Regulatory Impact Statement

Government Response to the Family Carers Case

Agency Disclosure Statement

This Regulatory Impact Statement has been prepared by the Ministry of Health (the Ministry).

It provides an analysis of options to respond to the Courts' decisions on the Family Carers case and options for managing risks associated with the Government's preferred response.

The Courts found that the Ministry's current policy of not paying family carers (parents, spouses and resident family members) to provide disability support services to disabled family members does not comply with the New Zealand Bill of Rights Act 1990 because it is unjustifiable discrimination on the basis of family status (Ministry of Health v Peter Atkinson (on behalf of the Estate of Susan Atkinson) & Others (O'Regan P, Glazebrook, France, Harrison and White JJ), 14 May 2012, [2012] NZCA 184). The Government needs to agree on and implement a response to the Tribunal's declaration before the Order suspending its effect is lifted, which could be as early as May 2013.

The Government has decided that the immediate focus of its response will be on the issues that directly arise from the Courts' decisions, which is the discrimination that arises within Ministry of Health funded home and community support services (HCSS) through not paying parents and resident family members to provide these services to their adult disabled family members. Although the Courts said that the policy as a whole was discriminatory, the Family Carers case specifically addressed the existing policy's prohibition on parents providing HCSS to their adult sons and daughters. This means that the Government can be certain that it needs to change its policy to address these circumstances.

This Statement includes analysis of policy options for addressing this discrimination. A key constraint in the analysis was the poor information available to estimate the number of family carers who would be eligible for payment under each of the options and the proportion of eligible family carers in each option who would choose to be paid. The cost analysis therefore used two approaches, each of which has its own uncertainties, to estimate costs and to provide a measure of the accuracy of the estimation.

The Government has decided on a preferred response to the Courts' decisions but recognises that there are a number of significant risks and issues, including legal risks, associated with this response. This Statement therefore includes advantages and disadvantages of proceeding to implement the preferred response and options for reducing the associated risks, including legislative options.

Don Gray
Deputy Director-General
Policy Business Unit

15.03.13

Status quo and problem definition

1. For over 20 years, the Ministry of Health (the Ministry) and its predecessors have operated a blanket policy of not paying family carers (parents, spouses and resident family members) for the support that they provide to disabled family members receiving disability support services (DSS)[1] funded through the Vote Health National Disability Support Services appropriation. In January 2010, the Human Rights Review Tribunal (the Tribunal) declared that this policy resulted in unjustified discrimination that is inconsistent with Section 19 of the New Zealand Bill of Rights Act 1990 (NZBORA) (see: Atkinson & others v Ministry of Health [2010] NZHRRT 1). Following the declaration that this policy was discriminatory, the Tribunal, by consent, made an Order suspending the effect of the declaration until further order of the Tribunal. The period of suspension the Ministry sought was 12 months from the date of determination of all appeals.

2. The Crown subsequently appealed the Tribunal's decision to the High Court and the Court of Appeal. Both Courts, however, upheld the declaration (see: Ministry of Health v Peter Atkinson (on behalf of the Estate of Susan Atkinson) & Others (O'Regan P, Glazebrook, France, Harrison and White JJ), 14 May 2012, [2012] NZCA 184). The Government elected to not appeal to the Supreme Court, which means that the Tribunal's declaration stands and the Ministry must now either change its blanket policy of not allowing family carers to be paid for providing disability support, or it must enshrine the policy in legislation (or both). The date by which the Ministry's policy must be changed is determined by the date that the Suspension Order is lifted. This means that the policy needs to change with some urgency. The plaintiffs agreed that they would not initiate action to lift the Suspension Order before May 2013, but even in the absence of the plaintiffs taking this step, if an extension beyond 12 months is required, the Crown should seek such an extension.

3. The Family Carers case specifically addressed the existing policy's prohibition on parents providing HCSS[2] to their adult sons and daughters. This means that the Government can be certain that it needs to change its policy to address these circumstances. In the absence of compelling policy reasons to do otherwise, the Government is adopting a conservative approach to addressing the broader implications of its policy.

APPROACH TO THE ISSUES IN THIS DOCUMENT

4. This document outlines the key policy issues, summarises the analysis of options, and makes recommendations to Government on how to respond to the Court findings in the Family Carers case. These are laid out in the following order:

    - ***Objectives***
        - Immediate objectives
        - Cabinet's preferred response
    - ***Regulatory Impact Analysis***
        - Payment options and analysis
        - Targeting options and analysis
        - Financial costs of combined options
        - Recommended option
        - Significant legal issues and risks with the preferred response
        - Legal risks arising from other agencies' policies
        - Potential fiscal risks of broadening the scope and introducing similar allocation rates
        - Options for managing the risks of implementing the preferred response
        - Advice on whether to implement the preferred response
        - Options for dealing with the broader implications

[1] The Ministry funds a range of disability support services including home and community support services for people who meet DSS eligibility criteria. Other examples include residential services, carer relief and respite services, and supported living services.

[2] HCSS provide assistance with personal cares (such as showering and dressing) and household tasks.

- ***Consultation***
  - Approach and outcomes
- ***Conclusion and recommendations***
- ***Implementation***
  - Legislative options
  - Dealing with existing and future claims
- ***Monitoring, evaluation and review***

Objectives

RESPONDING TO ISSUES ARISING FROM COURT DECISIONS

5. The overall objective is to develop a response to the implications of the Courts' decisions. These implications arise across the range of family relationships and services where there is a significant risk that discrimination may arise. These relationships and services include:

   - parents and other resident family members of disabled adults
   - other family relationships, particularly spouses and parents of young disabled children
   - disability support services funded by the Ministry
   - support services funded by District Health Boards (DHBs)
   - [redacted in reliance on s 9(2)(h) OIA]

6. Due to the short time frame available to agree on and implement a new policy, the Government has decided to focus its immediate response on the issues most directly arising from the Courts' decisions, which is the discrimination arising from not allowing parents and resident family members to be paid for providing Ministry-funded HCSS to adult disabled family members.

7. Specific objectives include that the policy:

   - supports positive outcomes for family carers and disabled people
   - is legally defensible (does not unjustifiably discriminate under the NZBORA or the Human Rights Act)
   - can be implemented by the time that the Suspension Order is lifted, or soon after
   - is affordable (Vote: Health costs met within Vote Health baselines and its operating allocation for 2013)
   - supports Government's strategic directions (those for disability support and broader policy objectives).[3]

CABINET DECISION ON PREFERRED RESPONSE

8. On 12 December 2012, Cabinet Social Policy Committee agreed, subject to further advice, that the Ministry's policy be changed to allow adult disabled people (18 years or over) to employ their parents, or other adult family members (other than spouses) who reside with them, to provide them with HCSS. This policy change would not allow the spouses of disabled adults or parents (or other resident family members) of disabled children, to be paid to provide HCSS.

9. The preferred response allows eligible family carers in the following situations to be paid for providing up to forty hours[4] of HCSS per week:

   - very high need situations (e.g. where the family situation is at risk of breakdown, jeopardising the disabled person's ability to remain living in their family home)

[3] Strategic directions for disability support include promoting disabled people's choice, control and flexibility over the support they receive to achieve their goals.

[4] The 40 hour cap is on HCSS provided by paid family carers. Disabled people assessed as needing more than 40 hours of HCSS per week will be able to access additional HCSS through contracted providers.

- high need situations (e.g. where the family carer's caring responsibilities are so significant that they are unable to work in another job outside the home)
- in other exceptional circumstances where there is a very good case for paying a family carer (e.g. where no other suitable carer is available).

10. The mechanism for paying eligible family carers under the preferred approach is through a Section 88 Notice issued under the New Zealand Public Health and Disability Act 2000 (NZPHDA) at a payment rate that is based on the minimum wage plus associated employment costs (about $16 per hour). Consultation findings informed Cabinet's preliminary decision to include the following additional elements in the implementation of the future policy:

    - independent support for the disabled person who is considering employing family carers
    - independent monitoring of disabled people's quality of life when family carers are paid
    - strengthening the current principles-based approach used by Needs Assessment and Service Coordination organisations (NASCs)[5], to improve consistency and transparency in how the level of unpaid support that family carers are able to provide is determined.

Regulatory impact analysis

Key choices - how to pay and approach to targeting

11. With Cabinet approval, the Ministry carried out a seven-week public consultation process between September and November 2012 to help inform the development of the future policy that will apply to Ministry funded HCSS. The key questions that informed the consultation and the main themes that emerged from an independent review of the findings are included in the consultation section of this paper (refer p24).[6] These findings and further analysis by officials clarified that the key choices affecting the Government's response were how family carers should be paid and the approach to targeting.

HOW TO PAY

12. The consultation document outlined two main options for how family carers could be paid - as employees or by an allowance. It also included an alternative approach of a family carer's payment administered through the welfare system. Further analysis led to this option being discounted because: it would not recognise the specific work family carers do; it would involve significant costs and delayed implementation (as substantial changes would be needed to government agencies' systems); and, it was the option least favoured by the public (only one in four submitters supported this approach).

13. After the consultation process, officials identified an additional option that involved elements of employment and payment by an allowance. The three broad options analysed by officials were therefore:

    - Option One: Family carers paid as employees
    - Option Two: Family carers paid an allowance
    - Option Three: Family carers paid as employees through an alternative payment mechanism under Section 88 of the NZPHDA.[7]

14. The existing policy of not paying family carers of disabled people to provide disability support was used as the 'base case' against which the various options were assessed. The criteria used to assess each option included: impact on family carers and disabled people; legal defensibility; feasibility to

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[5] NASCs are contracted by the Ministry to: assess disabled people's eligibility for DSS; assess what supports they need to help achieve their goals; and to allocate Ministry-funded supports and facilitate access to other support.

[6] The consultation document and the independent review of submissions are available on the Ministry's website: http://www.health.govt.nz

[7] Under Section 88 of the NZPHDA, the Crown or a district health board (DHB) gives notice of the terms and conditions on which it will make a payment. Acceptance by the person of the payment constitutes their acceptance of the terms and conditions, which may be enforced by the Crown or DHB.

implement within the time available; affordability; and, consistency with Government's strategic directions. The following section briefly describes and summarises the analysis of each option. The analysis is also presented in Tables One and Two below.

Option One – Allow family carers to be employed

15. This option would remove the restriction on parents and resident family members of adult disabled people allocated Ministry-funded HCSS being employed to provide HCSS that are above the level they are willing to provide unpaid. The family carer would be employed through the Ministry's existing systems (contracted provider or individualised funding (IF)).[8] The hourly rate they would receive would depend on their method of employment.[9] Analysis of the consultation findings showed that just over one in three submitters supported payment through employment as a means of giving carers greater status and ensuring that family carers were treated equitably in comparison with non-family carers.

16. Paying family carers as employees recognises their contribution by giving them status as an employee. It also gives them the opportunity to acquire a formal work record. For disabled people, this option supports choice and flexibility in the support they receive as it gives them the ability to employ a family carer under IF. It also incorporates mechanisms for assuring service quality and safety (e.g. meeting providers' training requirements or quality monitoring by IF host providers). Some family carers and disabled people may, however, be discouraged from taking up this option due to concern either about having to meet employment obligations[10] or about employment undermining their family relationships. Paying family carers as employees complies with the NZBORA and general employment law and would require relatively minor changes to Ministry systems. Though the costs of setting up this option are expected to be relatively low, the Government would have significantly less control over costs than under the other options because it would have to ensure that the hourly rate paid to contracted providers and under IF is sufficient to ensure that at least the minimum hourly rate can be paid to family carers, once overheads are deducted. It could be feasible to implement this option by May 2013 if policy decisions were made quickly.

Option Two – Pay family carers an allowance

17. Under this option, parents and resident family members of adult disabled people allocated Ministry-funded HCSS would be able to be paid an allowance to provide HCSS that are above the level they are willing to provide unpaid. The allowance could be set at a similar level to the hourly rate that support workers typically receive and the Government would not incur the overheads that are incurred by contracted providers (e.g. training, administration, monitoring). Analysis of the consultation findings showed that more submitters (almost one in two) preferred payment through an allowance than employment as it was considered to be flexible and easy to administer.

18. Advantages of this option for family carers and disabled people are that it is: relatively easy for carers to access (as they would not have to meet employers' criteria); likely to have less adverse impact on family relationships than employment; and likely to provide more flexibility to respond to individual families' situations than employment under contracted providers. Disabled people, however, would not have the option of being the employer under this approach, potentially giving them less control over the support provided. The lower administrative burden of this approach could lead to high uptake and increased demand putting pressure on available funding. This option also presents considerable design and system challenges such as creating assessment, payment and quality monitoring systems but, once established, would be relatively easy to administer. Legislation would be needed to be clear that an employment relationship does not exist. The system and legal implications mean that it would not be possible to implement this option by May 2013.

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[8] IF is a mechanism for funding HCSS which enables disabled people to directly employ carers and have more choice and control over the support they receive. People using IF are supported with setting up and administering these arrangements by IF host providers.

[9] Rates vary under different employment arrangements.

[10] This was a particular concern raised by some older carers in the consultation process.

Option Three – Employ family carers through a Section 88 Notice

19. This option involves paying adult disabled people allocated Ministry-funded HCSS an allowance under Section 88 of the New Zealand Public Health and Disability Act 2000 (NZPHDA) and allowing them to use this funding to employ family carers. A Section 88 Notice would allow the Minister of Health to specify the terms and conditions that apply when people accept payments made in accordance with the Notice. As under Option Two, the allocation could be set at the same rate as the rate most carers employed through contracted providers or under IF receive, although paying the higher rate would have significant fiscal implications (discussed later).

20. This option may have similar impacts on family relationships to the first option, but offers families more flexibility than simply removing the restriction on people being employed. As employer, the disabled person would have more say over the support provided than under the allowance option. A Section 88 Notice would enable the Government to exercise considerable control over the parameters of paid family care as family carers and disabled people would have to agree to the specific terms and conditions that apply. This is likely to aid budget management and monitoring of the quality of services provided. Some system development would be required, but less than would be the case for an allowance, as the Ministry already uses Section 88 Notices. Although it is unlikely to be possible to implement this option by May 2013, there is a reasonable likelihood that it could be implemented later in 2013.

TABLE ONE: ANALYSIS OF OPTIONS FOR HOW FAMILY CARERS ARE PAID TO PROVIDE HCSS					
Option	**Impact on family carers and disabled people**	**Legal defensibility** **[Contents of this column legally privileged]**	**Feasibility to implement in time available**	**Affordability – costs able to be met within Vote Health allocation (refer Table Three for estimated costs)**	**Consistency with Government directions**
Employment	• Gives carers status and opportunity to acquire a formal work record • Supports disabled people's choice and flexibility of support provided as will be able to employ family carers under IF • Employment obligations and concern about effects on family relationships may deter some from taking up this option • Provides level of assurance of service quality and safety through contracted HCSS/IF host provider monitoring	Significantly reduces legal risks as complies with the NZBORA and general employment law	Could be feasible to implement by May 2013 if policy decisions were made quickly (relatively minor changes needed to existing Ministry systems)	• Highest cost option on a per person basis as allocation includes overheads for contracted providers and disabled people using IF • Government will have significantly less control over costs than under the other options because it will have to ensure that the hourly rate allocated is sufficient to ensure that employees receive at least the minimum wage once overheads are deducted	Consistent with Government's strategic directions for disability support – can operate under IF framework
Allowance	• Relatively easy for family carers to access as would not have to meet employment criteria • Avoids risks to family relationships associated with employment • Likely to provide more flexibility to respond to individual families' situations than employment under contracted providers • Potentially gives disabled people less choice and control over support provided as not the employer under this approach • Offers less assurance of quality and safety of support than provided through formal mechanisms under other options	Would require legislation to be clear that an employment relationship does not exist	Not feasible to implement by May 2013 - longer lead-in time required to implement than under the employment option (requires new assessment, payment and quality monitoring systems)	• Less costly for Government on a per person basis than employment option as allocation does not need to include overheads, but would involve significant initial set-up costs (new administrative and payment system within the Ministry) • Ease of access and lack of formal employment obligations likely to result in higher uptake and associated cost pressures	Choice and flexibility consistent with Government's strategic directions but, as the disabled person is not the employer under this option, offers disabled people less control over the support they receive than the other options provide

Section 88 Notice	• Easier for family carers to access than employment through a contracted provider • Carers will receive a pay rate similar to that received by most other carers employed through contracted providers • A form of employment, therefore can expect similar impacts on family relationships to the first option • Offers more flexibility to respond to individual situations than employment through a contracted provider but less than under the allowance option (as bound by terms and conditions in the Notice) • Provides level of assurance of service quality and safety as the terms of Notice can specify monitoring and accountability requirements	Would not require legislation to implement	Not feasible to implement by May 2013 but reasonable likelihood that could be implemented later in the year	• Similar per person cost to allowance option but initial set-up costs (to amend assessment, contracting and payment systems) would be significantly less than under the allowance option • Allows Government to have more control over on-going costs than under employment	Allows Government to build in terms and conditions that support its strategic directions

HOW TO TARGET

21. The Government has indicated that the cost of paying family carers of people receiving Health funded supports will need to be met from within Vote Health's existing funding,[11] which means that difficult trade-offs will need to be made. The consultation document outlined a range of different targeting options. Analysis of the consultation findings showed that there were divided views on whether targeting should apply. However, if targeting were to be implemented, there was support for targeting situations where family carers are caring for: disabled people with high and complex needs and/or where there are significant risks to safety and wellbeing (two in three submitters); those living in remote locations where there is limited access to carers (one in two submitters); and, where a person has specific cultural or religious needs that cannot be met by a non-family carer (four in ten submitters).

22. After more detailed analysis of submissions and further work on costings, officials identified three possible targeting options. These included:

    - Option A: Tight targeting to very high need situations
    - Option B: Medium targeting to high and very high need situations
    - Option C: No targeting.

    The following section briefly describes and summarises the analysis of each of these options. It also addresses how exceptional circumstances under any targeted approach could be treated.

Tight targeting - Pay family carers supporting disabled people in very high need situations

23. This would involve targeting payment to families where the disabled person's ability to remain living at home is under threat because their family situation is at risk of breakdown, often because of multiple factors, including the extent of the family carer's caring responsibilities. The Ministry estimates that there are approximately 1,100 people in this situation.[12]

24. Targeting this group would support families potentially most at risk (in very high needs situations) and is likely to be affordable as there are very limited numbers in scope. The disabled person and the family carer would be likely to experience improved well-being, have support to maintain the stability of the family unit, have a reduced risk of abuse (where family stress exacerbates this risk), and be able to continue to live in their community of choice. There is some risk that targeting based on need may give rise to an indirect claim of discrimination based on treating different kinds or severity of disability differently. But, as targeting to those with high needs is supportable both for fiscal reasons and because of the greater impacts on family carers of those disabled people with higher needs, any differential treatment based on need is likely to be justifiable. Disadvantages of this approach include creating an incentive for some families to present as vulnerable and potentially applying a 'short-term fix' to situations where more fundamental intervention is needed. There would be operational challenges in developing the criteria for this target group and in designing and implementing a process for identifying and working with these families. Implementation may also require cross-agency data sharing.

Medium targeting - Pay family carers supporting disabled people in high and very high needs situations

25. This would involve targeting payment to the group outlined above and also to family carers supporting disabled people with such high support needs that meeting those needs means that a

[11] Vote Health funding is the total funding allocated by government for Ministry and DHB funded services.

[12] Estimates of the number of people are based on data from Statistics New Zealand's 2006 Disability Survey on the number of people receiving personal care from informal carers and Ministry of Health data on a known population of people it already supports receiving high and very high support packages. The estimates include adjustment for population growth since 2006, with the Ministry data used to determine the proportion of carers who receive high and very high support packages.

family carer who wishes to work in a job outside the home is unable to do so. The Ministry estimates that there are approximately 1,600 disabled people in this situation.[13]

26. Targeting this group would support family carers and disabled people in high and very high need situations, is likely to be affordable (as the scope of the eligible group is relatively narrow), and would be consistent with feedback from consultation on the minimum scope of the future policy. As with tight targeting, there is some risk that this approach may give rise to an indirect claim of discrimination based on treating different kinds or severity of disability differently but any differential treatment based on need is likely to be justifiable. A disadvantage of this approach is that family carers who largely meet these criteria but are able to work very limited hours may not be eligible to be paid, resulting in some family carers exiting other employment to enable them to be paid as a family carer. The Ministry plans to do further policy work to identify whether the new policy should allow family carers who are able to work only very limited hours outside the home to be employed as paid family carers. Another disadvantage of this approach is that some people's eligibility or payment rate for the Domestic Purposes Benefit – Care of Sick or Infirm (DPB-CSI) will be affected.[14]

27. Operationally, developing guidelines on how to determine that a family carer is unable to work due to caring responsibilities (as opposed to other factors) is feasible but will be challenging.

No targeting – Pay all family carers

28. If no targeting were applied, any family carer of a DSS eligible person allocated HCSS would be able to be paid to provide these services to adult disabled family members. The Ministry estimates that there are approximately 5,400 disabled people in this situation.

29. Such universal eligibility to be paid (subject to meeting employment or allowance criteria) would address the discrimination found by the Courts and therefore significantly reduce the risk to the Government of further litigation. This approach would be considerably less complex to implement than a targeted approach but would be significantly more costly, as people who currently do not approach DSS NASCs for assessment because their family carers cannot be paid, might now do so and access funded support. Higher numbers accessing paid family care would also result in a lower rate of payment to family carers. An associated shift from contracted non-family carers to family carers could also affect the viability of some providers, especially smaller providers in low population areas, reducing choice for some disabled people.

Exceptional circumstances

30. If a targeted approach is adopted, there are likely to be some particular circumstances arising where people's situations fall outside the targeting criteria but there is a very good case for family carers to be paid to provide care. An example would be where a disabled person is living in a remote rural area and there is no alternative non-family carer available to provide support. An explicit exceptional circumstances provision could be developed but this could lead to an unintended broadening of the range of family carers paid over time because of the considerable uncertainty about what constitutes 'exceptional circumstances'. An alternative would be to allow a degree of flexibility in operational policy to provide for these types of situations.

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13 This number includes the estimated 1,100 people in very high need situations included in the 'tight targeting' estimate.

14 This would not affect eligibility for, or the level of, New Zealand Superannuation older family carers receive.

TABLE TWO: ANALYSIS OF TARGETING OPTIONS					
Option	**Impact on family carers and disabled people**	**Legal defensibility** **[Contents of this column legally privileged]**	**Feasibility to implement in time available**	**Affordability – costs able to be met within Vote Health allocation (refer Table Three for estimated costs)**	**Consistency with Government directions (and broader implications for Government)**
Tight targeting – pay in situations where the disabled person's ability to remain living in the home is under threat because their family situation is at risk of breakdown	• Supports families/whānau most at risk • For disabled people, families, whānau in very high need situations: – improved well-being – support to maintain family unit – less risk of abuse – able to continue to remain living in their community of choice • No benefit for those who are not in very high need situations but whose life choices are significantly constrained by the extent of their caregiving responsibilities	Though targeting based on level of need is not a prohibited ground of discrimination under the NZBORA, some risk that it may give rise to an indirect intra-ground disability discrimination claim. However, any differential treatment based on need is likely to be justifiable	Feasible but will be operational challenges in developing the criteria for this target group and designing and implementing a process for identifying and working with these families	Likely to be affordable as very limited numbers in scope (est. 1,100 people)	• Paying family carers in these situations may improve family circumstances in the short-term but risk masking more fundamental underlying issues that are contributing to family stress • Potential implications for cross-agency data sharing
Medium targeting – pay in both the above situations and also in situations where family carers are supporting disabled people with such high support needs that they are unable to work in another job outside the home	• Supports families most at risk and also those whose life choices are significantly constrained by the extent of their caregiving responsibilities • Benefits as above for these groups • No benefit for those in medium to low need situations	As above	Feasible but will be operational challenges in developing guidelines on how to determine that a family carer is unable to work due to caring responsibilities (as opposed to other factors)	Likely to be affordable as relatively low numbers in scope (est. 1,600 people)	Consistent with public expectations, expressed through consultation process, of minimum acceptable scope of a targeted policy
No targeting – any family carer of a DSS eligible person allocated HCSS can be paid	• All family carers providing, and disabled people receiving, Ministry-funded HCSS have the choice of paid family care irrespective of their circumstances • Higher numbers accessing paid family care would result in a lower rate of payment to family carers • Reprioritisation of funding could have a significant impact on DSS levels	No legal risks	Easiest of options to implement	Significantly more expensive than other options as more people would be attracted into the DSS system (those who prefer family as carers - est. 5,400 people)	Shift from contracted non-family carers to family carers could affect the viability of some smaller HCSS providers potentially leading to reduced access to home and community support

FINANCIAL COSTS OF COMBINED OPTIONS

31. Nine options arise from combining the payment and targeting options. The fiscal costs assume a cap of 40 hours per week paid family care - generally equivalent to a full working week. This cap is intended to help ensure that the future policy is affordable and that the paid care arrangements are sustainable and in family carers' and disabled people's best interests.

32. The costs of each option are summarised in Table Three below.[15] These estimates include the direct cost to Vote Health and assume that any savings from reduced welfare benefit payments will be used to offset costs to Vote Health. The expected increase in income tax revenues from paying family carers is not reflected in these estimates.

TABLE THREE: ESTIMATED COSTS TO VOTE HEALTH (NET OF REDUCTION IN BENEFIT PAYMENTS) OF OPTIONS FOR RESPONDING TO THE FAMILY CARERS CASE

Targeting approach	**Payment Options (estimated per year)**		
	Option 1: Allow family carers to be employed	**Option 2: Pay family carers an allowance**	**Option 3: Employ family carers through a Section 88 Notice**
Option A: Tight targeting: pay family carers in very high needs situations	**Option 1A** *Mid-point $26 M* Range: $22-30 M	**Option 2A** *Mid-point $15 M* Range: $11-20 M	**Option 3A** *Mid-point $15 M* Range: $11-20 M
	Family carers of 1,100 disabled people are paid		
Option B: Medium targeting: pay family carers in high and very high needs situations	**Option 1B** *Mid-point $40 M* Range: $35-46 M	**Option 2B** *Mid-point $23 M* Range: $17-30 M	**Option 3B** *Mid-point $23 M* Range: $17-30 M
	Family carers of 1,600 disabled people are paid		
Option C: No targeting: pay all family carers providing Ministry HCSS	**Option 1C** *Mid-point $65 M* Range: $56-75 M	**Option 2C** *Mid-point $40 M* Range: $35-46 M	**Option 3C** *Mid-point $40 M* Range: $35-46 M
	Family carers of 5,400 disabled people are paid		

RECOMMENDED OPTION – EMPLOYMENT THROUGH SECTION 88 NOTICE AND MEDIUM TARGETING

33. Option 3B in the table above appears to achieve the most appropriate balance when assessed against the criteria of: impact on family carers and disabled people; legal defensibility; feasibility to implement in the time available; affordability; and consistency with Government directions. This option involves paying adult disabled people eligible for Ministry funded HCSS, who have high and very high needs, an allowance under Section 88 of the NZPHDA to employ family carers.

34. This is the preferred option because:

- disabled people as employers will have more control and influence over the support they receive than if family carers were paid directly, and flexibility within the terms and conditions of the Notice
- family carers are able to gain the benefits of employment (a work record, employment status) and to be paid an hourly rate that is similar to that received by most carers employed through contracted providers

[15] There are limitations to these estimates. There is a greater than usual degree of uncertainty around them as: they rely on drawing inferences from existing data sets that were gathered for different purposes; in some cases they rely on self-reporting; and, it is very difficult to estimate the extent to which family carers may elect to become paid under any of these options. The welfare benefit impacts are also difficult to estimate because of uncertainty about the number of eligible carers.

- this arrangement will be relatively easy to administer for all parties once the initial assessment has been completed and contractual arrangements are in place
- targeting people in high and very high needs situations is consistent with carer and disability communities views (expressed through the consultation) that targeting should recognise those most in need and be based on complexity of care
- it reduces legal risks as it responds directly to the Courts' finding that family carers were discriminated against in employment and does not target on any grounds that could be considered unjustifiable discrimination under the NZBORA
- it is feasible to implement close to the date from which the Suspension Order could be lifted
- the costs of implementing this approach (mid-point estimated cost of $23 million per year after tax) are likely to be able to be sustained from within the overall Vote Health allocation
- it supports the Government's management of quality and safety of publicly funded care and budget management through specifying the terms and conditions within the Notice
- it is consistent with Government's strategic directions for disability support.

REASONS FOR DISCOUNTING OTHER OPTIONS

Payment options

35. The option of payment through employment was discarded because it would result in significantly higher costs than the other options. The mid-point estimated cost of paying family carers through employment in high and very high need situations is $40 million per year (compared with $26 million per year under tight targeting, or, $65 million per year under the 'no targeting' option). This compares with a mid-point estimated cost under payment by an allowance or under a Section 88 Notice of $23 million per year (compared with $15 million per year under tight targeting, or, $40 million per year if no targeting is applied).

36. The option of payment by an allowance, though involving operational costs similar to those under the Section 88 option, was also discarded. This is because it would involve significant initial set-up costs (developing new assessment and payment systems) and ease of access would be likely to result in higher uptake and considerable cost pressures. It would also not be feasible to implement payment through an allowance by the time the Suspension Order is lifted or soon after.

Targeting options

37. The option of only paying family carers in very high needs situations ('tight targeting') was discounted because the access threshold was considered to be too high - family carers with such significant caring responsibilities that they are unable to work in another job outside the home would not have the opportunity to be paid. The 'no targeting' option was discounted on the basis that it would be significantly more expensive ($40 - $65 million per year depending on the payment option chosen).

SIGNIFICANT LEGAL ISSUES AND RISKS ARISING FROM THE PREFERRED RESPONSE

[Paragraphs 38-41 legally privileged]

38. [redacted in reliance on s 9(2)(h) OIA]

39. [redacted in reliance on s 9(2)(h) OIA]

40. [redacted in reliance on s 9(2)(h) OIA]

41. [redacted in reliance on s 9(2)(h) OIA]

42. The mid-point estimate of extending the preferred policy to pay non-spouse resident and non-resident family members for caring for their adult disabled family members who have high or very high needs, and whose support is funded through DHBs, is $41 million a year. (Refer Table Four below for further analysis).

TABLE FOUR: IMPLICATIONS OF INCLUDING OR EXCLUDING FAMILY CARERS OF PEOPLE RECEIVING DHB-FUNDED HCSS					
Option	**Impact on family carers and disabled people**	**Legal defensibility [Contents of this column legally privileged]**	**Feasibility to implement in time available**	**Affordability – costs able to be met within Vote Health allocation**	**Consistency with Government directions**
Include	• Adults receiving DHB funded HCSS have access to paid family care • Enables family carers in these situations to earn an income through providing care, receive better recognition for their caring role and potentially come off welfare benefits	[redacted in reliance on s 9(2)(h) OIA]	Not feasible in timeframe available – requires further consultation and policy development	The mid-point of estimated costs is $41 million per annum[16]	Might help support strategic direction to support older people to live in their own homes for longer (further policy work needed to determine this)
Exclude	• People with similar impairments and support needs to those receiving Ministry-funded supports are treated differently • Constrains the level of choice and control people receiving DHB-funded HCSS have over the support they receive • Precludes family carers of people receiving DHB-funded HCSS from being able to earn an income through providing care, receive better recognition for their caring role and potentially come off welfare benefits	[redacted in reliance on s 9(2)(h) OIA]	Feasible	No impact on operating costs but potentially significant costs associated with defending Court cases.	No particular impact on strategic directions for these groups
Exclude in short term with option to include following further policy work	• No immediate benefit or certainty but does not preclude these groups from being paid in future, if further policy work indicates this is appropriate and affordable	[redacted in reliance on s 9(2)(h) OIA]	Feasible	• No immediate impact on operating costs • Additional costs in medium-term if policy work results in decision to allow paid family care for these groups (included in estimate for first option) - further work required to separate out specific costs	Dependent on whether further policy work leads to inclusion of these groups

[16] Does not include spouses or parents of children needing support.

43. Spouses of adult disabled people, parents and other resident family members do not have the option of being paid family carers despite many having extensive caring responsibilities. The views expressed through the consultation process indicate that, if Government excludes these groups from payment, it is highly likely that it will be faced with claims of unjustified discrimination under the NZBORA.

[Paragraphs 44-46 legally privileged]

44. [redacted in reliance on s 9(2)(h) OIA]

45. [redacted in reliance on s 9(2)(h) OIA]

46. [redacted in reliance on s 9(2)(h) OIA]

47. The mid-point estimate of the cost of extending the preferred policy to pay spouses and parents of children for providing HCSS to disabled family members (receiving Ministry or DHB funded support) is $46 million a year. (Refer Table Five below for further analysis).

TABLE FIVE: IMPLICATIONS OF INCLUDING/EXCLUDING SPOUSES AND PARENTS OF DISABLED CHILDREN PROVIDING VOTE HEALTH SERVICES					
Option	**Impact on family carers and disabled people**	**Legal defensibility** **[Contents of this column legally privileged]**	**Feasibility to implement in time available**	**Affordability – costs able to be met within Vote Health allocation**	**Consistency with Government directions**
Include	• Adult disabled people who prefer to have their partner providing support have access to paid family care • Disabled children who prefer to have their parent providing support (e.g. for trust or privacy reasons) have access to paid family care • Responds to Māori and Pacific communities' cultural norms • Enables family carers in these situations to earn an income through providing care, receive better recognition for their caring role and potentially come off welfare benefits • Risks a spouse or parent feeling obliged to become a full-time carer when this might not otherwise be their preference • Risks spouses or parents continuing to support a disabled person because they are paid, even though it is not in the disabled person's best interests • Risks relationships between spouses and between parents and children being undermined through placing too strong an emphasis on the role of the carer	[redacted in reliance on s 9(2)(h) OIA]	Not feasible in timeframe available - requires further consultation and policy development	The mid-point of estimated costs of allowing spouses and parents of disabled children, supporting Ministry or DHB funded clients, is $46 million per annum	• Consistent with strategic directions for disability support of increasing disabled people's choice and flexibility in the support they receive • Inconsistent with strategic directions of building up natural support (unpaid) networks
Exclude	• Limits choice for adult disabled people who may prefer to have their partner providing paid support • Limits choice for disabled children who may prefer to have their parent providing paid support • Precludes family carers in these situations from being able to earn an income through providing care, receiving better recognition for their caring role and potentially coming off welfare benefits	[redacted in reliance on s 9(2)(h) OIA]	Feasible	No impact on operating costs but additional costs associated with defending Court cases	• Inconsistent with focus on increasing disabled people's choice and flexibility in support they receive • Consistent with emphasis on building up natural support networks
Exclude in short-term with option to include later	No immediate benefit or certainty for family carers or disabled people but does not preclude these groups from being paid in	[redacted in reliance on s 9(2)(h) OIA]	Feasible	• No immediate impact on operating costs • Additional costs in medium-term	Dependent on whether further policy work leads to inclusion of these groups

(following further policy work)	future, if further work indicates this is appropriate and affordable			if policy work results in decisions to allow these groups to be paid (included in estimate for first option) - further work required to separate out specific costs	

Preferred policy of not paying family carers to provide any services other than HCSS

48. [redacted in reliance on s 9(2)(h) OIA]

TABLE FIVE: IMPLICATIONS OF INCLUDING/EXCLUDING FAMILY CARERS PROVIDING OTHER MINISTRY DSS					
Option	**Impact on family carers and disabled people**	**Legal defensibility** **[Contents of this column legally privileged]**	**Feasibility to implement in time available**	**Affordability – costs able to be met within Vote Health allocation**	**Consistency with Government directions**
Include	• Increases choice for all disabled people receiving Ministry funded DSS and their family carers • Increases risk of some disabled people and some family carers becoming 'trapped' in caring relationships • For some disabled people, would create barriers to acquiring the skills to live independently in the community	[redacted in reliance on s 9(2)(h) OIA]	Not feasible in timeframe available - requires further policy work to confirm implications and develop appropriate policy	May be minimal costs arising from changing the policy and allowing family carers to be paid for providing some services	• Where not contrary to specific service objectives, consistent with focus on increasing disabled people's choice and flexibility in the support they receive • Inconsistent with emphasise on building up natural support networks
Exclude	Limits choice for some disabled people and family carers	[redacted in reliance on s 9(2)(h) OIA]	Feasible	• No impact on operating costs • May be costs associated with defending Court cases (though expected to be less claims relating to this exclusion than to relationship exclusions)	• Inconsistent with focus on increasing disabled people's choice and flexibility in the support they receive • Consistent with emphasise on building up natural support networks
Exclude in short term with option to include some services after further policy work	No immediate benefit or certainty for those seeking payment but does not preclude payment to family carers providing these services in future, if further policy work indicates appropriate and affordable	[redacted in reliance on s 9(2)(h) OIA]	Feasible	No immediate impact on operating costs, but additional costs in medium-term if policy work results in allowing paid family care for other services (included in estimate for first option) - further work needed to separate out specific costs	Dependent on whether further policy work leads to inclusion of additional services

49. [redacted in reliance on s 9(2)(h) OIA]

Table Six: [redacted in reliance on s 9(2)(h) OIA]

Level of proposed payment, resulting in a differential treatment under the preferred response from allocating about $16 an hour[17] to pay family carers rather than the $25 an hour that providers are allocated to pay non-family carers

50. [redacted in reliance on s 9(2)(h) OIA]

51. Non-family carers can be employed through contracted providers or directly by disabled people under IF arrangements. Employers in these situations face overheads. This means that they cannot pay non-family carers providing personal care the full $25 an hour. (Providers are expected to cover business overheads and people using IF have a portion of their allocated funding 'top-sliced' to pay IF host providers).[18] They are, however, able to pay more than the minimum wage (currently $13.50 an hour, but rising to $13.75 an hour on 1 April 2013) that the approximately $16 an hour allocation is based on. The approximately $16 an hour allocation does not include the cost of making independent support available to disabled people considering, or receiving, paid family care.

52. Changing the rate paid to the different groups would be problematic. Reducing the amount of funding allocated for HCSS provided by non-family carers to about $16 per hour would be contrary to current contracts and mean that providers and disabled people using IF would not be able to cover their full costs. The alternative of increasing the amount allocated to parents and other resident family members to $25 per hour would increase the estimated cost of the response for Ministry funded HCSS by about $13 million a year, from $23 to $36 million a year. If this increase was also applied across all Vote Health funded support, the mid-point of estimated costs would increase by a further $49 million a year (with total costs across Vote Health increasing from $110 to $172 million a year). This means that the risk arising from the differential payments to family carers can only be effectively addressed through legislation or additional funding.

RISKS ARISING FROM OTHER AGENCIES' POLICIES [PARAGRAPHS 53-54 LEGALLY PRIVILEGED]

53. [redacted in reliance on s 9(2)(h) OIA]

54. [redacted in reliance on s 9(2)(h) OIA]

POTENTIAL FISCAL RISKS ASSOCIATED WITH THESE RISKS

55. The uncertainty about how the Courts would decide in any particular case creates significant potential financial risks for the Government. Table Eight below sets out the level of financial risk - up to $172 million per year for Vote Health funded services [redacted in reliance on s 9(2)(h) OIA]. These cost estimates are based on paying family carers who provide HCSS to people with high and very high needs and an allocation rate of $16 an hour.

TABLE EIGHT: ESTIMATED FISCAL RISKS ASSOCIATED WITH THE FAMILY CARERS CASE

Groups of carers	Mid-point estimated costs ($ million a year)		
	Ministry of Health	**DHBs**	**Combined**
Cost of implementing the preferred response across family carers and funders i.e. allocating disabled adults with high and very high needs $16 an hour employ family carers			
• Parents of disabled adult sons and daughters • Other family members of disabled adults	**23***	41	*64*
• Parents of disabled children • Spouses • Other family members of disabled children	21	25	*46*
Sub-total: cost of extending preferred policy	***44***	***66***	***110***

[17] The estimated cost will change as a result of changes to the minimum wage.

[18] IF host providers support disabled people with set-up and on-going administration of IF.

Additional cost of increasing family carer allocations from $16 to $25 an hour for people with high and very high needs			
• Parents of disabled adult sons and daughters • Other family members of disabled adults	13	23	*36*
• Parents of disabled children • Spouses • Other family members of disabled children	12	14	*26*
Sub-total: cost of increasing allocations	***25***	***37***	***62***
Potential fiscal cost for Vote Health	**69**	**103**	**172**
[redacted in reliance on s 9(2)(h) OIA]			
Total potential fiscal cost for the Crown			**175**

*****The preferred response for Ministry funded HCSS

Note: Costs would be significantly higher if funds are allocated to pay family carers when disabled people do not have high or very high needs.

OPTIONS FOR MANAGING THE RISKS ASSOCIATED WITH IMPLEMENTING THE PREFERRED RESPONSE

56. A fundamental tenet of Government funded social support is that, in general terms, families have primary responsibility for the wellbeing of their members. Care and support provided by family members to each other is part of this responsibility and the expectation is that it will be provided out of love and affection rather than for money. Consistent with this expectation, Government's primary role is to support families in their role, but not to pay them to undertake it. Funding for care and support is therefore appropriately targeted to meet needs families are not able to meet. There are, and will be in the future, circumstances where Government considers there are social benefits and other advantages to family members being paid to provide care and support to each other, but these circumstances are the exception rather than the rule.

Implementing a cross-government policy of paying family carers

57. Responding to the Tribunal's declaration by adopting a policy of paying all family carers would have the effect of changing this fundamental tenet. There is a risk that paying family carers will have adverse impacts on some disabled people's and family carers' lives. Considerable further work, including public consultation, would be required to inform advice to Ministers on the most appropriate way of paying family carers who are not covered by the preferred response for Ministry funded HCSS. While implementing this approach would eliminate any legal risk of the policy not complying with the NZBORA, the potential fiscal costs of implementing such a policy could be up to $175 million a year.

'Do nothing' option

58. Similarly, retaining the status quo is not acceptable as it would mean that the Government did not comply with the law. It would lead to the possibility of a very large number of claims for unjustified discrimination on the basis of family status across health services and disability support that are funded through the Ministry, DHBs [redacted in reliance on s 9(2)(h) OIA]. Responding to each of these claims would take a considerable amount of time and effort and create considerable fiscal costs that are very hard to estimate.

Legislative option – recommended approach

59. Having discounted these options on the basis of legal and fiscal risk, the only feasible way of managing these risks is through legislation that allows the Government to continue to restrict paying family carers to provide disability support services. Legislation would reduce the risks and uncertainties inherent in the status quo, and significantly reduce the on-going litigation risks, while allowing the Government to implement policies of paying family carers where that is fiscally sustainable and there are good policy reasons to do so.

DECISION WHETHER TO IMPLEMENT THE PREFERRED RESPONSE

60. If the Government decides to legislate to reduce risks associated with the status quo, the first issue it needs to address is whether to confirm its preferred response for Ministry-funded HCSS. Confirming that response would mean that, from October 2013, the Ministry would allocate about $16 an hour to adult disabled family members in high and very high need situations for paying parents and resident family members (other than spouses) to provide care that is over and above the support it is reasonable to expect the family carers to provide unpaid. This approach would include allowing for payment in exceptional circumstances where the target group criteria are not met but where paying a family carer is the only practical option (such as in remote rural areas when there is no suitable carer available).

61. Implementing the preferred response directly addresses the Courts' decisions and is a proportionate response to the issues raised in the Family Carers case. It is also affordable and can feasibly be implemented within the time frame available. However, the tight targeting and the lower level of funding allocated to family carers (about $16 an hour) compared with about $25 an hour for non-family providers may lead to adverse reactions from some people.

OPTIONS FOR DEALING WITH BROADER IMPLICATIONS

62. The preferred response does not address the broader implications for other relationships (such as spouses of disabled people, and parents and other family carers of disabled children), other Ministry-funded DSS, or family carers of people receiving DHB [redacted in reliance on s 9(2)(h) OIA]. This means that the Government needs to decide how to respond to these issues. The document that formed the basis for the consultation process noted the potential broader implications of the Courts' decisions and indicated that the policy development and consultation process would establish a framework for considering the implications of policy options for these. Officials also indicated in public meetings that policy work on these broader implications would be undertaken once decisions were made on the immediate response.

63. There are two broad options available to the Government. These are:

- Option One: announce an intention to carry out further work on these issues when the Government has sufficient funding to pay for any policy responses
- Option two: not carry out any further work on these issues.

64. Option One would provide some level of confidence to disability and carer communities that the issues will be addressed at a time when the Government has a better understanding of them. It would also enable the Government to make decisions based on better quality information as specific consultation and further analysis of the implications could be undertaken over a longer period. (Limited work has been done to date on these broader implications as officials' focus has been on options for responding to the Courts' decisions). Taking this approach would, however, result in ongoing debate and create a strong expectation that the approach taken in the preferred policy will be a precedent that is extended to these other groups.

65. If this approach were to be adopted, the estimated fiscal costs that would result at the conclusion of the further work would be the following:

- $46 million a year for paying spouses and parents of children who are supported through the Ministry and DHBs, and
- $41 million a year for paying parents and other family members to provide HCSS to adults receiving DHB funded support.

66. Option Two would provide certainty but is likely to generate an adverse public reaction and negative media coverage, at least in the short-term. Feedback through the consultation process indicated that developing a policy that applied only to a narrow group would result in considerable adverse reactions from disability and carer communities.

67. Whether or not Cabinet decides to carry out further work on the broader issues, there are likely to be some support services funded by the Ministry where allowing family carers to be paid will involve minimal fiscal risk that can be managed within baseline funding and may allow improved quality of services. The Ministry will consider whether this is the case for other services that it funds – such as residential care - as part of the Ministry's regular review of these services.

Consultation

Sector consultation

68. Consultation with the disability and carers communities and the wider public took place in the first phase of the policy process that led to Cabinet decisions on the preferred response.

TECHNICAL ADVISORY GROUP

69. A Technical Advisory Group provided advice on consultation processes and contributed to the development of the initial options in the consultation document. This group consisted of people with expertise in or lived experience of disability, caring, the disability support system, and managing funds for disability support.

EXPERT ADVISORY GROUP

70. The Ministry was also assisted by an Expert Advisory Group with technical expertise and experience relevant to the case. This group reviewed and discussed the Ministry's analytical work on the benefits, costs and fiscal implications of policy options.

PUBLIC CONSULTATION

71. The Ministry consulted with disability and carers communities, and the wider public, on options for responding to the Family Carers case between 19 September and 6 November 2012. A consultation document was posted on the Ministry's website and distributed to key stakeholders by email and post.

72. The consultation process included:

- twelve regional workshops with interested people, most of whom were carers
- two hui with people from Māori carer and disability communities
- a fono with people from Pacific carer and disability communities
- a separate meeting with the plaintiffs in the Family Carers case.

73. 632 people made submissions. 82% made their submissions via an online survey, 16% made written submissions and 2% attended public meetings. Two thirds of those making submissions were family carers of a disabled person aged 18 years or over.

74. The consultation covered six key areas:

1. How can we ensure good outcomes for disabled people and their families?
2. Should eligibility for payment be targeted?
3. How should family carers be paid?
4. What should family carers be paid for?
5. Should a family carers payment be established through the welfare system?
6. Possible trade-offs within disability support services to fund paying family carers.

75. Some of the key themes that emerged from an independent review of the submissions included the following:

- good outcomes should be supported by: carrying out regular external audits (1/2 submitters); providing independent support to disabled people to plan and build support networks (1/3 submitters); adopting a modified developmental evaluation tool (1/4 submitters)

- there were polarised views on whether targeting should apply
- if targeting was implemented, submitters supported targeting family carers supporting: people with high and complex needs and/or where there are significant risks to safety and wellbeing (2/3 submitters); in remote locations where the disabled person has limited access to carers (1/2); disabled people with specific cultural or religious needs that could be met by a non-family carer (4/10)
- a preference for payment through an allowance (1/2 submitters) - considered to be flexible and easy to administer, particularly for older carers
- those supporting employment (1/3 submitters) considered that it would give carers greater status and treat family carers equitably in relation to contracted support workers
- split views on whether family should determine how much unpaid support families should provide or whether NASC organisations should make this judgement; if NASCs have this role, there was a preference for a principles-based approach over a generic (set number of unpaid hours) approach
- little support for a requirement for family carers to provide a specified level of unpaid support before they could become eligible to be paid
- limited support for a payment administered through the welfare system (1/4 submitters); a preference for family members being paid through employment or allowance (1/2)
- little support for trade-offs within DSS to fund paying family carers; this role is important and additional funding should be found
- widespread rejection of reducing the level of disability support funding allocated across all disabled people to free up funding to pay family carers
- ensure the policy supports strategic directions for disability supports – increases disabled people's choice, flexibility and control and supports better outcomes for disabled people.

Government agency consultation

76. A Senior Officials Group comprised of officials from key government agencies reviewed and helped refine policy options and provided advice on implementation considerations.

77. The Ministry of Health consulted with the Treasury, the Ministry of Social Development, the Inland Revenue Department, the Ministry of Business, Innovation and Employment, the Ministry of Justice, the Ministry of Pacific Island Affairs, the State Services Commission, Te Puni Kōkiri, Crown Law Office, the Office for Disability Issues, Veterans' Affairs New Zealand, the Ministry of Women's Affairs and ACC on the Regulatory Impact Statement.

Conclusions and recommendations

78. The recommended option resulting from analysis of how the Government could respond to immediate issues arising from the Courts' decisions in the Family Carers' case is to allocate adult disabled people with high and very high needs, who are eligible for Ministry-funded HCSS, an allowance under Section 88 of the NZPHDA to employ family carers.

79. This is the preferred option because:

- family carers gain the benefits of employment and are paid an hourly rate that is equivalent to that received by most other carers
- allocating funding for paying family carers to disabled people gives those receiving care greater control over their supports and flexibility, consistent with the Government's strategic directions
- this arrangement is relatively easy to administer once established
- targeting people in high and very high needs situations supports those for whom the option of paid family care is most important (based on consultation findings)
- it responds directly to the Courts' finding of discrimination in employment and does not involve targeting on grounds that could be considered discriminatory under the NZBORA

- it is feasible to implement this approach within the time available
- the costs are likely to be affordable within the overall Vote Health allocation.

80. Other options were discounted because implementing them would be too expensive, would not be feasible within the time frame available, or, would exclude family carers of disabled people with high needs.

[Paragraphs 81-83 legally privileged]

81. There are significant legal risks associated with the Government's preferred response (decided by Cabinet in December 2012, subject to further advice). It does not address any potential discrimination that arises in relation to other relationships [redacted in reliance on s 9(2)(h) OIA]. It also allocates a lower rate to disabled people for paying family carers than the rate allocated to contracted providers and disabled people using IF. [redacted in reliance on s 9(2)(h) OIA]

82. [redacted in reliance on s 9(2)(h) OIA]

83. [redacted in reliance on s 9(2)(h) OIA]

Implementation

Implementing the preferred response

84. If the Government decides to confirm its preferred response, the Ministry will implement the new policy through changing policies and procedures for funding and contracting disability support. Ministry officials will work with their existing network of carer and disability community representatives, and contracted organisations affected by the policy changes (such as NASCs), to design and implement operational policies and processes. Officials will also work with other relevant government agencies, such as the Ministry of Social Development and the Ministry of Business, Innovation and Employment, to identify and work through broader implications of the new policy, such as benefit and employment implications.

Legislative options [Legally privileged]

PROTECTING FAMILY CARERS POLICIES THROUGH LEGISLATION

85. If the Government decides to implement the response to the Courts findings that it has previously indicated is its preferred response (subject to further advice), then the proposed legislation will need to ensure that the Ministry and DHBs are able to operate policies which restrict or prohibit payments to family carers but still allow the Government to pay or fund payment of family carers where it wishes to do so. This can be achieved through legislation which authorises the Crown or a DHB to adopt a policy under which providers of health or disability support services are not paid, or only paid in specified circumstances, or paid at reduced rates because they are a family member of the person receiving the services. The legislation will need to make it clear that such policies are lawful, even if they breach Section 19 of the NZBORA. Otherwise courts may "read down" the provision as only permitting non-discriminatory practices.

86. Expressly permitting the operation of a discriminatory policy will be controversial and there is likely to be a strong public reaction to it from the disability and carers communities. It will also likely invite strong criticism, including from the Human Rights Commission, the Law Society and legal academics. New Zealand may also face adverse comments from international legal bodies.

APPROACH TO LEGISLATION

87. Legislation could be applied solely to health and disability support services that are funded through Vote Health or to health and disability support services funded by a wider range of government agencies. The three legislative options that could achieve the Government's objectives of reducing the risk of claims while still allowing payment of family carers include:

    - Option One: Amend the NZPHDA

- Option Two: A specific legislative response for all family carers (new Family Carers' Act)
- Option Three: Amend the NZBORA and the HRA.

Option One: Amend the New Zealand Public Health and Disability Act 2000 (NZPHDA)

88. [redacted in reliance on s 9(2)(h) OIA] public funding would not be available to enable specific close family members to provide health or disability support services to a person who is close family member, except in specified circumstances. These specified circumstances would sit outside the legislation. The amendment would also need to make express provision that any policy or decision not to pay or fund health and disability support services provided by family members is not unlawful discrimination under the Human Rights Act (HRA) or the NZBORA. Amending the NZPHDA would address risks of further litigation in relation to family carers for both Ministry funded DSS and DHB funded health and disability support services.

89. [redacted in reliance on s 9(2)(h) OIA]

90. [redacted in reliance on s 9(2)(h) OIA]

Option Two: A specific legislative response for family carers (new Family Carers Act)

91. Specific legislation could be enacted to address the issues arising from the Family Carers Case. [redacted in reliance on s 9(2)(h) OIA] This would reduce the risk of claims being made against other government agencies but increase the risk of unintended consequences because the policies of funders other than Vote Health [redacted in reliance on s 9(2)(h) OIA] have not been examined closely. For example, there is a risk that it could unintentionally affect ACC's policy of allowing the payment of family carers.

Option Three: Amend NZBORA and HRA

92. Amendments to the HRA and the NZBORA could be made to protect the Crown, the Ministry, DHBs and other government departments from all future claims of discrimination on the basis of family or marital status of family carers.

93. [redacted in reliance on s 9(2)(h) OIA]

Recommended option - amend the NZPHDA

94. Officials' view, informed by advice from the Parliamentary Council Office (PCO) and Crown Law, is that the most straightforward way of achieving whichever legislative option is chosen is through an amendment to the New Zealand Public Health and Disability Act 2000. While a broader approach, such as a standalone Act, reduces the risk of claims being made against other parts of the Government [redacted in reliance on s 9(2)(h) OIA], it increases the risk of unintended consequences because the policies of Government funders have not been examined closely and it would be difficult to do so in the time available.

95. The legislation would not, however, need to address the risks for other funders. [redacted in reliance on s 9(2)(h) OIA]

96. [redacted in reliance on s 9(2)(h) OIA]

HOW THE POLICY IS PROMULGATED

97. Consideration was given to whether any policies allowing for the payment of family carers needed to be in regulations. This approach was, however, seen as inflexible and would unnecessarily constrain the future options of disabled people and their families and the Government. Rather, it would be sufficient to have any existing policies confirmed, or any new policies approved, by the body with the necessary decision making authority. Policies relating to health services or disability supports that are administered by Government departments would require Ministerial (or Cabinet) confirmation or approval. Policies relating to Crown entities - such as DHBs – would normally require Board approval.

Addressing current and future claims

98. In addition to deciding whether it wishes to prevent future claims against the new law/policy, Cabinet also needs to decide whether it wishes to restrict, in any way, existing or future claims against the current policy. If it did, the legislation would need to make this explicit. The different groups of claims to address are discussed below. (Note this does not include the nine claims in the Family Carers case itself. The Ministry has entered into an interim payment arrangement pending remaining remedies being heard by the Tribunal in the near future).

99. [redacted in reliance on s 9(2)(h) OIA]

100. [redacted in reliance on s 9(2)(h) OIA]

101. [redacted in reliance on s 9(2)(h) OIA]

Monitoring, evaluation and review

102. The Ministry will monitor quality and safety of services provided by paid family carers using its existing mechanisms such as complaints processes, developmental evaluations and/or audits.

103. The Ministry will also closely monitor actual expenditure on HCSS provided by family carers through monthly reporting. This will require minor changes to the Ministry's administrative systems to differentiate HCSS provided by paid family carers from HCSS provided by carers employed by contracted providers or by disabled people under IF. This monitoring will enable the Ministry to both ensure that expenditure on paid family care remains within its allocated budget and to identify any savings that might indicate scope for broadening the application of the policy.