

Cabinet Social Policy Committee

PAID FAMILY CARERS CASE: IMPLICATIONS OF THE COURT OF APPEAL'S DECISION

Proposal

- 1 This paper identifies the implications of the Court of Appeal's decision in *Ministry of Health v Atkinson & Others*¹ (the Family Carers case) and sets out a process for responding to those implications.

Executive summary

- 2 The Court of Appeal upheld the decisions of the Human Rights Review Tribunal and the High Court that the Ministry of Health's policy of not paying family carers of adults with disabilities is unjustified discrimination on the basis of family status, which is prohibited under Sections 5 and 19 of the New Zealand Bill of Rights Act 1990 (NZBORA). The next step in the legal process is for the Attorney-General to decide whether to seek leave to appeal the decision to the Supreme Court. If that does not happen, or an Appeal to the Supreme Court is unsuccessful, then the plaintiffs can seek a remedies hearing.
- 3 The most immediate implications of the Court of Appeal's decision are for the organisation and funding of disability supports that are managed by Disability Support Services in the Ministry of Health. The additional costs of implementing the Court's decision without making other changes to the disability support system could be in the range of \$20 to \$680 million per annum, depending on the proportion of people who seek to be paid.
- 4 Officials have identified some possible implications for some services funded through District Health Boards (DHBs) and through Votes Social Development and Education. There may also be other implications that have not yet been identified. Further work is being done to quantify the financial and service delivery implications and risks for other agencies and possible policy responses to them.
- 5 An initial analysis suggests that there are several broad policy responses possible to the impact of the Court of Appeal's decisions on Disability Support Services:
 - a Changing the entire system so that the issue of whether family carers are paid is addressed in completely different ways to present.
 - b Implementing a mechanism for paying family carers alongside, or within, the current system.
 - c Using legislation to overturn the Courts' decisions.
- 6 Each of these options has different service delivery, legal and financial costs and risks and differing impacts on disabled people and family carers. The Ministry of Health has appointed a Technical Advisory Group from the disability sector to help it work through the issues and options.
- 7 I will update Cabinet again once a final decision has been made on whether to appeal *Ministry of Health v Atkinson & Others* to the Supreme Court.

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

Background

- 8 Needs assessment and service coordination organisations (NASCs), allocate paid disability supports (such as Home and Community Support Services²) to meet gaps in identified needs where natural supports (primarily family carers) are unable or unwilling to provide the care required (known as 'unmet need'). Families are not, however, compelled to provide a minimum level of support.
- 9 Since at least 1991, the Ministry of Health and its predecessors have operated a policy of not paying spouses, parents or resident family members to provide care for their disabled relatives. The policy was not explicitly adopted by Parliament or Cabinet, but was based on a premise that there is an implicit social contract that families have primary responsibility to provide support to their family members, with the care provided by families regarded as "natural support".
- 10 The policy means that parents, spouses and resident family members cannot be paid to deliver support services that are funded by the Ministry of Health, such as Home and Community Support Services (including when this type of support is accessed through Individualised Funding rather than a contracted provider).
- 11 Rather than being paid, the caring roles of families is acknowledged and supported through assistance such as carer support, which provides a subsidy to a full-time unpaid carer towards the cost of paying another person to provide care; respite care, which is designed to provide short-term breaks for the carers of a disabled person; and the provision of information and advice through, for example, Disability Information and Advisory Services.

THE CASE

- 12 In 2001, the Ministry's policy of not paying family carers was challenged by Susan Atkinson, who was joined by eight other people who were either disabled adults or the parents who provided care to those disabled people. They made complaints to the Human Rights Commission and, in 2005, the Director of the Office of Human Rights Proceedings agreed to represent them and took the case to the Human Rights Review Tribunal.
- 13 The Human Rights Review Tribunal released its decision in January 2010 which declared that the policy is discriminatory. The plaintiffs sought other remedies, including damages, but the Tribunal has yet to determine remedies other than declaratory relief because the parties agreed at the outset that would be heard later. Following the declaration that the policy was discriminatory, the Ministry was granted an order suspending the effect of the declaration until further order of the Tribunal.
- 14 The Crown appealed that decision to the High Court, with the Court upholding the Tribunal's decision in December 2010. The Crown subsequently appealed that decision to the Court of Appeal, which released its decision on 14 May 2012.
- 15 The Court of Appeal found that:
 - a The Ministry of Health's policy of not paying family carers is a distinction on the basis of family status that materially disadvantages family carers, which is a prohibited ground of discrimination under section 19 of the New Zealand Bill of Rights Act 1990 (NZBORA). That was because the effect of the Ministry's policy was that family members, who were willing and able to care for their family members, were denied payment for doing so, with the only point of difference

² People may access Home and Community Support Services through contracted providers or through self-directed purchasing arrangements (also known as individualised funding).

between them and others who provided care being family status. For the disabled respondents, the material disadvantage was being denied their choice of carer.

- b *This distinction on the basis of family status cannot be justified in a free and democratic society, which means that it is not justified under section 5 of NZBORA. The Court did not accept the Crown's argument that there was a social contract under which families have the primary responsibility for providing care to their adult children. In its view there is no "social contract to care for adult children who are disabled for the remainder of their lives on a full-time basis, subject to respite care."*

Neither did it accept that the policy was a proportionate response because paying family members would undermine the independence of disabled people or affect normal family relationships, as it considered that the risks identified could be properly managed. The Court did not accept that the Ministry had shown that removing the policy would have sufficiently significant fiscal impact to justify it in the circumstances. It also noted that the policy was not properly formulated or was uncertain, there were no defined exceptions, and it operated more as a blanket rule than properly developed or formulated policy.

- 16 While it is clear that the Court of Appeal considers that there is unjustified discrimination against the family carers of adult disabled people, it did not specifically consider whether this unjustified discrimination arose in other family caring situations. The Court did not reach specific conclusions on whether it applied to disability supports other than Home and Community Support Services (such as Supported Living).
- 17 *{redacted under Official Information Act 1982 Section 9(2)(h) to maintain legal professional privilege}*
- 18 It is possible for either party to appeal any decisions that are made relating to remedies or the suspension order.

Implications of the Court of Appeal's Decision

- 19 The most immediate implications of the Court of Appeal's decision are for the organisation and funding of disability supports that are managed by Disability Support Services in the Ministry of Health and funded through the National Disability Support Services appropriation. Those impacts arise from family carers seeking to be paid for the support they provide.
- 20 There might be substantial additional cost pressure on Vote Health if disabled people and their families received payment for care which is currently provided free of charge or in residential facilities. These costs would have to be met by increases in Vote Health or by reducing access to other health and/ or disability support services. In 2008, the New Zealand Institute of Economic Research (NZIER) undertook preliminary modelling and estimated the costs of paying family carers might range from about \$20m to about \$680m (\$2011).
- 21 The wide range of NZIER estimates reflects uncertainty, at that point, about how a change in policy would be implemented and the size of the response from disabled people and their carers. The top end, for example, reflects assumptions that 90 per cent of home-based high use or severely disabled clients would seek additional funded care to pay family members, and that 50 per cent of disabled people currently in residential care would move to home-based care provided primarily by family members. The NZIER estimates would be lower if the Government interprets the Court of Appeal's decision as applying only to family carers of adult children (rather than the family carers of disabled people of all ages).

WIDER IMPLICATIONS – VOTE HEALTH

- 22 The Court of Appeal's decision could have implications for some services that are funded through District Health Boards (DHBs). To date, the following types of services have been identified that may be affected by the Court of Appeal's decision:
- a *Support for people with age-related disabilities*, including personal care and household management, assistance with community participation (e.g. as an alternative to day services), and transport to, and support for, participating in other community activities.
 - b *Support for people with mental health conditions*, including visiting clients to check on their welfare, living circumstances and whether they have taken their prescribed medication, and assisting clients with community participation.
 - c *Support for people with chronic health conditions*, including personal care and household management services for people unable to care for themselves due to their condition. Family can also be involved in undertaking procedures at home that would otherwise occur in a clinical situation, for example, home-dialysis.
 - d *Support for people requiring palliative care*, including personal care and household management, assistance with turning people and the maintenance of pain relief.
 - e *Short-term support (less than six months) for people following discharge from hospital*, including personal care and household management, wound care and the administration of medication.
- 23 DHBs, like the Ministry of Health, have a general policy of not paying family caregivers. It should be noted, however, that there are differences between the detailed exceptions arrangements adopted by different DHBs. This means that it is possible that some DHBs may comply with some of the Court of Appeal's approach in the Family Carers case, but others may not.

{Paragraphs 24-26 redacted under Official Information Act 1982 Section 9(2)(f)(iv) to maintain confidentiality of advice between Ministers of the Crown and officials}

Comment

- 27 The policy development process to address the Courts' decisions needs to take place alongside the legal process. The first issue to address is how to respond to the Court of Appeal's decision for Disability Support Services, as these supports are the direct subject of the Family Carers case. An initial analysis suggests that several broad approaches are possible:
- a Changing the entire system so that the issue of whether family carers are paid is addressed in completely different ways to present.
 - b Implementing a mechanism for paying family carers alongside, or within, the current system.
 - c Using legislation to overturn the Courts' decisions.
- 28 The choice of approach is by no means straightforward as each of the broad approaches, and each option within those broad approaches, will have differing service delivery, legal and financial costs and risks, and differing impacts on disabled people and family carers. For example, while paying family carers would address the material disadvantage that the Courts have determined they suffer under the Ministry's current arrangements, doing so can reduce the independence of disabled people, the risk that families will become financially reliant on the income (thereby 'trapping' the disabled person), undermine the development of normal family relationships through professionalising them, and make it difficult to ensure the quality of publicly funded support.

- 29 There are also considerable differences of view within the disability community on the appropriate approach to take and there is no accepted approach internationally to guide us. Accordingly, the Ministry of Health has established a Technical Advisory Group who have strategic thinking skills and a range of lived experience and expertise from across the disability sector to help officials to work through these issues. The Technical Advisory Group includes family carers and disabled people, and people with expertise in Disability Support Services financial management, monitoring, quality and service delivery. The Technical Advisory Group's initial meeting will take place before a final decision is made on whether to appeal to the Supreme Court. They may have insights that assist the Attorney General to make his final decision.
- 30 Further work is required to determine the full implications of the Court of Appeal's decision for other parts of Vote Health and for Votes Social Development and Education. There is also a possibility that the decision has implications for other government agencies. Once the scope of those implications is clearer, the Minister of Health, who will continue to take an overview of this work, will work with the Ministers of Social Development and Education to put in place processes to develop responses to the identified issues. The response to the issues affecting Disability Support Services will be taken into account in developing responses affecting these other areas. The Minister of Health expects that this work will include:
- a The Ministry of Health working with the Technical Advisory Group to identify the service delivery, legal and financial costs and risks, and differing impacts on disabled people and family carers of the options for responding to the Court of Appeal's decision for Disability Support Services.
 - b The Ministry of Health working with DHBs to work out the implications of the Court of Appeal's decision for services that are funded through DHBs.
 - c The Ministries of Education and Social Development, with assistance from Crown Law and the Ministry of Health, working out the broader implications of the Court of Appeal's decision.
- 31 The Minister of Health will update Cabinet once a final decision has been made on whether to appeal to the Supreme Court. That update will include a timeline for addressing the substantive issues raised by *Ministry of Health v Atkinson & Others*.

Consultation

- 32 The Treasury, Crown Law Office, the Ministries of Education and Social Development and ACC were consulted on this paper. The Department of Prime Minister and Cabinet was informed of the contents of the paper.

Financial implications

- 33 If the Court of Appeal's decision in the Family Carers case stands, paragraphs 20 and 21 above comment on the extent of financial implications for Disability Support Services. As discussed in the paper, there may also be financial implications for DHBs and for other Votes. The work programme outlined in this paper will identify and seek to understand and address the financial implications.

Regulatory impact analysis

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

Human Rights

- 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 the New Zealand Bill of Rights Act 1990.

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 is people who provide unpaid care to their adult family members who have disabilities. The majority of this unpaid care is provided by female family members.

Disability Perspective

- 38 There are divergent views in the disability sector on whether family members should be paid for providing care, with many people recognising the dilemmas raised by the Family Carers case. On the one hand, there is a view that support from people in freely given relationships with a disabled person is most likely to lead to the disabled person living an everyday life that is connected to the community. Under this approach, paid support workers – including family members – are seen as having an adverse impact on disabled people's lives as they can inappropriately control the person's life. These risks are exacerbated with the payment of family members because of the risk that both the disabled person and/or the family member feel trapped in unsatisfactory arrangements.
- 39 On the other hand, there is a view that the substantial and on-going support provided to disabled people by family members should be recognised through them being paid. Under this approach, paying family carers allows them to live a more everyday life as they may have had to give up the opportunity to work and earn an income to support the family member with a disability.
- 40 Changes to the way family carers of disabled people are recognised should be consistent with the Disability Action Plan's shared outcome of Enabling Good Lives.

Publicity

- 41 The Minister of Health will take the lead role in making public statements about the Family Carers case.

Recommendations

- 42 The Minister of Health recommends that Cabinet Social Policy Committee:
- 1 **Note** that on 14 May 2012 the Court of Appeal upheld the decisions of the High Court and Human Rights Review Tribunal in *Ministry of Health v Atkinson & Others* that the Ministry of Health's policy of not paying the family carers of adult children with a disability represented unjustified discrimination on the basis of family status.
 - 2 **Note** that the Attorney-General needs to make a final decision on whether to seek leave to appeal to the Supreme Court by 12 June 2012.
 - 3 **Note** that *Ministry of Health v Atkinson & Others* has substantial implications for support funded through the Vote Health National Disability Support Services appropriation, and may have significant implications for some services funded through District Health Boards, the Ministry of Education and the Ministry of Social Development.

- 4 {redacted under Official Information Act 1982 Section 9(2)(f)(iv) to maintain confidentiality of advice between Ministers of the Crown and officials}
- 5 **Note** that the Minister of Health has established a Technical Advisory Group of experts from the disability sector to help officials to work through the issues raised by *Ministry of Health v Atkinson & Others* for supports funded through the Vote Health National Disability Support Services appropriation.
- 6 **Invite** the Minister of Health to update Cabinet again once a final decision has been made on whether to appeal *Ministry of Health v Atkinson & Others* to the Supreme Court.



Hon Tony Ryall
Minister of Health

28/5/12

