skill required of family carers, and some because of the inequity of non-family carers being paid a higher rate for the same work. Three organisations representative of disabled people and carers thought family carers deserved to be better financially supported financially under FFC.
- Nearly four in every five FFC funded family carers had not taken any paid annual leave or sick leave at the time of the interview for a variety of reasons.

- The minority of FFC funded families interviewed who had sought a review were critical of the process for what they perceived to be a lack of transparency of decision-making and/or poor communications.
- All FFC funded families interviewed had had follow-up contact from the local NASC. Over two-thirds of the FFC funded families said that the follow-up visits had gone well with the NASC staff member. Regardless of whether the follow-up visits had gone well or not, about one-quarter of the FFC funded families questioned their purpose or value. Most organisations representative of disabled persons or carers interviewed agreed with the visits if they were fair and supportive of the disabled person and their family carer, rather than judgemental and punitive of the family carer.

4 Factors influencing FFC uptake

4.1 Introduction

This Chapter looks at some of the factors influencing FFC uptake. It draws on some of the same and additional qualitative information obtained as part of the interviews with FFC funded families and organisations representative of disabled people and carers and the survey of the NASCs, as well as a limited number of interviews with some families who were not accessing FFC but had some knowledge of, or contact with NASC staff about it.

Some of the barriers to FFC uptake have already been alluded to in the previous Chapter. Supporting information related to these as factors is referred to in some places.

The most frequently mentioned barriers – actual and potential - to FFC uptake are set out first, followed by some others that the evaluation participants identified.

4.2 Requirement of the disabled person to give informed consent

Under the policy, if a disabled person has been assessed as eligible for FFC ‘the NASC must ensure that the person is able to make an informed decision whether to choose this service option or not.’ (6, page 10). The disabled person may make the decision with or without the assistance of an advocate (6.1, page 10). Either way, ‘the NASC must still be satisfied that the disabled person has made an informed and willing choice about the FFC option.’

From the perspective of FFC funded families and some organisations for disabled people or carers, the requirements of the disabled person to give their informed consent to take up FFC created significant challenges and barriers to accessing FFC. The majority of those most likely to benefit from FFC were thought to lack the intellectual capacity to comply with these requirements. (See section 3.4 for details.)

In addition, two of the NASC survey participants identified elsewhere in their survey response that this requirement posed a potential barrier to uptake even if the disabled person had the assistance of an advocate.

Two representatives of disabled persons and their carers favoured broadening the FFC policy to provide for supported decision making within the family (in place of a specific advocate role).

4.3 The disabled person as employer

The responsibilities of the disabled person as employer are set out in paragraph 20 (pages 21-22). The list of their responsibilities is the longest of any of the parties to the agreement. It includes responsibilities related to compliance with employment requirements such as complying with all laws as an employer, ensuring that payments relating to employment obligations are made, and resolving any employment problems.

Feedback from some FFC funded families and one organisation representative of disabled people or carers that this arrangement acts as a potential barrier to uptake is presented in Chapter 3. To quote a FFC funded family carer:

'It's farcical that my son is my employer because he is no more capable of employing me as flying to the moon, you know? So, I do think it's been the most ill-conceived piece of legislation in terms of practicalities.'

FFC funded family carers commonly said they were largely managing the employer's responsibilities under FFC as well as their own. These families quite frequently had spoken of having received official documents from IRD and ACC for the attention of the employer that they had not known what to do with.

The requirement for the disabled person as employer to have a bank account for receiving the Ministry payments could also act as a barrier to uptake. As one FFC funded family carer explained:

'It was a classic catch 22 situation. We needed to open a bank account for him which could have direct debits taken from it so it needed to be a cheque account. I couldn't open it in my name, I couldn't open it as a trust account. So we were at a brick wall, really, because he couldn't sign his name which was the prerequisite to having an account like that. And if it wasn't for the lovely lady at the bank who said to me "Well, can he hold a pencil?", and I said "If somebody holds his hand", and she said "Well then", and that's how we got around it. But she agreed it was a farcical situation. ... For some people that would be too hard. The alternative was for me to go through the courts and apply for enduring power of attorney which would have been a lengthy and costly process. So I just think that people shouldn't be put into that situation where, really, they've brought in wonderful legislation, it sounds fabulous, but it's just too difficult to access for a lot of people.'

4.4 Awareness of FFC and misinformation about FFC

Access to information about FFC was mentioned as a potential barrier by some FFC funded families, some families not currently accessing FFC, some NASC survey participants and three representatives of disabled persons' or carers' organisations.

When those accessing FFC (as FFC recipients or employed family carers) were asked how they had first learned about FFC, only a very small number mentioned sources that could be described as 'promotional' of FFC by the Ministry or the NASC. Two mentioned the Ministry's consultation process prior to the FFC policy development, one had by chance picked up a FFC information brochure at a seminar, and one had found out through her disabled daughter's annual review of support needs at the local NASC.

The following two examples illustrate the passive nature of the 'promotion' of FFC.

'I was at a seminar for my son who was transitioning out of high school into the workplace. There just happened to be a brochure on display. When I got home and read it I thought "Oh my goodness." And I phoned up our local [NASC] office and said: "I'm just reading this here. Do we qualify?" and they said: "Oh, yes, that's new." I am relatively active in the disabled world, very active in the autism world. I was really surprised that I wasn't told about this system from the agent of the Ministry of Health.'

'[In March 2014] I was having an annual evaluation to see that [disabled daughter]'s services were up-to-date and they [NASC] asked if I had any issues and I burst into tears and said "I can't survive financially. I'm living off the credit card. Work and Income have made life difficult." And they said: "Well, this has just happened. These

payments have just become available and you are a prime candidate as you are a sole income family.” So, that’s how I found out.’

Misinformation about some aspects of FFC (such as how the funding may or may not affect access to other funding such as carer support or respite care) also had the potential to put potential FFC recipients off. (Also see next section 4.5.)

‘NASCs have been saying “Well you know if you get this [FFC] you’re going to lose some hours from here” and all this kind of stuff. It’s the process of confusing people.’ (an organisation representative of disabled people and carers)

This meant that potential recipients and their families were most commonly left to their own devices to search out the correct information about FFC. Some may not have the energy to do so.

‘People with adult disabled children may not have the experience and the confidence to actually speak up and assert themselves, because the reality of what they are dealing with has usually got them sort of reeling and beaten down, and it’s really, really hard for them.’ (an organisation for disabled people and carers)

FFC funded families spoken with would most commonly advise others in similar circumstances who were considering whether to apply for FFC to first seek information, advice and assistance from others, and if they decided to investigate it further to approach the NASC assessment process with determination and patience (Chapter 2).

Some evaluation participants’ views included in this report strongly suggest a need for greater and better information and communication about FFC.

4.5 FFC and its relationship to other sources of funding

Under section 4.1 of the policy, FFC recipients may employ their family carer to provide ‘some or all of their personal care and household management supports identified as part of their HCSS allocation.’ Other supports such as supporting the disabled person to access community activities are not funded under FFC.

There appears to be some confusion as to whether the provision of these other supports might be provided through some other funding channel such as carer support. For example, one person not accessing FFC had enquired about FFC and been informed by the NASC that *‘If we did receive Funded Family Care it would become an either/or situation and that X [her disabled daughter] would not be entitled to any outside assistance, so that was as far as I got with it really.’*

As mentioned earlier, a couple of FFC funded families were unhappy about the loss of pre-existing conditions or entitlements which they understood would not be affected under FFC. The loss of such conditions or entitlements also posed as a potential barrier to uptake.

Under section 13 of the policy, FFC recipients ‘may also be able to receive an allocation of respite care and possibly carer support days.’ It goes on to say in 13.1 that ‘the amount of [respite care] support that the family are paid to provide to their disabled family member under FFC will therefore be taken into account from this assessment.’

A family carer who was not accessing FFC had been assessed as eligible by the NASC but had decided not to take it up because s/he was informed by the NASC that it might affect the respite allocation. *‘[Respite care] is probably the best thing we’ve ever had and I didn’t want*

to jeopardise that.' When asked whether s/he felt s/he was given a satisfactory explanation of how the respite care allocation could be reduced by FFC, s/he replied that the NASC staff member had not given her a reason.

4.6 Design of the FFC policy

While all five organisations representative of disabled people and carers spoken with supported the existence of a policy, none gave their full support to FFC in its current form. In fact, four were extremely critical of its design as 'flawed', as having 'convoluted and conflicting goals', as lacking 'a principled approach' and for being 'complex' and 'highly bureaucratic.' To quote one of them:

'I think it comes back to the attitude of the officials who designed the adjustable parts of this policy in the way they did and I think that they should be ashamed of themselves. And I hope you quote me on that. ... I think that the culture of the Ministry and the way they wrote their rules, the culture of the way they think, their culture of suspicion and mistrust of carers is that, you know, you're fine if you're doing it for nothing but suddenly you're a greedy, grasping, potential fraudster if we are going to give you a few hours at minimum wage? ... The way they [the Ministry] are acting is the worst possible example of a really 1950s highly bureaucratic, tick-all-the-boxes mentality. They don't have to do that, but they choose to do it.'

Some FFC funded families described the FFC application process as very bureaucratic and time consuming. They said they needed determination and grit to see the process through. It could involve them in:

- participating in one or more appointments with the NASC for the eligibility assessment (sometimes soon after another assessment for a related purpose)
- finding an advocate
- participating in a two-hour visit from a FASS facilitator (and assisting with the development of an ISP plan)
- requesting one or more reviews (usually for the allocation of hours)
- visiting the bank to set up an account for the disabled person as employer
- signing up to and learning how to operate a payroll solution
- sorting out the implications for tax and ACC for the disabled person as employer and the nominated family carer as employee.

The policy assumed families would have ready access to a computer and the internet for managing FFC payments. For families that did not have ready access, this posed a potential barrier to accessing FFC.

The complexity and bureaucracy associated with FFC may be experienced differently by different groups, for example, some may experience more difficulties accessing FFC than others. For example:

'We are working with a number of Pacific Island families at the moment and they are clearly having greater struggles than other people in establishing bank accounts and that kind of thing, you know.'

Two NASC representatives reported that substantial time was required to schedule, undertake and check to ensure that the follow-up visits with FFC funded families had been completed. The 'very manual' process associated with their claiming reimbursements for FFC visits added to the time required.

4.7 Other barriers

Other barriers mentioned by at least one participant (including from among the group who were not currently accessing FFC) included:

- financial barriers, specifically the inability of a single income family to make ends meet on the minimum wage
- the stopping of payments to the family carer should the disabled person be hospitalised for any length of time, and the difficulty of the family carer finding paid work over that time

'If I go to hospital for more than 28 days there is some discretion but the assumption is that the money will be cut off and so presumably Mum is meant to leave me in hospital and go and find work and tell the potential employer "As soon as my daughter is better, I will quit. Is that OK?"' (daughter)

- the 40 hours cap on the number of hours a FFC employed carer could be in paid employment

'The other thing that really grinds my gears ... is that I've got 32 hours a week (FFC) and I'm never allowed to work over 40 hours a week. ... I'm not an idle person. I can only go and do another 8 hours a week. And I think that's a little bit sucky.'

- the higher pay rates of non-family providers providing the same care through Individualised Funding (IF)
- the restriction of FFC to support the disabled family member's personal care and household management needs and the exclusion of supervision

4.8 Chapter Summary

The most common (and related) barriers to FFC uptake identified were:

- the requirement of the disabled person to make an informed decision about FFC
- the disabled person as employer
- the difficulty of accessing information about FFC and being misinformed about FFC
- the confusion around how FFC impacted or didn't impact on other sources of funding
- the design of the policy, with some FFC funded families describing the processes as very bureaucratic and time consuming.

Other barriers included:

- financial barriers, specifically the inability of a single income family to make ends meet on the minimum wage;
- the stopping of payments to the family carer should the disabled person be hospitalised for any length of time, and the difficulty of the family carer finding paid work over that time
- the 40 hours cap on the number of hours a FFC employed carer could be in paid employment
- the higher pay rates of non-family providers providing the same care through Individualised Funding (IF)
- the restriction of FFC to support the disabled family member's personal care and household management needs and the exclusion of supervision.

5 Concluding remarks

The Funded Family Care policy was introduced on 1st October 2013. The aim of the evaluation is to assess the impact and effectiveness of Funded Family Care and the reasons influencing its uptake in its first year of operation.

Impacts

Clearly, FFC is having positive impacts for most of those who are accessing FFC. We interviewed just over one fifth of all FFC funded families throughout the country, and nearly nine in every ten we interviewed identified one or more direct benefits of accessing FFC.

The positive impacts that FFC funded families most frequently mentioned were that FFC had put their household on a better financial footing (mentioned by almost two-thirds), and that it had contributed to improvements in the health status of the disabled person or the family carer (mentioned by nearly one half). The formal recognition of family carers as members of the paid workforce added to their sense of well-being.

The positive impacts were such that almost all FFC funded families we spoke with would recommend uptake of FFC to others in similar circumstances. About three-quarters would do so without hesitation.

When prompted, none of the FFC funded families responded that the employer-employee arrangement under FFC had a negative impact on family dynamics. Rather, it was the source of banter for some.

Effectiveness

There is no doubt the FFC policy is effective for some, but its overall effectiveness is constrained by its limited uptake. As at 1 April 2015, only 191 disabled persons nationwide were accessing FFC.

One needs look no further than the barriers identified by evaluation participants to see how the removal of all or some of them may lead to an increase in FFC uptake among the families it is intended to support.

Reasons influencing its uptake and some possible solutions

The majority of those most likely to benefit from FFC may lack the intellectual capacity to comply with the current requirement of the disabled person needing to give their informed consent to take up FFC. From the perspective of FFC funded families and some organisations representative of disabled people and carers, the requirement of the disabled person to give their informed consent to take up FFC created significant challenges and barriers to accessing FFC.

While the use of an advocate may go some way towards assisting an adult disabled person with their decision-making, some participants favoured broadening the FFC policy to provide for supported decision making within the family (in place of a specific advocate role) such that the disabled person would be supported by family/whānau to the extent s/he needed to come to an individual or collective family/whānau decision about FFC.

There is an acknowledgement within the policy (under 11.1 Circle of support page 19) that “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.” Certainly this was the experience of FFC funded families we spoke with, with the family carers effectively managing the disabled family member’s responsibilities as employer as well as their responsibilities as employees.

Given criticisms of the FFC policy as being too complicated and bureaucratic, consideration should be given to make it simpler and easier to access. Some evaluation participants offered solutions of their own, including that family carers be employed by the NASCs or other appropriate health care providers, or that the funding be assigned direct to family carers as a benefit or in a similar way to Contract Board. The value of a wage (as opposed to a benefit or rent) to family carers is that it provides formal recognition of the work family carers do and is looked upon by banks as income.

A lack of awareness of FFC among those who had not been directly involved in or had not followed the related court cases seemed to be a barrier to uptake. A small number of FFC funded families told us they had come across FFC by happenstance. One option to address this could be to increase the modes and channels by which information about FFC is disseminated.

Some other aspects of the policy that did not find favour with a significant number of the evaluation participants we spoke with included the restriction of funded support hours to ‘personal care’ and ‘household management’ and family carer payment set at the minimum wage. They too acted as barriers to uptake, and solutions to which would make FFC more attractive to those for whom the policy is intended to support.

Appendix 1 Evaluation methodology

The Ministry of Health commissioned an evaluation from Artemis Research NZ Ltd (Artemis Research) to assess the impact and effectiveness of Funded Family Care (FFC) and the reasons influencing its uptake in its first year of operation.

The evaluation design employed a mix of qualitative (interviews) and quantitative (survey) methods.

The code of ethics of the Australasian Evaluation Society guided the evaluators' conduct throughout the project.

Interviews with disabled people and their family/whānau carers

The Ministry of Health assisted with the recruitment of potential interview participants. Through the NASCs, FFC recipients and/or their family/whānau carers nationwide were invited to supply their names and contact details to the Contract Relationship Manager, Disability Support Services, in the knowledge that this information would be forwarded to Artemis Research. This recruitment method yielded 30 pairs of names of both the disabled person and their family/whānau carer and four names of family/whānau carers living throughout the country.

In addition, some organisations representative of disabled people and family/whānau carers publicized the evaluation among their networks. Subsequently, approximately 15 family/whānau carers contacted Artemis Research directly to express an interest in participating in an interview. These people represented a mix of families who were accessing FFC and those who were not.

Artemis Research evaluators then made contact with almost all the families who wished to contribute to the evaluation. Initial contact was usually by phone with the family/whānau carer. The evaluators explained in general terms what involvement to an interview would mean, and a time and a place for the scheduling of the interview was agreed. Most families were offered a choice of being interviewed by a Māori or Pacific interviewer, but none took this up. The interviewers then usually sent an email confirming the interview time and place.

All interviews were conducted by two interviewers (Judy Paulin and Sue Carswell) between November 2014 and February 2015 with the informed consent of participants. Thirty seven interviews were conducted face-to-face with the disabled person and/or their family/whānau carer¹³ (usually in their homes) and eight were conducted by phone with the family/whānau carer.¹⁴

In almost all of the 45 interviews with disabled persons and/or family/whānau carers, it was the family/whānau carer who did most of the talking. However, the carers spoke in a way that was considerate and inclusive of their disabled family member. Many of the disabled family members were profoundly intellectually disabled which severely limited their ability to participate in the interview process.

The semi-structured interviews averaged approximately one hour. A copy of the information and consent form, plus two interview guides – one for those accessing FFC and one for those not – follow.

13 In a small number of interviews the partner or advocate of the disabled person was also present.

14 In one case this was with the partner of the family/whānau carer.

All but three were digitally recorded and transcribed verbatim by a professional transcription company. Hand written notes were kept by interviewers during the remaining three interviews. The informed consent of participants interviewed face-to-face was obtained in writing, and that of participants interviewed by phone was recorded on the digital recording.

At the end of each interview, participants were given a \$30 Warehouse voucher in consideration for their contribution to the evaluation. Participants were also offered a summary of the evaluation findings at the end of the evaluation.

Forty interviews were conducted with interview participants who were accessing FFC (or approximately one fifth of all those accessing FFC) and five interviews were conducted with interview participants who were not.

The evaluators think that the 40 interviews with disabled persons or their family/whānau carers enabled them to glean a full range of perspectives and experiences of families accessing FFC. In other words, 'saturation' could be said to be achieved.

However, the perspectives and experiences of the five family/whānau carers interviewed who were not accessing FFC are not numerous enough to be considered typical of this larger group.

Interviews with FASS & organisations representative of disabled people and family/whānau carers

Seven Ministry-nominated organisations representative of disabled people and family/whānau carers were invited to participate in the evaluation. Five - three via face-to-face interviews in person, one by Skype, and one by phone – did so during February 2015.

No feedback was received from the other two organisations despite at least three attempts by the interviewer (Judy Paulin) to engage with them for the purposes of the evaluation.

The FASS manager was interviewed by phone.

A copy of the information and consent form and the interview guide follow.

All semi-structured interviews were conducted on the basis of their voluntary and informed consent, and were digitally recorded and transcribed verbatim by a professional transcription company.

Participants were offered to receive a summary of the evaluation findings at the end of the evaluation.

Feedback from NASCs via online survey

The evaluators invited feedback on the FFC policy from the 15 NASC services through an online survey (supported by SurveyMonkey). A copy of the PDF version of the survey is available on request.

In late January 2015, a designated person within each of the 15 NASCs was emailed an introduction to the evaluation and a URL link to the survey. Thirteen survey responses were received from 13 NASCs within the three week timeframe (and with up to two reminders). One provided only a very limited response.

Analysis

Transcribed qualitative interview materials were entered into the NVivo software package and analysed around key themes related to the interview questions. Quotes are used in the report to illustrate a commonly held view or a unique perspective.

The ethnicity of disabled people and family/whānau carers is not presented since the information collected was a mix of self-report and report of the family/whānau carers on behalf of the disabled people and is not complete.

Responses to closed ended questions to the online survey were analysed in Excel.



Evaluation of Funded Family Care Information & Consent Form for Interview Participants

The Ministry of Health wants to evaluate the impact of its Funded Family Care (FFC) policy one year after its introduction. The Ministry has contracted an independent company, Artemis Research NZ Ltd (Judy Paulin and Nicolette Edgar), to find this out by carrying out an evaluation.

The evaluation includes interviews with disabled people and their family/whānau carers – some who are accessing FFC and some who are not - as well as feedback from the Needs Assessment and Service Coordination (NASC) services, FASS (the host provider), and some organisations that represent disabled persons and their family/whānau carers.

Findings from the evaluation may provide the Ministry with an empirical basis to support possible changes to the FFC policy.

Your participation in an interview is your choice. What you tell the interviewer will be kept confidential. You can refuse to answer any specific question or stop the interview at any time without giving a reason. With your permission the interview may be digitally recorded.

- I have had the chance to ask any questions about the evaluation and I am satisfied with the answers I have been given.
- I understand that the interviewer will keep confidential what I say.
- I understand that what I say may be quoted in the evaluation report but only in a way that does not identify me.
- I understand that the evaluator will file this signed consent form in a secure place.
- I understand that the evaluator will provide me with a summary of the evaluation findings at the end of the evaluation (estimated to be June 2015), if I wish.

I _____ (name) voluntarily consent to take part in the evaluation of *the Funded Family Care policy* on the basis of these understandings.

Signature _____

Email _____

Mobile _____

Date _____

- Please tick to receive a summary of the findings at the end of the evaluation (estimated to be June 2015)

P +64 4 473 9597

Artemis Research NZ Ltd
Prime Property House
2 Woodward St
Wellington 6011
PO Box 10780
The Terrace
Wellington 6143

www.artemis-research.co.nz

Evaluation of Funded Family Care (FFC)

Interview Guide for FFC recipients &/or family/whānau carers

Note:

The questions will be used to *guide* the interview.

Where adult disabled person is not present or is not actively participating at interview, refer to the adult disabled person by name.

Replace "NASC" with name of local NASC provider (for example, Taikura Trust).

Interviewer may need to describe the FASS provider by its function.

1. Can you please briefly describe your day-to-day living arrangements? Your relationship (adult disabled person/carer)? Who else lives with you?
2. How many hours/week FFC funding do you receive funding for?
Is there just one FFC carer in your household?
When did the FFC funding start?
Any other related funding?
3. Going back to the beginning, how did you learn about Funded Family Care?
Through the Ministry website? Through a NASC? Through a group representative of disabled persons and their carers? Another way?
4. [Adult disabled person's name] would have undergone an assessment for eligibility for FFC with a local NASC* person and a support plan would have been developed. Do you recall being told by the NASC person how many hours were allocated for personal care and household management?
What worked well about the assessment & support plan development from your perspective? What didn't work so well? What could have been improved?
5. The eligibility criteria for FFC says that [adult disabled person's name] must be assessed as having high or very high disability-related needs and would not be able to remain at home if they could not employ a family carer. Do you think these criteria are fair/unfair? How so?
6. Was [adult disabled person's name] assessed as eligible for FFC at their first assessment? Or was the initial assessment subject to a review? How did that work?
7. Once [adult disabled person's name] learned s/he was eligible for FFC, about how long did it take to make a decision to take up FFC? Was that decision made with the help of an advocate? Who was that? How did that work? What was good about that process? What wasn't so good? What could have been done better?
8. A person from the FASS host provider would have met with you to give you advice and information on being an employer and employee.
Did they visit once or more than once? About how long did they spend with you?
Do you recall being given a copy of the Funded Family Care Notice? Did that person explain what the Notice meant in a way you [or adult disabled person's name] could understand?
Do you recall helping put together an individual service plan (ISP) that documented all of the personal care and household management tasks for you [or adult disabled person's name] that your carer would undertake?
Did you discuss the individual service plan against the goals in your [or adult disabled person's name] support plan (set up with the NASC)?

What worked well about these processes from your point of view? What didn't work so well? What could have been improved?

9. Once you had all signed the Individual Service Plan (ISP), about how long did it take before you were advised by the NASC of the start date of FFC funding? A couple of weeks? A month? Longer?
10. How is the FFC arrangement working out from your point of view? What's changed for the better? Are there any downsides? What are these? How might it work better?
11. Did you get the number of hours of FFC funding you (or adult disabled person's name] wanted? Are there some activities you think should be funded for, but aren't? What are these?
12. Do you think the hourly rate paid to family carers under FFC is fair? Why?
13. Have there been any issues with FFC payments? If yes, what were/are these?
14. Have you (the carer) taken any paid leave?
If yes: How did this work? Was a replacement carer available to cover?
If no: Why not?
15. Has a person from the NASC visited to check how you're getting on under the FFC arrangement? Any comments on this?
16. Would you recommend uptake of FFC to others in similar circumstances? Why? Why not? What advice would you give them?
17. Have you any additional comments you'd like to make?
18. Just one last thing. To help us describe the sample of people we're speaking with for the evaluation can you please tell me your ethnicity? (See over)

Many thanks!

Collection of ethnicity information

Face-to-face interview

[Interviewer to read out]

Please use this card to tell me which ethnic group or groups you belong to.

Showcard

New Zealand European

Māori

Samoan

Cook Islands Maori

Tongan

Niuean

Chinese

Indian

Other (such as Dutch, Japanese, Tokelauan). Please state.

Telephone interview

I'll read out a list of ethnic groups. Can you tell me which ethnic group or groups you belong to:

New Zealand European?

Māori?

Samoan?

Cook Islands Maori?

Tongan?

Niuean?

Chinese?

Indian?

Another ethnic group such as Dutch, Japanese or Tokelauan? Please say what it is.

Telephone interview

I'll read out a list of ethnic groups. Can you tell me which ethnic group or groups you belong to:

New Zealand European?

Māori?

Samoan?

Cook Islands Maori?

Tongan?

Niuean?

Chinese?

Indian?

Another ethnic group such as Dutch, Japanese or Tokelauan? Please say what it is.

Evaluation of Funded Family Care (FFC)
Interview Guide for
Adult disabled persons & Family/whānau carers
who are NOT accessing FFC

Note:

The questions will be used to *guide* the interview.

Personalise questions by using names of adult disabled person and carer.

Replace "NASC" with name of local NASC provider (for example, Taikura Trust).

Interviewer may need to describe the FASS provider by its function.

Ask numbered questions, as relevant.

1. Can you please briefly describe your day-to-day living arrangements? Your relationship (adult disabled person/carer)? Who else lives with you?
2. I understand that you are not currently receiving Funded Family Care funding. Am I right in this? *Yes/no*
3. How did you learn about Funded Family Care? Through the Ministry website? Through a NASC? Through a group representative of disabled persons and their carers? Another way?
4. Was [adult disabled family person] assessed by a local NASC person for eligibility for FFC? *Yes/no*.
If *no*: Please explain why not?
If *yes*: Was [adult disabled person] assessed as eligible for FFC? *Yes/no*.
If *yes*: Did [adult disabled person] continue on with the process (e.g. have a support plan developed)?
If *no*: What were the reasons you were given as to why [adult disabled person] was not eligible for FFC? Did you ask for a review? What did the review find?
5. The eligibility criteria for FFC include that [the adult disabled person] must be assessed as having high or very high disability-related needs and would not be able to remain at home if s/he could not employ a family carer. Do you think these criteria are fair/unfair? How so?
6. Once [adult disabled person] learned s/he was eligible for FFC, about how long did s/he take to make a decision NOT to take up FFC?
Was that decision made with the help of an advocate? Who was that?
Did [adult disabled person] take that decision before or after the meeting with a person from the FASS host provider organisation?
Why did [adult disabled person] decide not to take up FFC?
7. Do you think the hourly rate paid to family carers under FFC is fair? Why or why not?
8. What advice would you give to others in similar circumstances about whether to go through the assessment process for eligibility for FFC?
9. Have you any additional comments about FFC you'd like to make?

10. Just one last thing. To help us describe the sample of people we're speaking with for the evaluation can you please tell me your ethnicity? (See over)

Many thanks!

Collection of ethnicity information

Face-to-face interview

[Interviewer to read out]

Please use this card to tell me which ethnic group or groups you belong to.

Showcard

New Zealand European

Māori

Samoan

Cook Islands Maori

Tongan

Niuean

Chinese

Indian

Other (such as Dutch, Japanese, Tokelauan). Please state.

Telephone interview

I'll read out a list of ethnic groups. Can you tell me which ethnic group or groups you belong to:

New Zealand European?

Māori?

Samoan?

Cook Islands Maori?

Tongan?

Niuean?

Chinese?

Indian?

Another ethnic group such as Dutch, Japanese or Tokelauan? Please say what it is.



Evaluation of Funded Family Care Information & Consent Form for Interview Participants

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Findings from the evaluation may provide the Ministry with an empirical basis to support possible changes to the FFC policy.

Your participation in an interview is your choice. What you tell the interviewer will be kept confidential. You can refuse to answer any specific question or stop the interview at any time without giving a reason. With your permission, the interview may be digitally recorded.

- I have had the chance to ask any questions about the evaluation and I am satisfied with the answers I have been given.
- I understand that the interviewer will keep confidential what I say.
- I understand that what I say may be quoted in the evaluation report but only in a way that does not identify me.
- I understand that the evaluator will file this signed consent form in a secure place.
- I understand that the evaluator will provide me with a summary of the evaluation findings at the end of the evaluation (estimated to be June 2015), if I wish.

I _____ (name) voluntarily consent to take part in the evaluation of *the Funded Family Care policy* on the basis of these understandings.

Signature _____

Email _____

Mobile _____

Date _____

Please tick to receive a summary of the findings at the end of the evaluation (estimated to be June 2015)

P +64 4 473 9597

Artemis Research NZ Ltd
Prime Property House
2 Woodward St
Wellington 6011
PO Box 10780
The Terrace
Wellington 6143

www.artemis-research.co.nz

Evaluation of Funded Family Care (FFC)

Interview Guide for FASS and stakeholder bodies representative of disabled persons & their carers

Note: The questions will be used to *guide* the interviews with individual interviewees or small groups of staff from the same organisation.

1. Can we please begin by you giving me an overview of your organisation (the types of services you provide, who you provide them to, etc.) and your role(s) within your organisation?
2. On a scale of 1 to 5, where 1 = no knowledge and 5 = complete knowledge, can you please rate your knowledge of the Ministry of Health's Funded Family Care policy?
3. To what extent has your organisation been involved with, or have stakeholders who have been impacted by, the operation of the FFC policy? How?
4. For each of the following provisions of the FFC policy, what in your view is going well, not so well, and what could be improved? If you don't have a view on an aspect we will just move on to the next.
 - a. The numbers of adult disabled persons taking up FFC so far?
 - b. The NASCs' decision-making about adult disabled people's eligibility for FFC or the number of FFC hours that eligible adult disabled people are allocated by their NASC?
 - c. The process for review of decisions about adult disabled people's eligibility or allocations for FFC?
 - d. The way the FFC funding is arranged with the adult disabled person as the employer and their family carer as their employee?
 - e. The use of advocates to help adult disabled persons with their decision-making about FFC?
 - f. The FASS host provider's provision of information and advice to the adult disabled person as employer about their employment obligations (including information and advice about tax and ACC obligations, handling of any surplus in employer's account at year's end)?
 - g. The use of software options such as SmartPayroll for the making of fortnightly FFC payments to family carers?
 - h. The funding provisions for leave (sick leave, annual leave etc) for family carers?
 - i. The follow-up visits by NASC staff to FFC recipients and family carers?
 - j. How FFC impacts or doesn't impact on disabled peoples' access to other related funding (such as respite care)?
 - k. The Ministry of Health's oversight of the FFC policy?
 - l. The Ministry of Health's responsiveness to queries related to implementation of FFC?
 - m. Any other aspects?
5. Are there any other comments you'd like to make about FFC for the evaluation?

Many thanks!

