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.

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.

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;
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;


**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.

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.

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.

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.

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.
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

<table>
<thead>
<tr>
<th>Option</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Retain Part 4A (no repeal).</td>
<td>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.</td>
</tr>
<tr>
<td>Repeal and replace Part 4A with a litigation bar to prevent challenge to FFC policies in place between 2013 and the time of repeal.</td>
<td>s 9(2)(f)(iv), s 9(2)(h), s 9(2)(j)</td>
</tr>
<tr>
<td>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.</td>
<td>s 9(2)(f)(iv), s 9(2)(h), s 9(2)(j)</td>
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</table>
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 Whaiakah 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 Whaiakah - 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

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.
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

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

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

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
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

<table>
<thead>
<tr>
<th>Health “Funded Family Care” or “FFC” comprises legislation and policy:</th>
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<tbody>
<tr>
<td><strong>LEGISLATION</strong></td>
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<tr>
<td>Part 4A of the New Zealand Public Health and Disability Act 2000 (Part 4A)</td>
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<tr>
<td>- the legislative framework for FFC policies in the health sector</td>
</tr>
<tr>
<td><strong>POLICY</strong></td>
</tr>
<tr>
<td>The Ministry of Health’s Disability Support Services Funded Family Care policy (DSS/FFC):</td>
</tr>
<tr>
<td>- for specific family members who live in the same residence as the person being supported to provide personal care and household management support in the home for eligible disabled people aged 18 years or over, assessed as having high or very high needs, employed and paid by the disabled person with funding from the Ministry.</td>
</tr>
<tr>
<td>The District Health Board Paid Family Care policy (DHB/FFC):</td>
</tr>
<tr>
<td>- for specific family members who live in the same residence as the person being supported to provide personal care and household management support for eligible people aged 18 years or over, assessed as having high or very high needs through long term chronic health conditions, mental health and addiction and aged care needs, employed and paid by a provider with funding from DHBs.</td>
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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*

<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
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<tbody>
<tr>
<td>s 70A(1)</td>
<td>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.</td>
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<tr>
<td>s 70C</td>
<td>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.</td>
</tr>
<tr>
<td>s 70D(3)</td>
<td>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.</td>
</tr>
<tr>
<td>s 70E</td>
<td>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.</td>
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</table>
**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

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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  

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).

s 9(2)(f)(iv), s 9(2)(g)(i)

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.

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.

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.
Impact Summary: Repealing the legislative framework for Funded Family Care

Section 1: General information

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<thead>
<tr>
<th>Purpose</th>
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<tr>
<td>The Ministry of Health (the Ministry) is solely responsible for the analysis and advice set out in this Regulatory Impact Assessment except as otherwise explicitly indicated. This analysis and advice has been produced for the purpose of informing in-principle decision for the approach to the repeal of Part 4A of the New Zealand Public Health and Disability Act 2000 to be taken by or on behalf of Cabinet.</td>
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Key Limitations or Constraints on Analysis

On 27 September 2018, the Government announced plans to change Funded Family Care (FFC), including its intention to repeal Part 4A of the New Zealand Public Health and Disability Act 2000 (Part 4A). Part 4A is the legislative protection for FFC. Part 4A came into force in 2013 after the Ministry was found to have discriminated against family carers on the basis of family status with its explicit policy of not paying family carers. Part 4A was introduced to manage the legal and fiscal risks associated with FFC that involved the differential treatment of some family carers (and could, therefore, be seen as inconsistent with the NZ Bill of Rights Act 1990).

The purpose of Part 4A is to keep funding of support services provided by family members within sustainable limits and to affirm the principle that, in the context of funding support services, families generally have responsibility for the wellbeing of their family members.

To achieve this purpose Part 4A, amongst other things, requires the Ministry and District Health Boards (DHBs) to have family care policies, and allows those policies to specify which groups of family carers will be paid (with others not paid), the conditions that must be satisfied, to set the pay rates for family carers and place limits on the amount that will be funded. Part 4A also allows family care policies to differentiate on grounds that are prohibited under the Human Rights Act 1993 eg, marital status, disability, age and family status, and prohibits post 2013 human rights claims on the basis of such discrimination.

The Ministry’s FFC policy applies to disabled people who meet the disability support services (DSS) eligibility criteria, which is mostly people under 65 with a long-term physical, sensory and/or intellectual disability. The DHBs’ FFC policies, known as Paid Family Care, apply to people who have long-term chronic health conditions, mental health and addiction or aged care needs. These policies provide for the payment of certain resident family carers to provide personal care and household management services to people with high or very high support needs, for an assessed and allocated number of hours. Both policies exclude spouses, partners and family of under 18 year olds from being paid to provide family care. The Ministry’s policy also restricts payment of family carers to the minimum wage whereas DHBs pay family carers comparable rates to contracted support workers.

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1 Despite the Ministry’s policy, family carers were sometimes paid under informal arrangements. The Accident Compensation Corporation had a policy of paying family members to provide Home and Community Support Services (HCSS) prior to 2013.

2 Section 70E prevents unlawful discrimination claims on the grounds stated in section 21(1)(B), (h), (i) and (l) of the Human Rights Act 1993.

Impact Summary: Repealing the legislative framework for Funded Family Care | 1
Since the FFC policy was introduced, there have been ongoing national and international challenges to the policy, including litigation, petitions, correspondence and media coverage. All the litigation claims relating to discrimination under the existing FFC policy have been resolved.\(^3\)

Independent targeted engagement with the health and disability sector was undertaken in October 2018 on options to improve FFC. Feedback from stakeholders strongly supported the repeal of Part 4A, in particular the inability to challenge FFC under human rights legislation and removing discriminatory aspects of FFC policies. In addition to the targeted consultation with the sector, the Ministry has consulted, and is working, with DHBs and other government agencies. Those other government agencies include the Accident Compensation Corporation (ACC), Crown Law, Ministry of Justice, the Treasury, the Department of Prime Minister and Cabinet, Ministry of Social Development (MSD), Oranga Tamariki, Office for Disability Issues, Ministry of Education, Te Puni Kōkiri, Ministry for Pacific Peoples, Ministry of Business, Innovation and Employment, Ministry for Women and the States Services Commission. The Ministry will continue to work with MSD, within data limitations, on the potential benefits to MSD clients as a result of the repeal of Part 4A and proposed policy changes.

This regulatory impacts analysis focuses on the approach to repealing Part 4A.

The overall objective is to develop the most appropriate response to the Government’s intention to repeal Part 4A. The specific objectives of changes to the FFC policy and the criteria which options will be measured against are:

- improves consistency with human rights legislation
- minimises litigation risk
- improves living standards for disabled people and family carers
- minimises fiscal costs and risks to the government
- improves public trust and confidence
- aligns with the Government’s strategic direction.

Options considered include doing nothing (the counterfactual), repealing Part 4A with and without a litigation bar, and repealing Part 4A with and without a compensation framework.

This statement has been written using two assumptions:

- that Cabinet will only agree in principle to repeal Part 4A if Cabinet first agrees to policy changes to expand eligibility for payment and increase pay rates and that funding is allocated in Budget 19. Those policy changes would remove the key discriminatory aspects of Part 4A and funding is required to implement them (as they cannot be funded within baselines).\(^4\) If Cabinet does not agree to the policy changes and/or funding is not allocated then the Ministry recommends the repeal of Part 4A is delayed to mitigate unknown legal and fiscal risk

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\(^3\) The Budget bid is fund removing the exclusions on eligibility for payment to two currently excluded groups, increase pay rates to family carers under the Ministry FFC policy to be comparable with the pay of contracted support workers, and to fund provider overheads to allow the option of employing family carers through personal care and household management provider organisations (if required).
The Ministry is working on advice to Health Ministers on potential further operational changes to FFC. This includes advice on removing the requirement, under the Ministry’s FFC policy, that a disabled person receiving FFC must be the employer of their funded family carer, and exploring alternative options.  

All of these potential changes will be considered in the context of broader cross government work, including the Carers Strategy Action Plan 2019-23 and the government response to the Welfare Expert Advisory Group (WEAG) report.

5 When the United Nations reviewed New Zealand’s progress in implementing the United Nations Convention on the Rights of Persons with Disabilities in 2012, the UN Committee’s concluding observations (31 October 2014) noted that:

1. The Committee notes that, in 2012, the New Zealand Court of Appeal affirmed that the policy of not paying some family carers to provide disability support services to adult disabled family members constituted unjustifiable discrimination on the basis of family status. The Committee is concerned that the Public Health and Disability Amendment Act 2013 reversed this court decision by denying carers’ pay to some family members. The Committee is also concerned that these provisions also prevent some family members who are carers from making complaints of unlawful discrimination with respect to the Government’s family care policy. The Committee notes that the independent monitoring mechanism has recommended reconsideration of this matter.

2. The Committee recommends that the State party reconsider this matter to ensure that all family members who are carers are paid on the same basis as other carers are, and recommends that family members who are carers be entitled to make complaints of unlawful discrimination in respect of the State party’s family care policy.
Impact Summary: Repealing the legislative framework for Funded Family Care

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<thead>
<tr>
<th>Responsible Manager (signature and date):</th>
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<tbody>
<tr>
<td>Adri Isbister</td>
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<tr>
<td>Deputy Director-General Disability</td>
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<td>Disability Directorate</td>
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<td>Ministry of Health</td>
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Section 2: Problem definition and objectives

2.1 What is the policy problem or opportunity?

The problem with the current FFC policy is that Part 4A is inconsistent with the Human Rights Act and NZBORA (right to freedom from discrimination, and for any limitations to rights and freedoms to be justified). Disabled people and their family carers are treated differently to other paid carers because Part 4A allows discriminatory policies and prevents legal challenges on the basis of discrimination. On 27 September 2018, the Government announced plans to change FFC, including its intention to repeal Part 4A.

What is the context for considering change?

Part 4A has been the subject of ongoing national and United Nations challenges since it was introduced, including litigation (a small number of pre 2013 claims of discrimination), petitions, correspondence and media coverage. The previous Government faced criticism for introducing legislation under urgency and without consideration by Select Committee.

All three parties now in Government noted their intention to make changes to FFC in their election manifests and policy development on potential changes to FFC has been underway since late 2017. On 19 September 2018, Cabinet agreed to announce that the Government intends to make changes to health FFC policies, including the intention to repeal Part 4A [SWC-18-MIN-0129 refers]. On 27 September 2018, the Government announced plans to change FFC, including its intention to repeal Part 4A.

Targeted engagement with the health and disability sector was undertaken in October 2018 on options to improve FFC. Feedback from stakeholders strongly supports the repeal of Part 4A, in particular the inability to challenge FFC under human rights legislation and removing discriminatory aspects of FFC policies.

Without any changes to the FFC policy, in particular Part 4A, high profile challenges to the policy will continue, with particularly strong emphasis on function d). Further, the wellbeing and living standards of disabled people and their natural support will continue to be negatively affected by their inability to choose a resident family member to provide them with paid care.

What is FFC?

FFC refers to Ministry and DHBs’ policies of paying certain resident family carers to provide personal care and household management services to people with high or very high support needs, for an assessed and allocated number of hours. All policies exclude spouses, and partners and family of under 18 year olds from being paid to provide services. The Ministry’s policy also restricts payment of family carers to the minimum wage whereas DHBs pay family carers comparable rates to contracted support workers.
The allocation of hours of support is assessed by looking at what the disabled person can do, what natural supports\textsuperscript{6} are available for the things they cannot do, and what extra support is required. That extra support is usually provided by a contracted support worker, but the disabled person (if eligible for FFC) and/or their family can choose for a resident family member to provide that support and be paid for it, subject to exclusions about who can be paid eg, spouses.

The Ministry’s policy applies to disabled people who meet the DSS eligibility criteria, mostly people under 65 with a long-term physical, sensory and/or intellectual disability. As at 1 December 2018, there were approximately 409 Ministry-funded family carers. The DHBs’ FFC policy, known as Paid Family Care, applies to people who have long-term chronic health conditions, mental health and addiction issues, or aged care needs. FFC accounts for a small proportion of HCSS spend for the Ministry and DHBs (approximately 2-3%). As at 1 March 2018, there were approximately 207 DHB funded family carers (comprised of 159 for aged care clients, 47 for long-term chronic conditions and one for mental health).\textsuperscript{7}

**Background to the current FFC policy**

Prior to 2013 the Ministry and DHBs had explicit policies of not paying family carers. Part 4A came into force after the courts found that the Ministry discriminated against family carers on the basis of family status by not paying them.\textsuperscript{8}

The development of the current policy, including Part 4A, 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 members’

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 focusing support on paying families where there were high or very high needs, rather than paying all family carers, and limiting the amount they were paid

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 NZBORA).

The preferred option was to base payments to family carers on the minimum wage, topped up to reflect the full costs of employment such as sick and annual leave and ACC levies but excluding the higher prices that are usually paid to providers for overheads when employing care and support workers. Initially, the rate was $16 an hour, and was estimated to cost in the order of $23 million (net) a year. 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 NZ Public Health and Disability Act 2000 to:

\textsuperscript{6} Natural support is unpaid care provided primarily by family members. That support is freely given, but may also be based on a sense of obligation or duty.

\textsuperscript{7} There were 409 DSS family carers at 1 December 2018 - It is unclear why uptake is lower for DHBs.

\textsuperscript{8} 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.
expressly permit some or all family carers to not be paid, or to be paid at reduced rates, to provide care to family members

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 NZBORA.

Whilst minimum wage payments manage fiscal risk, they are inconsistent with human rights legislation by discriminating against certain groups in two ways. § 9(2)(f)(iv), § 9(2)(h)

Secondly, minimum wage payments are only applied to Ministry family carers and are below wage rates paid to family carers under DHB policies. This is because family carers are employed by HCSS providers under DHB policies, who pay rates comparable to the wider care and support workforce.

What are the functions of Part 4A?

Part 4A was passed under urgency in 2013. The Attorney-General at the time noted that Part 4A could potentially be in breach of the non-discrimination right guaranteed by s19(1) of NZBORA and concluded that the limitation in s70E cannot be justified under s5 of the NZBORA.

Part 4A has the following key functions:

a) The purpose is to keep the funding of support services provided by family members within sustainable limits, in order to give effect to section 3(2) of the Act (which states that the objectives of the Act stated in section 3(1) are to be pursued to the extent that they are reasonably achievable within the funding provided).

b) Affirms the principle that families generally have primary responsibility for the well-being of their family members within the context of funded support services (stated in 70A(1))

c) Permits paid family care policies to be implemented that are discriminatory (eg, family status and pay rates) and may inconsistent with the Human Rights Act 1993 (HR Act). This may be in breach of the right to freedom from discrimination as set out in section 19(1) of the NZBORA. This is laid out in Part 4A section 70D.

d) Prevents claims under the HR Act and the NZBORA from being taken against family carer policies that have been implemented since 2013. However this may not be justifiable under section 5 of the NZBORA (which allows for justified limitations of rights and freedoms). Part 4A Section 70E includes this limitation.

e) Requires the Crown and DHBs to have family care policies, restricting payment to family carers for the provision of support services in accordance with these policies.

In accordance with Part 4A, the Ministry and DHBs have had FFC policies since 2013 and 2014 respectively, and these policies exclude resident spouses, partners and family of under 18 year olds from being paid for providing care. The Ministry policy also limits the amount eligible family carers can be paid to the minimum wage.

The proposed policy changes, if agreed by Cabinet and if funding is made available, will treat family carers fairly in comparison with other care and support workers (subject to function d) and resolve the discrimination issues in function c) of the Act. Therefore function c) can be repealed.

The financial sustainability principle in function a) of the Act can be repealed as it is also in s 3(2) of the Act which governs all health and disability services, except ACC.

Function e) requiring FFC policies can be removed because there is no legislative mandate for policies anywhere else in the health and disability sector. Other policies existed prior to Part 4A and continue to be implemented in accordance with s 3(2).

Function b), the principle of primary family responsibility, can also be repealed. The principle in Part 4A only applies to services funded through Vote Health so its removal is unlikely to have a wider effect for
social support services. The principle of primary family responsibility is not confirmed elsewhere in health and disability legislation, or in more general Government policy statements.

The disability support system has always been based on the principle of natural support, with the role of publicly funded support to augment and enable this support. DSS support is allocated to meet the additional needs of a disabled person that cannot be met by their natural support networks. This is common across other supports in the social sector (e.g. Home and Community Support Services provided by the ACC). The principle of natural support is embedded in Needs Assessment and Service Coordination processes to determine the level of funded support for disabled people.

Despite function b) the Ministry is experiencing cost allocation increases across all DSS supports for families already using FFC (see Other Impacts section). Data provided by DHBs has shown that they are not experiencing any cost allocation increases under their paid family care policies. Therefore, subject to further analysis, function b) may be having little effect on DSS operational practices.

There could be opportunities to consider this principle and how families can be helped further as part of any future work on the Government’s response to the Welfare Expert Advisory Group (WEAG), which was asked to consider interfaces between welfare and health. If Ministers wish to keep this principle it could be included elsewhere eg, policies, strategies if Part 4A is repealed.

How much confidence is there in the evidence and assumptions for the problem definition?

There is a broad range of evidence for the problem definition. The Ministry is confident in the evidence and the two assumptions noted above. The existing evidence includes:

- the Attorney-General noted when the Part 4A was being considered for introduction, that Part 4A could potentially be in breach of the non-discrimination right guaranteed by s19(1) of NZBORA and concluded that the limitation in s70E cannot be justified under s5 of the NZBORA
- the United Nations’ Committee on the Rights of Persons with Disabilities recommendation that New Zealand reconsider allowing payments to all family carers and allowing complaints of unlawful discrimination (2014)
- targeted stakeholder consultation undertaken by the Ministry in 2018, including an online survey and 22 meetings and interviews with stakeholder groups and affected parties. Family carers (both paid and unpaid) made up the majority of survey respondents.
- a report published by the Carers Alliance9 on paid family care, including FFC.10 The report stated that reliance on family as the first line of support is no longer sustainable (eg, economic pressures including having to leave employment in order to care, people with support needs living longer at home). The report called for urgent action on several issues, including aligned, simplified legislation, strategies, policies and systems for paid family care, with the Ministry’s FFC policy a priority
- 14 claims of discrimination filed since 2013 (based on the pre 2013 Ministry policy)
- a petition (Sushila Butt and 964 others), currently before the Health Select Committee, requesting the repeal of Part 4A and pay equity for family carers
- a significant number of media articles
- significant correspondence with the Minister of Health and the Ministry, and Official Information Act requests.

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9 A consortium of over 40 national not-for-profit organisations promoting better support and recognition for family, whanau, and aiga carers

2.2 Who is affected and how?

Whose behaviour do we seek to change, how is it to change and to what purpose?

This analysis is focused on the approach to repeal Part 4A, not the potential policy changes.

- If Cabinet directs, the Ministry and DHBs will amend their FFC policies to remove key discriminatory elements, ie. Allow resident spouses and partners, and family of under 18 year olds to be paid for providing family care, and increase pay to comparable rates with support workers (this is subject to a Budget 2019 bid to fund these policy changes)
- Disabled people who currently or may in future benefit from care provided by resident family members that is paid, and that want to have:
  - the option to take discrimination claims and be heard
  - trust and confidence in the government
- Resident family carers to:
  - have the option to take discrimination claims and be heard
  - receive acknowledgement of their role
  - have trust and confidence in the government
- People who would like to be paid resident family carers but currently are not caring or are excluded from being paid under FFC to
  - acknowledge their role
  - improve equity: many family carers are women, Māori or Pasifika, who are caring for parents or parents-in-law or a disabled child (including adult children) and are unable to make discrimination claims.

Who wants this to happen? Who does not?

There has been widespread concern about FFC and calls for change since its introduction in 2013 (see evidence of problem above). There is general agreement in the disability community that Part 4A was introduced through a process that was not fair.

Independent targeted stakeholder consultation was commissioned by the Ministry in 2018. This included an online survey and 22 meetings and interviews with stakeholder groups and affected parties. Family carers (both paid and unpaid) made up the majority of survey respondents, with others including disabled people and support service provider organisations. Feedback from stakeholders strongly supported the repeal of Part 4A, in particular the inability to challenge FFC under human rights legislation and removing discriminatory aspects of FFC policies.

Some people believe that changes to the current operational policies for FFC and how they are implemented is where the key impacts will occur, rather than repealing Part 4A. The Ministry intends to undertake further operational policy work on these issues eg, employment relationship, cap on hours, training and quality assurance. Other stakeholders are concerned that family carers under the current policy will lose what they have already.\(^\text{12}\)

\(^{11}\) As at June 2018, approximately 8,600 people received SLP Carer (spouses and partners are not eligible for SLP carer). MSD does not have information on the reason that care is required but it does have data on the benefit that is being paid to care recipients. From this MSD can infer that SLP Carers are most commonly caring for parents or parents-in-law or a child (including adult children) with a disability.\(^{11}\) The average SLP Carer recipient is 45 years of age and female. Of the people receiving SLP Carer, 38 percent are Māori, 30 percent are New Zealand European, 17 percent are Pacific and 15 percent are unspecified or other. The high numbers of Māori and Pasifika carers is consistent with the current Ministry and DHB FFC policies.

2.3 Are there any constraints on the scope for decision making?

**Constraints**

- The Government has already announced its intent to repeal Part 4A. This does not constitute a final decision, however there would be reputational risks if Part 4A is not repealed fully (the most controversial aspect being section 70E which prevents human rights claims).

- That Cabinet will only agree in principle to repeal Part 4A if Cabinet first agrees to policy changes to expand eligibility for payment and increase pay rates and that funding is allocated in Budget 19.

- The unknown potential interdependencies with the yet to be published Welfare Expert Advisory Group (WEAG) report (and the future government response to the report) which is looking more broadly at how the welfare system supports people with health conditions and disabilities and their family carers. There is also unknown interdependencies with the New Zealand Health and Disability System Review which is currently underway.

**Out of scope**

- ACC paid care.
- Veteran paid care.
- decisions on potential changes to operational policies – policy work is ongoing.
- change to the principle of financial sustainability for health and disability support services in section 3(1) of the Act.
- other policies allowing for the provision of health and disability support services. They are not required to be mandated by legislation.
- non Vote Health supports based on the principle of natural support, including family responsibility. Part 4A only applies to Vote Health support services and not any other government supports such as MSD benefits, and ACC payments. Therefore, repealing the principle of primary family responsibility for the wellbeing of family members in Part 4A is unlikely to be viewed as a change in government direction to the principle of natural support.

**What interdependencies or connections are there to other existing issues or ongoing work?**

Repealing Part 4A is a small but specific part of a much broader issue of societal and government expectations regarding the role of family members to provide unpaid ‘natural support’. Part 4A only exists as a response to litigation about the failure of the Ministry to allow family carers to be paid to provide allocated funded HCSS supports. Part 4A applies only to Vote Health support services and not any other government supports such as MSD benefits, and ACC payments. Therefore, repealing the principle of primary family responsibility for the wellbeing of family members in Part 4A is unlikely to be viewed as a change in government direction to the principle of natural support.

The broader issues of the expectations of family providing unpaid ‘natural support’; assessment and allocation processes based on this principle; and the government’s objectives for the financial wellbeing of family carers are likely to be dealt with in the Government response to the WEAG report, the
development of a Carers Strategy Action Plan 2019-2023 and long term policy work on the transformation of the disability support system.

In summary, the issues related to FFC have links to a number of cross-government initiatives, including the:

- development of the New Zealand Carers’ Strategy and Action Plan 2019-2023 (MSD lead)
- New Zealand Disability Strategy and development of the new Action Plan 2019-2022 (Office for Disability Issues lead), particularly Outcome 7 ‘Choice and Control’
- WEAG report and future government response (MSD lead)
- Health and Disability System Review (MOH lead)
- Mana Whaikaha – Disability Support System Transformation (MOH lead)
- government response to the Inquiry into Mental Health and Addictions (MOH lead).

If Cabinet agrees to repeal Part 4A and the key policy changes, and funding is available to implement the changes, opportunities or requirements to link with these cross-government initiatives will be considered. Any impacts will be considered during implementation. There will also be cross-government consultation on the ongoing policy work on operational changes to FFC.
### Section 3: Options identification

#### 3.1 What options have been considered?

Each of the five feasible options have been assessed against each of the six criteria that have been identified in table one below. Option 1 has been used as the counterfactual (do nothing) which the four other options have been considered against using a scale of:

- ✓ ✓ Significantly superior to the do nothing option
- ✓ Better than the do nothing option but with some issues
- = The same or equivalent to the do nothing option
- X Worse than the do nothing option
- xx Significantly inferior than the do nothing option

The criteria include consideration of the Treasury Living Standards Framework. To avoid repetition, the domains and capitals have been included in the pros and cons of the most aligned criteria, rather than purely in the alignment with government strategic direction criteria. Note there is no impact on natural capital.

**TABLE ONE: SUMMARY OF OPTIONS ANALYSIS (SEE TABLE TWO FOR MORE DETAILED ANALYSIS)**

<table>
<thead>
<tr>
<th>Option/Criteria</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retain Part 4A (Do nothing)</td>
<td>=</td>
<td>s 9(2)(f)(iv), s 9(2)(h)</td>
<td>=</td>
<td>s 9(2)(f)(iv), s 9(2)(h)</td>
<td>=</td>
<td>=</td>
</tr>
<tr>
<td>Modified Status Quo – based on assumption that Cabinet will only agree in principle to repeal Part 4A if Cabinet first agrees to policy changes to expand eligibility for payment and increase pay rates and that funding is allocated in Budget 19. Otherwise the Government cannot mitigate the legal and fiscal risks of the policy changes.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Repeal Part 4A but replace with a litigation bar for period 2013 to repeal date</td>
<td>✓</td>
<td>s 9(2)(f)(iv), s 9(2)(h)</td>
<td>✓</td>
<td>s 9(2)(f)(iv), s 9(2)(h)</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Repeal Part 4A but replace with a litigation bar for period 2013 to repeal date and include compensation framework</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Repeal Part 4A and potential for two remedies: no litigation bar and a compensation framework</td>
<td>✓ ✓</td>
<td>✓ ✓</td>
<td>✓ ✓</td>
<td>✓ ✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Repeal Part 4A in full</td>
<td>✓ ✓</td>
<td>✓ ✓</td>
<td>✓ ✓</td>
<td>✓ ✓</td>
<td>✓ ✓</td>
<td></td>
</tr>
</tbody>
</table>
### TABLE TWO: DETAILED ANALYSIS OF OPTIONS IDENTIFIED IN TABLE ONE ABOVE

<table>
<thead>
<tr>
<th>Option/Criteria</th>
<th>A: Improves consistency with human rights legislation</th>
<th>B</th>
<th>C: Improves living standards for disabled people and family carers</th>
<th>D</th>
<th>E: Improves public trust and confidence</th>
<th>F: Aligns with the Government’s strategic direction</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Retain Part 4A (Do nothing)</td>
<td>-</td>
<td>-</td>
<td>Part 4A will continue to prohibit claims of discrimination (since 2013) despite inconsistency with human rights law</td>
<td>-</td>
<td>Human and social capital will remain the same: living standards (unless wider government changes occur), same choice of carer and risk of residential care, limited (MSD only) financial acknowledgement of the opportunity cost of caring.</td>
<td>-</td>
</tr>
</tbody>
</table>

**Modified Status Quo** – based on the assumption that Cabinet will only agree in principle to repeal Part 4A if Cabinet first agrees to policy changes to expand eligibility for payment and increase pay rates and that funding is allocated in Budget 19. Otherwise the Government cannot mitigate the legal and fiscal risks of the policy changes.

*Impact Summary: Repealing the legislative framework for Funded Family Care*
### Impact Summary: Repealing the legislative framework for Funded Family Care

<table>
<thead>
<tr>
<th>Repeal Part 4A but replace with a litigation bar for period 2013 to repeal date</th>
<th>✓</th>
<th>✓</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legislation will continue to prohibit claims of discrimination for defined period so inconsistency with human rights for that period</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Human and social capital and income: more carers can receive payment and at comparable rates so their income and living standards are likely to improve(^\text{13}), financial stress reduced. Modelling suggests an increase of 483 Ministry FFC clients and 240 DHB clients over four years. In the 2019/20 financial year the current cohort of DSS family carers will receive an average earnings increase of $6,500 before tax.</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Disabled people requiring care (or their advocate) have more options about who cares for them (intrinsic value), with potential decrease in need for residential care</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Better financial and social acknowledgement of family carers</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Widening the eligibility for payment of family carers may serve as a means for some unemployed/underemployed individuals to join the workforce and could lead to family members who are at the end of their tenure as a paid carer (eg, client has moved into residential care) in the Home and Community Support Services sector. This opportunity is especially true for carers who decide to pursue NZQA qualifications.</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Where people are not already providing unpaid care, there may be more carers available in rural areas, care in a culturally appropriate manner and know and are able to communicate well with the disabled person they care for.</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Risk that caring relationships may continue longer than is desirable eg, client’s condition has worsened to an extent that the carer cannot adequately look after them, due to the fact that the carer derives a steady income and does not wish to transition to another job. Conversely a disabled person may wish to continue with their family carer when it is in their best interests to receive other help.</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Having a family member provide care may, from the disabled persons’ point of view, limit their social connections with a wider group of people.</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

\(^{13}\) There is currently no way of knowing the income of people prior to taking up FFC.

\(^{14}\) The magnitude if this impact is uncertain due to data limitations.

---

\[s 9(2)(a)(i), s 9(2)(b)\]
### Impact Summary: Repealing the legislative framework for Funded Family Care

<table>
<thead>
<tr>
<th>3</th>
<th>Repeal Part 4A but replace with a litigation bar for period 2013 to repeal date and include compensation framework</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓</td>
<td>Legislation will continue to prohibit claims of discrimination for defined period so inconsistency with human rights for that period. However, acknowledgement of human rights breach.</td>
</tr>
<tr>
<td>✓</td>
<td>As above but provides extra income through compensation.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4</th>
<th>Repeal Part 4A and potential for two remedies: no litigation bar and a compensation framework</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ ✓</td>
<td>A compensation framework allows the government to acknowledge human rights inconsistency. Inconsistencies with human rights legislation removed.</td>
</tr>
<tr>
<td>✓ ✓</td>
<td>As above. Offered opportunity for legal redress.</td>
</tr>
</tbody>
</table>

<p>| ✓ ✓ | As above but compensation framework acknowledges inconsistency and provides remedy. |
| ✓ ✓ | As above. Does not contribute to Government priority to govern responsibly by carefully managing the government’s books. |</p>
<table>
<thead>
<tr>
<th>5</th>
<th>Repeal Part 4A in full</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Inconsistencies with human rights</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>Human and social capital and income: more carers can receive payment and at comparable rates so their</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Action to restore inconsistency with human rights legislation and enable disability</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Consistent with Government’s announcement of its intention to repeal Part 4A.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Legislation removed | Income and living standards are likely to improve, financial stress reduced. | Community access to courts.  
Consistent with Government’s announcement of its intention to repeal Part 4A.  
The disability sector and carers will get opportunity to be heard and views taken into account at Select Committee.  
Positive response to UN Committee concerns.  
Family carers funded through Vote Health are currently excluded in the Care and Support Workers (Pay Equity) Settlement Act 2017 (Pay Equity settlement).  
The majority of both care and support workers and family carers are women, so there is a gender equity consideration to improving opportunities for women to earn through providing funded support. |
|---|---|---|---|
| | Disabled people requiring care (or their advocate) have more options about who cares for them, with potential decrease in need for residential care.  
Better financial and social acknowledgement of family carers.  
Where people are not already providing unpaid care, there may be more carers available in rural areas, care in a culturally appropriate manner and that now the needs of, are able to communicate well with, the disabled person they care for. | Social, cultural and equity benefits may be realised from repeal for women, Māori and Pasifika carers and disabled family they support.  
Helps contribute to Government priority outcome ‘to ensure everyone who is able to, is earning, learning, caring and volunteering’ (family carers able to be paid for care role) as encourages future family carers and acknowledges role of carers.  
Partially contributes to Government priority to govern responsibly by carefully managing government finances (subject to policy changes being made and funded). |
3.2 Which of these options is the proposed approach?

Which is the best option? Why is it the best option? How will the proposed approach address the problem or opportunity identified?

After assessing the options under both a human rights framework and cost benefit analysis, there are two potential approaches to resolve the problem.

The first approach is to repeal Part 4A in full – no litigation bar or compensation framework.

This approach is consistent with the Government’s announcement of its intention to repeal Part 4A and removes the discriminatory aspects of the current FFC policy that are inconsistent with human rights legislation. In particular, this option removes the legislative protection that permits discriminatory policies based on family status and prevents legal challenges on the basis of that discrimination, thereby treating disabled people and their family carers differently to paid carers. The repeal will help restore the disability sector’s trust and confidence in the Government. Recent targeted consultation has been clear that affected parties want Part 4A repealed.

If Part 4A is repealed the living standards of disabled people and their family carers should improve because disabled people have more choice about who cares for them, and if a resident family carer is chosen to provide care the household income rises. Some carers currently ineligible to be paid will also be acknowledged socially and financially for the care they provide. This supports the Government’s priority to “ensure everyone who is able to, is earning, learning, caring and volunteering”. Other benefits of this approach include disabled people being able to stay in their own home, have carers that understand their support, cultural and spiritual needs and carers who know how to communicate best with them. Many of these carers are also women, Māori and Pasifika.

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

The Ministry cannot fund the policy changes within baselines. If funding for the policy changes is provided, over time there is potential for savings to the Government from disabled people entering residential care later (if at all). However, this benefit cannot be calculated accurately in monetary terms as it is dependent on uptake and the case by case needs of the disabled person.

Repealing Part 4A and the subsequent policy changes are also likely to lead to savings for Vote Social Development as carers may become financially independent and no longer need SLP Carer (or have their SLP abated) due to income derived from being a family carer. However, this benefit also cannot be calculated accurately in monetary terms.

There is also a risk of costs for DSS in general. Greater uptake of FFC may lead to allocation increases for other DSS supports. Further analysis needs to be done to assess whether allocation increases over the last five years is purely due to FFC uptake or if there are other factors at play too, and the magnitude of any factors.
The repeal of Part 4A will remove the specific legislative protection for FFC under the Act. Family care policies will then be treated the same as other health and disability support policies under the Act in the pursuit of funding and providing health and disability services to the extent that is reasonably achievable within the funding provided. Consequently there are no areas of incompatibility with the Government’s ‘Expectations for the design of regulatory systems’.

The second approach is to repeal Part 4A but retain a litigation bar for claims from 2013 to date of repeal.

This approach is partially consistent with the Government’s announcement of its intention to repeal Part 4A. This option removes most of Part 4A but would retain the litigation bar on claims for 2013 to the date of repeal to mitigate litigation risk and fiscal costs, and therefore is inconsistent with human rights legislation and the recommendation of the United Nations.

The policy changes make the provision in Part 4A that allows discriminatory policies redundant but a litigation bar prevents access to the Human Rights Commission and courts. The litigation bar would treat disabled people and their family carers differently to paid carers by restricting their access to justice. The policy changes may help restore the disability sector’s trust and confidence in the Government but the litigation bar may reduce that impact. This approach would have the same impact on the living standards of disabled people and family carers as the first approach.
# Section 4: Impact Analysis (Proposed approach)

## 4.1 Summary table of costs and benefits

<table>
<thead>
<tr>
<th>Affected parties (identify)</th>
<th>Comment: nature of cost or benefit (eg ongoing, one-off), evidence and assumption (eg compliance rates), risks</th>
<th>Impact</th>
<th>Additional costs of proposed approach, compared to taking no action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabled people and family carers</td>
<td>No cost to disabled people and family carers who will receive support and payment as a result of the repeal of Part 4A and the policy changes.</td>
<td>Some people who may wish to choose to take up FFC may have their other benefits like MSD funded Supported Living Payments abated given FFC is treated like any other income by the benefit system. However, this will come down to individual choice of the relative benefits of providing FFC.</td>
<td></td>
</tr>
<tr>
<td>Ministry of Health and DHBs</td>
<td>Cost of litigation claims</td>
<td>$9(2)(f)(iv), s 9(2)(h), s 9(2)(j)</td>
<td></td>
</tr>
</tbody>
</table>

Impact Summary: Repealing the legislative framework for Funded Family Care
### Impact Summary

#### Ministry of Health and DHBs

Budget bid to fund policy changes to mitigate risk of removal of discriminatory aspects of Part 4A – expanding eligibility to be paid to spouses and partners and families of under 18 year olds, increasing pay rates DSS FFC from the minimum wage, allowing for option for Ministry family carers to be employed by a provider.

#### Ministry of Health

Risk of funded support allocation increase in DSS, increasing the costs of FFC or increasing the demand for HCSS services if families reduce the level of natural support they currently provide.

A cost increase across total support packages of FFC clients of 28% has been realised over the past 2 years (2016/17 and 2017/18). This risk and likely cost impact is increased due to the proposals to increase FFC eligibility (to including partners, spouses and family of under 18s), and increase pay rates for DSS, which are likely to result in increased FFC uptake.

The risk of any increased funded support allocation costs for DHBs is unknown, however there is no evidence of increased costs associated with DHB paid family care clients at this stage.

#### DHBs

Risk of funded support allocation increase in DHBs, increasing the costs of FFC or increasing demand for

An analysis of DHB’s FFC administrative data has shown there is no significant correlation between the uptake of FFC and an increase in HCSS allocation or supports. However, this risk must be acknowledged.

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Impact Summary: Repealing the legislative framework for Funded Family Care | 21
### Impact Summary

<table>
<thead>
<tr>
<th></th>
<th>Budget Sensitive and Subject to Legal Privilege</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HCSS services if families reduce the level of natural support they currently provide</strong></td>
<td></td>
</tr>
<tr>
<td><strong>DHBs</strong></td>
<td>Increased risk of injury to elderly carers</td>
</tr>
<tr>
<td><strong>Wider government</strong></td>
<td>None – Part 4A relates only to Vote Health support services</td>
</tr>
<tr>
<td><strong>Other parties</strong></td>
<td>Costs to providers of implementing policy changes covered in Budget Bid if future decisions are made to change the employment relationship under the Ministry FFC policy.</td>
</tr>
</tbody>
</table>

#### Total Monetised Cost

There is uncertainty about the likely total monetised cost which will be made up of:

- **DSS allocation increases** (may be up to 28% cost increase across support packages based on previous data) which is built into the above Budget bid. DHB allocation cost increase risks are unknown.

#### Non-monetised costs

Social and/or health outcomes may not be consistently improved for disabled people.

Medium: Risk of co-dependency of family carers on FFC income, or risks of abuse of FFC policies (e.g. lack of alignment with supported decision making principles or use of FFC when this is not the preference of the disabled person or in their best interests).

### Expected benefits of proposed approach, compared to taking no action

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabled people</strong></td>
<td>Ability to receive care from their family member if they choose</td>
</tr>
<tr>
<td></td>
<td>See family carers below. Disabled people will benefit from increased income opportunities for their family carer under FFC, through improved financial wellbeing of the wider family (benefits may include, for example, family resilience and decreased stress due to financial strain, health and wellbeing benefits due to increase income). Also benefits in disabled people receiving culturally appropriate care by someone who knows how and can communicate with them.</td>
</tr>
<tr>
<td>Family carers</td>
<td>Current paid family carers: increased income, acknowledgement of care provided.</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Unpaid family carers:</td>
<td>who will be eligible in future for FFC if policy changes are made.</td>
</tr>
<tr>
<td>Ministry of Health and DHBs</td>
<td>Savings from residential care. Clients may be offered this support if they would be unable to live in their chosen living environment (in the family home) without FFC and would otherwise need residential level care. However, in reality this may be difficult to assess and people with high and very high disability support needs are likely to be eligible for FFC.</td>
</tr>
<tr>
<td>Ministry of Health and DHBs</td>
<td>Savings to current Home and Community Support Services (HCSS) costs</td>
</tr>
<tr>
<td>Wider government</td>
<td>Financial independence of family carers</td>
</tr>
<tr>
<td><strong>Total Monetised Benefit</strong></td>
<td>There is uncertainty about the likely total monetised benefit given this depends on FFC uptake and other social factors. The majority of benefits from repealing Part 4A and funding changes to policies which currently discriminate on the basis of family status will be non-monetised. There is considerable uncertainty in estimating the potential total monetised benefit from new FFC clients, which may include:   - Savings from residential care (subject to uptake, and will be realised if FFC clients would otherwise require residential care)</td>
</tr>
</tbody>
</table>
4.2 What other impacts is this approach likely to have?

Potential risks of proposed approach

The risk of paid family care policies in general is that they may undermine the principle of natural support, including:

- The expectation that care and support which was previously provided freely will now be paid, leading to increased support allocation costs; and / or
- That families will refuse to continue to provide ongoing care unless they receive payment (leading to increasing cost of contracted provider support, increased paid family care cost, or lack of care and poor outcomes for disabled people).

Evidence shows that since FFC was introduced people receiving DSS FFC have, on average, been allocated a higher overall service package (across all services, not just FFC) than what they were allocated prior to commencing FFC:

- Over the past 5 years to December 2017, the average service allocation increase based on weekly hours was circa 200%;
- This has equated to a net cost increase across allocation packages of 54% over the 5 years to December 2017;
- However, the net cost increase has reduced to an average of 28% during the past 2 years (2016/17 and 2017/18), which is likely due to improved consistency of support needs assessment processes.

Further analysis needs to be done to assess whether the DSS allocation increases over the last five years is purely due to FFC uptake and a withdrawal of natural support, or if there are other factors at play too eg, social determinants, and the magnitude of any factors. However, an analysis of DHB’s FFC administrative data has shown there is no significant correlation between the uptake of FFC and an increase in HCSS allocation or supports. Therefore, there is uncertainty in assessing the risk of increased total cost to DSS if there is increased uptake of paid family care policies due to the policy changes and if Part 4A is repealed or repealed with a litigation bar. The potential for cost allocation...

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### Non-monetised benefits

| Ability to make claims of discrimination | High: equity and ability to challenge policies, consistency of human rights for disabled people and their families. |
| Reputations of the Ministry of Health | Medium: Likely to improve relationships with the disability and carer sectors, and improve trust and confidence. |
| Disabled people able to remain living with family if they choose to receive FFC and the alternative would be residential care. | High: Benefits include social connectedness and ability to remain living with family or whanau if this is the choice of the disabled person. |
Impact Summary: Repealing the legislative framework for Funded Family Care

Increase has been included in the bid submitted to Budget 2019 to secure funding for the policy changes to DSS and DHB policies.
## Section 5: Stakeholder views

### 5.1 What do stakeholders think about the problem and the proposed solution?

Targeted engagement with the health and disability sector was undertaken in October 2018 on options to improve FFC. Feedback from stakeholders strongly supports the repeal of Part 4A, in particular the inability to challenge FCC under human rights legislation and removing discriminatory aspects of FFC policies. The targeted engagement was done with an online survey as well as 22 meetings and interviews with stakeholder groups and affected parties. Family carers (both paid and unpaid) made up the majority of survey respondents.

A report published by the Carers Alliance on paid family care, including FFC, stated that reliance on family as the first line of support is no longer sustainable (eg, economic pressures including having to leave employment in order to care, people with support needs living longer at home). The report called for urgent action on several issues, including aligned, simplified legislation, strategies, policies and systems for paid family care, the Ministry FFC policy a priority.

Other government agencies that have been consulted on the proposal to repeal Part 4A and the preferred policy changes include; the ACC, Crown Law, Ministry of Justice, the Treasury and Department of Prime Minister and Cabinet, MSD, Oranga Tamariki Office for Disability Issues, Ministry of Education, Te Puni Kōkiri, Ministry for Pacific Peoples, Ministry of Business, innovation and Employment, Ministry for Women and the State Services Commission. The Ministry will continue to work with MSD on the transfer of costs between Votes (if any) as a result of the repeal of Part 4A and proposed policy changes.

There are concerns from health and disability sector groups, including providers, about the implementation of the proposed policy changes and future operational policy work still be done (eg, employment relationship, cap on hours, training and quality assurance). The Ministry will continue to work with MSD, within data limitations, on the potential benefits to MSD clients as a result of the repeal of Part 4A and proposed policy changes.

There has been further engagement to ensure that the views of Māori and Pacific People inform changes to FFC. Broadly, Māori and Pacific People support change in FFC. However, the changes to FFC and carer support in general, need to be culturally appropriate and mindful of the diversity of families, whānau and aiga and their circumstances which can change quickly. Choice, flexibility and simplicity are key themes that mirror those in the overall engagement.
Section 6: Implementation and operation

6.1 How will the new arrangements be given effect?

Legislative change and implementation

A request for inclusion in the 2019 Legislation Programme has been submitted by the Minister of Health. The timeframe for legislative change will be dependent on other legislative priorities. The Ministry also recommends that legislative change is not progressed if funding for policy eligibility and pay rate changes does not receive funding through Budget 2019, as this will result in high legal litigation and fiscal risks that cannot be effectively managed.

If Budget 2019 funding is secured, repeal of Part 4A could come into force in mid to late 2020. Budget 2019 funding was based on implementation for policy changes commencing on 1 December 2019. Policy changes to key discriminatory policies can in theory be implemented prior to the repeal of Part 4A however funding cannot be met within current baselines: eligibility for FFC payment to partners and spouses of eligible disabled people, family members of eligible disabled people under the age of 18, and increased pay rates for DSS FFC carers to be comparable with other care and support workers. Depending on funding decisions, these changes to FFC policies could be considered for implementation in late 2019 or early 2020.

The Ministry and DHBs are responsible for implementation, and will review operational policies and procedures if policy and legislative changes are agreed by Cabinet and funded through Budget 2019. The Ministry will work with DHBs to implement policy changes, if agreed by Cabinet, and consider further operational policy changes. The Ministry will provide guidance to DHBs to encourage a nationally consistent approach to supporting family carers. Updated guidance will be provided to Needs Assessment and Service Coordination and Home and Community Support Service providers.

There are several ways that the views of Māori and Pacific People will inform the implementation of the changes and broader carer support. Engagement already undertaken and to continue includes:

1. The targeted stakeholder engagement carried out in September and October 2018 included Māori and Pacific People in meetings and the online survey.
2. Further analysis of the survey responses by participants who identified as Māori and Pacific People has recently been completed and is now being considered.
3. The Ministry is consulting with the following Māori and Pacific groups and will continue to engage with them in relation to any changes:
   a. Te Ao Mārama - Māori Disability Advisory Group
   b. Te Arero (Needs Assessment and Service Coordination)
   c. Māori Disability Information and Advisory Service
   d. Te Tumu Whakarae (Māori General Managers of District Health Boards)
   e. Faiva Ora Leadership Group – Pacific Peoples Disability Advisory Group
   f. Regional DHB Pacific Advisory Groups
   g. Pacific General Managers of DHBs
   h. Pacific Disability Information and Assessment Service

More broadly, the Ministry is working closely with the Ministry of Social Development and other agencies in the preparation of the draft New Zealand Carers’ Strategy Action Plan 2019-23. This will have a particular focus on Māori, Pacific People, and young and older carers. Early engagement toward the development of the Plan collected valuable information from Māori and Pacific People which was shared with the Ministry of Health.
Any future litigation claims if full repeal is chosen by Cabinet will be managed on a case-by-case basis, in line with the approach agreed between the Ministry and Crown Law for pre-2013 discrimination claims.

**Communications**

Subject to Cabinet decisions in this paper and related Budget 2019 decisions, communication relating to FFC will include the Government's decision to repeal Part 4A, change eligibility, increase pay rates for DSS FFC, and consider further policy change and stakeholder engagement. The Ministry will also develop communications to help stakeholders understand what policy change will mean for them, and the intended implementation timeframes.

### Section 7: Monitoring, evaluation and review

#### 7.1 How will the impact of the new arrangements be monitored?

DSS financial and service monitoring will take place, with close monitoring of uptake and changes to allocation for other DSS supports to assess fiscal risk. The data on uptake is captured in the DSS database called Socrates – this will enable regular reports to be provided on the number of new applications. DHBs will continue to be funded for FFC through a Crown Funding Agreement variation, with a possible phasing to funding through Population Based Funding Formula (PBFF) overtime. This arrangement allows the Ministry to closely monitor the uptake and implement the changes.

The close monitoring of uptake is important as there is no completely accurate method to estimate uptake of these policy changes. However, feedback from NASCs will provide key information on uptake. Further consideration of safety and quality of FFC will be given prior to implementation (e.g. safeguarding the choice of disabled people, ensuring carers have access to support or training).

#### 7.2 When and how will the new arrangements be reviewed?

The initiative will be evaluated to check whether the health and support needs of disabled people are being met, that the costs are similar to professional carers and that safeguarding of the choice of disabled people is occurring.

The Ministry will monitor feedback from carers and disabled people about whether they feel better supported compared to the current situation. This monitoring may include an evaluation of funding and other matters 12 – 24 months post implementation. However, as the FFC population is very small and diverse, the Ministry anticipates it will be hard to derive any statistically significant conclusions about quality of care or outcomes for disabled people that this initiative will have.
Funded Family Care Policy Change

Portfolio Health / Associate Health (Hon Julie Anne Genter)

On 22 May 2019, the Cabinet Social Wellbeing Committee:

Pay rates and employment arrangements

1 agreed 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 agreed 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 noted that the government is considering options to implement alternative employment arrangements that do not place unreasonable obligations on disabled people;

Eligibility for FFC

4 agreed to allow:

4.1 people with high or very high disability support needs to receive FFC from resident spouses or partners;

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 noted 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 noted 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;

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

8 noted that parallel policy changes to remove discriminatory aspects can reduce this litigation risk;
noted 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;

noted 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-0174.19];

agreed 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;

noted 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;

noted that it is the intention of the Minister of Health and Associate Minister of Health (Hon Julie Anne Genter) to seek additional cost pressure funding as required in future Budget rounds;

agreed to repeal Part 4A in its entirety without a litigation bar;

noted that the New Zealand Public Health and Disability (Repeal of Funded Family Care) Amendment Bill holds a category 4 priority on the 2019 Legislation Programme (to be referred to a select committee);

invited the Associate Minister of Health (Hon Julie Anne Genter) to issue drafting instructions to the Parliamentary Counsel Office to give effect to paragraph 14;

Other operational policy issues associated with FFC

noted that the Minister of Health intends to consider other policy and operational issues raised by stakeholders during 2019;

noted that improvements to Funded Family Care may be considered as part of the New Zealand Carers’ Strategy Action Plan 2019-23;

Communications

agreed to announce repeal of Part 4A and changes to FFC policy.
Present: 
Rt Hon Jacinda Ardern 
Rt Hon Winston Peters 
Hon Kelvin Davis 
Hon Grant Robertson 
Hon Phil Twyford 
Hon Chris Hipkins 
Hon Andrew Little 
Hon Carmel Sepuloni (Chair) 
Hon Nanaia Mahuta 
Hon Stuart Nash 
Hon Jenny Salesa 
Hon Tracey Martin 
Hon Peeni Henare 
Hon Willie Jackson 
Hon Aupito William Sio 
Hon Julie Anne Genter 
Michael Wood, MP 
Jan Logie, MP

Hard-copy distribution: 
Minister of Health 
Associate Minister of Health (Hon Julie Anne Genter)

Officials present from: 
Office of the Prime Minister 
Office of the Chair 
Officials Committee for SWC