In Confidence and Legally Privileged

Office of the Minister of Health

Office of the Acting Associate Minister of Health

Chair, Cabinet Social Wellbeing Committee

Funded health services provided by family and whānau – Funded Family Care

Proposal

1 To seek Cabinet's agreement to publicly announce the intent to repeal Part 4A of the New Zealand Public Health and Disability Act 2000 and to undertake targeted stakeholder engagement on potential improvements to policy settings for Funded Family Care (FFC).

2 Options for policy change and phasing of decisions will be put to Cabinet for consideration in November 2018. Change to FFC is one of the 2018 initiatives contributing to the Government priority outcome of: *"Ensure everyone who is able to is earning, learning, caring and volunteering"* [CPC-18-MIN-0006].

Executive Summary

3 We are seeking agreement to report back on proposed changes to FFC for Cabinet's decision in November 2018. Pending Cabinet agreement to proceed, we will:

a announce the intent to make changes to FFC including the repeal of Part 4A and to undertake targeted stakeholder engagement;

b ask the Ministry to:

i develop policy options for change that take into account legal, financial and human rights implications

ii model options to determine the financial implications

iii coordinate targeted stakeholder engagement with an independent facilitator.

4 Many New Zealanders who need personal care and household support receive a significant amount of this care from family members. While the majority of family care is unpaid, the Ministry of Health (the Ministry), District Health Boards (DHB) and the Accident Compensation Corporation (ACC) have policies that allow for the payment of family carers in specific circumstances.

5 This paper focuses on the Ministry's Disability Support Services (DSS) FFC policy and the DHB Paid Family Care (PFC) policy for people assessed as having high or very high needs (for disability, long term chronic health conditions, mental health and addiction and aged care needs). The ACC policy is referenced for comparative purposes but is not in scope for change.

6 FFC accounts for a small proportion of Home and Community Services Support (HCSS) spend for the Ministry and DHBs (approximately 2-3%). However, ongoing national and international challenges to FFC since its introduction in 2013 includes litigation, petitions, correspondence and media coverage.

7 We recognise the need for change to FFC and the strong calls from the disabled and carer communities.

8 Announcing intended repeal of Part 4A is needed in order to maintain good faith with the families who will be part of the targeted stakeholder engagement. Targeted stakeholder engagement will need to be done by an independent facilitator.

9 Targeted stakeholder engagement with affected families is needed in order to recommend policy settings on certain aspects of a new FFC policy and how it will work in practice.

10 Areas of particular concern which require policy change include:

a Part 4A (s 70E), which prohibits complaints to the Human Rights Commission (HRC) or the courts about discrimination on the grounds of family status and is inconsistent with the Bill of Rights Act 1990 (BORA).

b The exclusion of adults from employing spouses/partners and exclusion of people under 18 years from employing a family carer.

11 Targeted stakeholder engagement will also address issues such as:

a the requirement for an employment relationship between the disabled person and family member (this only applies to the Ministry's DSS/FFC policy)

b lower pay rates under the FFC policy than paid to contracted providers

c the limit of 40 hours per week per family carer

d limitations on the type of 'care' that can be paid for.

12 The legal, financial and human rights implications of change need to be considered including current litigation, any future claims and possible increased uptake and costs as a result of expanded eligibility and/or increased pay rates.

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

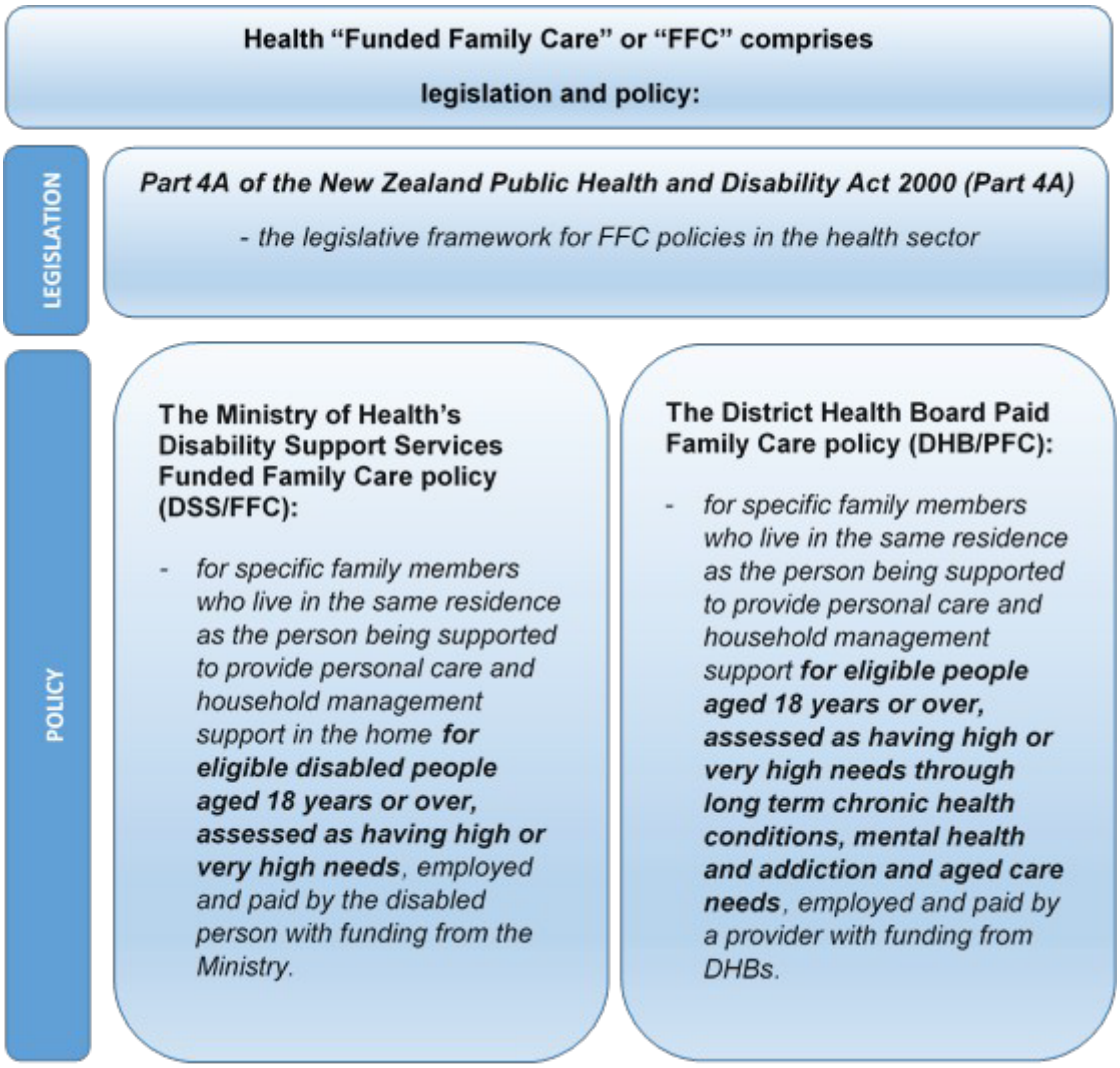
[redacted]

14 Change to FFC is one of the 2018 initiatives contributing to the Government priority outcome of: *"Ensure everyone who is able to is earning, learning, caring and volunteering"* [CPC-18-MIN-0006].

Background

Definitions

15 In this paper we use the terms 'Funded Family Care' and 'FFC' to broadly describe the following components. Where necessary, we refer to the individual components:



The origin of FFC legislation and policy

16 The origin of FFC is described briefly here with further information in Appendix A.

17 In 2010, legal action was taken against the Ministry's previous policy of not paying family carers (parents, spouses and resident family members) for the support that they provide to disabled family members. This related to DSS funded by the Ministry of Health[1].

18 The 'family carers case' (*Atkinson*[2]) was a landmark decision in New Zealand human rights law[3]. The Human Rights Review Tribunal declared that the Ministry had acted in breach of Part 1A of the Human Rights Act 1993 on the grounds of family status. The Crown's appeals were dismissed and a decision was made against any further appeals.

19 In order to comply with the law as soon as possible, the previous Government focussed on the issue directly arising from the Courts' decisions ie, the discrimination arising from not allowing payment of parents and resident family members. Statutory and policy changes were then made.

1 Disability support services (DSS) include home and community support services for people who meet DSS eligibility criteria. Other support includes residential services, carer relief, respite services, and supported living services.
2 *Atkinson v Ministry of Health* (2010) 8 HRNZ 902 (HRRT); *Atkinson v Ministry of Health* (2010) 9 HRNZ 47 (HC); *Ministry of Health v Atkinson* [2012] NZCA 184, [2012] 3 NZLR 457
3 Under Part 1A of the Human Rights Act 1993 – *Discrimination by Government, related persons and bodies, or persons or bodies acting with legal authority* (commenced on 1 January 2002)

PART 4A OF NEW ZEALAND PUBLIC HEALTH AND DISABILITY ACT 2000

20 In May 2013, Part 4A of the Act became the statutory framework for the Government's family care policies operated by the Ministry and DHBs. In summary, Part 4A:

a affirms that:

i families generally have primary responsibility for the wellbeing of their family members

ii the Government's role is to manage fiscal risk and keep the funding of support services within sustainable limits

b requires the Crown and DHBs to have family care policies to pay family carers

c restricts payment to family carers in accordance with the policies

d prevents legal challenge on the basis of family status discrimination (s 70E).

PART 4A IS INCONSISTENT WITH THE NEW ZEALAND BILL OF RIGHTS ACT 1990 (BORA)

21 The then Attorney-General considered the New Zealand Public Health and Disability Amendment Bill (No 2) [4] and:

a noted that it 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.

Family care policies operated by the Ministry of Health, DHBs and ACC

22 While the Ministry and DHB FFC operational policies are essentially the same, they serve different client groups and have different payment mechanisms. The Accident Compensation Corporation (ACC)'s attendant care policy also allows for payment of family carers but differs significantly from FFC policies.

23 We have agreed with the Minister for ACC that the ACC attendant care policy is not in scope for change. However, it is included here for comparative purposes and as further reason for change to health FFC arrangements.

24 A summary of the key differences between the Ministry (DSS/FFC), DHB and ACC policies is provided below, with a more detailed comparison in Appendix B.

	Ministry (DSS/FFC)	DHB	ACC
People ineligible to be a funded carer	• Spouses/partners • Parents of children under 18 years • Anyone under 18 years		No restrictions
Pay rates for carer	Adult minimum wage	Pay rates comparable to contracted carers	Pay rates comparable to contracted carers
Employment of carer	By disabled person	Contracted provider	Decided by injured person and family carer

FFC IS A SMALL PROPORTION OF HOME AND COMMUNITY SERVICES SUPPORT SPEND

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

25 Overall, FFC accounts for only a small proportion of total Home and Community Services Support (HCSS) spend for the Ministry and DHBs:

- DSS/FFC is 3.2 percent of the DSS HCSS expenditure
- DHB/PFC is 2 percent of the DHB HCSS expenditure

FFC UPTAKE HAS BEEN LOW

26 For DSS/FFC, $23 million was appropriated for the first year. This was on the possibility that the 1,600 people estimated to be eligible might apply. For a number of reasons, the expected uptake did not occur. In following years a more conservative allocation was made for FFC, using the previous year's uptake as a guide. DSS/FFC is expected to cost $9.92m in the 2018/19 financial year. The DHB/PFC was originally estimated to cost $41 million per annum and is expected to cost $4.021m in the 2018/19 financial year.

27 Some of the reasons for the low uptake included: people preferring their current arrangements and not wanting to change; not wanting to be either a carer or a paid carer to a family member; not wanting to be an employer (under the DSS/FFC policy), some people not being physically able to care for a family member, including issues of health safety for both person being cared for and the carer, eg, lifting. While uptake of DSS/FFC has been low, there has been a corresponding increase in the uptake of community care and the volume of paid hours of support.

Funded Family Care policy and legislation has been the subject of extensive challenge

28 Since introduction in 2013, FFC has had many challenges, some continuing, including litigation, petitions, correspondence (ministerial, departmental, HRC), media coverage and international recommendations for change.[5] The previous Government faced criticism for introducing legislation under urgency and without consideration by Select Committee.

29 Most recently, the Carers Alliance[6] has published a report on paid family care, including FFC.[7] 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 DSS/FFC a priority.

30 A petition (Sushila Butt[8] and 964 others) currently before the Health Select Committee requests the repeal of Part 4A and pay equity for family carers. Filed in February 2018, there is no scheduled date for the Committee's report. However, any announcement on proposals for change to FFC (including repeal of Part 4A and to address pay rates), prior to the Committee's report, may inform its report to Parliament.

31 The directions of the courts following the *Atkinson*, *Spencer* and *Chamberlain* cases, have been responded to:

5 The United Nations Committee on the Rights of Persons with Disabilities recommended that New Zealand allow payments to all family carers and allow complaints of unlawful discrimination
6 A consortium of over 40 national not-for-profit organisations promoting better support and recognition for family, whānau, and aiga carers
7 Commissioned from the Sapere Research Group, see http://carers.net.nz/wp-content/uploads/2018/05/Paid-Family-Care-Discussion-Paper-FINAL-24-April-2018.pdf
8 A claimant in the *King* Proceedings

a *Atkinson*: the courts held that the government's policy of not paying family members for care to disabled adult children was discriminatory. Funded Family Care policy allowing payment for family members providing care to disabled adult children has been implemented.

b *Spencer*: the courts held that Mrs Spencer was entitled to compensation and that the Ministry of Health carry out human rights training. Both have been implemented.

c *Chamberlain*: the courts held that the Ministry (through the NASC) had failed to take into account intermittent personal care as part of its assessment of Mr Chamberlain's needs. Reassessment has been undertaken for Mr Chamberlain, taking into account the Court of Appeal's guidance. An easy-read version of the Funded Family Care policy has been published.

The FFC scheme was amended in 2016

32 In 2015, an independent evaluation of FFC was completed following the first year of operation.[9] While the evaluation found that the policy was having a positive impact for most families accessing the supports, there was a comparatively low uptake.

33 A number of improvements were identified to improve access to and usability of the scheme. In 2016, the operational policy for the scheme was amended to:

d clarify the role of the advocate and introducing supported decision-making for the disabled person

e raise awareness with disabled people and their carers that FFC may be an option to consider for those eligible

f improve the application, informed consent and supported decision-making processes

g reduce follow-up monitoring visits to one in the first month with annual reassessments.

Comment

There is an opportunity to make positive changes to FFC arrangements

34 We have an opportunity to make positive changes to Government policy on health service arrangements for FFC to improve options and outcomes for both carers and people being cared for. This will also help us to:

a meet and advance our international obligations including the United Nations:

i Universal Declaration of Human Rights (UDHR)

ii Convention on the Rights of Persons with Disabilities (CRPD)

iii Convention on the Rights of the Child (CRC)

b meet our legal obligations including:

i the New Zealand Bill of Rights Act 1990

ii the Human Rights Act 1993

c meet and advance wider government responsibilities and priorities including:

i the New Zealand Carers' Strategy and Action Plan

9 See www.health.govt.nz/publication/evaluation-funded-family-care

ii the New Zealand Disability Strategy and Action Plan

iii supporting the Enabling Good Lives vision and principles (Appendix C)

iv the transformation of the disability support system including the MidCentral prototype from 1 October 2018.

35 Change to FFC is also one of the 2018 initiatives contributing to the Government priority outcome of: *"Ensure everyone who is able to is earning, learning, caring and volunteering."* [CPC-18-MIN-0006].

Options for change to FFC

36 We recognise the need for change to FFC and the strong calls from the disabled and carer communities. With Cabinet's agreement, we propose to announce the intent to make changes to FFC, including the repeal of Part 4A, and to carry out targeted stakeholder engagement with an independent facilitator. We intend to report back to Cabinet in November with our preferred options for policy and legislative changes, describing the human rights, legal, policy and financial implications and phasing of implementation.

37 The concept and practice of family care, natural supports and the uptake of support services can vary widely between different groups. The voices and experience of Māori, Pacific and other ethnicities will be included in the work on both changes to FFC and the development of the next New Zealand Carers' Strategy Action Plan.

38 The November FFC Cabinet paper will include policy options for expanding eligibility for DSS and DHB FFC to enable payment of:

a spouses/partners of people with high or very high needs

b parents and close family members who live in the same residence as people under 18 years with high or very high needs

39 Targeted stakeholder engagement is being planned with an independent facilitator on several issues including:

a removing the requirement under the DSS/FFC policy for an employment relationship between the disabled person and family member. This could be replaced with an alternative payment / employment arrangement or choice of arrangement

b the type of 'care' that can be paid for

c pay equity rates for family carers.

40 The following sections outline key information relating to:

a options and implications for change to Part 4A

b pay rates

c estimated costs of expanding FFC eligibility

d how FFC fits with the transformation of the disability support system

e proposed approach to targeted stakeholder engagement

f public communications.

Repeal of Part 4A is important

41 Since its introduction, there have been regular calls for Part 4A to be repealed in entirety. This has included two petitions to Parliament – one in 2014 (reported in 2016) [10], and the petition currently before the Health Committee. United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) concerns of excluding access to the courts continues to feature in monitoring reports as an outstanding issue. For the disability community, Part 4A has become a symbol of frustration with FFC.

42 The most contentious element of Part 4A is s 70E preventing human rights redress. This was introduced to limit the government's financial liability by prohibiting claims for compensation for discrimination. As noted, s 70E was found by the Attorney-General to be inconsistent with s 27(2) of BORA and could not be justified under s 5.

Legal, financial and human rights implications of repealing Part 4A

43 The legal, financial and human rights aspects of repeal or change to Part 4A are described here and include:

a implications for current legal action

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

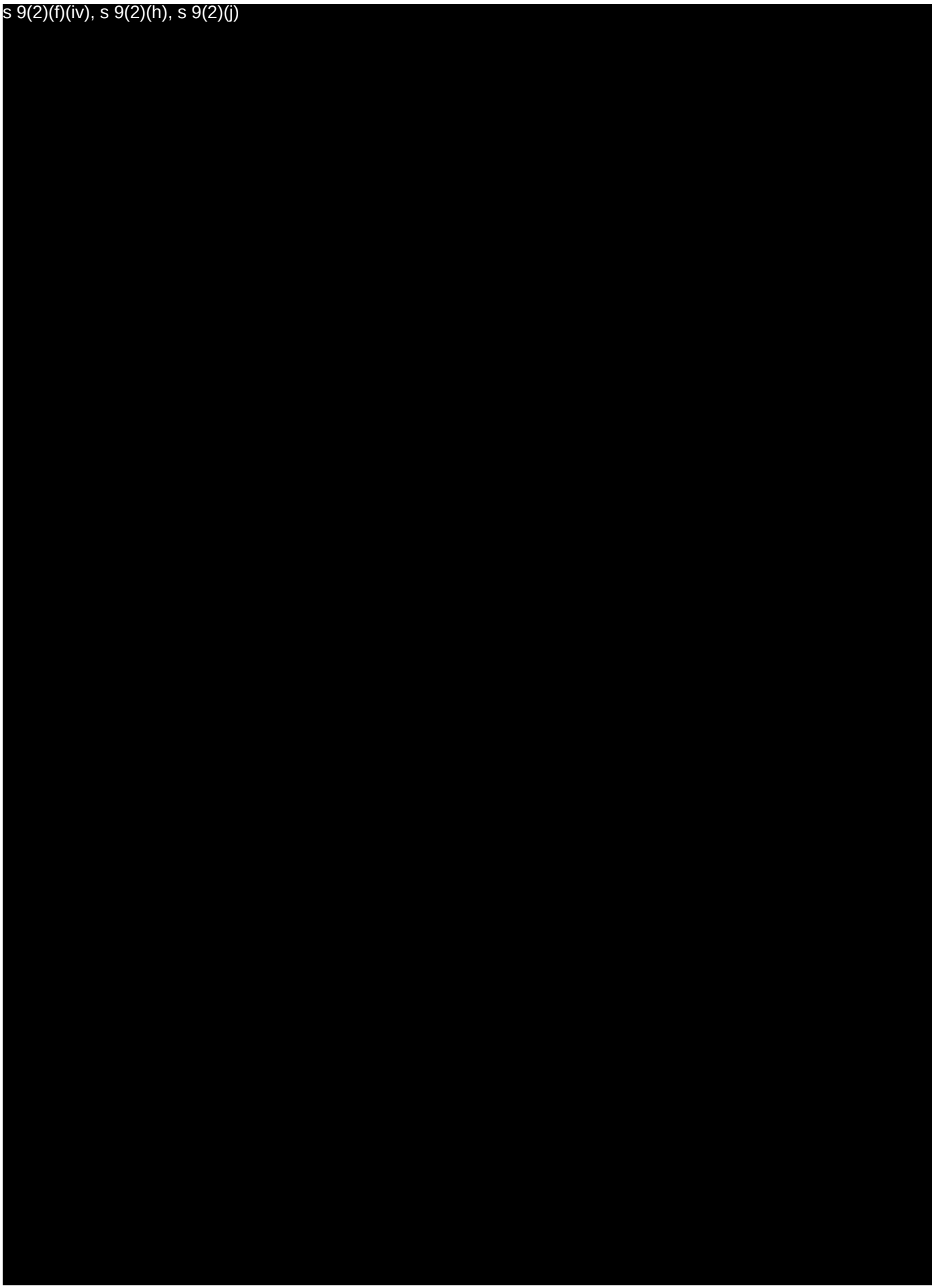
[redacted]

d potential reduction or removal of discriminatory aspects.

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

[redacted]

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



[redacted]

53 Other effects of repeal will include the removal of:

a the statutory principle that in the context of funding support services, that families generally have primary responsibility for the wellbeing of their family members

b the specific affirmation of the Government's role to manage fiscal risk and keep funding of support services within sustainable limits (although the general purpose of the Act provides that the objectives of the Act are to be pursued within the funding provided)

c the requirement for the Crown and DHBs to have family care policies to be able to lawfully pay family carers

d the restriction of payment to certain family members unless allowed for in policy

e the statutory requirement for the Ministry and DHBs to take into account various circumstances in family care policy (eg, age of eligibility, residence of the disabled person and carer, the disabled person's needs or impairment and rate of payment).

Changes to funded family care policies

54 Part 4A is not required to support the government's policy on FFC. Apart from s 70E (preventing claims), Part 4A is simply the framework for the Ministry and DHBs family care policies. However, the Ministry's and DHB's policies and their application can be changed at any time and do not need a statutory basis. As with all other health policies, a statutory framework is unnecessary provided it is supported by an appropriation.

55 With the agreement of Cabinet, we will direct the Ministry to undertake further policy work and targeted stakeholder engagement by an independent facilitator, to inform decisions in November.

56 In assessing options for change, the following will be considered:

a human rights, legal and financial implications

b other aspects such as employment relationships for the DSS/FFC policy (eg, we would not normally expect a person under 18 years to be an employer)

c how repeal of Part 4A should be managed and whether any replacement / statements about protections for carers and those receiving care are required

d stakeholder views, including:

i the interrelationship between issues such as pay rates, opportunities for training, assurance for safe and quality care, and options for employer relationship

ii targeted engagement including with affected families, carers organisations and Māori and Pacific people

iii issues and themes arising from consultation on the development of new action plans for the New Zealand Carers' Strategy and the New Zealand Disability Strategy

e options for phased implementation

f the way in which FFC will be managed in the MidCentral prototype of the transformed disability system[12]

g links and flow-on effects for other government policies and sectors, including:

i whether expanding FFC eligibility would affect other parenting or 'natural supports' that could attract funding, such as paid parental leave and education provided at home

ii the Government's overall position on carers and the payment of carers.

57 A government position on care, carers and payment of carers is important, particularly with the anticipated increase in demand for care with demographic changes. This statement is possible given the work to develop a new Carers Strategy Action Plan. This should take into account societal expectations of the 'natural supports' reasonable for family members to provide and the conditions under which the state needs to provide support to ensure the wellbeing of carers and those being cared for. This is of significant concern to the health and social sectors.

Pay rates

58 Differential pay rates for family carers are arguably discriminatory and also contentious. As noted, the FFC petition currently before the Health Select Committee requests pay equity for family carers as well as repeal of Part 4A.

59 Family carers employed under FFC are legally entitled to the minimum adult wage whereas care and support workers employed by contracted carers are legally entitled to the higher minimum pay rates in the Care and Support Workers (Pay Equity) Settlement Agreement 2017. Family carers employed by DHBs and ACC are receiving comparable pay rates to contracted carers.

60 The background to this is that in 2017, the former Government approved and underwrote the settlement with Unions representing Kristine Bartlett and 55,000 co-workers providing disability support services across the three distinct categories of the sector. This was in response to a Court decision about pay equity being a reasonable interpretation of the Equal Pay Act 1972. However, family carers were specifically excluded from the Settlement Agreement, and the Care and Support Workers (Pay Equity) Settlement Act 2017. This raised concerns among some family carers.

61 We propose to consider whether pay rates for family carers under DSS FFC should be increased. General estimated costs are outlined in the following section. Key issues to consider in relation to pay rates are whether the type and quality of support services provided to a disabled person by family and contracted carers is the same. There are no qualification requirements for family carers directly employed by a person receiving care (under FFC and ACC attendant care).

Anticipated costs of expanding FFC policies eligibility and increasing pay rates

62 Additional funding will be required if Ministers wish to expand FFC to include spouses/partners being able to care for their spuses/partners assessed as having high or very high needs and parents and close family members who live in the same residence as children under 18 years assessed as having high or very high needs, and / or to increase pay rates.

63 Estimating the possible uptake of the health FFC policies through increasing eligibility and different pay rates is difficult given a number of uncertainties. The following factors have required a sensitivity analysis:

12 beginning 1 October 2018

a people's desire to have a break from family care

b potential abatement of any benefits to support carers

c willingness to formally employ, or be employed by, a family member (only applies to DSS/FFC)

d difficulties associated with separating family and professional relationships

e issues concerning administrative and tax compliance

f publicity and word of mouth about FFC, both positive and negative

g actual or perceived economic advantage of taking up the service.

64 Initial modelling of estimated total additional costs of including partners/spouses and parents of children under 18 has been completed, along with a sensitivity analysis for four year totals for:

a DSS/FFC at adult minimum wage

b DSS/FFC at pay equity entry level wage, pay equity weighted average wage, and pay equity maximum wage

c DHB/PFC at current family carer wage (pay equity).

65 This modelling suggests additional costs totalling $33.7 million over four years, comprising:

a DSS/FFC - $3.6 million (adult minimum wage) to $28.4 million (including pay parity with home and community support workers at weighted average rate); and

b DHB/PFC - $5.3 million.

66 Four year estimates work on the assumption of a gradual increase in the uptake of DSS/FFC and DHB/PFC. At the end of the four years, the estimated yearly cost is expected to be around $8.1 million per year for DSS/FFC, and $1.4 million per year for DHB/PFC. This suggests that FFC eligibility changes would lead to an increase of less than 1% for each of the current DSS operating budget[13] and DHB spending for home and community support services.

REASON FOR COST INCREASE

67 Generally, any increase in the uptake of DSS and DHB FFC should be cost neutral. This is because the provision of care is transferred from contracted providers to family members. By rights, the amount of care provided to all HCSS clients should not vary. In practice, however, DSS/FFC clients receive a significantly larger allocation (up to 30 percent) of disability support services compared to that received before becoming FFC clients.

68 The Ministry's cost projections are based on:

a the increase in uptake of FFC if partners/spouses and parents or close family members of children under 18 are included

b the effect of service allocation increase of approximately 30 percent described above

c the direct effect of pay increase on both increase in uptake, and operational costs of existing clients.

13 the total DSS budget is $1.1 billion per annum

69 The analysis will be refined to provide more detailed advice on estimated costs of options for policy change in the proposed November Cabinet decisions paper. This will include working with other agencies to consider cross government implications that would impact on costs / savings and a person's experience eg, the way in which receipt of FFC interacts with other payments and benefits.

Health and Disability System Review

70 Proposed policy work and engagement on FFC will occur alongside the Health and Disability System Review recently considered by Cabinet [CAB-18-MIN-0207 refers]. Care and carer issues including natural support, recognition, carer support and payment may arise in the review's investigation, advice and consultation. FFC history, current arrangements and the desire for change may also be raised. Information will be shared where practical to inform the respective work.

Welfare Expert Advisory Group

71 The proposed change to FFC policy to fund care provided by spouses/partners of people assessed as having high or very high needs raises the issue of whether the Supported Living Payment qualifying criteria should be similarly changed. There may be other benefits implicated. The Welfare Expert Advisory Group is currently reviewing the whole welfare system. Information will be shared where practical to inform the respective work.

How FFC fits with the transformation of the disability support system

72 Cabinet recently approved planning toward the MidCentral prototype of a transformed disability support system, to start on 1 October 2018. System transformation is based on the Enabling Good Lives (EGL) vision of disabled children and adults and their families having greater choice and control over their supports and lives, and making more use of natural and universally available supports (see Appendix C).

73 System transformation will implement the DSS FFC policy whether current or changed and take place in a very different environment from the current system. In the transformed system, people will typically work with Connectors to build broader support networks, and develop safeguarding arrangements that reduce the reliance on family carers. Over time, this is expected to reduce the expectation that family carers will focus on supporting their disabled family member full-time. It is important that changes to FFC are in keeping with the vision, principles and operation of the transformed disability support system.

Targeted stakeholder engagement

74 We propose to undertake targeted stakeholder engagement with disabled people and those being cared for under the DHB/PFC policies, carers and wider stakeholders on options for change. This is consistent with the expectation of disabled people under the EGL principles (Appendix C).

75 The Ministry of Health will appoint an independent facilitator who will assist in the planning and coordination of the engagement and report back on findings. As disabled people, carers and wider stakeholders are critical of the current arrangements and wary of the approach to change given the Ministry's role in managing FFC and involvement in litigation, an independent facilitator is likely to be positively received.

76 Targeted stakeholder engagement will take place October to December and focus on options for change rather than a revison of the current problems which are already well

known. Opportunities for engagement being considered include meetings, focus groups, and online feedback.

77 As the 13 pre-2013 claims are still before the Court, it will be made clear that legal remedies for these claims are outside the scope of the engagement process.

78 Engagement on FFC will coincide with a busy period of consultation with the disability sector on related issues. We have agreed with the Minister for Social Development and Disability Issues that the respective agencies will work together to ensure careful planning and coordination. Consultation includes:

a the draft Government response to the *UN Committee on the Rights of Persons with Disabilities' List of Issues* and

b the new Disability Strategy Action Plan (2019-2022) (separate report to Social Wellbeing Committee on 15 August)

c early engagement on the development of a new Action Plan for the New Zealand Carers' Strategy (separate report to Social Wellbeing Committee on 12 September).

79 The findings from this engagement would be considered alongside policy and legal work to inform our preferred options. It is proposed that the preferred options are reported back to Cabinet in November for decision. There is also an opportunity for a later engagement phase following decisions on policy and legislative change, to work with those receiving care, carers, and communities to inform how these changes will be implemented.

Communication on FFC and related issues

80 Communication issues relating to FFC include:

a the intention of the government to make options for changes to FFC

b how people receiving care and carers will be involved in defining the options and providing their views and preferences (targeted stakeholder engagement rather than a broader public consultation programme)

c the need for clear communications to manage parallel sets of engagement relating to people receiving and providing care.

81 There needs to be an appropriate balance between encouraging feedback and views and managing expectations ahead of Government decision-making on FFC.

82 Subject to Cabinet's decisions we will announce the intent to make changes to FFC including the intended repeal of Part 4A and undertake targeted stakeholder engagement with an independent facilitator.

Financial Implications

83 Policy decisions on FFC will be made in November as part of Budget 19 considerations. This will be informed by advice on options, implementation, phasing of further decisions and the outcome of targeted stakeholder engagement.

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

[redacted]

85 There are financial implications relating to the early announcement of intent to repeal Part 4A of the New Zealand Public Health and Disability Act 2000. This would essentially

commit the Government to this action ahead of Budget 19 decisions. The Treasury has a separate comment on this under the Consultation section.

86 The financial implications of repealing Part 4A depend on the policy decisions to be made in November, and are in three areas:

a management of current and potential future litigation (if any) as an impact of repeal of Part 4A

b expansion of eligibility for the FFC policies

c pay rates for family carers.

Human Rights

87 Human rights are a key consideration in the origin and current FFC policy and legislation and any proposed change. The Ministry of Health's former policy of not paying family carers for the support that they provided to disabled family members was ruled to be discriminatory. However, the protections introduced in the 2013 FFC policy and legislation to help manage fiscal risk are also inconsistent with human rights legislation and have contributed to calls for change.

88 Part 4A has two specific areas with human rights implications: payment based on eligibility; and preventing complaints of discrimination. Any legislation preventing a person from being able to commence litigation or make a claim means that they are prevented from accessing justice. As considered by the Attorney-General in 2013, this is inconsistent with the right to justice affirmed in s 27 of BORA and could not be justified under s 5.

89 Proposals for change to the current arrangements for FFC policy and legislation that differentiate on the basis of family status will continue to be problematic.

90 Each part of the programme of work agreed to support change to FFC arrangements will be managed to ensure they are consistent with the New Zealand Bill of Rights Act 1990 and the Human Rights Act 1993.

Legislative Implications

91 A decision to repeal Part 4A of the New Zealand Public Health and Disability Act 2000 would need to be scheduled on the 2019 Legislation Programme with possible commencement on 1 July 2019.

Impact Analysis

92 No Impact Analysis statement has been prepared for this paper.

Gender Implications

93 There are gender implications with health sector paid family care policy and legislation and any changes to these. Women continue to contribute the majority of the unpaid labour for disabled people depending on family and whānau for support.

94 Relying on partners for support can strain relationships and lead to a loss of independence that can mainly affect women. Impacts can include lost opportunities for employment and income and social isolation.

95 Positive changes to FFC alongside system transformation will benefit women in terms of their role in caring for a disabled family or whānau member and their wider family or whānau care and leadership roles.

Disability Perspective

96 The concern over FFC has contrasted markedly with the broader positive programme to transform the disability support system (based on the Enabling Good Lives principles). The objective of the transformed system is to give disabled people and their family and whānau more options and decision making authority about their supports and lives, to improve their outcomes, and create a more cost-effective disability support system.

97 System transformation has been developed through a co-design process with the disability sector which is very supportive of this work.

98 There is considerable expectation of change to FFC from the disability and carer community. The announcement of change and a programme to address particular aspects will be welcomed. There will also be an expectation that disabled people (and those receiving support under the DHB/PFC policies) and their carers will be involved in both determining the options for change and providing their views and preferences.

Publicity

99 The expectation of change in FFC arrangements means that an announcement that options for change are to be considered will be greeted positively and help to manage expectations. There will be ongoing communications including Ministerial announcements about the decisions in this paper.

Consultation

100 Wider public consultation is not proposed on FFC arrangements and options for change as the issues of concern have been well known since introduction. Instead, targeted engagement with key stakeholder groups including affected families, is proposed to inform later decisions on proposals for change.

101 The following government agencies have been consulted in relation to the issues in this paper and their views incorporated: Accident Compensation Corporation, Crown Law, Ministry of Justice, New Zealand Treasury, 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 State Services Commission. The Department of the Prime Minister and Cabinet have been informed of the paper.

COMMENT FROM TREASURY

102 This paper seeks agreement to formally announce the intention to repeal Part 4A. This effectively commits the government to this decision before the policy work and costings have been completed. Since this decision also has financial implications, it should go through the Budget process in order to allow prioritisation across all government initiatives. At this stage, we recommend announcing the intention to review rather than repeal Part 4A.

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

[redacted]

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

[redacted]

Recommendations

The Minister of Health recommends that the Committee:

1 **note** that 'Funded Family Care' and 'FFC' are used to describe:

a Part 4A of the New Zealand Public Health and Disability Act 2000 (Part 4A)

b the Ministry of Health's Disability Support Services (DSS) FFC policy

c District Health Board's Paid Family Care policies;

2 **note** that Part 4A of the NZ Public Health and Disability Act 2000 (May 2013), and subsequent Ministry FFC policy (October 2013) has been the subject of considerable national and international criticism, particularly because s 70E of Part 4A is inconsistent with the Bill of Rights Act 1990 by preventing people from making claims of discrimination on the grounds of family status (except for retrospective claims (pre-2013) following a decision of the High Court in October 2013);

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

[redacted]

4 **invite** Ministers to report back in November 2018 on the policy, financial and human rights implications, options and phasing for decisions on:

<u>Legislation</u>

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

<u>Eligibility</u>

b expanding eligibility for FFC arrangements to enable payment of:

i spouses/partners of people assessed as having high or very high needs

ii parents or close family members who live in the same residence as people under 18 years assessed as having high or very high needs

<u>Operational policy issues</u>

c changing the requirement for an employment relationship between the disabled person and family member under the DSS FFC policy

d the type of 'care' that can be paid for

e pay rates (similar to pay equity rates of contracted family carers)

f the way FFC would be managed in the MidCentral prototype of the transformed disability support system commencing 1 October 2018;

5 **agree** that the Ministry of Health undertake targeted stakeholder engagement with an independent facilitator on change to FFC arrangements;

6 **note** that targeted stakeholder engagement on FFC will be coordinated appropriately with other government consultation occurring at approximately the same time on:

a the draft Government response to the *UN Committee on the Rights of Persons with Disabilities' List of Issues*

b a new Action Plan (2019-22) for the New Zealand Disability Strategy

c the development of a new Action Plan for the New Zealand Carers' Strategy;

7 **agree** to formally announce that the Government intends to make changes to FFC arrangements including the repeal of Part 4A and to undertake targeted stakeholder engagement;

8 **note** that an early announcement of intent to repeal Part 4A would essentially commit the Government to this action ahead of:

a Budget 19 decisions

b receipt of detailed legal advice from Crown Law on the risks of doing so and opportunities to mitigate those

9 **note** that change to FFC is one of the 2018 initiatives contributing to the Government priority outcome of: *"Ensure everyone who is able to is earning, learning, caring and volunteering."*

Authorised for lodgement.

Hon Dr David Clark
Minister of Health

_____/_____/_____

Hon James Shaw
Acting Associate Minister of Health

_____/_____/ _____

Appendix A: Funded Family Care policy and legislation – supporting information

Overview of the Government's current health Funded Family Care policy framework

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 funded family care policies for the Ministry and DHBs. The policies are essentially the same but serve different client groups and have different payment mechanisms. In summary:
    a. ***The Ministry's Disability Support Services (DSS) administers the Funded Family Care (FFC) policy (DSS/FFC)*** (introduced on 1 October 2013) for *disability support* in the home for eligible disabled people aged 18 years or over, who have been assessed as having high or very high needs, to employ a resident family member (not including spouses and partners and parents of people under 18 years) to provide some or all of their allocation of personal care and household management supports. The family member is employed and paid by the disabled person with funding from the Ministry
    b. ***District Health Boards (DHBs) administer a similar Paid Family Care (PFC) policy (DHB/PFC)*** (introduced May 2014) covering personal care and household management support for people with *long term chronic health conditions*, *mental health and addiction* and *aged care* needs. In contrast to the DSS/FFC policy, employment and payment of family carers for DHB/PFC is through a contracted provider with funding from the DHB. This mechanism minimises discrimination and potential for claims (eg, family carers are paid at pay equity rates).

2. The majority of the focus in this document is on the DSS/FFC policy for services for disabled people with high or very high needs. Policy work for change will include DHB/PFC policies.

Rationale for the Government's current policy on FFC

3. Before 1 October 2013, the Ministry of Health (Ministry) operated a blanket policy of:
    - not paying resident parents providing personal care and household management for their disabled adult children
    - allowing only spouses or parents of adult children to be employed as family carers if they lived with the disabled person
    - allowing other relatives to be paid for care if they were non-resident family members (eg, lived next door).
4. The 'old' policy was founded on the principle that, in the context of funding support services, families generally have primary responsibility for the wellbeing of their family members.

The policy was developed in response to litigation

5. 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.
6. The development of the current policy was guided by several considerations:
    - an overarching principle that: 'in the context of public funding of support services, families generally have primary responsibility for the wellbeing of their members'

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- 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
- 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
- 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
- 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 NZ Bill of Rights Act 1990).

7. The preferred option was to pay family carers the minimum wage of $16 an hour ($23 million (net) a year, or almost $100 million over four years). 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:
   a. expressly permit some or all family carers to not be paid, or to be paid at reduced rates, to provide care to family members
   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.
8. 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

9. Part 4A is the statutory framework for the Government's family care policy. The following table describes the main features.

Table 1. Main features of Part 4A

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

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

1 In considering the consistency of the New Zealand Public Health and Disability Amendment Bill (No 2) (the Bill), with the rights and freedoms affirmed in the New Zealand Bill of Rights Act 1990 (BORA)[1], the Attorney-General:

[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

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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

10. Family carers can be paid to provide home based support services only. There are two main categories:
    i. 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 your home
    ii. Household management can include help for meal preparation, washing, drying or folding clothes, house-cleaning, vacuuming and tidying up.
11. 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 activities, such as meal preparation, eating, bathing, dressing, toileting, or transferring, is not covered by the policy.[2]

Rationale for Ministry of Health Funded Family Care operational policy

Needs assessment

12. *FFC policy / practice* – FFC incorporates the Ministry's needs assessments policy and practices into the Ministry's Part 4A policy. A disabled person is assessed as eligible for publicly funded health and disability services by a Needs Assessment and Service Coordination (NASC) organisation. If the person is eligible, a NASC facilitator will then assess the disabled person to identify their needs, goals, priorities, and disability support needs. During the needs assessment, the NASC facilitator will record the disabled person's individual circumstances that may support their potential eligibility for FFC.
13. Service coordination is the process of identifying all people and services funded and non-funded that could provide support to the disabled person to meet their assessed needs and goals. It determines which of the assessed needs can be met by the person's natural supports, which may be met by other government agencies or community groups and which can be supported through DSS funded services including FFC. A support plan results from this process.
14. *Rationale* – FFC assessment is undertaken in the same way as assessment for support from a formal provider. All assessments and allocations of support take into account natural support. 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. Originally, FFC hours were seen as a substitute for hours already allocated to a provider, however, in practice the Ministry has observed people seeking FFC hours in addition to a previous provider allocation, resulting in cost growth.

Services funded under FFC and allocation of hours

15. *FFC policy/ practice* – An eligible disabled person can employ one or more family carer for up to 40 hours per week for Home and Community Support Service (HCSS) needs for personal care eg, assistance with showering or eating, household management eg, cleaning and cooking, and night time support (but not sleepover).
16. *Rationale* - The idea behind the current regime was to remove the barrier for family to be paid in the same way as formal providers are paid to deliver the care. These are the tasks that formal providers deliver under an HCSS contract. A 40 hour week equates to a 'normal' working week for most employees. If the FFC policy were to be extended beyond service tasks, and as far as recognising supervision, it may result in payment for 168 hours per week in many cases ie, 24/7 care.

https://www.justice.govt.nz/assets/Documents/Publications/BORA-No.-2-New-Zealand-Public-Health-and-Disability-Amendment-Bill.pdf

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

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Payment

17. *FFC policy / practice* - FFC is paid at the adult minimum wage rate for employees 16 years or older: $16.50 an hour before tax. The actual funding to the disabled person is slightly higher to cover employer obligations (eg, leave entitlements, ACC levies, Kiwi Saver).

18. *Rationale* – A decision was taken to pay family carers the minimum wage because, at the time the policy was introduced, this was understood to be comparable to the wages that care and support workers were receiving from contracted providers.

Employment

19. *FFC policy / practice* – Payment for family carers is made directly into the disabled person's bank account for the weekly hours allocated (under the DHB/PFC policy family carers are employed and paid by a contracted provider). A host organisation funded by DSS supports people to set up the administration process and access an online payroll system (if they choose) at a weekly cost of about $3. The host can also provide support to manage IRD requirements and opening a bank account.

20. *Rationale* - Feedback from the sector at the time FFC was introduced indicated that an employment arrangement was the most supported option so that people would feel recognised as skilled workers. A decision was then needed on who the employer role. For a range of reasons, the Ministry and formal providers were rejected as employers and the disabled person was determined to be the employer to recognise they are at the centre of the arrangement. The disabled person needs to confirm they want a family member to deliver their care to avoid the potential for abuse of the person for financial gain.

Quality and safety

21. *FFC policy / practice* - The disabled person is formally responsible for managing the service, including ensuring that the family carer provides the care, notifying the Ministry of any problems that affect delivery, safety or quality and notifying the Ministry if the disability support services become unsafe or are harmful to them.

22. *Rationale* – It is important to ensure families do not take advantage of the potential for payment to provide a home and support that was not the disabled person's preference.

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Concerns about Funded Family Care

23. A range of concerns have been raised about FFC operated by the Ministry and DHBs.

Legislation and legal concerns

24. Part 4A (section 70E) prohibits people from making complaints to the Human Rights Commission or another court.
25. However, while Part 4A prevents claims of unlawful discrimination relating to family care policies after 15 May 2013, the Court's decisions have rendered it ineffective in preventing the consideration of claims before that date.
26. There are 13 ongoing claims by family carers and disabled people that commenced before Part 4A was enacted and relate to claims of unlawful discrimination arising from the former policy (pre-2013). The claim is that the disabled people were unlawfully discriminated against on the grounds that they were unable to choose their preferred carer. The cases are schedule for hearings in the High Court in February 2019.

Concerns about Ministry of Health Funded Family Care operational policy

27. The policy excludes spouses and parents of children under 18 from being paid to provide family care.
28. The policy requires an employment relationship between a disabled adult and their family member being paid to provide care.
29. There is a limit on the maximum number of hours (40 per week) that a resident family carer can be paid for, although there is an exceptions process.
30. The definition of 'care' that can be paid for under the policy is narrow. For example, 'supervision' is excluded from needs assessments when considering HCSS. More recently, the *Chamberlain* court case has challenged the policy for not allowing intermittent care at night by carers.
31. The policy (including more widely the DSS policy) is often difficult for disabled people, their families and the Courts to understand and is perceived to be inflexible, with different parts developed at different times.

Concerns about DHB paid family carer policies

32. The Ministry and DHB policies have the same eligibility exclusions. The DHB policies face the same human rights risk of unjustifiable discrimination because they exclude spouses/partners, and parents of disabled people under 18 years from being paid for family care.
33. The group primarily affected by the DHB policies is adult sons and daughters caring for their elderly parent(s). Another affected group are parents caring for adult children who have long-term conditions, for example, chronic medical conditions or mental health conditions where impacts on the person and the family are very similar to those of *Atkinson* claimants.
34. No additional government funding was provided to DHBs to pay family carers. DHBs are expected to manage fiscal costs within their population funding baselines. Any changes to increasing the scope of the Government's family care policy are likely to lead to increased uptake of DHB paid family care, and greater costs to DHBs.

Human rights concerns

35. The current policy is inconsistent with the Government's international obligations. 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).[3]
36. Part 4A has two specific areas with human rights implications, described below.

[3] UN Committee on the Rights of Persons with Disabilities. *Concluding Observations on the initial report of New Zealand* CRPD/C/NZL/CO/1(2014)

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Payment is based on eligibility

37. Part 4A requires that payments to family members for support services is to be in accordance with FFC policies. Part 4A does not state which family members are eligible for payment as this is set out in the policies.

38. Current FFC policies allow payment of some family carers in specified circumstances and, for clarity, excludes other family carers (eg, spouses/partners of people with high or very high needs and parents of children and young people under 18 years with high or very high needs).

39. The FFC policies could be changed to expand eligibility without needing to amend Part 4A. This would address an indirect discriminatory feature of Part 4A.

Complaints of discrimination are prevented

40. Section 70E of Part 4A prevents any complaint to the Human Rights Commission or courts based on an assertion that a person's right to freedom from discrimination has been breached by Part 4A, a family care policy or any action or omission related to Part 4A or a family care policy.

41. This provision was found by the Attorney-General to be inconsistent with s 27(2) of the NZ Bill of Rights Act 1990:

> *Every person whose rights, obligations, or interests protected or recognised by law have been affected by a determination of any tribunal or other public authority has the right to apply, in accordance with law, for judicial review of that determination.*

Concerns that family carers are excluded from pay equity

42. The Care and Support Workers (Pay Equity) Settlement Act 2017 was enacted to address historical inequities and achieve pay equity in the care and support sector, including to ensure minimum wage rates and employer assistance for training.

43. Family carers paid under the DSS/FFC policy were also excluded from the pay equity agreement. They were not part of the union claim or the pay equity legal action.

44. The policy provides for the payment of family carers at the adult minimum wage. The disability sector's expectation is that family carers should receive the pay equity pay rates.

Concerns about family care policy and other sector approaches and government strategies

45. The current policy is inconsistent with broader social policy objectives, including the New Zealand Carers and Disability Strategies and their respective Action Plans and the transformation of the disability support. These promote full accessibility to health and disability services and put people at the centre of services, allowing choice and control over the services they receive and from the people who provide them with care and support.

46. This paper does not address the implications for other agencies that offer funded family support (eg, ACC's attendant family care).

Funded Family Care and System Transformation

47. The Ministry of Health is currently leading work with the disability sector on a nationwide transformation of the disability support system to give disabled people and their whānau more options and decision making authority over their lives. The current policy is inconsistent with the proposed new approach where eligible disabled people will receive a personal budget which they can use flexibly to purchase disability supports to achieve their vision for a good life.

48. FFC within the transformed system would take place in a very different environment from the current system. Typically, people will work with Connectors to build broader support networks, and develop safeguarding arrangements that reduce the reliance on family carers. Over time, this is expected to reduce the expectation that family carers will focus on supporting their disabled family member full-time.

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Appendix B: Comparison of Funded Family Care policies

The table below identifies the shared elements and key differences of paid family care policies between the Ministry of Health (the Ministry), District Health Boards (DHBs) and the Accident Compensation Corporation (ACC).

Family care policies operated by the Ministry and DHBs are provided for through Part 4A of the New Zealand Public Health and Disability Act 2000 (the Health and Disability Act). ACC paid family care or 'attendant care' is provided primarily through sections 81 to 84 of the Accident Compensation Act 2001 (attendant care is one aspect of social rehabilitation support which ACC is liable to provide).

Carers NZ and the Carers Alliance will shortly publicly release a report on Paid Family Care. This report calls for the government to urgently address issues relating to paid family care across the system, including the MoH, DHB and ACC policies.

Key elements of policy	Ministry of Health, 'Funded Family Care'	DHBs, 'Paid family care'	ACC, 'attendant care' usually in relation to serious injuries
Who is eligible • ***impairment type***	People with physical, sensory, intellectual disabilities (or a combination of these) and certain other disabilities (eg, ASD).	People with chronic conditions or chronic mental health problems or medically frail older people living at home (includes medically fragile children).	People with an assessed injury-related need that requires human assistance support. This generally applies to long term impairment or disability resulting from an injury. The assessment is needs based, not impairment based, where the injured person is assessed as requiring support that cannot be met by assistive technology, modification or rehabilitation/ support intervention.
• ***Duration of impairment***	Six months or longer.		No duration limitations; care can be funded for a short term period (e.g. orthopaedic injury) through to lifelong disability.
• ***Needs complexity***	People with high or very high needs only.		A need for human support that is unable to be met by assistive technology, modification or rehabilitation/support intervention.
• ***Age limits***	Adults 18 and over.		No upper or lower age limit. For children, ACC assesses age related developmental needs and typical parental responsibility.
• ***Residence***	In home.		In home and community.
Scope of policy	Under the MoH Funded Family Care (FFC) policy, a disabled person who is eligible for Home and Community Support Services (HCSS) may be eligible to receive support services through FFC by meeting all of the eligibility requirements as set out in the Funded Family Care Operational Policy https://www.health.govt.nz/system/files/documents/publications/funded-family-care-operational-policy-mar16.pdf These criteria include core eligibility requirements (eg, over 18 and the following secondary FFC criteria: ▪ the disabled person is assessed as not being able to remain at home if they could not employ a family carer because: ▪ the disabled person is assessed as having high or very high disability-related needs and they would not be able to remain supported in their chosen living environment(s) if they could not employ their parent(s) or resident family/whānau member(s) to provide them with some or all of their personal care and household management supports, and/or ▪ the disabled person is assessed as having high or very high disability-related needs and meeting these needs prevents their chosen parent(s) or resident family/whānau carer(s) from working in alternative full-time employment.	DHBs paid family care policies enable people aged 18 years and over, who are eligible to receive publicly funded Health of Older People (HOP), Mental Health and Addiction (MH&A) and Long Term Support-Chronic Health Conditions (LTS-CHC) services, to receive their allocated personal care and home management supports from a paid family member (not including spouses and partners and parents of children under 18 years) through a contracted provider.	ACC provides attendant care where necessary and appropriate to assist in restoring a claimant's independence to the maximum extent practicable. ACC supports attendant care provided by contracted agencies, non-contracted agencies, private carers and family members (complementary to a client's natural support networks).

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Key elements of policy	Ministry of Health, 'Funded Family Care'	DHBs, 'Paid family care'	ACC, 'attendant care' usually in relation to serious injuries
Services funded	Home-based support services only (ie, personal care, household management).		Attendant care, and home help and child care can also be funded and provided by family members. ACC can also support community participation and access activities.
Carer eligibility – relationship to person	Resident family member as outlined in Part 4A (spouses, civil union, *de facto* partners or parents of children under 18 excluded).		ACC does not restrict relationship eligibility, any family member can provide attendant care (client choice).
Pay rate	Adult minimum wage.	Wage negotiated with provider.	Family member can be paid directly at private non contracted rates, or employed by contracted agencies and paid by the agency.
Funding mechanism	Notice under Section 88 of the Health and Disability Act.	Provider employment contract.	Paid to client to pay family member or can be paid directly to family member at client's request. ACC deducts Withholding Tax from the payments.
Funding limit	There is no limit on how many hours of FFC can be allocated to the individual. There are limits however on the hours a family member can be employed ie, 40 hrs/ week (exceptions considered).	DHBs may limit the maximum hours of paid home based support services to not exceed the DHB cost of residential care.	No limits, but ACC will talk to the client and family about reasonable expectation of working week, burden of care and role responsibilities.
Payments • ***employment***	Disabled person employs resident family member via contract.	Provider employs family carer via contract.	Employment relationship decided by injured person and family member. Carer is generally engaged under contract for services arrangement.
• ***performance***	Disabled person's standard.	Provider standard.	Under a private arrangement, the client sets standards. If family member is employed by an agency, the agency is responsible for performance.
Service access • **assessment**	Ministry NASC.	DHB NASC.	Referral from ACC to contracted independent assessors for needs assessment.
• **eligibility decision**	Ministry NASC.	DHB NASC.	ACC.
• **service set up**	Host agent (FASS).	DHB NASC or contracted provider.	Client and/or family.

Terms:
ASD – Autism Spectrum Disorder

FASS – Funding Advisory & Support Services[1] are a not-for-profit NGO contracted by the Ministry, and they provide advice and tools for people to assist with their responsibilities under the Funded Family Care Operational Policy[2].

Medically fragile – children with high health needs and/or multiple impairments whose health status has not yet stabilised and for whom a physical, sensory and/or intellectual disability with ongoing support needs has not been identified.

NASC - refers to a Needs Assessment and Service Coordination process (eg, assessment of eligibility and support needs) which may be provided by a separate organisation.

[1] https://www.fass.org.nz/resources
[2] https://www.health.govt.nz/publication/funded-family-care-operational-policy

Appendix C: Enabling Good Lives (EGL) Vision and Principles

In 2011, a group of people from the disability community prepared a report for the Minister of Disability Issues - Enabling Good Lives (EGL). The report included a vision and principles for a transformed disability support system.

Vision

1. In the future, disabled children and adults and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports.
2. Disabled people and their families and whānau, as appropriate, will be able to say:
    a. I have access to a range of support that helps me live the life I want and to be a contributing member of my community.
    b. I have real choices about the kind of support I receive, and where and how I receive it.
    c. I can make a plan based on my strengths and interests.
    d. I am in control of planning my support, and I have help to make informed choices if I need and want it.
    e. I know the amount of money available to me for my support needs, and I can decide how it is used – whether I manage it, or an agency manages it under my instructions, or a provider is paid to deliver a service to me.
    f. The level of support available to me is portable, following me wherever I move in the country.
    g. My support is co-ordinated and works well together. I do not have to undergo multiple assessments and funding applications to patch support together.
    h. My family, whānau, and friends are recognised and valued for their support.
    i. I have a network of people who support me – family, whānau, friends, community and, if needed, paid support staff.
    j. I feel welcomed and included in my local community most of the time, and I can get help to develop good relationships in the community if needed.
3. The government will get better value for the funding it provides because:
    a. the new approach will generally provide better quality of life outcomes for disabled people and their families and whānau (based on international evidence);
    b. less money will be spent on providers premises and more on support;
    c. government agencies will work more closely together, for example using shared way to determine support needs, integrated funding and contracts.

Acknowledging the Relationship between Māori and the Crown under the Treaty of Waitangi

4. The Treaty relationship as set out in the New Zealand Disability Strategy, and the Māori Disability Action Plan, will continue to be core to this future vision. It will be based on three key principles of participation at all levels; partnership in delivery of support, and the protection and improvement of Māori wellbeing.

Principles

- *Self-determination:* Disabled people are in control of their lives.
- *Beginning early:* Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support

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disabled children to become independent, rather than waiting for a crisis before support is available.

- *Person-centred:* Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.
- *Ordinary life outcomes:* Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.
- *Mainstream first:* Disabled people are supported to access mainstream services before specialist disability services.
- *Mana enhancing:* The abilities and contributions of disabled people and their families and whānau are recognised and respected.
- *Easy to use:* Disabled people have supports that are simple to use and flexible.
- *Relationship building:* Supports build and strengthen relationships between disabled people, their whānau and community.

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