



Carer Support Subsidy Review and Recommendations

“The broad policy issue is simply whether the Government believes that there are social, ethical and economic benefits in providing support for family carers which recognises their contribution and helps to make their caring role sustainable, or that family carers are doing no more than fulfilling their individual family duties when they provide unpaid care and that the Government has no interest in supporting them. The Carers’ Strategy actually sets the broad policy framework for recognising and supporting the contribution of family carers, and the steps necessary to resolve the problems with the Carer Support Subsidy would be relatively simple if the Government was committed to supporting and affirming family carers.”

Executive Summary

1. Family carers make a vital and substantial contribution to the care of New Zealanders of all ages who are ill, disabled or elderly. The systems in place to support unpaid carers and to make their role more sustainable include the Carer Support Subsidy and other carer support and respite care options. There are flaws and deficiencies in how these systems are operating in practice.
2. In particular, there are problems with the Carer Support Subsidy, which is designed to only provide a partial contribution towards the cost of arranging support care while the full-time carer takes a break. The Carer Support Subsidy usually requires top up payments from carers and those they support to meet the full cost of relief care, despite the fact that they often do not have the financial resources to do this.
3. The Guidelines under which the Carer Support Subsidy is allocated are inconsistent, discriminatory and lack transparency. The Carer Support Subsidy system is split between the Disability Support Services Group of the Ministry of Health, GPs and District Health Boards (DHBs), and there are arbitrary and inconsistent differences. The DHB and Ministry of Health contracted Needs Assessment and Coordination Service providers are often (but not always) responsible for making Carer Support Subsidy allocation decisions, as well as decisions about other carer support options. There is little transparency in how these decisions are made, and there is a high degree of discretion and discrepancy in the process.

4. The public consultation conducted for the Carers' Strategy during 2008 identified a wide range of issues and concerns with the Carer Support Subsidy and carer support generally, and the Ministry of Health has been tasked with taking action on these issues under the Carers' Strategy. The issues predate the term of the current government.
5. One of the issues is that the Carer Support Subsidy Guidelines used by the Disability Support Services Group include restrictions about who is eligible to be a support carer which upon analysis appear to be unjustifiable, as well as being a *prima facie* breach of the Human Rights Act and the New Zealand Bill of Rights Act. The Crown argued its case on the Carer Support Subsidy Guidelines before the Human Rights Review Tribunal in September 2008; the Tribunal has yet to release its decision. Action on the Carer Support Subsidy issues has been stalled pending the Tribunal decision.
6. The Crown's argument that it is justifiable to discriminate against family carers by restricting their eligibility for the Carer Support Subsidy is inconsistent with the principles, policies and actions accepted by the Government in its Carers' Strategy and many of the objectives of the Government's Disability Strategy. It is also inconsistent with the comments made in favour of carer support and respite care in the Social Services Select Committee report on the Inquiry into the Quality of Care and Services Provided to People with Disabilities (September 2008).
7. The solutions are not difficult, but they will require good faith and leadership to implement.

Recommendations

8. We recommend that the Minister,
 - (a) Directs the Ministry of Health and DHBs to develop a standardised and transparent set of guidelines and procedures for the Carer Support Subsidy which will apply across all categories of unpaid carers.
 - (b) Agree that the new guidelines and procedures should be based on the work already done by the Northern DHB Support Agency.
 - (c) Agree that the new guidelines should not include any restrictions on access to the Carer Support Subsidy by spouses, partners, parents and other family members which breach the Human Rights Act.
 - (d) Agree that the new guidelines should not include any restrictions on what carers may do with their time when subsidised support care is being provided, including either working or staying with the person being cared for.
 - (e) Agree that the Crown should not continue to attempt to justify *prima facie* discrimination under the Human Rights Act in the Carer Support Subsidy

Guidelines of the Disability Support Services Group of the Ministry of Health, including not appealing any decision that the Human Rights Review Tribunal might issue in relation to those guidelines.

- (f) Directs the Ministry of Health to carry out its commitments under the Carers' Strategy Action Plan, including reviewing the Carer Support Subsidy system in the context of other carer supports and respite care options, and recognising the contribution of unpaid carers, and the social and economic benefit of making the role of unpaid carers more sustainable by removing barriers and providing for them to be able to take a break.
- (g) Directs the Ministry of Health to review whether it is principled or appropriate for the Carer Support Subsidy to only be a partial contribution towards the actual costs of formal or informal support care, and for the system to be designed to require family carers to fund top up payments themselves.
- (h) Directs the Ministry of Health to review calls by the NZ Carers Alliance during the Carers' Strategy consultation process for the Government to consider a two tier payment system for the Carer Support Subsidy, with a lesser daily rate paid for 'ordinary' support needs, and a higher rate allocated for those supporting someone with high or complex needs, both at rates that reflect the actual cost of care for the level of need.
- (i) Agree to take a paper to Cabinet on the issues concerning the Carer Support Subsidy and carer support and respite options generally, so Cabinet has the opportunity to endorse the approach and action plans referred to in the Carers' Strategy, and to set a clear policy direction for the Ministry of Health and DHBs in relation to carer support issues.
- (j) That this paper be developed in partnership or with strong input from the Carers Alliance, as the Government's ongoing governance partner for the Carers' Strategy, and that DHBs also be closely involved in its development.

Carers' Alliance – Review of Carer Support Subsidy

Introduction

9. Approximately 420,000 people aged 15 and over indicated in the 2006 New Zealand Census that they had provided unpaid care to someone with ill-health or disability in the previous four weeks.¹ The proportion of people reporting unpaid caring work in the previous four weeks was:
- 7.8% (6.3% of men, 9.1% of women) caring for an ill or disabled household member
 - 9.1% (6.5% of men, 11.5% of women) caring for an ill or disabled adult not living in their household
 - 16.2% (11.4% of men, 20.6% of women) caring for a child not living in their household
10. Providing unpaid care to family members and friends is a difficult, stressful and under-recognised task. Recent research by the University of Auckland has shown that two-thirds of unpaid carers suffer from depression, and 85% find their role stressful. The stresses they report include lack of sleep, gross financial worries, no appropriate respite, lack of friends or people to talk to about common interests, lack of time, too many responsibilities, lack of information to help them cope, no ability to return to the workforce, and no change within the foreseeable future.²
11. The Carers Alliance instigated the New Zealand Carers' Strategy for the Government to address the difficulties faced by informal and unpaid family carers.³ The Carers' Strategy was developed by government agencies in consultation with carers, and endorsed by the Cabinet of the Labour-led government in April 2008. The Carers' Strategy outlined the Government's vision for carers in New Zealand, and it has also been adopted by the new National government. Government departments and agencies are working towards implementing their responsibilities under the five-year Action Plan in the Carers' Strategy. Enabling carers to take a break is the priority objective the Ministry of Health is responsible for in the Carers' Strategy.

¹ Census Data from Statistics New Zealand, cited in the National Advisory Committee on the Employment of Women report "Financial support for family carers" (March 2008) www.nacew.govt.nz/publications/workandcare

² Diane Jorgensen, Matthew Parsons, Stephen Jacobs "The experiences of informal caregivers in New Zealand" (January 2009) page 21

³ The New Zealand Carers Alliance is a network of 45 national NGOs in the health and disability sector

12. Carers currently rely on the Carer Support Subsidy and other carer support and respite care options to take a break from their caring responsibilities. There is anecdotal evidence and formal research which indicates that these systems are not always delivering fair, consistent, transparent or desirable outcomes for the carers they are designed to support. The Action Plan for the Ministry of Health specified in the Carers' Strategy in relation to carers taking a break includes,
- investigating what changes can be made to the Carer Support Subsidy for respite care to improve its fairness for carers regardless of their financial circumstances
 - enhancements to the Carer Support Subsidy that can be adopted by individual funders within current financial parameters
 - identifying additional ways of improving respite care provision as part of a 2008 review of respite care options currently funded through Vote Health
13. The 2008 review of respite care options has not yet been completed by the Ministry of Health, and the purpose of this paper prepared on behalf of the NZ Carers Alliance is to advance the proposed Action Plan, specifically in relation to the Carer Support Subsidy.

Carer Support Subsidy

14. The Carer Support Subsidy is available to help pay for support for unpaid carers who provide full-time care in the homes of people with disabilities and illnesses, and of older people. Usually, unpaid full-time carers and those they support live together. The Carer Support Subsidy is intended to help pay for relief support so full-time carers can have breaks from their role from time to time. The objective of the Carer Support Subsidy is to make the full-time carers' role sustainable, so the people being supported can continue to live in the community rather than in a hospital or other institution.
15. There are clear social and economic benefits in having disabled, ill and elderly people living in the community rather than in institutions. There are also strong cultural values which encourage families, whanau and aiga to care for their own. This is arguably a widely held cultural value among New Zealanders; this is particularly so among Maori, Pacific Island, and ethnic immigrant communities.
16. The Carer Support Subsidy is generally described as being a contribution towards the cost of providing support care for a number of days during each year, while the primary full-time carer has a break. The support care may be provided informally by family, friends or neighbours in the home of the person being cared for, or formally through a commercial in-home care provider or a residential facility providing respite care.
17. The Carer Support Subsidy is provided through the Ministry of Health, but the route through which the funding is administered varies according to the age or needs of the person being supported. The Carer Support Subsidy for the full-time carers of people under 65 years old who have a disability is paid through the

Disability Support Services Group (DSS) of the Ministry of Health. The Carer Support Subsidy for the full-time carers of older people and people with personal or mental health needs is funded through District Health Boards (DHBs). Personal health needs include chronic conditions such as cardiac or respiratory diseases, diabetes, and cancer, or terminal illnesses. Children with Attention Deficit Disorders are also categorised as having personal health needs, so the Carer Support Subsidy for them is paid through DHBs rather than DSS.

18. There are common features and differences in how DSS and the DHBs administer the Carer Support Subsidy. The common features reflect the common overall design of the Carer Support Subsidy system, and some of the common features are in fact problems. The common features create the false impression that there is one Carer Support Subsidy system, when there are significant differences in the systems operated by DSS and the DHBs. Some of the significant differences are actually partial improvements, but they are not always well understood, and they contribute to the confusion among carers and the wider community about the Carer Support Subsidy.
19. The common features between the systems operated by DSS and the DHBs include,
 - The idea that the Carer Support Subsidy is only a *contribution* towards the cost of arranging alternative care for a disabled or ill person with an unpaid full-time carer. The Carer Support Subsidy is not designed as a subsidy for the full cost of the support care, so a top-up payment is required if the subsidy is going to actually achieve its objective of enabling full-time carers to take a break. The fact that the Carer Support Subsidy is only intended to be a partial subsidy obviously limits the overall cost of the subsidy to the Government, but it also limits its utility.
 - The Carer Support Subsidy system involves an allocation process, where an allocation of available days of support care is made in advance of the support care being arranged. Generally (although not universally), the assessment of Carer Support Subsidy allocations is carried out by a Needs Assessment Coordination Service (NASC) organisation contracted by DSS or the relevant DHB. The needs of carers are assessed in conjunction with the needs of the people being cared for. There is no entitlement to be allocated Carer Support Subsidy payments for a set number of days, and the allocations actually made depend on the discretion of the NASCs. The NASCs use various criteria and scoring systems to make the allocations, but these are neither transparent nor consistent across the NASCs or different carer groups.
 - The Carer Support Subsidy may be provided as a standalone support for carers, or it may be provided as part of a suite of other support, respite care or home-based support services which may be available. Other carer support services may be available to bridge the top-up gap caused by the Carer Support Subsidy not meeting the full cost of support care, especially in high needs cases.

- The NASCs contracted by DSS and the DHBs are responsible for putting together different packages of carer support, respite and home-based support which include Carer Support Subsidy payments as one element of the package. The NASCs all know about how different carer support packages can be put together, but how the NASCs apply that knowledge when they make discretionary decisions on the allocation of Carer Support Subsidy days and other carer support elements is not transparent. NASCs seem to be influenced by the effectiveness of the advocacy by or on behalf of carers, which may not always lead to fair results.
- The allocation of the Carer Support Subsidy for individual full-time carers is approved for a number of days of support care over a year, and it is for the carer and the person being supported to coordinate how and when the approved allocation should be used. For example, the full-time carer and the person being supported may elect to obtain relief care from an informal carer (i.e. friends, family, neighbours), or from a formal carer (i.e. a commercial in-home or residential care provider). Support care may be arranged on a part-day or full-day basis, or it may be arranged in blocks. Providing the choices for the support care to the carers and those they care for has the advantage of providing them with a high degree of autonomy, although in practice the options available are limited because there is a shortage of experienced in-home carers and respite care facilities. The autonomy also means it is for the full-time carer and the person being supported to find and organise relief care when there is a shortage of support carers, and they are also likely to be required to make top-up payments to meet the full cost of relief care.
- The Carer Support Subsidy is not available for convalescent care, for people covered by ACC, or for people who live in full-time residential care.
- The daily rates for the Carer Support Subsidy are consistent between DSS and the DHBs. The subsidy rate for informal support carers is \$76.00 per day (excluding GST), and the rate for formal support care is \$85.50 per day (including GST) for a 24 hour period. These rates were set in 2007. The difference in GST treatment is because formal carers will be in the business of providing care, and will be registered for GST and required to collect GST on the value of their services. Informal carers will not be in the business of providing care, so they are not required to collect GST on the value of their services.
- There is a significant gap between the actual cost of 24 hour formal or informal support care and the amount of the Carer Support Subsidy (despite the subsidy amounts having been increased in 2007). The gap must be met by top-up payments, and this can be a barrier for full-time carers accessing support care. Sometimes the top-up can effectively be met by other carer support elements put together by the NASCs. If the full-time carers are left to meet the gap, this creates an incentive for full-time carers to claim for more days than they actually use. The amount of

support care is therefore reduced to the point where the subsidy meets the actual costs of the support care. This is of course a breach of the rules under which the Carer Support Subsidy is provided.

- HealthPac (which has been rebranded as Sector Support) is an operational unit within the Ministry of Health, and it receives details of all the approved Carer Support Subsidy allocations and the claims as they are made, and makes the payments on behalf of DSS and the DHBs to full-time carers or the relief carers they engage. Part of Sector Support's function is to ensure that Carer Support Subsidy claims are properly eligible to be paid.
- The Carer Support Subsidy received by relief carers is taxable income in their hands, whether they are formal or informal support carers.
- Putting the responsibility for arranging support care on the full-time carers means they are blamed for delays by Sector Services in processing Carer Support Subsidy claims, and payments can take many weeks to process after claims are submitted to Sector Services. These delays make it harder for full-time carers to find people who are prepared to provide relief care, and can create unhelpful tensions with providers of relief care.

20. Although there are common features between the DSS and DHB systems for allocating and paying the Carer Support Subsidy, there are also significant differences. The differences include,

- DSS has Guidelines which its NASCs use to determine Carer Support Subsidy allocations in cases where the subsidy is paid by DSS. The current version of the DSS Carer Support Guidelines is dated April 2005. The DSS Guidelines are not available on the internet, other than in summary form. The DSS Guidelines are under review as part of a comprehensive review of carer support policy being conducted by the Ministry of Health.
- It is very difficult to tell when DHBs might use the DSS Guidelines, or whether they might use their own different guidelines. When DHBs do have different guidelines, they are difficult to track down and the guidelines do not seem to apply comprehensively to all DHB Carer Support Subsidy claims. For example, the Northern Region Carer Support Subsidy Review identified that Carer Support Subsidy guidelines were produced for the Regional Health Authority in 1994 and adopted by the Health Funding Authority in 1996.⁴ These guidelines were further adopted in 2000 as draft guidelines for the NASCs engaged by the northern region DHBs to allocate Carer Support Subsidies for older people, but no guidelines seem to be in place which are specific to people

⁴ Manjula Sickler "Northern Region Carer Support Subsidy Review" Northern DHB Support Agency (October 2006) page 15

with mental health or personal health needs. This contributes to the impression that Carer Support Subsidy allocation decisions can be arbitrary and inconsistent.

- DSS and DHBs rely on NASCs to allocate the Carer Support Subsidy days paid for by DSS for people under 65 with disabilities, and for the subsidised carer support days for older people paid for by the DHBs, but different arrangements apply for carer support for people with mental health and personal health needs. GPs, hospital-based social workers, hospital and community-based mental health workers and paediatricians assess the allocations of Carer Support days for people with mental health and personal health needs, without reference to a NASC. There is also a reported practice of GPs authorising allocations of DHB-funded Carer Support Subsidies for older people, even though they are supposed to be subject to a NASC assessment.⁵
- The number of subsidised days of support care available varies according to the category of the claims. The maximum normal allocation from the DHBs is 28 days per annum, and any extra allocation requires special approval on a discretionary basis. The allocations funded by the DHBs tend to run to the full 28 days. The DSS Carer Support Subsidy Guidelines say the *average* Carer Support Subsidy allocation by the relevant NASC must be no more than 25 days (which is obviously less than 28 days). The maximum allocation is 50 days, with any greater allocation requiring approval from a DSS manager. Although the DSS system for subsidy allocations seems to be more flexible than the DHB system, the averaging mechanism means every day allocated above 25 days per annum must be taken from another person who is therefore allocated less than 25 days. So for some people in high needs cases the DSS scheme is potentially more generous than the DHB scheme, but for others with 'average' needs or less, the DSS scheme is less generous because it is more difficult for them to achieve a full allocation. These differences are arbitrary, and do not necessarily reflect the needs of the carers being supported.
- There are other key differences between the DSS Carer Support Guidelines and the guidelines used by the NASCs appointed by DHBs to allocate Carer Support Subsidies to older people. One of the critical differences is that under the DSS Guidelines, spouses, partners and parents cannot be paid to provide relief support for their disabled family member, even if they do not live at the same address. People who live in the same house as a disabled person are also ineligible to receive the Carer Support Subsidy from DSS for support they might provide. Often young adult siblings are the most appropriate and trusted support carers, especially for those with complex support needs, yet they are ineligible for the Carer Support Subsidy under the DSS Guidelines if they live at home. There is an assumption that spouses, partners, parents and other people

⁵ *Ibid* page 21

living together (including siblings) will already be, or otherwise should be, carers, and that they should not be subsidised for fulfilling that role. These exclusions are not referred to in the DHB guidelines, which are therefore more flexible in who is eligible to be a subsidised support carer.

- Another difference is that the DSS Guidelines explicitly say that full-time carers are not eligible for the Carer Support Subsidy if they are in paid employment while the support care is being provided. The rationale is that the full-time carers must take a break while the subsidy is being paid. Full-time carers cannot be in full-time employment because of their carer responsibilities, but some carers consider time spent in paid employment *is* a break from their primary carer responsibilities. This also ignores the fact that full-time carers are likely to need to top up the Carer Support Subsidy because it is not intended to be sufficient to cover the full cost of support care. The guidelines used by the NASCs appointed by DHBs to allocate Carer Support Subsidies are silent on whether or not the full-time carer can undertake paid employment in these circumstances.
- The DSS Guidelines also preclude full-time carers and those they support from taking a break together, with additional support from a relief carer. Often family members prefer to stay together, with the relief care still providing a "break" for the full-time carer. The DSS Guidelines take this option way from families, while the Carer Support Subsidy guidelines used by the NASCs appointed by DHBs leave this decision up to the families concerned.

21. The overall picture is that the Carer Support Subsidy seems to be unduly complicated. The combination of centralised (DSS) and devolved (DHB) funding for the subsidy payments has added complexity, even though the actual payments are administered centrally by the Ministry of Health through Sector Support . Sector Support also checks Carer Support Subsidy claims against different guidelines, according to the category of people being cared for. The devolution to the DHBs has added some flexibility, and DHBs seem to have moved beyond some of the restrictions on eligibility for the Carer Support Subsidy in the DSS Guidelines. However that flexibility and the potential for DHBs to make *ad hoc* improvements through changes to the various guidelines have also added to the complexity and uncertainty of the system.
22. The NASCs appear to be a unifying feature between the DSS and DHB systems, but the NASCs themselves are affected by the differences and inconsistencies between the different guidelines for each category of person they deal with. Those categories are all based on the needs of the person being cared for, and only bear indirect relation to the needs of the carers.
23. Another complicating feature which is not immediately obvious is that the Carer Support Subsidy itself is only one element of carer support. The fact that it is designed to be a "subsidy" which is insufficient to meet the full cost of support care creates a situation where the unmet costs somehow need to be met. Often carers do not have the money to meet the top up payments themselves, especially if they are not permitted to work during the days when the support care is being provided. The NASCs have the discretion to package together other

publicly funded carer supports or respite options to meet the shortfall, but otherwise the costs fall on the person being cared for, or on the full-time or support carers whose costs are unable to be fully met.

24. There is an obvious incentive for carers to claim the full allocation while using less days than are allocated if they cannot afford the required top up. Short-funding the Carer Support Subsidy is clearly a deliberate and inherent feature of the design of the system, which is one of the reasons why addressing this issue has been identified as a priority action point in the Carers' Strategy.

Information from Carers

25. There has been recent research into the experiences of unpaid carers, and there is a consistent theme of dissatisfaction with the Carer Support Subsidy and the other supports carers rely on to take a break. The Carers Alliance and the Ministry of Social Development organised the public consultation which formed part of the process for developing the New Zealand Carers' Strategy. Enabling carers to have a break to protect their health and well-being was one of the key priorities which was identified in the consultation. The consultation included 200 written submissions, including 79 from carers and 42 from health and disability NGOs, and a series of public meetings attended by a total of 1000 people.
26. The feedback from the Carers' Strategy consultation which was specific to carers being able to take time out was summarised by the Ministry of Social Development as follows,

“Time out from caring

- 26 The current relief care system is seen as confusing with many access barriers. Issues ranged from the application process, to the family having to source and train their own relief carers, to inefficiencies and inequities in the system. Some respondents raised the issues of inequities across regions and rural areas and between ACC and the health and disability system. The main barriers to taking time out from caring that were identified in submissions are listed below.

Information

- 27 Carers wanted more information on what options were available, how to access them, and the costs. Some people had been caring for many years (e.g. in one instance for 45 years) with little knowledge about options for a break.

Assessment

- 28 A number of people stated that the assessment for relief care should consider the whole family, whether the carer is supporting more than one person, the level of need of the person being supported, and the natural resources of the carer (e.g. the carer's health). People also raised issues with the timeliness of assessment and delays in accessing relief care after an assessment.
- 29 Many people commented on the number of forms carers were required to complete to access services either for themselves or for the person they

supported. The annual assessment process for Work and Income clients with permanent disabilities was mentioned several times as being bureaucratic.

Access

- 30 A number of people commented that it was difficult to find formal care workers and respite when "carer support or respite days" were allocated to them. This included options for care in the daytime, at night time, for short periods and for 24-hour periods, and the availability or existence of respite facilities or beds. This seemed to be a particular concern for those in the working-age bracket. In some areas of the country a core concern for those in the youth-age bracket was the cessation of eligibility for some respite options (i.e. respite-specific houses with skilled staff) at age 17. In other locations there were fewer options for those under age 17.

Emergency Planning and Back Up

- 31 The access issues mentioned above also impact on supporting carers through emergency situations. Issues reported including lack of support to develop emergency plans, lack of funding to enact emergency plans, the need for a proactive approach to help prevent emergencies, and the amount of help available immediately after a crisis.

Quality

- 32 The quality of caring options for a break was a significant concern for respondents. The most frequently mentioned issues were reliability (e.g. paid carers not turning up), age-appropriateness and workforce skills. Some carers either felt disempowered to challenge service providers if they felt contract specifications were not being met, or were unsure what standard of service should be delivered.

Flexibility and Policy Restrictions

- 33 Respondents' feedback focused on two policy restrictions on how they are able to use their respite or relief options:
- the inability to pay family members to undertake respite care
 - the activities the carer can undertake while the relief care is in place (e.g. employment, convalescent care, healthcare, use of respite for childcare for wider family as well as the disabled person, and the carers still being with the person they support while the relief is in place, such as on holiday).

"Respite care should be reconceptualised ... to allow whanau carers to take relief for undertake education, employment and other pursuits." *Maori Development Research Centre*

Financial

- 34 The most common financial barriers raised were the need to "top up" carer support payments and the cost of travel to relief options."⁶

27. Many of those concerns are a direct reflection on how the Carer Support Subsidy has been set up and administered. It is confusing and seems bureaucratic. There are inequities and unnecessary barriers. It is difficult to access information

⁶ Ministry of Social Development "Summary of the New Zealand Carers' Strategy Consultation Findings" (www.msd.govt.nz/documents/about-msd-and-our-work) page 6

- about the Carer Support Subsidy. Much of the information which is available focuses on who is eligible or ineligible for the Carer Support Subsidy, and the information about how the allocation decisions are made is incomplete because those decisions are highly discretionary. Even when the Carer Support Subsidy has been allocated, it is difficult to access the support. The availability of the Carer Support Subsidy for support care provided by family members, and the limitation on full-time carers being able to work while the support care is provided, or to spend time with the person being cared for, were identified as major issues. The inherent reliance on top up payments is a fundamental weakness in the Carer Support Subsidy system.
28. The ineligibility of family members to receive the Carer Support Subsidy when they provide support care is particularly controversial. The restrictions on family members who live together being eligible for the Carer Support Subsidy unfairly and unjustifiably penalises people who live in extended family or whanau situations. There are also examples where the parents of adult and even middle-aged "children" have been denied the Carer Support Subsidy when they provide support care because they are "parents", even if they live in a different city from the person being supported.
 29. In part, these issues arise from an unnecessarily legalistic and inflexible application of the DSS Guidelines which include the eligibility/ineligibility criteria. There is no reason why discretion could not be exercised to provide the Carer Support Subsidy when support is being provided by parents or other family members in appropriate cases. Sector Support appears to take a gatekeeper role, which can defeat the objectives for which the Carer Support Subsidy is provided.
 30. There is also a wider policy issue as to why there should be any restrictions on subsidising support care provided by spouses, partners, parents or other people or family members who live with the person being cared for. The restrictions do not seem to exist in the Guidelines used by DHBs, and they could be removed from the DSS Guidelines.
 31. The reason for the restrictions seems to be the assumption that spouses, partners, parents and other family members have a moral obligation or duty to provide care for ill, disabled or an elderly family members, and they are therefore less deserving of support than other unpaid carers. There is also possibly a related assumption that spouses, partners, parents, siblings and other family members who live with the person being cared for are already involved as primary carers, and should therefore be ineligible for a subsidy as a support carer. If this assumption applies, it unfairly prejudices people who choose to live in an extended family situation, and that probably disproportionately affects Maori and Pacific Island families.
 32. These assumptions go to the heart of the role of family carers, and the Government's attitude to them. If the prevailing attitude is that family carers are performing a family duty in undertaking their carer role, then it is not surprising that the family care role is under-recognised and under-valued in New Zealand.

33. Is interesting that general policy and political statements concerning family carers are always affirming and supportive of the carer role. For example, the Disability Strategy and the Report of the Social Services Select Committee into the Quality of Care and Services for People with Disabilities each refer to the importance of family carers. The Carers' Strategy is fundamentally about supporting family carers, and it does not say that carers have a moral obligation or duty to care for their family members without support from the Government. The eligibility restrictions for family members receiving the Carer Support Subsidy are therefore inconsistent with the Carers' Strategy and the broader policy settings of government.

Legal Context

34. There is no section in any Act of Parliament which refers to the Carer Support Subsidy, or any other carer support entitlement or initiative. This is consistent with the general approach to the delivery of health services through the Ministry of Health and DHBs under the New Zealand Public Health and Disability Act 2000. Access to public health and disability services in New Zealand is not expressed as a legal right or an enforceable entitlement.
35. The Public Health and Disability Act operates by establishing public institutions with high-level objectives, and providing governance mechanisms for the management of these institutions. The “purposes” section of the Act sets out the objectives of achieving the best care and support for those in need of health and disability services, and facilitating access to appropriate, effective and timely health services (section 3(1)). However the Act does not specify *how* the Ministry of Health or DHBs are required to achieve these objectives.
36. There is nothing unusual in the fact that the health and disability legislation does not specifically provide an entitlement for carers to receive Carer Support Subsidies or any other carer supports. People with illnesses or disabilities cannot point to a legislative right or entitlement to be treated either, even though there is an expectation that public health services will be available to meet their needs. The whole public health system in New Zealand operates on the basis of the expectation that appropriate and timely services will be provided, and the legislation has been designed to ensure that citizens generally do not have any legally enforceable entitlements. This is because decisions about what kinds of health services should be available through the public system involve a combination of political, financial and clinical elements, and the policy decision has been taken that injecting legal rights into this already complex context would not be constructive.
37. This approach is deliberate and understandable, but one of its consequences is a lack of transparency around particular service areas or programmes like the Carer Support Subsidy. There are other related areas outside the health system where a different approach has been taken. For example, the criteria for carers to receive the “Domestic Purposes Benefit - Care of Sick or Infirm” are set out in section 27G of the Social Security Act 1964, and a qualifying person does have a

legally enforceable right to receive the benefit. This difference illustrates that the health and social security systems operate under different paradigms.⁷

38. Even though the Carer Support Subsidy and other carer supports are not referred to in the Public Health and Disability Act, the governance instruments provided through the Act mandate the context and policy direction of the public health system within which the Carer Support Subsidy exists. Specifically, the Minister of Health is required to determine a New Zealand Health Strategy and a Disability Strategy under the Act, and these are priority and direction setting documents for the Ministry of Health and the DHBs.
39. One of the goals in the New Zealand Health Strategy is "healthy communities, families and individuals," and two objectives of this goal are to,
 - ensure adequate support for caregivers in families with dependent members; and
 - support policies and programmes that enable people to be cared for in the community.⁸

This goal and the related objectives have been in place since the New Zealand Health Strategy was set by the Minister of Health in 2000. Having DHBs providing adequate carer support systems and programmes, including the Carer Support Subsidy, is clearly relevant to these objectives.

40. The Disability Strategy from 2001 is the guiding document for DSS and it is also relevant because it provides a framework for the Government to begin removing the barriers that prevent disabled people from participating fully in society. The Carer Support Subsidy payments provided by DSS relate directly to disabled people who are being supported in the community. There are 15 Objectives and over 100 action points in the Disability Strategy, and Objective 15 is to "Value families, whanau and people providing ongoing support".⁹
41. Making the role of unpaid full-time carers more sustainable by providing the Carer Support Subsidy so they have opportunities to take breaks clearly meets DSS's requirement to provide ongoing support for the carers of people with disabilities.
42. The Health of Older People Strategy from 2002 is another government strategy which is relevant to the Carer Support Subsidy because carers of older people are one of the categories eligible for the subsidy paid by DHBs. The strategy refers to families and whanau being involved with older people in choices about

⁷ This is relevant to the Carer Support Subsidy because it was originally the responsibility of the Department of Social Welfare, and it was transferred to the Ministry of Health and the health sector in 1994 (Manjula Sickler *op. cit.* page 10)

⁸ www.moh.govt.nz/moh.nsf (Goal 5)

⁹ www.odi.govt.nz/nzds (Objective 15)

options for (among other things) disability support needs, and integrating services for older people, family, whanau and carers.¹⁰

43. The Health of Older People Strategy does not have the same legal status as the New Zealand Health Strategy or the Disability Strategy, because the Minister is not specifically required to promulgate a Health of Older People Strategy under the Public Health and Disability Act. The Health of Older People Strategy is therefore an additional non-statutory strategy which the Government has agreed to, and which therefore has a similar status to the Carers' Strategy.
44. The commitments in the New Zealand Health Strategy and the Disability Strategy (and the Health of Older People Strategy and the Carers' Strategy) are given effect through the provision of funding and operational policies. The funding to provide the Carer Support Subsidy (and other carer supports) comes through Vote Health and the Government budget, and DSS and the DHBs then determine the policy framework for applying that funding. There is no indication that Cabinet has ever approved or agreed to the Carer Support Subsidy, or the DSS Guidelines.
45. The Estimates for Vote Health and the 2009/10 budget include amounts for DSS, and for funding DHBs, although the Carer Support Subsidy does not show up as a separate line item for DSS or the DHBs.¹¹
46. The Carer Support Subsidy is therefore a product of administrative policy, with no higher-level legal status. This means DSS and the DHBs have a high degree of latitude in how they administer the Carer Support Subsidy, and the guidelines they operate under are no more than administrative instruments. They are not "binding" in the way a regulation or other legal rule might be binding. The fact that they are described as "guidelines" suggests they are not intended to be applied inflexibly, although it is interesting that the DSS Guidelines are written quite prescriptively, and seem to be applied as if they were "rules".
47. The uncertain status of the DSS Guidelines as an administrative instrument or as rules is illustrated by the recent issue concerning the "30 day rule" in the Guidelines. Section 7 of the DSS Guidelines says,

"The completed Carer Support Claim Form should be lodged [with HealthPac/Sector Support] within 30 days of the relief support ending."

Although the DSS Guidelines are not readily available on the internet, and although this 30 day requirement is not referred to in any of the summaries of the DSS Guidelines or the other guidance material provided on the Ministry of Health web site (or any other web site), Sector Support decided earlier this year that it

¹⁰ www.moh.govt.nz/moh.nsf

¹¹ The Report of the Social Services Select Committee on the *Inquiry into the Quality of Care and Service Provision for People with Disabilities* (September 2008) reported that \$26.2 million was spent on carer support and \$15.1 million was spent on respite care in 2006/07 (page 19).

should have been enforcing the "30 day rule". An unknown number of full-time or support carers who saved up their claims for longer than 30 days were distressed to have their claims rejected on the basis of the "rule" they were unaware of. To its credit, DSS reversed this approach and has instructed Sector Support to process claims up to 90 days after the relief support has been provided. The fact that the operation of the "30 day rule" could be changed so easily demonstrates that the DSS Guidelines are actually only an administrative instrument, and the 30 day requirement should never have been treated as a rule in the first place.¹²

48. It is also telling that DHBs seem to administer the mental and personal health aspects of the Carer Support Subsidy without seeming to have formally adopted any guidelines at all. The reason this works is that DHBs can make the administrative decisions as to who should be allocated the Carer Support Subsidy or not, and how much the allocation should be for, without necessarily having to refer to any formal guidelines or rules.¹³
49. Public officials are however constrained and how they make decisions affecting the interests of individuals, whether they are operating under policy guidelines or under no "rules" at all. They have overriding public law obligations to act fairly, reasonably and otherwise lawfully. Fairness requires each case to be considered individually on its merits, and for the decision maker to consider the full range of circumstances. Requiring NASCs to individually assess Carer Support Subsidy allocations is designed to achieve fairness, but the process needs to be consistent, and it needs to be followed properly in each case. It is clear that NASCs assessments are not undertaken in every case, and even if a NASC assessment is undertaken, the guidelines and assessment tools used by the NASCs are not transparent and do not seem to be consistent.
50. Consistency is one of the hallmarks of reasonableness; it would be unreasonable to treat similar cases very differently. Guidelines need to be transparent if they are going to fulfil their functions effectively. One of the advantages of guidelines is that they can support the reasonableness of decisions by helping to ensure consistency. Requiring decisions to be consistent is easy in a general sense, but it is more difficult when there are a large number of decisions and everyone's situations are unique. For this reason, the requirement to make consistent decisions is not a hard and fast rule, and consistency is a subset of reasonableness.
51. Officials are required to make Carer Support Subsidy allocation decisions "lawfully", but this requirement does not relate to the Public Health and Disability Act, because that Act does not refer to the Carer Support Subsidy, or any other specific programmes. Failing to follow any guidelines that might apply could lead

¹² The "30 day rule" example also graphically illustrates the gatekeeper function being exercised by Sector Support.

¹³ It may also be that carers of people with mental or personal health needs miss out on Carer Support Subsidy allocations which they should in fact receive, or they may receive allocations which they would not have received under the DSS or DHB Guidelines.

to inconsistent and unreasonable decisions, but the failure to follow the guidelines is not necessarily “unlawful”, because the guidelines have no status as “law”. There are however overriding legal obligations which must be followed whenever administrative decisions are made, and the overriding obligations which are relevant to the Carer Support Subsidy are in the Human Rights Act 1993 and the New Zealand Bill of Rights Act 1990.

Discrimination under the Human Rights Act

52. The Human Rights Act 1993 is the principal legislation which protects people in New Zealand from discrimination. The Human Rights Act prohibits discrimination on grounds of sex, marital status, religious or ethical belief, colour, race, ethnic origin, disability, age, political opinion, employment status, family status and sexual orientation.¹⁴ The Human Rights Act applies to everyone in their day-to-day activities: landlords; employers; retailers; service providers; schools, and anyone else who might potentially discriminate against another person on the prohibited grounds.
53. The way the Human Rights Act applies to the Government is quite subtle. Until 2002, the Human Rights Act did not apply directly to the Government at all, and the Human Rights Review Tribunal¹⁵ had no jurisdiction over the Government under the Human Rights Act. This was illustrated by the *Hill v IHC* cases, which held that the Government could have a policy which discriminated against the parents of people in IHC care by not allowing them to be employed to look after their own children, but the IHC itself could not have an employment policy discriminating against parents because it was not part of the Government, and therefore was subject to the Human Rights Act.¹⁶ This distinction between the Government (which *could* discriminate) and other organisations and people (which *could not* discriminate) was changed in 2002, when Part 1A was added to make the Human Rights Act apply to the acts of the legislative, executive and judicial branches of government.
54. What Part 1A does is to link possible discrimination by the Government to the New Zealand Bill of Rights Act 1990. The Bill of Rights Act sets out the legal rights of people in New Zealand in relation to the actions of the Government. Since 2002, the rights under the Bill of Rights Act include the right not to be discriminated against by the Government under the Human Rights Act.¹⁷
55. Part of the reason for linking discrimination under the Human Rights Act by the different arms of government to the Bill of Rights Act is that the rights under the

¹⁴ Human Rights Act 1993 section 21

¹⁵ Which was called the Complaints Review Tribunal until 2002

¹⁶ *Hill v IHC NZ Inc* (2000) 6HRNZ 213 and 449 (Complaints Review Tribunal)

¹⁷ New Zealand Bill of Rights Act 1990 section 19

Bill of Rights Act, including the right not to be discriminated against by the Government, are not absolute. There are circumstances where it might be appropriate or justified to limit the rights and freedoms in the Bill of Rights Act in the wider public interest, so the rights and freedoms in the Bill of Rights Act are subject to,

"such reasonable limits as prescribed by law as can be demonstrably justified in a free and democratic society" (section 5 BORA)

56. This contrasts with the Human Rights Act, because there are no "reasonable limits" allowing otherwise prohibited discrimination under the Human Rights Act. Relying on the Bill of Rights Act to control discrimination by the Government means the test in section 5 applies to actions by the Government which might otherwise be prohibited discrimination under the Human Rights Act. The Government is therefore subject to the Human Rights Act, but it has a justification for laws which might be discriminatory which is not available to anyone else. The issue of what limits on rights or freedoms might be demonstrably justified in a free and democratic society is essentially a political issue, although the Courts have developed an approach to considering the issue when it arises.
57. The Human Rights Review Tribunal has a wide range of orders it can make if it finds there is a breach of the Human Rights Act, including breaches by the Government. However, it cannot strike down legislation or regulations made by order in council. The remedy in relation to laws which include prohibited discrimination by the Government under Part 1A of the Human Rights Act (i.e. which constitute discrimination that is not justified in terms of section 5 of the Bill of Rights Act) is a "declaration of incompatibility" from the Human Rights Review Tribunal, or a higher Court on appeal. The declaration of incompatibility does not override or invalidate any discriminatory laws, but the Minister is required to explain to Parliament the Government's response to a declaration of incompatibility from the Tribunal. Effectively these Human Rights Act provisions rely on the good faith of the Government and its desire to avoid political embarrassment for their effectiveness, but any greater power in the hands of the Tribunal would compromise the sovereignty of Parliament.
58. So far, only one declaration of incompatibility has been made by the Human Rights Review Tribunal, and that decision is subject to appeal to the High Court.¹⁸ This case concerned age discrimination by ACC not making rehabilitation services available to people over 65 years old, so it is not directly relevant to the Carer Support Subsidy.

¹⁸ *Howard v A-G* (2008) 8HRNZ 378

DSS Carer Support Subsidy Guidelines and the Human Rights Act

59. There are various restrictions on the availability of the Carer Support Subsidy under the DSS Carer Support Subsidy Guidelines, and some of these restrictions are likely to be *prima facie* discrimination on grounds which are prohibited under the Human Rights Act. The right not to be discriminated against by the Government is a right protected by section 19 of the New Zealand Bill of Rights Act.
60. The prohibited grounds of discrimination under the Human Rights Act include marital status, employment status and family status.
61. The restrictions on the availability of the Carer Support Subsidy under the DSS Guidelines discriminate on the ground of marital status because the subsidy is not available when spouses or partners are providing support care, even if they do not live at the same address as the person requiring support.
62. The restrictions also discriminate on the ground of employment status because the Carer Support Subsidy is not available if the full-time carer uses the subsidised support time to work in paid employment. This discriminates against the full-time carer who might choose to work at those times.
63. The restrictions discriminate on the ground of family status because the Carer Support Subsidy is not available when the relief carer lives at the same address as the full-time carer or the person receiving support. The people who live at the same address will usually (although not necessarily) be family, whanau, or aiga members, including siblings.
64. Finally the Carer Support Subsidy is also excluded when the relief carers are parents, even if they do not live at the same address as the person being cared for, and irrespective of the age of the "child". This is also discrimination on ground of family status.
65. The Director of Proceedings under the Human Rights Act has taken a case to the Human Rights Review Tribunal challenging the DSS Carer Support Subsidy Guidelines, and the Director of Proceedings presumably made claims in relation to the restrictions in the DSS Guidelines along these lines. The case was heard in September 2008, and the Tribunal has yet to issue its decision.
66. Although the prohibited grounds for discrimination seem to be relatively straightforward, in practice their application is not straightforward at all. There are complex technical arguments over whether particular acts or policies are in fact discriminatory, or whether they disadvantage a particular group.
67. A similar case was brought by the Child Action Poverty Group in relation to the In Work Tax Credits included as part of the Working for Families package

introduced between 2003 and 2005.¹⁹ The argument was that the In Work Tax Credits provided for in the Income Tax 2004 discriminated on the grounds of employment status because the tax credits were only available to people with children and full-time jobs, and people with children who are on benefits because they do not have full-time jobs were disadvantaged.

68. The *Child Poverty Action Group* case is relevant because it provides an example of the type of analysis the Tribunal will be undertaking in relation to the Carer Support Subsidy, and it also shows the types of arguments the Crown is likely to have raised in defence of its policy. The *Child Poverty Action Group* case is very long (105 pages), and it is difficult to summarise concisely. The key points from the case which are relevant to the DSS Carer Support Subsidy Guidelines are:

- The initial question is whether the policy or law being challenged treats two comparable groups differently by reason of a prohibited ground of discrimination under the Human Rights Act. In the case of the Carer Support Subsidy, the question will be whether support carers who are spouses or partners, parents, family members or full-time carers who work while the support care is being provided are treated differently from other carers.
- In the *Child Poverty Action Group* case, Crown Law argued that the comparison should be between beneficiaries who are *not* in work and beneficiaries who *are* in work, and because beneficiaries who are in work do not receive the In Work Tax Credit then there was no discrimination against beneficiaries who are not in work. There are of course relatively few people who work and who also receive benefits, and the Crown seems to have been making quite a technical and artificial comparison. The Human Rights Review Tribunal rejected the Crown's comparison between beneficiaries who do or do not work, and opted for the common sense comparison between beneficiaries who are not in work and other people who are in work.
- The Crown also argued that people who do not receive the In Work Tax Credit because they are on benefits are not necessarily "disadvantaged" by the discrimination against them because people on benefits receive *more* social assistance than people who work. Again the Tribunal rejected this argument and held that there was a real and substantive disadvantage for people on benefits not receiving the In Work Tax Credit.
- These points are relevant to the Carer Support Subsidy case because they show the Crown is likely to have argued that the DSS Guidelines are not discriminatory, no matter how unmeritorious the argument might be. They might have argued, for example, that all spouses or parents are treated the same because none of them are eligible for the Carer Support Subsidy. They might also have argued that the restrictions on the

¹⁹ *Child Poverty Action Group Inc v The Attorney-General* HRRT Decision No.31/08 16 December 2008

eligibility for Carer Support Subsidies due to the status of the support carer do not disadvantage the full-time carers, and that the support carers are not disadvantaged because they do not have to provide the support care.

- These sorts of arguments would be consistent with the arguments made by Crown Law in the *Child Poverty Action Group* case. It would be surprising if these arguments are successful in the face of the common sense view that the DSS Guidelines are clearly discriminatory, but the point is that Crown Law has demonstrated that it is prepared to make unwinnable arguments before the Human Rights Review Tribunal.
- The second line of analysis following a finding of *prima facie* discrimination in a Human Rights Act case is whether laws or government policies which may on their face be discriminatory under the Human Rights Act are reasonable limits prescribed by law that are "demonstrably justified in a free and democratic society" (section 5 BORA). This essentially opens up a policy argument.
- One obvious point in relation to the DSS Carer Support Subsidy Guidelines is that the guidelines have no formal legal status. As we have seen, the guidelines are simply an administrative instrument. If that is the case, then the protection under section 5 of the Bill of Rights Act will not be available to the Crown because reasonable limits on protected rights which might be demonstrably justified in a free and democratic society are only permitted under section 5 if they are "prescribed by law".
- Assuming that the section 5 point is even arguable by the Crown, the relevant legal issues to decide whether a policy is demonstrably justified are,
 - does the *prima facie* discrimination serve a purpose sufficiently important to justify the curtailment of a right or freedom?
 - is the *prima facie* discrimination rationally connected with its purpose?
 - does the *prima facie* discrimination impair the right or freedom no more than reasonably necessary for the sufficient achievement of the purpose?
 - is the limit on a protected right in due proportion to the objective?
- The context in which the alleged discrimination is occurring, and the overall purpose and objectives of the policy, are crucial to this analysis. In the case of the In Work Tax Credit, Cabinet made the political decision that the best way to reduce child poverty was to have as many people as possible working. The idea was to "make work pay", which involved maintaining a sufficient income gap between people on benefits and people in work to incentivise people to take up jobs. The Tribunal decided that a case had been made by the Crown justifying the In Work Tax Credits in the context of the overall purpose of reducing child poverty, and that the other legal tests had been met.

- The Human Rights Review Tribunal did however express deep reservations about this policy, especially since the In Work Tax Credit was extended as a *de facto* tax cut for very well off people. The Tribunal said it was a difficult decision, but it decided it should defer to the policy decisions of the Government in this area, principally because it was such a “macro” level political and economic decision. The Tribunal therefore dismissed the application for it to issue a declaration that the In Work Tax Credit scheme was inconsistent with the right of beneficiaries not to be discriminated against under the Human Rights Act.
- A declaration of inconsistency was the only relevant order the Tribunal would have been empowered to make, because the offending provision was in the Income Tax Act, which is legislation. A declaration of inconsistency would not have affected the validity of the provisions in the Income Tax Act, but the Minister would have had to report to Parliament on the Government’s response to the declaration (section 92K HRA).
- The reason the *Child Poverty Action Group* case is important and worth summarising is that it provides a clear signpost for what is likely to happen when the Human Rights Review Tribunal releases its decision on the Carer Support Subsidy. The Tribunal is likely to decide that some of the provisions in the DSS Carer Support Guidelines are *prima facie* discrimination under the Human Rights Act. The Tribunal may also hold that the guidelines are not justifiable under section 5 because they are not “law”. Even if the Tribunal does wrestle with the issue of whether the discriminatory elements in the guidelines are “demonstrably justified in a free and democratic society” (section 5 BORA), the arguments successfully used by the Crown in the *Child Poverty Action Group* case will not have been available in the Carer Support Subsidy case. In particular, there does not seem to be any weighty policy justification or purpose for the discriminatory provisions in the DSS Carer Support Subsidy Guidelines. The restrictions in the DSS Guidelines do not seem to have any well thought through “purpose” at all, apart from restricting the availability of the Carer Support Subsidy. The policy also affects a relatively low number of people compared to the In Work Tax Credit, so the Tribunal will not feel so constrained to defer to the Government on a “macro” policy issue.
- It is therefore very likely that the Human Rights Review Tribunal will issue a declaration that the DSS Carer Support Subsidy Guidelines are inconsistent with the Human Rights Act when it releases its decision. The Carer Support Subsidy case does not concern legislation, so the Tribunal has the discretion to issue a wider range of orders that were available to it in the *Child Poverty Action Group* case. In particular, the Tribunal could effectively issue an injunction, or an order requiring the Government to take any action, and the Government will need to decide how it should respond at that time. Depending on the terms of the decision, the Government may elect to appeal the decision, which would further hold

up any strategic resolution of the Carer Support Subsidy issues by a year or more.

69. There is a chance that the Human Rights Review Tribunal decision will politicise the Carer Support Subsidy for the first time. This could be an opportunity to make progress on the problems with the Carer Support Subsidy, both in terms of the discriminatory allocation guidelines and more widely. Having said that though, the *Child Poverty Action Group* case received virtually no publicity of all when it was released in December 2008, despite being very significant in its own right. It would be disappointing if the same thing happened with the Carer Support Subsidy case, especially if the claim is successful.

Improvements to the Carer Support Subsidy system

70. The problems with the Carer Support Subsidy system have been implicitly acknowledged in the Carers' Strategy, which has tasked the Ministry of Health with enhancing and improving the fairness of the Carer Support Subsidy. The Northern DHB Support Agency (NDSA), an organisation representing the four DHBs from Counties Manukau north, commissioned a review of the Carer Support Subsidy affecting older people in 2006. The Ministry of Health is also reviewing carer supports - possibly independently of its obligations under the Carers' Strategy action plan.
71. Apparently the pending Human Rights Review Tribunal case on the eligibility of family members to receive the Carer Support Subsidy has held up the Ministry of Health review, because the Crown has not conceded that the restrictions on providing Carer Support Subsidies for spouses, partners, parents, siblings or other family members are a breach of the Human Rights Act. The Crown is reluctant to consider extending the eligibility for the Carer Support Subsidy among family members at the same time as it is arguing that the current restrictions are valid. As we have discussed, it is doubtful whether the Crown's position will be sustainable under the Human Rights Act. The arguments the Crown will have made before the Human Rights Review Tribunal, and the fact that the case has effectively blocked any progress in dealing with the problems with the Carer Support Subsidy, tend to undermine any commitment to affirming and supporting the valuable role played by family carers which Ministers or officials might express.
72. Not only has the Human Rights Review Tribunal case been cited as the reason for holding up the Ministry of Health review of the policy concerning the Carer Support Subsidy and other carer supports, but the Ministry of Health review itself has been cited as the reason why the NDSA work has not been progressed.

73. The NDSA produced a widely consulted final report in October 2006.²⁰ The report includes useful information on the history of the Carer Support Subsidy and how it operates in practice, as well as on the various guidelines used by DHBs and DSS. The report focuses on the NASC assessment services and the specific assessment criteria used by the NASCs, as well as the Sector Support claims process.
74. The NDSA report called for the Carer Support Subsidy rates to be increased, and for the guidelines (including the NASC assessment criteria) to be improved. The Carer Support Subsidy rates were increased in 2007, and presumably this was connected to the NDSA report. The NDSA also prepared and consulted on revised guidelines and assessment criteria in 2008.²¹
75. The existing DHB Carer Support Subsidy Guidelines do not include the provisions which are included in the DSS Guidelines, and which have been the subject of the Human Rights Review Tribunal case. Nevertheless the process for agreeing the revised DHB guidelines, and the revised assessment criteria, has been halted pending the Ministry of Health review and the outcome of the case.
76. The current position is therefore untenable and the value of the NDSA work is being wasted. The Ministry of Health should pick up the work that the NDSA has done and carry it forward. A consistent set of guidelines should apply nationally, across all categories of carers eligible for the Carer Support Subsidy. Those guidelines should not include restrictions on the eligibility of family members for the Carer Support Subsidy which are either *prima facie* or actual discrimination under the Human Rights Act, irrespective of the outcome of the Human Rights Review Tribunal case. The NASC assessment criteria should also be consistent and transparent, along the lines recommended by NDSA.
77. One of the recommendations of the Carers' Alliance during the Carers' Strategy consultation process was for the Government to consider a two tier payment system for the Carer Support Subsidy, with a lesser daily rate paid for 'ordinary' support needs, and a higher rate allocated for those supporting someone with high or complex needs, both at rates that reflect the actual cost of care for the level of need. The working group which developed the Carers' Strategy and its Action Plan, which included representatives from the Carers Alliance, were told that changes to the Carer Support Subsidy did not need to be included in the Action Plan, as the Ministry of Health was reviewing the Subsidy. We believe the two-tier payment proposal for the Subsidy is an important development priority and ask that it be included in the Ministry's current review of the Subsidy.
78. The broad policy issue is simply whether the Government believes that there are social, ethical and economic benefits in providing support for family carers which

²⁰ Manjula Sickler "Northern Region Carer Support Subsidy Review" (October 2006) Northern DHB Support Agency

²¹ "Guidelines for the authorisation of the Carer Support Subsidy" Northern Region District Health Boards (June 2008)

recognises their contribution and helps to make their caring role sustainable, or that family carers are simply fulfilling their individual family duties when they provide unpaid care, and that the Government has no interest in supporting them. The Carers' Strategy actually sets the broad policy framework for recognising and supporting the contribution of family carers, and the steps necessary to resolve the problems with the Carer Support Subsidy would be relatively simple if the Government was committed to supporting and affirming family carers.

79. Delaying resolving these issues while the Crown waits for the Human Rights Review Tribunal case has been a strategic error, and whatever the outcome of the Tribunal decision when it is released, the Crown should put the decision to one side and focus on resolving the issues. In particular, the Crown should resist any advice it may receive from its lawyers to appeal the decision if it loses the case because an appeal will involve further unnecessary delay in resolving issues which require no more than good faith and leadership.

Recommendations

80. We recommend that the Minister:
- (a) Directs the Ministry of Health to develop a standardised and transparent set of guidelines and procedures for the Carer Support Subsidy which will apply across all categories of unpaid carers.
 - (b) Agrees that the new guidelines and procedures should be based on the work already done by the NDSA.
 - (c) Agrees that the new guidelines should not include any restrictions on access to the Carer Support Subsidy by spouses, partners, parents and other family members which breach the Human Rights Act.
 - (d) Agree that the new guidelines should not include any restrictions on what carers may do with their time when subsidised support care is being provided, including either working or staying with the person being cared for.
 - (e) Agrees that the Crown should not continue to attempt to justify *prima facie* discrimination under the Human Rights Act in the DSS Carer Support Subsidy Guidelines, including not appealing any decision that the Human Rights Review Tribunal might issue in relation to those guidelines.
 - (f) Directs the Ministry of Health to carry out its commitments under the Carers' Strategy action plan, including reviewing the Carer Support Subsidy system in the context of other carer supports and respite care options, and recognising the contribution of unpaid carers, and the social and economic benefit of making the role of unpaid carers more sustainable by providing for them to be able to take a break.

- (g) Directs the Ministry of Health to review whether it is principled or appropriate for the Carer Support Subsidy to only be a partial contribution towards the actual costs of formal or informal support care, and for the system to be designed to require family carers to fund top up payments themselves.
- (h) Directs the Ministry of Health to review calls by the NZ Carers Alliance during the Carers' Strategy consultation process for the Government to consider a two tier payment system for the Carer Support Subsidy, with a lesser daily rate paid for 'ordinary' support needs, and a higher rate allocated for those supporting someone with high or complex needs, both at rates that reflect the actual cost of care for the level of need.
- (i) Agrees to take a paper to Cabinet on the issues concerning the Carer Support Subsidy and carer support and respite options generally, so Cabinet has the opportunity to endorse the approach and action plans referred to in the Carers' Strategy, and to set a clear policy direction for the Ministry of Health and DHBs in relation to carer support issues.
- (j) That this paper be developed in partnership or with strong input from the Carers Alliance, as the Government's ongoing governance partner for the Carers' Strategy, and that DHBs also be closely involved in its development.

This Review was completed on behalf of the NZ Carers Alliance by Roger Palairret of Palairret Law.