Consultation on Paying Family Carers to Provide Disability Support

2012
Foreword

The Government has decided not to appeal the Court of Appeal decision in the family carers case (Ministry of Health v Atkinson and Others). The Government accepts that the Ministry of Health’s blanket policy of not paying certain family carers (parents, spouses and resident family members) for providing home and community support to their disabled family members is discriminatory under the New Zealand Bill of Rights Act 1990.

Deciding how the Government should respond to the court’s decision is challenging. The future policy needs to balance the interests of those who are being cared for, those doing the caring and taxpayers. It needs to address the discrimination but it must be affordable. This decision requires difficult trade-offs.

Views in the community on these issues are strong and divergent. Before it decides how to respond to the court’s decision, the Government is interested in hearing the views of people in the disability and carer communities, as well as in society more broadly.

There are increasing pressures on health and disability expenditure in a tight financial environment. The cost impact of the future policy needs to be explicitly considered. If family carers were to be paid for support they are currently providing, the cost of disability support services would increase significantly. Those cost increases would need to be managed so that the change in policy is affordable. For example, increased costs associated with paying family carers might mean reprioritising other government expenditure. Trade-offs between different policy options will need to be made.

The Ministry of Health has engaged a technical advisory group of individuals from the disability and carer sectors to help it understand the potential issues and develop a policy allowing family carers to be paid for providing home and community support. This group has provided valuable insight into some of the issues facing family carers and the people they support, and group members have provided their perspectives on the issues in this consultation paper.

This consultation paper describes a variety of possible policy options for paying family carers to support disabled people and seeks your feedback on these options. You are also welcome to suggest other options.

The Ministry of Health and I will consider all feedback carefully and make final decisions in early 2013. The new policy is expected to come into effect in May 2013. Please consider the proposed policy options and send in your feedback.

Hon Tony Ryall
Minister of Health
How to make a submission

The Ministry of Health is seeking submissions on policy options for paying family carers for providing home and community support to their disabled adult family members. There are three ways you can make a submission.

1. Complete the online survey at www.surveymonkey.com/s/familycarersconsult

2. Complete the submission form. Download it from www.health.govt.nz/familycarersconsult and either print it out and post it to:

   Family Carers Consultation
   Ministry of Health
   PO Box 5013
   Wellington 6145

   or email it to:

   familycarersconsult@moh.govt.nz

3. Alternatively, you can write a letter if you prefer to raise other issues or address the questions in the document in other ways. You can post or email your letter to the addresses above. Please remember to include your name, address and contact details.

Closing date for submissions

The closing date and time for submissions is 5 pm, Tuesday 6 November 2012.

Future report

The Ministry will publish a report on the analysis of submissions on its website (www.health.govt.nz) in due course.

Official Information Act 1982

All correspondence and submissions on this matter may be the subject of a request under the Official Information Act 1982.

If you consider that any part of your submission or related correspondence should be withheld under the Official Information Act 1982, please include a comment to that effect with your submission and say why you would want it withheld.
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1 Introduction

1.1 Purpose

This consultation paper describes a range of possible policy options for paying family carers providing disability support to disabled people and seeks your feedback on these options. The Government’s immediate priority is to respond to the client groups and services most central to the court’s decision on the family carers case.¹ This means that this consultation paper focuses on seeking your input on options for a policy to deliver Ministry of Health-funded home and community support services to disabled adults that does not discriminate on the basis of family status.

The Government recognises that the court’s decision may have broader implications for other Ministry of Health-funded disability supports and for family carers of other people receiving government-funded support services (such as older people receiving district health board funded supports). This policy development and consultation process will establish a framework for considering the implications of policy options for these broader services and groups.

1.2 References to ‘Ministry’ mean Ministry of Health

References to ‘the Ministry’ in this paper mean the Ministry of Health, unless otherwise specified.

1.3 Structure of document

This first section provides background on the family carers case, the implications of the Tribunal and court decisions, and the Government’s process to develop a response to those decisions. The paper then outlines the considerations that need to be taken into account when developing a policy (section 1.4), describes and analyses possible policy options for paying family carers (sections 4–7), and seeks your views on some ‘hard choices’. Each section is followed by questions on which the Ministry is seeking your views.

1.4 Background

Ministry-funded disability support services

The Government allocated about $13.6 billion in 2012/13 to Vote Health to buy health and disability support services, for New Zealanders. This is a significant portion (approximately 18.5 percent) of total government expenditure. The Government must manage this funding responsibly and ensure the wider health and disability system is efficient and effective while also delivering continuous improvements in health and disability services. The challenge is to ensure high-quality services within costs that are sustainable over the long term.

The Ministry directly spends about $1.028 billion a year of Vote Health funding on a variety of disability support services² for around 30,350 people (usually aged under 65)³ with physical, sensory and intellectual disabilities who need ongoing support, and their carers. Appendix 1 shows the proportion of this funding spent on particular service types, key support the Government funds for carers, and examples of support packages. In addition, government funds significant support for people with a wide variety of other impairments and their carers through district health boards (DHBs) and agencies such as Veterans’ Affairs New Zealand.

Access to most Ministry-funded disability support, including home and community support, is through a needs assessment by a needs assessment and service coordination (NASC) organisation that the Ministry contracts. (See Appendix 2 for information on NASC organisations’ role and the needs assessment and service coordination process.)

Current Ministry policy on paying family carers

For over 20 years, the Ministry and its predecessors have operated a policy of not paying parents, spouses or resident family members to provide support for their disabled relatives.⁴ This approach was based on the view that government-funded disability support services should be allocated to help meet disability support needs that family were unable or unwilling to meet.

² Ministry-funded disability support services include: home and community support; respite and carer support; day programmes; supported living; community residential support; environmental supports; disability information and advisory services; and needs assessment and service coordination services.

³ District health boards fund disability and long-term support for people who are first assessed as needing support at age 65 or over; people aged between 50 and 65 years assessed as having health and support needs because of long-term conditions more commonly experienced by older people; people needing support because of mental illnesses or addictions; and people with chronic health conditions. The Accident Compensation Corporation funds support for people with personal injuries that meet the definition of disability in the Accident Compensation Act 2001.

⁴ Contracted providers of disability and support services may employ family members who are not spouses, parents or living with the disabled person to deliver home and community support services.
Family carers case

In 2001, Susan Atkinson and eight others (the plaintiffs) challenged the Ministry policy of not allowing family members to be paid for providing disability support services by taking complaints to the Human Rights Commission. Their case (known as the family carers case) focused on the parents of disabled adult sons and daughters who required an ongoing and high level of care. The Human Rights Review Tribunal considered the case, and in January 2010 released its decision that the policy was discriminatory. The Tribunal issued a declaration that the Ministry’s policy was inconsistent with section 19 of the New Zealand Bill of Rights Act 1990 because it limited the right to freedom from discrimination on the grounds of family status and was not a justified limitation under section 5 of that Act.

The Crown appealed the Tribunal’s decision through the High Court6 and the Court of Appeal.7 In May 2012, the Court of Appeal released its decision that declined the Crown’s appeal. The Government decided not to appeal this decision. This means the Ministry must change its policy to avoid discriminating against family carers providing funded disability support services.

Following the Tribunal’s decision in 2010, the Ministry applied for a suspension order to suspend the Tribunal's declaration. This order would allow the Ministry to continue to operate its policy without acting unlawfully until all appeals had been heard. Also, if the Ministry was ultimately unsuccessful, the Ministry would have a further 12 months to develop a replacement policy. The Tribunal’s decision has been suspended with the plaintiffs’ consent. However, if the plaintiffs withdraw their consent, the Tribunal would need to determine whether to order ongoing suspension. The possibility that the suspension order could be lifted at any time means the Government must make its decisions as quickly as reasonably possible.

Cost implications of paying family carers

At the Tribunal, the Ministry presented expert evidence from Mr De Raad, an economist and Deputy Chief Executive of the New Zealand Institute of Economic Research (NZIER), on the estimated increased cost of allowing family carers to be paid for providing disability support.

Mr De Raad estimated the increased costs to be between $17 million and $593 million per year. This range reflected the difficulty of accurately predicting the extent to which families would seek payment if it was available.

The lower end of the range assumed 10 percent take-up from family members of an estimated 29,000 eligible people with severe disabilities that did not currently receive government funding and were assumed to be cared for by unpaid family members. The upper end assumed 90 percent take-up in this population, that disabled people in residential care would return to community care and that this shift would be more costly for government than continuing to support these people in residential care settings. Mr De Raad noted that his estimates were based on services funded by the Ministry of Health and would be twice as much again if it included disability support services funded by DHBs because DHBs fund services for a much larger number of people.

The plaintiff’s expert economist, Dr Easton, disputed the NZIER evidence and concluded that the likely impact would be at the lower end of the range, and at most $32 million to $64 million per year, but probably considerably lower.

The Tribunal and the High Court preferred the evidence that costs would be at the lower end of the range. They both expressed a view that it would be possible to contain the take up and therefore the fiscal impact.

The High Court’s view was that the take up could be relatively modest if “changes were initiated cautiously, with training and monitoring” and that the policy could be reviewed in the event that it became financially unsustainable.

The Tribunal considered a number of strategies could be available to limit the financial impact and gave two examples. One example was to limit eligibility and operate an exceptions policy, with approvals given on a case by case basis and scaled to the availability of funding. Criteria for approval could include the personal and family circumstances, the carers preparedness to be trained and monitored and the need for regular carer relief. The other example was to limit the financial impact by control through the Individualised Funding option.

Implications of the court’s decision on policy

The family carers case raises issues that go to the heart of the relative responsibilities of government and families, and the degree of responsibility that family members in different situations have towards each other. The effect of the Tribunal’s declaration is to change the relative responsibility of government and family for the provision of disability support services.

While the Ministry’s policy also did not allow spouses and resident family members as well as parents to be paid with Ministry funding, the plaintiffs in the case were all disabled adults who wished to have their parent provide paid support, or the parent who provided care to an adult disabled son or daughter in the family home.

Individualised funding is a mechanism for paying for disability support. It offers disabled people more choice and control by allocating a certain number of hours of support and enables disabled people to have more choice and control over how their support needs are met. It is currently applied to home and community support services.
A significant part of the court’s reasoning was that society does not generally expect that parents will continue to provide life-long unpaid support to disabled adult family members. The court’s determination focused on the provision of home-based support services because the other services considered in the proceedings were designed for people who wished to live independently of their family.

In response to the court’s decision, the Ministry’s focus is on developing a policy that will not unjustifiably discriminate on the basis of family status in the provision of Ministry-funded home and community support to a disabled adult. The Ministry expects that family members will continue to provide some unpaid care. This expectation may vary according to the family relationship and circumstances. The courts do not require government to fund all support that disabled people need.

An objective of the new policy to be developed is that any different treatment of family carers that causes material disadvantage must be justifiable under section 19 of the New Zealand Bill of Rights Act 1990.

**Policy development process**

The new policy needs to be able to be implemented quickly so it can be in place when the suspension order is lifted. This means the Ministry must focus first on the client groups and services most central to the court decision. Therefore, the focus of this consultation process is on parents and resident family members of disabled adults and the provision of home and community support services.

The family carers case may have broader implications for other Ministry-funded disability support services such as carer support, and for other client groups such as those funded by district health boards and other government agencies. This consultation does not focus on these services and groups as there are limits on the range and scope of issues that can be effectively addressed in the current process. This is because the range of people to be consulted on the broader services would be considerably wider than is the case for Ministry funded disability supports and there are likely to be a range of different factors to consider when thinking about the carers of different groups of people. This policy development and consultation process will establish a framework for considering the implications of policy options for these broader services and groups.

The Ministry is aware that individuals in the disability and carers communities have different views about whether family members should be paid for providing support and what form any payment should take. This approach also highlights that paying family members brings with it an associated risk that both the disabled person and/or the family member feel unable to change unsatisfactory arrangements. Others consider that the substantial and ongoing support family members provide to disabled people should be recognised through payment. This policy process aims to address the issue while recognising and respecting these differing views.
A technical advisory group of people with expertise in or lived experience of disability, caring, the disability support system, and managing funds for disability support is assisting the Ministry to develop policy options. An expert advisory group on economic issues is advising the Ministry on the financial risks and economic impacts of policy options. People from key government agencies are also contributing to policy development through a senior officials group.

Further development and evaluation of the options in this paper is needed before Ministers make decisions about the policy. Your input to this public consultation process is an important contribution to the policy development process.

**Important considerations in designing a good policy**

The policy needs to address the discrimination issue that the courts identified. It also needs to take account of other considerations.

The cost of any policy needs to be explicitly considered, especially given the increasing pressure on health and disability expenditure in a tight financial environment. If family carers were to be paid for support they are currently providing unpaid, the cost of disability support services would increase significantly. Cost increases need to be managed, so that the change in policy is affordable. For example, increased costs associated with paying family carers will require government to reprioritise other expenditure or reduce the level of funded support for the wider disability client group. Costs may need to be managed, for example by developing a policy that targets people in certain situations (such as people caring for disabled family members with very high needs). Trade-offs between different policy options need to be made.

The Ministry’s economic evidence in the family carers case was that the cost of eliminating the policy might range from $17 million to $593 million (in 2006 dollars). The lower end of the range assumed 10 percent of people receiving minimal or no support from the Ministry would come forward to be paid as carers. The courts held that the Ministry had not provided sufficient evidence to establish costs would be higher than those at the bottom end of the range, which it said were not of sufficient magnitude to justify any discriminatory effect. However, the courts did recognise that cost is a legitimate issue to take in to account when designing, managing and implementing any policy.

The Government also needs to consider:

- how the policy affects disabled adults’ choices in and control over their lives
- how the policy affects family carers’ life choices and opportunities
- how the policy affects the level of unpaid family support available to disabled people
- how the policy affects the quality and safety of the paid support received by disabled people
- whether the policy is acceptable to disabled people and family carers
• how the policy affects other government agencies and processes and society generally
• how consistent the policy is with the Government’s strategies and directions for disability support
• how affordable the policy is
• how easy the policy is to implement and apply on an ongoing basis.

**International approaches**

Internationally, countries take a variety of approaches to supporting family carers. Whether to allow family members to be paid for providing disability support is a question that also challenges other jurisdictions.

New Zealand’s current policies for providing support to family carers are most similar to policies in Australia, the United Kingdom and Ireland. These countries focus on relief and respite for family carers, and provide some form of means tested benefit to carers. Australia and Ireland also provide small non-means tested allowances to resident caregivers (who may be family members). Where self-directed purchasing (sometimes known as individualised funding) and direct employment of support workers by disabled people are involved, spouses and resident family members cannot usually be paid for services. (For more information on international approaches to supporting family carers, see Appendix 3.)

**Strategic directions for disability support**

**New Zealand Disability Strategy**

The New Zealand Disability Strategy presents a long-term plan for changing New Zealand from a disabling to a fully inclusive society. The strategy seeks to:
• create long-term support systems centred on the individual
• ensure the disabled person is at the centre of service delivery
• value families, whānau and other people providing ongoing support to disabled people.

**United Nations Convention on the Rights of Persons with Disabilities**

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) builds on generally accepted understandings of what is required to implement existing human rights as they relate to disabled people. New Zealand signed the convention at a United Nations meeting on 30 March 2007, and ratified it on 26 September 2008. The convention makes it explicit that countries must progressively work towards ensuring the full realisation of all human rights and fundamental freedoms for all disabled people, on an equal basis with others, and without discrimination of any kind on the basis of disability. All new legislation and policy must be consistent with the convention.
New directions for disability support

The Ministry (and increasingly other government agencies) is changing the disability support system to increase disabled people’s choice about, and control over, the support they receive and the lives they lead. The Ministry has a stronger focus on building and providing assistance to personal networks (which may include family carers), with funding being used to develop disabled peoples’ strengths so that they can live a ‘good life’. An important principle of this new direction for the disability support system (as envisaged by, for example, the New Model for Supporting Disabled People)\(^9\) is that freely given natural support networks (family/whānau, friends, and people from the wider community) are the basis for a rich and varied life in the community.

Carers Strategy

The Government has also published the Carers Strategy and Five-year Action Plan\(^10\) to improve support for carers. The Strategy and Action Plan were developed through a partnership between government agencies and the New Zealand Carers Alliance and published in 2008. Progress on the Action Plan has included publication of information for carers about the support and help that is available across government.\(^11\)

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2 Summary of questions to be answered

Paying family carers to provide home and community support without discriminating on the basis of family status requires the Government to answer important questions.

- How can we ensure good outcomes for the disabled person and their family under a policy allowing family carers to be paid?
- Should eligibility for payment be targeted?
- How should family carers be paid?
- What should family carers be paid for?
- Should a new family carers payment be established through the welfare system?
- What can the Government afford?

The questions are summarised in sections 2.1–2.6. Sections 3–7 provide more detail on these questions and some possible options. Scenarios explaining how the options might work in practice and their impact are also provided.

Each question relates to a separate consideration in the development of the new policy. The answers are not independent of each other, so the final policy is likely to be a combination of approaches that balances the answers to all the questions.

2.1 How can we ensure good outcomes for disabled people and their families?

Any policy allowing family members to be paid to provide support will need to ensure that the disabled person’s interests and the quality of life of the disabled person and their family are protected. This is discussed in section 3.

2.2 Should eligibility for payment be targeted?

Payment could be targeted to carers supporting disabled adults in particular circumstances. This option is discussed in section 4.
2.3 **How should family carers be paid?**

Family carers could be paid for providing assessed support through:

- employment income – family carers become eligible to be employed to provide support
- an allowance – family carers are paid an allowance for providing support.

These options are discussed in section 5.

2.4 **What should family carers be paid for?**

Family carers could be paid for:

- providing home and community support above a level of support that families determine they will provide unpaid
- providing home and community support above a level of support that NASC organisations determine that families are expected to provide unpaid.\(^{12}\)

These options are discussed in section 6.

2.5 **Should a family carers payment be established through the welfare system?**

An alternative to paying family carers for providing support could be a family carers payment administered through the welfare system. This payment would recognise the contribution family carers make in supporting disabled adults, rather than reimbursing them for providing home and community support services. This payment would be instead of any other payment. This option is discussed in section 7.

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\(^{12}\) NASC organisations are contracted to determine eligibility for government-funded disability support, assess the support needs of eligible clients and coordinate services to meet those needs. See Appendix 2.
2.6 What can the Government afford?

The above questions cannot be answered in isolation. They need to be made in the context of what costs the Government can sustain over the longer term given the many other pressures on the health and disability budget and other areas of public expenditure.

The Government needs to decide how best to meet the increased costs to the disability support system associated with paying family carers. This could be achieved by:

- reprioritising government expenditure to allocate additional funding to disability support services
- reducing the level of funded support across all currently funded disability support clients to enable family carers to be paid within the current or revised budget
- funding from the new spending envelope in each budget
- a combination of the above three approaches.

The Government also needs to consider specific measures to manage the costs of implementing a policy allowing family members to be paid. Examples could include capping the amount available to pay family carers and/or only paying family carers in particular high-needs situations.

Affordability and the potential trade-offs needed to fund a new policy involve issues beyond the provision of disability support and the health and disability system. The Government must weigh the impact of its policy options against all other priorities and funding pressures. The Government must also decide whether legislation would be required to implement or support the new policy.
3 Ensuring good outcomes for disabled people and their families

Any policy allowing family members to be paid to provide support will need to be accompanied by measures that provide assurance that the disabled person’s interests and the quality of life of the disabled person and their family are protected. This includes providing assurance that neither a disabled person nor family carers become unable to change unsuitable arrangements. Measures for doing this could include, for example:

- using a modified developmental evaluation tool to monitor disabled people’s quality of life when family carers are paid\(^ {13} \)
- requiring disabled people to have independent support for planning and building networks before family carers can be paid
- requiring regular auditing of the quality of services provided.

Question 1

What do you think is the best way to ensure that disabled people’s interests and quality of life and those of their family are protected under a policy allowing family to be paid for providing support?

- Use a modified developmental evaluation tool
- Require disabled people to have independent support for planning and building networks
- Carry out regular external audits of the quality of services provided
- Other (please specify)

\(^ {13} \) Person-centred and outcomes-focused developmental evaluation tools focus on the experiences of, and the outcomes for, people who receive support, and on helping providers to develop. They consider how effective an organisation and its services are at positively affecting independence, choice and person-centeredness within services through “painting” a picture of the life people are living. A modified tool would need to be developed for a paid family carers context.
4  Should eligibility for payment be targeted?

4.1  Target payment to specific family carers or specific circumstances

Description of option

The Government needs to decide the circumstances under which family carers could be paid. It may be necessary to target eligibility for payment to manage the additional costs of removing the restriction against paying family carers to provide support. This means some family carers could be funded to provide home and community support where the circumstances of the family and disabled person meet specified criteria.

Examples of the types of circumstances under which family carers could be eligible for payment might include:

- the remoteness of the disabled person’s residence making it difficult for non-family carers to provide support
- specific cultural or religious requirements that cannot be met by an otherwise suitable carer (for example, a Muslim man requiring care when the only man available to care is a family member)
- the person being supported having high or complex needs
- there are significant risks to the safety and wellbeing of the person and/or non-family carers if family do not provide the support.

This option has been developed in response to the High Court’s finding that the blanket restriction on paying certain family members was a disproportionate response to the importance of the objectives for the policy put forward by the Crown.

Counsel for the plaintiffs submitted to the High Court the possibility of a policy for payment of family members based on exceptions to a general policy. The court noted in response that it, ‘may well be that a policy of “tailored exceptions” [is] the way forward, but we [the court] express no view on that’. The court did note that criteria for exceptions to a general policy prohibiting payment of family carers should ‘not be exhaustive, and should leave discretion to consider all the circumstances of the individual on a case by case basis’.

Implementing this option would mean there was no longer a blanket restriction on funding certain family carers to provide home and community support, and each case would be considered on its own merits against certain targeting criteria.
Needs assessment could continue to be through the current NASC system. Whether family carers would be eligible to be paid could be established through the service coordination process.

**Comparison of option with current process**

This option differs from the current process because:

- family carers in certain circumstances would be eligible to be paid for providing support services
- eligibility for payment would be assessed against criteria (that is, eligibility would be targeted).

**Comment**

**Aligns with the New Model for Supporting Disabled People**

This approach aligns with the New Model for Supporting Disabled People as it fosters and encourages people with disabilities to develop and grow unpaid natural support from both their family and wider community, while allowing family carers to be paid in targeted circumstances. The practice of family members freely providing a level of unpaid support as part of a family relationship would continue and family carers would not generally be eligible to provide paid support.

**Support quality improves when external providers are unavailable or unsuitable**

Targeting payment is expected to improve the quality of support received by disabled people in circumstances where external support providers are unavailable or unsuitable. Implementing this option would involve some changes within NASC organisations, because a process to target eligibility for payment would be needed. This option would treat families differently in different circumstances, but would be flexible and address court criticisms of blanket policies.

**Paid home and community support is sustainable**

This approach would assist in managing the increase in cost to Government of removing the restriction on family carers being paid to provide home and community support as payment would be targeted to family carers in specified circumstances, such as those providing support for disabled people most in need of this support. Targeting payment in this way would help ensure the continued sustainability of government-funded home and community support services for disabled people.
Scenario 1
Joanna and David have a 25-year-old son, Sam, who has muscular dystrophy and requires 28 hours of home and community support each week. Sam lives with his parents and prefers that they provide him with support. Joanna and David work full time. Together they have been providing 11 hours per week of unpaid home and community support. A support worker (employed by a Ministry-contracted home and community support services provider) provides the additional 17 hours of home and community support each week. David is self-employed and has some flexibility over his hours of work. He would be willing to provide more support to Sam, if he were paid to do so.

Joanna and David do not meet the targeted criteria and are not eligible for payment. The current arrangements continue; that is, Joanna and David provide 11 hours of unpaid support per week and a support worker employed by a Ministry-contracted home and community support services provider provides the remaining support.

Scenario 2
This scenario builds on scenario 1. Sam and his family’s situation meet the targeted criteria. Therefore, Joanna and David provide a certain level of home and community support unpaid (for example 7 hours) based on a NASC organisation’s assessment, and a family member is paid to provide the remaining 21 hours of support to meet Sam’s assessed needs.

Under this scenario the cost of Sam’s care would increase 23 percent and all the paid support would be delivered by family.

Question 2
Do you generally agree with a targeted approach to paying family carers?
☐ Yes
☐ No
☐ Not sure
Please give reasons for your response.
Question 3
What do you see as the benefits and/or issues with a targeted approach to paying family carers?

Question 4
If a targeted approach to paying family carers was implemented, in which of the following circumstances do you think that family carers should be paid? (Tick one or more of the circumstances).

- The remoteness of the disabled person’s home makes it difficult for non-family carers to provide support
- The person has specific cultural or religious requirements that cannot be met by an otherwise suitable carer
- The person being supported has high or complex needs
- There are significant risks to the safety and wellbeing of the person and/or non-family carers if family do not provide the support
- Other (please specify)
5 How should family carers be paid?

The two main methods to pay family carers for providing home and community support services to disabled adults are to:

- remove the restriction on employing family carers (see section 5.1)
- pay eligible family carers an allowance (see section 5.2).

5.1 Remove the restriction on employing family carers

Description of option

Family carers may be considered for employment as a carer for disabled people, if they meet the conditions for employment.

What it means to be employed

Certain rights and obligations come with employment relationships that are different to those in the usual caring relationships that exist between family members. These rights and obligations include:

- being responsible to the employer for performance
- needing to satisfy recruitment or selection criteria (that is, to be suitable for the position)
- needing to comply with an employment agreement
- being covered by the Employment Relations Act 2000
- having access to annual holidays, parental leave and holiday pay
- being subject to the benefits and responsibilities of being part of the tax system (for example, income tax, GST, KiwiSaver, student loan repayments, and access to the Working for Families tax credit).

Different types of employment

The Ministry and NASC organisations do not employ carers directly. Carers are employed through disability support service providers, which the Ministry or the disabled person (using an individualised funding mechanism) contracts to provide disability support.
Family members paid to provide home and community support would need to be employed by a recognised home and community support service provider or would need to set themselves up as service providers. Alternatively, the disabled person could employ them directly through an individualised funding arrangement.

**Employment by a disability support services provider**

Family carers wishing to be employed by providers would need to satisfy the provider’s recruitment and employment criteria. The provider, as the contracted support service provider, would be ultimately responsible for the quality of support provided to the disabled person.

As employees, family carers would be entitled to employment benefits such as annual leave, parental leave, sick leave and access to KiwiSaver.

Family carers might still be able to access respite care, although the period when respite care is provided may be treated as annual holidays for the purposes of the Holidays Act 2003.

**Family carers establish themselves as service providers**

Family carers could establish themselves as providers to be contracted by the Ministry to provide support to a disabled person. Under this scenario, family carers would be required to meet the conditions associated with being a Ministry-contracted disability support service provider, including:

- meeting and maintaining quality standards of care
- being responsible for all tax obligations (including GST)
- meeting quality and character tests for being contracted for services by the New Zealand Government on behalf of the Crown
- being subject to monitoring and audit requirements
- being responsible for any obligations arising from being self-employed
- being responsible for any employment obligations arising from being an employer of other carers.

Those who were unable to meet these tests might not be able to register as home and community support service providers.

**Disabled people employ family carers using individualised funding**

This option would allow family carers to be employed directly by the disabled person to provide home and community support where the person receives individualised funding. An individualised funding host provider would facilitate and support this arrangement.
Family carers employed under this option would be engaged in an employment relationship with the disabled person with all the associated legal rights and obligations of employment. Family carers would be accountable to the disabled person for the quality of support provided and all other aspects of the employment relationship (through an advocate if necessary).

This means family carers, as employees of the disabled person, would be entitled under law to the same employment benefits as they would if employed by a contracted provider (for example, access to annual and parental leave, KiwiSaver, and sick leave).

Family carers might still be able to access respite care, although the period when respite care is provided may be treated as annual holidays for the purposes of the Holidays Act 2003.

Alternatively, family carers could be engaged as a contracted support provider to the disabled person. This would require the family carer to establish themselves as a provider of home and community support services. The family carer would be treated as self-employed, although they would be in a contractual relationship with the disabled person (through an individualised funding host) to provide allocated home and community support services.

**No guarantee of employment**

This proposal removes the restriction on employing family carers to provide home and community support services. However, this is not a guarantee that family carers would be employed to provide support. Carers would be required to meet the same criteria as non-family carers when being considered for employment.

**Comment**

**Simplest way of removing discrimination on the basis of family status**

Removing the restriction on employing family carers to provide paid home and community support is the simplest way to remove the discrimination on the basis of family status. As carers are only employed by providers or the disabled person, allowing family carers to be employed does not (in itself) alter the responsibility or systems within the NASC organisations. Family carers would be able to choose whether to seek employment to provide paid home and community support or to continue providing unpaid support only.

**Employment may not suit everyone**

This option may easily comply with the court decisions in the family carers case, but employment may not suit everyone. Being employed to provide support to a loved one might disrupt normal family relationships and may go against cultural or social practices.
Carers assisted to move from benefit receipt to paid employment

This option may encourage carers who currently rely on income support to provide care to seek employment providing home and community support. This may help carers to transition from relying on a benefit to entering paid employment.

Any payment from employment as a carer would be considered income, and may affect any benefits that carers (or their partner or spouse) might receive from the Ministry of Social Development. Any effects would depend on how much carers earn: the more carers earn, the more this might affect their entitlement to additional income support.

Employment relationship means legal obligations and responsibilities

This option would require family carers wanting to be employed and people with disabilities (as potential employers) to understand the obligations and responsibilities that come with entering an employment relationship. It would not be the responsibility of the NASC organisations to provide this training, as they are not equipped or qualified to provide business or financial advice. Instead, family carers and disabled people would need to know their employment obligations and responsibilities. This might include establishing some form of information sharing between the Ministry and other agencies (such as the Inland Revenue Department and Accident Compensation Corporation) to encourage people with disabilities and their families to fulfil their tax obligations.

Some unpaid carers will be discouraged from seeking payment, others will be encouraged

The requirement to be employed in order to be paid for providing disability support may discourage some family carers from seeking payment for the care they provide, particularly for those who provide less intensive support. Family carers who provide high or complex levels of support might be more inclined to seek to be employed.

Potential for conflict of interest or abuse in the caring relationship

Under this payment option, there is some risk of a conflict of interest or abuse within the caring relationship, particularly where either the carer or the disabled person uses the employment relationship to exert unreasonable pressure or influence over employment decisions or practices. While this would occur only in the minority of cases, NASC organisations and contracted providers would need to monitor relationships between disabled people and their family carers to ensure the type of care continues to be in everyone’s best interests.
Scenario 3
This scenario also builds on scenario 1 on page 15. David approaches the current contracted provider to employ him as the carer for Sam for the hours of support that are eligible for payment. While the provider is agreeable, the secondary tax obligations on top of David’s current job out-weigh the benefits of being paid to provide support. David does not pursue the option and current support arrangements continue.

5.2 Pay family carers an allowance
As an alternative to the formal employment of family carers, the home and community support a family member provides to meet a disabled family member’s assessed needs could be recognised through the payment of an allowance. This allowance would be paid from Ministry of Health funding, and, as with previous options, the impact on overall disability support funding would need to be managed.

Description of option
The value of the allowance could be set at a proportion of the disability support package allocated by a NASC organisation. This could be at the same or lower rate as the equivalent wage paid to an employed carer. If the allowance were paid at less than the equivalent wage, consideration would need to be given as to whether this option is fair.

Eligibility for respite and carer support would continue to be assessed through the NASC system. Carers in receipt of this allowance might need to meet criteria aimed at supporting the quality and safety of the support situation, including training and monitoring requirements.

Further work is required on whether the allowance would be chargeable income for benefit and tax purposes and whether it would affect eligibility for social security benefits.

Comment
Funding is likely to be attached to the carer receiving the allowance not the disabled person
This option is likely to attach funding to the carer receiving the allowance. This would represent a significant shift away from the current funding model, which attaches eligibility and funding for home and community support services to the person receiving the support – the disabled person. A decision would need to be made as to whether an allowance would be limited to one family carer, or whether an allowance could be paid to more than one family carer.
Support tasks and reimbursement not directly linked, so disabled person has less control

An allowance-based approach means that provision of support tasks and reimbursement would not be directly linked. This would allow more flexibility in support, but control over that flexibility on a day-to-day basis would be with the carer receiving the allowance. The disabled person would not have the level of control that goes with an employment relationship.

The payment of family carers through an allowance would need to be structured in a way that avoids turning family relationships into employee–employer relationships. Eligibility for income-associated entitlements such as Accident Compensation Corporation earnings compensation, KiwiSaver employer contributions and Working for Families tax credits would also depend on how the Government structured the allowance.

Disabled person may have less choice and control over funding

If the allowance portion of the disabled person’s funding package were taken out of the total package, the disabled person would have a lower level of direct choice and control over the funding.

Family carers would need to meet allowance criteria

Although the payment would be an allowance, family carers would still need to meet criteria. These criteria might include requirements for quality, safety, training and monitoring. New systems would be required to support the quality, safety, training, and monitoring of allowance-funded support arrangements.

Scenario 4

This scenario also builds on scenario 1 on page 15. David agrees to undertake a training programme to be eligible to receive an allowance for providing the assessed level of paid support. He is able to adjust his hours of work to continue in his self-employed work.
Question 5
Which of these two ways of paying family carers for providing home and community support services do you generally agree with? (Tick one)

☐ Employment – family carers are employed to support the disabled person, if they meet the conditions for employment

☐ Allowance – family carers are paid an allowance for the assessed home and community support they provide

Question 6
What are the benefits and/issuers with paying family carers through employment?

Question 7
What are the benefits and/issuers with paying family carers through an allowance?
6  What should family carers be paid for?

The Government needs to establish what supports family carers could be paid for providing to their adult disabled family member. The two broad options for paying family carers are that family carers are paid for providing assessed home and community support above a level of support that:

- families determine they will provide unpaid (see section 6.1)
- NASC organisations assess that the families are expected to provide unpaid (see section 6.2).

6.1  Families determine the level of unpaid support they will provide

Description of option

This option represents the minimum change from current practice, but the maximum potential cost. This option removes the current restriction against family members receiving payment for support they provide.

The process would be as follows.

1. A NASC organisation would assess, in consultation with the disabled person and their family, the level of support the disabled person requires (as happens now).
2. The family would say how much unpaid support they could provide to meet the disabled person’s assessed needs.
3. The NASC organisation would determine a package of funded support to meet the assessed needs the family will not provide unpaid.
4. Family carers would be eligible to be paid to provide the funded home and community support services.

Comparison of option with current process

This option maintains the current NASC process with families determining the level of unpaid support they can provide. However, the option differs because family carers would be eligible to be paid to provide funded support.
Comment

Choice and flexibility increased, but amount of unpaid support decreases

This option is consistent with the aim of increasing choice and flexibility for both the disabled person and their family, because it allows the disabled person to choose to have a family member as a paid carer. However, the final decision on the level of paid support allocated would lie with the family. This could create an incentive for families to minimise the unpaid support they were prepared to provide in favour of providing paid support. The availability of unpaid support is likely to decrease, which would run counter to the new directions for the disability support system.

Demand for paid services increases, but Government unable to control costs

Under this option, the total demand for paid disability support services would likely increase but the Government would have no way to control costs. This would put at risk the ongoing provision of the current level of paid disability support.

Some families may over-commit to providing paid services

This option might encourage families to try to provide more paid disability support services than they are able to do, leading to families committing to a level of support they cannot sustain. This could result in the disabled person not receiving the full level of support they have been assessed as requiring or receiving lower-quality support.

In some cases, family carers or disabled people might be unable to change unsatisfactory caring arrangements, especially if households became reliant on the income from providing support.

Responsibility for supporting disabled people shifts further towards the state

Increasing the level of paid support over unpaid support would shift the balance of responsibility for supporting disabled people from family and further towards the state. Greater government involvement is accompanied by increased monitoring and quality assurance requirements, which brings a level of intrusion into people’s lives.

Government’s ability to decide how best to allocate taxpayer funding is limited

Although this option increases government responsibility for supporting disabled people, it will affect the extent to which Government can ensure that taxpayer funding is applied in a way that achieves the best outcomes.

A particular risk is that, as the pool of potential claimants under this option is large and the cost high, the level of support currently provided to funded clients may need to be reduced as funding is spread across the larger client group.
This option does not meet several of the key tests for a successful policy for paying family carers. It removes spending decisions from Government (as funder), which is inappropriate in a system that allocates paid support from public funding. This policy is unlikely to be affordable and would be difficult to implement effectively without a complete reshaping of funded disability support.

**Scenario 5**

This scenario also builds on scenario 1 on page 15. Under this option, if Joanna and David decided to no longer provide any unpaid home and community support, David could be paid to provide all 28 hours of support. He would reduce his hours of self-employment to accommodate this. The cost of Sam’s home and community support would increase by 65 percent.

### 6.2 Needs assessment and service coordination organisations determine the level of unpaid support that family carers are expected to provide

**Description of option**

Under this option, family carers would be expected to provide a certain level of unpaid home and community support for their disabled adult family member. A NASC organisation would determine the level of support a family would be expected to provide unpaid. (See Appendix 2 for information about the role of NASC organisations and the NASC process.)

This determination could be done using a principles-based approach or a more generic approach, and other approaches are also possible.

**Principles-based approach to determining level of unpaid support**

A principles-based approach could be used to determine how much unpaid support a family would be expected to provide. (See Appendix 4 for principles that could be used.)

For example, a resident family member might be expected to clean the house without payment, because a family would do this activity anyway. On the other hand, the same family might not be expected to provide personal care (such as support with showering, toileting and dressing) for their adult son or daughter. In this scenario, the family would be expected to carry out the household tasks without payment, but the family carer could be paid for providing personal care for the disabled adult family member.
Generic approach to determining level of unpaid support

A more generic approach to determining the level of unpaid support would require resident family members to provide a fixed level of unpaid support, irrespective of their particular circumstances. Exceptions could apply for families that were clearly unable to provide this level of unpaid support. For example, family members could be required to provide an hour or more of unpaid home and community support a day to a disabled adult family member who lives with them.

Capped level of paid support

Under any approach, the level of paid support a family would be allowed to provide might be capped at, for example, 30 or 40 hours per week.

Once the level of unpaid support is determined, families would be eligible to be paid for providing additional home and community support that the NASC organisation assesses is required. The family may be able to decide, within certain guidelines, which forms of assessed support they provide unpaid and which they are employed to provide.

Resident family carers who were unwilling or unable to provide the support that the NASC organisation assessed should be provided unpaid, would not be eligible to receive payment for that support. The NASC organisation might decide to allocate paid support provided by a contracted home and community support service provider, if appropriate.

Process and guidelines would need amending and training developed

The NASC process would need to be amended to enable NASC organisations to assess the support families would be expected to provide unpaid. A clear set of guidelines would need to be developed for these organisations. They would also need additional training to implement this option. A generic approach based on fixed minimum levels of unpaid support would require less change to the NASC system and less training than would a principles-based approach.

Key to the success of this option is ensuring a fair balance between paid and unpaid support that:

- does not undermine the freely given nature of some family relationships to help disabled people to build natural networks that are the basis of a rich and varied life in the community
- enhances the choice and control that disabled people have to achieve a ‘good life’ by enabling family carers to remain involved in disabled people’s lives when this is consistent with the disabled person’s plans
- enables disabled people to use their allocated funding effectively and in a way that supports their independence and life choices.
Comparison of option with current process

This option differs from the current process because.

- families would be expected to provide a level of unpaid support, regardless of whether they were seeking payment for providing support
- family carers would be eligible to be paid to provide additional assessed home and community support services (subject to employment or allowance criteria) up to a certain level.

Comment

This option builds on the current process and gives the NASC organisation responsibility for identifying the level of unpaid support families are expected to provide. It also avoids any potential conflict of interest inherent in families determining how much unpaid care they will provide and, therefore, how much support they will be paid for.

Government maintains more control

This option allows the Government (through the NASC organisation) to maintain a greater level of control over the amount of paid support allocated to people with disabilities. This is appropriate because the Government is the primary funder of paid disability support services.

Choice and flexibility increased

This option is consistent with the aim of increasing choice and flexibility for both the disabled person and their family, as the disabled person could choose to receive paid support from a family carer. It would set an upper limit on the amount of paid support families could choose to provide, as this would be determined by the NASC organisation.

Alignment with the New Model for Supporting Disabled People

Requiring the NASC organisation to identify the level of unpaid support each family is expected to provide is also consistent with the New Model for Supporting Disabled People. A key principle underpinning the new model is that freely given (and unpaid) natural support networks are the basis for a rich and varied life in the community. Natural support networks can, and often do, include family members, and are likely to include friends and other people from the wider community.

Needs assessment and service coordination process changes

This option would require changes to the NASC process to assist decision-making on the level of unpaid support each family could be expected to provide. This is not without its challenges, so measures might be needed to achieve consistent decision making. Consistency might be achieved through:
detailed criteria that sit beneath any guiding principles
moderation, where NASC organisations discuss and compare decisions made on families providing levels of unpaid support
a complaints or appeals process, which would allow people with disabilities and their families to challenge decisions relating to the level of care they are expected to provide.

A simpler but less flexible method might be for the Ministry to develop a national standard level of unpaid support required of all families providing support to an adult disabled family member. This approach would be:
easier to implement consistently across the NASC organisations, avoiding regional variations, and avoiding changes in interpretation over time
less responsive to the varying circumstances of different families.

However, this approach might be the only practical way the Ministry could manage the increased costs of paying family carers to provide home and community support. This approach:

maintains a level of unpaid home and community support to people with disabilities, so is consistent with the new directions for the disability support system
establishes a means of fiscal control over the allocation of paid support, so enables taxpayer money to be focused where it is most needed.

**Scenario 6 – principles-based approach to determining unpaid support level**

This scenario builds on scenario 1 on page 15. The NASC organisation assesses that Joanna and David should provide a certain level of unpaid home and community support (for example 7 hours) as a contribution towards meeting Sam’s assessed needs. David agrees to provide the remaining hours of support (for example 21 hours) to Sam as a paid carer and does not need to change his normal hours of self-employment.

Under this scenario, the cost of Sam’s care increases (by 23 percent) and the family delivers all the paid support.
**Scenario 7 – generic approach to determining unpaid support level**

This scenario also builds on scenario 1 on page 15. Joanna and David are required to provide (at least) a set number of hours of unpaid home and community support (for example 7 hours) as a contribution towards meeting Sam’s assessed needs. David agrees to provide the remaining hours of support to Sam as a paid carer (for example 21 hours) and does not change his usual hours of self-employment.

Under this scenario, the cost of Sam’s care increases (for example, by 23 percent) and the family delivers all the paid support.

While the hours of support families are expected to provide unpaid in these two scenarios are the same, using different methods for determining this level of unpaid support could lead to people in different situations facing different expectations. The actual expectations will depend on the principles or rules that are used and how these relate to people’s particular circumstances.

### Question 8

Which of the following ways of paying family carers for providing home and community support services do you generally prefer? (Tick one).

- Family determining how much unpaid support they will provide
- NASC organisations using a principles-based approach to determine how much unpaid support each family is expected to provide
- NASC organisations using a generic approach with every family being expected to provide a certain level of unpaid support

Please give reasons for your response.

### Question 9

What do you see as the benefits and/or issues of family carers determining how much unpaid support they will provide?

### Question 10

What do you see as the benefits and/or issues of NASC organisations using a principles-based approach to determine how much unpaid support each family is expected to provide?
**Question 11**

What do you see as the benefits and/or issues of NASC organisations using a generic approach with every family being expected to provide a certain level of unpaid support?

**Question 12**

If NASC organisations were to determine what unpaid support family carers are expected to provide using a principles-based approach, which of the following suggested principles do you generally agree with? (Tick all those you generally agree with).

- The unpaid support family provide to meet assessed needs is consistent with the outcomes in the disabled person’s support plan
- The disabled person is comfortable with the family member providing this type of support.
- Paid support should not displace support that is provided by a family carer freely and willingly, and that is within their capacity and ability.
- Greater expectations within some cultures and families of the amount of support family members should provide, should not mean that government expects these family carers to provide more unpaid support than family carers in other situations.
- At a minimum, the type and level of support provided by family to disabled family members without payment should be equivalent to that which a family would provide for a non-disabled family member at a similar age and stage of development.
- The family member should be capable of providing the necessary support for their disabled family member without compromising their own and their disabled family member’s safety.
- Alternative options for supporting a family’s ability and capacity to provide unpaid support for their disabled family member should be considered before considering paying a family member to provide support.
- Expectations of the type and level of support that family should provide unpaid should take account of possible adverse effects on the family carer’s and other family members’ usual responsibilities and commitments.

Please give reasons for choosing these principles.

Please suggest any changes to the suggested principles or alternative principles.
Question 13
If family were required to provide a certain number of hours per week of home and community support to their disabled family member without payment, how many hours per week do you think they should provide unpaid? (Tick one)

☐ Up to 4 hours per week
☐ Up to 7 hours per week
☐ Up to 10 hours per week
☐ Up to 15 hours per week
☐ Up to 20 hours per week
☐ Up to 30 hours per week
☐ Up to 40 hours per week
☐ More than 40 hours per week
☐ 0 hours – I do not agree that family should be expected to provide unpaid home and community support.

Please give reasons for your responses.
7 Should a new family carers payment be established through the welfare system?

7.1 Establish a new family carers payment through the welfare system

An alternative to paying family carers for providing support could be a family carers payment administered through the welfare system. The payment would recognise the contribution family carers make in supporting disabled people, rather than reimburse them for providing home and community support services.

Description of option

Establishment of a family carers payment could stand as an alternative to removing the restriction on paying certain family members to provide home and community support services.

A family carers payment would recognise the contribution family carers make in supporting disabled people, but it would not be a payment for providing specific home and community support services. This option would address the material disadvantage inherent in the current policy. The family carers payment would recognise the role of carers, not the specific work they do.

Consideration of a ‘carers allowance’ was proposed under the Carers’ Strategy, but was not retained in the strategy’s second five-year action plan. The carers allowance was intended to be an extension of the existing child disability allowance into adulthood. The child disability allowance is currently about $45 a week and is not taxed or subject to income or asset testing. However, the family carers payment could be means tested or made subject to tax, if considered appropriate.

Access to the family carers payment would be through a NASC organisation, and could be tied to qualification for respite and carer support payments. The Ministry of Social Development might pay the family carer through one of their systems.

Two approaches could be used. The family carers payment could:

- be broadly tiered according to the disabled person’s assessed support needs (high, medium, low needs) as determined by a NASC organisation
- paid at a flat rate (with eligibility assessed by a NASC organisation).
Payment of a family carers payment would not replace funded home and community support services. Where families received the family carers payment, the disabled family member would still be eligible for Ministry-funded support, respite services and carer support.

For this reason, the value of the family carers payment would be likely to be lower than payment for delivery of support through either employment or an allowance, as the Ministry of Health would continue to fund the provision of those services.

Currently, a person providing full-time care in their own home for someone other than their spouse or partner may qualify for the Domestic Purposes Benefit – Care of Sick or Infirm (DPB – CSI), if the person they are caring for is someone who would otherwise require hospital care, rest home care, residential disability care or the equivalent. People caring for a disabled partner or spouse may qualify jointly with them for the Invalid’s Benefit. These are income-tested social security benefits, so they are available only to people on low-incomes. From July 2013, both the DPB – CSI and Invalid’s Benefit will be replaced by a new supported living payment, although eligibility rules and benefit rates will remain broadly the same.

If a new family carers payment were to be introduced, the interface with the main social security benefits would need to be carefully considered to avoid overlapping entitlements. The interface with other forms of social assistance, including the Disability Allowance, may also need to be considered.

Quality, safety, training and monitoring requirements would likely be lower than those required for higher value payment systems (for example, where carers were employed or contracted).

**Comment**

A family carers payment would not affect access to Ministry-funded disability support.

**Natural support fostered and choice and control not compromised**

Payment of a family carers payment would be compatible with the new directions for disability support because it fosters natural support and does not compromise disabled people’s choice and control over the Ministry-funded support they use. The payment would not be directly linked to the particular support provided, so would be likely to require a relatively low level of compliance and monitoring.

**Contribution of family carers recognised without an employment relationship**

A family carers payment would recognise the contribution of family carers, without introducing an employment relationship into the family relationship. It would also avoid the duties and obligations associated with employment.
Implications for government systems

Payment of a family carers payment administered through the welfare system is likely to require significant and potentially costly changes to government agency systems. This may affect the timeframe within which any family carers payment could be implemented.

Scenario 8

This scenario also builds on scenario 1 on page 15. David and Joanna continue to provide 11 hours of unpaid home and community support. They are eligible for and receive an appropriate level of family carers payment. The remaining hours continue to be provided by a support worker employed by a Ministry-contracted home and community support services provider. Both David and Joanna continue in paid employment.

Question 14

If a family carers payment administered through the welfare system was established, which of the following payment types do you prefer? (Tick one)

☐ A payment that is broadly tiered according to the level of the disabled person’s assessed support needs (high, medium, low) as determined by a NASC organisation

☐ A payment at a flat rate for those who are eligible (with eligibility assessed by a NASC organisation).

Please give reasons for your response.

Question 15

What do you see as the benefits and/or issues of recognising the contribution of family carers through a family carers payment, administered through the welfare system?
Question 16

Which approach to recognising family carers’ support for their disabled family member do you prefer? (Tick one)

☐ Paying family carers through either employment or an allowance for the home and community support services they provide

☐ Recognising the contribution family carers make through a family carers payment administered through the welfare system.

Please give reasons for your response.
8  Hard choices

Paying family carers for support they are currently providing unpaid will significantly increase the cost to the Government of disability support. While the Government will look at a wide range of options for funding these increased costs, some or all of them may need to be funded from within the funding that is already allocated to disability support. If this is the case, we would appreciate your views on how those additional costs might be funded, while having the least impact on quality of life for carers and disabled people.

We have identified a range of options for doing this in Question 18 below. We ask you to rank each of them from 1 to 5, with 1 being your most preferred option and 5 being your least preferred option.

Question 17

If these increased costs need to be funded from within the funding that is already allocated to disability support, what would you be willing to trade off to enable family carers to be paid for providing home and community support? Please rank the following from 1 to 5, with 1 being your most preferred option and 5 being your least preferred option.

- Only allowing some families to be paid (for example, only families supporting disabled family members with high support needs).
- Paying family carers a lower hourly rate than the hourly rate paid to contracted home and community support providers.
- Paying most families providing support but at a relatively low level flat or tiered rate.
- Only paying families for some of the support they provide.
- Reducing the level of disability support funding allocated across all disabled people receiving Ministry funded disability supports.
- Other (please specify)
9  Indicative timeline

Table 1 sets out an indicative timeline for the work to finalise and implement the new policy.

This timeline is based on an assumption that a year is available to develop, consult on and implement the new policy. However, if the suspension order is lifted in less than 12 months, the consultation process may need to be shortened.

Table 1: Indicative timeline for Ministry of Health disability support services policy change

<table>
<thead>
<tr>
<th>Date</th>
<th>Deliverable</th>
</tr>
</thead>
<tbody>
<tr>
<td>September 2012</td>
<td>Consultation document circulated</td>
</tr>
<tr>
<td>October 2012</td>
<td>Consultation workshops with the sector</td>
</tr>
<tr>
<td>6 November 2012</td>
<td>Consultation period closes</td>
</tr>
<tr>
<td>December 2012 to January 2013</td>
<td>Government considers the results of the consultation process and policy proposals</td>
</tr>
<tr>
<td>January to February 2013</td>
<td>New policy announced, and implementation process begins</td>
</tr>
<tr>
<td>May 2013</td>
<td>Agreed policy option(s) implemented</td>
</tr>
</tbody>
</table>
Appendix 1: Background information

Vote: Health expenditure

The Government allocated about $13.6 billion in 2012/13 to Vote Health to buy health and disability support services, for New Zealanders. The Ministry of Health allocates more than three-quarters of the public funds it manages through Vote Health to district health boards. District health boards use this funding to plan, purchase and provide health and support services in their areas.

Most of the remaining public funding provided to the Ministry is used to fund important national services, including disability support services. The variety of Ministry-funded disability support services is broad and includes household management services, personal care services, carer support, respite services, supported living services, day programmes and residential services. Many people receiving Ministry-funded disability support services receive multiple services.

The Ministry spends about $1.028 billion a year on disability support services for around 30,350 people with physical, sensory and intellectual disabilities who need ongoing support. Of this amount, $124 million was spent on home and community support services in 2011/12.

Figure 1: Disability support services expenditure by service, 2011/12

Note: ESS = environmental support services; HCSS = home and community support services; SIL = supported independent living services.
Ministry of Health-funded support for carers of people receiving disability support services

Carer support
A carer support subsidy is available to unpaid full-time carers of disabled people. A full-time carer is the person who provides more than four hours per day unpaid care to a disabled person. The subsidy reimburses some of the costs of having a support person care for and support a disabled person while the unpaid full-time carer takes a break from the caring role. The number of hours or days of carer support funded depends on the carer’s needs and those of the person they care for.

The Ministry’s spends about $33.8 million a year on carer support.

Respite services
The Ministry funds respite services to provide short-term breaks for people whose primary role is caring and supporting a disabled family member. Respite is generally short term, intermittent and available in community settings. Several options are available. The amount of funded respite support available is based on need and availability of services. Use of respite support may be planned, so that respite care is accessed regularly for a pre-arranged period, or it may be unplanned (for example, in response to an emergency or unforeseen event).

The Ministry spends about $17.1 million a year on respite services.

Ministry of Social Development-funded support for carers
The Ministry of Social Development (MSD) also supports carers (through Work and Income) by providing benefits and allowances such as the Domestic Purposes Benefit – Care of Sick or Infirm (DPB-CSI); child disability allowance; and disability allowance.

Domestic Purposes Benefit – Care of Sick or Infirm
The DBP-CSI is a weekly payment. This benefit is available to a person providing full-time care in their own home for someone other than a spouse or partner, who would otherwise need hospital care, rest home care, residential disability care, extended care services for severely disabled children and young people, or care of a similar kind. This is an income-tested social security benefit, so is available only to people on low incomes. From July 2013, this benefit and the Invalid’s Benefit will be replaced by a new supported living payment. Eligibility rules and benefit rates will remain broadly the same.
Invalid’s Benefit
People caring for a disabled partner or spouse may qualify jointly with them for the Invalid’s Benefit. This is a weekly payment. This is an income-tested social security benefit, so is available only to people on low incomes. From July 2013, this benefit and the DPB-CSI will be replaced by a new supported living payment. Eligibility rules and benefit rates will remain broadly the same.

Child Disability Allowance
The Child Disability Allowance is a fortnightly payment to the parent or guardian of a seriously disabled child who lives at home and requires constant care and attention. This allowance is paid in recognition of the extra care and attention that child needs. This allowance may also be available when the child lives in a home or hostel and the child’s parent or guardian is required to contribute to the costs of maintaining them.

Disability Allowance
The Disability Allowance is a weekly non-taxable payment for people who have regular, ongoing costs because of a disability. This allowance helps pay for things such as regular visits to the doctor or hospital, pharmaceuticals (medicines), medical alarms, extra clothing or travel if they arise from the person’s disability. A carer may apply on behalf of a child if the child is aged 18 or under and financially dependent on the carer.

Examples of packages of support received by disabled people
The following case studies are examples of the kinds of support and funding received by disabled people and their families. They are based on real cases but names have been changed and identifying information removed.

Case study A
Peter has a severe intellectual disability and lives at home with his mother, who is his full-time carer. Peter is unable to speak, is incontinent and requires support with all personal cares, including eating. He is able to walk but needs supervision outside the home as he has no sense of safety.
Peter’s support funding is $39,952 per year, together with one-off additional funding of $18,000. The support package is made up of:

- Ministry funding of $6,000 per year, including:
  - 80 days per year of carer support for Peter’s mother as primary family carer
- Ministry of Social Development income assistance of $33,952 per year made up of the:
  - Invalids Benefit at $13,322 per year
  - Disability Allowance at up to $3,130 per year
  - Domestic Purposes Benefit – Care of Sick or Infirm for Peter’s mother of $17,500 per year.
- a home modifications package of $18,000 for alterations to be made to Peter’s home to give him a safe shower area and install other safety devices.

Case study B
Michelle has autism, a severe intellectual disability and health issues. She lives in a city and is cared for by her parents in the family home, with help from extended family. She has behavioural and sleep problems, so it is not safe for her to be alone. Michelle’s mother gave up paid work so that she could stay at home and support Michelle. No suitable residential placement is available so residential care is not an option.

The support funding for Michelle is $56,893 per year (not including vocational services), together with one-off additional funding of $5,800. The support package is made up of:

- Ministry funding of $40,441 per year, including:
  - 20 hours per week of personal care services
  - 50 days per year of residential respite care
  - 70 days per year of carer support for Michelle’s primary family carer
- Ministry of Social Development income assistance of $16,452 per year made up of the:
  - Invalids Benefit at $13,322 per year
  - Disability Allowance at up to $3,130 per year
- Ministry of Social Development–funded vocational day service for six hours a day, three days per week (cost unavailable)
- an equipment and modifications package of $5,800 for alterations to be made to Michelle’s home to give her safe access to the bathroom and shower.

The Ministry funds a range of Environmental Support Services for a broader group than the Ministry DSS client group, such as equipment, housing modifications and vehicle purchase and modifications, to help people manage or access everyday activities. Home modification costs are generally one-off costs, while most equipment will be periodically upgraded/replaced.
**Case study C**

Angela has a rare progressive neurological disorder and uses a powered wheelchair. She lives with her elderly parents in the family home in a rural area. Angela needs full personal care such as toileting, bathing and turning at night and needs to have someone present at all times. Although willing to help, Angela’s ageing parents are no longer able to provide much assistance.

Angela’s support package is $106,452 per year together with total additional funding (not an annual payment) of $43,000. The support package is made up of:

- individualised funding from the Ministry of $90,000 per year for 70 hours personal care per week
- Ministry of Social Development income assistance of $16,452 per year made up of the:
  - Invalids Benefit at $13,322 per year
  - Disability Allowance at up to $3,130 per year
- an equipment and modifications package of $43,000, including powered and back-up manual wheelchairs, a hoist, a hospital bed, bathroom modifications and home-access modifications.

**Case study D**

Kelly is in her early 20s and has a progressive disease. She lives with her parents and several other family members in a rural town near extended family. Kelly uses a powered wheelchair and has developed respiratory issues, requiring respiratory equipment from the local district health board.

Kelly’s support package is $74,552 per year, together with total additional funding (not an annual payment) of $42,600. This support package is made up of:

- Ministry funding of $58,100 per year for:
  - 24 hours of personal care support per week
  - 20 days of carer support per year
  - 36 days of residential respite care per year
- Ministry of Social Development income assistance of $16,452 per year made up of the:
  - Invalids Benefit at $13,322 per year
  - Disability Allowance at up to $3,130 per year
- an equipment and modifications package of $42,600, including bathroom and other access modifications, a hoist, a powered wheelchair and a back-up manual wheelchair.
**Case study E**

Susie has multiple severe impairments, including physical and intellectual disabilities and medical conditions. She lives at home with her parents and other family members. Susie requires full-time care, including overnight care, and is frequently in hospital. Susie’s mother is her full-time carer and her father is in paid work.

Susie’s support funding is $24,356 per year together with total additional funding (not an annual payment) of $70,000 made up of:

- Ministry funding of $7,904 per year for 100 days of carer support
- Ministry of Social Development income assistance of $16,452 per year made up of the:
  - Invalids Benefit at $13,322 per year
  - Disability Allowance at up to $3,130 per year
- an equipment and modifications package of $70,000, including a ceiling hoist, shower table, powered wheelchair and seating, and wheelchair hoist for the family vehicle.
Appendix 2: Description of needs assessment and service coordination

What is needs assessment and service coordination?

The Ministry of Health funds a variety of disability support services allocated by needs assessment and service coordination (NASC) organisations. Generally, to access these services, people must be assessed by a Ministry-contracted NASC organisation or, where eligible, by a regional intellectual disability care organisation (RIDCA), and then go through the service coordination process.

The functions of the NASC organisation are:

- eligibility determination
- needs assessment
- service coordination
- budget management.

*Eligibility determination* begins with screening referrals to ensure eligible disabled people gain early access to a needs assessment for disability support services.

*Needs assessment* is the process of working with the disabled person and their family, whānau or guardian to identify their strengths and goals, priorities and disability support needs.

*Service coordination* is the process of assisting the person with a disability to have their needs met from all appropriate support that is available in the community (including the person’s natural supports), referring to other government agencies, and allocating support and services that are funded by Ministry disability support services contracted providers. This combination of support and services makes up the person’s *support package* and is what assists them to meet the support needs and goals identified in their needs assessment.

As part of service coordination, the prioritisation and allocation of resources to people must be achieved within the overall service budget. Consideration is given to ensure all that all disabled people in the region receive fair access to support consistent with their individual situations, and subject to the availability of natural support, with people’s safety and risk needs being met first.
Once a service has been allocated, the NASC organisation provides information on which service providers are available to provide the support. The person chooses a provider and together the person and the provider look at the person’s prioritised life goals and needs and develop an individual service plan that outlines how these, as in their support plan, are to be achieved through the service.

The needs assessment and service coordination processes are shown in Figure 2.

**Disability support services allocated by NASC organisations**

As part of service coordination, the NASC organisations are responsible for providing access to and allocating, for example, the following disability support services:

- home and community support services such as household management and personal care services
- respite care
- carer support
- supported living
- behavioural support
- community day programmes
- contract board
- community residential support services.

There are other disability support services purchased by the Ministry of Health that the NASC organisation does not allocate funding for but may refer people to. These services include, for example:

- environmental support services,
- assessment, treatment and rehabilitation services
- child development services.
Figure 2: Needs assessment and service coordination processes

Referral received

Gather eligibility related information

Is specialist information required?

Yes

Request specialist assessment

No

Is person eligible?

Yes

Carry out needs assessment

Does eligibility need to be considered?

Yes

Is person eligible?

Yes

Determine needs

Are there any support needs?

Yes

Carry out planning

Carry out service coordination

Is support allocated?

Yes

Coordinate support

Access support

No

Process ends. No funded supports.
Appendix 3: International approaches to supporting family carers

Internationally, countries take a wide variety of approaches to supporting family carers. These approaches include respite services, tax relief, payments to the person receiving care, and/or direct payments to the carer. The amount and eligibility of allowances vary, for example, some countries apply means testing.

Approaches by country

Countries with similar approaches to New Zealand

New Zealand’s current policies for providing support to family carers are most similar to policies in Australia, the United Kingdom (UK) and Ireland. These countries focus on relief and respite for family carers, and provide some form of means tested benefit to carers. Australia and Ireland also provide small non-means tested allowances to resident caregivers (who may be family members).

United Kingdom

The UK allows family caregivers to receive direct payment only in exceptional circumstances (for example, for reasons of culture or geographical isolation). The UK does, however, have a small means-tested and taxable allowance for a caregiver who may be a relative. An additional pension and a potential discount on council tax are also available for carers in the UK.

United States and Canada

The United States permits family carers to be paid through Medicaid. It also provides tax credits for dedicated carers, and carer assistance programmes to allow carers to continue working. In contrast, most Canadian provinces exclude family members from payment (four provinces allow payment), although Canada does provide a tax credit to family carers. Respite for Canadian carers is authorised in legislation, although availability and funding varies by province.

France

France allows payment to be made to most family carers, although spouses and partners are excluded. Family carers of disabled people can receive a tax deduction and pension benefit.
Germany

Germany uses a social insurance scheme to provide payments to carers. There is no exclusion from family carers receiving payment for providing care services. A care allowance is available to the disabled person, which can be used to pay family carers. Germany also provides pension insurances to carers who provide long-term unpaid care in the receiver’s home. An additional tax benefit is available to family carers when the financial burden of caregiving exceeds a certain percentage of their income.

Sweden

Sweden allows payment to family members who provide care, although they must be employed by the municipality or a free-standing body. Sweden also provides some tax relief, and respite services are available in almost all municipalities.

Other arrangements

Some countries have allowances that are paid to the disabled person or person receiving care, which can be used to pay the family carer. The Netherlands allows home care users to choose in-kind services or cash to pay a relative, including spouses and parents, to provide care. About 40 percent of budget holders hire family members or neighbours.

Some countries also have leave and other work arrangements for carers. This includes paid leave (for example, Sweden has 100 days’ paid leave for care of a person with a terminal illness) and unpaid leave (for example, Germany allows unpaid leave for the care of a family member for up to six months).
Appendix 4: Principles for establishing what support a family might be expected to provide without payment

What support a family might be expected to provide for a disabled family member without payment

Establishing what support a family member might be expected to provide without payment for a disabled family member is complex and challenging. Disabled people live in a variety of living situations and all families are different in terms of the support and care they provide for family members (whether disability is a factor in this or not). An option that funded disability support on the basis that the family provides some support without payment would need to be flexible.

An approach that allows some flexibility in assessment for and allocation of paid support is to apply principles, criteria or a set of considerations to each disabled person’s family situation. Draft principles and considerations are outlined in the next section that could guide needs assessment and service coordination (NASC) organisations in their assessment of what support families might be expected to provide unpaid.

Draft principles for assessing what family would be expected to provide unpaid

The Ministry proposes the following eight draft principles and considerations to guide a NASC organisation in assessing what disability support a family would be expected to provide without payment.

a The unpaid support family provide to meet assessed disability support needs is consistent with the outcomes in the disabled person’s support plan.

b The disabled person is comfortable with the family member providing this type of support. Factors affecting this might include the:
   - nature of the support required
   - type of familial relationship between the disabled person and family carer
   - and developmental stage of the person receiving the support.

c Paid support should not displace support that is provided by a family carer freely and willingly, and that is within their capacity and ability to provide.
d Greater expectations within some cultures and families of the support family members should provide, should not mean that government expects these family members to provide a higher level of unpaid support than family carers in other situations.

e At a minimum, the type and level of support provided by family to disabled family members without payment should be equivalent to that which a family would provide for a non-disabled family member at a similar age and stage of development.

f The family member should be capable of providing the necessary support for their disabled family member without compromising their own and their disabled family member’s safety.

g Alternative options for supporting a family to enhance their ability and capacity to provide unpaid support for their disabled family member should be considered before considering paying a family member to provide support.

h Expectations of the type and level of support that should be provided unpaid should take account of potential adverse impacts on the family carer’s and other family members’ usual responsibilities and commitments. The expected duration of the care relationship and whether the disabled person lives with the family carer are relevant considerations.
## Appendix 5: Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>disability</td>
<td>According to the social model of disability, disability is what happens when society’s infrastructure and systems cannot accommodate the diverse abilities and needs of people with impairments.</td>
</tr>
<tr>
<td>disability support services</td>
<td>Disability support services in this context refer to a variety of services for people with physical, sensory and/or intellectual disabilities (usually aged under 65). DSS can also be provided by district health boards for other age and impairment groups (refer definition of district health boards).</td>
</tr>
<tr>
<td>district health boards</td>
<td>District health boards fund health and some disability support services. They fund long-term supports for older people, people with mental illnesses and addictions, and people with chronic health conditions. District health boards were established under the New Zealand Health and Disability Services Act 2001.</td>
</tr>
<tr>
<td>environmental support services</td>
<td>Environmental support services are equipment and modifications that the Ministry of Health Group funds to assist people who meet the eligibility criteria. Environmental support services include equipment, communication aids (including hearing aids), home modifications, and vehicle purchase and modification assistance.</td>
</tr>
<tr>
<td>home and community support services</td>
<td>Home and community support services include support such as for personal care, household management and caregiver sleepovers that assist people with disabilities and their families who live in the community (that is, not in a residential service) and who have been assessed as needing assistance with activities for daily living (for example, showering, mobility, or maintaining and managing their home environment such as cleaning and preparing meals).</td>
</tr>
<tr>
<td>individualised funding</td>
<td>Individualised funding is an approach to funding disability support. People are allocated a sum of money that they can use to purchase home and community support services.</td>
</tr>
<tr>
<td>needs assessment and service coordination (NASC)</td>
<td>A NASC organisation works with the disabled person and their family and whānau to identify and prioritise a person’s care and support needs irrespective of funding constraints and the availability of services. Service coordination activities identify the most appropriate services and support options to meet the person’s assessed needs and outcome goals from within available services.</td>
</tr>
<tr>
<td>New Zealand Disability Strategy</td>
<td>The <em>New Zealand Disability Strategy: Making a world of difference</em> (Minister for Disability Issues, 2001) presents a long-term plan for changing New Zealand from a disabling to an inclusive society. The strategy adopts the social model of disability.</td>
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References

