

**IN THE MATTER OF A CLAIM UNDER THE
HUMAN RIGHTS ACT 1993 AND ITS AMENDMENTS**

BETWEEN **PETER ATKINSON (ON BEHALF OF THE
ESTATE OF SUSAN ATKINSON** of Auckland,
Former Caregiver)
First Plaintiff

AND **GILLIAN BRANSGROVE,** of Wellington,
Caregiver and Registered Nurse
Second Plaintiff

AND **JEAN BURNETT,** of Auckland, Caregiver
Third Plaintiff

AND **LAURENCE CARTER,** of Rotorua, Caregiver
Fourth Plaintiff

AND **PETER HUMPHREYS,** of Ngaruawahia,
Caregiver
Fifth Plaintiff

AND **CLIFFORD ROBINSON,** of Thames, Caregiver
Sixth Plaintiff

AND **LYNDA STONEHAM,** of Hamilton, Caregiver
Seventh Plaintiff

AND **STUART BURNETT,** of Auckland, Beneficiary
and Computer Technician
Eighth Plaintiff

AND **IMOGEN ATKINSON,** of Auckland, Beneficiary
Ninth Plaintiff

AND **THE MINISTRY OF HEALTH**
Defendant

BEFORE THE HUMAN RIGHTS REVIEW TRIBUNAL



J E Ryan - Chairperson
Dr W L McKean - Member
Dr S Solomon - Member

HEARING: 3-4, 8-11, 15-18, 22-25 September and
6-9 October 2009

APPEARANCES:

Mr R Hesketh, Ms F Joychild and Mr D Peirse for Plaintiffs.
Ms M Coleman, Ms V Casey and Ms M Silverwood for Defendant.

DATE OF DECISION: 8 January 2010

DECISION

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A INTRODUCTION

[1] By their third Amended Statement of Claim filed on 14 August 2008 (the proceedings having been commenced in the Tribunal by the original Statement of Claim on 20 October 2005) the nine plaintiffs allege that the practice and/or policy of the Ministry of Health ("the Ministry" or "the defendant") of excluding specified family members of people who are eligible under Ministry policies for disability support services from payment for their provision of such services by reason of their family relationship to such an eligible person, contravenes provisions of the Human Rights Act 1993 (the "HRA" or the "Act"). The relevant provisions are s.20L which provides that an act or omission is in breach of Part 1A of the Act if it is inconsistent with s.19 of the New Zealand Bill of Rights Act 1990 ("NZBORA") in that it limits the right to freedom from discrimination affirmed by s.19 and is not under s.5 NZBORA a justified limitation on that right and s.21(1)(i)(iv) which provides that family status, namely being a relative of a particular person, is a prohibited ground of discrimination for the purposes of the Act.

[2] Complaints to the Human Rights Commission have not been resolved. The plaintiffs are all represented by the Director of Human Rights Proceedings.

[3] The seven first named plaintiffs are parents and resident family members who have cared for and/or currently care for their adult children who qualify, by reason of the level of their disability support needs for paid disability support services funded by the Ministry. To assist an understanding of the issues general descriptions of the nature of their disabilities are set out at paragraphs [17] to [40]. With a view to maintaining as far as possible the personal privacy of the individuals involved the Tribunal has at all stages of the proceedings ordered that any report thereof is not to include private personal health and disability information. That order will continue. Therefore, the information set out at paragraphs [17] to [40] should not be published.

The eighth plaintiff is the son of the third plaintiff. The ninth plaintiff is the daughter of the first plaintiff. Both eighth and ninth plaintiffs have at some stage in their lives



chosen or are choosing to reside with a parent and have that parent provide some or all of the disability support services for which they would otherwise be funded by the Ministry. We record that the proceedings were commenced by Susan Atkinson as first plaintiff but sadly she died before the claim could be heard. With the acquiescence of counsel for the Ministry her husband Peter Atkinson as executor of his late wife's estate has been substituted as first plaintiff. There do not appear to be any issues arising from this.

[5] As might be expected in light of the large number of persons who qualify for disability support (not related to aging or injury, these were 291,000 in 2006) the Ministry has a number of services for delivering support or providing funding. Many and possibly most involve contracting with providers of services who employ staff to provide home based support services, manage contract board arrangements, manage supported independent living arrangements, manage independent funding arrangements or manage residential care for qualifying persons. The services at issue in these proceedings are Home Based Support Services, Supported Independent Living, Contract Board and Individualised Funding.

[6] We were told a longstanding and overarching policy and/or practice applying to these services is that parents, spouses and other resident family members of the qualifying persons are excluded from being paid for providing disability support services to their adult child, spouse or resident family member who qualifies for such support services. Ministry policy is that support services provided by such family members are regarded as "natural supports" which do not attract payment but when the same services are provided by others they are treated as disability support services for which payment can be made.

[7] The plaintiffs allege this unlawfully discriminates in that otherwise available and willing carers are excluded from being paid for provision of disability support services by reason of their family status. Further, persons who are eligible to receive paid disability support services are denied the opportunity to choose to have their parent or spouse or resident family member be the paid provider of disability support services to them by reason of their family status. Although the statement of claim from which this recital is taken refers to a spouse at many points, it is the case that none of the specific claims before the Tribunal involve a spouse. All are concerned with adult children.



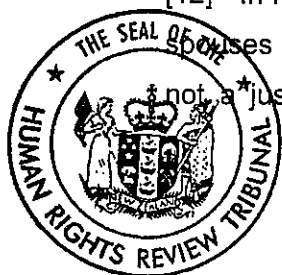
[8] By way of particulars in support of their claims details of the living circumstances both in the past and at the time of hearing are set out in the statement of claim. We do not find it necessary to recite them all. There is no dispute about those factual matters. Dispute arises when it comes to considering how the various living arrangements should be classified for the Ministry's purposes (natural support or disability support) and what consequences should follow from any such classification.

[9] We note at this point that contrary to Ministry policy the fifth and sixth plaintiffs do receive and have for some time received funding to care for their children who live with them. That was also the case for the second plaintiff up until September 2005 when payment ceased. The Ministry has agreed to leave the existing arrangements in place but if these proceedings are resolved in its favour expects to revisit these payments. In fact preparation by the Ministry to resist this claim brought to light the fact that 272 people with disabilities had paid family caregivers providing disability support services (agreed Bundle of Documents p.428 et seq). That is 1.4% of the approximately 19,591 people with disabilities accessing Disability Support Services ("DSS") funding when the survey was undertaken prior to July 2007.

[10] The Ministry asserts almost all of those arrangements were entered into without its knowledge and in breach of its policy. The Tribunal observes this stance could give rise to interesting arguments about the extent of delegated authority to the various persons or organisations involved in approving payments in any given case but we were not asked to examine that issue.

[11] The Ministry filed a comprehensive and detailed Reply to the Third Amended Statement of Claim. As mentioned, it does not dispute factual matters but in response to the assertion by each of the plaintiffs that they provide or are provided with disability support services, those claims are denied. Rather, the Ministry pleads, what each parent plaintiff provides their child is care through natural family support. It is asserted these services are different from the care provided by paid disability support services. There is also a pleading in respect to plaintiffs caring for or wishing to care for their children that it is not generally in the interests of such people to be employed to provide disability support services to a disabled family member.

[12] In response to the plaintiffs' pleading that the policy or practice not to pay parents, spouses or resident family members to provide care in the circumstances described is not a justified limitation on the right to be free from family status discrimination the



Ministry pleads that its practice is justified because (inter alia) it reflects the social contract between families and the state under which the family is recognised as the fundamental social unit in our society. It is an aspect of the social contract, so the argument runs, that the state does not pay families to look after their own.

[13] In addition the Ministry relied on other matters to support the policy not to fund employment of family members, including:

- [a] Funding the employment of spouses, parents and resident family members would create perverse incentives to refuse to provide care or to under-acknowledge the care they are able to provide lest they forego an opportunity to be employed. It was pleaded that this may have serious cost implications for government;
- [b] That funding the employment of spouses, parents and resident family members is inconsistent with the current model of individual assessment aimed at government meeting a gap in natural supports. The Ministry argued that revision of the current model may be necessary;
- [c] The policy promotes equality of outcomes for disabled people;
- [d] The policy encourages the independence of disabled people;
- [e] The policy supports the development of family relationships in the same way as they develop for non-disabled people;
- [f] The policy avoids professionalising or commercialising family relationships;
- [g] The policy avoids the risk that families become financially reliant on the money and thereby discourage disabled family members from leaving;
- [h] The policy ensures that the Ministry keeps control of the services it funds and that publicly funded services meet quality standards and can be monitored;
- [i] The policy avoids unsustainable care burdens and distress and social isolation of family members undertaking extensive care; and
- [j] The policy is fiscally sustainable.

[14] The Tribunal will address these points but they can await our conclusion on the fundamental issue of the social contract which is invoked so as to preclude such payment as the plaintiffs seek.

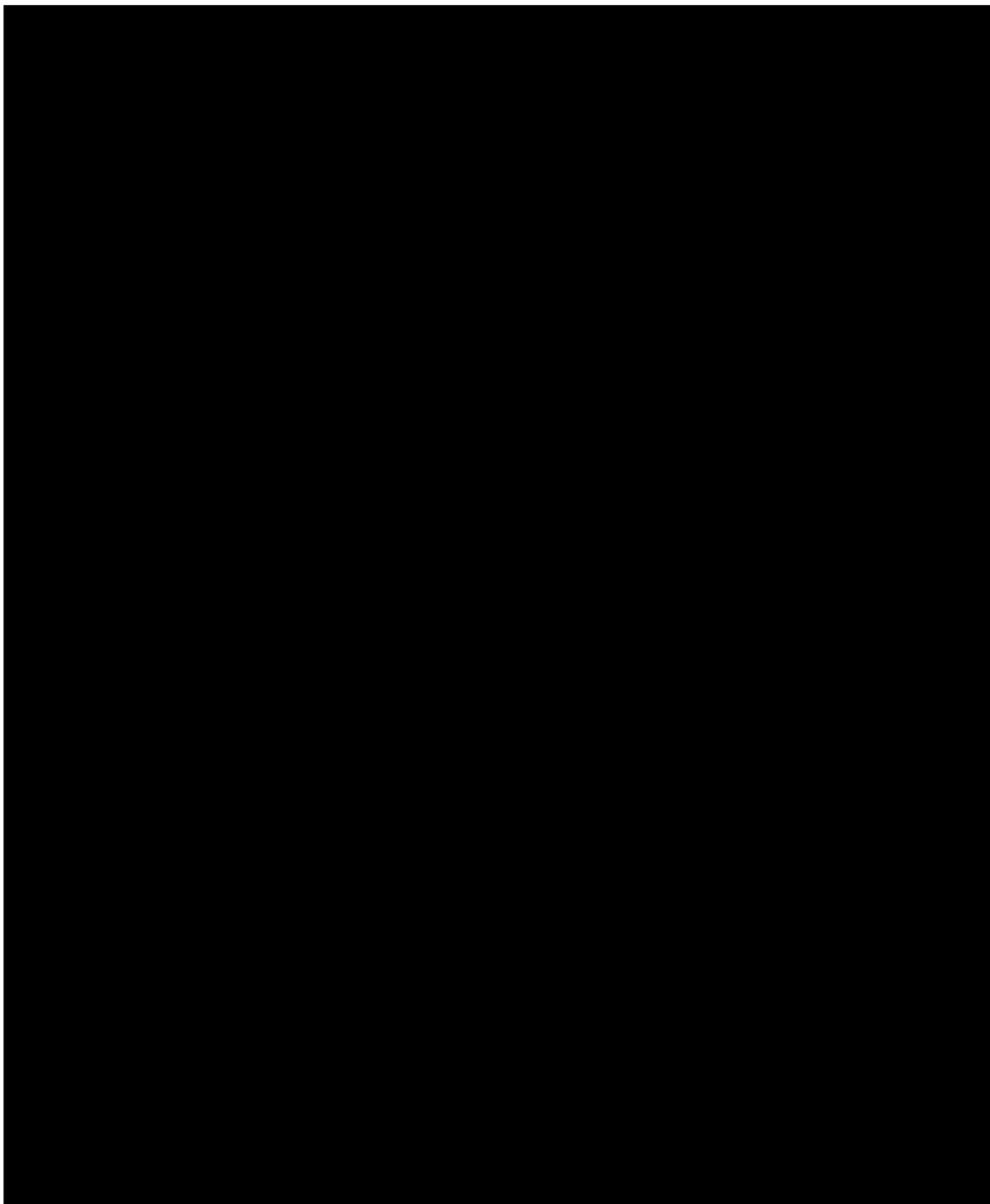


[15] The relief the plaintiffs sought is wide-ranging. It is:

- (i) A declaration pursuant to section 92I(3)(a) of the Act, that the defendant's practice and/or policy of excluding specified family members from payment for the provision of funded disability support services is inconsistent with section 19 of the New Zealand Bill of Rights Act 1990 in that it limits the right to freedom from discrimination, both directly and indirectly, on the grounds of family status and is not, under section 5 of that Act, a justified limitation.
- (ii) An order pursuant to section 92I(3)(b) of the Act, restraining the defendant from continuing with or repeating such a breach of the Act, or from engaging in, or causing or permitting others to engage in, conduct of the same kind as that constituting the breach, or conduct of any similar kind.
- (iii) Damages pursuant to section 92I(3)(c) and section 92M(1)(a) of the Act for pecuniary loss suffered by each of the plaintiffs as a result of the practice and/or policy at issue in these proceedings. The amounts sought under this head of damages will be particularised later.
- (iv) Damages pursuant to section 92I(3)(c) and section 92M(1)(b) of the Act for loss of other benefits suffered by each of the plaintiffs as a result of the practice and/or policy at issue in these proceedings. The nature of and amounts sought under this head of damages will be particularised later.
- (v) Damages in an amount to be determined by the Tribunal pursuant to section 92I(3)(c) and section 92M(1)(c) of the Act to compensate each of the plaintiffs for humiliation, loss of dignity and injury to feelings as a result of the defendant's practice and/or policy.
- (vi) An order for the defendant to pay the plaintiffs' costs pursuant to section 92L(1) of the Act.
- (vii) Such further relief as the Tribunal thinks fit pursuant to section 92I(3)(h) of the Act including, but not limited to, an order for the defendant to pay interest on any judgment debt in the plaintiffs' favour, from the date of judgment, at the rate for the time being prescribed by section 87 of the Judicature Act 1908.

[16] However, in opening, counsel for the plaintiffs made it clear that all that was sought at this stage was an initial declaration. If the plaintiffs are successful in that then at a reconvened hearing the question of further or other remedies will be addressed. The Tribunal accepts that approach. However, it is noted that the issue of costs is resolved by a memorandum dated 26 April 2006, by which counsel for the parties agreed that costs, including costs of any appeal, would lie where they fall.





[41] In addition to the contention that they were discriminated against on the basis of their family status, the plaintiffs expressed some other more general concerns.

[42] Some expressed concern (as did some of the recipients of this care) that they had to have a person from outside the home attend to provide intimate cares that they would prefer a family member provide. Some found such carers to lack appropriate cultural sensitivity at times and were not comfortable with a stranger entering their home and intruding upon family life, particularly when there were regular changes in personnel.



Comment was also made on the minimal levels of training some carers seemed to have (the defendant did outline work currently being undertaken to improve levels of recruitment and training). Some family carers believed that their own standard of care was higher than that of paid carers entering the home.

[43] There were also personal concerns expressed about the standard of the care given by paid carers and some expressed concern about their reliability in attending at agreed times, together with the fact that carer availability was sometimes difficult on weekends and public holidays, in which case they would need to step in. We were also told that the restricted lifting (physically moving) policies of the services provider limited carer support availability.

[44] Several plaintiffs disputed the contention that being cared for at home by a family member would inhibit the development of the independence of the disabled person – and pointed to the efforts, and considerable success of some the disabled persons referred to above, in their academic and sporting endeavours.

[45] Some expressed frustration at the lack of choice for them and their disabled children inherent in the policy of excluding them from paid care, and others of the additional stress, frustration and humiliation that often presented in already stressful home circumstances.

C CONTEXT

Background to the policy issue

[46] The current framework for the purchase of disability support services (“DSS”) by the Ministry dates back to the early 1990s when four Regional Health Authorities (RHAs) were established in a major reorganisation of the New Zealand public health sector. They were given the responsibility for purchasing a range of personal health and disability support services for their geographic area from the providers of such services, on a contestable basis (called the “funder-provider split”).

[47] The range and type of services RHAs were to purchase were broadly defined by way of a Crown Funding Agreement actioned through the also newly created Ministry of



[48] In 1997, the RHAs were amalgamated into a single national Health Funding Authority ("HFA"), later (in the year 2000) to be disbanded with its purchasing functions relocated into the Ministry of Health, which is now responsible for the policy setting, planning and funding of DSS (it is one of eleven government agencies that fund supports for people with long term disabilities.)

Key organisations in the DSS system

[49] The present day key DSS organisations were described to us as follows:

- [a] The Ministry of Health Disability Support Services Group, responsible for the funding, policy and planning of disability supports. The Ministry then contracts with Needs Assessment and Service Coordination ("NASC") agencies and other providers of services.
- [b] NASCs are organisations that are contracted by the Ministry to provide needs assessment and coordination services. There are currently 15 contracts with various NASC agencies.
- [c] Service providers, which are organisations that also contract with the Ministry to provide the various other services that the Ministry funds. There are currently about 800 service providers contracting with the Ministry.

The Needs Assessment and Service Coordination process

[50] As noted, the framework for the current Ministry's disability support services was established by the four RHAs. In summary, it set out a system whereby a disabled persons disability support needs are identified and the services needed then provided to them are coordinated – called the needs assessment and service coordination ("NASC") system. The key principle of this model is the use of individualised assessments and the separation of these needs from the coordination and provision of the services agreed to.

[51] Needs assessment was described to us as a process to determine the current abilities, goals and needs of an individual with a disability and identifying which of these needs and goals are the most important. The purpose of the process is said to be to decide what is needed to maximise the individual's independence so they can participate as fully as is possible in society, in keeping with their abilities, resources, culture and goals.

[52] At the needs assessment interview, the disabled person (or their representative) and the assessor work through a form, ensuring all relevant information is to hand. The



interview is about establishing what the individual can do, what the individual's goals are and the areas where they need support.

[53] We were advised that main topics covered in the needs assessment cover the following areas: living situation; current support networks (to include family members, neighbourhood and community/social groups, schools, church groups, Scouts, Girl Guides, service groups, sports and other clubs); communication; sensory function; mobility; leisure; income support; household management; personal care; social; memory; behaviours and cognition; education; vocational; cultural; spiritual, goals and the situation of carers.

[54] The individuals and organisations bracketed in the last paragraph above were described to us as "natural supports" for the family and this topic will be reviewed later.

[55] Once the level of "natural support" has been determined by way of the assessment process, the additional support needed by the disabled person is then supplied by an agreed service provider – their staff come to the place of residence on a regular basis to provide this care, for which the service provider is reimbursed.

Services that are the subject of these proceedings

[56] There is a range of services purchased and provided to support people with disabilities; those which were the subject of this hearing are described as follows:

- [a] Home based support services. These cover two types of support to assist with daily living:

Personal care: which includes assistance with personal hygiene and grooming; toileting and bathing; dressing; transfers (moving from a bed to a wheelchair) and mobility (ensuring safe mobility around the home), and feeding.

Household management: which are services that assist a person to maintain, organise and control their household/home environment such as cleaning, laundry, meal preparation and shopping. It may also include temporary or short term night support (sleepovers) where the caregiver is given the opportunity to have an uninterrupted sleep.

Other services included:

- [b] Individualised Funding (IF): this allows a disabled person (or their agent) to hold and manage their own budget for the home based support services they have been assessed as needing; it is not a personal entitlement for funds (the scheme gives disabled people more control over who comes into their home and the timing for these services). The IF Agency works with individuals referred to them to



determine whether they can be approved as a budget holder. If approved, also helps to coach people on how to implement their funding package and monitors how they are managing.

- [c] Contract Board: This is a service where an individual moves in with another family when the person no longer wants to, or is not able to continue living with their own family but still wish to have the sort of supports that the family environment can provide. The service is primarily for people with intellectual disability.
- [d] Supported Independent Living: this is a relatively new service which aims to support people living independantly in the community. It consists of individual support services and household and accommodation support services. The service is for people who are assessed as being capable of the skills to do the tasks themselves.

[57] It should be stressed that the care and support given to those - with a few exceptions - who are disabled and over 65 years (who, since 2003, are the responsibility of District Health Boards) and those disabled as a result of injury (the responsibility of the Accident Compensation Corporation and reviewed later) are excluded from the Ministry of Health Disability Home Based Support Services.

The policy to disallow payments to “family members” for the care of a disabled relative

[58] As discussed, the basis of the decision to prohibit the payment of family members providing care in the family home appears to date back to the time of the Regional Health Authorities (RHAs) and their definition of purchasing policies and service specifications, in the early 1990s.

[59] The process and the evidence base behind the initial formulation of this policy were not clear to the Tribunal. We were told that it would have been broadly covered by the Crown Funding Agreement with RHAs and that the “policy” would have come from the Ministry; we were told that the decision to exclude family members from payment would have been implicit rather than an explicit direction.

[60] In any event, no evidence was presented to us that analysed and justified this exclusion in the original specification and operational manuals for the purchase of disability support services, drawn up by the RHAs.

[61] We were also told that “The underlying fundamental policy, that the state does not pay families to look after their own, goes so far back that it is just one of those foundation principles which is taken for granted in the basic articulation of the role of the



state versus the role of the individual and the family unit.” (paragraph 85, defendant’s closing submissions, part one).

[62] Again, we were advised that “The state is not concerned to take control of or take responsibility for the way in which parents raise their children.” (paragraph 86) – apart from some carefully delineated and negotiated exceptions, and that “This assumption does not change because the child is disabled.” (paragraph 87) – the state offers support and assistance to families caring for a disabled child but does not step in to and take control of the families care decisions or take responsibility for the care provided.

[63] Further, we were told that “...the underlying principle remains constant – the state provides support, it does not usurp the functions of families and it does not employ families to perform these functions...” (paragraph 88).

[64] In other submissions, this proposition was seen to be an inherent part of a “social contract” that influences a national consensus; this is referred to elsewhere in our findings.

The Hill case

[65] The first time the policy to exclude the payment of family members was questioned at Ministry level, related to the findings in the “Hill case” (*Hill v IHC NZ (Inc)* [2001] 6 HRNZ 449). The *Hill* decision by the then Complaints Review Tribunal (CRT) in 2001 involved the parents of a man with physical and intellectual disabilities who applied to the IHC New Zealand Incorporated (“IHC”) to be caregivers for their son. The IHC informed the Hills that they could not be employed as their son’s caregivers because they were family members; his parents contended that in disallowing their application the IHC was in breach of the prohibition against family status discrimination in the Human Rights Act.

[66] The IHC argued that they were carrying out a policy of the (then) HFA that disallowed payment to family members. The CRT found that in fact there was no explicit or implicit policy on behalf of government to do so and found that the policy was at the discretion of the IHC and was discriminatory.

[67] This led to an executive level review of the policy and payments for the support of family caregivers. Policy work on the exclusion of payment to family caregivers began in



2002 with the creation of an Interdepartmental Working Group set up to review the issue of payments to caregivers.

[68] It followed the drafting of a Ministry of Social Development paper on "The Implications of the Hill case" (page 1002, agreed bundle) and noted that such payments had a number of difficult and complex ethical practical problems. The paper listed the following concerns (page 1007, paragraph 29, agreed bundle):

- payment to family caregivers through a contracted service provider will confuse the relationship between provider organisations and families.
- concern about the quality of family care giving, and how to monitor this and the intrusion into family "freedom of choice" and privacy.
- concern about protecting the rights of people with disabilities to exercise freedom of choice regarding who their caregivers are to be.
- concern that payment to family members as caregivers might distort the relationship between family and people with disabilities, in particular the "duty of care" by parents for a child with a disability.
- concern that payments to family members as caregivers might lock adults with disabilities into non normative living situations.

[69] This paper also noted that "...it may be possible to financially support caregivers on a different basis, thereby avoiding the inherent policy problems of paying them as contracted or employed service providers." (page 1012, paragraph 61, agreed bundle).

[70] It appears that the policy review work continued through 2002, with the involvement of the Office for Disability Issues (ODI) drafting a report (Payments to Family Caregivers: Preliminary Progress Report "Second Draft" 6 November 2002, page 911, agreed bundle) which concluded that "Issues around rights and responsibilities across families, individuals and the state require further debate, and are likely to be far broader than solely related to family caregivers of people with a disability." (page 922, paragraph 41, agreed bundle).

[71] In June 2003, the Cabinet Social Development Committee (SDC) agreed that the ODI lead a review of payments to and support for family caregivers of people with disabilities (Cabinet Social Development Committee Min (03) 12/5) (page 898, agreed bundle). A supporting policy paper suggested that before any options could be developed or evaluated "key questions need to be resolved about government's objectives for its caregiver policies in relation to people with disabilities, and



government's position on the respective responsibilities of people with disabilities, their families, and government in relation to the cost of caregiving".

[72] This SDC minute also noted that "...progressing the policy review of payments to and support of family caregivers of people with disabilities is crucial in light of the current legal framework that leaves the Government potentially in breach of the Human Rights Act 1993 and the New Zealand Bill of Rights Act 1990;" (page 898, agreed bundle).

[73] We were told that papers prepared for a report to the Cabinet SDC in March 2004 (Payments to and Support of Family Caregivers of Disabled People: Government Objectives and Position on Responsibilities in meeting costs of Caregiving) noted, for example (page 835, agreed bundle):

- while there are no financial implications for the paper, recommendations in the subsequent report may have significant financial implications.
- similar concerns to those raised in the earlier Social Development Committee paper (as set out above).
- commented that New Zealand, like most other countries, has tended to operate with an implicit social contract under which caring is accepted as a natural part of family life and undertaken as a familial duty.
- referred to the difficulty in making direct comparison of other countries' programmes and experience is difficult and not always appropriate, as respective countries' models generally reflect their own social milieu and public policy context.

[74] We were also advised that work on the issue went into recess until May 2005 when it was proposed to split the workstream, with one looking into the question of whether there was a "justified limitation" in terms of the Bill of Rights Act, with a second stream considering options for supporting family caregiving other than by the employment of family members.

[75] The workstream looking at the question of "justified limitation" noted its purpose was to consider whether there were good policy or practical reasons constituting a justified limitation in terms of the New Zealand Bill of Rights Act for the continuation of the policy preventing employment of family caregivers to deliver Ministry of Health funded support services.

[76] The first draft of its work was issued in August 2005 (Payments to and Support of Family Caregivers of Disabled People: ineligibility of family members for contractual employment as Caregivers: an assessment) and was reported as recommending the



continuation of the current policy but that “the Ministry of Health should retain the right to make exceptions to this policy, and should develop a consistent basis for this” (page 709, paragraph 5, agreed bundle).

[77] It appears that this draft report (an internal document) was revised in December 2005 and we were told it received an adverse response from the Department of Prime Minister and Cabinet and the Ministry of Social Development.

[78] Subsequently, we were told that the Minister for Disability Issues reached the view that no further work was required on the “justified limitation” paper as the issue had been “superseded by this case.”

A Carers Strategy and Carers Allowance

[79] However, it appears that related work did continue with a report to the Minister from the ODI (Payment to and Support for Family Caregivers, 20 October, 2006), setting out progress on the project and outlining a new approach, stating “We want carers to be able to provide care to a disabled family member, if they choose to and the disabled person wants them to provide that care, and it is appropriate for them to do so.” (page 491, agreed bundle).

[80] It recommended that further work should be undertaken as part of the development of a Carers Strategy, to develop options around the introduction of a Carers Allowance, that:

- recognises the contribution that carers make through the provision of unpaid care, and the impacts on them of providing this care;
- has no impact on the eligibility for access to available supports;
- is for the carer and has no impact on the disabled persons level of income support or eligibility to access other supports;
- replaces the Child Disability Allowance, but is available to carers of disabled people, whatever their age;
- is relatively easy to access (minimally intrusive, administratively simple);
- is respectable;
- is an entitlement rather than a discretionary benefit;
- is not means tested (to avoid any incentive to leave the paid workforce).



[81] The ODI was then told not to separately advance policy work on the payment of family caregivers, and instead to continue to support the development of the Carers Strategy.

[82] This proposed strategy was then consulted upon and the findings of this presented to a meeting (in October 2007) of the departments working on the project; the key priorities for action were identified as:

- protecting the health and well being of carers;
- having a break, a key part of protecting carers' health and wellbeing;
- information provision, a key factor in supporting the other priorities;
- financial support for carers; and
- the provision of training and pathways to employment for carers.

[83] We were told that in April 2008 the Cabinet Policy Committee approved a New Zealand Carers Strategy and Five Year Action Plan (Ministry of Social Development, April 2008, page 110, agreed bundle); the development of the carers allowance proposal within the first three years was discussed in an attached paper.

[84] In the Strategy and Action Plan, the carers allowance proposal is discussed thus "This action plan will develop a proposal for a Carers Allowance payment similar to the Child Disability Allowance, to be made available to some informal carers of adults to acknowledge their caring role" (page 136, agreed bundle) – this would be available to carers through the social welfare system.

Summary of the Policy Issues

[85] The above chronology of events shows that the topic of non payment to carers looking after family members in the family home has been the subject of considerable debate at executive and cabinet committee level, over many years.

[86] It appears that the 2001 ruling of the Complaints Review Tribunal ("CRT") decision in *Hill* led to the need for a review of the "policy", which spanned many committees and was the subject of numerous draft papers and reports, but without a clear cut position on the topic being reached.



[87] Instead, it seems that these proceedings and the CRT findings, together with the ongoing work and the Carers Strategy and the Five Year Action Plan, resulted in the matter being put on hold.

The “Exceptions Policy”

[88] As the proceedings progressed, the Tribunal was informed that there were a number of exceptions to the policy to exclude the payment of family members. It was apparent that in preparing for these proceedings, the Ministry found that a considerable number of family members were being paid for their care in the home, without appropriate authority.

[89] The Ministry then carried out a general review which revealed that there had been 272 exceptions made (out of approximately 11,000 home based service users). This approval was apparently given at the level of some assessment agencies. Ministry policy is that requests for exceptions to the non-funding policy need to be referred to head office and it advised that currently it has agreed to short term exceptions in a few cases only, to allow families to make alternative care arrangements.

[90] Reasons given by the approving NASC agencies for such exceptions were stated as being cultural; client/family choice; unavailability of carers or of carers skilled enough to care for the complex high need disabled; geographic isolation and safety reasons.

[91] It is of relevance to this hearing to note that the assessing agencies concerned felt there were good enough reasons to make such exceptions (where they were in fact aware of the policy) in such a number of cases. The range of reasons was notable.

[92] The Tribunal would observe that, albeit not knowing of the details behind the situations where these exceptions were made, it is not surprising that in such a complex and wide ranging field of disability needs and family dynamics the need for flexibility in policy application will arise from time to time.

The Accident Compensation Corporation (ACC)

[93] The plaintiffs did not plead that they were discriminated against compared to those permanently disabled by injury, where there is legislative provision which allows the ACC to employ relatives including parents and spouses to undertake their care at home, on a contractual basis. We were advised that more than half of the ACC's home



support services were provided in this way. However, although both the defendant and the plaintiffs made repeated reference to this distinction, only one witness was called (by the plaintiffs) specifically to refer to the care of some persons with disability resulting from injury; no expert witness was called by the defence on this matter.

[94] We were also advised that the Ministry and the ACC recently met to produce a combined service specification concerning the eligibility for and the delivery of home care – in other words, with regard to care in the home, when defining these needs, no distinction is made for those with disabilities whether accidental or non-accidental in causation.

[95] The information which was made available to us allowed for some conclusions to be drawn as to the pros and cons of reimbursing family members for their care in the home, based on the experience of the ACC.

[96] The experience of involving family members in the care at home of those disabled through an accident has recently been reviewed by the corporation, as revealed by several internal documents. Some focus groups they set up and reporting in 2007, sought feed back from some ACC staff, comparing the outcomes in the use of contracted and non-contracted (family members and informal carers) in home care. It was reported that “Participants unanimously agreed that there is no discernable difference in quality and rehabilitation outcomes between these two approaches to purchasing home support services. All participants identified that contracted and non-contracted services are complementary and essential to the smooth running of the system”. (page 1294, paragraph 14.2, agreed bundle).

[97] The participants are also said to have made it clear that there are risks with both contracted and non contracted services for claimants and the ACC, and that these risks could be reduced with better monitoring and accountability mechanisms.

[98] Also of note is that it was reported that the ACC carried out a search for information about the outcomes for the paid provision of home support services by family and friends relating to people with disability through injury. It found that a number of countries reimburse family and friends for this care under certain circumstances.

[99] The ACC documentation provided to us also outlined some risks where the family provided home support care such as the lack of standards for non contracted care;



changes in normal relationships when family members provide care; the risk of family dependence on income if a large package of care is provided to the family; no limits on the amount of care support members can provide (not a risk with the Ministry assessment process for the non-injured) and social isolation of the claimant and/or family member.

[100] Other documentation supplied to us referred to four work streams set up to assist in the development of its purchasing strategy; one of these being to develop and implement a policy on non contracted providers so as to ensure claimants make informed decisions about the appropriate mix of providers, receive quality care and are supported in putting appropriate arrangements in place for supporting home support services, together with appropriate levels of pay, training and support for family care givers.

[101] Overall, all this information demonstrated to us that the payment of non-contracted family members to provide care, is an integral part of the ACC's strategy for caring for persons disabled by injury, in the home setting.

[102] The Corporation has identified some inherent risks in this approach (just as there are for contracted providers) which can be mitigated by further policy development and subsequent implementation to improve monitoring, accountability and relief for home carers. It is also evident from their wider research and evaluation, both locally and internationally, that there is little discernable difference in the outcomes of care for the disabled, whether or not family members are paid for their caring functions.

[103] It would therefore appear from the experience of ACC in the payment of family members as home carers that there is insufficient evidence to suggest that excluding the parents of those with non accidental disability from equivalent payment arrangements is a supportable policy position. This is particularly so when both the ACC and the defendant have jointly developed and are applying a common set of service specifications for the home based care of disabled persons, no matter what the cause of the disability. It would seem artificial to us to make a distinction as to payment options to family members for home care, purely on the basis of the cause of the disability.



The New Zealand Disability Strategy

[104] The New Zealand Disability Strategy (the NZDS) has significant relevance to these proceedings and was described to us as a fundamental document underpinning policy development for the care of the disabled. (Agreed Bundle, pg 1035). For example, a Cabinet decision in 2004 concerning objectives for policies in this area indicated that its statement of objectives needs to be consistent with the overarching goals of the NZDS.

[105] The New Zealand Public Health and Disability Act 2000, which took effect on 1 January 2001 required the Minister for Disability Issues to develop a strategy for disability support services. A sector reference group was appointed to advise the Minister. This group comprised fifteen people with a wide range of expertise and knowledge of disability issues. In liaison with the Ministry of Health, it developed a discussion document which was released as part of the consultation process.

[106] Input from this was reflected in the recommendations for the NZDS presented in December 2000 by the sector reference group to the Minister for Disability Issues and the Minister of Health. The NZDS was prepared, based on a modified summary of the groups' recommendations. We were told that the strategy is a wide ranging overarching document that applies to all of government – it is a guide to government to promote an inclusive society for disabled people and is about establishing a framework for government departments to work within.

[107] The NZDS as set out on the website of the Office for Disability Issues set out the vision and objectives of the strategy (of note was that the vision statement differed from that in the strategy included in the agreed bundle made available to us) and some of these are relevant to this hearing.

[108] The initial summary section of the NZDS states that "Disabled people will be integrated into the community on their own terms, their abilities will be valued, their diversity and interdependence will be recognised and their human rights will be protected." (page 1044, agreed bundle). It then goes on to present a vision of a non-disabling society in which "individual choices are available and respected" and that "interdependence is recognised and valued, especially the important relationships between disabled people and their families..." (page 1044, agreed bundle).



[109] This vision statement is then carried through to a number of objectives, some again being of relevance to us, for example:

Objective 7.1 sets out that "...eligibility criteria and allocation of resources are nationally consistent, but that individual needs are treated flexibly"; (page 1064, agreed bundle)

Objective 7.2 refers to the need for government agencies to "...ensure that the disabled person is at the centre of service delivery"; (page 1064, agreed bundle)

Objective 15.2 asks for improvement in "...the support and choices for those who support disabled people" and (page 1072, agreed bundle)

Objective 15.4 asked that, where appropriate "...the family, whanau and those who support disabled people are given an opportunity to have input into decisions affecting their disabled family member." (page 1072, agreed bundle)

[110] Also of note is the reference to the NZDS in the Ministry of Health Service Specifications, in force for several years before recently being replaced by a common set shared with the ACC. In the section of the specifications relating to Home Based Support services (page 2027, agreed bundle) it refers to the Disability Support Directorate Philosophy statement which says "The aim of this service specification is to build on the vision contained in the...NZDS" and further says "Disability support services should ensure that people with impairments have control over their own lives. Support options must be flexible, responsive and needs based. They must focus on the person and where relevant, their family and whanau, and enable people to make real decisions about their own lives." (page 2027, agreed bundle). A footnote states "Subsequent references in this document to the 'person' or 'people' should be understood as referring to a person/people with impairment(s)." (page 2027, agreed bundle)

[111] The defence argued that the policy decision not to pay parents and spouses to care for family members can be supported on the grounds that a disabled person is in fact, free to choose a resident family member to provide their personal cares. The Tribunal can only speculate as to how many families have in fact felt not able to choose the option of care by resident family members for the reason that it was not financially viable.

[112] The defence also stated that Ministry funded disability support services step in and provide options available to a disabled person by providing other options but this



seems to miss the point that the option of having close family members provide their care, is one option that is not available where funding support (if needed) is not available to them .

[113] On the surface, the policy ruling of the Ministry seems to act contrary to objective 15 of valuing "...families, whanau and people providing ongoing support" and in fact, has the potential to lessen the supports and choices to those who support disabled persons.

[114] Overall, we would have to question how far relevant parts of the vision and objectives of the NZDS have been carried through into policy formulation, where these specifically exclude the option of paying parents or a spouse – but approves payment for other family members. Acknowledging that the plaintiffs are few in number in relation to the total number of persons receiving funded disability care, there would appear to be an apparent dichotomy between the vision and objectives of the NZDS and the reality of its application in practice, in those family situations brought before us.

[115] We would agree with the comment of the report of the parliamentary Social Services Committee (Inquiry into the quality of care and service provision for people with disabilities, September 2008) which said "In particular, the New Zealand Disability Strategy, introduced in 2001 to widespread support from the disabled community, has not been effectively implemented." (page 8).

[116] We would agree with the NZDS objective 15.7, to "Encourage debate around responsibility for caring, payment for caring and how to further recognise and value the caring role." – such a debate seems long overdue and has only recently commenced in the discussions around the question of a Carers Allowance. We would encourage such a debate, as a matter of considerable urgency and importance.

The Concept of "Natural Support"

[117] Disabled people in New Zealand can be assessed for access for government funded support services to help meet their disability related needs. The Needs Assessment and Coordination functions (the NASC process, see para [50] is the means of assessing these needs, identifying options for such support services and accessing (but not providing) these services.



[118] In determining the level of support that can be offered to a disabled person cared for at home, the Ministry requires the assessment agencies contracted to undertake this process, to assess the level of "natural support" available to each person.

[119] The concept of natural support is defined in paragraphs [53] and [54] above.

[120] The assessing agency is required first to determine the level of support available to each disabled person from within their natural supports so defined, before it allocates any additional assistance to the family. One Ministry witness stated the framework is based on the expectation that in general, families will provide a reasonable level of support for their disabled family member, so that assistance will step in only where needed in addition to this support. In other words, this natural support must be fully explored and engaged before additional outside help is considered, approved and then funded.

[121] Another Ministry witness commented that "Under the current model, supports are only assessed as needed if they cannot be met by natural supports. I cannot see how a person can say that they should be paid for support they have already indicated they are not able to provide." (Statement of Evidence, Deborah Hughes, paragraph 75).

[122] By implication, once family assistance is fully utilised in providing this support, then there is no place for a family member to be further involved in the care of the disabled person (whether paid or not) and any such further assistance must be provided from outside the home.

[123] This position appeared to be modified in the closing submission of the defendant, which stated that "The NASC process is subjective from the point of view of the disabled person and their family and other natural supports – it is based on what the individual and their family say they can and/or want to do in terms of meeting the disabled person's support needs." (paragraph 58, defendant's closing submissions, part one).

[124] This closing statement suggests that there is an element of choice for the family support as to what they are willing to undertake. If these expressed needs exceed what the family and their supports is able, or prepared, to provide as part of their "natural support" then these are funded and provided by the Ministry without an expectation (judgement) that family members should provide them, as a matter of course.



[125] In other words, it appears from this statement that it is not an absolute requirement for family support to be fully engaged before Ministry funding assistance can be considered.

[126] The Tribunal is of the view that the concept of natural support is, in reality and practice, a very flexible concept. The "boundary" between what could be considered to be natural support and that which the Ministry should fund by way of DSS is a movable and fluid interface, depending upon a number of variables.

[127] The first, obvious variable is the type and level of disability of the disabled person themselves – those with mainly cognitive disabilities differ in their support needs compared to those with a predominantly physical disability. From the plaintiffs personal histories', it was evident to us that some severely disabled persons can have a high level of intellectual function, whereas others function well below their chronological age. The resulting care burdens placed on a family can vary considerably, as a result.

[128] The level of available "natural support" in the home setting will also of course vary considerably according to the number of potential support persons living in the house.

[129] The wishes and the needs of the family themselves also need to be taken into account; some family members will readily give as much help as they can, and others will wish to limit their support, to enable them to engage in other out of home activities, often with other dependants. In some such cases, the disabled person would need to leave the family home to be cared for in a residential home or by contract board, particularly if they are heavily dependent.

[130] Then there is the obvious difference between ethnic groups, as to what is regarded as natural family support; it was noted to us that Maori and Pacific peoples generally have wider family/whanau/aiga support networks and higher expectations from such family support than for non-Maori, for example.

[131] The disabled person themselves will also have views (where these can be expressed) as to the level of family support that they would prefer, which can also change over time, as they age.

[132] It was also evident to us that the level of support the family is expected to provide can vary according to the day of the week – weekend support from visiting carers is



generally less than on week days, and on public holidays, it appears that only core support is provided by contracted agencies – the result is that the family members pick up the slack, so moving the boundary of natural support, according to the calendar.

[133] In summary, we see the concept of family support as being significantly influenced by a number of variables; a standard approach is not appropriate to determine where the boundary is drawn between what a family can do or should do, in support of a disabled family member.

[134] The Tribunal would also note the general societal expectation that the family is the prime care giver for infants and children without major disability, functioning as the natural support until such time as the individual reaches self supporting adulthood and is able to leave home and care for themselves.

[135] Also of relevance is the fact that many non-disabled adults elect to stay in the family home once having reached independence – they may assist in the running of the home but there is no expectation that their daily personal support needs are to be provided by other family members.

[136] We were also advised that the ACC (which by law is able to offer the option of paid parental care for persons with long term disablement as the result of an accident) sees the age of 14 years as the time at which this additional support can be made available.

[137] As noted above, in determining care needs, assessing agencies are required to determine the level of natural support available including what the family could provide, taking into account such considerations as the wishes of the disabled person; the type and extent of the disability being supported; ethnic factors and the need for carers to have regular, reliable relief - all being very relevant issues to take into consideration.

[138] The Service Specifications of the Ministry (recently modified) did set out the range of personal cares that a disabled person may need in the home setting – including help with feeding, toileting (in some cases, requiring nappy changes), bathing, dressing and grooming and in communication. The care needed can be extensive as assistance with feeding can take an hour or more per meal, if swallowing difficulties exist. Similarly, help with washing and dressing can be a time consuming exercise.



[139] Many of the cares required as set out in these Service Specifications would be a considerable burden on any family – and much more for a single parent family (which was the situation for many of the plaintiffs appearing before us) and many would be of a very intimate nature.

[140] The Tribunal does not regard it as natural for the support required for an infant or a child to be carried on into adolescence and adulthood with the expectation that this personal care should continue on an unquestioned basis. We would classify this as a need for “disability support” as distinct from the concept of “natural support”; a clear distinction needs to be drawn between the two.

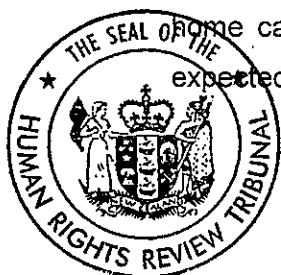
[141] It is a matter of choice for the disabled person and their family to decide if they wish to undertake this, sometimes life long, commitment. In doing so, long term planning needs to be undertaken for the time when an adult carer will no longer be able to undertake such care and it was clear to us that those concerned are aware of this and are anticipating and planning for that day.

[142] As discussed, family members (with adequate relief and support networks) may be able to provide some assistance with personal and household cares, but in many cases this assistance may be minimal, particularly in the case of the severely disabled. The Tribunal accepts that once adulthood is reached, the expectations placed on the family of a disabled person should not be greater, because a family member is disabled.

[143] This is not to say that if it is the wish of the disabled person, many families are willing and happy to give assistance over and above what we would regard as reasonable natural support, but it must not be a uniform expectation of them. Ministry witnesses spoke of the concept of “reasonable” support provided by families – described as the minimum measure of the basics a family would normally be expected to provide.

[144] These were described as things like a bed, access to a shower and toilet, the ability to share a family meal, assistance in getting to school or other day activities, such as work.

[145] It was said to be a minimum that the Ministry expects families to provide, which for adult family members was said to be “very low”. We note that the ACC, in determining some care entitlements takes into account “what family members can reasonably be expected to provide.”



[146] The Tribunal sees the test of “reasonableness” as key in determining the level of personal cares family members would be expected to provide to a disabled family member. It must be assessed on an individual family/whanau/aiga, case by case basis taking all the variables listed above into account. Needless to say, this evaluation of family circumstances must be carried out with considerable sensitivity.

[147] We were told that the NASC system first assesses what a person actually needs in the context of what they and their natural supports can provide, and then allocates services to address the gaps. We would prefer this statement to read “what their natural supports can reasonably provide” so as to incorporate the test of reasonableness as an accepted part of the assessment process.

[148] Once what is reasonable is determined for each family, it is then another matter as to whether additional personal care and home support services (if needed) are provided through Ministry funding, over and above this “reasonable” level of family support.

[149] Family members should not feel guilty if they are not able to extend the supports for daily living given to a developing child with a disability, into adulthood. But if they do decide that they are able to provide care over what would be regarded as a reasonable level of natural support, they should not be disadvantaged because they are prepared to do it.

[150] At the other end of the spectrum is the interface with medical and nursing care; many more severely disabled persons need help with bowel management, catheterisation for bladder control and in some cases, parenteral (non oral) medications to control aggression or to lessen excessive sexual drives. In these cases, we see a clear delineation as to who should provide this care – it is not a responsibility of the DSS carer staff but instead a matter for the local Health Board district and home nursing services. The care coordination plan worked out by the DSS assessing agencies for such persons would link into these nursing and medical services, as a matter of course.

Financial Considerations

[151] Historically, one of the “demonstrably justified” limitations given for prohibiting payment to parents and spouses for caring for a family member were the “substantial fiscal implications” of such a policy decision. We were informed that the Crown Law



Office has stated that a general change to the government's policy regarding employment/payment of parental caregivers would have significant financial implications for the government's resources and that in the disability sector resource limitations are often accounted for in arguments concerning reasonable accommodation and that reasonable accommodation is generally understood to involve some kind of cost benefit analysis.

[152] These statements are not backed by any apparent detailed review of the potential fiscal impact of such a policy change in the disability sector. The original policy decision dates back to the early 1990s when the newly established Regional Health Authorities were given the responsibility of purchasing health and disability services from the providers of such care throughout the country.

[153] No evidence was presented to us indicating that a detailed study of the costs and benefits (and the wider impact of a policy to prohibit payments to parents and spouses) was carried out, prior to the implementation of this purchasing strategy for disability care. It appears that the first detailed costing review as to the implications of paying parents and spouses as carers, was undertaken by the defendant in preparation for this hearing.

[154] Both the plaintiffs and the defendant engaged expert witnesses to assess the financial implications of any such policy change. The defendant's expert witness carried out a number of modelling scenarios, primarily focusing on the financial impact of these models on the disability sector itself, with passing reference to the potential wider fiscal impacts for the public sector.

[155] From the briefs presented to us by each expert witness, it is evident that several factors influence the assessment of the likely financial impact of any policy change:

- [a] The first issue is the need to determine the total number of persons with a disability in New Zealand and related to this, the number not currently receiving disability support services (with the potential to access these in the future).
- [b] One set of data presented was extracted from the Statistics NZ New Zealand Household Disability Survey 2006 and the related Disability Survey of Residential Facilities, together with a specially prepared estimate of the number of people with disabilities by age and severity of limitation (excluding those with disability due to age and injury), also prepared by Statistics NZ. These data relate to information that was



self reported and reflects the respondents own assessment of their condition.

- [c] The second set of data was based on the cost of disability services being funded by the Ministry of Health and therefore reflects the support care as assessed at the time, for persons with disabilities – disability status is therefore externally validated, in contrast to self-reporting. Again, this data (except in a few cases) excludes the provision of care to persons over 65 years (as provided by District Health Boards) and those assisted by the ACC. Ministry transaction data for the 2006 year reported total expenditure for disability services as being \$429.9 million, of which \$11 million was spent on low use non-residential care; \$86.7 million for high use non-residential care and \$332.2 million for residential care. (Statement of evidence of Jean-Pierre de Raad, the Ministry's expert witness, page 9, table 3).

[156] In summary, the defendants analysis is focussed on the disability support needs for those with major disabilities (moderate and severe disabilities) under 65 years and as funded by the Ministry.

[157] Not surprisingly, these various sets of data provided information that was not easy to reconcile. But it was evident (and agreed by the parties) that there is a significant number of people with severe disabilities who do not receive Ministry funded disability support services – this group could total up to 29,000 in all.

[158] We were also advised that the Ministry's expenditure data does not have direct measures as to the severity of disability and also that Statistics NZ survey data does not show how much or little help people receive, for their disability. Also, it does not show whether disabled persons have been formally assessed (by the NASC process) as to their disability needs and therefore found to be entitled to disability assistance from the Ministry.

[159] Similar difficulties were experienced in defining the number of disabled people in receipt of residential care, with the suggestion that Statistics NZ data excluded those residing in small scale facilities – some of whom also receive funding from non-governmental sources.

[160] Noting these difficulties, the assessment of the financial impact of a change in Ministry policies was evaluated by the defendant's expert witness according to four major groupings of disabled persons:



- [a] Those disabled people currently being cared for by external (non-family) caregivers who may, in the future, wish to be cared for by a family member. The financial impact of this change is likely to be zero, because the funding currently allocated would simply switch from a non-family to a family member.
- [b] Some highly dependant disabled persons who already receive non-residential support care may currently receive some care from immediate family members in preference to care from "outsiders" – no information was provided as to how much of this "unfunded" care is currently being provided.

However, if the switch involved 10% of such persons, the cost impact was estimated to be \$8.7 million per annum; if there was a 90% switch, the potential cost was said to be in the order of \$78 million per annum.

- [c] The third grouping would be those people currently receiving no or minimal services. As noted above there is agreement that it appears approximately 29,000 persons with severe disabilities do not receive funded support. It could be anticipated that a full Ministry assessment would find the majority of them eligible for funding assistance (and as they are not currently in receipt of such assistance, this was described by the plaintiffs' expert witness as a significant failure of public policy.) The funding implications of this were tested at various probability percentages ranging from a 10% uptake (\$11 million per annum) through to \$272 million per annum for a 90% uptake.
- [d] The fourth significant group would be those currently in residential care, who may wish to switch to non-residential care provided in the family home.

Here, questions about the economy of scale were raised – in a residential home, one staff member can provide care for several residents, whereas in a private home the care is usually one to one. Conversely, residential facilities require 24 hour, seven days a week staffing coverage, this being provided automatically in the family home setting; (other difficulties in comparison would be the overhead costs which are inherent in a purpose built and maintained facility versus the already established family home, whose maintenance is by the family). Again switching percentages were assessed, ranging from a 10% switch through to 50%, the potential extra costs being \$16.1 million per annum to \$116.4 million per annum, based on a facility cost of \$315 per day.

[161] In total, for all groups, the defence expert witness estimated that the total additional costs could range from \$17 million to \$593 million – the plaintiffs expert witness assessed these at \$32-64 million.



The Potential Impact of a Change in Policy

[162] A range of issues present when trying to anticipate how many moderately to severely disabled persons would wish to take up the option of care in the family home, should there be a policy change to allow a parent or spouse to be funded for this care. The first and vital question would be how many parents/spouses of a disabled person would wish to change their life style so as to become a permanent home carer. In reality, there is no well researched and soundly based evidence as to how many disabled persons and their potential carers in the categories outlined above, would come forward to take up the change in funding options.

[163] We would agree with the statement of the defence expert witness that "The total cost impact depends crucially on the probability (or strength) of the response by clients and their family members to the proposal [to fund family carers]. I believe it is reasonable to assume that there will be some change as a result of a change in financial support. It is clear that people make decisions about care and support roles for a variety of reasons, which include societal or community expectations, a sense of duty, personal beliefs, and financial considerations, although there is little New Zealand specific research." (Statement of Evidence of Jean-Pierre De Raad, paragraph 35).

[164] Another significant uncertainty entering the equation is the potential financial impact of persons in residential care switching to funded home based care. Evidence from a Ministry of Health witness said that "The very high need category [of disabled persons] has a discretionary ceiling level that requires the NASC manager's approval. This level of funding however needs to comply with a range of Ministry guidelines and policies. For example, the cost of home-based care support services should not exceed the average cost of living in residential services. The NASC manager is expected to obtain the Ministry's approval if they believe a person's support package should be funded at a level that is outside [the Ministry's] funding guidelines" (Statement of Evidence of Deborah Ann Hughes, paragraph 52). In other words, the Ministry's approval should be sought as to whether an exception should be made (and if so, the level of financial assistance to be approved).

[165] Clearly, the application of such funding policies means that the assessment of their impact depends on a range of decisions made at the individual level and in aggregate, and these would be very difficult to quantify with any certainty.



[166] We are therefore unable to place a precise dollar figure on the likely financial impact of any policy change, with any confidence. But we do believe that it is possible to estimate generally the likely impact for each category, below:

- [a] Those disabled people currently being cared for by external, non-family care givers who may wish to change to paid family members – as noted earlier, this would be cost neutral.
- [b] Some highly dependant disabled persons, already receiving non residential support care from immediate family members, who could now be paid. The number of such persons in this category is not known and research would be required to determine how many people currently are receiving such unfunded support from their family; but we would not expect there to be a high number in the moderate to severe category.
- [c] Similar to this group are those with severe disabilities currently receiving no or minimal services from any source. As discussed earlier, this group appears to total up to 29,000 disabled persons. No information was provided to us as to why they are not accessing Ministry funded care, whether it be home based care, contract board, individualised funding or residential care, but there is likely to be a range of reasons. In any event, it is likely that almost all persons in this category would (through the NASC assessment process) be found to be entitled to financial assistance under current policy settings. The fact that they might, as the result of a policy extension to pay family members, pick up the funding assistance they are already eligible for (in whatever category) would not come under the “justifiable limitation” argument. They are already entitled to funding assistance and funding for their care would rightly be an entitlement under current policy settings.
- [d] Those currently in residential care who may wish to switch to care in the family home, provided by parents or spouses. Intuitively, we would not expect this to be a significant number, but again, more substantive research data would be needed, including the reason for them selecting the residential care option as their current preference. Also of note is the Ministry policy position reviewed above, where it is stated that any payment for home based support services should not exceed the average cost of living in residential services.

[167] Combined together, we believe the more likely potential cost increment is at the low end of the range quoted to us by the defence expert witness, if not well below if category (c) costings are excluded, for the reasoning set out above.

[168] Noting the difficulty inherent in trying to evaluate the financial impact of any change in policy, we believe that the case made for the fiscal impact to be a significant reason for this to be a “demonstrably justified” limitation – at least as far as disability support funding by the Ministry is concerned, to be based on an unproven foundation.



Much more solid policy and funding analysis would be needed, to make a convincing case, one way or the other.

[169] Certainly, it appears that this evidence base was not clearly formulated when the policy ruling was first applied and then maintained in subsequent years and then given as being a “justifiable” limitation.

Measures to limit the financial impact

[170] Any decision to allow close family members to be paid for their care, need not have open ended fiscal implications – there could be a number of strategies available to control this exposure.

[171] For example, one option would be for the Ministry to permit the payment of a parent or spouse to be treated on an exceptions basis (see paras [88]-[90] above); a policy could be formulated to extend the present very limited exceptions criteria of the Ministry, the criteria for approval could include the personal and family circumstances of the applicant, the carers preparedness to be trained and audited for this care and the need for regular carer relief to be undertaken. Approval could be given on a case by case basis, provided these criteria are met. The level of these approvals could be influenced by the budgetary allocation available.

[172] Another control could be through the Individualised Funding option which is being gradually developed and expanded by the Ministry (and which some plaintiffs said they favoured) and which is administered within a budgetary ceiling set by the Ministry. Each applicant is assessed as to their ability to take up this option and their ability to administer the payment obligations is evaluated and monitored, with assistance provided as required. We note the observation from a Ministry witness that this scheme gives disabled people more control over who comes into their home, who provides them with the services they have been assessed as needing and how these services are provided.

The wider Public Policy implications

[173] Passing reference was made as to the fiscal impact of a decision favouring the plaintiffs, in the wider public policy area. We were told that District Health Boards are responsible for resourcing the care of persons over 65 years with disabilities, many of



whom are supported at home by family members. Accident Compensation Corporation funding for those disabled by accident is resourced from its own income sources and is not relevant to this issue.

[174] This consideration was outside our brief, but clearly is a matter for wider policy review and in this regard, could come within current work on the Carers Strategy and the issue of a carers allowance. A Ministry witness told us that there has been extensive work on the issue of further financial support to carers in relation to the Carers Strategy and that the Strategy includes in its action plan the development of a proposal for a Carers Allowance. This allowance would be paid through the Ministry of Social Development.

[175] This comment indicates that there is policy work already being undertaken to assist (and potentially to fund) carers for those looking after dependants, not only in the disability field, and would not be the consequence of any finding in the plaintiffs' favour, by this Tribunal.

Social Contract

[176] Submissions from counsel for the plaintiffs disputed the claimed significance of a social contract observing that despite its critical place in the Ministry's justification for the challenged policy, no evidence of such a contract was offered and no definition was given. The Tribunal appreciates that Dr Easton was called on behalf of the plaintiffs to give evidence on the possible fiscal implications of any change in the policy but the opportunity might have been taken to have his assistance on the notion of a social contract. In a paper published in 1990 under the heading "The Social Foundations of New Zealand Governance" Dr Easton reminded us of some of the origins of the expression. He observed that many important political philosophers have contributed to the theorisation of the contract. As he observed, John Locke's writings in the seventeenth century arose out of the political turmoil of the "Glorious Revolution of 1688". It was Jean Jacque Rousseau writing in the middle of the eighteenth century who popularised the phrase.

[177] Recognising that debate continues as to the theory of the social contract Dr Easton contends that New Zealand certainly has a social contract by reason of the Treaty of Waitangi. Dr Easton also refers to the work of John Rawles who published his *Theory of Justice* in 1972. More recently and closer to home the Tribunal notes the



publication in 2007 "*Society and Politics New Zealand Social Policy*" by Grant Duncan of Massey University, Albany a social scientist and university teacher in social policy and public policy. While these passing references from our own researches leave the Tribunal in no doubt that a social contract in some form or another can be identified and may have importance for many purposes, we are a long way short of being able to specify the actual ingredients of a social contract in New Zealand. This is the case of course with all witnesses who were asked about a social contract.

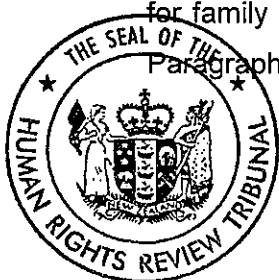
[178] Counsel for the plaintiffs pointed to the various references to a social contract in the evidence. The first is a paragraph in a Cabinet Social Development Committee paper included in the Agreed Bundle of Documents Vol 2 p.835 at 838 which has at paragraph 17:

"New Zealand like most other countries has tended to operate with an implicit social contract under which caring is accepted as a natural part of family life and undertaken as a familial duty. There is an underlying, though not formally articulated principle that people should not receive payment from the state to provide care for family members, including disabled family members, to whom they owe this 'familial duty'."

[179] However the authors of that paper qualified that proposition by recognising that families caring for disabled people have responsibilities over and above those ordinarily faced by families. There is also the ruling of our predecessor the Complaints Review Tribunal in the *Hill* case (see paragraph [65]). Also of particular significance is that ACC allows disabled clients to engage immediate family members as caregivers. ACC's legislation requires consideration of the extent to which "household family members" and other family members can reasonably be expected to provide care.

[180] Dr Peter Watson in evidence for the Ministry referred to payment to parents as caregivers requiring a change in the social contract we have had up until this point in time. He thought that should happen only after appropriate debate. In cross examination Dr Watson accepted that a social contract varies as between societies and cultures, it is fluid, changes over time and that payment of family members by ACC may be part of the evolution of the social contract.

[181] We are all aware that there are many circumstances in which the state makes financial provision for a variety of people, sometimes in cases to assist people in caring for family members, usually younger children in the cases we presently have in mind. Paragraph 83 of the decision of the Tribunal in *Child Poverty Action Group Incorporated*



v Attorney-General [2008] NZHRRT 31 is a convenient summary of five forms of financial assistance available to families caring for children. They are:

- [a] The Family Tax Credit
- [b] The In-Work Tax Credit
- [c] The Child Tax Credit
- [d] The Parental Tax Credit
- [e] The Minimum Family Tax Credit

[182] Those with longer memories will recall the Family Benefit which was a feature of New Zealand society for many years and for many families assisted in the purchase of a first home through the Family Benefit Capitalisation scheme.

[183] The Tribunal concludes that notwithstanding the invocation of a social contract as the main reason for not paying parents and resident family member in the circumstances described in this case we are unable to discern the existence of a social contract having the force contended for. This is particularly so when legislation has authorised, indeed requires, payment under the ACC scheme to be made to those who may be parents or resident family members of persons who qualify for payments under that scheme. This conclusion is all the more compelling if, as the Plaintiffs contend, and we accept, the policy derived from the notion of a social contract is contrary to relatively newly established law as being discriminatory.

D JURISDICTION OF THE HUMAN RIGHTS TRIBUNAL

[184] Counsel for the defendant rightly pointed out that it was not within the jurisdiction of this Tribunal to “interfere” with the powers and functions of the legislator. However, it is within the jurisdiction of this Tribunal to inquire and if appropriate declare an act or omission of the legislative, executive and judicial branches of government as being inconsistent with the Human Rights Act and the New Zealand Bill Of Rights Act. The matter of deference to parliament will be discussed separately in this decision as this does not go to the question of jurisdiction.

[185] There is significant case law precedent to support the role of the judiciary and in this case the Tribunal as to the extent and scope of its jurisdiction in dealing with matters under the Human Rights Act and the New Zealand Bill of Right Act. As stated by Tipping J in *R v Hansen* [2007] 3 NZLR 1 at p 46; p10 “The Court’s function is not



immutably to substitute its own view for that of the legislature...In this way and to this extent the Court's function is one of review."

[186] For the purposes of the present proceedings before us, the Tribunal does not have the function of Judicial Review as that is the function of the Court, but it does have the function of inquiry.

[187] We therefore think there is no further purpose in deliberating this point, but, to affirm the inquisitorial role of this Tribunal.

E MATERIAL PRESENTED

[188] The Tribunal acknowledges the extensive and valuable submissions and legal argument from Counsel. As was the case before the Tribunal in *Child Poverty Action Group* (see paragraphs [112] and [113]) therof:

"[112] Counsel on both sides of this case presented very full and comprehensively researched arguments, drawing attention to various aspects of the problem, and describing the approaches in other jurisdictions (particularly, but certainly not limited to, Canada and the United Kingdom). We cannot hope to do justice to all that was argued, or to refer to (much less analyse) all of the various authorities and materials that we were directed to. In any event we come to the problem as first instance adjudicators recognising that, ultimately, any definitive description of what it means to say that there has been 'discrimination' under NZBORA or the HRA is a task more appropriate to the courts of higher jurisdiction. All we can realistically hope to do is to give a clear statement of the approach that we have taken, and explain our reasons for taking that approach.

[113] In addition, while we mean no disrespect to the submissions that we heard, we think it preferable to approach our task paying particular attention to the New Zealand authorities and other writings on the subject. That is not to say that decisions from other jurisdictions will not be referred to at all, or to suggest that cases from other jurisdictions are not persuasive. Far from it. We do, however, think it needs be recognised that the NZBORA solution to the problem of discrimination is not exactly the same as that embodied in (for example) the Canadian Charter of Rights and Freedoms, or in the European Convention on Human Rights, as incorporated into the law of the United Kingdom in the Human Rights Act 1998 (UK). In the end, the approach taken in New Zealand must reflect the New Zealand legislation and respond to New Zealand experience."

F STATUTORY FRAMEWORK

Relevant sections of the HRA and the NZBORA

[189] Section 20L of the HRA sets out which acts and omissions are in breach of Part 1A and provides:



- (1) An act or omission in relation to which this Part applies (including an enactment) is in breach of this Part if it is inconsistent with section 19 of the New Zealand Bill of Rights Act 1990.
- (2) For the purposes of subsection (1), an act or omission is inconsistent with section 19 of the New Zealand Bill of Rights Act 1990 if the act or omission-
 - (a) limits the right to freedom from discrimination affirmed by that section; and
 - (b) is not, under section 5 of the New Zealand Bill of Rights Act 1990, a justified limitation on that right.
- (3) To avoid doubt, subsections (1) and (2) apply in relation to an act or omission even if it is authorised by an enactment.

[190] Section 19 of the NZBORA provides:

- (1) Everyone has the right to freedom from discrimination on the grounds of discrimination in the Human Rights Act 1993.
- (2) Measures taken in good faith for the purposes of assisting or advancing persons or groups of persons disadvantaged because of discrimination that is unlawful by virtue of Part 2 of the Human Rights Act 1993 do not constitute discrimination.

[191] Section 5 of the NZBORA provides:

5 Justified Limitations

Subject to section 4 of this Bill of Rights, the rights and freedoms contained in this Bill of Rights may be subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.

[192] Section 21 of the Human Rights Act sets out the prohibited grounds of unlawful discrimination. The prohibited ground of discrimination relevant in this matter, Family status, is set out in s 21(1)(l) and in particular at 21(1)(l)(iv):

- (1) For the purposes of this Act, the prohibited grounds of discrimination are- [...]
 - (l) Family status, which means-
 - (i) Having the responsibility for the part-time care or full-time care of children or other dependants; or
 - (ii) Having no responsibility for the care of children or other dependants; or
 - (iii) Being married to, or being in a civil union or de facto relationship with a particular person; or
 - (iv) Being a relative of a particular person.



[193] The term "relative" is defined in s.2 of the HRA:

- 2 Interpretation
- (1) In this Act, unless the context otherwise requires,—
- relative**, in relation to any person, means any other person who—
- (a) is related to the person by blood, marriage, civil union, de facto relationship, affinity, or adoption; or
 - (b) is wholly or mainly dependent on the person; or
 - (c) is a member of the person's household

The two step test

[194] As is clear from s.20L of the HRA (refer paragraph [189] above) the Tribunal must first consider whether the policy breaches s.19 of the NZBORA. If the Tribunal determines that the policy does breach s.19 (*prima facie* discrimination) the Tribunal must then consider whether that breach is justified in terms of s.5 of the NZBORA.

[195] Although the parties agree that the test to be applied is the "two step test" they disagree as to how it is to be applied. The two step test is:

1. Is there discrimination as prohibited under s.19 NZBORA (plaintiffs must prove);
2. If so, is it a justified limitation under s.5 NZBORA (defendant must prove).

G THE FIRST STEP – *PRIMA FACIE* DISCRIMINATION: COMPARISON AND DISADVANTAGE

[196] The Tribunal must look firstly as to whether there has been discrimination on a prohibited ground. It is accepted and has been supported by Counsel that difference of treatment will not necessarily in itself amount to discrimination; and not all discrimination will be illegal.

[197] Under the first step the parties agree that it must be shown that there is:

- [a] a distinction based on a prohibited ground; and
- [b] that there is disadvantage.

[198] The Tribunal will need to identify the relevant comparator group to ascertain distinction and then see what, if any, disadvantage results.



Relevant Comparator Group

[199] The parties, in their closing submissions, both refer to *Quilter v Attorney-General* [1998] 1 NZLR 523, 573 in which Tipping J said that:

"The essence of discrimination lies in difference of treatment in comparable circumstances. For discrimination to occur one person or group of persons must be treated differently from another person or group of persons. Of course difference of treatment will not necessarily in itself amount to discrimination; and not all discrimination will be unlawful."

[200] It is critical therefore that the Tribunal identifies the correct and appropriate comparator group, that it ensures it is comparing apples with apples.

[201] Defendant's counsel submitted the appropriate comparator is someone who does not provide natural support and who has not previously indicated they are unwilling or unable to perform the work (page 1, paragraph 3, defendant's closing submissions, part 1).

[202] Plaintiff's counsel submit that the groups to be compared are parents, spouses and resident family members providing disability support services to a particular person (their child, spouse or resident family member) and everyone else able and willing to provide disability support services to the same particular person (page 61, paragraph 236, plaintiffs' closing submissions, volume 1).

[203] After the hearing was completed the Supreme Court issued its decision in *McAlister v Air New Zealand Ltd* [2009] NZSC 78. Both parties have filed further submissions dealing with the relevance of the decision to this proceeding. Mr McAlister was demoted by Air New Zealand when he turned 60 years old "because his age meant that he could no longer fly as pilot-in-command of a Boeing 747-400 aircraft in the airspace of the United States of America." (paragraph 2). The Supreme Court decided that the proper comparator was with pilots/instructors who have not attained 60 years of age (described as "a simple before and after age 60 comparison" at paragraph 33). The Supreme Court rejected the idea that the correct comparator was with pilots/instructors of any age who are for any reason debarred from acting as pilot-in-command in the United States on the basis that it would lead to an obvious result and leave no work for the relevant statutory exceptions.

[204] Unlike *McAllister* there is no specific wording of what best fits the statutory scheme (as found in s104 of the Employment Relations Act) to guide the Tribunal in this matter. Therefore under s19 of the HRA the Tribunal must find the appropriate comparator using



the wide and liberal application of the general anti-discriminatory wording of the HRA and the NZBORA, without applying the unnecessary and burdensome application to all and sundry acts or omissions of the Crown. The Supreme Court in *McAllister* stated that (paragraph 34):

"The task of the court is to select the comparator which best fits the statutory scheme in relation to the particular ground of discrimination which is in issue, taking full account of all facets of the scheme, including particularly any defences made available to the person against whom discrimination is alleged. A comparator which is appropriate in one setting may produce a completely inapt result in another. It will certainly do so if it effectively deprives part of the statutory scheme of its operation."

[205] In addressing the comparator issue the Tribunal also bears in mind the comments of the Tribunal in *Child Poverty Action Group* (paragraph [136]-[137]):

"[136] In their argument counsel for the plaintiff drew attention to the pitfalls inherent in placing too great an emphasis on comparator groups. Of the many references we were given we think it sufficient to illustrate the point by reference to the observations by Lord Carswell in R v Secretary of State for Work and Pensions ex parte Carson:

"Many discrimination cases resolve themselves into a dispute, which can often seem more than a little arid, about comparisons and identifying comparators, where a broader approach might more readily yield a serviceable answer which corresponds with one's instinct for justice. ... Much of the problem stems from focussing too closely on finding comparisons ..."

[137] We are inclined to agree with the plaintiff that in the analysis of discrimination a search for precise exactness of circumstances before one group can be regarded as a proper comparator for another, carries a risk of injustice."

[206] The plaintiffs' counsel argued "This is a case of blatant, direct discrimination. In this sense the application of the tests is straightforward and not complex. The prohibited ground of discrimination is written into the actual overarching policy itself. The groups to be compared are obvious. The Tribunal need not become further involved in the complicated legal arguments that sometimes arise as to who the proper comparator is." (page 83, plaintiffs' closing submissions, volume one). This we accept.

[207] The determination of the relevant comparator group as promoted by the plaintiffs above (para [202]) is that which we accept.

[208] Having accepted that the correct comparator group is that put forward by the plaintiffs then what is the factual matrix for our assessment? The witnesses for both parties identified similar if not identical care giving services, whether the care giver was a resident family member or not. This included feeding, showering, attending to



personal cares, lifting (in the evidence of some plaintiffs Burnett and Atkinson non-family care givers were prohibited from lifting duties) by way of examples. This approach was taken by the Supreme Court in *McAllister* where it compared the duties and relevant qualifications of pilots who were in command of a Boeing 747-400 aircraft.

[209] If the roles, or more importantly the tasks of the comparator group are similar if not identical to the roles and tasks of the plaintiffs then, what is the point of difference or distinction? The point of difference or distinction in *McAllister* was the prohibited ground of age. In the matter before this Tribunal, the point of difference or distinction is the prohibited ground of family status.

Has there been disadvantage?

[210] As to disadvantage, the Tribunal points out at this stage that it is not in a position to make an assessment on the successful, or otherwise, delivery of health and disability care to disabled persons in New Zealand. That is not our role.

[211] The personal circumstances of the plaintiffs have been referred to previously in this decision and need not be repeated here, nor will they assist this Tribunal as to whether there has or has not been a breach of Human Rights. We agree with the defendant's counsel that "The individual stories of seven or eight families are essentially irrelevant to that consideration." (page 7, paragraph 14, defendant's closing submissions, part 1). However, we comment and assume all parties to these proceedings agree, that these stories are relevant to these seven or eight families themselves.

[212] The disadvantage claimed by the plaintiffs is they are not allowed to be paid for the services they provide to their child (or children) while anyone else providing the very same care to their child (or children) is able to be paid. The two parents who are paid point to disadvantage arising from the Ministry's threat to discontinue payment. The plaintiff children said the disadvantage is lack of choice of a care giver.

[213] We find that the plaintiffs have been disadvantaged in the manner they describe.

[214] The Tribunal therefore finds that the plaintiffs have discharged their burden of proof and have established there is a prima facie case of discrimination as prohibited under s.19 NZBORA. They have satisfied the first of the two steps.



H THE SECOND STEP – JUSTIFICATION

[215] We now address the second step to determine if an exception is justified. It is for the defendant to prove the act or omission is justified and therefore a valid exception under HRA and BORA.

[216] As already noted s.5 NZBORA is:

5 Justified Limitations

Subject to section 4 of this Bill of Rights, the rights and freedoms contained in this Bill of Rights may be subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.

Prescribed by law

[217] In deference to the comprehensive arguments put forward by the parties in relation to whether the policy is “prescribed by law” as required by s.5 NZBORA the Tribunal briefly addresses this point. The plaintiffs assert that there is no evidence that there is a law (statutes, regulations, common law, orders in council or tertiary legislation) that provides authority for the Ministry’s policy (plaintiffs’ closing submissions, volume one, page 65-66). The defendant asserts that the Ministry’s policy is prescribed by law because “The...policy, as expressed in a series of guidelines and specifications, is given legal effect through the exercise of power in s10(2) New Zealand Public Health and Disability Act 2000 (NZPHDA) to enter into numerous Crown funding agreements on terms consistent with that policy” (page 74, paragraph 234, defendant’s closing submissions, part two).

[218] However, the Tribunal notes the statement of the Ministry in the revised draft (dated 22 December 2005) of *Payments to and support of family caregivers of disabled people: ineligibility of family members for contractual employment as caregivers: an assessment* (paragraph 32, page 617, agreed bundle):

“The policy of ineligibility of family members for contractual employment as caregivers of disabled people has never been set out in legislation, or been subject to formal executive approval by Cabinet. Because of this, it lacks a clear and transparent basis.”

[219] Assuming, but not deciding that the Ministry’s policy is prescribed by law the Tribunal will consider whether the policy is justified.



Deference to Parliament

[220] Before addressing justification it is appropriate to address the issue of deference to Parliament. This argument was put forward by Counsel for the defendant and rightly so. As noted at paragraphs [210] through to [214] of *Child Poverty Action Group* Tipping J provides an informative approach to this issue in *Hansen*. The Tribunal's position is in accord with that taken in CPAG at paragraphs [210] through to [214] of that decision:

"[210] The assessment of justification must allow appropriate deference to Parliament. This engages a principle of proportionality:

'Whether a limit on a right or freedom is justified under s.5 is essentially an enquiry into whether a justified and is achieved by proportionate means. The end must be justified and the means adopted to achieve that end must be proportionate to it. Several sub issues inform that ultimate head issue. They include whether the practical benefits to society of the limit under consideration outweigh the harm done to the individual right or freedom. The Court's function is not immutably to substitute its own view for that of the legislature. If the Court agrees with the legislature that the limit is justified, no further issue arises. If the Court does not agree, it must nevertheless ask itself whether the legislature was entitled to come to the conclusion under challenge. It is only if Parliament was not so entitled that the Court should find the limit to be unjustified.

In this way and to this extent the Court's function is one of review. It is not one of directly substituting the Court's own judgment. But the more intensely it is appropriate to review Parliament's appreciation of the matter, the closer the Court's role will approach a simple substitution of its own view. This is the regime under which the Courts manage the ever-present potential for tension between democratically elected representatives and unelected Judges concerning when and to what extent a parliamentary majority may limit rights and freedoms."

Approach to justification

[221] We can do no better than adopt that which the Tribunal had to say at paragraphs [207] and [208] in *Child Poverty Action Group*:

"[207] The cornerstone authority on s.5 NZBORA is R v Hansen [2007] 3 NZLR 1. Furthermore, both counsel for the plaintiff and Crown counsel adopted the approach for the evaluation of justification that is given by Tipping, J at para [104] of the Supreme Court judgments:

'This approach [i.e., as discussed by the Supreme Court of Canada in R v Oakes [1986] 1 SCR 103] can be said to give rise to the following issues:



- (a) *does the limiting measure serve a purpose sufficiently important to justify curtailment of the right or freedom?*
- (b) (i) *is the limiting measure rationally connected with its purpose?*
- (ii) *does the limiting measure impair the right or freedom no more than is reasonably necessary for sufficient achievement of its purpose?*
- (iii) *is the limit in due proportion to the importance of the objective?'*

[208] *Our analysis of the evidence relating to justification is organised in the form of responses to each of these questions, as they relate to this case."*

Step a Does the limiting measure serve a purpose sufficiently important to justify curtailment of the right or freedom?

[222] The first question is whether a limiting measure, in this case the policy decision not to pay family members, serves a purpose sufficiently important to justify curtailment of the right to be free from discrimination (by reason of family status)? We conclude it does not serve such a sufficiently important purpose because the purpose is stated by counsel for the defendant to be the upholding of a social contract which is not a proposition which finds favour with us (see paragraphs [176] – [183]).

[223] We do not consider that the policy (limiting measure) is sufficiently important so as to limit the rights or freedoms of disabled people and/or their carers so as to attain the Ministry's additional objectives, which include, the equality of outcomes; encouraging independence; enhancing family relationships; helping to support families and sustain care, or that it would adversely effect the quality of care; or would be fiscally unsustainable, as we have set out elsewhere.

Step b(i) Is the limiting measure rationally connected with its purpose?

[224] As noted, we do not find that there exists a social contract in New Zealand of sufficient force to have a rational connection to policy. As pointed out, we see a distinction between the disability support required by a moderately to heavily disabled person cared for in the family home to that which could be regarded as "natural support".

[225] We found some irrationality in the defendant's position that a fundamental part of the social contract is that families are not employed to provide natural support to family members. We see the support needed by heavily dependent persons in the home in many respects goes beyond "natural support" and is actually "disability support" and as such can be funded by the Ministry.



[226] Nor do we sustain the argument that some of the other purposes listed have a rational connection to the policy. These include:

- [a] To promote equality of outcomes for people with disability.

We have not seen evidence to suggest that there is a difference in outcomes from those cared for by caregivers external to the home, compared to the care given by family members. We have already referred to the findings of the ACC on this point. No matter who was funded to provide the care, the NASC assessment process of the Ministry of Health, by its very definition takes a needs based approach in determining the support needs of each individual and funds the purchase of these needs accordingly. In fact, better outcomes for those currently not receiving NASC assessed care, may result from the assessment and review process; in other words, there is the potential for better outcomes for family provided care where this is subject to the NASC process.

- [b] To encourage the independence of disabled persons

No researched evidence on this point was given to us, but several opinions were presented for and against this objective, where family members provide the care. The personal life and case histories put before us showed that where the level of disability allowed, some plaintiffs had achieved a considerable degree of independence in their day-to-day living.

We note a reference (page 1295, paragraph 14.7, agreed bundle) where the ACC reported that “. . . research has highlighted the difference direct payments have made in enhancing independent living in terms of giving choice and control to disabled people and facilitating social inclusion”.

It is not rational to suggest that some plaintiffs with major cognitive and behavioural problems (including potential risks to other persons) could achieve greater levels of independence as a result of the policy of not paying family members for their care. In fact, the reverse is likely – if placed in positions where their day-to-day/hour-to-hour/minute-to-minute care is less than provided by parental oversight at home, then the degree of independence allowed them could be much reduced in the out of home setting.



- [c] To avoid the risk that families will discourage disabled family members from leaving home because they will become financially reliant on the money.

On the face of it, this would appear to be a tenable argument and this was stressed to us by the defence witnesses. The most immediate experience on this issue would come from the ACC payment to family members to provide care and it did comment on the risk of family dependence on income if a large package of care is provided to the family; they did however suggest that risks could be reduced with better supported and monitored care.

- [d] To support the development of family relationships in the same way they develop for non-disabled people.

Several defence witnesses saw this to be of concern, this concern being more anecdotal than research based. We would have to observe that the development of family relationships where one or more members is moderately to severely disabled, must be influenced by the dynamics of this situation. It is therefore not reasonable to suggest that the non-payment of family members enhances or encourages the development of family relationships as for non-disabled persons. The Tribunal does not see it as a rational or convincing linkage.

- [e] To avoid professionalising or commercialising family relationships.

The Tribunal finds this to be an interesting objective and asks why this should be directed at families because one or more of them is disabled. We note the numerous commercial/contractual relationships which exist in New Zealand society involving family companies and partnerships which have existed in some cases, over several generations. Conflict does arise in these relationships not infrequently but many continue for decades without conflict.

The Tribunal sees it as nothing unusual for family members with a disability entering into commercial arrangements with their families if that is their wish. Whether paid care is provided by family members or otherwise it should be monitored and evaluated as to the appropriateness of the care, its standards and outcomes.



To deny this opportunity because of disability, would in fact be discriminatory (and against the objectives of the NZDS) and we see no rational connection in the policy, in this circumstance.

- [f] To ensure that the provision of publicly funded support services meet quality standards and can be properly monitored.

There needs to be public accountability in all situations where public funds are committed and the application of such funds to disability care, is no exception. The same requirement for appropriate standards and monitoring applies.

Both the defence and the plaintiffs' counsel and the plaintiffs themselves when asked, agreed to the need for monitoring and audit of the publicly funded care given to them. (However in practice, this objective appears to fall short at present, with both the Ministry of Health and the ACC indicating they have plans to extend and develop their current auditing and monitoring processes.)

It would be irrational to suggest that the need for monitoring of care and the evaluation as to the standards of this care, should be waived because family members are involved in the provision of this paid care to other family members – it is a rational connection which should apply in all circumstances.

- [g] To avoid unsustainable care burdens and distress and social isolation of family members undertaking extensive care.

The need for carers (family or not) to have regular, planned breaks from their responsibilities was not questioned by counsel and the carers themselves. The NASC policies and funding mechanisms allow for such relief to be as of right, and to be regularly undertaken.

We would expect family caregivers in the home, paid or otherwise, to have this right. Although several carers presenting before us understood the benefit of this and some reported as doing so, we suspect that in some instances regular relief from care was not undertaken.



In fact, only by being reimbursed through the NASC system, would this requirement be required and action to take regular relief, be facilitated and monitored.

In other words, we see no rational connection between the policy and the stated objective – in fact, the opposite would apply if the NASC process was introduced into the family setting where it is currently not applied.

[h] To be fiscally sustainable.

As discussed earlier (paragraphs [151]-[161]), there has been no structured or detailed analysis as to the cost implications until this hearing, with detailed analyses being presented by both counsel. Certainly there was no evidence presented to us that showed that the fiscal implications of paying family members had been fully evaluated when the policy was first formulated.

Our conclusion was that the fiscal impact of a policy change is likely to have limited financial implications within the disability sector and therefore this cannot be sustained as a rational connection; certainly more researched evidence would be needed to sustain this connection, if in fact it was found to be proven.

Again, we see urgency in the need to develop a carers' payment policy, particularly in terms of the wider application of this to the care of the elderly in the home setting.

Step b(ii) Does the limiting measure impair the right or freedom no more than is reasonably necessary for sufficient achievement of its purpose? and

Step b(iii) Is the limit in due proportion to the importance of the objective?

[227] We can deal with steps (b)(ii) and b(iii) together since the argument of counsel for the Ministry invariably (and inevitably) found its way back to aspects of the notion of upholding the social contract as to which we believe we have made our views clear. If the "limiting measure" the policy decision not to pay family members impairs the right to be free from discrimination on the grounds of family status as we conclude it does then that is not a purpose which ought to be achieved. It follows that it cannot be said to be necessary. Similarly with the question of the limit being in due proportion to the importance of the objective. The Tribunal can attach no importance to the objective of



discriminating against family members caring for their disabled family members so that the question of proportionality does not arise.

[228] In addition to maintaining the social contract the Ministry says that its policy is no more than reasonably necessary to achieve the objectives listed at paragraph [226] above. While the Tribunal considers that some of these objectives are important it does not consider that the policy is reasonably necessary, or the only way, to achieve the additional objectives, nor does the Tribunal consider that the policy is in due proportion to the importance of the additional objectives for the reasons stated elsewhere. Nor does the policy enhance and promote objectives of the NZ Disability Strategy which should guide policy development in this area.

Summary of findings: is there a justified limitation?

[229] We have carefully considered as to whether the policy decision of the Ministry of Health, to exclude certain family members from payment of disability support services by reason of their family relationship, can be an exception which is justified.

[230] We do not accept the overall argument of the defence that it is justified, for these reasons:

1. We do not accept that such support by family members given to heavily dependent persons, particularly when they reach adolescence and adulthood, can be considered as "natural" support. The NASC model should acknowledge the difference between the natural support families can provide, as distinct from the disability support needed by disabled persons.
2. Additionally, we do not find the argument that this support should be given as part of a "social contract" is supportable – we are not convinced that there is an unwritten contract in New Zealand of sufficient force to justify this policy position, particularly when there are numerous instances, as set out, whereby the state has offered financial assistance to families, precisely because of family status.
3. As to a "rational connection to its purpose", we do not believe it is justified because it does not appear to promote equality of outcomes; encourage the independence of disabled persons or support the development of family relationships in the same way as for non disabled people – in fact, it could have the opposite effect on these grounds.



4. Nor do we accept that the argument that it is rational because it avoids professionalising or commercialising family relationships when, as we point out, numerous such arrangements already exist and have existed for generations. We question why persons with disabilities should be excluded from such relationships, because they are disabled.
5. We do accept that there is a risk that such payments may discourage disabled family members from leaving home because of the financial repercussions, but note that such risks can be mitigated by careful monitoring and counselling.
6. We agree with the need to ensure that carers do not undertake unsustainable care burdens and become socially isolated. We see the risk of this as likely to be greater where care is rendered by family members outside of Ministry assessment and funding practices. The Ministry monitors these concerns and has policies in place to alleviate these risks.
7. As to the important issue that such a policy is needed for reason of financial sustainability; we have found no evidence to show, convincingly and unarguably, that the financial impact of a policy to pay family members currently excluded by the policy would not be sustainable. Certainly, a detailed assessment does not appear to have been undertaken when the policy was first formulated and in subsequent years, to date. The analyses carried out for this hearing by expert witnesses for the parties, do not clarify the potential impact of a policy change, to the extent that a precise or even approximate financial impact could be stated with any confidence.

Our own intuitive view is that the impact is not likely to be great, within the disability sector.

8. Finally, significant policy decisions in the disability sector should seek to apply the objectives of the NZ Disability Strategy, and as noted, the application of the policy to exclude certain family members from paid care, acts against several of the accepted objectives of the strategy.



I RESULT

[231] The decision of the Tribunal is that the plaintiffs are successful at this stage of the proceeding.


[232] We declare, pursuant to section 92(3)(a) of the Act, that the defendant's practice and/or policy of excluding specified family members from payment for the provision of funded disability support services is inconsistent with section 19 of the New Zealand Bill of Rights Act 1990 in that it limits the right to freedom from discrimination, both directly and indirectly, on the grounds of family status and is not, under section 5 of that Act, a justified limitation.

[233] We direct that the proceedings stand adjourned to a date to be fixed. The Tribunal awaits advice from the parties as to further steps.

[234] As recorded in paragraph [16] above costs are to lie where they fall and no order is made.



Judge J E Ryan
Chairperson



Mr S Solomon
Member