

PAID FAMILY CARERS CASE: PROPOSED RESPONSE

Proposal

- 1 This paper seeks Cabinet's agreement to a proposed initial response to the paid Family Carers case (Ministry of Health v Atkinson & Others) and to a process for developing a wider response to the issues raised by the case.

Executive Summary

- 2 The Government needs to change the Ministry of Health's current blanket policy of not paying family carers. The initial focus of the policy work is on family carers who are parents of adult disabled children and other family members who reside with an adult disabled family member. This approach excludes spouses of disabled adults and parents of disabled children.
- 3 The key choices involved in developing a policy for paying family carers involve deciding on the way in which family carers will be paid and deciding on the approach to targeting payments to family carers. Policy work identified three options for each of these issues.
- 4 The preferred approach to allowing the parents of adult disabled children and family members who reside with an adult disabled family member to be employed involves the following:
 - a allocating approximately \$16 per hour to the disabled person to allow them to employ family carers, with the terms and conditions on which they can employ the family carer being specified in a Notice under Section 88 of the New Zealand Public Health and Disability Act 2000;
 - b allowing family carers to be employed when they are in very high and high needs situations – that is, disabled people whose ability to remain living at home is under threat because their family situation is fragile and those who have such high support needs that meeting those needs means that a family carer who wishes to work full time in another job outside the home is unable to do so.
- 5 This approach: allows family carers to be employed; targets funding to pay family carers to disabled people in high and very high needs situations; enables disabled people to retain control over the funding they are allocated; limits the net costs to Vote Health to an estimated \$23 million a year; and pays family carers \$16 per hour (i.e. the minimum wage per hour plus associated employment costs such as allowances for holiday and sick pay, Kiwisaver contributions and ACC earner levies). This is the amount that contracted providers pay most non-family carers, which is lower than the \$25 per hour paid to contracted providers.
- 6 This approach, however, has risks associated with it that may need to be addressed through changes to other parts of the disability support system and/ or supported through legislation. The Minister of Health will report back to Cabinet on these issues in early 2013, before the preferred approach is confirmed.
- 7 There are also significant broader implications, arising from this case, for support funded through District Health Boards (DHBs) and aspects of support funded through the Ministry of Health. Cabinet needs to decide whether it wishes to continue to address these issues through an ongoing policy process, or to investigate the possibility of legislating to remove these risks.

Background

- 8 Family carers play an important role in supporting disabled people to live an everyday life. The New Zealand Disability Survey, for example, suggests that family carers (and other unpaid natural supports) provide in the order of 75 percent of the care of disabled people. The government complements the role of family carers and other natural supports through funding support that assists disabled people to live everyday lives. At present, the Ministry of Health (the Ministry) funds support for about 30,000 people (most of whom are aged under 65) with physical, sensory and intellectual disabilities who need ongoing support. Other support is also funded through DHBs and a range of other government agencies.
- 9 The Ministry currently has a blanket policy of not allowing the payment of certain family carers (parents, spouses and resident family members) who provide disability support services (DSS). The Ministry is now required to change this blanket policy as a result of the Human Rights Review Tribunal's (the Tribunal's) declaration, which was upheld by the High Court and the Court of Appeal, that the policy involves unjustified discrimination against family carers under the New Zealand Bill of Rights Act 1990 (NZBORA). Changing that policy means that families are likely to be paid to provide support that they currently provide unpaid.
- 10 The Ministry is currently able to continue to operate its policy lawfully by an order of the Tribunal suspending its own declaration. Under agreement with the plaintiffs, the earliest that action could be initiated in the Tribunal to lift the Suspension Order is May 2013. If the Government's response to change the payment to family carers policy cannot be implemented by May 2013, it would be prudent for the Crown to seek agreement from the plaintiffs that they would further defer taking action to have the Suspension Order lifted. If agreement cannot be reached with the plaintiffs, the date for lifting the Suspension Order would be decided in the Courts. Crown Law considers it is unlikely that the Courts would lift the Suspension Order before the policy is implemented as the Crown is moving to decide on and implement its policy change with all reasonable haste.
- 11 Cabinet has previously agreed to a staged process for addressing the most significant legal risks arising from the Family Carers case (CAB Min (12) 25/13 refers). The initial focus has been on the issues most directly addressed in the case, which is the discrimination that arises within Ministry funded Home and Community Support Services (HCSS) - which help people to live at home - that was the focus of the Family Carers case. That discrimination arises from the Ministry not paying carers who are parents of adult sons and daughters and/or family members who reside with disabled adult family members (SOC Min (12) 13/15 refers). On 17 September 2012, Cabinet agreed to the release of a consultation document as the basis for a public consultation process on the options for responding to this discrimination (CAB Min (12) 33/13 refers). A draft analysis of submissions received is attached as Appendix One.
- 12 Under the staged process, consideration would subsequently be given to a range of other cases of differential treatment of family carers where there is a significant risk that they could involve unjustified discrimination under NZBORA. In support funded by the Ministry, that discrimination arises in support other than Home and Community Support Services, and support from spouses of disabled adults and parents of disabled children. It also arises in support funded by DHBs; *{redacted under Official Information Act 1982 Section 9(2)(f)(iv) to maintain confidentiality of advice between Ministers of the Crown and officials}*. It was envisaged that the first stage response could provide a precedent for addressing these wider issues. The implications for this other potential discrimination are now becoming clear and steps need to be put in place to address them.

Comment

- 13 A policy of paying family carers of disabled people represents a change to one of the fundamental assumptions on which the disability support system is based in New Zealand and internationally. That is, that family carers are 'natural supports' and are supported to carry out this role, rather than being paid to do so (although there are some exceptions to this approach). This means that there is limited experience to draw on in designing the policy, with the result that, whichever policy option is adopted, there will be a considerable degree of risk and uncertainty to manage. For example, the estimated gross cost (i.e. payments from Vote Health) of the options identified in this paper range from \$21 million to \$74 million a year for Ministry funded support, with net costs ranging from \$15 million to \$65 million if the estimated reduction in benefit payments is taken into account. The estimates for the various options are themselves subject to uncertainty.
- 14 Meeting these additional costs is a significant challenge for the Government, particularly in the current fiscal environment. This means that the Government must now make some hard decisions that will not be universally popular if we are to be fiscally responsible. While many participants in the consultation process indicated preferences on the trade-offs that could improve the affordability of paying family carers, there were relatively low response rates on this question, meaning there was no clear consensus on the most appropriate way of addressing the hard decisions confronting the Government.

KEY POLICY CHOICES

- 15 There are a range of policy options for responding to the Courts' decisions in the Family Carers case. The key choices, which are discussed below, are around:
- a the way in which family carers are paid; and
 - b the approach to targeting which family carers can be paid.

Payment mechanisms

- 16 Family carers can be paid under one of the following options:
- a **Option One: Allow family carers to be employed.** This involves removing the restriction on employing family carers so that family carers can be employed to provide HCSS through the Ministry's existing mechanisms (e.g. through contracted providers or by the disabled person under individualised funding arrangements). Under both these arrangements, the cost to the Ministry is an average of about \$25 an hour (although employees receive around \$16 an hour - i.e. the minimum wage of \$13.50 plus allowances for holiday and sick pay, Kiwisaver contributions, and ACC earner levies). The higher amount paid to providers covers such things as administration and contracting costs, profit, supervision and staff training.
 - b **Option Two: Pay carers an allowance.** This approach involves directly paying family carers an allowance that reflects the hours of allocated funded HCSS that family carers provide. The allowance could be set at \$16 per hour (i.e. the minimum wage of \$13.50 plus allowances for holiday and sick pay, Kiwisaver contributions and ACC earner levies), which is the amount that most support workers currently employed by contracted providers receive. While Government would incur additional costs for administration and quality assurance and, possibly, training, these costs are taken into account in the overall cost estimates and will be significantly less than the \$9 per hour difference between the rate for contracted services and under individualised funding, and the amount paid to care workers. Legislation would be required to implement an allowance and there would be some challenging design and implementation issues, such as its relationship to social security benefits, tax status, and employment law.

- c **Option Three: Employment through an alternative payment mechanism.** This option involves allocating disabled people funding as part of their overall package that they can use to employ family carers. The disabled person would then be able to use the funding they are allocated to employ a family carer on the terms and conditions that would be set out in a Notice that is issued under Section 88 of the New Zealand Public Health and Disability Act 2000. The funding that disabled people are allocated to pay family carers would be based on the total cost of employment for many support workers currently employed by contracted providers of about \$16 per hour. The Ministry has experience of working with Section 88 notices (e.g. for paying lead maternity carers) that would assist in working through the implementation issues.

Targeting options

- 17 Officials have identified three broad options for targeting payments to family carers, as a key tool in managing the costs of paying family carers who are in the groups being considered in this paper (i.e. parents of adult sons and daughters and/ or family members who reside with disabled adult family members, excluding spouses):
 - a **Option A: Tight targeting - pay family carers supporting disabled people in very high need situations** (approximately 1,100 disabled people). This would involve targeting to disabled people whose 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 family carer's caring responsibilities. For example this could be a combination of: the family carer might be supporting a disabled family member with significant support needs; the family carer might have multiple caring responsibilities; the family may be facing significant socio-economic disadvantage; and/or the family carer might be a sole parent with limited natural networks.
 - b **Option B: Medium targeting - pay family carers supporting disabled people in high and very high needs situations** (approximately 1,600 disabled people). This would involve targeting to disabled people whose family situation is at risk of breakdown, and disabled people who have such high support needs that meeting those needs means that a family carer who wishes to work full time in another job outside the home is unable to do so. For example, family carers may be unable to work because they are supporting one or more disabled people who need high levels of personal support regularly throughout the day and someone in the home 'on call' both day and night to meet personal care needs.
 - c **Option C: No targeting.** This option involves paying all family carers of disabled people receiving HCSS who meet the Ministry's eligibility criteria (approximately 5,400 disabled people).

Assessment

- 18 Each of the combined options of payment method and targeting offers different balances between the impact on disabled people and family carers, legal risks, implementation issues and potential fiscal costs and risks. Both employment and an allowance recognise the contribution that family carers make to the disabled person, but there are also differences between them:
 - a **Paying family carers as employees** (estimated costs under Options 1A, 1B and 1C in Table One below) complies with NZBORA and treats family carers similarly to other paid carers under employment law, and uses existing mechanisms for promoting quality (such as training requirements through the employer). It also gives family carers status through being employed, but may deter some family carers from seeking payment because of what some see as the onerous requirements arising from employee/ employer relationships and a concern that being an employee will undermine family relationships.

If decisions are taken in December 2012, it is likely to be feasible to implement this option by May 2013.

- b ***Paying family carers an allowance*** (estimated costs under Options 2A, 2B and 2C in Table One below) may have less adverse impact on family relationships and, depending on the design, could be more flexible at meeting disabled people's and their families' changing needs and could be easier and cheaper for families to administer than employment. There was some preference in the submissions for an allowance, or for being offered the choice of employment or an allowance. Those attending consultation meetings tended to prefer employment, or a choice of employment or allowance. An allowance would almost certainly require supporting legislation because of the need to clarify its legal status (e.g. the impact on tax, benefits, and employment law). Depending on how the terms of an allowance are dealt with in legislation, it may be very difficult to adjust payments and other conditions over time to more effectively manage fiscal costs and risks.

It would not be possible to implement this option by May 2013 as it would require legislation and considerable development and implementation work (e.g. new computer systems might be required to support the payment). Legislation would, however, provide an opportunity to limit the risks associated with any unjustified discrimination.

- c ***Employment through an alternative payment mechanism*** (estimated costs under Options 3A, 3B and 3C in Table One below) may have similar impacts on family relationships to the employment option. The Section 88 Notice could spell out the particular requirements that must be met if family carers are employed and put suitable monitoring and accountability mechanisms in place. Adopting this approach more broadly may allow for more cost-effective approaches to supporting disabled people more generally, although further analysis is required to determine whether this is the case. This approach is similar to suggestions made during the consultation process, that family carers could be directly contracted to provide care.

It is likely to be feasible to implement this option by October 2013, which would require plaintiff cooperation or support from the Courts. As with the option of paying family carers an allowance, it may require legislation, and will involve considerable development and implementation work.

- 19 The different approaches to targeting may result in carers who are currently receiving a benefit (in particular the Domestic Purposes Benefit – Care of the Sick and Infirm [DPB-CSI]) either losing their entitlement or having their benefit and/or any supplementary support reduced. However, they also have differing impacts:

- a **Tight targeting: paying family carers in very high needs situations** (Options 1A, 2A and 3A in Table One below). This approach helps maintain the stability of the family unit, reduce the risk of abuse, and enable the family to live in their community of choice. The approach may lead to some people on DPB-CSI becoming employed as family carers and creates incentives for families to present as vulnerable and may be a short-term 'fix' when the focus should be on addressing more fundamental underlying factors contributing to the families vulnerability. There could also be operational challenges such as developing and implementing detailed criteria for determining 'fragile' families. I note that there is a possibility that some of the plaintiffs would not receive funding under this targeting option, and they may pursue further legal action.

- b **Medium targeting: pay family carers in high and very high needs situations** (Options 1B, 2B and 3B in Table One below). This option would enable family carers who are unable to earn an income because of their caring responsibilities to earn an income as paid carers of a family member, and may lead to some people on benefits such as DPB-CSI becoming employed as family carers. It might also result in some family carers stopping work outside the home so they could be paid as carers.
 - c **No targeting: pay all family carers** (Options 1C, 2C and 3C in Table One below). This approach is consistent with the Courts' decisions in the Family Carers case as it involves no differential treatment of family carers who are being considered for payment at this point, that is parents of adult sons and daughters and/ or family members who reside with disabled adult family members (SOC Min (12) 13/15 refers).
- 20 Payment options that treat family carers differently from other carers, and any targeting option, involve an element of differential treatment on a prohibited ground of discrimination. The question is whether such differential treatment is justifiable under NZBORA. If not, the Government may need to make further policy changes in response to any future adverse findings by the Courts, with potentially significant fiscal consequences. Supporting the policy with legislation would reduce this litigation risk because, although the Courts could still find the policy to be inconsistent with NZBORA, they could not overturn it. There is recognition in the recent Day Services decision (*Attorney-General v IDEA Services Ltd* (2012) NZHC 3229) that prioritising expenditure was an important objective which could override the right to non-discrimination, especially as Section 3 of the New Zealand Public Health and Disability Act 2000 states that disability support and health services are to be provided within available funding. The potential consequences of adverse findings by the Courts may, however, make legislation desirable.
- 21 Under each of these options, caps will be placed on the amount of support that will be paid for to help manage fiscal costs and risks. Two forms of cap could be applied:
- a The total amount of support funding allocated to a disabled person (whether or not provided by families) cannot exceed the cost of that person living in a residential service. This currently averages \$61,000 per person, with some packages being considerably higher than this, as actual packages reflect the level of assessed need. Although this policy operates implicitly now, there are quite a few exceptions to it. Clarifying that such a policy applies will reduce the uncertainty about whether this is the case and assist with the consistent application of the previously mentioned exceptions policy. Current exceptions would, however, be grand-parented to avoid unnecessary disruption to people's lives.
 - b The amount of funding that is allocated to a disabled person to pay family carers cannot exceed 40 hours per week, which is equivalent to a full working week. As well as reducing fiscal costs and risks, this will help ensure that paying family carers does not result in them providing an unsustainable amount of paid care for their disabled family member.
- 22 It may also be possible to further target payments by income and/or asset testing family carers, so that carers from households with very high income or assets are not able to be paid. It seems inequitable, for example, to pay wealthy people to care for adult disabled children when they have access to sufficient resources. I have, therefore, asked my officials to investigate whether this is a feasible option and to report back to me in February 2013.

Other parts of the policy response

23 The discussion above highlights the key choices that are open to the Government. In addition, the following proposals should also form part of the response:

- a ***Strengthen the existing Needs Assessment and Service Coordination (NASC) process*** for determining disabled people's support needs but extend NASC's role to include determining the extent to which family carers could be paid. The process for determining how much support family carers can provide unpaid would be strengthened through clarifying the principles that are used to determine this and putting in place clearer processes for people to request reconsideration of NASC decisions. This would respond to concerns that were raised during the consultation process about NASCs existing principles-based assessment of the extent to which unpaid family carers can meet the needs of the disabled person. Overall submitters preferred NASCs to use a principles-based approach, although feedback revealed a lack of trust in NASC organisations to carry out the required assessments in a fair and reasonable way. Some felt more transparency and consistency and an improved system for reviewing NASC decisions may help address this. Furthermore, a more robust and consistent approach by NASCs would help counter the incentive that the possibility of payment will reduce the amount of unpaid support offered by family carers.
- b ***Adopting an exceptional circumstances policy*** which would allow for consideration to be given to paying family carers who fall outside the targeting criteria but where there is a very good case for paying them. For example, people may seek funding because of a lack of availability of formal carers, safety risks for the disabled people or family carers or there are no other practical alternatives available. This discretionary policy will allow for the Ministry to respond to the wide range of circumstances that can arise.
- c ***Making available independent support during the NASC process when consideration is being given to paying family carers.*** This would help reduce the risk that disabled people may become trapped in situations of being supported by family carers who have come to rely on the income, but when this is inconsistent with their wishes. The disabled person should, however, be able to explicitly decline this support.
- d ***Independent monitoring of disabled people's quality of life*** when family carers are paid. This monitoring will help respond to concerns that disabled people may become 'trapped' by family carers who come to rely on the payments they receive. There was strong support in the consultation process for monitoring that is carried out by evaluators who are independent of the family carer and the disabled person.

Fiscal Costs

- 24 Estimates of the fiscal cost for the nine options that arise from combining the payment and targeting options, all with family carer support limited to 40 hours per week, are summarised in Table One below. These estimates include the direct cost to Vote Health and assume that any reduction in benefit payments will lead to a fiscally neutral transfer to Vote Health. The expected increase in income tax payments is not reflected in these estimates.
- 25 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 and, in some cases, rely on self-reporting, which can be problematic; and it is very difficult to estimate the extent to which family carers may elect to become paid under any of these options. The benefit impacts are also difficult to estimate because of uncertainty about the number of eligible carers. These costings do not include estimates of the costs of introducing similar policies for other groups such as

spouses of disabled adults, and parents of disabled children, and people supported through DHBs. These costs are discussed in paragraph 34 below.

TABLE ONE: 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 carers an allowance	Option 3: Employment through an alternative payment mechanism
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	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		

Preferred option

- 26 The decision about the most appropriate option rests on achieving an appropriate balance between fiscal costs, legal risks, and the impact on family carers and disabled people. Option 3B in Table One above, which involves medium targeting – allowing family carers in high and very high needs situations to be paid – and making those payments using a Section 88 Notice, appears to offer the most appropriate balance. This option:
- Targets funding to pay family carers who are so significantly impacted by their caring responsibilities that they are unable to work full time in another job outside the home. With this degree of targeting, it is likely that the plaintiffs will be funded (whereas this may not be the case under a tighter targeting regime).
 - Allows family carers to be employed, which responds directly to the Courts' finding that family carers were discriminated against in employment.
 - Allows disabled people to retain control through allocating funding to them, rather than directly to their family carer. This gives them the choice of engaging family carers under the Section 88 Notice or non-family carers through either a contracted provider or under an individualised funding arrangement. It also places conditions on the payment of family carers.
 - Limits **net** fiscal costs, estimated to be \$23 million per year, to a level that can be sustained from within the overall Vote Health allocation, although achieving this will require a transfer from Vote Social Development as a result of the expected reduction in benefit payments (particularly in the DPB-CSI).
 - Pays family carers \$16 per hour (i.e. the minimum wage of \$13.50 plus allowances for holiday and sick pay, Kiwisaver contributions and ACC earner levies), which is the amount that most other carers receive when they are employed through contracted providers.

- 27 The approach is not, however, without its risks. *{redacted under Official Information Act 1982 under Section 9(2)(h) to maintain legal professional privilege}*. This is because, under individualised funding arrangements, some disabled people will take responsibility for administrative duties that contracted providers normally carry out and, in return, pay their carers higher hourly rates than contracted providers are able to. Under the Section 88 Notice, a disabled person will not be allocated sufficient funding to enable them to pay family carers higher rates than contracted providers are able to.
- 28 This risk could be addressed through allocating similar levels of funding to family carers as are allocated to people purchasing services through individualised funding arrangements (which is also the same amount as allocated to contracted providers) – at a net additional cost to Vote Health (over and above the costs of Option 3B) of \$17 million per year. Vote Health does not have this level of additional funding available if it is to manage the overall pressures facing it. Alternatively, changes could be made to either the individualised funding arrangements or the overall way that the Ministry funds disability supports to align them with the approach taken to paying family carers. If additional funding is not available, or if changes are not made to align all disability support allocations to family carers with the proposed approach, legislation would be the only effective way of managing this risk.

APPROACHES NOT RECOMMENDED

- 29 The consultation document outlined several other options that further analysis and the consultation process suggest should not form part of the initial Government response. Those options are the following:
- a Expecting families to provide fixed minimum levels of HCSS to reduce overall costs. It would be very difficult to enforce minimum requirements for support and there were concerns that the 'minimum' expectation could easily become the default level of unpaid support that families provide, although families may be prepared to provide more.
 - b Paying an allowance that is lower than a non-related carer would be paid. Such an allowance may be inconsistent with the Minimum Wage Act 1983 and may be inconsistent with NZBORA through treating family carers differently to other carers. There was no support for this approach during the consultation process.
 - c Offering a flat-rate (or broadly tiered) carers allowance payable through the welfare system (which does not have the capacity to determine the specific levels of support a disabled person might require). This does not respond directly to the Courts' decision in the Family Carers case, although it could complement employment or the combined option above. Such an allowance would also complement support funded through Vote Health by recognising people's caring role, but could cost a considerable amount of money, while providing relatively limited amounts of funding to any one person. For example, the Ministry of Social Development estimates that the cost of providing a flat-rate non-taxable weekly allowance of \$45.34 (the same as the Child Disability Allowance) for the estimated 73,000 family carers who are identified in the New Zealand Disability Survey would be \$176 million in 2013/14 rising to almost \$200 million in 2016/17. There would also be operational costs of approximately \$5 million in 2013/14 and \$3 million in 2014/15 and out-years. Adoption of such an option would, therefore, be contingent on additional funding being available.

RELATIONSHIP TO FUTURE DIRECTIONS FOR DISABILITY SUPPORT

- 30 There was support in many submissions for the response to the Family Carers case to be consistent with the Government's new directions for disability support that emphasise flexibility, choice and control for disabled people. Several elements of those future directions have the potential to improve the way in which the Ministry manages paying family carers:
- a The introduction of facilitators (an example of which is local area coordinators) who can support people to plan and build up natural support networks could significantly reduce the pressure that many family carers face and might reduce the demand for family carers to be paid. For example, a recent initiative by the Ministry involved facilitators working with a group of 16 families of young people who were in crisis, with the young people at risk of moving into residential care at an estimated support cost of \$3 to \$4 million a year. The outcome has been that none of the young people have moved to residential care (and some have got jobs), the families have remained intact and support costs are in the order of \$500,000 a year.
 - b Increasing the flexibility, choice and control that people have over the funding they are allocated would allow funding to be used in the most appropriate way, thereby reducing pressure on family carers. Consistent with this, the Ministry is now moving to make the Carer Support Subsidy (a payment intended to allow unpaid carers to take a break from their caring responsibilities) more flexible. This will complement the current individualised funding scheme for HCSS.
 - c The Ministry is currently modifying its funding allocation process, which will result in significant changes to some parts the current NASC process. It is anticipated that the modified approach will result in more consistent funding allocations than occur at present, although more development and testing is required to be confident that this is the case. During development of the funding allocation process, explicit consideration will be given to the issues raised by the Family Carers case.

NEXT STEPS

- 31 The Ministry expects to be able to implement the new policy for paying family carers by 1 October 2013. This will allow time to develop the Notice under Section 88 of the New Zealand Public Health and Disability Act 2000. Such a Notice would set out the detailed terms and conditions with which disabled people who are allocated Ministry funding to employ family carers will need to comply.
- 32 The extent of the risk and uncertainty means that the Ministry will need to ensure that the actual cost of paying family carers does not exceed the allocated funding. It is envisaged that this will involve ring-fencing within NASCs and closely monitoring the funding allocated to pay family carers. Ring-fencing would avoid the risk that unexpectedly high payments to family carers would lead to reductions in other parts of disabled people's packages, which was seen as unacceptable during the consultation process. Close monitoring would give the Ministry the information it needs to advise on any adjustments to the family carer policy settings.
- 33 The next steps in responding to the broader issues will depend on the particular approach that Cabinet elects to take to addressing that issue. I have also asked my officials to report back to me in February 2013 on whether legislation is necessary and desirable to support the Government's preferred option (and, if so, how it might be done) and whether it is feasible and desirable to further target payments by income and/or asset testing family carers. If necessary, the Ministry of Social Development will work with the Ministry of Health to develop a process to transition clients from DBP-CSI to the new arrangement.

Broader implications

- 34 The Family Carers case has implications for a range of other areas where the government funds support for people with short or long-term disabilities. Current indicative estimates of the net cost to Vote Health of paying an expanded group of family carers are the following:
- a Paying spouses who care for disabled adults who are supported through the Ministry would increase costs by about 80 percent. For example, the mid-point estimate of Option 3B in Table One above, would increase by about \$18 million (from \$23 million to \$41 million) a year, with proportional increases in the upper and lower bounds.
 - b Paying parents of disabled children who are supported through the Ministry would increase costs by about 13 percent. For example, the mid-point estimate of Option 3B in Table One above, would increase by about \$3 million (from \$23 million to \$26 million) a year, with proportional increases in the upper and lower bounds.
 - c Paying family carers of people who are supported through DHBs - primarily people with age-related support needs - could make a significant difference to estimated costs. For example, the mid-point estimate of Option 3B in Table One above, would increase by about \$66 million a year if spouses can be paid and \$41 million a year, if spouses cannot be paid. There would also be a proportional variation in the upper and lower bounds of these estimates.
 - d *{redacted under Official Information Act 1982 Section 9(2)(h) to maintain legal professional privilege}*
- 35 There is a need to decide whether these broader issues should be determined through one of the following processes:
- a Continuing with the previously agreed approach of carrying out a policy process that addresses the broader risks - thereby diverting those resources from other high-priority initiatives such as the transformation of the disability support system through initiatives to implement 'Enabling Good Lives'. If this approach is adopted, the Minister of Health would report back to SOC in October 2013 on how he proposed to carry out this work.
 - b Investigating the possibility of legislating to remove the risk that these other groups of family carers will be paid. In addition to removing the substantial fiscal risks, it also removes the risk that paying these other groups of family carers will significantly undermine family relationships and be contrary to current expectations of family support, including that spouses of disabled adults and parents of disabled children will support their family members. If this approach is adopted, the Minister of Health would report back to SOC in late February 2013 on the options for legislative change.¹

Consultation

- 36 The Treasury, Ministry of Social Development, Inland Revenue Department, Ministry of Business, Innovation and Employment, Ministry of Justice, Ministry of Pacific Island Affairs, the State Services Commission, the Ministry of Women's Affairs and Te Puni Kōkiri were consulted on this paper. Crown Law Office, the Office for Disability Issues, Veterans' Affairs New Zealand and ACC were also consulted on the paper. The Department of Prime Minister and Cabinet was informed of the contents of the paper.

¹ Note that, if the Government elects to support the Optional Protocol to the United Nations Convention on the Rights of Persons with a Disability, people would be able to challenge any legislation at the United Nations.

- 37 The Ministry consulted with the disability and carers communities, and the wider public between 19 September and 6 November 2012 based on the release of a public consultation document. The consultation process included:
- a twelve regional public workshops;
 - b two hui with people from Māori carer and disability communities;
 - c one focus group with people from the Pacific carer and disability communities;
 - d a separate meeting with the plaintiffs in the Family Carers case.
- 38 In addition to feedback provided during the meetings, 617 people made written submissions. The key themes are summarised in the draft Analysis of Submissions which is attached as Appendix One.

Regulatory impact analysis

- 39 A Regulatory Impact Analysis was required for this paper as legislation is one of the options the Government needs to consider in developing its response to the Family Carers case. A draft Regulatory Impact Statement that summarised the analysis was prepared based on developing a response to issues directly raised in the case. Initially, this was to be the focus of the Cabinet paper, with policy work on responding to the broader risks raised by the case being deferred.
- 40 During the later stages of preparing the Cabinet paper, the scope of issues being considered in the paper was extended to cover whether legislation should be used to respond to those broader risks. This meant that the draft Regulatory Impact Statement was no longer relevant as it did not consider that broader issue.
- 41 If Cabinet agrees that the possibility of legislation to address any of the risks arising from the Family Carers case should be considered further, then a Regulatory Impact Statement that is relevant to the scope of issues being considered will be attached to the Cabinet paper that addresses those issues.

Human Rights Implications

- 42 The proposals in this paper respond to the Tribunal's declaration that the Ministry's policy of not paying family carers amounts to unjustified discrimination under NZBORA. The preferred option for responding to the Family Carers case itself, however, involves the differential treatment of family carers compared with other carers. There are two ways in which differential treatment of family carers arises:

- a Family carers will be paid less than some non-family carers are paid when the disabled person employs those carers through individualised funding arrangements. This situation arises because the amount that the Ministry will allocate to pay family carers is less than the amount allocated to people using individualised funding arrangements to employ non-family carers, with some non-family carers who are contracted under individualised funding arrangements receiving significantly higher wages than those employed through contracted providers. The payment will, however, be the same as paid to most carers who are employed through contracted providers.

Unless other changes are made to the disability support system to reduce the differential treatment, it is very likely that this option will breach the right to freedom from discrimination under NZBORA. It will, therefore, be desirable to consider supporting this approach through legislation in order to avoid damages for pecuniary loss being awarded in any future litigation. Given the likelihood that any legislation would be discriminatory, it is likely that the Attorney-General would need to report that to Parliament under Section 7 of NZBORA.

- b Payments to family carers will be targeted to those who have a very high or high level of need. This means that some family carers will not be eligible to be paid.

Further analysis is required to reach an informed view on whether legislation is desirable to address this risk. There is some support from the Courts for targeting funding to people with the highest need. As indicated above, the recent Day Services decision recognised that prioritising expenditure was an important objective under Section 3 of the New Zealand Public Health and Disability Act 2000 which could override the right to non-discrimination, as disability support and health services are to be provided within available funding. Supporting the policy with legislation would, however, reduce both the likelihood of litigation and the consequences of any adverse findings by the Courts because the only remedy available would be a declaration of inconsistency with NZBORA.

- 43 The exclusion of some types of support and some types of carers from the response outlined in this paper could be seen as discriminatory if effective steps are not taken to address them. Options for that further work are discussed in paragraph 35 above.

Legislative Implications

- 44 At this time, it is unclear whether legislation will be desirable as part of the Government's response to the Family Carers case. There are two areas where further work may lead to recommendations that legislation is the most appropriate course of action:

- a To address any risks associated with the Government's approach to paying parents of adult sons and daughters and/ or family members who reside with disabled adult family members. Those risks might arise in relation to employment and human rights legislation.
- b To address the broader risks associated with paying other family carers.

- 45 In each case, officials need to carry out further work to determine whether legislation is the most appropriate approach to address either of these issues. If legislation is required, it is more likely to involve amendments to the New Zealand Public Health and Disability Act 2000 than amendments to broader legislation such as the Human Rights Act 1993 or NZBORA.

Gender Implications

- 46 The Government's response to the Family Carers case is likely to primarily affect women as they are the majority of people who provide unpaid care to disabled family members. This was reflected in 75% of submissions during the public consultation process being from women. Paying these family carers a wage will improve their income and increase the range of choices open to them. However, it could also create incentives for some women to switch from higher paid work outside the home to provide paid care, thereby locking them into low paid jobs. This may lead to difficulties re-entering the wider labour market.

Disability Perspective

- 47 The public consultation process has confirmed that there are diverse views in the disability and carers communities on how family carers should be paid for providing care, with many people recognising the dilemmas raised by the Family Carers case. The disabled people who presented submissions generally supported the option of family carers being paid, but had different views on how this should occur.

Financial Implications

- 48 The net cost to the Crown of policy changes affecting services funded through Vote Health will be met within Vote Health baselines, and from the Vote Health operating allocation for Budget 2013. Cabinet noted that Budget Ministers will assess whether the

indicative allocation for Vote Health needs to be reviewed, given savings and reprioritisation opportunities, as work on the Government's response to the Family Carers case is progressed and the cost of policy options clarified (CAB Min (12) 30/8 refers).

- 49 Budget Ministers are yet to receive and consider the Vote Health Four Year Plan and, at this point, no decision is sought on reprioritisation options in Vote Health, or on any change to Health's Budget 2013 operating allocation. Further advice will be provided on detailed costings and changes to appropriations, including any offsetting savings and reprioritisation options. The policy costings are subject to considerable uncertainty as they depend on the demand response by disabled people and family carers, and the uncertainties of implementation. These forecasting risks will also be managed within Vote Health.
- 50 If policy changes result in forecast savings in Vote Social Development (for example, from abatement of DPB - CSI payments), these savings will be applied to offset the gross costs to Vote Health through fiscally-neutral adjustments between Votes.

Publicity

- 51 The Minister of Health will continue to take the lead role in making public statements about the Family Carers case. The public consultation document indicated that the Government would announce its response in early 2013. An announcement of the final policy will be deferred until early March 2013, by which time the Government will have had an opportunity to consider the issues included in paragraph 35 above. That is because those decisions may change the tenor of the Government's announcement.
- 52 I intend to make the final Summary of Submissions available at the time that I make public announcements on the Government's response to the Family Carers case.

Recommendations

- 53 The Minister of Health recommends that Cabinet Social Policy Committee:
- 1 **note** that the plaintiffs have agreed that they will not take further action to lift the Order suspending the Human Rights Review Tribunal's declaration in the Family Carers case (Ministry of Health v Atkinson & Others) until at least May 2013;
 - 2 **note** that the Ministry of Health consulted with the disability and carers communities and the wider public on possible options for responding to the discrimination against family carers;

Preferred approach for an initial response

- 3 **agree** that the Ministry of Health's existing policy of not paying family carers be changed to allow adult disabled people to employ their parents, or other adult family members who reside with them, to provide them with Home and Community Support Services;
- 4 **agree** that the policy change in recommendation 3 above would not allow spouses of disabled adults and parents of disabled children to be paid as family carers or for funding to be allocated to a disabled person to enable them to employ spouses, or parents of disabled children;
- 5 **agree** that the preferred approach for changing the Ministry of Health's policy be the following:
 - 5.1 **targeting:** Ministry of Health funding be allocated to adult disabled people to enable them to employ their parents or other adult family members who reside with them to provide them with Home and Community Support Services in the following circumstances:

- 5.1.1 in very high need situations, which means the ability of disabled people to remain living at home is under threat because their family situation is at risk of breakdown, often because of multiple factors including the family carer's caring responsibilities;
- 5.1.2 in high needs situations, which means that disabled people have such high support needs that meeting those needs means that a family carer who wishes to work full time in another job outside the home is unable to do so; and
- 5.1.3 in other 'exceptional circumstances' where consideration would be given to paying family carers who fall outside the targeting criteria but where there is a very good case for paying them.
- 5.2 **amount of funding allocated:** the funding allocated to adult disabled people to employ their parents, or other family members who reside with them, to provide them with Home and Community Support Services be based on the minimum wage plus associated employment costs such as annual and sick leave, public holidays, Kiwisaver contributions and ACC levies;
- 5.3 **independent support:** that when consideration is being given to allocating funding to enable the employment of family carers in the Needs Assessment and Service Coordination process, that a disabled person be supported by a person who is independent of anyone who could be paid to provide disability support services unless they explicitly decline such support;
- 5.4 **monitoring:** that there will be independent monitoring of disabled people's quality of life when family carers are paid to provide support;
- 6 **note** that, based on the current minimum wage, the funding that will need to be allocated to adult disabled people to enable them to employ their parents or other family members who reside with them to provide them with Home and Community Support Services is estimated to be approximately \$16 an hour (which is based on the costs that contracted providers currently pay most non-family carers);
- 7 **note** that the Ministry of Health, working in conjunction with the Needs Assessment and Service Coordination Association, will strengthen the current principles-based approach to determining the extent of unpaid support that family carers are able to provide so that decisions are more consistent and transparent and reflect the implications of paying some family carers to provide disability support;

Implementation

- 8 **note** that the terms and conditions on which disabled people who are allocated Ministry of Health funding can employ family carers will be set out in a Notice that will be issued by the Minister of Health under Section 88 of the New Zealand Public Health and Disability Act 2000;
- 9 **note** that the Minister of Health intends to implement the proposed initial response by October 2013, but that the lawful continuation of the Ministry of Health's current policy between May and October 2013 will require either cooperation from the plaintiffs or the Courts deciding to not lift the Suspension Order until that date;
- 10 **note** that there is uncertainty around the estimated fiscal costs that are outlined in this paper and that the Ministry of Health will need to closely monitor actual versus expected expenditure;

Financial implications

- 11 **note** that the net cost to the Crown of policy changes affecting services funded through Vote Health will be met within Vote Health baselines, and from the Vote Health operating allocation for Budget 2013;
- 12 **note** that on 27 August 2012, Cabinet noted that Budget Ministers will assess whether the indicative allocation for Vote Health needs to be reviewed as work on the Government's response to the Family Carers case is progressed and the cost of policy options clarified. [CAB Min (12) 30/8 refers];
- 13 **note** that Budget Ministers are yet to receive and consider the Minister of Health's 4 Year Plan for Budget 2013, and at this point, no decision is sought on reprioritisation options in Vote Health, or on any change to Health's Budget 2013 operating allocation;
- 14 **note** that, during the budget decision cycle, further advice will be provided on any required changes to appropriations;
- 15 **agree** that if the policy of paying family carers results in forecast savings in Vote Social Development (for example, from the abatement of Domestic Purposes Benefit – Care of the Sick and Infirm payments), that these savings will be transferred to Vote Health through fiscally-neutral adjustments;

Next steps

- 16 **note** that the preferred approach itself may result in potential discrimination that the courts may find to be unjustified under the New Zealand Bill of Rights Act 1990;
- 17 **invite** the Minister of Health to report back to the Cabinet Social Policy Committee in February 2013 (and before final budget decisions are taken by Budget Ministers), with further advice and recommendations on:
 - 17.1 legal issues with the preferred approach;
 - 17.2 changes to the preferred approach above that may be required to address those legal issues; and
 - 17.3 regulatory and/or legislative changes that would be required to support implementation of the preferred approach.
- 18 **note** that the Governments' preferred approach will be confirmed following the report back in recommendation 17 above;

Broader implications

- 19 **note** the following outstanding significant risks generated by the Family Carers case:
 - 19.1 for support funded by the Ministry of Health, such as whether the spouses of disabled adults and the parents of disabled children should be paid, and the impact on support other than Home and Community Support Services;
 - 19.2 for support funded by District Health Boards, particularly for people with age related disabilities; and
 - 19.3 {redacted under Official Information Act 1982 Section 9(2)(f)(iv) to maintain confidentiality of advice between Ministers of the Crown and officials}

- 20 **invite** the Minister of Health to report back to Cabinet Social Policy Committee in February 2013 with options, which may include legislative change, to reduce the risks associated with responding to the outstanding significant risks generated by the Family Carers case;

Publicity

- 21 **invite** the Minister of Health to make public statements about the response to the Family Carers case at appropriate times.



Hon Tony Ryall
Minister of Health

11/12/12

