

Cabinet Social Policy Committee

PAID FAMILY CARERS CASE: WORK TO DATE AND SCOPE OF FUTURE POLICY WORK

Proposal

- 1 This paper updates Ministers on work to date and outlines a future work programme for responding to *Ministry of Health v Atkinson & Others*¹ (the Family Carers case).

Executive summary

- 2 In May this year the Court of Appeal found the Ministry of Health's policy of excluding specified family members from payment for the provision of care to be unjustified discrimination. The case was focused on the parents of disabled adult sons and daughters who wished to deliver Ministry of Health funded support at home.
- 3 The Government has decided not to seek leave to appeal the Court of Appeal's decision in the Family Carers case to the Supreme Court (CAB Min (12) 20/13 refers). This means the Ministry of Health must change its policy of not allowing the payment of family carers (parents, spouses and resident family members) who deliver disability support services.
- 4 The Ministry of Health has developed three preliminary policy options to respond to the discrimination against the parents of disabled adult sons and daughters that was the focus of the case:
 - a Option One – Remove the prohibition on the payment of these parents so that they can be paid on the same basis as formal carers.
 - b Option Two – Pay these parents for care provided above a reasonable level.
 - c Option Three – Pay these parents for care they provide in exceptional circumstances (which could also be combined with Option Two).
- 5 For each of these options, consideration needs to be given to a range of issues, including:
 - a whether payment can be limited to the parents of disabled adult sons and daughters, or whether an approach encompassing all family carers would be required;
 - b whether the immediate policy change can be limited to Home and Community Support services only, or if a broader approach would be required;
 - c whether family members should be paid as employees or in some other way (e.g. an allowance);
 - d what level of payment should be made;
 - e what is required to monitor the quality of support; and
 - f the likely fiscal costs and risks.
- 6 Further development and evaluation is required before a preferred option can be selected. As part of this work, there will be public consultation on how the Government might respond. The Technical Advisory Group, established to provide advice during the policy process, strongly supports consultation with the disability and carers communities to gain their input. An Expert Group will also be established to provide assurance about the estimated fiscal costs and risks.

¹ *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

- 7 Officials have also considered the broader implications of the case for other government policies and programmes. The most significant of the broader legal risks arising from the Family Carers case is related to the general Vote Health policy of not allowing the payment of parents, spouses and resident family members to deliver support to a range of other groups, including older people. *{redacted under Official Information Act 1982 Section 9(2)(f)(iv) to protect confidentiality of advice between Ministers of the Crown and officials}*
- 8 The Ministry of Health is seeking agreement from the plaintiffs to have a year from the date of the Court of Appeal decision in which to develop, consult on and implement an alternate policy. If agreement cannot be reached with the plaintiffs, the Ministry of Health will approach the Courts. Having less than a year may limit or prevent consultation.

Background

- 9 The decision by the Government to not seek leave to appeal the Court of Appeal's decision in the Family Carers case to the Supreme Court means the Human Rights Review Tribunal's declaration stands (CAB Min (12) 20/13 refers). That declaration was that the Ministry of Health's policy of not allowing the payment of specified family members for the provision of funded disability support services is inconsistent with section 19 of the New Zealand Bill of Rights Act 1990 (NZBORA) in that it limits the right to freedom from discrimination, both directly and indirectly, on the grounds of family status and is not, under section 5 of that Act, a justified limitation.
- 10 The Family Carers case focused on the parents of disabled adult sons and daughters who required an ongoing and high level of care. These parents wished to support their adult sons and daughters at home but were not able to be paid to do this with Ministry of Health funding. The Courts held that the policy of not paying parents to provide this care when non-family members would be paid to do so was not justified. That was because there is no duty or expectation to provide ongoing unpaid care to adult sons and daughters.
- 11 Work responding to the Family Carers case is led by the Ministry of Health and overseen by the Social Sector Forum, which comprises Chief Executives from the Ministries of Health, Education, Social Development, Housing and Justice, and supported by a multiagency Senior Officials Group established to address issues related to Family Carers. The focus of the work has been on the following two issues:
 - a developing policy options the Ministry of Health could implement in the near future to respond to the discrimination in the particular programmes that were identified by the Courts. The Ministry of Health has been assisted by the Senior Officials Group, as well as a Technical Advisory Group consisting of people with expertise and/or lived experience of disability, caring, the disability support system, and fiscal management; and
 - b understanding the implications of the case for other support and programmes funded by the Ministry of Health, District Health Boards (DHBs) and other government agencies.

NEXT STEPS IN THE LEGAL PROCESS

- 12 The next step in the legal process for the specific programmes considered by the Courts is for the parties to try and agree on when the order suspending the Human Rights Review Tribunal's declaration (that the policy of not paying family caregivers contravenes the NZBORA) will be lifted. This date is crucial in determining how long the Government has to develop, consult on and implement an alternative policy. That is because once the suspension order is lifted, the current policy will become unlawful.
- 13 The Crown will be seeking to have 12 months after the Court of Appeal decision to develop and implement a new policy for parents of adult disabled sons and daughters before the suspension order is lifted. If a date to lift the suspension cannot be agreed

between the parties, the Courts will need to determine the date. A separate remedies hearing is expected to take place near the end of 2012.

Comment

- 14 The Family Carers case raises issues which go to the heart of the relative responsibilities of the state and families, and the degree of responsibility that family members in different situations have towards each other. Resolving this issue will involve making choices on issues on which there are deeply held and difficult to reconcile views across society, with substantial implications for the way that government overall operates and/or fiscal costs. At the same time, it will be necessary to choose an option that, if it involves discrimination that is contrary to section 19 of NZBORA, can be justified under section 5 of that Act.

OPTIONS

- 15 The primary focus of work to date has been on responding to the discrimination against the parents of disabled adult sons and daughters who wish to deliver Ministry of Health funded Home and Community Support Services, as that will have the most direct bearing on the future legal process. The following options are currently being considered:
- a **Option One – Remove the prohibition on the payment of parents of disabled adult sons and daughters so that they can be paid on the same basis as formal carers:** this would involve allowing these parents to be paid to deliver Home and Community Support Services when the level of support required is above what unpaid family carers are willing to provide. The current needs assessment and service coordination (NASC) process (under which paid supports complement gaps that are not met by unpaid natural supports) would continue to be used.
 - b **Option Two – Pay the parents of disabled adult sons and daughters to provide care when the amount of care provided by unpaid natural supports is above a reasonable level:** this would involve allowing these parents to be paid to deliver Home and Community Support Services when the level of support required is over and above what it is reasonable for unpaid natural supports to provide. What constitutes reasonable care would need to be defined, and a process for determining it developed, both of which could be controversial.
 - c **Option Three – Pay the parents of disabled adult sons and daughters for care in exceptional circumstances:** this would involve allowing these parents to be paid to deliver Home and Community Support Services when the level of support required is exceptional. What constitutes exceptional circumstances would need to be defined, and a process for determining it developed, both of which could be controversial.

Some possible scenarios

Joanna and Michael have a 25 year old son, Sam, who has muscular dystrophy and requires 28 hours of support each week. Sam's strong preference is that his parents provide him with support. Together, Joanna and Michael are willing to provide five hours each week unpaid, but are not willing to give up their jobs or their weekend to provide the other 23 hours of support each week without payment. Michael is self-employed and has some flexibility over his hours of work, so would be willing to provide the additional support provided he got paid to do so.

Under Option One, Michael could be paid to provide the 23 additional hours of support each week.

Under Option Two, the assessment may show there is a reasonable expectation on Joanna and Michael to provide ten hours of natural support for Sam. So Michael could be paid to provide the 18 additional hours of paid support each week.

Under Option Three, Joanna and Michael are unlikely to be paid to provide support as there are no exceptional circumstances.

INITIAL ASSESSMENT

- 16 Because of the complex challenges raised by this work, there has been a strong focus on developing criteria to evaluate the policy options. The following criteria have been identified:
 - a the impact on disabled people's choice and control over the support they receive
 - b the impact on carers' life choices and opportunities
 - c the impact on the quality and safety of paid support received by disabled people
 - d the broader implications for other parts of government and society generally
 - e the impact on the availability of unpaid natural supports
 - f fiscal costs and risks
 - g whether any discrimination under NZBORA can be justified
 - h operational feasibility and implementation issues and risks
 - i the likelihood that disabled people and family carers will understand and accept the approach.
- 17 Officials' initial assessment is that no option is clearly better than the others when considered against these criteria, with each of the options involving trade-offs. Whichever option is chosen, consideration also needs to be given to a range of other issues, including the following:
 - a whether it is possible to limit consideration only to parents of disabled adult sons and daughters, or if a broader approach encompassing other close family members is required;
 - b whether any policy change is limited only to Home and Community Support Services or if it should also be applied at the same time to other support that is funded by the Ministry of Health;
 - c whether family members should be paid as employees or treated in some other way, and paid another form of payment (such as allowances, grants, subsidies or tax credits) and what level of payment should be made;
 - d determining what steps may be required to monitor the quality of support provided by paid family members and to maintain the choice and control of the disabled person or the family carer (e.g. preventing people becoming 'trapped' in an unsuitable caring arrangement); and
 - e determining what steps may be required to manage the overall fiscal cost and risks that arise from paying family carers, aside from the changes to the allocation process that result from allowing them to be paid (e.g. having a cap on payment to family carers).
- 18 Further development and evaluation of the policy options is required before a preferred option can be selected. This should include a public consultation process to ensure wide input on this complex policy issue. The Technical Advisory Group is of the view that the disability and carers communities should be widely consulted before any decisions are made. Such an approach is likely to be viewed favourably by the Courts, result in a greater degree of acceptance by the disability and carers communities of the agreed approach, and lead to policy that is more robust than would otherwise be the case.

Broader implications

- 19 The focus of work to date on identifying the broader implications of this case has been on assessing the extent of legal risk arising from the particular decisions made by the Court in the Family Carers case. Agencies have undertaken a comprehensive assessment of the areas of potential legal risk arising from the Family Carers case. Their assessments

were reviewed by the Crown Law Office, with a summary considered by the Family Carers Senior Officials Group and Social Sector Forum Chief Executives. Appendix One summarises the range of potential risks that were identified by agencies.

20 Some policies or programmes have been assessed as having a significant risk of being found to involve unjustified discrimination. Significant risks arise when the Government is prepared to pay non-family members to provide support and/or assistance to another family member, but not pay family members for the same support and/or assistance in circumstances where the expectation of unpaid family support goes beyond what is normally expected of a family.

21 The areas assessed as having the most significant level of legal risk are the following:

a Vote Health: There are two areas of significant risk that were not the direct focus of the Family Carers case:

i Ministry of Health: Family carers, other than the parents of disabled adult sons and daughters, who are not able to be paid to provide support. These family carers include spouses, parents in the case of younger children, and other resident family members. The support these family carers cannot be paid to provide includes Home and Community Support Services, Carer Support and, potentially, other services such as Respite Care, Day Services and Residential Care.

ii DHBs: Family carers who are not able to be paid to support people with age-related and long-term medical conditions, people requiring short-term support following discharge from hospital and people experiencing mental health conditions. The support these family carers cannot be paid to provide includes Home and Community Support Services, Carer Support and, potentially, other services such as Respite Care and Residential Care.

Current expenditure across Vote Health on professionally-provided Home and Community Support Services is about \$350 million per annum. The Ministry of Health's early estimates of the additional fiscal risk implied by the Court decision is in the order of \$120 million to \$200 million per annum across Vote Health (of which, \$40 to \$70 million per annum relates to disability support funded through the Ministry of Health). The actual fiscal costs, however, will depend on the policy option chosen, how it is implemented and behavioural response by disabled people and carers (i.e. there is an element of how long is a piece of string).

b *{redacted under Official Information Act 1982 Section 9(2)(f)(iv) to protect confidentiality of advice between Ministers of the Crown and officials}*

22 Estimating the possible fiscal impact of these risks is a complex and challenging task as they involve modelling how people will change their behaviour in response to alternative policy options and, in the early stages, making assumptions relating to their design that may have a significant impact on the actual costs. To provide assurance that its future cost estimates are reasonable, the Ministry of Health will establish an Expert Group, including external reviewers, to oversee this work. Other agencies will be able to access the Expert Group to assist with assessing their fiscal risks.

23 There is also a range of areas where there is differential treatment on the basis of family status but where the risk that policies or programmes will be found to involve unjustified discrimination is lower. The lower level of risk arises primarily because the differential treatment arises in circumstances where there is a higher level of expectations that families have the primary responsibility for providing care and support to each other and that they would not normally be paid by the Government to meet those responsibilities.

Examples of such family responsibilities include the care and support that spouses provide to one another and parental care and support to children and young people.

- 24 Some policies and programmes that were considered as posing a potential risk were found to involve no differential treatment of the sort that was at issue in the Family Carers case.

OTHER RISKS

- 25 There may also be non-legal risks arising from the wide-spread attention that the Family Carers case has received that need to be taken account of in the policy development process. One risk is that families may seek to increase their use of existing mechanisms that transfer responsibility from unpaid natural support to the government. For example, more families than at present may indicate during the NASC process that they will not provide unpaid support for family members with disabilities. This risk relates to support funded through both the Ministry of Health and DHBs. This would effectively mean that the Government will either need to fund increased demand for paid support and/or reduce the amount of support or funding allocated to other people.
- 26 There may be similar risks arising for other Government programmes. There is also a risk that the Family Carers case may highlight the differential treatment of families when caring for family members depending on which agency is providing the funding.

Next steps

- 27 The decision on when the suspension order is lifted determines when an alternative policy for the payment of family carers needs to be in place. The Ministry of Health is seeking agreement from the plaintiffs to a year from the date of the Court of Appeal decision to develop, consult on and implement an alternative policy. If a date to lift the suspension cannot be agreed between the parties, the Courts will need to determine the date.
- 28 Table One sets out an indicative timeline for future work, assuming that a year is available to develop, consult on and implement an alternate policy. If, however, the Suspension Order is lifted in less than 12 months, the work programme may need to be streamlined, e.g. by limiting consultation, not consulting, and/or by considering only the immediate issue of discrimination arising from not being able to pay parents of disabled adult sons and daughters. The indicative timeline will be revised once the date on which the suspension order will be lifted is known.

TABLE ONE: INDICATIVE TIMELINE RELATING TO MINISTRY OF HEALTH FUNDED SUPPORT

Date	Deliverable
Early to mid-August 2012	TAG and Social Sector Forum consider policy options, costings and implementation issues
29 August 2012	SOC considers detailed policy options, costings and implementation issues and a draft consultation document
3 September 2012	Consultation document circulated
September/ October 2012	Consultation workshops with the sector
31 October 2012	Consultation period closes
10 December 2012	Cabinet considers the results of the consultation process and decides on new policy
January 2013	New policy announced
February to June 2013	Ministry of Health implements the agreed policy option(s)

- 29 While there will continue to be ongoing work assessing the risks arising from the case for support funded through DHBs, the in-depth policy work needed to develop, consult on and implement any policy responses for DHBs will begin once Cabinet has made decisions

relating to disability support funded through the Ministry of Health. If the timetable outlined in Table One above is followed, the in-depth work relating to DHB funded support could commence in the first part of 2013.

- 30 *{redacted under Official Information Act 1982 Section 9(2)(f)(iv) to protect confidentiality of advice between Ministers of the Crown and officials}*

Consultation

- 31 The Treasury, Crown Law Office, the Ministries of Education and Social Development, Veterans' Affairs New Zealand, the Office for Disability Issues, the State Services Commission and ACC were consulted on drafts of this paper. The Department of Prime Minister and Cabinet was informed of the contents of the paper.
- 32 Information on the risks arising from the Family Carers case was also sought from the Departments of Building and Housing, Corrections, Labour and Internal Affairs, the Ministries of Pacific Island Affairs, Women's Affairs, Transport and Foreign Affairs and Trade, the New Zealand Defence Force, the New Zealand Customs Service, the New Zealand Transport Agency, Te Puni Kokiri and the Housing NZ Corporation.
- 33 The Technical Advisory Group was consulted on the options that are included in the Cabinet paper. It strongly recommends consulting with the disability and carers communities on this issue prior to final decisions being taken. They saw consultation as likely to improve the quality of the decisions that are made and the ownership of them within the disability and carers communities.

Regulatory impact analysis

- 34 There are no proposals in this paper that require the preparation of a Regulatory Impact Statement.

Human Rights Implications

- 35 The Court of Appeal has upheld the decisions of the High Court and the Human Rights Review Tribunal that the Ministry of Health's policy of not paying family carers amounts to unjustified discrimination under NZBORA. The Courts' rulings have given some guidance on tests for compliance with NZBORA, and ensuring that policy solutions do not involve unjustifiable discrimination will be a key criterion for policy design.

Legislative Implications

- 36 There are no legislative implications arising from the recommendations in this paper.

Gender Implications

- 37 The group of people most directly affected by the Family Carers decision are those who provide unpaid care to their adult sons and daughters who have disabilities. The majority of this unpaid care is provided by female family members.

Disability Perspective

- 38 There are differing views in the disability and carers communities on whether family members should be paid for providing care, with many people recognising the dilemmas raised by the Family Carers case. A core objective of the policy process is to find a way of addressing the issue that recognises and respects these differing views.

Financial Implications

39 The financial implications are discussed in paragraph 21 above.

Publicity

40 The Minister of Health will continue to take the lead role in making public statements about the Family Carers case. The Ministry of Health and Crown Law are considering the best way to communicate with plaintiffs during the policy development process provided that doing so does not jeopardise the legal process.

Recommendations

41 The Minister of Health recommends that Cabinet Social Policy Committee:

- 1 **Note** that the decision to not appeal the Court of Appeal's decision in the Family Carers case (CAB Min (12) 20/13 refers) means that the focus of future work is now on understanding the implications of the decision and developing policy responses.
- 2 **Note** that the highest priority for future work is developing a response to the particular discrimination that was considered by the Courts in reaching their decisions - the Ministry of Health's policy of not paying the parents of adult sons and daughters to deliver Home and Community Support services.
- 3 **Note** that the next highest priority is developing responses to the other significant legal risks that have been identified as arising from the general policy across Vote Health of not allowing the payment of parents, spouses and resident family members to deliver support *{redacted under Official Information Act 1982 Section 9(2)(f)(iv) to protect confidentiality of advice between Ministers of the Crown and officials}*
- 4 **Note** that the date on which the order suspending the Human Rights Review Tribunal's declaration of discrimination is lifted will be determined either through agreement with the plaintiffs or through a decision by the Courts.
- 5 **Agree** that, if the timeframe for lifting the Suspension Order allows, the Ministry of Health consult with the disability and carers communities on how the Government might respond to the issues raised by the Family Carers case.
- 6 **Invite** the Minister of Health to report to Cabinet Social Policy Committee in August 2012 on:
 - 6.1 the policy options, costings and implementation issues for responding to the particular discrimination that was considered by the Courts in the Family Carers case.
 - 6.2 If there is sufficient time to consult with the disability and carers' communities, a document on which to base a consultation process.



Hon Tony Ryall
Minister of Health

15/7/12