

Budget Sensitive and Legally Privileged

Office of the Minister of Health
Office of the Associate Minister of Health

Chair, Cabinet Social Wellbeing Committee

FUNDED FAMILY CARE POLICY CHANGE

Proposal

1. To seek agreement to policy and legislative changes to Funded Family Care.

Executive Summary

2. On 19 September 2018, Cabinet Social Wellbeing Committee (SWC) agreed to announce that the Government intends to make changes to health Funded Family Care policies including the intention to repeal Part 4A of the New Zealand Public Health and Disability Act 2000 (Part 4A), and to undertake stakeholder engagement [SWC-18-MIN-0129 refers].
3. Funded Family Care (FFC) policies allow eligible disabled people with high or very high needs to choose to have their resident family member provide the support services that would otherwise be provided by a state funded care and support worker. The Ministry of Health (the Ministry) Disability Support Services and District Health Boards have FFC policies.
4. There have been ongoing national and international challenges to FFC since 2013, which include litigation, petitions, correspondence and media coverage. We have considered feedback from targeted engagement and are seeking a Cabinet decision to remove discriminatory policy settings and legislation. We are seeking agreement to:
 - 4.1. repeal Part 4A without a litigation bar;
 - 4.2. remove eligibility criteria exclusions based on family status and age;
 - 4.3. raise pay rates for funded family carers by applying the same pay and employment framework as the wider care and support workforce, recognising that they provide the same funded disability supports as other care and support workers;
 - 4.4. remove the requirement for an employment relationship between the disabled person and funded family carer under the Ministry's FFC policy.
5. Part 4A includes a litigation bar in section 70E preventing any legal challenge to FFC policies on the basis of unlawful discrimination, which is inconsistent with the New Zealand Bill of Rights Act 1990. Part 4A protects current discriminatory FFC policies.
6. We propose to repeal Part 4A in its entirety to ensure consistency with human rights legislation. Funding of \$32 million over four years for FFC policy change has been set aside as an operating contingency in the Budget 2019 package for Vote Health. This is expected to meet the projected cost of \$8.13 million to implement FFC policy change in year one intended for 2019/20. It is our intention to seek additional cost pressure funding as required in future Budget rounds.
7. We are not proposing to change the type of care that the Government funds, or the principle that families ordinarily have the primary responsibility to care for their family members, notwithstanding any support provided by Government.

Background

8. Many New Zealanders who need personal care and household support receive a significant amount of this care from family members. Prior to 2013 the Ministry of Health (the Ministry) had a policy of not paying resident family carers to provide allocated support to eligible disabled people. Legal action resulted in a declaration that the Ministry had acted in breach of Part 1A of the Human Rights Act 1993 on the grounds of family status.
9. The current policy on paying family carers was developed in response to litigation and fiscal risk, with Part 4A of the New Zealand Public Health and Disability Act 2000 (Part 4A) introduced under urgency in 2013. Part 4A covers:
 - 9.1. the principle of primary family responsibility for the wellbeing of family members, in the context of funded support services;
 - 9.2. the Government's role to manage fiscal risk and ensure sustainable funding of support services;
 - 9.3. the requirement for the Crown and District Health Boards (DHBs) to have family care policies, and restriction of payment to family carers in accordance with the policies;
 - 9.4. a 'litigation bar' which prevents people from taking a claim to the Human Rights Commission or a court on the basis of unlawful discrimination such as family status (section 70E).
10. An overview of current FFC policies is attached at Appendix A. FFC covers policies that have operated since 2013 by both the Ministry Disability Support Services (DSS) for eligible disabled people and DHB paid family care for eligible people with long term chronic health, mental health and aged care needs. The Accident Compensation Corporation (ACC) also operates an attendant care policy (under which family members may be paid for care) which is not in scope for change.
11. FFC is currently only available to people with high and very high needs who are eligible for Home and Community Support Services, and accounts for a small proportion of these services funded by the Ministry and DHBs. Support services are allocated through Needs Assessment and Service Coordination agencies.
12. There have been ongoing national and international challenges to FFC since 2013, which include litigation, petitions, correspondence and media coverage. The most recent court case involved the 13 claims addressed through the *King* Proceedings which were settled in December 2018 [CAB-18-MIN-0641 refers].
13. Part 4A is inconsistent with the New Zealand Bill of Rights Act 1990 (BORA) section 5 (justified limitations to rights and freedoms). Discriminatory policy settings were also a concern raised by the United Nations Committee on Disability Issues in 2014.
14. Targeted engagement was undertaken by an independent facilitator in October 2018 and the reports are available on the Ministry's website. Stakeholders are supportive of our priority policy issues for change presented in this paper, and feedback is summarised in Appendix B.
15. FFC is part of the broader cross government support available to disabled people and carers. This includes Supported Living Payments (SLP) led by the Ministry of Social Development (MSD). The SLP benefit provides income support to people who care full time at home for someone (other than their spouse or partner) who would otherwise require hospital, rest home or residential disability care. The SLP is income tested and eligible family carers are able to receive both the SLP Carer and FFC (SLP rates are abated by FFC income).

Policy and legislative change - Funded Family Care policies

16. In September 2018, Government announced the intention to repeal Part 4A and make FFC policies fairer. Our first focus is on removing key discriminatory elements that are inconsistent with human rights law, and improving living standards for disabled people and family carers through pay parity with other care and support workers and change to employment arrangements. Three priority policy issues are proposed to be addressed:
 - 16.1. pay rates for funded family carers under the Ministry's FFC policy who currently receive minimum wage, while other carers receive higher hourly rates;
 - 16.2. change to the requirement for high/very high needs disabled people to be the employer of their family member under the Ministry's FFC policy;
 - 16.3. eligibility for FFC (partners and spouses, and family of under 18s with high and very high needs are currently not able to provide funded family care).
17. The issue of maximum hours has also been raised as a key issue by stakeholders. Family carers under DSS and DHB policies are currently restricted to being paid for providing a maximum of 40 hours of a person's allocated support per week (further hours can be provided by another funded family carer or a care and support worker). This was implemented to set expectations of a regular working week and manage fiscal costs (see Appendix C for further detail). There is currently an exceptions process.
18. Notwithstanding the concerns raised by stakeholders, we have prioritised resolving other issues ahead of any changes to the 40 hour maximum and do not intend to change the current limit.
19. These proposals address the small number of family carers providing specific home care services under Ministry and DHB policies. This proposal is not intended to set a policy precedent for other caring workforces in other sectors.

Priority policy change - pay rates and employment arrangements

20. Funded family carers are employed to provide the same work as would otherwise be provided by a care and support worker but they are treated differently in terms of pay. Funded family carers are not covered by the Care and Support Workers (Pay Equity) Settlement Act 2017 (Support Workers Act), which implemented the settlement agreement resulting from the TerraNova pay equity claim brought by E tū and other unions.
21. The agreed TerraNova settlement increased care and support workers' pay rates to align with rates paid to comparable workforces who exercise similar skills and experience, recognising that the majority of the care and support workforce is female. Funded family carers were not included because they were outside the scope of the settlement.
22. Under the Support Workers Act, care and support workers will receive rates of between \$20.50 and \$25.50 per hour from July 2019 subject to qualifications and/or years of service. Currently, funded family carers:
 - 22.1. under DHB FFC policies receive pay rates comparable to Support Workers Act rates through employment by Home and Community Support Services providers (service providers), despite the exclusion of funded family carers in the Support Workers Act;
 - 22.2. under ACC's attendant care policy also receive pay rates comparable to Support Workers Act rates, and care recipients have more flexibility to choose the employment arrangement with their family member.
23. In contrast, funded family carers under the Ministry's DSS FFC policy are paid the adult minimum wage (\$17.70 per hour from 1 April 2019) and are employed by their disabled family member.

25. We want to ensure a consistent and equitable approach to paying family members who provide allocated support under different government policies in the health sector.

Treating funded family carers as comparable to care and support workers

26. We consider that the best way to ensure pay parity for funded family carers, is to treat them as comparable to care and support workers and by applying the same pay and qualifications framework set under the Support Workers Act. This will provide a more consistent approach to the paid care workforce, and support high standards of care and training, and minimise the risk of discrimination claims after the repeal of Part 4A.
27. The Support Workers Act is intended to ensure a skilled workforce and consistency of training and qualifications. It requires employers to take reasonable steps to ensure workers are able to attain New Zealand Qualifications Authority (NZQA) or equivalent qualifications in order to progress on the pay scale.
28. We recommend that pay parity for funded family carers is implemented through policy rather than amendment to the Support Workers Act. The purpose of the Support Workers Act is to implement the 2017 settlement agreed between the Crown and unions to address historical pay equity issues related to gender, and funded family carers were outside the scope of those settlement negotiations. The central issue in FFC is the need to address discrimination on the basis of family status.
29. We recognise that many funded family carers are likely to be unqualified, and some may not wish to take up qualifications. DHB service providers report that funded family carers are required to undertake entry level training to obtain their employment agreement, however they tend to have difficulty encouraging them to undertake formal qualifications.
30. New care and support workers without qualifications can receive the starting Support Workers Act pay rate (\$20.50 per hour from July 2019) but must achieve qualifications to progress. We propose that FFC policies reflect this approach.
31. We are also considering how to treat previous care experience of funded family carers, subject to Cabinet's decision on whether to implement pay parity. Under the Support Workers Act, care and support workers who are new to the workforce must attain qualifications for increased pay, but transitional arrangements allowed workers employed prior to commencement of the legislation to progress on the pay scale based on length of service or qualifications.
32. Unpaid care experience is not recognised as 'length of service'. Length of service is defined in the Act as the length of time that the worker has been continuously employed by the worker's current employer or continuously employed by a previous employer if the worker was transferred as a result of restructuring. We will consider how to apply an equitable approach consistent with this framework.
33. We gave consideration to an alternative approach which would require designing a unique pay framework and treating funded family carers differently to other care and support workers. However, we decided against this option given the intention to ensure a non-discriminatory approach to paying funded family carers, in particular:
 - 33.1. lower qualification levels or length of service linked to higher pay rates could risk undermining the TerraNova settlement and be criticised by unions;

- 33.2. an allowance or separate payment model set at a lower rate to other care and support workers would still risk claims on the basis of a family status discrimination or require legislative protection against litigation.
34. FFC carers are a specific group that are providing the same work as care and support workers and should therefore be treated as comparable. We acknowledge that the stakeholder feedback in the targeted engagement included calls for the Government to consider its approach for financial support for family carers more broadly, of which the majority are unpaid. We believe this is best considered through:
- 34.1. the Carers' Strategy Action Plan 2019-2023;
- 34.2. Government's response to the report of the Welfare Expert Advisory Group.

Proposed change to employment relationship requirement

35. We are seeking a Cabinet decision to remove the requirement for the disabled person to be the employer of their funded family carer under the Ministry's FFC policy. Subject to Cabinet's decision, this would be implemented alongside pay parity proposals.
36. Litigation against this requirement is underway, and it has been criticised by stakeholders on the basis that some high or very high needs disabled people do not have the capacity to fulfil their employer obligations, such as administration and quality assurance of the care they receive from their family member.
37. The Support Workers Act framework places an obligation on employers to ensure access to training for qualifications. This presents a further risk if the same approach is applied to disabled people with high or very high needs without choice of other options or support to manage this additional employer obligation.
38. We are considering options to implement alternative employment arrangements that do not place unreasonable obligations on disabled people. Stakeholder feedback strongly supported choice of employment options depending on the circumstances of disabled people and their families. Options we are considering include:
- 38.1. employment of funded family carers by third party service providers, who would then be responsible for relevant employment checks, training and standards of care;
- 38.2. allowing disabled people or their agent acting on their behalf to employ or contract a resident family member through personalised budgets such as Individualised Funding. Current policies allow disabled people to employ or contract non-resident family, friends or support workers, and would be reviewed to ensure any potential conflicts of interest can be managed for FFC. Personalised budgets allow more choice and control for disabled people over who provides their support, and can include help to manage employment or tax obligations;
- 38.3. a choice between the above arrangements.
39. Employment arrangement options will have associated costs, such as employment overheads. These were included in FFC Budget 2019 cost estimates. Further detail of pay and employment options for implementation is provided in Appendix C.
40. The Ministry is discussing these proposed changes with DHBs, including the feasibility of developing a more nationally consistent approach.

Priority policy change - eligibility for Funded Family Care

41. Under the current FFC policy, some family carers are treated differently to others depending on their relationship to their disabled family member and are not eligible for FFC. Eligible disabled people can receive FFC from their resident family member, unless that family

member is their spouse or partner or the disabled person is under the age of 18. This results in an inequitable approach to supporting disabled people and their family carers, and will be at risk of challenge if Part 4A is repealed.

42. We propose to change FFC policies to allow:
 - 42.1. spouses and partners to provide FFC to people with high or very high disability support needs;
 - 42.2. children and young people under the age of 18 with high or very high needs to receive FFC from resident parents or family members (who are over 18).
43. We intend to retain the current policy framework which offers FFC to those people with high and very high support needs. This will allow access for those people who are most likely to benefit from payment to family members to provide their allocated disability support, while also managing the risk of high fiscal costs to government.

Budget 2019 funding and cost implications

44. Funding of \$32 million over four years for FFC policy change has been set aside as an operating contingency in the Budget 2019 package for Vote Health to fund the changes to FFC eligibility, pay rates and alternative employment options.. We consider that this funding will be sufficient to meet the projected cost of \$8.13 million to implement policy change in year one intended for 2019/20.
45. We have directed the Ministry to monitor and report on the actual costs of policy changes, projected to increase year on year depending on the rate of FFC uptake. We intend to seek additional cost pressure funding as required in future Budget rounds.
46. As part of Budget 2019, Cabinet agreed that the Ministers of Health and Finance could jointly draw down this tagged contingency funding following the repeal of Part 4A [CAB-19-MIN-0174 refers]. We recommend that key changes to discriminatory policy settings are progressed by early 2020, prior to the repeal of Part 4A. This will ensure that any delays in the legislative process will not be a barrier to address the current inequities in FFC policies, and is expected to contribute to minimising the risks of litigation after Part 4A is repealed. We are therefore seeking agreement from Cabinet that FFC contingency funding can be drawn down prior to repeal of Part 4A.
47. When we determine the level of government funded support a person can receive, the assessment process takes into account natural support already available from family, friends and community support. Natural support includes care that family members are willing and able to provide unpaid. FFC hours are intended to be a substitute for support hours which would otherwise be allocated to a support services provider.
48. Family members are likely to be providing unpaid care in addition to any funded support. Paying family members to provide allocated support hours may raise the societal expectation of payment for family members and lead to more people taking up FFC (in addition to providing natural support). This may result in increased costs for government. The Ministry has built this expected cost growth into the estimated costs of FFC policy change, and will monitor and report on the management of any costs associated with implementing FFC policy changes.
49. FFC eligibility and pay rate changes may result in some transfer of costs or abatement of the Supported Living Payment Carer benefit led by MSD for carers currently supported by this benefit. There is uncertainty about the potential level of transfer which depends on FFC uptake. The Ministry will continue to work with MSD during service design and implementation.

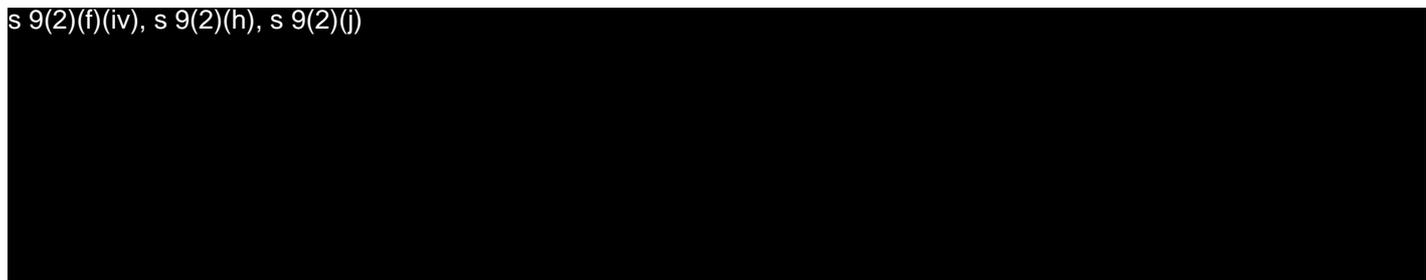
Legislative proposals – repeal Part 4A of the New Zealand Public Health and Disability Act 2000

50. In September 2018, SWC noted that the decision on whether Part 4A should be repealed in its entirety or replaced with some form of legal mitigation, would be addressed in the next paper to Cabinet on FFC [SWC-18-MIN-0129 refers]. The Government also announced the intention to repeal Part 4A.
51. We are seeking agreement to repeal Part 4A, in full, alongside key changes to FFC eligibility and pay rates to remove discriminatory policy settings. The key issue is the litigation bar included in Part 4A which prevents claims challenging FFC policies on the basis of unjustified discrimination under human rights legislation. Past successful challenges were based on discrimination due to family status.

Future discrimination claims

52. If the proposed changes to increase eligibility and pay rates are implemented, we expect the likelihood of retrospective claims and claims against the government post-repeal will be reduced.
53. The Government has previously been criticised for maintaining the litigation bar. There is a strong human rights case for removing the litigation bar to ensure disabled people and their families have the same access to the courts as everyone else.

s 9(2)(f)(iv), s 9(2)(h), s 9(2)(j)



55. Positive policy changes to remove discriminatory aspects will minimise the risk of future claims from the point of policy change and repeal, given this will remove the grounds to challenge FFC policies based on family status discrimination under the Human Rights Act 1993.

s 9(2)(f)(iv), s 9(2)(h), s 9(2)(j)



Proposed approach to repeal of Part 4A

- 61. We propose to repeal Part 4A in full, without retention of legislative protection to prevent litigation claims on the basis of discrimination. We consider that this risk is best managed by treating family carers more fairly in the future.
- 62. This approach is proposed to ensure full consistency with human rights legislation, allow a fair and transparent process for disabled people and family carers to challenge policies, and support wider Government policies to improve wellbeing and raise living standards. Repeal of Part 4A without a litigation bar must also be supported by policy change to current discriminatory FFC policies.

- 64. The Minister for Social Development will also report back to Cabinet on how damages and other payments resulting from human rights breaches are treated for the purpose of income and asset tested assistance, to ensure entitlement to support is not unduly affected for potential claimants [CAB-18-MIN-0641 refers].
- 65. The options for legislative change are the focus of the attached Regulatory Impact Assessment prepared by the Ministry of Health. Other legislative options we have considered, and are not recommended, are outlined in Table 1.

Table 1: Alternative legislative options

<i>Option</i>	<i>Comment</i>
Retain Part 4A (no repeal).	This option is not recommended as it does not support the key outcomes sought by Government such as consistency with human rights legislation and treating family carers fairly.
Repeal and replace Part 4A with a litigation bar to prevent challenge to FFC policies in place between 2013 and the time of repeal.	s 9(2)(f)(iv), s 9(2)(h), s 9(2)(j)
Providing compensation to affected families. This could be implemented alongside a litigation bar for claims between 2013 and the time of repeal, or without a litigation bar to reduce the risk of litigation.	

Timing for repeal of Part 4A

66. It is recommended that Part 4A is repealed at the time of, or after policy changes to eligibility and pay rates, to minimise legal, fiscal and reputational risks.
67. A request for inclusion in the 2019 Legislation Programme has been submitted. Depending on other legislative priorities, we recommend that repeal of Part 4A come into force in mid to late 2020.

Other operational policy issues to be considered

68. We intend to consider other policy and operational matters raised by stakeholders alongside the key policy changes proposed in this paper (see Appendix C for detail).
69. Many stakeholders are not satisfied with the process for allocating funded support. The Ministry will consider how to address these issues as part of the disability support system transformation through the Mana Whaikaha prototype in the MidCentral DHB region which is currently trialling a new allocation process.

Interdependencies and links to cross-government support

70. Issues related to FFC have links to a number of cross-government initiatives, including:
 - 70.1. New Zealand Carers' Strategy and Action Plan 2019-2023 (MSD lead);
 - 70.2. New Zealand Disability Strategy and Action Plan 2019-2022 (Office for Disability Issues lead);
 - 70.3. the Government's response to the recommendations of the Welfare Expert Advisory Group and Government overhaul of the welfare system;
 - 70.4. Health and Disability Service Review (reporting to Minister of Health - interim report in July 2019, and final by 31 March 2020);
 - 70.5. Mana Whaikaha - Disability Support System Transformation;
 - 70.6. the Government's response to the Mental Health and Addiction Inquiry.
71. Any further changes to funded family care policies will take account of these cross-government initiatives (see Appendix C).

Next steps

72. Subject to Cabinet decisions, the implementation of policy changes is planned for early 2020, prior to the repeal of Part 4A. Service design and implementation will be informed by further stakeholder engagement in 2019.
73. We have directed the Ministry to provide further advice to inform final decisions by Health Ministers in 2019 on the implementation of increased pay rates and employment arrangements for funded family carers. This will include consideration of the treatment of previous experience, access to training or qualifications, and any oversight or safeguarding to ensure care quality and management of potential conflicts of interest. This will also reflect supported decision making principles to ensure disabled peoples' choice of carer is upheld.

Consultation

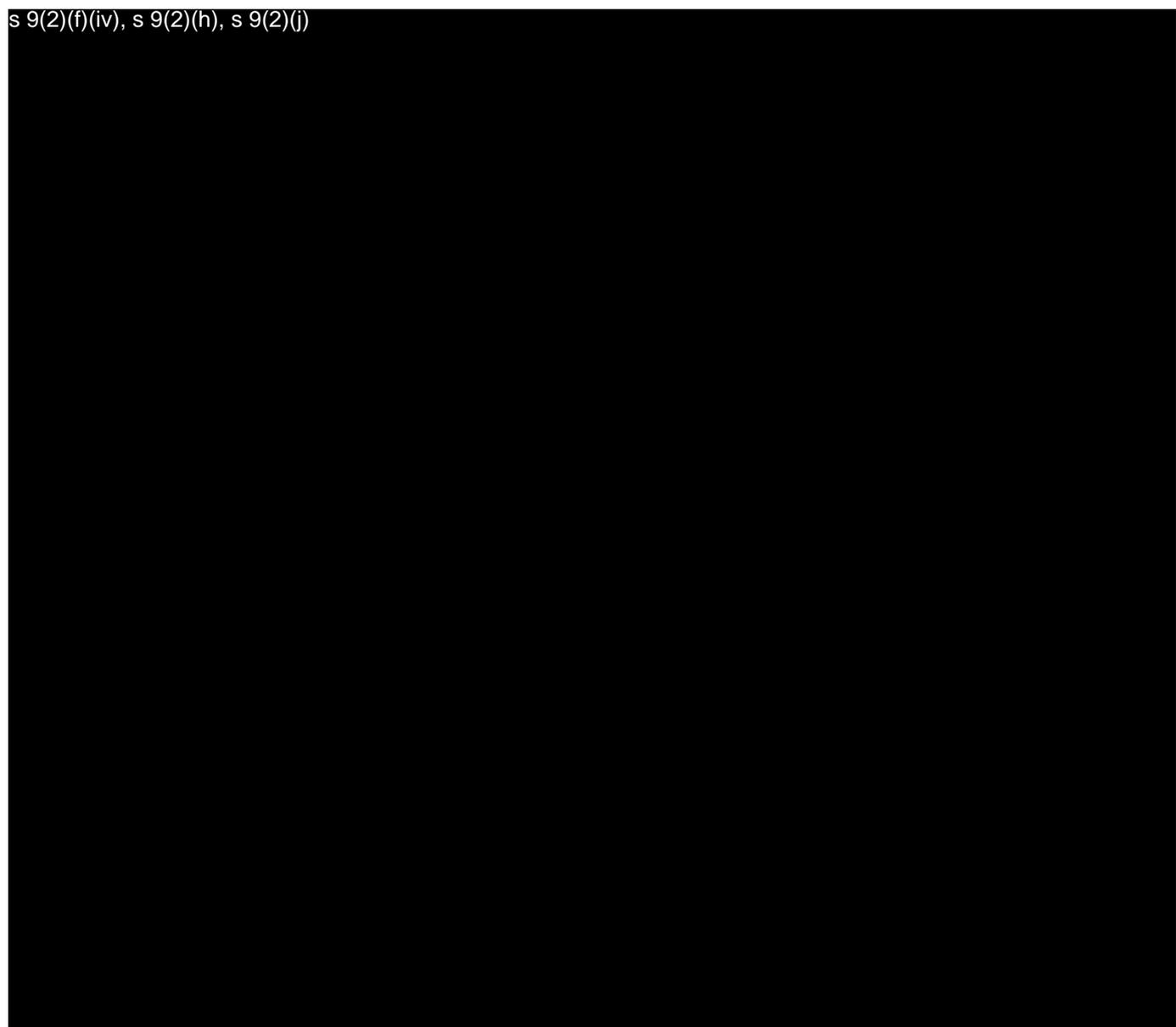
74. Targeted engagement with key stakeholder groups including affected families was undertaken by an independent facilitator in October 2018 to inform the development of policy options. This included an online survey which received 911 responses, and 22 meetings and interviews with stakeholder groups and affected families.

75. Further engagement is ongoing with key groups, including DHBs, service providers and Māori and Pacific people, to ensure that FFC policies are appropriate and support equitable outcomes.
76. The following departments have been consulted on the proposals in this paper: Accident Compensation Corporation, Crown Law, Ministry of Justice, New Zealand Treasury, the Department of the Prime Minister and Cabinet, Ministry of Social Development, Oranga Tamariki, Office for Disability Issues, Ministry of Education, Te Puni Kōkiri, Ministry for Pacific Peoples, Ministry for Business, Innovation and Employment, Ministry for Women and the State Services Commission.

Financial Implications

77. The proposed policy changes will have financial implications. Funding of \$32 million over four years for FFC policy change has been set aside as an operating contingency in the Budget 2019 package for Vote Health, and the Minister of Finance and Minister of Health have authority to draw down this funding.
78. We consider that Budget 2019 funding will be sufficient to meet the projected cost of \$8.13 million to implement policy change in year one intended for 2019/20. We have directed the Ministry to monitor and report on the actual costs of policy change implementation. It is our intention to seek additional cost pressure funding as required in future Budget rounds.

s 9(2)(f)(iv), s 9(2)(h), s 9(2)(j)



83. The Minister of Finance was consulted on the proposals in this Cabinet paper.

Legislative Implications

84. Legislative change, as outlined in this paper, is required to repeal Part 4A of the New Zealand Public Health and Disability Act 2000 in order to ensure consistency with human rights legislation. The principle Act binds the Crown.

85. A request for inclusion in the 2019 Legislation Programme has been submitted, proposed as a Category 4 priority (to be referred to Select Committee in 2019). The Parliamentary Counsel Office has been consulted.

Impact Analysis

86. The Impact Analysis requirements apply to the proposal in this paper and an Impact Summary has been prepared and is attached. The Ministry of Health's Papers and Regulatory Committee has reviewed the Impact Summary and considers that the information and analysis partially meets the quality assurance criteria. The Summary is comprehensive, and the analysis in the tables in section 3 is convincing, and sets out trade-offs and uncertainties, and consultation has been wide. However, it could be significantly briefer without losing content.

Human Rights

87. If implemented, the policy and legislative changes proposed would improve consistency with BORA and the Human Rights Act 1993.

Gender Implications

88. Women contribute the majority of the unpaid labour as carers for disabled people who depend on their family and whānau for support. Given this high proportion in the carer population, women will be more affected by current FFC policy settings and future policy change.

89. Improving policies to pay family carers will contribute to increased opportunities for family carers, many of them women, to provide funded support to their disabled family member. This may benefit their family and whānau wellbeing.

Disability Perspective

90. There is considerable expectation of change to FFC from the disability and carer community. The announcement of change and a programme to address these issues has been advocated by this community, in particular the ability to challenge policies and improved consistency with human rights legislation.

91. The UN Committee on the Rights of Persons with Disabilities (UNCRPD) has recommended that New Zealand allow payments to all family carers and allow complaints of unlawful discrimination (the right to justice).

Publicity

92. Subject to agreement by Cabinet, communication relating to FFC will include:

92.1. the repeal of Part 4A;

92.2. allowing more family carers of people with high and very high needs to receive payment under FFC (partners and spouses and family of under 18s);

92.3. increasing pay rates to ensure an equitable and consistent approach to paying funded family carers in the health sector;

92.4. change to the DSS requirement for disabled people to be the employer.

93. The Ministry will also develop communications to help stakeholders engage in the service design process and understand what policy change will mean for them.

Proactive Release

94. This paper is not proposed for proactive release, as these proposals are Budget sensitive and some sections are subject to legal professional privilege. The paper will therefore be withheld beyond 30 business days, and reconsidered after announcement of change to FFC policies (if agreed).

Recommendations

We recommend that the Committee:

Pay rates and employment arrangements

1. **agree** to treat family carers under the Ministry of Health and District Health Board Funded Family Care (FFC) policies in the same way as other employed support workers, by implementing a pay and employment framework consistent with approach in the Care and Support Workers (Pay Equity) Settlement Act 2017
2. **agree** to remove the requirement for a disabled person to be the employer of their family member under the Ministry Disability Support Services FFC policy
3. **note** that we are considering options to implement alternative employment arrangements that do not place unreasonable obligations on disabled people

Eligibility for FFC

4. **agree** to allow:
 - 4.1. people with high or very high disability support needs to receive FFC from resident spouses or partners; and
 - 4.2. people under the age of 18 with high or very high needs to receive FFC from resident parents or family members (who are 18 years and over)

Repeal of Part 4A

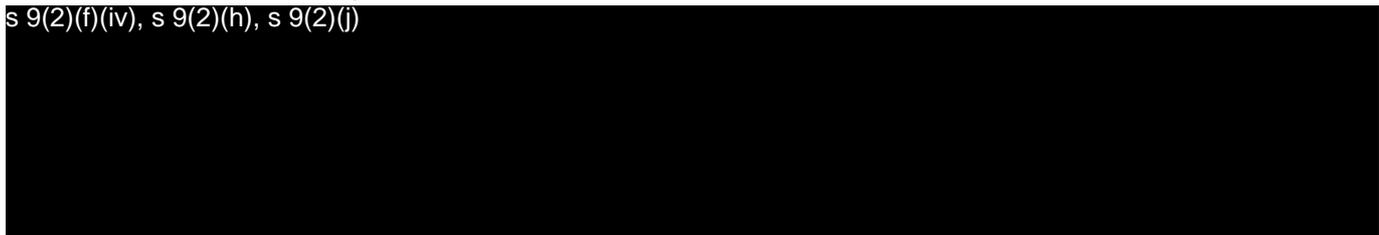
5. **note** that the Government announced the intention to repeal Part 4A of the New Zealand Public Health and Disability Act 2000 (Part 4A) in September 2018
6. **note** that Part 4A includes a litigation bar which prevents discrimination claims about FFC policies, which is inconsistent with the New Zealand Bill of Rights Act 1990

s 9(2)(f)(iv), s 9(2)(h)

8. **note** that parallel policy changes to remove discriminatory aspects can reduce this litigation risk
9. **note** that funding of \$32 million over four years has been set aside as an operating contingency in the Vote Health Budget 2019 package for the proposed policy changes
10. **note** that as part of Budget 2019, Cabinet authorised the Minister of Finance and the Minister of Health jointly to draw down the FFC tagged contingency following the repeal of Part 4A [CAB-19-MIN-0174 refers]

11. **agree** that the Minister of Finance and the Minister of Health can agree to draw down the FFC tagged contingency after the Budget moratorium period, to implement non-discriminatory FFC policies prior to the repeal of Part 4A
12. **note** that Budget 2019 funding is expected to meet the projected cost of \$8.13 million to implement FFC policy changes in year one intended for 2019/20
13. **note** that it is our intention to seek additional cost pressure funding as required in future Budget rounds
14. **agree** to repeal Part 4A in its entirety without a litigation bar
15. **agree** that the Associate Minister of Health issue drafting instructions to Parliamentary Counsel Office to give effect to recommendation 14

s 9(2)(f)(iv), s 9(2)(h), s 9(2)(j)



Other operational policy issues associated with FFC

18. **note** that Health Ministers intend to consider other policy and operational issues raised by stakeholders during 2019
19. **note** that improvements to Funded Family Care may be considered as part of the New Zealand Carers' Strategy Action Plan 2019-23

Communications

20. **agree** to announce repeal of Part 4A and changes to FFC policy.

Authorised for lodgement

Hon Dr David Clark
Minister of Health

Hon Julie Anne Genter
Associate Minister of Health

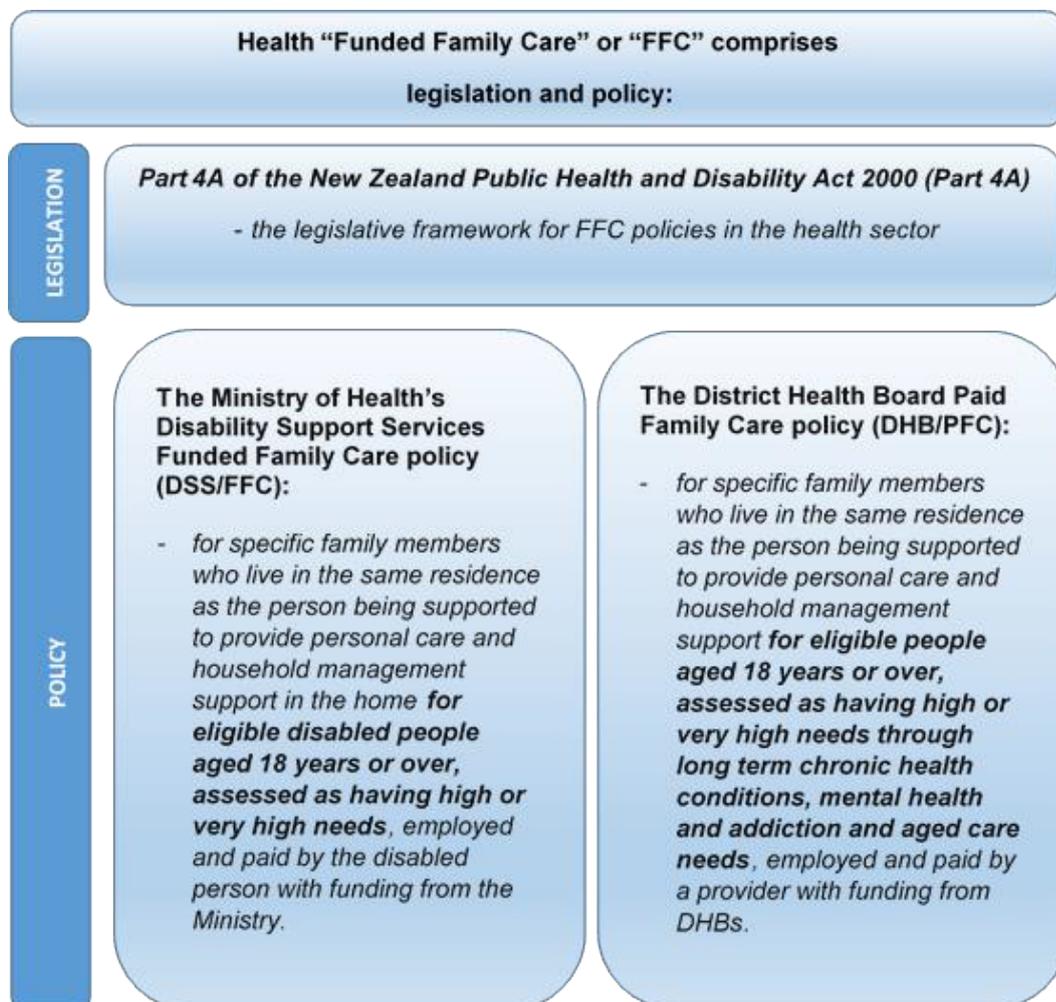
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Appendix A: Overview of Funded Family Care policy and legislation

1. Part 4A of the New Zealand Public Health and Disability Act 2000 (Part 4A) is the legislative framework for the two health sector family care policies for the Ministry of Health (Ministry) and DHBs. The policies are essentially the same but serve different client groups and have different payment mechanisms.

Summary of Family Care policies



Background to the Government's current family care policies and legislative framework

2. Before 1 October 2013, the Ministry:
 - a. did not fund any allocated disability supports provided by parents or resident family of a DSS eligible person
 - b. funded allocated disability supports if they were provided by an eligible disabled person's non-resident family members.

The policy was developed in response to litigation

3. The current policy on paying family carers was developed in response to litigation. The most significant litigation was the Court of Appeal's decision in May 2012 in Ministry of Health v Atkinson and Others which upheld the High Court's view that the Ministry's policy breached the Human Rights Act 1993 because it was discriminatory and therefore inconsistent with the New Zealand Bill of Rights Act 1990. It was discriminatory on the basis of family status, specifically that contracted carers were paid to provide care but family carers who provided the same care were not paid. The Crown's appeals to the High Court and Court of Appeal were dismissed and the Crown did not appeal to the Supreme Court.
4. The development of the current policy was guided by several considerations:

- a. an overarching principle that: ‘in the context of public funding of support services, families generally have primary responsibility for the wellbeing of their member’
 - b. responding only to the particular discrimination identified in Atkinson, ie, the Ministry was formerly not paying parents and resident family members to provide home and community support for their disabled adult family members
 - c. adopting a conservative policy initially because of the considerable uncertainties associated with any new policy, with the option of extending the policy in the future when there was greater experience to draw on
 - d. managing fiscal risks by funding resident family support only for people assessed with high or very high disability needs and excluding some family members
 - e. using legislation to manage the legal and fiscal risks associated with the policy that necessarily involved the differential treatment of some family carers (and could, therefore, be seen as inconsistent with the New Zealand Bill of Rights Act 1990).
5. The preferred option was to fund family provided supports at the minimum hourly wage. This rate was considered close to that paid to employed support workers through a provider and therefore comparable to sector employees’ earnings at the time. A decision was also made to manage risks by amending the New Zealand Public Health and Disability Act 2000 to:
- a. expressly permit only some family carers to be paid to provide care to a disabled family member
 - b. prohibit new claims and limit remedies for existing claims (other than the Atkinson and Spencer claims) to declarations of inconsistency with the right to freedom from discrimination affirmed by s 19 of the New Zealand Bill of Rights Act 1990.
6. This response was considered to be in proportion to the Court’s decision, although excluding other groups from payment was highly likely to bring further claims of unjustified discrimination.

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

7. Part 4A is the statutory framework for the Government’s family care policy.

Table 1. Main features of Part 4A

s 70A(1)	Affirms the principle agreed by Cabinet in 2013, recognising also in the context of the funding of support services, that families generally have primary responsibility for the well-being of their family members. Affirms the Government’s role is to manage fiscal risk and keep funding of support services within sustainable limits.
s 70C	Restricts payments to family members for disability support services in accordance with Crown or DHB family care policies. It therefore allows payment of only some family carers in specified circumstances, excluding spouses and parents of minors.
s 70D(3)	Allows Ministry and DHBs to take into account various circumstances in the family care policy, such as age of eligibility, residence of the disabled person and carer, the disabled person’s needs or impairment and the rate of payment.
s 70E	Prevents any legal challenge to the current family policy on the basis of family status discrimination. It was intended to limit the risk to the Crown from claims of compensation, specifically to extinguish retrospective claims and prevent new ones.

Part 4A inconsistent with the New Zealand Bill of Rights Act 1990

8. In considering the consistency of the New Zealand Public Health and Disability Amendment Bill (No 2), with the rights and freedoms affirmed in the New Zealand Bill of Rights Act 1990 (BORA),¹ the Attorney-General:
 - a. noted that the legislation could potentially be in breach of the non-discrimination right guaranteed by s 19(1) of BORA
 - b. concluded that the limitation in s 70E cannot be justified under s 5 of BORA.

Home-based support services funded under family care policies

9. Resident family carers can be paid to provide allocated home based support services only. There are two main categories:
 - a. personal care can include help with eating and drinking, getting dressed and undressed, getting up in the morning and getting ready for bed, showering and going to the toilet, getting around the home
 - b. household management can include help for meal preparation, washing, drying or folding clothes, house-cleaning, vacuuming and tidying up.
10. In some cases a disabled person's specific need for night support may be considered under personal care for FFC allocation purposes. 'Supervision' of the disabled person performing the above activities, is not covered by the policy.²

¹ Report of the Attorney-General under the New Zealand Bill of Rights Act 1990 on the New Zealand Public Health and Disability Amendment Bill (No 2) pursuant to Section 7 of the New Zealand Bill of Rights Act 1990
<https://www.justice.govt.nz/assets/Documents/Publications/BORA-No.-2-New-Zealand-Public-Health-and-Disability-Amendment-Bill.pdf>

² <https://www.health.govt.nz/publication/funded-family-care-operational-policy>

Appendix B: Stakeholder engagement on Funded Family Care policy change

1. Targeted engagement was undertaken in October 2018. Feedback from stakeholders strongly supports the removal of discriminatory aspects of legislation and policy, in particular the ability to challenge policies under Human Rights legislation.
2. Stakeholder engagement included an online survey (911 responses) and 22 meetings and interviews with stakeholder groups and affected families. Family carers (both paid and unpaid) made up the majority of survey respondents, with others including disabled people and support service provider organisations. The Ministry published the engagement findings in December 2018.
3. Common engagement themes included:
 - a. repeal of legislation: support for the repeal of Part 4A
 - b. eligibility and pay rate: changes to remove family status discrimination
 - c. simplify: remove administrative burden and simplify payment mechanisms
 - d. choice: flexibility to determine the employment arrangement and real choice about how support is provided to disabled people
 - e. quality and safety: most stakeholders agreed that some level of oversight to ensure safety of care is needed, dependent on circumstances
 - f. needs assessment: call for changes to the process of assessment to determine support needs
 - g. support allocation: feedback that allocation of funded support is often lower than actual support need – support to remove the current 40 hour per week cap on FFC (but recognition that it is not sustainable to pay carers for 24 hour/day care)
 - h. natural support: more clarity is needed around what constitutes ‘natural support’ provided freely by families compared to paid support (allocated support)
 - i. family and whānau: suggestions for a whole of family approach
 - j. type of care covered eligible: call to widen FFC beyond home and community support and person care
 - k. wider government approach: some views that paid support should be one part of a much wider Government policy approach, and review of whether payment to families should remain in Vote: Health.
4. There has been further engagement undertaken in 2019 to ensure that the views of Māori and Pacific People inform changes to FFC, and the Ministry will continue to consult with key representative groups to inform decisions on any future operational policy changes.

Appendix C: Other policy and operational issues for consideration

Employment and payment mechanisms

1. The current Disability Support Services (DSS) Funded Family Care (FFC) policy that a disabled person receiving FFC must be the employer of their funded family carer has been criticised in the courts, and is currently the subject of litigation before the Employment Court about whether some disabled persons have the capacity to enter into employment agreements.
2. Some disabled people may not have the capacity to fulfil their employer obligations, including administration and quality assurance of the care they receive from their family member. In reality, the family member providing support may be undertaking their own employment role.
3. Feedback from the sector at the time FFC was introduced indicated that an employment arrangement was the most supported option so that family provided supports would be recognised as meaningful employment. The other factor taken into account was the overhead costs associated with an external provider model.
4. Under the current policy, disabled people can receive support in their decision making through an independent advocate who can be recommended to assist them with the FFC employment requirements, or a network of family or friends to provide support in monitoring the arrangement.
5. Removing the requirement to have an employment relationship to receive FFC is supported by stakeholders. However, there was a lack of consensus on the preferred approach and some stakeholders requested that this be the choice of the disabled person and their family. Some disabled people may wish to continue to employ their family member (giving them more control over how they receive their support).
6. Employment options which may be considered by Health Ministers include:
 - a. employment of family carers by third party Home and Community Support Service (HCSS) providers, with employment requirements and quality of care monitored according to provider standards;
 - b. allowing disabled people or their agent acting on their behalf to employ or contract a resident family member through existing mechanisms like Individualised Funding (IF) which is a personalised budget,¹ and negotiate individual rates of pay consistent with the approach agreed by Cabinet;
 - c. allowing choice between personalised budgets or employment by HCSS providers, depending on the disabled person and family member's preferences.
7. The Ministry will continue to engage with disabled people and carers on this issue, and consider guidance to support consistency of pay rate implementation, including the treatment of previous experience and expectation of training or qualifications.

Maximum hours for allocated Funded Family Care

8. Family carers under FFC for DSS and DHBs are currently restricted to being paid for providing a maximum of 40 hours per week (which includes any additional hours of employment elsewhere). The Ministry DSS policy has an exceptions process to determine exceptions beyond 40 hours of allocated FFC per week and the number of funded support hours provided by a single family carer per week. Any support allocated to a disabled person beyond 40 hours per week may be provided by a contracted provider, or by second eligible family member if an exception is granted.
9. The limit of 40 hours per week was implemented to ensure that the maximum number of funded support hours that are worked is sustainable for carers (similar to a normal working week), as well as to manage

¹ IF budgets allow flexible purchasing of support by disabled people, which can include support for employment or tax obligations. IF does not currently allow employment of resident family members, partners or spouses.

fiscal impacts. Stakeholders have raised concerns that this does not reflect the reality of providing care.

10. This is a complex issue revolving around the concept of natural support. Allocation of FFC hours is undertaken in the same way as assessment for support from a third party HCSS provider.
11. All assessments and allocations of support take into account natural support in determining the level of support which may be funded. FFC could be seen as blurring the line between what a family will do willingly (and unpaid) and what they want to be paid to do. FFC hours were seen as a substitute for hours already allocated to a provider. In practice, the Ministry has observed people seeking FFC hours in addition to a previous provider allocation, resulting in cost growth.
12. Notwithstanding the concerns raised by stakeholders, we consider that the response to this issue should be based on the principle of treating family carers in a similar way to other paid carers to ensure that policy settings are non-discriminatory. Consequently, we have prioritised resolving other issues and do not intend to change the current 40 hour maximum.

Safety and quality of care

13. We will consider options to seek to ensure that the care provided to disabled people is safe and meets their needs. This will include issues related to safety for both disabled people and their carers. Options may include access to training and professional development as appropriate.
14. Consideration will be given to safeguarding measures to ensure that disabled people are able to choose who provides their care, and that any risks of abuse of the policy by family carers can be managed. This approach should be consistent with the principles of self-determination and supported decision making, so that disabled people are supported to make decisions about their life.

Funded family carers under the age of 18

15. At this stage, we have not included a firm proposal to allow young people, for example those aged 16-17, to provide FFC to eligible family members. This will be considered by Health Ministers in 2019, and aligned with the Carers' Strategy Action Plan 2019-23 focus on young carers.
16. This will include consideration of concerns for the health and safety of young carers. In some cases it may be appropriate from the family or whānau perspective, and the choice of the person receiving care and the young person providing it. We will need to consider how to address this whilst mitigating perverse incentives that have an adverse impact on young people's education and wellbeing.

Allocation process and the Mana Whaikaha MidCentral Prototype

17. Many stakeholders are not satisfied with the process for allocating funded support. The Ministry and DHBs will consider how to address these issues, including through Mana Whaikaha. Mana Whaikaha is the Prototype of the transformed disability support system being rolled out in the MidCentral DHB region. The Prototype aims to give disabled people more decision-making authority over how they are supported, more options for their support, and to create a more cost-effective system.
18. Implementation of FFC in the MidCentral DHB region reflects the Government's overall FFC policy. No changes to FFC eligibility, maximum hours, types of support or pay rates have been made, to avoid pre-empting Cabinet decisions on FFC.
19. However, the processes for accessing FFC (allocation, safeguarding and contractual arrangements) are being aligned with overall funding process within the Prototype. For example, disabled people and their whānau will typically work with Connectors to build broader support networks and develop safeguarding arrangements that reduce reliance on family carers.
20. The approach to assessment and allocation of funded support in Mana Whaikaha has been significantly updated to reflect the use of personal budgets, and includes considering the disabled person in the context of their family and whānau. This may alleviate the concerns of some stakeholders about the current support allocation process.

FFC secondary eligibility criteria

21. Currently, FFC is limited to people who are assessed as having high and very high support needs and to those who:
 - a. would not be able to remain in their chosen living environment without FFC (and likely require residential care); or
 - b. have disability support needs that precludes their family member(s) from working in alternative full-time employment.
22. This approach is intended to ensure that the policy is targeted towards those who are most in need, such as those people's families who may experience financial stress if they are not paid to provide allocated support services.
23. Changes to the targeted approach (people with high and very high support needs) is not proposed at this stage due to anticipated additional costs and broader implications for DSS and services provided by DHBs. However, we intend to consider the secondary eligibility framework as part of ongoing implementation and policy work, and discussions with DHBs on options for change.

Equity and FFC suitability for Māori, Pacific and other communities

24. We will continue to examine the role of FFC in supporting equitable health and social outcomes. Gender equity is an important consideration, given that women comprise the majority of family carers providing unpaid care ('natural support') or employed through existing FFC policies.
25. The Ministry is engaging further with DHBs and Māori and Pacific representative groups. Under the Ministry FFC policy for disabled people, there are higher proportions of Pacific and Māori people supported through the policy. This may be a reflection of different family structures and cultural expectations that home support and personal care is provided primarily by family members.
26. The Ministry and DHBs will consider how FFC can best work for Māori and Pacific people and wider communities, and geographical inequities (such as rural locations).

The Carers' Strategy Action Plan 2019-23

27. The Carers' Strategy Action Plan 2019-23 is currently under development. During targeted engagement for the new Action Plan, carers spoke about the importance of being supported financially to undertake the care role, including FFC policies. Further changes to FFC may be identified in the new Action Plan over the medium to long-term.