Number of informal carers

1. 2006 Disability survey results

Table 1

Row number			Total population	15-64 year olds
1	Total population (StatsNZ)		4168500	348300
2	Total disabled population		539200	
3	Disabled population receiving any kind of assistance		192700	75300
4	Assistance includes informal help		133500	65400
5	Only receives informal help		102300	
6	High support needs		67200	36600
7	Receive informal care daily		66500	37000
8	Disability caused by aging		137308	
9	Receive informal personal care daily		16500	X
10	Receive help with personal care		35600	19600
11	Receives formal personal care		12200	5100
12	Assistance with personal care includes informal		24600	14900
13	Receive only informal assistance with personal care		23300	14500

How these estimates can be used, further steps to be taken:

- Compile from 2006 survey this information across all household management tasks (for Friday, will be done)
- Update for change in population and prevalence of disability since 2006
- Population increase: 2012 Q1 total NZ population had increased by about 6%, to 4,426,500
- HDI had previously estimated that prevalence of disability would increase by a bit over 6% between 2006 and 2011, due to demographic factors alone. Higher estimates also made for changes in epidemiology of disability, which we can use in sensitivity analysis.
- At the moment, estimates of formal care less than formal care actually provided - further work underway. Likely we will use a ratio rather than the numbers.

2. FAT data

Survey of 220 clients by DSS, included question about extent of natural supports.

Gives information allowing us to compare the following:

- natural supports
- assessed service need, and how varies with natural supports need as assessed under SPA tool
- Type of care (not looked at yet)
- Age (under 65, over 65 and age-related disability)
- Current funding allocation

Note that the results shown below are indicative only – dataset includes people in residential care.

Graph 1 shows the distribution of natural support scores for the sample.

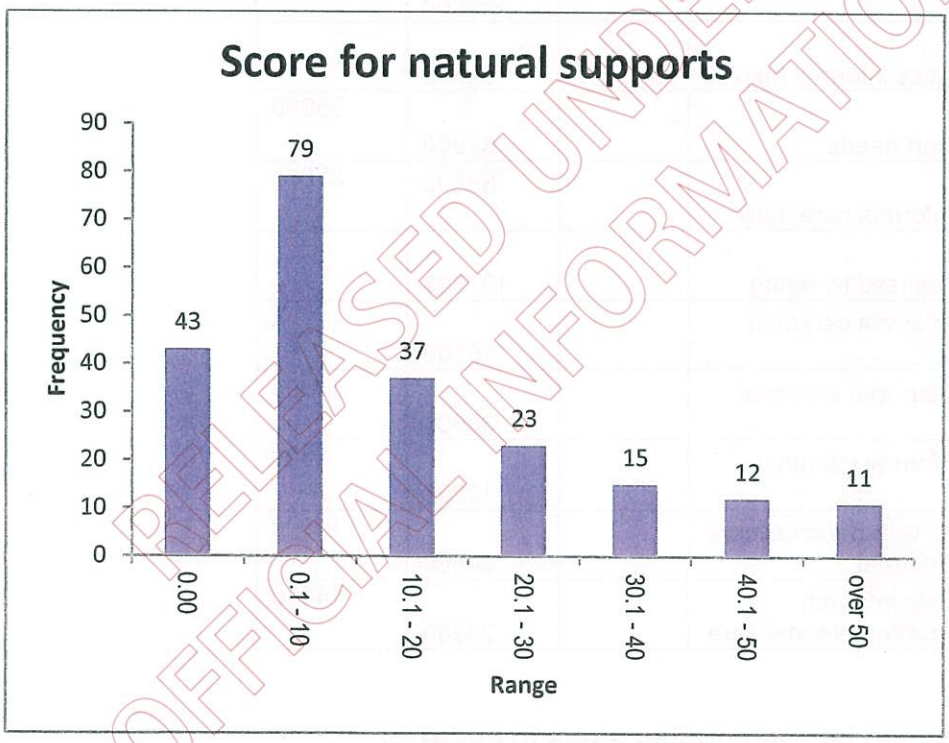


Table 2 describes the sample, by level of need as assessed by the SPA tool and by broad age group.

	Number of people			Average "score" (including natural supports)*			average natural supports score*			Current funding (excluding natur supports)*		
SPA Need Level	All	65 Plus and Age Related	School Leavers to 65	All	65 Plus and Age Related	School Leavers to 65	All	65 Plus and Age Related	School Leavers to 65	Average current funding	65 Plus and Age Related	School Leavers 65
Low	6	2	4	11	12	11	3	2	4	$ 44	$ 28	$ 52
Medium	46	4	42	21	18	21	9	4	9	$ 126	$ 152	$ 123
High	79	4	75	39	64	38	12	18	11	$ 611	$ 670	$ 607
Very High	89	7	82	64	66	64	19	12	20	$ 1,464	$ 1,357	$ 1,47
Grand Total	220	17	203	45	48	44	14	10	14	$ 839	$ 755	$ 846

Table 3 shows the funding implications, if natural supports were paid at the same rate per score unit as external providers are currently paid.

SPA Need Level	Current funding (excluding natural supports)*	Implicit "price" per score unit for current services (excluding natural supports)*	Increase in funding if pay nat supports at implicit rate*	Total funding if pay nat supports*
Low	$ 44	$ 7	$ 22	$ 66
Medium	$ 126	$ 16	$ 104	$ 230
High	$ 611	$ 27	$ 260	$ 871
Very High	$ 1,464	$ 38	$ 912	$ 2,376
Grand Total	$ 839	$ 29	$ 485	$ 1,324

**Average expenditure, by SPA need level.*

Table 4 groups the data by "score".

Grouped total scores	Count of Person	Total Score*	**Natural supports score***	**Current Funding***	**Adjusted Funding if pay natural supports on same basis***
0-9.9	20	6	2	$ 151	$ 211
10-19.9	31	15	5	$ 200	$ 326
20-29.9	23	25	8	$ 395	$ 539
30-39.9	28	35	12	$ 570	$ 916
40-49.9	30	45	12	$ 955	$ 1,444
50-59.9	19	55	16	$ 1,167	$ 1,760
60-69.9	24	65	21	$ 1,312	$ 1,970
70-79.9	20	75	25	$ 1,223	$ 1,987
80-89.9	15	85	33	$ 1,562	$ 3,237
90-100	10	94	16	$ 2,011	$ 2,652
Grand Total	**220**	**45**	**14**	**$ 839**	**$ 1,324**

**Average within each group of scores*

3. ACC data

ACC currently pay family carers. Information will be tabled on Friday.

4. Current DSS clients

Table below summarises the current active DSS clients who are receiving NASC allocated support

SPA Level (*)	Age group					
	Birth to 5 years	5 to School Leavers	School Leavers to 65	65 Plus and Age Related	No info	**TOTAL**
Very Low	6	12	9	1		**28**
Low	118	463	653	169		**1,403**
Medium	562	4,627	5,539	728	2	**11,458**
High	395	3,024	6,732	619	1	**10,771**
Very High	141	1,200	5,147	475		**6,963**
TOTAL	**1,222**	**9,326**	**18,080**	**1,992**	**3**	**30,623**

(*) SPA level proxy for level of support provided

The table below is a subset of the previous one. It summarises the number of clients receiving Carers Support and Respite Care funding. Both these categories provide a good proxy for those clients who currently are receiving unpaid support from families.

Type of care	Clients	Approved expenditure	Total units (days)	Average units (days) per client
Carers Support	13,928	$31,397,575	409,059	29
Respite	551	$3,718,483	25,536	46
TOTAL	14,479	$35,116,058	434,595	

TAKE UP RATES

We spoke this morning about the issue of eligible non-claimants and take up rates for various different types of government transfers.

Tax credits

The 2010 evaluation of Working for Families (joint report by IRD and MSD) estimated take up rates for WFF tax credits of around 95-97%. This seems relatively high by comparison with similar programmes overseas. For example,

- The estimated participation rate for the earned income tax credit in the US is around 75% (*EITC participation rate for tax year 2005*, Dean Plueger, IRS).

- The estimated participation rate for tax credits in the United Kingdom has been estimated as varying around 84-90% by caseload and 88-95% by expenditure over the period 2003-04 to 2009-10 (*Child Benefit, Child Tax Credit and Working Tax Credit Take-up rates 2009-10*, HMRC 2011). These take up rates are higher than for the predecessor tax credit regimes in the UK – e.g. WFTC had a take up of around 72-76% by caseload and 82-88% by spending in its final year of operation (2002-03).

- A broadly analogous system in Ireland (Family Income Support) is estimated to have had much lower take up rates - c 30% by caseload and 36% by expenditure in 2005. (*Non-take-up of means-tested benefits: National Report for Ireland*, Tim Callan and Claire Keane (2008).) It is not clear why take up is so low in this case. The estimates are based on a small sample so may not be reliable.

Benefits

I am not aware of evidence about benefit take up rates in New Zealand (which doesn't mean it doesn't exist). In practical terms, MSD normally costs benefit changes using its administrative data for the existing benefit population. This means that take up rates are automatically factored into estimated impacts without the need for a specific variable (as non-claimants will not be in the data).

Unusually amongst OECD countries, the UK publishes officials take up estimates for its benefits (*Income related benefits: estimates of take up in 2009-10*, DWP).

- Pension credit: 62-68% by caseload, 73-80% by expenditure.
- Council tax benefit: 62-69% by caseload, 64-71% by expenditure
- Housing benefit: 78-84% by caseload, 84-90% by expenditure
- Income support: 77-89% by caseload, 82-92% by expenditure
- Jobseeker Allowance: 60-67% by caseload, 61-70% by expenditure

Child Benefit (universal, non-means tested) has a take up rate estimated at around 96-97% (*Child Benefit, Child Tax Credit and Working Tax Credit Take-up rates 2009-10*, HMRC 2011).

As far as I am aware, there are no take up statistics for the most closely analogous UK benefits, Disability Living Allowance and Attendance Allowance. A feasibility study into possible research in this area was published some years ago (Diana Kasparova, Alan

Marsh and David Wilkinson, *The take-up rate of Disability Living Allowance and Attendance Allowance: Feasibility study*, 2007) but does not seem to have led to any published statistics. That feasibility study noted that:

> ...the size of the population eligible for DLA/AA and the take-up rate are unknown. Research using the Family Resources Survey (FRS) Disability Follow-up Survey suggested a figure ranging between 40 and 60 per cent in the case of AA, between 30 and 50 per cent in the case of the DLA Care component and between 50 and 70 per cent in the case of the DLA Mobility component (Craig and Greenslade, 1998). These estimates were not robust and they did not include people living in residential care. The MacMillan Group commissioned research that suggested about half of those diagnosed with terminal cancer, who qualify automatically under Special Rules, failed to claim (MCR, 2004).

Factors

Various factors can influence take up. In particular pecuniary factors (value and duration), compliance and information costs, administrative delays and uncertainty, and stigma. (For a useful summary, see Hernanz et al, *Take up of Welfare Benefits in OECD countries: A review of the evidence*, OECD 2004.) The relative influence of these factors is difficult to quantify (I have not seen anyone attempt it).

The best direct evidence relates to the value of support. There seems to be a clear link between participation rate and amount of award. For example:

- United States earned income tax credit: Those eligible for less than $100 were paid EITC less than 50 percent of the time. Those eligible for amounts greater than $4,000 were paid 90 percent of the time. (*EITC participation rate for tax year 2005*, Dean Plueger, IRS.)

- United Kingdom. When WFTC replaced family credit, take up rates dropped from around 72% by caseload (81% by spending) to around 62% by caseload (76% by spending). This difference is best explained by the fact that changes to the eligiblity rules [i.e. the reduction in abatement rate from 70% to 55%] led to a larger number of low value awards. Under WFTC, 36% of eligible non-claimants had awards of less than $20 a week, 59% had awards of less than $40 a week; 76% had awards of less than $60 a week. (S McKay, *Low / moderate income families in Britain: Work, WFTC, and Childcare in 2000,* DWP Research paper #161 (2002)).

- Note also the high level of take up of Child Benefit in the UK (96%), which may be partly explained by the fact that everyone qualifies for a full, unabated payment.

Conclusions

For most types of benefits and tax credits, take up rates seem generally to fall somewhere in a range between about 60% and 95%.

There is little evidence of which I am aware that directly relevant to take up of disability supports. There are some not particularly robust unofficial estimates cited in the DWP's feasibility study suggesting take up rates for this type of support in the UK may be as low as c 50%.

There is considerable variability between programmes. Programme design and administration is therefore likely to influence take up rates. It is reasonable to assume that practical constraints - such a requirement to seek full employment status - may reduce take up.

The value and duration of awards is also important. People are much more likely to navigate administrative hurdles when the money at stake is significant to them.

Important not to double count the take-up discount. If we assume that employment status will substantially reduce the take up rate, I don't think we can then factor in a general take up discount on top of that. The employment-status discounts that were floated this morning (>90%) would completely overshadow the take up issues outlined in this note.

In Confidence
Office of the Minister of Health

Cabinet

RESPONSE TO PAID FAMILY CARERS CASE: CONSULTATION ON POLICY OPTIONS

Proposal

1 This paper seeks Cabinet's approval to release a public consultation document on options for responding to the Family Carers case *(Ministry of Health v Atkinson & Others*).

Executive Summary

2 The next steps in the process of developing a response to the Family Carers human rights case are to consult with the disability and carers communities and the wider public. This Cabinet paper provides an overview of the possible responses that are described in more detail in the attached Consultation document. It is intended that the Government will decide on its response in December 2012 following the completion of the consultation process.

3 The immediate focus of the Government's response to the Family Carers case is the high-risk discrimination that arises within Ministry of Health funded home and community support from not paying parents and resident family members to care for adult disabled family members. Other potential discrimination in, for example, District Health Board (DHB) and Veterans' Affairs funded support, will be considered subsequently.

4 There are several ways in which the Government could modify its existing policy of not paying family carers in response to the Family Carers case, with options potentially including one or more of these modifications:

a targeting eligibility for payment, for example, to people with very high needs;

b paying allowances that are lower than wages;

c only paying family carers when the support provided is above an amount that family carers are expected to provide;

d capping the number of hours per week that family carers can be paid; and

e allowing family carers to be paid (but making no other policy changes).

5 An alternative approach would be introducing a flat-rate or broadly-tiered carers payment.

6 The fiscal implications range up to $343 million per annum for people who are supported through the Ministry of Health, with costs depending on such things as the particular options that are chosen and uptake by disabled people and family carers. Costs may be in the order of 2.25 times higher than this if similar responses were made for people supported through District Health Boards (such as people with age related conditions).

7 The final design of the Government's response to the Family Carers case will, however, depend on a trade-off between competing interests. Options that have lower fiscal costs may require more careful consideration of whether the resulting differential treatment of family carers can be justified under the New Zealand Bill of Rights Act 1990 (NZBORA). They are also likely to have differing impacts on family members and carers and operational implications.

Background

8 The decision by the Government to not appeal the Court of Appeal's decision in the Family Carers case means that the Human Rights Review Tribunal's (the Tribunal's) declaration stands (CAB Min (12) 20/13 refers). This means that the Ministry of Health must change its blanket policy of not allowing the payment of certain family carers (parents, spouses and resident family members) who deliver disability support services.

9 A revised policy does not, however, have to be in place until an order suspending the Tribunal's declaration is lifted. On 18 July 2012, Cabinet agreed (CAB Min (12) 25/13 refers) that if there is sufficient time before the Suspension Order is lifted, the Ministry of Health would consult with the disability and carers communities prior to the Government deciding how to respond to the Family Carers case.

10 It is not yet clear when the Suspension Order will be lifted. At present, the declaration is suspended by consent, although the plaintiffs can at any point revoke that consent which would trigger a hearing of the Ministry's application for a 12 month suspension. The plaintiffs' lawyers have provided informal indications to Crown Law that they are likely to agree to the Suspension Order remaining in place until May 2013 (12 months after the Court of Appeal's decision), but they have not yet formally responded on this issue. This means that the Government faces an uncertain situation that may only be finally resolved through Court action that is likely to take several months to complete.

11 Delaying consultation until the end of the legal process would leave little time to decide on and implement a revised policy before the Suspension Order is lifted. Officials recommend that the Government begins a public consultation process now. The Tribunal is most unlikely to lift the Suspension Order so soon that the Government would not have sufficient time to consult prior to making decisions. Not allowing time for consultation would be inconsistent with the High Court's statement that the government must be given time to develop a new policy.

12 This Cabinet paper provides an overview of the possible responses that are described in more detail in the attached Consultation document. It is intended that the Government will decide on its response to the issues that are outlined in this Cabinet paper and the consultation document in December 2012 following the completion of the consultation process.

13 [redacted]

Redacted under s9(2)(f)(iv) of the Official Information Act 1982

APPROACH TO RESPONDING

14 Officials have previously identified several government agencies and programmes that present the most significant legal risks arising from the Family Carers case as a result of policies of not paying family carers (CAB Min (12) 25/13 refers). The affected agencies are the following:

a Disability Support that is managed by the Ministry of Health and funded through the National Disability Support Services appropriation. This focuses on people with intellectual, physical and sensory disabilities who are primarily aged under 65.

b Support funded through DHBs for people with age-related disabilities, people experiencing mental health conditions, people with chronic medical conditions and people requiring short-term support (less than six months) who have been discharged from hospital.

c Support funded through Veterans' Affairs New Zealand.

15 [redacted]

Redacted under s9(2)(f)(iv) of the Official Information Act 1982

16 The other high-risk discrimination arises in other support funded by the Ministry of Health, DHBs and Veterans' Affairs New Zealand, as well as that arising in respect of other family relationships, in particular spouses and parents of young disabled children. These other issues will be considered subsequently. This approach reflects:

a the limitations on the range and scope of issues that can be effectively addressed simultaneously in the consultation document, particularly because the range of people to be consulted on these other issues will be considerably wider than is the case for Ministry of Health funded disability support.

b the likelihood that there is a range of different factors to consider when thinking about the carers of different groups of people, such as adult sons and daughters caring for parents who have age-related disabilities.

17 The approach taken in addressing the narrow range of issues that will be considered initially could, however, provide a template (and precedent) for addressing those wider issues. This means that the potential implications for those other groups should be considered when making final decisions on the approach to the narrowest feasible range of issues.

Comment

18 The immediate policy work aims to develop a policy for the delivery of Ministry of Health funded home and community support services to disabled people that does not unjustifiably discriminate against the family carers of disabled people. A full list of criteria for evaluating potential responses against this objective was presented in SOC (12) 64 (see Appendix One), although more recent work indicates that the most critical factors affecting the choice of high-level approach are the following:

a the impact on disabled people and family carers;

b whether the approach is consistent with the New Zealand Bill of Rights Act 1990;

c whether the approach can be operationalised; and

d the potential fiscal costs and risks.

19 Work to date suggests that the design of the Government's response to the Family Carers case will involve a trade-off between these competing interests. Measures that have lower fiscal costs involve greater constraints on the number of family carers who are paid and/or paying each carer less. Against this, the greater the constraints on payments to family carers, the greater are the risks that the resulting differential treatment of family carers will be found to be unjustifiable under NZBORA. This means that careful consideration will be required of any differential treatment of family carers and whether this can be justified under NZBORA before final policy decisions are taken.

20 Whether a particular response will be seen as consistent with the Government's directions for supporting disabled people and carers and be publicly acceptable is more complex. There are strongly divergent views within the community on these issues. One view within the disability community is that any approach that involves paying family carers will

undermine family relationships and disabled people's ability to live an everyday life. People with this view may support an approach that places stronger limits on the circumstances in which family carers can be paid. Another view of many carers and disabled people is that paying family carers would recognise the significant role that they have in disabled people's lives. People with this view may support an approach with few limits on the circumstances in which they can be paid.

21 It should be noted that the following section contains high-level estimates of the estimated net fiscal costs and risks (i.e. the estimated costs to Vote Health adjusted for the potential impacts on taxes and benefits) assuming 100 per-cent take-up. The estimates are sensitive to choices about the detailed design, the way that the policy is implemented and the specific assumptions made about the eligible population, the extent to which family carers take up any payment, anticipated administration and operational costs, and the way that the option interfaces with the tax and benefit systems. Further analysis of these estimates will be carried out before final decisions are made. It is also possible that information obtained through the consultation process may help refine these estimates.

Possible modifications of current policy

22 There are several ways in which the Government could modify its existing policy of not paying family carers in response to the Family Carers case. Those modifications could include the following:

a ***Paying for support provided by family carers in targeted circumstances.*** Internationally, those circumstances include such things as: the remoteness of the location making it difficult for non-family carers to provide support; cultural or religious requirements which cannot otherwise be met (for example a Muslim man requiring care when the only man available to care is a family member); and/ or a person having a particularly high level of need.

b ***Paying family carers an allowance that is less than the $25 per hour currently paid to contracted Home and Community Support Service providers.*** Note: there is a risk that paying allowances rather than wages could lead to claims under the Minimum Wage Act, but it is unclear how significant this risk is.

c ***Only paying for support provided by family carers when this is above the amount that family carers are expected to provide.*** This involves adopting an explicit policy that family carers are expected to provide some support, with that amount determined either through a principles-based or a rules-based approach. Principle-based approaches are hard to cost and operationalise in practice as they require individualised approaches that are open to challenge. Rules-based approaches might require family members to provide a specified number of hours per week before they are paid.

d ***Capping the number of hours per week that family carers can be paid to support a disabled person.*** Caps could be set, for example, at 40 hours per week.

e ***Simply remove the restriction against paying family carers and make no other policy changes***. This would mean that family carers could be paid as employees to provide support when they are willing and able to do so, even if they would be prepared to provide this support without being paid.

23 An alternative to directly paying family carers is to introduce a flat-rate or tiered carers payment at a relatively modest rate that recognises the role of family carers more generally, rather than being tied to the particular level of support provided. This has previously been promoted by Carers New Zealand.

24 Each of these ways of modifying the existing policy of not paying family carers is discussed in more detail in the attached draft consultation document. It is also possible to

combine some or all of these modifications to develop more specific options that have different levels of expected costs. Consideration would also need to be given to whether the reduction in fiscal costs and risks of any option is sufficient to justify the additional administration and operational costs that are likely to be incurred.

Costed options

25 The economic modelling presented as evidence to the Tribunal suggested that the financial cost of removing discrimination on the basis of family status would be between about $17 million and $593 million per year (2006$) for people supported by the Ministry of Health only. The lower end of the range assumed that 10% of people receiving minimal or no support from DSS would come forward to be paid as carers. This is based on an assumption that only a small group of people would be eligible to be paid as family carers. Containing costs to anything near this level would require careful design and management of the policy and its implementation. This would include strict targeting of resources.

26 Officials have developed high-level costings of some options to provide Ministers with an indication of the potential fiscal implications of various responses to the Family Carers case. The options range from those that involve a very narrow change to the existing policy of not paying family carers (with relatively few family carers paid relatively low allowances) to those that involve broad changes to the existing policy (with many family carers paid a wage). Options that have been costed include the following, with the costs based on those arising for disabled people eligible for Ministry of Health funded support (note: Option numbers refer to those used in Appendix Two):

1 ***Highly targeted, with strong expectations of unpaid family support:*** These approaches would incorporate capping the number of hours that family carers are paid for, paying family carers for support above a level expected to be provided unpaid and only paying family carers of disabled people with a very high level of need. For example:

   i. if hours are capped at 30 per week and people receive an allowance of $8 per hour, estimated costs are up to $10 million per annum (Option 1B – Line N);

   ii. if hours are capped at 30 per week and people are employed by providers, estimated costs are up to $27 million per annum (Option 1B – Line L).

2 ***Capped payments with strong expectations of unpaid family support:*** These approaches involve broader access to payments but capping the number of hours that family carers are paid for and only paying family carers for support above an expected level. For example, if the amount of time that family carers can be paid for is capped at 40 hours per week and:

   i. family carers are paid an allowance of $8 per hour for support that is required above 10 hours per week (i.e. up to 30 hours of care is funded), the estimated fiscal costs are up to $51 million per annum (Option 2A – line N);

   ii. family carers are employed through contracted providers for support that is required above 4 hours per week (i.e. up to 36 hours of care is funded), the estimated fiscal costs are up to $216 million per annum (Option 2B – line L).

3 ***Capped payments for support by family carers:*** These approaches involve easier access to payment but limiting the amount of care family members can be paid for through capping the amount of time that family carers can be paid. For example, if the amount of time that family carers can be paid for is capped at 40 hours per week and:

   i. family carers are paid an allowance of $8 per hour, estimated costs are up to $70 million per annum (Option 3A – line N);

ii. family carers are employed by contracted providers, estimated costs are up to $272 million per annum (Option 3A – line L).

27 If the Government simply removes the current restriction on paying family carers, they could paid as employees, with estimated costs of up to $343 million per annum (Option 3B – Line L). By way of comparison, total expenditure on Home and Community Support Services by the Ministry of Health in 2012/13 is estimated to be $136 million, out of a total Vote Health, National Disability Support Services Appropriation of $1,053 million. It would result in the Ministry of Health paying two to three times what it pays now for Home and Community Support with no increase in the level of support for disabled people.

28 These cost estimates could be affected in two different ways:

a The estimated costs will be lower if not all eligible family carers elect to be paid. For example, under a 'targeted circumstances' policy (as set out in paragraph 26 (1) above), if only 30% of family carers who support disabled family members with a high level of need take up paid family care, this might reduce the estimated costs of up to $27 million per annum by about 2/3.

There are differing views on the likely extent of take up that cannot be easily reconciled from available information. A review of international experience suggests that take up could be in the range of 60 to 100%, although these are not comparable with the circumstances or payments that are envisaged here. The Technical Advisory Group, which was established to provide expert advice on the Family Carers issue, suggested that take-up is more likely to be around 25% if family carers are employed, as they consider that the requirements of being employed by the disabled person or a provider agency will deter many people from seeking payment.

b Each option could impact on benefits and income tax, as payments to family carers may be considered as income for these purposes (although detailed analysis would be required before it was clear that allowances were income for benefits purposes). For example, if they are regarded as income, they may abate the benefit paid to some people who qualify for the Domestic Purposes Benefit – Care of the Sick and Infirm and may reduce the number of people who qualify for this benefit. It is likely to only be possible to reach conclusions on these issues once more specific responses are developed.

29 The option of introducing a flat-rate or tiered carers payment involves a relatively high cost as a result of a large number of people receiving a relatively low level of payment each week, and would not directly respond to the issue that family carers are not currently paid. For example, an allowance of $50 per week, paid to an estimated 26,400 informal carers, would cost about $68.6 million per annum. It is possible that such an allowance could be means tested and that it may require legislative support.

30 If similar approaches to those outlined in paragraph 26 above were extended to other high-risk groups, the fiscal cost to Vote Health could be in the order of 225 percent (i.e. 2.25 times) higher than those set out above. This assessment reflects the 2006 Disability Survey which indicates that there are at least 2.25 times as many people with high needs receiving informal care under DHBs than are supported by the Ministry of Health. People supported by DHBs include people experiencing mental health conditions, people with age-related disabilities and people with long term health conditions.

31 Cabinet has previously noted (SEC Min (12) 14/2 refers) that the fiscal costs and risk associated with the Family Carers case may not be able to be managed within current Vote Health baselines. The level of fiscal cost and risk indicated in the previous paragraph could not even be funded entirely through reprioritising within Vote Health overall and it certainly could not be funded through reprioritising within the National Disability Support Services appropriation. Reprioritising only within this area would result in many disabled people (particularly those with little support from family carers) receiving

substantially lower allocations than at present. In contrast, those with higher levels of family support would tend to receive higher allocations, but this would pay for support previously provided unpaid. This could lead to better outcomes for some family carers but worse outcomes for many disabled people.

Other measures

32 A range of other measures could be implemented by the Ministry of Health, in its funder management role, such as the following:

a Funding payments to family carers from a capped 'fund' so that costs remain within the overall funding available. This could mean, for example, that there is a wait-list for family carers who seek payment for the first time or who are seeking an increase in payment.

b Increasing funding allocations by less than is required to fully fund the costs of paying family carers, which would require disabled people to make choices about the best way to use the available funding. Essentially, this would further reduce costs below those already built into the policy response.

33 Other measures could also provide assurance that disabled people have a good quality of life when family carers are paid. Possible measures for doing this include:

a Using personalised developmental evaluations that focus directly on whether disabled people have a good quality of life.

b Requiring disabled people to have independent support for planning and building networks before family carers can be paid.

Next steps

34 The next step is to consult with the disability and carer communities on the possible responses to the Family Carers case. A draft consultation document outlining possible responses and their implications is attached as Appendix Three. The draft document incorporates the option of simply removing the current restriction on paying family members even though it is unlikely to be fiscally viable. If it is not included, there is likely to be some adverse reaction from people who strongly support this option. For example, they could challenge the integrity of the consultation process and suggest that the Government is not responding to the Court's findings.

35 The consultation process aims to allow the disability and carer communities affected by the Government's response to the Family Carers case to have input into the development and evaluation of the options. There are questions for people to respond to in the consultation document that will be included in a separate submission form for people to fill out. Table One below sets out an indicative timeline for future work.

TABLE ONE: INDICATIVE TIMELINE FOR FUTURE WORK

Date	Deliverable
19 September 2012	Consultation document circulated
October 2012	Consultation workshops with the sector
6 November 2012	Consultation period closes
December 2012	Cabinet considers the results of the consultation process and decides on new policy
January/February 2013	New policy announced. Detailed implementation process begins
May 2013	Agreed policy option(s) implemented (assuming that legislation and significant IT system change is not required)
Early 2013	Begin in-depth consideration of issues affecting support funded by DHBs and Veterans' Affairs New Zealand.

36 It is proposed that:

a consultation take place over the seven weeks from 19 September to 6 November 2012.

b the consultation document be posted on the Ministry of Health's website and distributed to key stakeholders by email and post.

c five to six regional workshops be held, with disabled people offered support, such as sign language interpreters, to enable them to participate.

d targeted consultation will be included to engage with Māori and Pacific carer and disability communities.

e a separate meeting will also be offered to the plaintiffs should they wish to take up this opportunity.

37 The Minister of Health may decide to appoint a representative to chair the individual forums and will advise Cabinet on this in due course.

Consultation

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

39 The Technical Advisory Group, which includes people with expertise and/or lived experience of disability, caring, the disability support system and the management of disability support budgets, was consulted on the broad options that are included in the discussion paper, although more detailed sub-options have since been developed by the Ministry of Health. The Group strongly recommends consulting with the disability and carers communities on this issue prior to final decisions being taken. They saw consultation as likely to improve the quality of the decisions that are made and the ownership of them within the disability and carers communities.

Regulatory impact analysis

40 There are no proposals in this paper that require the preparation of a Regulatory Impact Statement and it is uncertain at this stage whether legislative or regulatory change will be required to support the Government's response to the Family Carers case. The Ministry of Health will, therefore, work with the Treasury to undertake a preliminary impact and risk assessment as work is progressed.

Human Rights Implications

41 The Court of Appeal has upheld the decisions of the High Court and the Tribunal that the Ministry of Health's policy of not paying family carers amounts to unjustified discrimination under NZBORA. Possible responses to these decisions will need to be assessed to determine whether any restriction on the payment of family carers involves unjustifiable discrimination under NZBORA. The Courts' rulings have given some guidance on the tests that should be applied to determine compliance with NZBORA.

Legislative Implications

42 There are no legislative implications arising from the recommendations in this paper. It remains unclear, however, whether legislation will be needed to implement the Government's response to the Family Carers case.

Gender Implications

43 The Government's response to the Family Carers case is likely to primarily affect women as they are the majority of people who provide unpaid care to disabled family members. The public consultation process will help with understanding the implications of the policy options on different groups of people.

Disability Perspective

44 There are differing views in the disability and carers communities on whether family members should be paid for providing care, with many people recognising the dilemmas raised by the Family Carers case. A public consultation process will help to draw out the range of perspectives and build public support for the approach that is finally agreed.

Financial Implications

45 Appendix Two summarises the current estimates of the fiscal implications of the responses that are outlined in this paper for the disability support that is funded through the Ministry of Health. There will also be implications for Vote Social Development and for tax revenue.

46 Paragraph 30 above provides an early indication of the flow-on implications of the case for other support that is funded through the Ministry of Health, DHBs and Veterans' Affairs New Zealand. Further work is required to more robustly estimate those flow-on implications and how they are affected by the various modifications that are described in Paragraph 22 above. Officials will include more robust estimates on these implications in the report back to Cabinet in December 2012.

Publicity

47 The Minister of Health will continue to take the lead role in making public statements about the Family Carers case, including statements relating to the public consultation process. The Ministry of Health will lead the public consultation process.

Recommendations

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

1 **note** that Cabinet has previously agreed (CAB Min (12) 25/13 refers) that, if the timeframe for lifting the Suspension Order allows, the Ministry of Health will consult with the disability and carers communities on how the Government might respond to the issues raised by the Family Carers case;

2 **note** that the plaintiffs have not yet agreed to a timetable for lifting the Suspension Order, but that the Ministry of Health's legal advice is that the Crown should proceed with a public consultation process rather than delay the consultation process until after a timetable is agreed;

3 **note** that the consultation paper focuses on the discrimination against family carers that arises within home and community support funded by the Ministry of Health as a result of not paying parents and resident family members;

4 **note** that the range of approaches for responding to the Family Carers case that are included in the consultation document are the following:

4.1 targeting eligibility for payment, for example, to people with very high needs;

4.2 paying allowances that are lower than wages;

4.3 only paying family carers when the support provided is above an amount that family carers are expected to provide;

4.4 capping the number of hours per week that family carers can be paid;

4.5 allowing family carers to be paid (but making no other policy changes); and

4.6 a flat-rate or broadly-tiered carers allowance;

5 **note** that policy options may combine one or more of the approaches to responding to the Family Carers case that are included in the consultation document;

6 **note** that further work is required to refine and peer review the costings that are set out in this Cabinet paper;

7 **agree** to the release of the attached consultation document as the basis for a public consultation process on the options for paying family carers;

8 **note** that minor editorial changes may be made to the consultation document prior to its release;

9 **note** that the Minister of Health intends to release the consultation document on 19 September 2012 with submissions due to close on 6 November 2012;

10 Redacted under s9(2)(f)(iv) of the Official Information Act 1982

11 **direct** the Ministry of Health, in consultation with the Ministry of Social Development and Veterans' Affairs New Zealand, to further develop the potential responses to the Family Carers case that are outlined in this paper, including considering the flow-on implications for Vote Health, Vote Social Development and Vote Veterans' Affairs; and

12 **invite** the Minister of Health to report back to Cabinet Social Policy Committee in December 2012 with recommendations on a preferred approach for responding to the Family Carers case.

Hon Tony Ryall
Minister of Health

___/___/_____

Appendix One

Criteria for Evaluating Potential Responses to the Family Carers case

1 The fuller list of criteria that were included in SOC (12) 64 for evaluating potential responses to the Family Carers case were the following:

a the impact on disabled people's choice and control over the support they receive

b the impact on carers' life choices and opportunities

c the impact on the quality and safety of paid support received by disabled people

d the broader implications for other parts of government and society generally

e the impact on the availability of unpaid natural supports

f fiscal costs and risks

g whether any discrimination under NZBORA can be justified

h operational feasibility and implementation issues and risks

i the likelihood that disabled people and family carers will understand and accept the approach.

Appendix Two: Estimated expenditure if we pay family carers of disabled adults aged 15 – 64 (excluding those with age-related and mental health conditions)

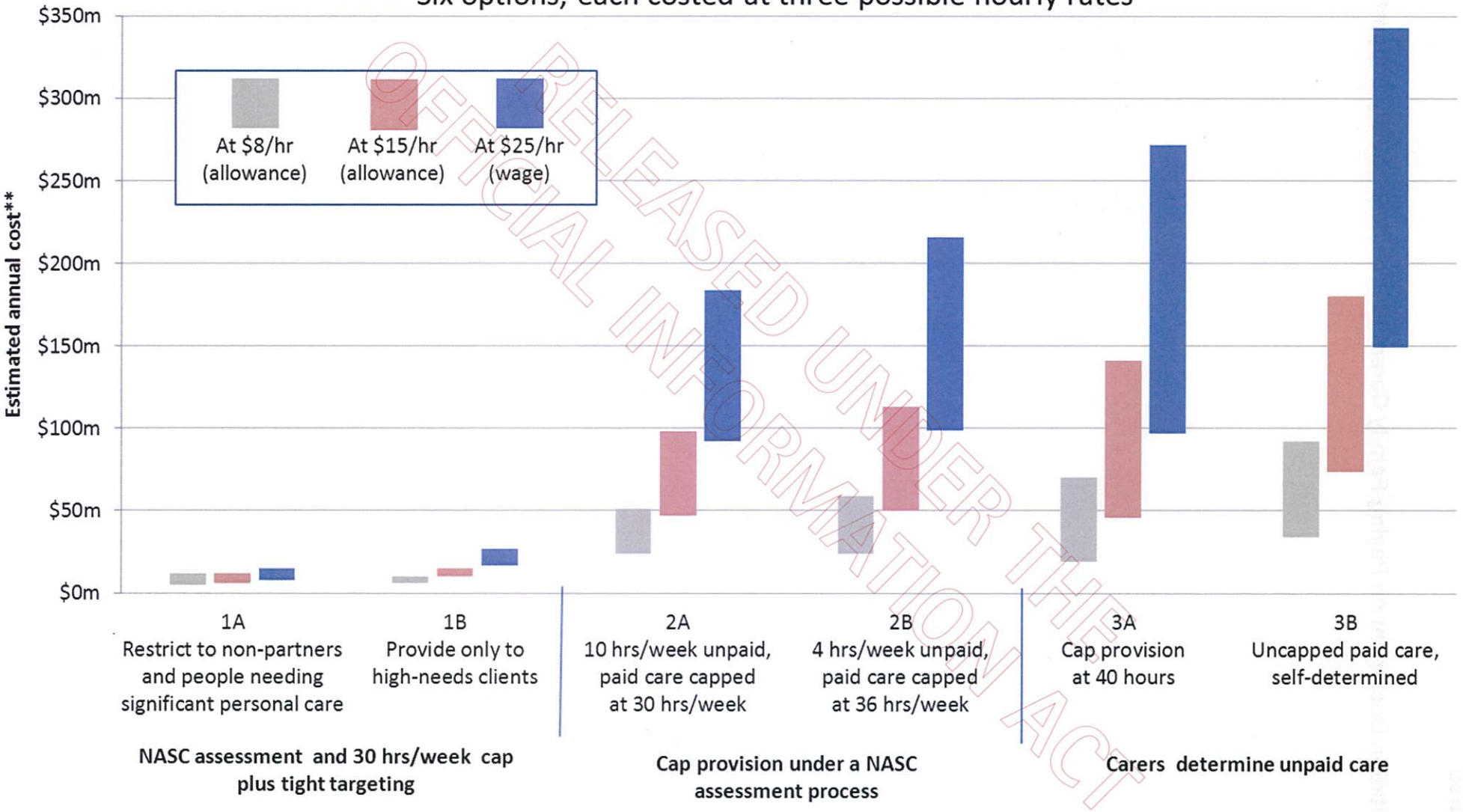
Row no.		NZIER ($2006)	**Option 1:** Tight eligibility, capped at 30 hours, and set expectations of the amount of unpaid family care		**Option 2:** Capped hours and set expectations of the amount of unpaid family care		**Option 3:** No expectations of unpaid family care (they determine care they will provide unpaid)	
			Option 1A *Restrict eligibility to non-partners and to disabled people needing significant personal care*	**Option 1B** *Provide only to high needs clients*	**Option 2A** *Require that families provide first 10 hours free, effective cap is 30 hours of funding*	**Option 2B** *Require that families provide first 4 hours per week free, effective cap is 36 hours of funding*	**Option 3A** *Cap funding for family carers at 40 hours per week*	**Option 3B** *No cap on funding for support by family carers*
A	Current HCSS clients who receive a mix of family care and paid services from external provider: - Assumed eligible population	Assumed additional $8.7m for people currently high users of DSS services, offset by saving of 3.1m from lower pay rate for family members	Assume 9% of HCSS clients have a family member, not a partner, providing personal care	23% of current HCSS clients "very high needs"	If 5,000 clients get family care for more than 10 hours per week	If 6,900 clients get family care for more than 4 hours per week	12,000 current clients	12,000 current clients
B	- Assumed average hours provided per week by paid family members		10.6	10.6	10.6	8.4	5.1	7.4
C	People not currently accessing HCSS, high support needs receiving all care from unpaid informal carers - Assumed eligible population	Assumed additional $11.4m, for people currently accessing minimal or no support services	9% of disabled clients receiving informal care from non-partner family member	8% non-HCSS clients receiving 30+ hours personal care from family carer	3000 - 6000	4,200 - 8400	7,300 – 14,600	7,300 – 14,600
E	- Assumed average hours of care provided per week by paid family members		10.6 – 18.6	10.6 – 18.6	10.6 - 18.6	8.4 - 16.4	5.1 - 13.1	7.4 - 15.4
F	Assumed uptake by eligible population	10%	100%	100%	100%	100%	100%	100%
G	Placeholder for additional operational expenditure, through NASCs		$ 1.9 – 3.7M	$ 1.9 – 3.7M	$ 1.9 – 3.7 M	$ 2.6 -5.2 M	$ 4.5 -9.0 M	$ 4.5 – 9.0 M
H	**Gross expenditure estimates*** **Employed through provider ($25)**	**$17m**	**$ 10 -18 M**	**$ 21 -31 M**	**$ 113 - 220 M**	**$ 124 -260 M**	**$ 132 -337 M**	**$ 190 - 417 M**
I	**Allowance ($15 per hour)**		**$ 8 -15 M**	**$ 13 -20 M**	**$ 68 - 133 M**	**$ 76 -158 M**	**$ 81 - 206 M**	**$ 116 - 254 M**
J	**Allowance ($8 per hour)**		**$ 6 -14 M**	**$ 8 - 13 M**	**$ 37 - 73 M**	**$ 41 - 87 M**	**$ 45 - 114 M**	**$ 64 - 139 M**
K	*Will be offset by* - *Reduced expenditure on benefits*** - *Additional tax revenue*** - *Reduced expenditure on carer support and other DSS programmes*		$ 2 – 3 M	$ 4 -5 M	$ 21 -36 M	$ 26 -45 M	$ 35 -65 M	$ 42 - 74 M
L	**Net expenditure estimates: Employed through provider ($25)**		**$8 -15 M**	**$17 -27 M**	**$ 92 -184 M**	**$99 -216 M**	**$97 -272 M**	**$149 -343 M**
M	**Allowance ($15 per hour)**		**$6 -12 M**	**$10 -15 M**	**$47 -98 M**	**$50 -113 M**	**$46 -141 M**	**$74 -180 M**
N	**Allowance ($8 per hour)**		**$5 -12 M**	**$6 - 10 M**	**$24 - 51 M**	**$24 -59 M**	**$19 - 70 M**	**$34 -92 M**

* The upper end of this range assumes 14,600 people would be eligible, and that they would need, on average, the same number of hours of paid care as people who are already receiving disability support services from paid external providers. The lower end of the range assumes that half of that number would be eligible, and that this smaller pool would, on average, have lower needs than existing clients.

** Estimated impact on tax revenue benefit system is indicative only and has not yet been agreed with relevant departments.

Estimated Cost Ranges to Pay Family Caregivers of Disabled Adults Aged 15-64*

Six options, each costed at three possible hourly rates



* For clients of Vote Health disability support. Excludes age-related , mental health and chronic medical conditions, and short-term after-hospital care.
**Net cost after offsets (reduced benefit costs, increased tax revenue, savings in other carer support.

Appendix Three

Draft Consultation Document on Paying Family Carers to Provide Disability Support

Handover – method behind fiscal impact estimates included in September 2012 Family Carers Cabinet Paper.

BASE MODEL

Appendix in Cabinet paper sets out several options as well as the results of a sensitivity analysis. All of the options are variants of a base model. To help clarify the base model estimates are circled below.

Row no.		**Option 1** Current situation if family members paid		**Option 2** Cap provision under a NASC assessment process		**Option 3** Target eligibility AND cap provision under NASC assessment process (Restrict hours as in 2B)		**NZIER** ($2006)
		Option 1A *Carers determine ability to provide care, no cap*	**Option 1B** *Cap provision to 40 hours per week*	**Option 2A** *Require that families provide first 4 hours per week free, effective cap is 36 hrs public funding*	**Option 2B** *Require that families provide first 10 hours free, effective cap is 30 hrs public funding*	**Option 3A** *Provide only to high needs clients*	**Option 3B** *Restrict eligibility to non-partners and to disabled people needing significant personal care.*	
A	Current HCSS clients who receive a mix of family care and paid services from external provider: - Assumed eligible population	12,000 current clients	12,000 current clients	If 6,900 clients get family care for more than 4 hours per week	If 5,000 clients get family care for more than 10 hours per week	23% of current HCSS clients "very high needs"	Assume 9% of HCSS clients have a family member, not a partner, providing personal care	Assumed additional $8.7m for people currently high users of DSS services, offset by saving of 3.1m since assumed lower payment rate for family members
B	- Assumed average hours provided per week by paid family members	7.4	5.1	8.4	10.6	10.6	10.6	
C	People not currently accessing HCSS, high support needs receiving all care from unpaid informal carers - Assumed eligible population	7,300 - 14,600	7,300 – 14,600	4,200 - 8400	3000 - 6000	8% non-HCSS clients receiving 30+ hours personal care from family carer	9% of disabled clients receiving informal care from non-partner family member	Assumed additional $11.4m, for people currently accessing minimal or no support services
E	- Assumed average hours of care provided per week by paid family members	7.4 - 15.4	5.1 - 13.1	8.4 - 16.4	10.6 - 18.6	10.6 – 18.6	10.6 – 18.6	
F	Assumed uptake by eligible population	100%	100%	100%	100%	100%	100%	10%
G	Placeholder for additional operational expenditure, through NASCs	$ 9.0 M	$ 9.0 M	$ 5.2 M	$ 3.7 M	$ 3.7M	$ 3.7M	
H	**Gross expenditure estimates [10]:** **Employed through provider ($25)**	**$ 190 - 417 M**	**$ 132 -337 M**	**$ 124 -260 M**	**$ 113 - 220 M**	**$ 21 -31 M**	**$ 10 -18 M**	**$17m**
I	**Allowance ($15 per hour)**	**$ 116 - 254 M**	**$ 81 - 206 M**	**$ 76 -158 M**	**$ 68 - 133 M**	**$ 13 -20 M**	**$ 8 -15 M**	
J	**Allowance ($8 per hour)**	**$ 64 - 139 M**	**$ 45 - 114 M**	**$ 41 - 87 M**	**$ 37 - 73 M**	**$ 8 - 13 M**	**$ 6 -14 M**	
K	*Will be offset by* - *Reduced expenditure on benefits* - *Additional tax revenue* - *Reduced expenditure on carer support and other DSS programmes*	$ 42 - 74 M	$ 35 -65 M	$ 26 -45 M	$ 21 -36 M	$ 4 -5 M	$ 2 – 3 M	
L	**Net expenditure estimates:** **Employed through provider ($25)**	**$149 -343 M**	**$97 -272 M**	**$99 -216 M**	**$ 92 -184 M**	**$17 -27 M**	**$8 -15 M**	
M	**Allowance ($15 per hour)**	**$74 -180 M**	**$46 -141 M**	**$50 -113 M**	**$47 -98 M**	**$10 -15 M**	**$6 -12 M**	
N	**Allowance ($8 per hour)**	**$34 -92 M**	**$19 - 70 M**	**$24 -59 M**	**$24 - 51 M**	**$6 - 10 M**	**$5 -12 M**	

The base model was estimated based on variables to capture the following:

Key variables for thinking about the impact of policies

1. *Number of disabled people with unpaid formal carers*
2. *Nature of the service for which carers will be eligible for payment*
3. *Payment method and amount*
4. *Institutions necessary for quality and safety*
5. *Offsetting reductions in crown spending*

The base model was estimated as follows:

			Source	Note reference
1.	Number receiving DSS HCSS	12,000	DSS (Elliot) & *Statistical Data on DSS Expenditure and Clients*	See note 1 below
2.	Cost per client HCSS	$10,400	*Statistical Data*	
3.	Average current paid support hours per week HCSS clients	8 hours	*Statistical Data.*	
4.	Average payment per hour per HCSS client	$25	*Statistical Data:* cost per client = $10,400; hours per client = 417.	
5.	DSS clients – proportion of care provided by informal carers	41%	F.A.T. survey	See note 2 below
6.	DSS clients – increase in expenditure if pay natural supports for all care they provide on same basis as formal providers	95%	Calculated from F.A.T. survey	Note 2
7.	→ average hours provided by informal carers to DSS clients	7.4 hours	Calculated from rows 3 and 6	
8.	→ average increase in expenditure per annum if pay natural supports of HCSS clients on same basis as formal providers	$9,600	Calculated from rows 4 and 7.	
Disabled people not currently accessing HCSS (Rows C and E above)				
9.	Number with high support needs also receiving informal care	27,335	Survey, adjustments as outlined	Note 3
10.	Number with high support needs NOT accessing DSS HCSS	14,615	Assumed – calculated by subtracting number receiving HCSS (row 1) from total with high needs. Assume all disabled people in this age group receive some informal care. Reasonable assumption - survey shows that none with high support needs live in single person households (p.45)	Note 3
11.	Average hours per week provided by informal carers	15.4	row 3 + row 7.	
12.	Average increase in expenditure if pay family carers on same basis as HCSS providers	$19,970	Row 2 + row 8 (note rounding error).	
13.	100% assumed, after discussion with key stakeholders	100%		
Additional operational expenditure (row G, above)				

14.	Average expenditure per NASC client		Elliot LJ	See Note 4 below
15.	Employed through provider	($25)	This is the approx. hourly rate paid by the Ministry of Health and b [redacted]	
16.	Allowance	($15)	[redacted] The Ministry does not generally enter into direct employment relationships, hence this would be likely to be paid as an allowance.	
17.	Allowance	($8)	Showing the significance of paying a lower hourly rate, directly by Ministry of Health therefore assumed to be paid as an allowance.	
18.	Change to Benefit payments		John Marney	See Note 5 below.
19.	Additional Tax Revenue		John Marney	Note 5
20.	Reduced expenditure on other disability programmes, including on Carer Support		Estimate from expenditure on Carer support	Note 5

OPTION DEVELOPMENT

The options were developed through an iterative process with key stakeholders.

Option 1B reflects a usual employment relationship.

Options 2A and 2B reflect both a cap at 40 hours, consistent with a normal employment relationship; and two different assumptions about what people might reasonably expect to have to provide free of charge. The choice of four hours is ad hoc; the choice of ten hours assumes about 1 hour per day on week days and slightly over two hours per day on weekends. The hours that would be provided by informal carers under each option were estimated using the results of the FAT tool survey, vis: (See Note 2 for an explanation of the way the FAT survey results were analysed).

	n	Average current funding (DSS)	Average implicit funding, natural supports	Proportion of care provided by natural supports, relative to care from paid provider	Average hours per week, HCSS	Implied hours per week, natural supports
All respondents, 15 – 64 in non-residential care	156	$500	$461	95%	8	7.4
If cap payments at 40 hours per week	156	$500	$315	63%	8	5.1
Require first 4 hours per week free, cap at 40 hours	90	$500	$525	105%	8	8.4
Require first 10 hours free, cap at 40 hours	65	$500	$662	130%	8	10.6

Options 3A and 3B reflect targeting eligibility to those with high needs and by the status of the informal carer.

- "Need" in option 3, for current HCSS clients (row A) is defined according to the Support Package Allocation (SPA) tool. This is used by NASCs to ensure a nationally consistent approach to identifying the level of need of individual clients and allocation of resources. For different age groups, the tool describes different levels of need and desired outcomes, and

a funding allocation range for each level. Need is assessed net of natural supports, which means that a change in payment arrangements may change the number of clients in each category. HCSS clients currently have the following distribution of need [Check source – think Statistical Information]

	low	medium	high	very high	unknown	**total**
Number of clients	535	3,889	4,730	2,740	33	**11,927**
Expenditure ($)	$846,543	$13,372,133	$47,830,388	$62,251,056	$136,807	**$124,436,928**

- "Need" for non-HCSS clients (row C) is defined according to the proportion of those with high needs receiving 30 hours or more help with personal care, as reported in the 2006 Disability Survey (8 percent). High need for personal care is used as a proxy for more intensive service need. It is also used as an indicator for services which clients may prefer to receive from a carer other than a family member.
- Option 3B restricts eligibility to family members, i.e. excludes partners. The 2006 Disability Survey reports that 9 percent of people receiving informal care receive personal care from a non-partner family member.
- For simplicity, the base model assumes that the average hours of care received by very high needs people is equivalent to the hours of care received in Option 2B. This is a conservative assumption, likely to understate the costs. To show the impact of this, if we instead assumed a doubling of average hours of care, table below shows that increases in net expenditure estimates by 130 to 175 percent (new assumptions and estimates marked with highlighter)

	Option 3 Target eligibility AND cap provision under NASC assessment process (Restrict hours as in 2B)	
	Option 3A *Provide only to high needs clients*	**Option 3B** *Restrict eligibility to non-partners and to disabled people needing significant personal care.*
Current HCSS clients who receive a mix of family care and paid services from external provider: - Assumed eligible population	23% of current HCSS clients "very high needs"	Assume 9% of HCSS clients have a family member, not a partner, providing personal care
- Assumed average hours provided per week by paid family members	10.6 – 21.2	10.6 – 21.2
People not currently accessing HCSS, high support needs receiving all care from unpaid informal carers - Assumed eligible population	8% non-HCSS clients receiving 30+ hours personal care from family carer	9% of disabled clients receiving informal care from non-partner family member
- Assumed average hours of care provided per week by paid family members	10.6 – 29.2	10.6 – 29.2
Net expenditure estimates: Employed through provider ($25)	**$17 -47 M**	**$8 -24 M**
Allowance ($15 per hour)	**$10 - 27 M**	**$6 -19 M**
Allowance ($8 per hour)	**$6 - 13 M**	**$5 -15M**

SENSITIVITY ANALYSIS

The gross expenditure estimates are sensitive to variations in all parameters. The upper limit of the ranges reflects the base model; the lower limits are based on a smaller high needs population cared for only by informal carers (about 7,300), with lower average needs than disabled people currently receiving care (paid family carers' hours approx. halved).

- Row C – sensitivity analysis halved the number of people assumed to be eligible and not currently receiving DSS services, reflecting informal feedback that likely to be fewer than 14,600. Assessed impact if halved number of eligible people currently not accessing services.
- Row E – sensitivity analysis tested the assumed that people not currently in receipt of DSS services have same average need of those who are. Average need, measured by hours of care received, for DSS clients is 8 hours formal plus 7.4 hours informal (in base model); Assessed impact if assumed receive only informal care at level received by DSS clients.
- Row G – variation reflects variation in assumed eligible population and hours
- Row K - Offsetting savings – range reflects changes in assumed number of people receiving family care, at the mid point of the payment estimate ($15).

NOTES

NOTE 1 – Estimation of disabled people currently accessing DSS services

12,000 disabled people currently receive Home and Community Support Services (HCSS) through Disability Support Services funding, administered by the Ministry of Health. Sources: Statistical Data on DSS Spending and Clients, unpublished; confirmed by personal communication from Elliot L-J.

Services accessed through NASC[1]	Number of clients	Cost per client	Further information
HCSS (requires CSC to be eligible)	11971	$10,369	Average support hours p.a. 417 (about $25 per hour) Number of clients by service (not mutually excl) [2] - personal care 7000 - household mgt 6800 -IHC home support 550
Residential	7832	$55,712	
SIL	2462	$2,462	
Carer support	13915	$2,204	
Day programme	1395	$16,012	
All DSS	30114	$21,677	

NOTE 2 F.A.T. Survey

[2] Unpaid informal care has been estimated for current HCSS clients from a survey conducted to test a new assessment tool ("FAT"). The sample included 220 clients, of whom 156 adults aged 15 - 64, currently receiving HCSS. It included questions about the hours of informal care provided by unpaid carers, and the types of services they provide. We used this to estimate the number of clients receiving informal care, the hours of care they provide, and the increase in expenditure if informal carers were paid, under various conditions. The sample may include people with higher needs, on average, than the whole population of HCSS clients and so may not be representative.

The logic of the FAT tool follows:

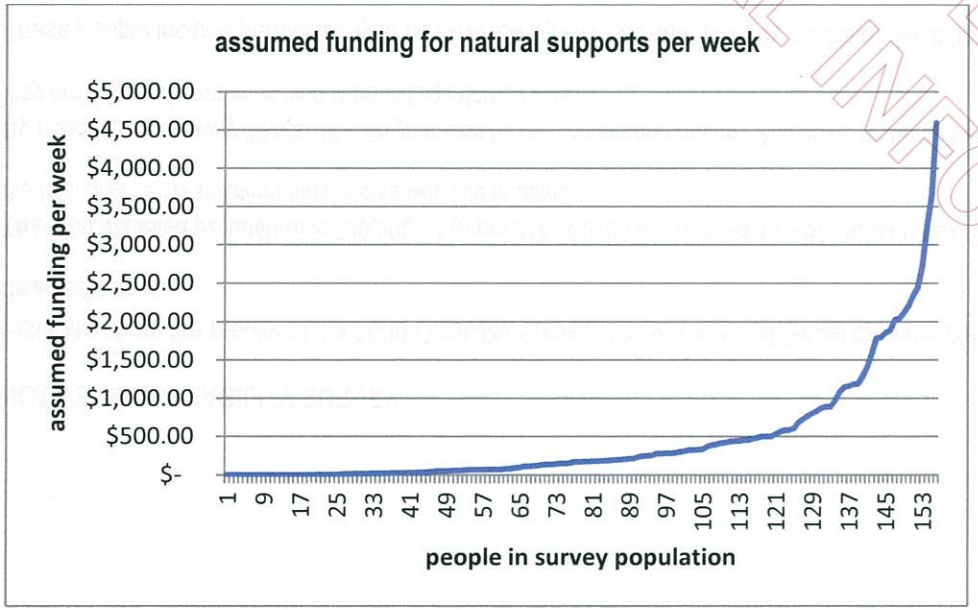
- The FAT tool calculates, for each person, a "score". The score is an assessment of their total needs, and is divided into a score for needs met by natural supports, and needs met by external providers. The results give an estimate of the extent to which DSS clients are assessed as needing fewer DSS services because of natural supports. *We will assume the ratio of natural supports: total assessed need for services can be used as an indicator for extent of unpaid family carers. Over the entire sample of non-residential clients, about 40% of their care was assessed as being able to be provided by natural supports.*
- Scores are grouped into bands, each band attracts funding. Funding is non-linear, i.e. higher scores attract disproportionately higher levels of funding, partly because higher needs are associated with multiple and/or more complex disabilities.
- Scores for DSS-funded services from external providers are mapped to the level of funding allocated for each individual. We can use this to map scores for natural supports to a notional funding allocation.

[1] Source: unpublished "Statistical data on DSS Expenditure and Clients"
[2] Source: ELJ

- Derive implicit hours per week of natural support for each individual from the relative funding allocation, compared to hours of HCSS.

	n	Assumed hourly "price" of care provided by DSS	Average current funding from DSS	Average implicit funding, natural supports	Proportion of care provided by natural supports, relative to care from paid provider (based on funding band)	Average hours per week, HCSS	Implied hours per week, natural supports
All respondents, 15 – 64 in non-residential care	156	$25	$500	$461	92%	8	7.4

Above assumes that pay for all of the natural support provided – ie if a family member is providing 80 hours of care this will be funded in the same way that formal care is funded. In the FAT data, if this is the case, the distribution of weekly funding looks like this:



For the development of Options 2 and 3 the FAT tool respondents were capped with the following results

	n	Average current funding (DSS)	Average implicit funding, natural supports	Proportion of care provided by natural supports,	Average hours per week, HCSS	Implied hours per week, natural supports

				relative to care from paid provider		
All respondents, 15 – 64 in non-residential care	156	$500	$461	92%	8	7.4
If cap payments at 40 hours per week	156	$500	$315	63%	8	5.1
Require first 4 hours per week free, cap at 40 hours	90	$500	$525	105%	8	8.4
Require first 10 hours free, cap at 40 hours	65	$500	$662	130%	8	10.6

NOTE 3 2006 DISABILITY SURVEY

Estimated from the results of the 2006 Disability Survey. These (non-residential care people only) were used to estimate the number of unpaid informal carers providing care to high needs disabled people.

The total disabled population is 539,200, of whom 348,300 (65%) are aged 15 – 65. *Assumption: This age group will be the proxy for DSS clients. It is imperfect – since the survey finds 137,300 people (25% of the total disabled population) have a disability due to aging.*

By needs. In the survey 36,600 15 – 65 year olds have "high support needs". According to the survey, none of these adults live in single-person households. This is relevant since consistent with hypothesis that they are living with someone who is providing informal care.

These people include people likely to be covered by ACC (ie with primary cause of disability being injury) or DHBs (ie those with mental health disabilities). We adjust the totals to remove these people.

We adjusted this number for population growth. **The New Zealand population** has increased by about 6% since 2006. Previous MoH work estimated that, between 2006 and 2011 disability prevalence would increase by at least 6 percent (See Martin Tobias paper). Martin suggested that we assume that any change is due to demographic factors alone (low end) given uncertainty about whether there are also epidemiological changes.

After making these adjustments, and removing the 12,000 people assumed to be covered by HCSS. The remainder – about 14,600 – is used in the base model as the population of disabled people with ONLY informal carers who might be eligible for payment, depending on policy parameters. Feedback suggests this is probably an upper bound for people with high needs, and so it was varied in sensitivity analysis.

The base model assumes that average needs in the non-HCSS population are comparable to those in the HCSS population. Since the HCSS population is assumed to receive, on average, the equivalent of 8 hours of formal care (in each option), and variable amounts of informal care, we assume that non-HCSS disabled people "need" the same total amount. Feedback suggests that this may overstate the level of unmet need and is a "worst case" scenario: it was tested in sensitivity analysis across the range indicated.

Row	Col 2	Column 3 2006 SURVEY Numbers 15-64s	Column 4 2006 ESTIMATED 15-64, not pscyh, not ACC (Refer rows 9 to 12 below)	Column 5 2012 Adjusted for population growth (6%)
1	Number disabled	348,300		369,198
2	Number with informal care	75,300	53,056	79,818
3	Number recorded as having "high support needs" & receiving informal care.	36,600	25,788	27,335
4	Estimated number not already accessing DSS-funded services (calculated by subtracting 12,000 from row 3)	24,400	13,788	14,615
5	Survey - number receiving any informal personal care	14,900	10,498	
6	Survey - number informal every day personal care	8600	9,116	
7	Number (proportion) receiving 30+ hours informal personal care	5,800 (8%)	4,087	
8	Number (proportion) receiving help with personal care from non pnr family member	6,900 (9%)	4,862	
9	• *Number with informal care & main disability caused by injury*	*18,400 (24%)*		
10	• *Assumed proportion of injured cared for by ACC*	*80%*		
11	• *Number with psych as main disability, adjusted for number caused by injury*	*7,524*		
12	• *Proportion informal not ACC injury or psych*	*70%*		

NOTE 4 Placeholder for additional admin / operational expenditure, through NASCs

There are likely to be two effects on NASCs: first, a pure volume effect, since NASCs will need to assess and then manage greater numbers of clients; and second, an intensity effect which will come into play as greater targeting is employed, since resource requirements for higher need clients are likely to be greater than those for lower need clients, reflecting the need for specialist assessments and so on. At this stage the estimates are indicative only, based on a linear function which assumes that all clients have the same level of resource intensity, equivalent to current average cost per client in NASCs. (Total funding for NASCs is $18.4 million per year, spent on about 30,000 clients.)

NOTE 5 Offsetting savings

The offsetting savings are indicative only, and have not been confirmed with relevant departments. The estimates presented here assume:

- Reduced expenditure on benefits, estimated using a multiplier derived from the average abatement across all options. The multiplier for reduced expenditure when hourly payment is $15-$25 (47) is about 7.5 times higher than the multiplier when hourly payment is $8 (6). See relevant spreadsheet for derivation of multiplier.

- Additional tax revenue is also estimated using a simple linear multiplier, with the multiplier = 95 when hourly payment is $15 - $25; and 51 for hourly payment of $8. See spreadsheet for derivation.
- At this stage reduced expenditure on carer support and other DSS programmes is included using a multiplier calculated from 50% of current average payments to clients for carer support ($2200). This is a placeholder, pending policy analysis about the likely impact on these programmes of paying carers under the different options.

Paying Family caregivers

Modelling and costing

Monday 5 November, 9 am -10 am.

Kathy Brightwell, Bronwyn Croxson, Nick Hunn, Harvey Steffens

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Agreed the main priorities for the modelling and costing work, once we've gained a good understanding of the current estimates, are:

- investigating and refining, where possible, the areas of largest uncertainty:
  - the numbers of people not currently in receipt of our services and what their likely uptake might be
  - responses of people to the availability of payments
  - possible implications for DHBs
- testing other assumptions in modelling such as impacts on existing benefits if people are treated as employed
- establishing contacts and processes for working with other agencies

We noted the need to refine the estimates of implementation costs. These are especially the cost for NASCs of options and any flow on effects of options for Ministry-funded services such as carer support. This later may arise, for instance, if employed family caregivers take leave.

We also discussed how best to get our approach tested and our results reviewed. We settled on working with a range of government agencies individually and, separately, working with a group of external reviewers including current external EAG members.

Action points	**Lead**
Explore the disability survey for additional useful information. Ministry adviser is Marianne Linton.	NH
Explore using the Health Survey to collect some information that may help us reduce key uncertainties in our estimates and the timeframes that might be possible in and the costs involved. May need to involve conversation between Kylie Clode and Jackie Fawcett	KB
Investigate examining ACC data: • in discussion with Cheryl Watson from ACC what uncertainties might be able to be addressed if we were able to use ACC data • consider asking Ministers to discuss access to ACC data for these purposes	NH KB
Understand and refine, if possible and worthwhile, tax effects – discuss with IRD. We may be able to incorporate provider tax contributions	NH
Establish link with MSD	KB to establish

	contact NH to follow-up
Confirm links to other relevant agencies at senior level through Don Gray. This is to ensure that agencies are aware of and agree our work and that this work is well coordinated with policy work within and between agencies.	KB
Prepare 1 pager for Wednesday's senior officials' meeting covering the main strands of work, key questions for the officials, and seeking to cement contacts and coordination	HS
Review the information received from DHBs, review how it is used in modelling so far, consider what is needed to refine the estimate of potential impacts on DHBs. Talk with Stephen Youngblood, here at MoH, who has previously worked on this.	NH
Convene an early meeting of external reviewers to explain the current model(s) and outline our approach. Involves retaining external reviewers.	KB

Family caregivers

Senior Officials Group meeting, 7 November 2012

Modelling and costing

Background

The starting point for the modelling and costing work is the quantitative work done for the September 2012 Cabinet paper seeking agreement to release a consultation document [CAB Min (12) 33/13 refers].

Our approach is to test the assumptions of this model and refine estimates where possible, to then apply to policy options (with additional development as needed) as these are worked up.

We plan to test our approaches with both external advisers and government advisers as we go and to ask them to review our results.

Priorities tasks (not exhaustive)

- Investigating the population of people with disabilities requiring funded care who are not current HCSS clients
- Estimating hours worked on average by family members caring for these people
- Reviewing assumptions for current HCSS clients to derive estimated additional hours of paid family care
- Considering impacts of transfers across care (e.g. residential to home; non-family to family) – if any
- Refining implementation costs – costs for NASCs and DSS
- Modelling and costing welfare impacts of all options, and costing options involving welfare payments
- Testing the impact of options on tax revenue
- Refining where possible modelling and costing of potential impacts on DHBs
- Refining where possible modelling and costing of potential impacts on veterans
- External testing of approaches and review of results

Key issues for senior officials

- Are these the right priorities?
- Are there additional data sources we should be investigating?
- Confirm way of working with your agency on modelling and costing
    - Key contacts – for data collection and for managing the process
    - Turn-around times
    - Coordination with policy aspects of work

Method used to estimate fiscal cost of paying family carers, September 2012

Paper to Economics Advisory Group, November 15 2012

Introduction

1. This paper outlines the method used to derive estimates of the fiscal impact of paying family carers, under a set of alternative policy options. The estimates were based on the best information available at the time, and represent only the first stage in the development of costings to support Government decisions.

2. These estimates have not been publicly released and are, at this stage, strictly confidential.

Background

3. The Ministry of Health (the Ministry) operates a policy of not funding payment to close family members (parents, spouses and resident family) for the provision of disability support services to disabled people. This is because funded support services for disabled clients are intended to complement, not replace, natural supports including the support provided by family.

4. In January 2010, the Human Rights Review Tribunal (HRRT) declared that the Ministry's policy is inconsistent with the New Zealand Bill of Rights Act (NZBORA). The declaration of the finding was suspended for an indefinite period, allowing the Ministry to continue to operate its policy lawfully while appeals were in progress.

5. The Crown appealed to the High Court and Court of Appeal, which have both confirmed the decision of the HRRT. The Crown has decided against further appeals. In mid 2012 Ministers instructed officials to begin work on refining estimates of fiscal risk and on future policy options.

6. In September 2012 a consultation process has been undertaken to solicit feedback on a range of proposals relevant to paying the family carers of adult disabled people. Cabinet intends taking a decision in December 2012 on approaches to responding to the Court case. The Ministry of Health, in collaboration with other agencies, will provide advice taking into account the results of the consultation and other relevant information.

7. The September Cabinet paper included estimates of the likely fiscal impact of paying carers of people directly affected by the Court decision – carers of adult disabled children - based on work conducted by the Ministry of Health in collaboration with other departments. The work was based on the best available information at the time, but further work is needed to refine the estimates, which currently have a very wide range. (See Appendix One) Refinement should be possible given that there will be additional

information from the consultation, from published evidence and from further analysis of existing data.

8. Additional work is also needed to expand the scope of the existing work to include family carers of clients indirectly affected by the Court decision – i.e. those who might be eligible for services funded by DHBs or by other Votes. This will be important so that when Ministers take decisions in December they are aware of wider implications.

Background about the New Zealand disability system, and its relationship to the court cases

9. Disability services are funded and purchased by different organisations:
   - Services for children(?) and adults under 65 years of age are funded and purchased by the Ministry of Health. These are generally called "disability support services" (DSS) and include intellectual disability. These are the services directly affected by the courts' decisions, and so were the focus of the estimates provided to Cabinet in September 2012.
   - Services for people whose disability is due to aging (usually aged over 65), to mental health problems or to illness are funded and purchased by District Health Boards (DHBs). DHBs are integrated organisations, which include both "funder" and "provider" arms and so may provide some of the services directly, themselves. These services are not directly affected by the Courts' decisions, however any decisions taken about DSS services are likely to also affect these services.
   - Services for people whose disability is caused by injury are funded and purchased by ACC. ACC has a policy allowing payment of family carers.

10. Other Government departments provide services which might be affected by the decision. Veterans Affairs is the most directly comparable, since they fund and purchase services for disabled people.

11. [Insert further details if relevant.]

Existing estimates of the likely impact of paying family carers

12. The Ministry of Health (the Ministry) contracted the New Zealand Institute of Economic Research (NZIER) to determine the likely cost of changing Ministry policy to allow payment of family carers. NZIER's original estimates suggested a change in policy would cost between $17m and $593m a year ($NZ 2006). The wide range reflects uncertainty, at that point, about how a change in policy would be implemented and the size of the response from disabled people and their carers. The top end, for example, reflects assumptions that 90 percent of home-based high use or severely disabled clients would seek additional funded care to pay family members, and that 50 percent of disabled people currently in residential care would move to home-based care provided primarily by family members. These were later revised to include District Health Board (DHB) expenditure, with an expected cost of $525m a year.

13. The plaintiffs contracted Brian Easton to review and critique NZIER's analysis. Dr Easton's assessment was that the overall maximum cost to Government would probably be between $32m and $64m a year including Ministry and DHB services. Dr Easton has indicated that the difference reflects different assumptions about the likely scope of new policies.

Derivation of September 2012 estimates

14. Appendix one shows the table presented to Cabinet in September 2012.

The population of informal carers

15. The first step was to estimate the number of people currently caring for family members and spouses, and not being paid explicitly for this. Important to note, however, that they might be in recipient of income support through the benefit system.

16. We assumed two different types of unpaid carer. First, the carers who provide unpaid services to disabled people alongside at least some formal Home and Community Support Services from paid providers, funded by the Ministry of Health. The number of carers was estimated by the number of clients who receive these services – about 12,000 – using routine data held by the Ministry of Health. These people receive, on average, 8 hours of Home and Community Support Services per week. (Table 1.)

Table 1 Services provided to disabled adults (aged 15 – 65), funded by the Ministry of Health DSS. Source: Statistical Data on DSS Spending and Clients

Services	Number of clients	Cost per client	Further information
HCSS (requires CSC to be eligible)	11971	$10,369	Average support hours p.a. 417 (about $25 per hour) Number of clients by service (not mutually excl) [1] - personal care 7000 - household mgt 6800 -IHC home support 550
Residential	7832	$55,712	
SIL	2462	$2,462	
Carer support	13915	$2,204	
Day programme	1395	$16,012	
All DSS	30114	$21,677	

17. The amount of informal care provided to these people was estimated from the results of a pilot survey conducted to test a new assessment tool ("FAT"). The sample included 220 clients currently receiving Ministry-funded Home and Community Support Services, of whom 156 were adults aged 15 - 64. The survey included questions about the extent of care provided by unpaid carers, and the types of services provided. We used the results to estimate that, on average,

[1] Source: ELJ

these clients received 7.4 hours of informal care per week. [insert note with details of how estimated this]

18. The second category of unpaid carer includes those who provide care for people who do not receive formal Home and Community Support Services funded by the Ministry of Health. These numbers were estimated from the 2006 Statistics New Zealand Disability Survey [ref]. As shown in Table 2, we assume that the 36,000 individuals identified as having high needs and receiving informal care are the target population. These people include people likely to be covered by ACC (ie with primary cause of disability being injury) or DHBs (ie those with mental health disabilities). We adjust the totals to remove these people, as shown in Column 4 of Table 2.

19. We also adjusted this number for population growth (Column 5, Table 2). The New Zealand population has increased by about 6% since 2006. Previous Ministry work estimated that, between 2006 and 2011 disability prevalence would increase by at least 6 percent. (See Martin Tobias paper). Martin suggested that we assume that any change is due to demographic factors alone (low end) given uncertainty about whether there are also epidemiological changes.

20. After making these adjustments, and removing the 12,000 people assumed to be covered by formal services the remainder – about 14,600 – is used in the base model as the population of disabled people with ONLY informal carers who might be eligible for payment, depending on policy parameters. Feedback suggests this is probably an upper bound for people with high needs, and so it was varied in sensitivity analysis.

21. The base model assumes that average needs of clients cared for by the two types of informal carer are the same. Since the population accessing services is assumed to receive, on average, the equivalent of 8 hours of formal care, and 7.4 hours amounts of informal care, we assume that disabled people not accessing formal services "need" the same total amount – ie 15.4 hours. Feedback suggests that this may overstate the level of unmet need and is a "worst case" scenario: it was tested in sensitivity analysis across the range indicated.

Table 2 Estimated population of informal carers, caring for clients who do not access formal services funded by the Ministry of Health (source, 2006 Disability Survey)

Row	Col 2	Column 3 2006 SURVEY Numbers 15-64s	Column 4 2006 ESTIMATED 15-64, not pscyh, not ACC (Refer rows 9 to 12 below)	Column 5 2012 Adjusted for population growth (6%)
1	Number disabled	348,300		369,198

2	Number with informal care	75,300	53,056	79,818
3	Number recorded as having "high support needs" & receiving informal care.	36,600	25,788	27,335
4	Estimated number not already accessing DSS-funded services (calculated by subtracting 12,000 from row 3)	24,400	13,788	14,615

Cost estimates

22. We estimated the hourly labour cost under the three scenarios presented in Table 3.

Table 3 Alternative hourly rates for paying informal carers

Employed through provider	($25)	This is the approx. hourly rate paid by the Ministry of Health and by ACC to external providers.
Allowance	($15)	ACC pays about $15 per hour to family carers when they contract with them directly. The Ministry does not generally enter into direct employment relationships, hence this would be likely to be paid as an allowance.
Allowance	($8)	Showing the significance of paying a lower hourly rate, directly by Ministry of Health therefore assumed to be paid as an allowance.

23. Operational costs were estimated using a linear function assuming that all clients will require the the same level of operational expenditure, equivalent to the current average cost per client for services coordinated by the organisations which assess and coordinate care - Needs Assessment Service Coordination (NASC) agencies. (Total funding for NASCs is $18.4 million per year, for about 30,000 clients.) In practice, there are likely to be two operational effects: first, a pure volume effect, since NASCs will need to assess and then manage greater numbers of clients; and second, an intensity effect which will come into play as greater targeting is employed, since resource requirements for higher need clients are likely to be greater than those for lower need clients, reflecting the need for specialist assessments and so on. At this stage the linear estimates are, therefore, indicative only.

Estimates of offsetting savings

24. The offsetting savings are indicative only, and while the relevant departments were involved they have not confirmed the estimates.

25. We assumed reduced expenditure on benefits, estimated using a multiplier derived from the average abatement across all options. The multiplier for reduced expenditure when hourly payment is $15- $25 (x=47) is about 7.5 times higher than the multiplier when hourly payment is $8 (x=6).[2]

[2] B = N * T * E * H * X

26. Additional tax revenue is also estimated using a simple linear multiplier, with the multiplier = 95 when hourly payment is $15 - $25; and 51 for hourly payment of $8.

27. At this stage reduced expenditure on carer support and other DSS programmes is included using a multiplier calculated from 50% of current average payments to clients for carer support ($2200). This is a placeholder, pending policy analysis about the likely impact on these programmes of paying carers under the different options.

Estimates of behavioural response - uptake

28. Following discussion with key stakeholders we assumed 100% uptake from the eligible population, at this stage. The results of the consultation should help inform estimates of this, and the parameters which will affect it.

OPTION DEVELOPMENT

29. The options shown in Appendix one were developed through an iterative process with key stakeholders.

30. Option 1B reflects a usual employment relationship.

31. Options 2A and 2B reflect both a cap of paid hours at 40 hours per week, consistent with a normal employment relationship; and two different assumptions about what people might reasonably expect to have to provide unpaid. The choice of four hours in Option 2A is ad hoc; the choice of ten hours in Option 2B assumes about one hour per day on week days and slightly over two hours per day on weekends. The hours that would be provided by informal carers under each option were estimated using the results of the FAT survey, shown in Table 4. We have not controlled for the likelihood that average intensity of Home and Community Support Services (column 3) will increase.

Table 4 Average hours of paid informal care under different options, derived from results of the FAT survey

Column 1	Column 2	Column 3	Column 4
	n	Average hours per week, HCSS (assumed)	Implied hours per week, natural supports
Base model – option 1A All respondents, 15 – 64 in	156	8	7.4

Where B = Benefit payments saved; N = population of informal carers; T = Targetting, ie % population eligible; E = elasticity of supply; H = average hours of care provided and X = linear multiplier.

non-residential care			
Option 1B If cap payments at 40 hours per week	156	8	5.1
Option 2A Require first 4 hours per week free, cap at 40 hours	90	8	8.4
Option 2B Require first 10 hours free, cap at 40 hours	65	8	10.6

32. Options 3A and 3B estimate the results of targeting based on need, and on the status of the informal carer.

33. "Need" in option 3A for clients currently receiving formal services is defined according to the Support Package Allocation (SPA) tool. This is a tool used by NASCs to ensure a nationally consistent approach to identifying the level of need of individual clients and allocation of resources. For different age groups, the tool describes different levels of need and desired outcomes, and a funding allocation range for each level. Need is assessed net of natural supports, which means that a change in payment arrangements may change the number of clients in each category. We have not allowed for this effect. The number of clients in each need group is shown in Table 5 [Check source – think Statistical Information]

Table 5 Distribution of current Home and Community Support Services Clients by need

	low	medium	high	very high	unknown	**total**
Number of clients	535	3,889	4,730	2,740	33	**11,927**
Expenditure ($)	$846,543	$13,372,133	$47,830,388	$62,251,056	$136,807	**$124,436,928**

34. "Need" in Option 3A for clients not accessing formal services is defined according to the proportion of those with high needs receiving 30 hours or more help with personal care, as reported in the 2006 Disability Survey (8 percent). High need for personal care is used as a proxy for more intensive service need. It is also used as an indicator for services which clients may prefer to receive from a carer other than a family member.

35. Option 3B restricts eligibility to family members, i.e. excludes partners. The 2006 Disability Survey reports that 9 percent of people receiving informal care receive personal care from a non-partner family member.

36. For simplicity, Options 3A and 3B assume that the average hours of care received by very high needs people is equivalent to the hours of care received in Option 2B. This is a conservative assumption, likely to understate the costs. To show the impact of this, if we instead assumed a doubling of average hours of care, Table 6 below shows that this increases in net expenditure estimates by 130 to 175 percent (new assumptions and estimates marked with highlighter).

Table 6 Impact on expenditure estimates for Options 3A and 3B if double the assumed paid hours of informal care

	Option 3A *Provide only to high needs clients*	**Option 3B** *Restrict eligibility to non-partners and to disabled people needing significant personal care.*
Current HCSS clients who receive a mix of family care and paid services from external provider: - Assumed eligible population	23% of current HCSS clients "very high needs"	Assume 9% of HCSS clients have a family member, not a partner, providing personal care
- Assumed average hours provided per week by paid family members	10.6 – 21.2	10.6 – 21.2
People not currently accessing HCSS, high support needs receiving all care from unpaid informal carers - Assumed eligible population	8% non-HCSS clients receiving 30+ hours personal care from family carer	9% of disabled clients receiving informal care from non-partner family member
- Assumed average hours of care provided per week by paid family members	10.6 – 29.2	10.6 – 29.2
Net expenditure estimates: Employed through provider ($25)	$17 -47 M	$8 -24 M
Allowance ($15 per hour)	$10 - 27 M	$6 -19 M
Allowance ($8 per hour)	$6 - 13 M	$5 -15M

Sensitivity analysis

37. The gross expenditure estimates are sensitive to variations in all parameters. The upper limit of the ranges shown in Appendix One reflects the base model; the lower limits are based on a smaller high needs population cared for only by informal carers (about 7,300), with lower average needs than disabled people currently receiving care (paid family carers' hours approx. halved).
    - Row C – sensitivity analysis halved the number of people assumed to be eligible and not currently receiving DSS services, reflecting informal feedback that likely to be fewer than 14,600. Assessed impact if halved number of eligible people currently not accessing services.
    - Row E – sensitivity analysis tested the assumed that people not currently in receipt of DSS services have same average need of those who are. Average need, measured by hours of care received, for DSS clients is 8 hours formal plus 7.4 hours informal (in base model); Assessed impact if assumed receive only informal care at level received by DSS clients.
    - Row G – variation reflects variation in assumed eligible population and hours
    - Row K - Offsetting savings – range reflects changes in assumed number of people receiving family care, at the mid point of the payment estimate ($15).

Family Carers – September 2012 estimates of fiscal impact

Presentation, 15 – 11 – 12
Bronwyn Croxson
Ministry of Health
IN STRICT CONFIDENCE

Basic model

$$X = x [F , C , S , B , T]$$

X - additional expenditure (net) as the result of paying family carers

F - payments to carers

C - additional operational costs

S - reduced expenditure on other Vote Health Payments – "carer support"

B - reduced expenditure in Vote Social Development – reduced benefit payments

T - additional tax revenue

Basic model

$$X = (\beta N * wH) + \Delta c\,(\beta N) - s\,(\beta N) - b\,(\beta N * H) - t\,(\beta N * H)$$

$$X_k = \Sigma_i\,(\varepsilon_i\,\tau_i\,n_i * \omega_k\,h_i) + c\,(\varepsilon_2\,\tau_2\,n_2) - \Sigma_i\,s\,(\varepsilon_i\,\tau_i\,n_i) - \Sigma_i\,b_k\,(\varepsilon_i\,\tau_i\,n_i\,h_i) - \Sigma_i\,t_k\,(\varepsilon_i\,\tau_i\,n_i\,h_i)$$

Where

X – net expenditure if pay family carers
n – total population of unpaid informal carers (n_1 = currently get paid formal care; n_2 = currently only informal care)
ε - elasticity of supply – proportion of population who take up payment
τ – targeting parameter – proportion of population deemed to be eligible by targetting criteria
ω – hourly payment rate
h – number of hours of informal paid care
c – average operational cost of paying informal carers
s - average reduction in carer support payments
b – linear multiplier for reduction in benefit payments
t – linear multiplier for additional tax revenue

i = 1,2.

k = 1,2,3
Three alternative payment rates (ω)
ω_1 = \$8, b_1 = 6, t_1 = 51
ω_2 = \$15, b_2 = 47, t_2 = 95
ω_3 = \$25, b_3 = 47, t_3 = 95

Population of informal carers

$$\Sigma_i\,(\varepsilon_i\,\tau_i\,n_i * \omega_k\,h_i)$$

n_1 = informal carers of clients who also access paid services

- Home and Community Support Services are provided to 12,000 disabled adults (aged 15 – 65)

n_2 = informal carers of disabled people not accessing paid services = 14,600

Table 2 Estimated population of informal carers, caring for clients who do not access formal services funded by the Ministry of Health (source, 2006 Disability Survey)

Row	Col 2	Column 3 2006 SURVEY Numbers 15-64s	Column 4 2006 ESTIMATED 15-64, not psych, not ACC (Refer rows 9 to 12 below)	Column 5 2012 Adjusted for population growth (6%)
1	Number disabled	348,300		369,198
2	Number with informal care	75,300	53,056	79,818
3	Number recorded as having "high support needs" & receiving informal care.	36,600	25,788	27,335
4	Estimated number not already accessing DSS-funded services (calculated by subtracting 12,000 from row 3)	24,400	13,788	14,615

Responsiveness

elasticity and targeting $\Sigma_i (\varepsilon_i \tau_i n_i * \omega_k h_i)$

- Initially 100% uptake ($\varepsilon_i = 100\%$)
- Alternative options for targeting (Options 3A and 3B) τ_i

  3A: Need (high needs only) & need for assistance with personal care
  - τ_1 = 23% "very high needs" under NASC SPA tool
  - τ_2 = 8 % report receive 30+ hours personal care

  3B: Family members only (excludes partners)
  - τ_2 = 9 % = τ_1 *(in survey, 9%* report receive a personal care from non-partner

Hourly wage

$\Sigma_i (\varepsilon_i \tau_i n_i * \omega_k h_i)$

Table 3 Alternative hourly rates for paying informal carers

Employed through provider	ω_1 = $25	This is the approx. hourly rate paid by the Ministry of Health and by ACC to external providers.
Allowance	ω_2 = $15	ACC pays about $15 per hour to family carers when they contract with them directly. The Ministry does not generally enter into direct employment relationships, hence this would be likely to be paid as an allowance.
Allowance	ω_3 = $8	Showing the significance of paying a lower hourly rate, directly by Ministry of Health therefore assumed to be paid as an allowance.

Hours worked

$$\Sigma_i (\varepsilon_i \tau_i n_i * \omega_k h_i)$$

h1 = hours paid for informal carers of clients who also access paid services

- On average, 8 hours per week of paid Home and Community Support Services.
- Used F.A.T. pilot survey to estimate on average 7.4 hours per week unpaid informal care.

h_2 = hours paid for informal carers of clients who don't access paid services

- If have same average needs as n_1, average hours per week informal care 15.4 hours.

Operational costs $c (\varepsilon_2 \tau_2 n_2)$

NASCs assess eligibility, contract and administer services, funded by Ministry of Health.
Additional costs of paying family carers (ideally):

- Volume effect
- Intensity effect – as needs and / or targeting rise

We estimated a linear volume effect. Current average cost per client in NASCs is ≈$600.

Reduced expenditure on other DSS programmes

$$\Sigma_i \, s \, (\varepsilon_i \, \tau_i \, n_i)$$

- $31m p.a. disbursed as a "Carer support" allowance paid to about 14,000 disabled people (average payment per person ≈ $2,200).
- Linear multiplier (s = $2,200 * 0.5) as a placeholder for offsetting savings.

Reduced expenditure on benefits

$$\Sigma_i \, b_k \, (\varepsilon_i \, \tau_i \, n_i \, h_i)$$

Number of people on benefit	
DPB CSI	7,500
SB / IB partners with caring exemption	3,500
Other beneficiary carers (estimate)	500
	11,500

1. Estimated the likely savings for each option, based on assumed abatement rates etc.

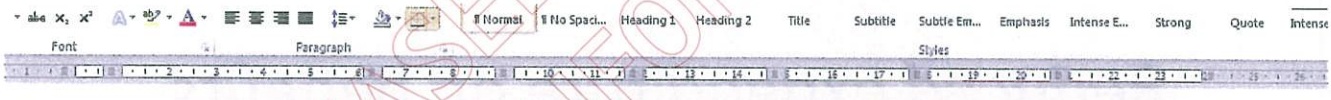
2. The average savings across all options used as a single linear multiplier. Effectively a placeholder for savings on benefits:
   b_1 = 6 (ie when hourly pmt = $8)
   b_2 = 47 (ie when hourly pmt = $15, $25)

Additional tax revenue

$$\Sigma_i t_k (\varepsilon_i \tau_i n_i h_i)$$

Simple linear multiplier used as a placeholder for additional tax revenue:

- t_1 = 51 (ie when hourly pmt = $8)
- t_2 = 95 (ie when hourly pmt = $15, $25)



Appendix One. Fiscal estimates presented to Cabinet in September 2012. All of the options are variants of a base model. To help clarify which is the base model estimates are circled below.

Row no.		Option 1 Current situation if family members paid		Option 2 Cap provision under a NASC assessment process		Option 3 Target eligibility AND cap provision under NASC assessment process (Restrict hours as in 2B)	
		Option 1A *Carers determine ability to provide care, no cap*	Option 1B *Cap provision to 40 hours per week*	Option 2A *Require that families provide first 4 hours per week free, effective cap is 36 hrs public funding*	Option 2B *Require that families provide first 10 hours free, effective cap is 30 hrs public funding*	Option 3A *Provide only to high needs clients*	Option 3B *Restrict eligibility to non-partners and to disabled people needing significant personal care.*
A	Current HCSS clients who receive a mix of family care and paid services from external provider: - Assumed eligible population	12,000 current clients	12,000 current clients	If 6,000 clients get family care for more than 4 hours per week	If 6,000 clients get family care for more than 10 hours per week	23% of current HCSS clients "very high needs"	Assume 9% of HCSS clients have a family member, not a partner, providing personal care
B	- Assumed average hours provided per week by paid family members	7.4	5.1	8.4	10.6	10.6	10.6
C	People not currently accessing HCSS, high support needs receiving all care from unpaid informal carers - Assumed eligible population	7,300 - 14,600	7,300 – 14,600	4,200 - 8400	3000 - 6000	9% non-HCSS clients receiving 30+ hours personal care from family carer	9% of disabled clients receiving informal care from non-partner family member
E	- Assumed average hours of care provided per week by paid family members	7.4 - 15.4	5.1 - 13.1	8.4 - 16.4	10.6 - 18.6	10.6 – 18.6	10.6 – 18.6
F	Assumed uptake by eligible population	100%	100%	100%	100%	100%	100%
G	Placeholder for additional operational expenditure, through NASCs	$ 9.0 M	$ 9.0 M	$ 5.2 M	$ 3.7 M	$ 3.7M	$ 3.7M
H	**Gross expenditure estimates (10):** **Employed through provider ($25)**	$ 190 - 417 M	$ 132 -337 M	$ 124 -260 M	$ 113 - 220 M	$ 21 -31 M	$ 10 -18 M
I	**Allowance ($15 per hour)**	$ 116 - 254 M	$ 81 - 206 M	$ 76 -158 M	$ 68 - 133 M	$ 13 -20 M	$ 8 -15 M
J	**Allowance ($8 per hour)**	$ 64 - 139 M	$ 45 - 114 M	$ 41 - 87 M	$ 37 - 73 M	$ 8 - 13 M	$ 6 -14 M
K	*Will be offset by* - *Reduced expenditure on benefits* - *Additional tax revenue* - *Reduced expenditure on carer support and other DSS programmes*	$ 42 - 74 M	$ 35 -65 M	$ 26 -45 M	$ 21 -36 M	$ 4 -5 M	$ 2 – 3 M
L	**Net expenditure estimates:** **Employed through provider ($25)**	$149 -343 M	$97 -272 M	$99 -216 M	$ 92 -184 M	$17 -27 M	$8 -15 M
M	**Allowance ($15 per hour)**	$74 -180 M	$46 -141 M	$50 -113 M	$47 -98 M	$10 -15 M	$5 -12 M
N	**Allowance ($8 per hour)**	$34 -92 M	$19 - 70 M	$24 -59 M	$24 - 51 M	$5 - 10 M	$5 -12 M

NEXT STEPS...

Paid Family Care-givers
Summary of Costing Methodology

Overview of progress – 21 November 2012

- Methodology
- Data sources
- Options (KB)
- Results
  - Preliminary "in progress" only
  - To demonstrate methodology and issues

Paid Family Care-givers:
Costing Methodology

- Top – down approach
  - Based on HDS data, using high support needs and personal care sub-sets
  - Family hours based on FAT survey (but only a small group)
  - Only identifies "loose" target group
  - No indication of actual take-up
  - Useful to set a high end of the expected range
- Bottom – up approach
  - Based on ACC data, and current actual DSS client group
  - Family hours based on FAT survey
  - Identifies actual take-up (assuming equivalence to ACC take-up)
  - Approximate only, but the best we currently have
- Together
  - Use both sets of data to give us a reasonable approximation of the range
  - Not precise, but consistency between approaches provides comfort

Data sources

Data sources – available to date

- HDS – household disability survey – formal and informal carers, including "high support needs" and "personal care" sub-sets
- FAT survey – funding allocation tool – for 156 existing paid carers, an estimate of current paid and current natural (family) care given
- DSS HCSS carer data – details of hours worked and level of needs for all current paid carers
- ACC – total contracted, non-contracted (family) and shared carers
- MSD – benefit numbers and abatement rates

Data sources – waiting

- DSS HCSS (NASC) carer data with details of natural support (to expand/improve the FAT Survey data)
- ACC – final data (US Veterans data?)

Existing information:

- Top-down approach
- HDS: All informal carers – before identifying eligible people

(A) Estimate of Number of Currently Unpaid Family Carers of Disabled Adults Aged 15-64 and 65+. Based on 2006 Household Disability Survey (HDS)

		Aged 15-64 (Table 16)		Aged 65+ (Table 16)	Total (Table 16)
Total All Carers		94,800		98,000	192,800
Less Formal Carers only (includes current MOH/DHB funded)		(19,500) 21%		(39,800) 41%	(59,300) 31%
Total Informal carers		**75,300**		**58,200**	**133,500**
Less spouses	38%	(28,900)	40%	(23,000)	(51,900)
Family carers (excl spouses)		**46,400**		**35,200**	**81,600**
Less Accident/injury	27%	(12,445)	12%	(4,327)	(16,773)
Less Psych cause	13%	(4,219)	0%	0	(4,219)
Less Ageing	5%	(2,503)	0%	0	(2,503)
Net Target Family Carer Population 2006		**27,233**		**30,873**	**58,105**
Carer growth 2006 to 2012		6%		6%	6%
Net Target Population 2012 - Unpaid Family Carers		**28,867**		**32,725**	**61,592**
Approximate MOH DSS Client Base		**28,867**		**5,832**	**34,698**

This includes unpaid family carers where there in no paid care being provided, and unpaid carers who supplement some currently paid care

- Spouses to be added back as required (add 40%)

Existing information:

- HDS: High Support Needs and Personal Care sub-groups

High Support Needs (as defined in HDS)
For adults – need (met or unmet) for any of the following - special equipment; work environment adaptations; help with meal preparation, shopping, everyday housework, finances, communication, washing, dressing or medication - provided that any support or help obtained to meet these needs is received on at least a daily basis.

Personal Care
Such as bathing, dressing, taking medication

Targeted groups percent of total population	Aged 15-64	Aged 65+	
Portion of total potentially eligible population that are High Support Needs:	36%	30%	< Per HDS
Portion of total potentially eligible population that are receiving personal care:	20%	16%	< Per HDS

- Neither group matches current DSS needs assessed clients
  - High Support Needs well in excess
  - Personal care – likely to be closer

Existing information:

- DSS Data:

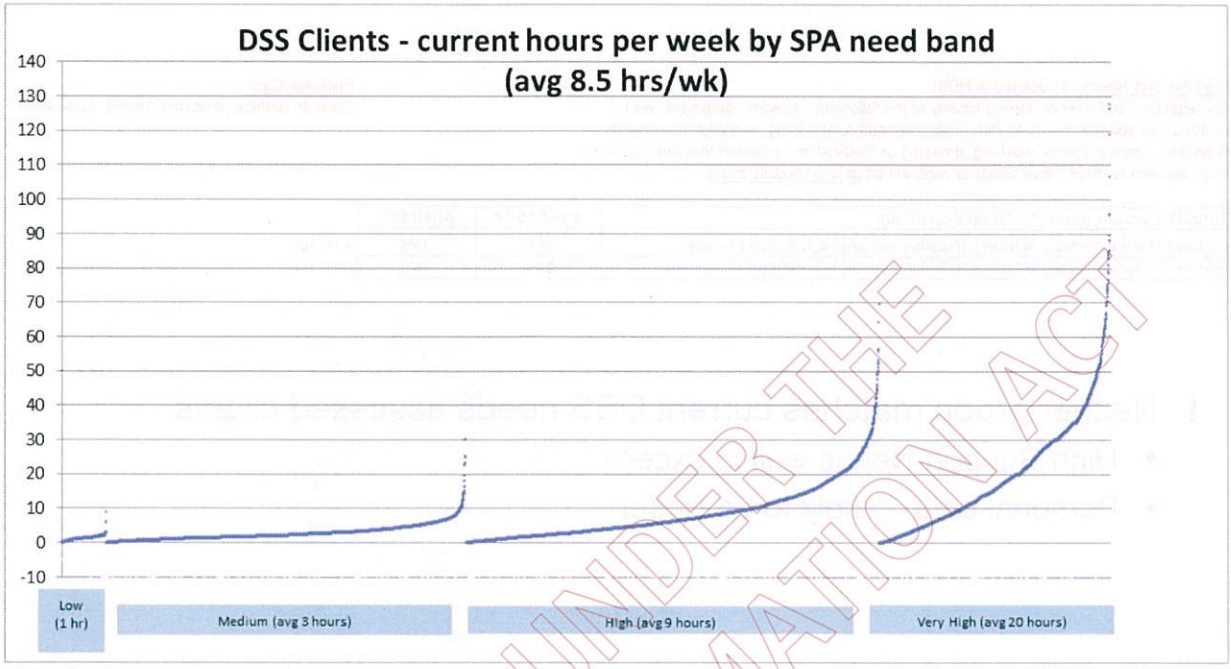
Current MOH DSS paid carers, by SPA need; current non-family paid hours (through DSS); and estimate of total hours including family care

SPA Need for disabled adults aged 15+ (incl 15-64 and 65+)	Clients aged 15-64	Clients aged 65+	Total Clients	Total Annual Costs	Avg Hours per carer per week	Avg Cost per carer per annum	Avg Hourly Rate
Low	355	177	532	844,897	1.3	1,588	$24/hour
Medium	2,857	832	3,689	12,971,352	2.8	3,516	$24/hour
High	3,273	494	3,767	42,905,577	8.8	11,390	$25/hour
Very High	1,836	178	2,014	52,500,975	20.3	26,068	$25/hour
Total	**8,321**	**1,681**	**10,002**	**109,222,801**	**8.5**	**10,920**	**$25/hour**
Not included, under 15's >>			*1,925*				
Total DSS Clients			***11,927***				

- Useful for:
  - Client numbers
  - Range of needs
  - Hours per carer

Existing information:

- DSS Data – current paid hours per week:



Existing information:

- ACC data:

Redacted under s9(2)(ba)(i) of the Official Information Act 1982

- Provides data to allow extrapolation from current DSS paid carers (non-family) to estimate total family carers

Existing information:

- FAT Survey data:

SPA Need	Clients aged 15-64			
	Average Current Paid Hours per week	Natural % of Total Time	Avg Hours per family carer per week (shared)	Avg Hours per family carer per week (family only)
Low	1.3	23%	0.4	1.7
Medium	2.8	31%	1.2	4.1
High	8.7	28%	3.4	12.1
Very High	20.0	31%	9.0	29.0
Total	**8.9**	**30%**	**3.8**	**12.6**

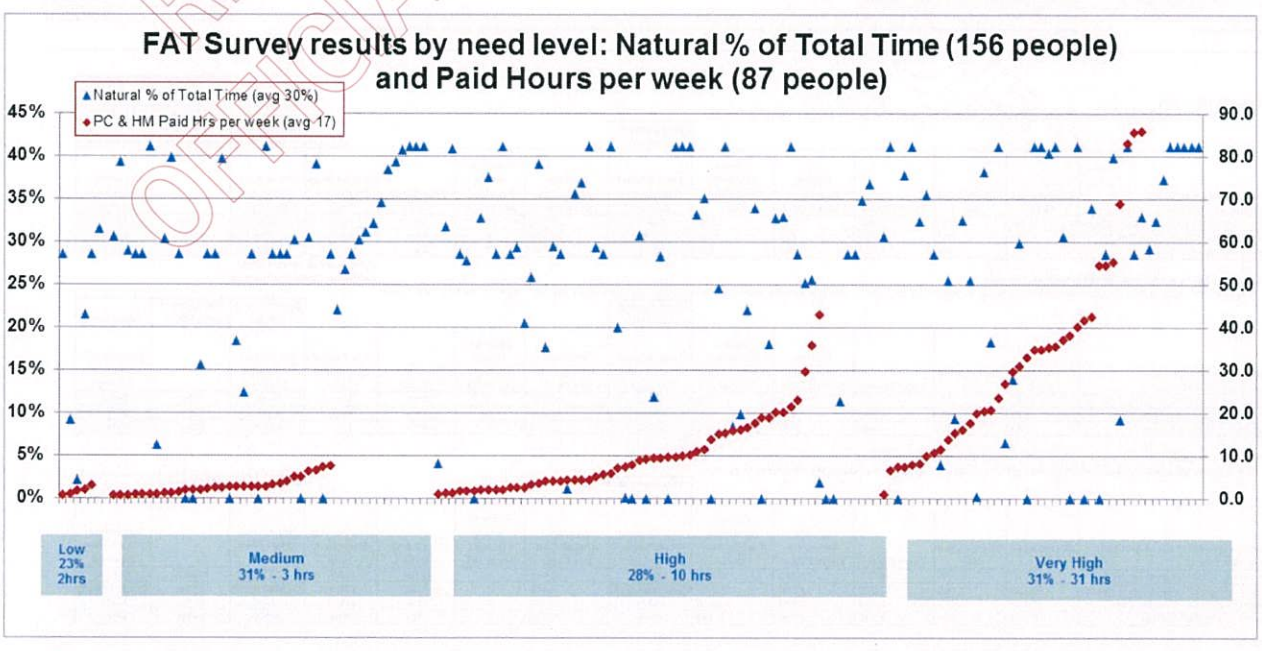
SPA Need	Clients aged 65+			
	Current Paid	Natural % of Total Time	Unpaid Natural Care	Total Future Paid Hours per week
Low	1.3	23%	0.4	1.8
Medium	2.8	31%	1.2	4.0
High	9.7	28%	3.7	13.4
Very High	23.5	31%	10.6	34.1
Total	**6.8**	**30%**	**2.9**	**9.7**

Shared care means Family care will supplement the current paid care being provided. Family only means no other paid care will be provided other than through the family.

- Provides:
  - Additional family hours worked on top of existing paid hours
  - Total hours expected to be worked by family when there are no other paid carers
- Small sample (156 people) – looking to improve data through additional NASC/DSS data

Existing information:

- FAT Survey:



- No noticeable change in % natural support regardless of need or hours

Policy Options

- Kathy

Results –
based on current assumptions and options

Summary of Modelled Scenarios

The following calculations show 3 targeting options: Fragile Families only; Families unable to work only; and all eligible families (similar to current needs assessments covering Low to Very High needs clients).
For each of these options a range of calculation methodologies are presented - based on available data sources:

Top-down High support needs method:	uses a Household Disability Survey grouping, and is likely to overstate the number of eligible families
Top-down Personal Care method:	uses a Household Disability Survey grouping
Bottom-up ACC Ratio method:	uses ACC data to develop a ratio of family paid care to non-family paid care. This ratio is applied against current paid carers to derive new family carers to be paid.
Maximum method:	uses all relevant informal carers from the Household Disability Survey. This significantly overstates the expected eligible clients and is presented for context only.

Current Paid carers by Needs

Low	532	5%
Medium	3,689	37%
High	3,767	38%
Very High	2,014	20%
Total	**10,002**	100%

(1) Fragile Families only

This scenario assumes that an approximation of this group is provided by all SPA clients who are "Very High" needs

											Additional Admin >	25%	50%
											IF Uptake >	50%	
												$25/hour	$18/hour	$15/hour
						Employment Option						Employment Option	Employment and 50% IF	Allowance
Fragile Families Targeting - by calculation method	**Clients aged 15-64**	**Clients aged 65+**	**Total Clients**	**Clients Receiving Shared Care**	**Clients Receiving Family Only Care**	**Total Annual Costs before Savings**	**Average Annual Cost per Carer**	**Average Hours Provided per Week**	**Plus Admin Costs**	**Less Savings (Benefits & Tax)**	**Net Annual Costs after Savings**			**Net Annual Costs after Savings**
Top-down (using HDS High Support Needs)	2,306	187	2,493	1,331	1,162	$59m	23,539	18	$2m	$4m	$57m	$49m		$35m
Top-down (using HDS Personal Care)	1,260	102	1,362	727	635	$32m	23,539	18	$1m	$2m	$31m	$27m		$19m
Bottom-up (using ACC Ratios)	962	93	1,055	564	492	$25m	23,539	18	$1m	$2m	$24m	$21m		$15m

(Admin & Savings based on earlier Cabinet Paper and subject to change)

(2) Family unable to work because of commitment to care

This scenario assumes that an approximation of this group is provided by SPA clients who are currently receiving 15+ hours per week care (from very high, high and medium SPA bands)

						Employment Option						Employment Option	Employment and 50% IF	Allowance
Unable to Work Targeting - by calculation method	**Clients aged 15-64**	**Clients aged 65+**	**Total Clients**	**Clients Receiving Shared Care**	**Clients Receiving Family Only Care**	**Total Annual Costs before Savings**	**Average Annual Cost per Carer**	**Average Hours Provided per Week**	**Plus Admin Costs**	**Less Savings (Benefits & Tax)**	**Net Annual Costs after Savings**			**Net Annual Costs after Savings**
Top-down (using HDS High Support Needs)	1,822	179	2,001	1,069	932	$65m	32,408	25	$1m	$3m	$63m	$55m		$39m
Top-down (using HDS Personal Care)	996	98	1,093	584	509	$35m	32,408	25	$1m	$2m	$34m	$30m		$21m
Bottom-up (using ACC Ratios)	760	90	849	454	396	$28m	32,384	25	$1m	$1m	$27m	$23m		$17m

(3) No specific targeting (screening consistent with current DSS client proceedures)

This scenario assumes all current informal carers within each of the calculation methodologies are entitled to be paid

						Employment Option						Employment Option	Employment and 50% IF	Allowance
Targeting equivalent client groups to current DSS clients	**Clients aged 15-64**	**Clients aged 65+**	**Total Clients**	**Clients Receiving Shared Care**	**Clients Receiving Family Only Care**	**Total Annual Costs before Savings**	**Average Annual Cost per Carer**	**Average Hours Provided per Week**	**Plus Admin Costs**	**Less Savings (Benefits & Tax)**	**Net Annual Costs after Savings**			**Net Annual Costs after Savings**
Maximum - all informal carers per HDS	*28,867*	*5,832*	*34,698*	*18,530*	*16,168*	*$327m*	*9,420*	7	*$21m*	*$51m*	*$297m*	$264m		*$197m*
Top-down (using HDS High Support Needs)	10,453	1,763	12,216	6,524	5,692	$116m	9,492	7	$7m	$18m	$105m	$94m		$70m
Top-down (using HDS Personal Care)	5,712	962	6,674	3,564	3,110	$63m	9,493	7	$4m	$10m	$58m	$51m		$38m
Bottom-up (using ACC Ratios)	4,360	881	5,240	2,799	2,442	$49m	9,420	7	$3m	$8m	$45m	$40m		$30m

Note:
These tables include preliminary data and results only.
Updated data is expected to be available shortly from ACC and DSS, and from MSD for estimated savings.

FAMILY CARERS ECONOMIC MODELLING REVIEW NOTES

Thursday 15th November 2012, 3.00am – 5.00pm
Venue: 2.12 The Boardroom, Level 2, 1 The Terrace

Attendees:	Bronwyn Croxson, Nick Hunn, Kathy Brightwell, Jean-Pierre De Raad, Harvey Steffens, Andrew Coleman, Andrew Harris
Apologies:	Brian Easton

1. **Purpose**

- Testing around costing. Need to know thoughts around data sources. Are there any others we could access? Are there factors around the modelling we've not considered? Ideally, how would we go about this?

Context

- Court of Appeal ruled that Family Carers policy was discriminatory. We don't pay parents, spouses or resident family members for providing care. We are exploring options for removing this discrimination.
- The Minister has asked for more work on costs. Previous work was assumption driven. Better estimates and narrower assumptions are needed. Estimates of care funded by DHBs and Vet Affairs requested.

2. **Presentation of summary papers by Bronwyn Croxson and Nick Hunn followed by general discussion**

- A survey from DSS people – small sample 200ish receiving NASC services. They were needs assessed and then scored to demonstrate proportion of formal/informal care provided. Average hours per week extrapolated from this data.
- It is assumed that any high needs disabled persons are already in the disability support system.
- Trying to look at how many sources of data can be used to cross-check and determine useful inputs for costings.
- The total population might need to include those who transfer from residential care to family care.
- Suggested that we look at the characteristics of people in the very high cost package category. Why do they require very high cost packages and are there any parallels? Will there be a great drive for exemptions? Autism care is risk for the future. Responsibility for ASD being discussed.
- Concentration is on parents caring for adult disabled children. Adult disabled

child has no natural support expectation on their parent. Siblings and extended family can be paid if they live outside of disabled person's home.

- Disability due to aging was removed as they are covered by DHB.
- Demographic change has been used to determine growth in disabled population.
- Figures of people with high disability support needs have been taken from the disability survey.
- It was noted that payment of family carers could create an incentive for people on other entitlements (e.g. sickness benefit to seek reclassification as disabled)
- It was noted that Victoria, Australia has a similar system and could inform this process.
- Capping is an option. For example, total support packages could be capped at the average cost of residential care.
- One option for capping is 40 hours per week. Another is to cap at 20 hours.
- Residential care for people with disabilities might have three disabled persons and three staff throughout the week. Need to remember economies of scale.
- Paid care and natural support are difficult to classify against each other. e.g. Someone at home providing general and continual care over ten hours might be synonymous to what could be provided in 2 hours of intensive care from a paid carer.
- The big question for estimating costs is volume and intensity – number of people and hours.
- In 2009/10 ACC introduced a threshold of unpaid care before family carers could be paid.
- TAG talked about definitions of reasonableness with regard to what it is reasonable to expect families to provide without payment. Diversity in opinions came down to different people are prepared to do different things. What one would do for a child or a spouse may be different to another. Principles and guidelines will need to be developed. Individuals may say "I refuse to do this" or "I want to be the only one who does this."
- The Netherlands just decided on what is reasonable for partners to provide and partners are not paid for the first three months caring for someone with a chronic condition.
- In sickness and in health but only for a while in disability
- FAT survey was done for a different purpose and gathered information that is at best, an 'indicator' for our needs.

Meeting closed at 5.00pm.

PAID FAMILY CARERS - MODELLING OF ESTIMATED COSTS

PURPOSE AND BACKGROUND

The purpose of this model is to calculate expected net costs to the Government arising from possible policy changes than may allow for the paying of family carers who look after disabled family members.
The model runs a number of different scenarios, options and variations around additional costs/savings as follows:

IMPORTANT NOTE: Very limited data was available to estimate carer numbers, expected hours to be worked and abatement of DPB-CSI
There is high risk around the results produced by this model. This risk has been fully disclosed to all parties using the outputs of the model.
All future users of the model and the model outputs should also be made fully aware of the risks.

3 targeting scenarios
(1) No specific targeting (based on current NASC needs assessment).
(2) Very High Needs; and High/Medium Needs over 15 Hours per Week.
(3) Very High Needs Only.
Scenario 2 equates to a medium level policy option, that should capture fragile families as well as those families providing care that prevents them from working.
Scenario 3 equates to a tight targeting policy that should capture fragile families only. (Refer to cabinet paper for further description).
The minimal data available only allowed modelling at the SPA band level, as well as by numbers of hours worked per week. For this reason, the SPA Band "Very High Needs" was used for the fragile family estimate; and then those in Medium and High Needs bands over 15 hours per week care were added to this to proxy a medium targeting option.

2 cap options
(a) No cap on maximum family hours paid per week (but still subject to NASC needs assessment processes)
(b) Cap of 40 hours per week for total paid family care (all those expected to work more than 40 hours would just be paid for 40 hours). This may be supplemented by paid non-family care.

2 payment options
(i) Employment through providers - which incurs a cost of $25 per hour. Of this, the carer would get near to the minimum wage of $13.50 per hour. The difference is employee costs and provider overheads.
(ii) Employment not through providers, or an allowance, at a cost of $16 per hour. Of this, the carer would get the same amount as above, near to the minimum wage of $13.50 per hour.

Other variations
- Removal of spouses
- Addition of under 15s
- Payment of parents only (removal of siblings, sons/daughters and other family)
- Impact of policy on DHBs

The modelling for these variations is only indicative as data is limited. The spouses and parents-only options flow through the model working but the other options are only performed as a variation on the total cost.

MODELING METHODOLOGY

Note: All Model Inputs are highlighted in blue background, dark blue font.

Carer numbers and average hours per week worked

Data from DSS on the current paid carers has been downloaded onto the 15-54 and 65 Plus sheets (see blue highlighted sections, Columns B to F). This data is for approx 10,000 clients aged 15+, with details of SPA band, total cost and total hours for the 2011/12 year. In these sheets, the data is sorted to put the DSS paid carers into a distribution by number of hours per week. The DSS distributions can be seen in the Charts 15-64 and Charts 65 Plus sheets.

The DSS data provides information for a number of purposes. Primarily it is used to provide:
- a starting point of paid carers which can be used to apply a ratio from ACC an derive an estimate of family carer numbers.
- distributions of the numbers of hours worked across the current non-family carer population - to be applied (after adjustments) to the total family carer numbers derived by the methodology.

The DSS data for hours worked (for current non-family care) needs to be adjusted to provide an estimate of the hours that would be expected to be worked by a family member, once family are able to be paid. This needs to take into account two situations: (a) where both family members and non-family carers provide care to the same disabled person (shared care); and (b) where only family members provide care (full family care).
In the 15-64 and 65 Plus sheets the calculation of equivalent family hours (shared and full-family) that would be worked for the DSS client base is shown in Columns G and H. This data does not yet relate to actual family carers, it is just an interim step to show the expected uplift/change in hours for family care, given the current DSS client base.

The calculation of family hours is based on a survey used in developing the Ministry's funding allocation tool (FAT). The FAT Survey was designed for another purpose, but as part of the request it asked people about their current levels of natural care that were being provided without pay, in addition to the paid non-family care they were receiving. See sheet Calcs (FAT) for the data from the survey and the percentage uplifts for full family care and for shared care.
The survey only provided data for 156 people - so this remains an area of high risk in the model estimates. This key risk has been flagged to the Policy team and the cabinet paper drafting team.

The shared family and full family care hours are shown in columns G and H. On average, shared care was estimated to be approximately 74% of paid care time, and total family-only care would therefore be equal to the sum of the two.
The distributions of hours from Columns G and H are shown in Columns J to O and W to AB. But what is used in the modelling are the percentage distributions of these columns, shown alongside in Columns Q to U and AD to AH.
It is these percentage distributions, for both shared and full-family care, by SPA band, that are applied to the total estimated carers under each scenario, and for each Model Method.

There are two Model Methods used in the calculations for family carers eligible for paid support and they are based on two key data sources:
- data from ACC showing the ratio of paid family carers to paid non-family carers for ACC's highest needs people (those requiring full time care).
- the 2006 Household Disability Survey (HDS) - in particular, people requiring at least personal care.

(1) ACC Data Source and Calculation Method

This scenario uses actual data from ACC regarding their highest needs (near to full-time care) clients (the NSIS group). ACC has a policy of paying either family or non-family carers, or a combination of both. If we assume that this is a likely "steady state" that a new MOH policy will tend towards, and we assume that the current paid DSS carers make up the future non-family paid carers once families are able to be paid, then we can apply the ACC ratios of family and non-family carers to derive an expected number of family carers for DSS.
This approach has its flaws - but it does provide the only indication of what actual take-up might eventuate. (We do not adjust for any future transfer from paid work to family care after the policy change. This is a conservative assumption as allowing for such movement will reduce the estimate of family carers).

(2) Targeted (identified) groups in the HDS Calculation Method

Among other things, the HDS includes details of:
(a) High Support Needs people; and
(b) people who need at least some amount of "Personal Care".
These two categories give an indication of the size of the target population of disabled people who are likely to be eligible for funding. However, neither group in the HDS exactly matches the type of needs currently serviced by DSS. Based on the description of High Support Needs, this category would appear to capture many more people than would be expected under the current needs assessments performed by DSS. Personal care is probably a closer approximation.

High Support Needs (as defined in HDS)	Personal Care
For adults – need (met or unmet) for any of the following - special equipment; work environment adaptations; help with meal preparation, shopping, everyday housework, finances, communication, washing, dressing or medication - provided that any support or help obtained to meet these needs is received on at least a daily basis.	Such as bathing, dressing, taking medication

On the basis of the above descriptions, discussions with MOH policy team, and a comparison of HDS paid care to DSS paid care, the Personal Care grouping appears a better fit than the High Support Needs grouping. The Personal Care method has therefore been used in the calculations in this model. Note: This differs to the previous cabinet paper and evidence in the court case that used High Needs as a basis for calculations.

The ACC Method ratios are calculated on the ACC data sheet and summarised on the Global Inputs sheet. See from Row 48 of Global Inputs for the application of the ratios to the DSS paid carers to derive the total family carers. The ratios produce an estimate of the number of family carers in both family-only situations as well as for shared care with non-family carers. The ACC method is based on 2011/12 data from DSS so it does not need to be adjusted for population growth.

Inputs and calculations for the Personal Care method are on the Global Inputs sheet, from Row 69. This is based on data from the HDS, inflated from 2006 to 2012 using Stats NZ population growth rates applied for identified age groups and for male/female splits. See Popn Growth sheet for inputs and calculations.

These total carer estimates for the ACC and Personal Care Methods are then taken into the 15-64 and 65 Plus sheets and they are distributed across the hours per week following the same distribution as the Paid DSS carers. The calculations for scenario 1 (no specific targeting) are shown in columns AJ to BJ, and the calculations for the targeted scenarios (2) and (3) are shown in Columns BL to CL. In these sections, total carer numbers are effectively allocated into the hours per week "bins" based on the DSS based distributions. (Total family hours is greater on average than the DSS paid hours as the assumption is that family would be paid for both the time currently being paid for non-family care plus the additional time that family is doing for free).

The resulting distributions of family carers and the hours per week are shown in the Charts 15-64 and Charts 65 Plus sheets.
For the purpose of the charts, all 40 hours per week and above people have been shown together.

The results from the 15-64 and 65 Plus sheets (being numbers of carers by SPA band, and average hours per carer) are summarised and shown on the Summary sheet, columns B to AD.

Total Employment / Allowance Costs

The calculations for total employment (or allowance) costs are contained in the Summary sheet in Columns AF to AS. This multiplies the carer numbers for each age group (15-64 and 65 Plus) and each SPA band, by the average hours per week worked, and the selected pay rates. Pay rates are selected in the Global Inputs sheet, Cell B8. The model can use a weighted average DSS rate; a standard Provider rate (currently $25 per hour); or a standard non-provider rate (currently $16/hr). The results are multiplied by 52 weeks to provide an annual cost.

Administration costs

Admin costs are based on current NASC costs per unit, times the number of new family carers. (This is a conservative calculation (ie providing a possibly higher cost) as it does not build in any efficiencies through adding more people to an existing process and system).
Additional admin costs are included for the $16 direct payment/allowance options to allow for systems development for either a new employment model (not using providers) or a new allowance model. The calculations allow for input of a fixed cost component, but review by MOH determined that the assumptions made around the MOH component of costs would be sufficient.
Admin cost inputs and calculations are in the Global Inputs sheet from Row 35. Results and allocations across Age Groups and SPA bands are in the Summary Sheet, Column AV.

Savings from Abatement of Benefits

If family carers move from non-paid care to paid care, a number of people will be expected to move off benefits and into employment (primarily current recipients of DPB-CSI, IB and SB).

Maximum numbers of people that could be abated are estimated (approximately) with reference to data received from MSD. This is shown on the Global Inputs sheet Row 202, and takes total numbers on DPB-CSI, adds IB and SB if spouses are included, and then subtracts those over 65 (as these are considered to be DHB responsibility) and subtracts a proportion for accidents (ACC responsibility) and mental health (DHB) and under 15s (not part of policy). The resulting number is the maximum potential abatement - and this is only used, as a cap, if calculated possible abatements exceed this number. Generally the calculations don't show this many people being abated so the cap is not required.

Abatement of benefits is shown in the 15-64 (Abate) sheet. It is assumed that abatement of 65+ would be minimal and therefore it is not modelled. All the scenarios and target options are modelled separately on the 15-64 Abate sheet, using the distributions of carers from the 15-64 and 65 Plus sheets (described above) and the DPB-CSI abatement regime. IB and SB have slightly different abatement rules but the difference to DPB-CSI is minimal. IB and SB are also mostly (or all) spouses so these are excluded in the "no spouses" options in the model (refer below). The abatement "steps" are input in the Global Input sheet at Row 205.

In Rows 14 to 206 in the 15-64 Abate sheet, the carers by SPA band and hours per week are brought in from the 15-64 sheet. Then, in Rows 209 to 405 the abatement is calculated. For each scenario and target option, and for shared care and full family care, an annual wage is calculated in each hour per week "bin". This wage is the hours per week x weeks per year times the minimum wage (being the expected amount to be received by the carer).

A floor has been assumed for the abatement calculations - currently set at 25 hours per week. This is based on the DPB-CSI only being available (ignoring minor exceptions) to people giving virtually full time care. The modelling assumption is that only those disabled people being needs assessed for family care (by NASCs) with over 25 hours per week total care would likely have been getting DPB-CSI. The calculations also allow for a cap of 40 hours per week total paid family care, if this option has been selected.

The abatement savings are summarised in Row 213 on the 15-64 Abate sheet, and taken to the Summary sheet in Column AZ.

Tax impact - personal tax on carers

The tax impact on carers is modelled on the 15-64 (Tax) and 65 Plus (Tax) sheets, using current tax rates and thresholds. These sheets are similar in structure to the 15-64 Abate sheet. The wages in each hours per week bin are calculated as described above. Tax on wages is calculated using IRD tax rates and thresholds, entered on the Global Input sheet at Row 239. The tax calculations are on the 15-64 (Tax) and 65 Plus (Tax) sheets from Rows 219 to 405. The results for each scenario and option are shown in Row 213 ad in the Summary sheet in Column BA.

Tax impact - tax on provider profits

This calculation is only relevant when the option to pay through Providers has been selected. See the Global Inputs sheet, Cell B8, option 2.
Tax impacts on providers is estimated based on a profit assumption and the corporate tax rate. This is not a significant balance and small variations in the profit assumption are not material to the model results. The provider tax calculation is shown on the Global Inputs sheet at Row 250 and results are taken to the Summary sheet in Column BB.

Total Costs and Results

The Summary sheet consolidates all the calculations and sets out the results for each scenario and target option.

The Output (cap) sheet summarises the results - using an average figure for the ACC and Personal Care methods. It shows a mid-point estimate as well as a range. The ranges are set based on selected %'s above and below the high and low points. If results are below $25m, the range uses a different percentage. These rates are input on the Output (cap) sheet at Cells U24 and U25.
The section from Row 6 to Row 35 shows the live model results. The default is to select the $16/hour payment option (Global Input Cell B8, option 3) and apply the 40 hour per week maximum paid family care (Global Input Cell E26, option "Yes").

Currently the model shows the same output, except changing from the $16/hr option to a $25/hr option, in the Rows 39 to 68 on the Output (cap). These results are pasted down from the rows above when the option has been selected.
Similarly, the results on the Output (no cap) sheet have been pasted from the top "live" section of the Output (cap) sheet when the respective options have been selected in the model.

Important: Once alternative scenarios have been run and pasted, the model should be re-set back to the default case as described above.

The Output All sheet is the main results sheet used in discussions with Ministers and provided for the drafting of the Cabinet Paper. This summarises the results from the Output (cap) and Output (no cap) sheets on the one page.

A copy of the final 6 December 2012 Output (All) sheet has been kept (at the end of the model). See sheet Output All (pasted).

Other Options/Variations

Columns Q to T of the Output All sheet show results of other variations calculated in the model.

The impact of spouses is calculated by running the model including spouses - see Global Inputs, Cell B16. The main model result (in Cell M22) is pasted into S9 (with spouses) and S10 (without).
An approximate calculation is performed to include costs of under 15s. This is based on a pro-rata of the current number of DSS paid carers of under 15s compared to over 15s. See Global Inputs sheet from Row 304, and Output All S16.
The impact on DHBs is shown in Output All S21 and the calculations are shown in Global Input P101 to W114.
The impact of paying parents only is calculated by running the model excluding spouses and other family members - see Global Inputs, Cell G 16 (and Cell B16). The main model result (in Cell M22) is pasted into S26.

VERSION CONTROL

Model Updates - after the reported numbers of 4-12-12.

5 December 2012

1 Re-calculated ACC data sheet to correctly reflect removal of spouses. A full recalculation, including using a consistent spouse percentage (see 2 below)

2 Adjusted spouse percentages to use total percentage of all formal carers, rather than personal care percentage. Based on HDS Table 19 likely to be missing data, and table 16 (now used) being more conservative.
This changed the formulae on Global Input: E73 and K73; and ACC Data: D28 and E28.
Net impact on most likely option:

Cost to Govt before tax: at 4-12-12	**$23m**
Current model result >>>	**$23m**
	$0m

< ensure model is set to: exclude spouses; use $16/hr wage rate; include 40 hour per week cap.

3 Added approximate calculations for adding spouses; under 15s; and DHB impacts. See Output All sheet - Cells Q8 to T22, and associated workings on Global Input sheet.

6 December 2012

4 Revisited the assumption above to use the family percent of all informal care for the ACC calculation. Remove the non family amount (7%) from the denominator as ACC family is all family.
See note on ACC data sheet: Row 29.
While it is more correct to make this change, there was no change to the targeted scenarios results, and only a $1m change to the highest option. On this basis the original numbers have been retained.

5 Split Mothers and Fathers from table of informal carers on Global Input sheet: Row 147 - to allow for scenario that only paid parents.
Added scenario for parents only on Global Input sheet, G16, and added to formulae used to adjust for spouses on the Global Input Sheet (E74, K74) and the ACC data sheet (D28, E28).
Added results (after running model) to Output All sheet, Cell Q25.

6 Added ACC method explanation - Global Input, Cell N54

7 Added fixed cost to Admin costs to reflect implementation and additional costs not included in Unit Costs already modelled. See Global Input sheet, Cell L44.

7 December 2012

8 In 15-64 Abate sheet, fixed the formulae that ensured that the model couldn't abate more people than the maximum number from the MSD calculations. This was not impacting the calculations but has been changed in case the model is used to run options at a later date that have much higher numbers. See rows 219 to 405 in Columns E, L, S, Z AG, AN, AU, and BB.

10 December 2012

9 Completion of model methodology notes above.

10 Removal of password as model will remain within MOH.

Also see Reconciliations file for comparisons to September cabinet paper and to de Raad and Easton evidence.

In Confidence
Office of the Minister of Health

Cabinet Social Policy Committee

PAID FAMILY CARERS CASE: PROPOSED RESPONSE

Proposal

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

Executive Summary

2 The Government needs to change the Ministry of Health's current blanket policy of not paying family carers. The initial focus of the policy work is on family carers who are parents of adult disabled children and other family members who reside with an adult disabled family member. This approach excludes spouses of disabled adults and parents of disabled children.

3 The key choices involved in developing a policy for paying family carers involve deciding on the way in which family carers will be paid and deciding on the approach to targeting payments to family carers. Policy work identified three options for each of these issues.

4 The preferred approach to allowing the parents of adult disabled children and family members who reside with an adult disabled family member to be employed involves the following:

a allocating approximately $16 per hour to the disabled person to allow them to employ family carers, with the terms and conditions on which they can employ the family carer being specified in a Notice under Section 88 of the New Zealand Public Health and Disability Act 2000;

b allowing family carers to be employed when they are in very high and high needs situations – that is, disabled people whose ability to remain living at home is under threat because their family situation is fragile and those who have such high support needs that meeting those needs means that a family carer who wishes to work full time in another job outside the home is unable to do so.

5 This approach: allows family carers to be employed; targets funding to pay family carers to disabled people in high and very high needs situations; enables disabled people to retain control over the funding they are allocated; limits the net costs to Vote Health to an estimated $23 million a year; and pays family carers $16 per hour (i.e. the minimum wage per hour plus associated employment costs such as allowances for holiday and sick pay, Kiwisaver contributions and ACC earner levies). This is the amount that contracted providers pay most non-family carers, which is lower than the $25 per hour paid to contracted providers.

6 This approach, however, has risks associated with it that may need to be addressed through changes to other parts of the disability support system and/ or supported through legislation. The Minister of Health will report back to Cabinet on these issues in early 2013, before the preferred approach is confirmed.

7 There are also significant broader implications, arising from this case, for support funded through District Health Boards (DHBs) and aspects of support funded through the Ministry of Health. Cabinet needs to decide whether it wishes to continue to address these issues through an ongoing policy process, or to investigate the possibility of legislating to remove these risks.

Background

8 Family carers play an important role in supporting disabled people to live an everyday life. The New Zealand Disability Survey, for example, suggests that family carers (and other unpaid natural supports) provide in the order of 75 percent of the care of disabled people. The government complements the role of family carers and other natural supports through funding support that assists disabled people to live everyday lives. At present, the Ministry of Health (the Ministry) funds support for about 30,000 people (most of whom are aged under 65) with physical, sensory and intellectual disabilities who need ongoing support. Other support is also funded through DHBs and a range of other government agencies.

9 The Ministry currently has a blanket policy of not allowing the payment of certain family carers (parents, spouses and resident family members) who provide disability support services (DSS). The Ministry is now required to change this blanket policy as a result of the Human Rights Review Tribunal's (the Tribunal's) declaration, which was upheld by the High Court and the Court of Appeal, that the policy involves unjustified discrimination against family carers under the New Zealand Bill of Rights Act 1990 (NZBORA). Changing that policy means that families are likely to be paid to provide support that they currently provide unpaid.

10 The Ministry is currently able to continue to operate its policy lawfully by an order of the Tribunal suspending its own declaration. Under agreement with the plaintiffs, the earliest that action could be initiated in the Tribunal to lift the Suspension Order is May 2013. If the Government's response to change the payment to family carers policy cannot be implemented by May 2013, it would be prudent for the Crown to seek agreement from the plaintiffs that they would further defer taking action to have the Suspension Order lifted. If agreement cannot be reached with the plaintiffs, the date for lifting the Suspension Order would be decided in the Courts. Crown Law considers it is unlikely that the Courts would lift the Suspension Order before the policy is implemented as the Crown is moving to decide on and implement its policy change with all reasonable haste.

11 Cabinet has previously agreed to a staged process for addressing the most significant legal risks arising from the Family Carers case (CAB Min (12) 25/13 refers). The initial focus has been on the issues most directly addressed in the case, which is the discrimination that arises within Ministry funded Home and Community Support Services (HCSS) - which help people to live at home - that was the focus of the Family Carers case. That discrimination arises from the Ministry not paying carers who are parents of adult sons and daughters and/or family members who reside with disabled adult family members (SOC Min (12) 13/15 refers). On 17 September 2012, Cabinet agreed to the release of a consultation document as the basis for a public consultation process on the options for responding to this discrimination (CAB Min (12) 33/13 refers). A draft analysis of submissions received is attached as Appendix One.

12 Under the staged process, consideration would subsequently be given to a range of other cases of differential treatment of family carers where there is a significant risk that they could involve unjustified discrimination under NZBORA. In support funded by the Ministry, that discrimination arises in support other than Home and Community Support Services, and support from spouses of disabled adults and parents of disabled children. It also arises in support funded by DHBs; and support funded through Veterans' Affairs New Zealand. It was envisaged that the first stage response could provide a precedent for addressing these wider issues. The implications for this other potential discrimination are now becoming clear and steps need to be put in place to address them.

Comment

13 A policy of paying family carers of disabled people represents a change to one of the fundamental assumptions on which the disability support system is based in New Zealand and internationally. That is, that family carers are 'natural supports' and are supported to carry out this role, rather than being paid to do so (although there are some exceptions to this approach). This means that there is limited experience to draw on in designing the policy, with the result that, whichever policy option is adopted, there will be a considerable degree of risk and uncertainty to manage. For example, the estimated gross cost (i.e. payments from Vote Health) of the options identified in this paper range from $21 million to $74 million a year for Ministry funded support, with net costs ranging from $15 million to $65 million if the estimated reduction in benefit payments is taken into account. The estimates for the various options are themselves subject to uncertainty.

14 Meeting these additional costs is a significant challenge for the Government, particularly in the current fiscal environment. This means that the Government must now make some hard decisions that will not be universally popular if we are to be fiscally responsible. While many participants in the consultation process indicated preferences on the trade-offs that could improve the affordability of paying family carers, there were relatively low response rates on this question, meaning there was no clear consensus on the most appropriate way of addressing the hard decisions confronting the Government.

KEY POLICY CHOICES

15 There are a range of policy options for responding to the Courts' decisions in the Family Carers case. The key choices, which are discussed below, are around:

a the way in which family carers are paid; and

b the approach to targeting which family carers can be paid.

Payment mechanisms

16 Family carers can be paid under one of the following options:

a ***Option One: Allow family carers to be employed.*** This involves removing the restriction on employing family carers so that family carers can be employed to provide HCSS through the Ministry's existing mechanisms (e.g. through contracted providers or by the disabled person under individualised funding arrangements). Under both these arrangements, the cost to the Ministry is an average of about $25 an hour (although employees receive around $16 an hour - i.e. the minimum wage of $13.50 plus allowances for holiday and sick pay, Kiwisaver contributions, and ACC earner levies). The higher amount paid to providers covers such things as administration and contracting costs, profit, supervision and staff training.

b ***Option Two: Pay carers an allowance.*** This approach involves directly paying family carers an allowance that reflects the hours of allocated funded HCSS that family carers provide. The allowance could be set at $16 per hour (i.e. the minimum wage of $13.50 plus allowances for holiday and sick pay, Kiwisaver contributions and ACC earner levies), which is the amount that most support workers currently employed by contracted providers receive. While Government would incur additional costs for administration and quality assurance and, possibly, training, these costs are taken into account in the overall cost estimates and will be significantly less than the $9 per hour difference between the rate for contracted services and under individualised funding, and the amount paid to care workers. Legislation would be required to implement an allowance and there would be some challenging design and implementation issues, such as its relationship to social security benefits, tax status, and employment law.

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

Targeting options

17 Officials have identified three broad options for targeting payments to family carers, as a key tool in managing the costs of paying family carers who are in the groups being considered in this paper (i.e. parents of adult sons and daughters and/ or family members who reside with disabled adult family members, excluding spouses):

a ***Option A: Tight targeting - pay family carers supporting disabled people in very high need situations*** (approximately 1,100 disabled people). This would involve targeting to disabled people whose ability to remain living at home is under threat because their family situation is at risk of breakdown, often because of multiple factors including the family carer's caring responsibilities. For example this could be a combination of: the family carer might be supporting a disabled family member with significant support needs; the family carer might have multiple caring responsibilities; the family may be facing significant socio-economic disadvantage; and/or the family carer might be a sole parent with limited natural networks.

b ***Option B: Medium targeting - pay family carers supporting disabled people in high and very high needs situations*** (approximately 1,600 disabled people). This would involve targeting to disabled people whose family situation is at risk of breakdown, and disabled people who have such high support needs that meeting those needs means that a family carer who wishes to work full time in another job outside the home is unable to do so. For example, family carers may be unable to work because they are supporting one or more disabled people who need high levels of personal support regularly throughout the day and someone in the home 'on call' both day and night to meet personal care needs.

c ***Option C: No targeting.*** This option involves paying all family carers of disabled people receiving HCSS who meet the Ministry's eligibility criteria (approximately 5,400 disabled people).

Assessment

18 Each of the combined options of payment method and targeting offers different balances between the impact on disabled people and family carers, legal risks, implementation issues and potential fiscal costs and risks. Both employment and an allowance recognise the contribution that family carers make to the disabled person, but there are also differences between them:

a ***Paying family carers as employees*** (estimated costs under Options 1A, 1B and 1C in Table One below) complies with NZBORA and treats family carers similarly to other paid carers under employment law, and uses existing mechanisms for promoting quality (such as training requirements through the employer). It also gives family carers status through being employed, but may deter some family carers from seeking payment because of what some see as the onerous requirements arising from employee/ employer relationships and a concern that being an employee will undermine family relationships.

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

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

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

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

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

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

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

b **Medium targeting: pay family carers in high and very high needs situations** (Options 1B, 2B and 3B in Table One below). This option would enable family carers who are unable to earn an income because of their caring responsibilities to earn an income as paid carers of a family member, and may lead to some people on benefits such as DPB-CSI becoming employed as family carers. It might also result in some family carers stopping work outside the home so they could be paid as carers.

c **No targeting: pay all family carers** (Options 1C, 2C and 3C in Table One below). This approach is consistent with the Courts' decisions in the Family Carers case as it involves no differential treatment of family carers who are being considered for payment at this point, that is parents of adult sons and daughters and/ or family members who reside with disabled adult family members (SOC Min (12) 13/15 refers).

20 Payment options that treat family carers differently from other carers, and any targeting option, involve an element of differential treatment on a prohibited ground of discrimination. The question is whether such differential treatment is justifiable under NZBORA. If not, the Government may need to make further policy changes in response to any future adverse findings by the Courts, with potentially significant fiscal consequences. Supporting the policy with legislation would reduce this litigation risk because, although the Courts could still find the policy to be inconsistent with NZBORA, they could not overturn it. There is recognition in the recent Day Services decision (Attorney-General v IDEA Services Ltd (2012) NZHC 3229) that prioritising expenditure was an important objective which could override the right to non-discrimination, especially as Section 3 of the New Zealand Public Health and Disability Act 2000 states that disability support and health services are to be provided within available funding. The potential consequences of adverse findings by the Courts may, however, make legislation desirable.

21 Under each of these options, caps will be placed on the amount of support that will be paid for to help manage fiscal costs and risks. Two forms of cap could be applied:

a The total amount of support funding allocated to a disabled person (whether or not provided by families) cannot exceed the cost of that person living in a residential service. This currently averages $61,000 per person, with some packages being considerably higher than this, as actual packages reflect the level of assessed need. Although this policy operates implicitly now, there are quite a few exceptions to it. Clarifying that such a policy applies will reduce the uncertainty about whether this is the case and assist with the consistent application of the previously mentioned exceptions policy. Current exceptions would, however, be grand-parented to avoid unnecessary disruption to people's lives.

b The amount of funding that is allocated to a disabled person to pay family carers cannot exceed 40 hours per week, which is equivalent to a full working week. As well as reducing fiscal costs and risks, this will help ensure that paying family carers does not result in them providing an unsustainable amount of paid care for their disabled family member.

22 It may also be possible to further target payments by income and/or asset testing family carers, so that carers from households with very high income or assets are not able to be paid. It seems inequitable, for example, to pay wealthy people to care for adult disabled children when they have access to sufficient resources. I have, therefore, asked my officials to investigate whether this is a feasible option and to report back to me in February 2013.

Other parts of the policy response

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

a ***Strengthen the existing Needs Assessment and Service Coordination (NASC) process*** for determining disabled people's support needs but extend NASC's role to include determining the extent to which family carers could be paid. The process for determining how much support family carers can provide unpaid would be strengthened through clarifying the principles that are used to determine this and putting in place clearer processes for people to request reconsideration of NASC decisions. This would respond to concerns that were raised during the consultation process about NASCs existing principles-based assessment of the extent to which unpaid family carers can meet the needs of the disabled person. Overall submitters preferred NASCs to use a principles-based approach, although feedback revealed a lack of trust in NASC organisations to carry out the required assessments in a fair and reasonable way. Some felt more transparency and consistency and an improved system for reviewing NASC decisions may help address this. Furthermore, a more robust and consistent approach by NASCs would help counter the incentive that the possibility of payment will reduce the amount of unpaid support offered by family carers.

b ***Adopting an exceptional circumstances policy*** which would allow for consideration to be given to paying family carers who fall outside the targeting criteria but where there is a very good case for paying them. For example, people may seek funding because of a lack of availability of formal carers, safety risks for the disabled people or family carers or there are no other practical alternatives available. This discretionary policy will allow for the Ministry to respond to the wide range of circumstances that can arise.

c ***Making available independent support during the NASC process*** **when consideration is being given to paying family carers**. This would help reduce the risk that disabled people may become trapped in situations of being supported by family carers who have come to rely on the income, but when this is inconsistent with their wishes. The disabled person should, however, be able to explicitly decline this support.

d ***Independent monitoring of disabled people's quality of life*** when family carers are paid. This monitoring will help respond to concerns that disabled people may become 'trapped' by family carers who come to rely on the payments they receive. There was strong support in the consultation process for monitoring that is carried out by evaluators who are independent of the family carer and the disabled person.

Fiscal Costs

24 Estimates of the fiscal cost for the nine options that arise from combining the payment and targeting options, all with family carer support limited to 40 hours per week, are summarised in Table One below. These estimates include the direct cost to Vote Health and assume that any reduction in benefit payments will lead to a fiscally neutral transfer to Vote Health. The expected increase in income tax payments is not reflected in these estimates.

25 There are limitations to these estimates: there is a greater than usual degree of uncertainty around them as they rely on drawing inferences from existing data sets that were gathered for different purposes and, in some cases, rely on self-reporting, which can be problematic; and it is very difficult to estimate the extent to which family carers may elect to become paid under any of these options. The benefit impacts are also difficult to estimate because of uncertainty about the number of eligible carers. These costings do not include estimates of the costs of introducing similar policies for other groups such as

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

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

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

Preferred option

26 The decision about the most appropriate option rests on achieving an appropriate balance between fiscal costs, legal risks, and the impact on family carers and disabled people. Option 3B in Table One above, which involves medium targeting – allowing family carers in high and very high needs situations to be paid – and making those payments using a Section 88 Notice, appears to offer the most appropriate balance. This option:

a Targets funding to pay family carers who are so significantly impacted by their caring responsibilities that they are unable to work full time in another job outside the home. With this degree of targeting, it is likely that the plaintiffs will be funded (whereas this may not be the case under a tighter targeting regime).

b Allows family carers to be employed, which responds directly to the Courts' finding that family carers were discriminated against in employment.

c Allows disabled people to retain control through allocating funding to them, rather than directly to their family carer. This gives them the choice of engaging family carers under the Section 88 Notice or non-family carers through either a contracted provider or under an individualised funding arrangement. It also places conditions on the payment of family carers.

d Limits **net** fiscal costs, estimated to be $23 million per year, to a level that can be sustained from within the overall Vote Health allocation, although achieving this will require a transfer from Vote Social Development as a result of the expected reduction in benefit payments (particularly in the DPB-CSI).

e Pays family carers $16 per hour (i.e. the minimum wage of $13.50 plus allowances for holiday and sick pay, Kiwisaver contributions and ACC earner levies), which is the amount that most other carers receive when they are employed through contracted providers.

27 The approach is not, however, without its risks. [redacted] This is because, under individualised funding arrangements, some disabled people will take responsibility for administrative duties that contracted providers normally carry out and, in return, pay their carers higher hourly rates than contracted providers are able to. Under the Section 88 Notice, a disabled person will not be allocated sufficient funding to enable them to pay family carers higher rates than contracted providers are able to.

28 This risk could be addressed through allocating similar levels of funding to family carers as are allocated to people purchasing services through individualised funding arrangements (which is also the same amount as allocated to contracted providers) – at a net additional cost to Vote Health (over and above the costs of Option 3B) of $17 million per year. Vote Health does not have this level of additional funding available if it is to manage the overall pressures facing it. Alternatively, changes could be made to either the individualised funding arrangements or the overall way that the Ministry funds disability supports to align them with the approach taken to paying family carers. If additional funding is not available, or if changes are not made to align all disability support allocations to family carers with the proposed approach, legislation would be the only effective way of managing this risk.

APPROACHES NOT RECOMMENDED

29 The consultation document outlined several other options that further analysis and the consultation process suggest should not form part of the initial Government response. Those options are the following:

a Expecting families to provide fixed minimum levels of HCSS to reduce overall costs. It would be very difficult to enforce minimum requirements for support and there were concerns that the 'minimum' expectation could easily become the default level of unpaid support that families provide, although families may be prepared to provide more.

b Paying an allowance that is lower than a non-related carer would be paid. Such an allowance may be inconsistent with the Minimum Wage Act 1983 and may be inconsistent with NZBORA through treating family carers differently to other carers. There was no support for this approach during the consultation process.

c Offering a flat-rate (or broadly tiered) carers allowance payable through the welfare system (which does not have the capacity to determine the specific levels of support a disabled person might require). This does not respond directly to the Courts' decision in the Family Carers case, although it could complement employment or the combined option above. Such an allowance would also complement support funded through Vote Health by recognising people's caring role, but could cost a considerable amount of money, while providing relatively limited amounts of funding to any one person. For example, the Ministry of Social Development estimates that the cost of providing a flat-rate non-taxable weekly allowance of $45.34 (the same as the Child Disability Allowance) for the estimated 73,000 family carers who are identified in the New Zealand Disability Survey would be $176 million in 2013/14 rising to almost $200 million in 2016/17. There would also be operational costs of approximately $5 million in 2013/14 and $3 million in 2014/15 and out-years. Adoption of such an option would, therefore, be contingent on additional funding being available.

RELATIONSHIP TO FUTURE DIRECTIONS FOR DISABILITY SUPPORT

30 There was support in many submissions for the response to the Family Carers case to be consistent with the Government's new directions for disability support that emphasise flexibility, choice and control for disabled people. Several elements of those future directions have the potential to improve the way in which the Ministry manages paying family carers:

a The introduction of facilitators (an example of which is local area coordinators) who can support people to plan and build up natural support networks could significantly reduce the pressure that many family carers face and might reduce the demand for family carers to be paid. For example, a recent initiative by the Ministry involved facilitators working with a group of 16 families of young people who were in crisis, with the young people at risk of moving into residential care at an estimated support cost of $3 to $4 million a year. The outcome has been that none of the young people have moved to residential care (and some have got jobs), the families have remained intact and support costs are in the order of $500,000 a year.

b Increasing the flexibility, choice and control that people have over the funding they are allocated would allow funding to be used in the most appropriate way, thereby reducing pressure on family carers. Consistent with this, the Ministry is now moving to make the Carer Support Subsidy (a payment intended to allow unpaid carers to take a break from their caring responsibilities) more flexible. This will complement the current individualised funding scheme for HCSS.

c The Ministry is currently modifying its funding allocation process, which will result in significant changes to some parts the current NASC process. It is anticipated that the modified approach will result in more consistent funding allocations than occur at present, although more development and testing is required to be confident that this is the case. During development of the funding allocation process, explicit consideration will be given to the issues raised by the Family Carers case.

NEXT STEPS

31 The Ministry expects to be able to implement the new policy for paying family carers by 1 October 2013. This will allow time to develop the Notice under Section 88 of the New Zealand Public Health and Disability Act 2000. Such a Notice would set out the detailed terms and conditions with which disabled people who are allocated Ministry funding to employ family carers will need to comply.

32 The extent of the risk and uncertainty means that the Ministry will need to ensure that the actual cost of paying family carers does not exceed the allocated funding. It is envisaged that this will involve ring-fencing within NASCs and closely monitoring the funding allocated to pay family carers. Ring-fencing would avoid the risk that unexpectedly high payments to family carers would lead to reductions in other parts of disabled people's packages, which was seen as unacceptable during the consultation process. Close monitoring would give the Ministry the information it needs to advise on any adjustments to the family carer policy settings.

33 The next steps in responding to the broader issues will depend on the particular approach that Cabinet elects to take to addressing that issue. I have also asked my officials to report back to me in February 2013 on whether legislation is necessary and desirable to support the Government's preferred option (and, if so, how it might be done) and whether it is feasible and desirable to further target payments by income and/or asset testing family carers. If necessary, the Ministry of Social Development will work with the Ministry of Health to develop a process to transition clients from DBP-CSI to the new arrangement.

Broader implications

34 The Family Carers case has implications for a range of other areas where the government funds support for people with short or long-term disabilities. Current indicative estimates of the net cost to Vote Health of paying an expanded group of family carers are the following:

a Paying spouses who care for disabled adults who are supported through the Ministry would increase costs by about 80 percent. For example, the mid-point estimate of Option 3B in Table One above, would increase by about $18 million (from $23 million to $41 million) a year, with proportional increases in the upper and lower bounds.

b Paying parents of disabled children who are supported through the Ministry would increase costs by about 13 percent. For example, the mid-point estimate of Option 3B in Table One above, would increase by about $3 million (from $23 million to $26 million) a year, with proportional increases in the upper and lower bounds.

c Paying family carers of people who are supported through DHBs - primarily people with age-related support needs - could make a significant difference to estimated costs. For example, the mid-point estimate of Option 3B in Table One above, would increase by about $66 million a year if spouses can be paid and $41 million a year, if spouses cannot be paid. There would also be a proportional variation in the upper and lower bounds of these estimates.

d Paying family carers of veterans who are eligible for support funded through Veterans' Affairs New Zealand is estimated to cost up to $3 million a year, which may require additional funding to be sought.

35 There is a need to decide whether these broader issues should be determined through one of the following processes:

a Continuing with the previously agreed approach of carrying out a policy process that addresses the broader risks - thereby diverting those resources from other high-priority initiatives such as the transformation of the disability support system through initiatives to implement 'Enabling Good Lives'. If this approach is adopted, the Minister of Health would report back to SOC in October 2013 on how he proposed to carry out this work.

b Investigating the possibility of legislating to remove the risk that these other groups of family carers will be paid. In addition to removing the substantial fiscal risks, it also removes the risk that paying these other groups of family carers will significantly undermine family relationships and be contrary to current expectations of family support, including that spouses of disabled adults and parents of disabled children will support their family members. If this approach is adopted, the Minister of Health would report back to SOC in late February 2013 on the options for legislative change.[1]

Consultation

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

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

37 The Ministry consulted with the disability and carers communities, and the wider public between 19 September and 6 November 2012 based on the release of a public consultation document. The consultation process included:

a twelve regional public workshops;

b two hui with people from Māori carer and disability communities;

c one focus group with people from the Pacific carer and disability communities;

d a separate meeting with the plaintiffs in the Family Carers case.

38 In addition to feedback provided during the meetings, 617 people made written submissions. The key themes are summarised in the draft Analysis of Submissions which is attached as Appendix One.

Regulatory impact analysis

39 A Regulatory Impact Analysis was required for this paper as legislation is one of the options the Government needs to consider in developing its response to the Family Carers case. A draft Regulatory Impact Statement that summarised the analysis was prepared based on developing a response to issues directly raised in the case. Initially, this was to be the focus of the Cabinet paper, with policy work on responding to the broader risks raised by the case being deferred.

40 During the later stages of preparing the Cabinet paper, the scope of issues being considered in the paper was extended to cover whether legislation should be used to respond to those broader risks. This meant that the draft Regulatory Impact Statement was no longer relevant as it did not consider that broader issue.

41 If Cabinet agrees that the possibility of legislation to address any of the risks arising from the Family Carers case should be considered further, then a Regulatory Impact Statement that is relevant to the scope of issues being considered will be attached to the Cabinet paper that addresses those issues.

Human Rights Implications

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

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

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

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

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

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

Legislative Implications

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

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

b To address the broader risks associated with paying other family carers.

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

Gender Implications

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

Disability Perspective

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

Financial Implications

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

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

49 Budget Ministers are yet to receive and consider the Vote Health Four Year Plan and, at this point, no decision is sought on reprioritisation options in Vote Health, or on any change to Health's Budget 2013 operating allocation. Further advice will be provided on detailed costings and changes to appropriations, including any offsetting savings and reprioritisation options. The policy costings are subject to considerable uncertainty as they depend on the demand response by disabled people and family carers, and the uncertainties of implementation. These forecasting risks will also be managed within Vote Health.

50 If policy changes result in forecast savings in Vote Social Development (for example, from abatement of DPB - CSI payments), these savings will be applied to offset the gross costs to Vote Health through fiscally-neutral adjustments between Votes.

Publicity

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

52 I intend to make the final Summary of Submissions available at the time that I make public announcements on the Government's response to the Family Carers case.

Recommendations

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

1 **note** that the plaintiffs have agreed that they will not take further action to lift the Order suspending the Human Rights Review Tribunal's declaration in the Family Carers case (Ministry of Health v Atkinson & Others) until at least May 2013;

2 **note** that the Ministry of Health consulted with the disability and carers communities and the wider public on possible options for responding to the discrimination against family carers;

Preferred approach for an initial response

3 **agree** that the Ministry of Health's existing policy of not paying family carers be changed to allow adult disabled people to employ their parents, or other adult family members who reside with them, to provide them with Home and Community Support Services;

4 **agree** that the policy change in recommendation 3 above would not allow spouses of disabled adults and parents of disabled children to be paid as family carers or for funding to be allocated to a disabled person to enable them to employ spouses, or parents of disabled children;

5 **agree** that the preferred approach for changing the Ministry of Health's policy be the following:

5.1 **targeting:** Ministry of Health funding be allocated to adult disabled people to enable them to employ their parents or other adult family members who reside with them to provide them with Home and Community Support Services in the following circumstances:

5.1.1 in very high need situations, which means the ability of disabled people to remain living at home is under threat because their family situation is at risk of breakdown, often because of multiple factors including the family carer's caring responsibilities;

5.1.2 in high needs situations, which means that disabled people have such high support needs that meeting those needs means that a family carer who wishes to work full time in another job outside the home is unable to do so; and

5.1.3 in other 'exceptional circumstances' where consideration would be given to paying family carers who fall outside the targeting criteria but where there is a very good case for paying them.

5.2 **amount of funding allocated:** the funding allocated to adult disabled people to employ their parents, or other family members who reside with them, to provide them with Home and Community Support Services be based on the minimum wage plus associated employment costs such as annual and sick leave, public holidays, Kiwisaver contributions and ACC levies;

5.3 **independent support:** that when consideration is being given to allocating funding to enable the employment of family carers in the Needs Assessment and Service Coordination process, that a disabled person be supported by a person who is independent of anyone who could be paid to provide disability support services unless they explicitly decline such support;

5.4 **monitoring:** that there will be independent monitoring of disabled people's quality of life when family carers are paid to provide support;

6 **note** that, based on the current minimum wage, the funding that will need to be allocated to adult disabled people to enable them to employ their parents or other family members who reside with them to provide them with Home and Community Support Services is estimated to be approximately $16 an hour (which is based on the costs that contracted providers currently pay most non-family carers);

7 **note** that the Ministry of Health, working in conjunction with the Needs Assessment and Service Coordination Association, will strengthen the current principles-based approach to determining the extent of unpaid support that family carers are able to provide so that decisions are more consistent and transparent and reflect the implications of paying some family carers to provide disability support;

Implementation

8 **note** that the terms and conditions on which disabled people who are allocated Ministry of Health funding can employ family carers will be set out in a Notice that will be issued by the Minister of Health under Section 88 of the New Zealand Public Health and Disability Act 2000;

9 **note** that the Minister of Health intends to implement the proposed initial response by October 2013, but that the lawful continuation of the Ministry of Health's current policy between May and October 2013 will require either cooperation from the plaintiffs or the Courts deciding to not lift the Suspension Order until that date;

10 **note** that there is uncertainty around the estimated fiscal costs that are outlined in this paper and that the Ministry of Health will need to closely monitor actual versus expected expenditure;

Financial implications

11 **note** that the net cost to the Crown of policy changes affecting services funded through Vote Health will be met within Vote Health baselines, and from the Vote Health operating allocation for Budget 2013;

12 **note** that on 27 August 2012, Cabinet noted that Budget Ministers will assess whether the indicative allocation for Vote Health needs to be reviewed as work on the Government's response to the Family Carers case is progressed and the cost of policy options clarified. [CAB Min (12) 30/8 refers];

13 **note** that Budget Ministers are yet to receive and consider the Minister of Health's 4 Year Plan for Budget 2013, and at this point, no decision is sought on reprioritisation options in Vote Health, or on any change to Health's Budget 2013 operating allocation;

14 **note** that, during the budget decision cycle, further advice will be provided on any required changes to appropriations;

15 **agree** that if the policy of paying family carers results in forecast savings in Vote Social Development (for example, from the abatement of Domestic Purposes Benefit – Care of the Sick and Infirm payments), that these savings will be transferred to Vote Health through fiscally-neutral adjustments;

Next steps

16 **note** that the preferred approach itself may result in potential discrimination that the courts may find to be unjustified under the New Zealand Bill of Rights Act 1990;

17 **invite** the Minister of Health to report back to the Cabinet Social Policy Committee in February 2013 (and before final budget decisions are taken by Budget Ministers), with further advice and recommendations on:

17.1 legal issues with the preferred approach;

17.2 changes to the preferred approach above that may be required to address those legal issues; and

17.3 regulatory and/or legislative changes that would be required to support implementation of the preferred approach.

18 **note** that the Governments' preferred approach will be confirmed following the report back in recommendation 17 above;

Broader implications

19 **note** the following outstanding significant risks generated by the Family Carers case:

19.1 for support funded by the Ministry of Health, such as whether the spouses of disabled adults and the parents of disabled children should be paid, and the impact on support other than Home and Community Support Services;

19.2 for support funded by District Health Boards, particularly for people with age related disabilities; and

19.3 support for veterans funded through Veterans Affairs New Zealand;

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

Publicity

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

Hon Tony Ryall
Minister of Health

___/___/_____

Cabinet Social Policy Committee

FAMILY CARERS CASE: IMPLEMENTATION OF PROPOSED RESPONSE AND CONSIDERATION OF BROADER ISSUES

Proposal

1 This paper provides further advice requested by Cabinet on the issues raised by the Family Carers case (Atkinson & Others v Ministry of Health [Atkinson]), and seeks agreement to measures for responding to the case.

Executive Summary

2 At its meeting of 12 December 2012, Cabinet Social Policy Committee (SOC Min (12) 28/2 refers) agreed, subject to further advice, to a preferred response for allowing adult disabled people to employ their parents, or other adult family members (other than spouses) who reside with them, to provide them with Home and Community Support Services (HCSS) funded through the Ministry of Health (the Ministry).

3 The preferred response involved allocating adult disabled people about $16 an hour to employ family carers to provide them with HCSS in situations of very high or high need, or in other exceptional circumstances where it is clearly desirable to do so. The mid-point estimated cost of this response is $23 million (net) a year, or almost $100 million over four years. Cabinet, however, sought further advice on the fiscal and legal risks of implementing the preferred response before confirming it.

4 A fundamental tenet of Government funded social support is that, in general terms, families have primary responsibility for the wellbeing of their members. Responding to the Family Carers case by paying all groups of family carers would undermine this fundamental tenet and would result in fiscal costs of as much as $175 million (net) a year. This would involve extending the preferred response to all groups of family carers (including spouses and parents of children) supported through District Health Boards (DHBs) and the Ministry at the $25 an hour rate that is paid to HCSS providers.

5 The only feasible way to manage these risks is through legislation. The most straightforward way of legislating would be through an amendment to the New Zealand Public Health and Disability Act 2000 that:

a expressly permits some or all family carers to not be paid, or to be paid at reduced rates, to provide care to family members;

b provides that new claims cannot be lodged and limits remedies for existing claims (other than the Atkinson claims) to declarations of inconsistency.

6 Implementing the preferred response for Ministry funded HCSS at this time represents a proportionate response to the Court's decision provided the broader risks are managed through the proposed legislation. The policy will be announced, and the proposed legislation introduced and passed, on Budget night.

7 The extent of potential fiscal cost means that the Government must make some difficult choices in deciding how to respond to the risks arising from the Family Carers case. The Government has previously indicated that further work will be carried out on whether to pay other groups of family carers. If this work was to proceed it would create an expectation that those other groups will be paid, leading to significant additional fiscal costs that cannot be afforded at a time of considerable fiscal constraint.

Background

COURT FINDINGS AGAINST CURRENT POLICY

8 In the Family Carers case, the Human Rights Review Tribunal (the Tribunal) declared that the Ministry's policy of not paying family carers involves unjustified discrimination on the grounds of family status under the New Zealand Bill of Rights Act 1990 (NZBORA). Under the Ministry's policy, parents, spouses and other resident family members cannot be paid to provide support to their disabled family members. This policy applies to funding for people with physical, sensory and intellectual disabilities who are primarily aged under 65. The Tribunal's declaration was subsequently upheld by the High Court and the Court of Appeal. This means that the Ministry's policy needs to change in ways that are consistent with NZBORA and the Human Rights Act or the Government needs to legislate to support an alternative approach.

9 The Courts held that the Ministry's blanket policy of not paying family carers is a distinction on the basis of family status that materially disadvantages family carers. They also considered that the policy was not a proportionate response to the risks for disabled people and family carers as it was possible to effectively manage the risks of disrupting normal family relationships if family carers were paid. Furthermore, the Courts did not accept that the Ministry had shown that the policy would have a sufficiently significant fiscal impact to justify it.

PREVIOUS CONSIDERATION BY CABINET

10 Cabinet's primary focus to date has been on managing the risks for two groups of people who are eligible for Ministry funded support. The first group was the parents of adult disabled sons and daughters. This was the group that the Courts considered in making their decisions. Central to the Courts' decisions was the finding that these parents would not normally expect to provide a significant level of on-going care for their adult sons and daughters if they did not have a disability. The second group is resident adult family members (other than spouses) of disabled adults. There is a very strong likelihood that the Courts would conclude that not paying these family members involved unjustified discrimination under NZBORA as they would also not normally be expected to provide significant ongoing care to adult family members. These are the groups most immediately affected by the Tribunal's declaration in Atkinson.

11 At its meeting of 12 December 2012, Cabinet Social Policy Committee (SOC Min (12) 28/2 refers) agreed, subject to further advice, that the Ministry's policy be changed to allow adult disabled people to employ their parents, or other adult family members (other than spouses) who reside with them, to provide them with HCSS. This policy change would not allow the employment of spouses of disabled adults or the parents or other family carers of disabled children. The following was identified as the preferred approach for changing the Ministry's policy, with a mid-point estimated cost of $23 million (net of social welfare payments) a year, or almost $100 million over four years. Eligibility would be targeted to the following situations:

a adult disabled people would be allocated funding to enable them to employ family carers to provide them with HCSS in situations where the support provided by family carers is over and above the support they are able to provide unpaid in situations of:

   i very high need (e.g. a family is at risk of breakdown); or

   ii high need (e.g. the support needs are such that a family carer is unable to work in paid employment); or

   iii other exceptional circumstances where there is a very good case for paying them.

b the amount of funding allocated would be based on the minimum wage plus associated employment costs such as annual and sick leave, public holidays, Kiwisaver contributions and ACC levies (about $16 an hour).

12 Cabinet was, however, concerned about two risks if it implemented this preferred response. One was that there were broader risks that are not covered by the preferred response. The other was that the preferred response may, itself, result in differential treatment that the Courts may find to involve unjustified discrimination under NZBORA. That was because the preferred approach excludes certain family members and, in respect of family members that are eligible to be paid, the amount of funding allocated limits payments to close to the minimum wage (whereas some formal home support workers are paid more than this).

13 Accordingly, Cabinet invited the Minister of Health to report back to it in early 2013 with:

a further advice and recommendations on any necessary changes to the preferred approach; and

b regulatory and/or legislative changes required to support implementation of the preferred response and to address the broader risks.

[redacted]

Redacted under s(9)(2)(h) of the Official Information Act 1982

Redacted under s(9)(2)(h) of the Official Information Act 1982

[redacted]

Redacted under s(9)(2)(h) of the Official Information Act 1982

[redacted]

POTENTIAL FISCAL COSTS ASSOCIATED WITH THESE RISKS

19 The uncertainty around how the Courts would decide in any particular case creates significant potential fiscal consequences. Table One below indicates that the mid-point estimates of the potential fiscal consequences from responding to these risks are up to $172 million (net) a year (or $175 million if Veterans' Affairs is included). These cost estimates are based on paying family carers when disabled people have high and very

[11] Note: the estimated cost will change as a result of changes to the minimum wage.

high needs. Actual costs will, however, be affected by a range of factors, such as which groups of family carers are paid and the responses disabled people and family carers make to the availability of payments.

20 It should be noted that costs would be significantly higher if family carers were paid when disabled people had a lower level of need. Furthermore, the actual costs are extremely uncertain, particularly if the Courts were left to determine these issues.

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

Groups of carers	Mid-point estimated costs ($ million a year, net of benefit reductions)		
	Ministry of Health	DHBs	Combined
Cost of implementing the preferred response across family carers and funders i.e. allocating disabled adults with high and very high needs $16 an hour to employ family carers			
• Parents of disabled adult sons and daughters • Other family members of disabled adults	**23***	41	*64*
• Parents of disabled children • Spouses • Other family members of disabled children	21	25	*46*
Sub-total: cost of extending preferred policy	***44***	***66***	***110***
Additional cost of increasing family carer allocations from $16 to $25 an hour for people with high and very high needs			
• Parents of disabled adult sons and daughters • Other family members of disabled adults	13	23	*36*
• Parents of disabled children • Spouses • Other family members of disabled children	12	14	*26*
Sub-total: cost of increasing allocations	***25***	***37***	***62***
Potential fiscal cost for Vote Health	**69**	**103**	**172**
Potential fiscal cost for Veterans' Affairs			**3**
Total potential fiscal cost for the Crown			**175**

* The preferred response for Ministry funded HCSS

Approach to managing risks

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

22 Responding to the Tribunal's declaration by adopting a policy of paying all family carers would have the effect of changing this fundamental tenet. Furthermore:

a there is a risk that paying family carers will have adverse impacts on disabled peoples' and family carers' lives. For example, it may cause some family members to care for other family members when this might not be their preference, or not be

the disabled person's preference. It remains uncertain whether this risk can be effectively mitigated through policy design even though there are measures aimed at achieving this included in the preferred response

b as set out in Table One above, the potential fiscal costs could be up to $175 million a year. This would not be the most effective use of these resources at a time of considerable fiscal restraint. This is particularly the case as the Government's fiscal strategy and the range of competing demands on Vote Health mean that this level of new funding is not available.

23 Similarly, retaining the status quo is not acceptable as it would mean that the Government did not comply with the law. It would lead to the possibility of a very large number of claims for unjustified discrimination on the basis of family status across health services and disability support that are funded through the Ministry, DHBs and (potentially) Veterans' Affairs. Responding to each of these claims would take a considerable amount of time and effort and create considerable fiscal costs that are very hard to estimate.

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

PROTECTING FAMILY CARERS POLICIES THROUGH LEGISLATION

25 The proposed legislation will need to ensure that the Ministry and DHBs are able to operate policies which restrict or prohibit payments to family carers but still allow the Government to pay or fund payment of family carers where it wishes to do so. This can be achieved through legislation which authorises the Crown or a DHB to adopt a policy under which providers of health or disability support services are not paid, or only paid in specified circumstances, or paid at reduced rates because they are a family member of the person receiving the services. The legislation will need to make it clear that such policies are lawful, even if they breach section 19 of NZBORA. Otherwise, the Courts may "read down" the provision as only permitting non-discriminatory policies.

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

APPROACH TO LEGISLATION

27 The most straightforward way of achieving whichever legislative options are chosen is through an amendment to the New Zealand Public Health and Disability Act 2000. While a broader approach, such as through a standalone Act, reduces the risk of claims being made against other parts of the Government (e.g. Veterans' Affairs), it increases the risk of unintended consequences because the policies of Government funders have not been examined closely and it would be difficult to do so in the time available. For example, there is a risk that it could unintentionally affect ACC's policy of allowing the payment of family carers.

28 The legislation would not, however, need to address the risks for other funders. The risk for Veterans' Affairs will be addressed through a forthcoming review of current operational policies, including the current policy concerning the payment of family members. It is intended that this review will follow the passing of the proposed Veterans Rehabilitation and Support Bill, which is due to be introduced later this year and to come into force on 1 July 2014.

29 [redacted]

Redacted under s(9)(2)(h) of the Official Information Act 1982

HOW POLICY IS PROMULGATED

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

ADDRESSING CURRENT AND FUTURE CLAIMS

31 In addition to deciding whether it wishes to prevent future claims against the new law/policy, Cabinet also needs to decide whether it wishes to restrict, in any way, existing or future claims against the current policy. If it did, the legislation would need to make this explicit. The different groups of claims to address are discussed below.

Plaintiffs in the Family Carers case

32 There are nine claims in the Family Carers case itself. The Ministry has entered into an interim payment arrangement with some of the claimants at the request of the claimants' solicitor. The issue of damages, including for pecuniary loss, has yet to be determined by the Tribunal. [redacted]

Redacted under s(9)(2)(h) of the Official Information Act 1982

Other Existing "claims"

33 In November 2012, the Human Rights Commission informed officials that it had received 35 complaints that were not considered in Atkinson. It is also possible that the Commission may have received further complaints since November 2012. We are aware that the Human Rights Commission has been operating in good faith by not seeking to progress these claims before the Family Carers case is resolved.

34 It is recommended that these complaints be allowed to be filed as proceedings in the Tribunal, but that the remedies should be limited to declarations of inconsistency. While this will lead to ongoing litigation costs, it will not offer anything to future plaintiffs as the Tribunal (supported by the High Court and Court of Appeal) has already declared current policy to be inconsistent with NZBORA. Further proceedings will not change that. It will, however, reduce the risk that Parliament will be seen as limiting people's ability to have their claim heard.

35 The alternative of stopping these claims from being lodged with the Tribunal could be seen as the Government interfering in people's ability to have claims that have already been initiated from being heard. Stopping the claims would, however, prevent the Government from needing to respond to each of the claims.

New claims against existing policy

36 New claims against the existing policy should not be permitted to proceed. The issues have already been addressed by the courts and will be responded to by Parliament.

Future policy on paying family carers

37 Once the legislation is passed, the Government will have greater flexibility around when and how it addresses the differential treatment of family carers that was identified by the Courts in the Family Carers case. The areas where the Government could respond are discussed below.

Ministry funded home and community support services

38 It is recommended that Cabinet confirm its preferred response for Ministry funded HCSS as agreed by Cabinet Social Policy Committee in December 2012 (SOC Min (12) 28/2 refers). Confirming that approach would mean that, from October 2013, the Ministry would allocate about $16 an hour to pay parents and resident family members (other than spouses) of disabled adult family members in high and very high needs situations for care, with an allowance for payment in exceptional circumstances. Allocations would be made for support that is over and above the amount family carers are able to provide unpaid (SOC Min (12) 28/2 refers).

39 The preferred response is proportionate to the issues raised by the Family Carers case and fiscally responsible. The preferred response will also be seen as responding directly to the Courts' decisions. It should be noted, however, that the tight targeting and the lower level of funding allocated to family carers (about $16 an hour) compared with about $25 an hour for non-family providers may lead to adverse reactions from some people. It will, however, be possible to simplify the policy relating to 'exceptional circumstances'. That will be achieved through allowing some flexibility within the detailed operational policy to consider particular circumstances where payment is clearly desirable (for example when an alternative carer is clearly unavailable, such as in remote rural areas). This approach will limit the risk that an explicit exceptional circumstances provision could lead to an unintended broadening of the range of family carers paid over time because of the considerable uncertainty about what constitutes 'exceptional circumstances', with each decision becoming a precedent for a wider and wider range of exceptions over time.

Other Vote Health services and funders

40 There will be considerable interest in the messages that the Government sends about whether, and how, it intends to respond to the broader issues raised by the Family Carers case. That is because frequent comments were made about those issues during the public consultation process, especially given the commitments made in the public consultation document to undertake further work on the broader issues raised by the case. There is, therefore, likely to be considerable disappointment within the community if those broader issues are not addressed.

41 Those broader issues are:

a whether spouses of disabled adults, and parents and other family carers of children, will be paid for providing HCSS for their disabled family member; and

b whether family carers (other than spouses and parents of children) can be paid to deliver HCSS funded through DHBs.

42 Indicating that further work on either or both of these issues will be carried out at a time when the Government has sufficient funding to pay for any policy response will give other family carers (and the people with health conditions or disabilities that they support) some confidence that they may be paid in the future. This approach would allow the Government to present the proposed legislation in a positive light and allow the broader

issues to be addressed at a time when the Government has a better understanding of the issues and risks involved. If this approach is adopted, further consideration would need to be given to the scope of issues that would be addressed and when that would occur.

43 On the other hand, if the Government decides to carry out further work there will be ongoing debate on the issue of whether family carers should be paid. It will also create a strong expectation that the approach taken in the preferred policy will be a precedent that is extended to these other groups. If this approach were to be adopted, the estimated fiscal costs that would result at the conclusion of the further work would be the following:

a $46 million a year for paying spouses, and parents and other family carers of children who are supported through the Ministry and DHBs; and

b $41 million a year for paying parents and other family members to provide HCSS to disabled adults who are supported through DHBs.

44 It is likely that the Government would need to declare a fiscal risk relating to the potential for additional fiscal costs arising from any decision to carry out further work on the broader issues in its 2013 Budget statements.

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

Implementation

46 It is intended that the Government announce its response to the Family Carers case on Budget Day 2013. As well as announcing the general approach, the announcement would indicate that legislation to support the Government's approach will be introduced and passed as part of the package of legislation to support Budget 2013. Announcing the policy and introducing and passing legislation on the same day will avoid the need for the legislation to include any backdating provisions.

47 The Ministry is currently able to continue with its current policy through an order indefinitely suspending the Tribunal's declaration. The Ministry sought a 12 month suspension and counsel for the plaintiffs has advised that the Office of Human Rights Proceedings will not provide public representation to lift the Suspension Order during the 12 month period. The legislation proposed in this paper would supersede the Suspension Order and an extension of it would not be required.

48 The Minister of Health will approve any operational policy needed to implement the preferred policy. This operational policy could include, for example, arrangements for transitioning from the existing to the new policy, such as when family carers who are currently being paid under ad hoc arrangements are transitioned to any new arrangements.

NEXT STEPS

49 The next steps are the following:

Budget Day 2013	Minister of Health announces the Government's policy
	Legislation introduced and passed as part of Budget Legislation
October 2013	Ministry implements the preferred response

Financial implications

50 The Government must make some difficult choices in deciding how to respond to the broader risks arising from the Family Carers case. If the choices proposed in this paper are adopted (i.e. only paying family carers other than spouses and parents of children for support funded through the Ministry) and using legislation to manage the wider risks arising from the case, then the estimated additional fiscal costs of $23 million can be funded from within Vote Health's indicative allocation.

51 If legislation to support this approach is not passed, then estimated fiscal costs increase from $23 million a year (for the preferred approach) to as much as $175 million or more a year, depending on decisions taken by the Courts and Ministers over time. It is unlikely, however, that all the additional costs would be incurred immediately and, depending on decisions of the Courts, some may never eventuate. The additional funding would need to be found through reprioritisation of baseline and new funding within Vote Health or by further increasing Vote Health funding.

Consultation

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

Regulatory impact analysis

53 The Regulatory Impact Analysis (RIA) requirements apply to the proposal in this paper and a Regulatory Impact Statement (RIS) has been prepared and is attached. The Regulatory Impact Analysis Team (RIAT) has reviewed the RIS prepared by the Ministry of Health and associated supporting material, and considers that the information and analysis summarised in the RIS meets the quality assurance criteria.

Human Rights Implications

54 The proposals in this paper appear to be inconsistent with the freedom from discrimination affirmed in section 19(1) of NZBORA and are unlikely to be justified under section 5 of that Act. The preferred option continues the differential treatment leading to material disadvantage that was considered by the Court of Appeal in Atkinson. Some family carers will not be eligible for payments and those who are eligible will receive less than some non-family carers undertaking the same work.

55 Furthermore, the proposed legislation would provide the Government with a broad power to discriminate on the basis of family status (because it would authorise the Government to not pay any family carers). This makes it likely that the legislation will be inconsistent with NZBORA regardless of whether the policy implemented under that legislation can be justified under section 5 of that Act.

56 The legislation options discussed in this paper will include provisions that appear to be inconsistent with the current rights to freedom from discrimination in the Human Rights Act and NZBORA. Under section 7 of NZBORA, the Attorney-General may consider it appropriate to bring those inconsistencies to the attention of the House when the Bill to implement these legislative changes is introduced to the House.

Legislative Implications

57 The proposals in this paper will require an amendment to the New Zealand Public Health and Disability Act 2000 in order to address the legal and fiscal risks outlined in this paper. It is proposed that the legislation form part of the Budget legislation package.

58 The proposed legislation will have some retrospective effect as it stops people from making future claims against the existing policy and restricts remedies in respect of existing complaints that have been lodged with the Human Rights Commission to declarations of inconsistency. It is not clear, however, that this will have a significant adverse impact. That is because the Government has elected to respond to the Courts' decisions in the Family Carers case through a combination of legislation and paying some family carers.

Gender Implications

59 The Government's response to the Family Carers case is likely to primarily affect women as they are the majority of people who provide unpaid care to disabled family members. When women are paid a wage when they would not otherwise have opportunities for paid employment, they will have improved income.

Disability Perspective

60 There are differing views in the disability and carers communities on whether family carers should be paid for providing care, with many people recognising the dilemmas raised by the Family Carers case. For example, some people strongly support family carers being paid while others see this as a barrier to disabled people being fully accepted into society. The disabled people who presented submissions during the public consultation process generally supported the option of family carers being paid, but had different views on how this should occur through, for example, a wage or an allowance.

Publicity

61 The Minister of Health will take the lead role in making public statements about the Family Carers case. The draft Questions and Answers appended to this paper are intended for Cabinet and are not for public release.

Recommendations

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

1 **note** that, on 12 December 2012, Cabinet Social Policy Committee agreed to a preferred approach to responding to the Family Carers case that would be confirmed following a further report back on issues and risks associated with the preferred approach and on the broader risks raised by the Family Carers case (SOC Min (12) 28/2 refers);

2 [redacted]
Redacted under s(9)(2)(h) of the Official Information Act 1982

3 **confirm** that a fundamental tenet of Government funded social support is that, in general terms, families have primary responsibility for the wellbeing of their members;

4 **note** that implementing a cross-government policy of paying family carers in response to the Family Carers case would contradict the fundamental tenet set out in recommendation 3 above and would result in risks for disabled people and family carers and considerable fiscal costs;

LEGISLATION

5 **agree** that the Government legislate to reduce the significant risks and uncertainties arising from the Family Carers case while still allowing the Government to implement policies of paying family carers if it wishes to do so;

6 **agree** that the proposed legislation reflect the following principles:

6.1 that the Crown or a District Health Board may adopt a policy under which providers of health or disability support services are not paid, or only paid in specified circumstances, or paid at reduced rates because they are a family member of the person receiving the services; and

6.2 that such a policy of the Crown or a District Health Board will not be unlawful whether or not it would otherwise amount to discrimination under the Human Rights Act 1993 or the New Zealand Bill of Rights Act 1990;

7 **agree** that the proposed legislation place the following limits on claims:

7.1 not allowing further claims to be made against any existing or any new policy relating to the payment of family carers;

7.2 allowing complaints that have already been lodged with the Human Rights Commission or claims that have already been lodged with the Tribunal to proceed, but that the only remedy available is a declaration of inconsistency;

8 **agree** that the legislation include a savings provision allowing the nine plaintiffs in the Atkinson and Others v Ministry of Health to have their claims resolved by the Courts if necessary if they cannot reach a settlement with the Crown;

9 **agree** that the limitations on claims that are outlined in recommendation 7 above apply from the date that the Government policy is announced;

10 **agree** that the proposed legislation be introduced through a Bill amending the New Zealand Public Health and Disability Act 2000;

PREFERRED RESPONSE

11 **note** that the preferred response to the Family Carers case agreed to by Cabinet Social Policy Committee involved the Ministry of Health allocating funds to disabled adults to allow them to employ their parents or resident family members (other than spouses) to provide them with Home and Community Support Services that are over and above the support family carers are able to provide unpaid (SOC Min (12) 28/2 refers);

12 **note** that the preferred response allowed for the payment of family carers in 'exceptional circumstances' where family carers fall outside the proposed targeting criteria but where there is a very good case for paying them (SOC Min (12) 28/2 refers);

13 **agree** that the provision for payment in exceptional circumstances set out in SOC Min (12) 28/2 be achieved by detailed policy allowing flexibility to consider particular circumstances where payment is clearly desirable;

14 **agree** that the preferred response for Ministry of Health funded Home and Community Support Services (SOC Min (12) 28/2 refers) be implemented from 1 October 2013;

BROADER ISSUES

15 **note** that there may be considerable interest in the response to the broader issues for Vote Health raised by the Family Carers case which are set out in recommendations 2.1 and 2.2 above;

16 **EITHER:**

16.1 **agree** that no further work will be carried out on the broader issues raised by the family carers case;

OR:

16.2 **invite** the Minister of Health to give further consideration to the broader issues raised by the family carers case;

17 **note** that the Ministry of Health will consider, as part of its regular review of services, whether its current policy of not allowing family carers to be paid to deliver support other than HCSS continues to be necessary;

FISCAL IMPLICATIONS

18 **note** that the mid-point estimate of the fiscal cost of the preferred option (recommendations 11 to 14 above) is $23 million (net) a year;

19 **note** that the mid-point estimate of the fiscal cost will increase, potentially by up to an additional $152 million (net) a year, if:

19.1 the legislation referred to in recommendation 5 above is not passed; and/or

19.2 decisions are made to pay further groups of family carers; and/or

19.3 funding allocations are higher than the approximately $16 an hour rate on which the preferred option is based;

20 **note** that, if Cabinet agrees to recommendations 16.2 above, this would significantly increase the likelihood that the potential fiscal costs will increase above $23 million (net) a year;

NEXT STEPS

21 **invite** the Minister of Health to announce the Government's policy on paying family carers on Budget day 2013;

22 **note** that a bid for a New Zealand Public Health and Disability Act Amendment Bill has been prepared for the 2013 Legislation Programme with a priority two classification;

23 **agree** that the legislation referred to in recommendation 5 above be introduced and passed as part of the Budget 2013 legislation package; and

24 **invite** the Minister of Health to issue drafting instructions to the Parliamentary Counsel Office for the legislation referred to in recommendation 5 above.

Hon Tony Ryall
Minister of Health

___/___/_____

Ministry of Health Aide Memoire

From: Kylie Clode, Group Manager, Policy Business Unit

To: Hon Tony Ryall, Minister of Health

Date: **26 March 2013**

Family Carers SOC Paper 27 March 2013

Purpose

1 This aide memoire provides you with information that you can use during the discussion at Cabinet Social Policy Committee (SOC) on 27 March 2013 on the paper entitled "Family Carers Case: Implementation of Proposed Response and Consideration of Broader Issues".

Previous consideration

2 SOC has previously agreed to a preferred response to the family carers case. The preferred response involves allowing adult disabled people to employ their parents, or other adult family members (other than spouses) who reside with them, to provide them with Home and Community Support Services funded through the Ministry of Health. There were, however, limits that would apply:

a disabled people would be allocated $16 an hour to pay family carers, which is less than the $25 an hour that is paid to contracted providers;

b payment would be made in situations of very high (e.g. a family is at risk of breakdown) or high need (e.g. the support needs are such that a family carer is unable to work in paid employment); and

c family carers could be paid for up to 40 hours per week.

3 The mid-point estimated cost of this response is $23 million (net) a year, or almost $100 million over four years.

4 Cabinet, however, sought further advice on the fiscal and legal risks of implementing the preferred response before making a final decision on the way forward. These risks were the following:

a Further claims from other groups not covered by the agreed approach. These groups include spouses, parents of disabled children, and people with dependent parents or family members with disabling chronic health conditions. We are aware, for example, that there is at least one existing claim from a spouse who is seeking to be paid.

b The difference between the $16 per hour allocated to family carers under the preferred approach and the $25 per hour paid to contracted providers. There is a risk that the difference may be seen as discriminatory.

Assessment of risk

5 *Redacted under s(9)(2)(h) of the Official Information Act 1982*

Managing risk through legislation

6 Legislation is central to managing these risks in a cost-effective and legally defensible way. The paper proposes amending the New Zealand Public Health and Disability Act to make it clear that the Crown and DHBs may operate any policies:

a That prohibit payment to family members for provision of health and disability services to their disabled relatives; and/or

b Allow some family members to be paid at a reduced rate for the provision of health and disability services to their disabled relatives.

7 This approach means that any policy of paying family carers would be lawful, whether or not it would otherwise amount to discrimination under the Human Rights Act 1993 or New Zealand Bill of Rights Act 1990. It is intended that the legislation would be introduced and passed along with other Budget night legislation.

8 The legislation would also spell out how any existing or potential claims that any policy does amount to unlawful discrimination under the Human Rights Act or the Bill of Rights Act would be addressed. The recommended approach is the following:

a The plaintiffs will be entitled to continue their claim for remedies.

b New claims against any existing or new policy concerning payment to family caregivers will be prohibited.

c In respect of any other claims (other than the plaintiffs' claims) made before enactment of the amendment, the only remedy available will be a declaration that the policy is inconsistent with the New Zealand Bill of Rights Act.

Responding to broader issues

9 While the legislation will help manage the legal risks associated with any policy of paying family carers, there will be considerable interest in the messages that the Government sends about whether, and how, it intends to respond to the broader issues raised by the Family Carers case. That is because frequent comments were made about those issues during the public consultation process, especially given the commitment made in the public consultation document to undertake further work on the broader issues raised by the case.

10 Consideration needs to be given to whether:

a the door should be firmly shut on extending the new policy to other groups such as spouses, parents of disabled children, and people caring for their elderly parents; or

b the door should be left open by indicating that the Minister of Health will give further consideration to these other groups.

11 Indicating that further work on these issues will be carried out at a time when the Government has sufficient funding to pay for any policy response will give other family carers (and the people with health conditions or disabilities that they support) some confidence that they may be paid in the future. This approach would allow the Government to present the proposed legislation in a positive light.

12 [redacted]

Redacted under s(9)(2)(f)(iv) of the Official Information Act 1982

($90 million if Veterans' Affairs is included).

MINISTRY OF HEALTH
MANATŪ HAUORA

Health Report number: 20130709

Action required by: **routine**

File number: HC45-76

Health report

Hon Tony Ryall (Minister of Health)

Preliminary estimates of extending the Paid Family Carers policy to people with chronic health conditions

Advice

1. On 2 April 2013, in confirming its response to the Court of Appeal ruling in *Atkinson and Others vs Ministry of Health* (the Family Carers case), Cabinet agreed that no further work would be carried out on the broader issues raised by the Family Carers case except to explore issues for people with chronic health conditions who are funded by district health boards (DHBs) [CAB Min (13) 10/14 refers]. You subsequently asked for preliminary estimates on the number of people receiving services for chronic health conditions who might be eligible for paid family care in line with the new policy and the potential cost.

Background

2. This briefing provides you with information on:
   a. the characteristics of the client group receiving DHB - funded support services through the Long Term Support – Chronic Health Conditions (LTS-CHC) funding stream
   b. estimated numbers of people likely to meet eligibility criteria for paid family care
   c. the estimated cost of applying the new policy to the LTS-CHC client group.

Characteristics of the LTS-CHC client group

3. The most common diagnostic groups receiving support through DHBs' LTS-CHC funding are people with: brain and nervous system disorders (e.g. severe epilepsy and stroke); nutrition and metabolic disorders (e.g. diabetes and morbid obesity); dementia (e.g. Korsakoff's syndrome and fronto-temporal dementia); respiratory disorders (e.g. chronic obstructive respiratory disorder and cystic fibrosis); and, cancer (e.g. brain tumours and other metastatic cancers). Further information on this client group is included in Appendix One.

Number of eligible clients and cost implications of applying the new policy to this group

4. The estimates of the number of people likely to meet eligibility criteria for paid family care and costs is based on data supplied by the Northern Regional Alliance (formerly the Northern DHB Support Agency) on people receiving chronic health supports in the four DHBs in the Northern Region. There has been insufficient time to collect accurate data from all DHBs and it was therefore decided to base the estimates on a regional sample. The Northern Region was selected as it has the largest population and the most comprehensive data on people receiving chronic health supports.

5. The data provided by the Northern Regional Alliance numbers of people and average hours of personal care and household management for specified chronic health conditions groups were extrapolated for the total New Zealand population. The data was then run through the costing model developed for the family carer policy to estimate the costs of paying family carers (other than spouses) of adults with chronic health conditions with high and very high needs.

6. The number of LTS-CHC funded clients likely to meet eligibility criteria for paid family care, under the new policy, is estimated to be 200 people nationwide.

7. The cost to Vote Health of extending the new policy to family carers providing Home and Community Support Services to adults eligible for LTS-CHC funded support is estimated to be $2 million (assuming that there is no amount for benefit savings transferred into the Vote). This estimate is based on:
   - only paying for care provided to people allocated 15 or more hours of personal care a week
   - including hours of both personal care and household management allocated to those people
   - a rate of payment of approximately $16 an hour (based on the minimum wage plus employment costs such as annual leave, sick leave and ACC levies)
   - excluding spouses from payment
   - capping hours per week at 40 for the care of any one person.

Further work to explore issues for people with chronic health conditions

8. The Ministry of Health will work with DHBs to explore issues related to family care for people receiving LTS-CHC funded support. This work will include comprehensive data collection from each DHB on the number of people receiving LTS-CHC funded services and the hours of Home and Community Support Services they currently receive, as well as informal care they may receive from family members. Issues associated with the payment of family carers for this group will be identified along with implications for DHBs of extending the new policy to this group.
9. It is proposed that this work take place over the second half of 2013 and a report provided to you on the findings and recommendations in early 2014.

The Ministry recommends that you:

a) **Note** that, if the new family carer policy were extended to people receiving DHB-funded services for chronic health conditions, an estimated 200 people nation-wide could be eligible for paid family care at an estimated cost to Vote Health of $2 million per annum

b) **Agree** to the Ministry of Health working with the DHBs to explore issues related to family carers of people with chronic health conditions who are funded by DHBs — Yes / No

Don Gray
Deputy Director-General
Policy Business Unit

Ryan
Minister's signature

Date 1 6 13

Ministry of Health contacts

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Minister's feedback on quality of report

Very poor (1)	Poor (2)	Neutral (3)	Good (4)	Very good (5)

ENDS

Appendix One

The LTS-CHC client group includes people who access long-term support services before the age of 65 due to a wide range of disabling chronic health conditions. Their supports are funded by DHBs rather than the Ministry of Health because the impairments arising from their conditions do not generally fit the operational definition of physical, sensory or intellectual disability used to determine eligibility for Ministry DSS. For example, the primary impairments arising from their conditions may be extreme fatigue, shortness of breath, pain or significant cognitive impairment, which affects their capacity to carry out basic daily living activities.

In addition, a significant number of people receiving LTS-CHC funded supports have a combination of complex health and support needs requiring the integrated health and support services that DHBs provide. People receiving supports through this funding stream continue to do so until their situation changes to the extent that their needs are more appropriately met through another funding stream (e.g. DHBs' palliative or older people's funding) or they no longer require support.

In order to access LTS-CHC funded support, a person must be assessed as meeting all of the following criteria:

a. aged under 65
b. not eligible for Ministry Disability Support Services (DSS) or other DHB-funded long-term support services (such as support services for older people)
c. have one or more chronic health condition(s) that is/are expected to continue for six months or more
d. have very high need for long-term support services1
e. not have an informal support system (family, whānau) or the carer is under considerable pressure and their ability to support the person is compromised.

Though all LTS-CHC clients have high to very high support needs (depending on the access threshold at the time they first received services), the type of impairments and support needs they have are diverse and the stability of their underlying health conditions vary. Some have similar characteristics to the Ministry DSS client group (relatively stable on-going needs requiring a similar service response). Others have medically unstable conditions and fluctuating support needs.

[1] Very high need is defined as requiring assistance with activities of daily living at least daily to remain safely in their own home or needing residential care. This is a minimum access threshold. DHBs may lower this threshold in response to service demand, as funding allows.