27th November 2014

Simon O’Connor, Chairperson

Health Committee

Parliament Buildings

Wellington 6160

Dear Mr O’Connor

**Petition 2011/122 Rachel Noble on behalf of the Disabled Persons Assembly New Zealand Inc. and 1,491 others**

In August 2013 the Disabled Person’s Assembly NZ Inc. launched a petition to repeal the New Zealand Health and Disability Act 2013. On 22 July 2014 the petition was presented to Green Party MP, Catherine Delahunty.

The following written submission is from the Disabled Person’s Assembly NZ Inc. and on behalf of 1,491 others outlining the reasons for repealing this Act.

The Disabled Person’s Assembly NZ Inc. requests an opportunity to meet with you to speak to this submission.

DPA Contact:

**Victoria Manning**

Senior Policy and Research Analyst

Email: [Victoria.manning@dpa.org.nz](mailto:Victoria.manning@dpa.org.nz)

Ph: 021 100 0292 \*Text only – Deaf\*

**Summary of this submission**

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**Introducing DPA New Zealand Inc.**

The Disabled Persons Assembly NZ Inc. (DPA) is the national assembly and collective voice of disabled New Zealanders.

DPA is a Disabled Person’s Organisation (DPO) meaning it is a national Organisation governed by disabled people, and the organisation’s main purpose is to articulate the aspirations of its members.

DPA has some 900 individual members who have disabilities themselves or are the parent, or guardian of a disabled person, and some 200 corporate members who represent or deliver services to disabled people. [DPA members](http://www.dpa.org.nz/our-organisation/our-members) form a network of regional assemblies to debate local and national issues.

DPA’s functions include:

* to promote the interests and wellbeing of all disabled people regardless of age, for our whole lives
* to engage with disabled people, DPOs and our valued allies
* to progress the UN Convention on the Rights of Persons with Disabilities (CRPD) in Aotearoa New Zealand.

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

Government accountability

The CRPD provides the mandate for disabled people to hold the Government to account on ensuring the full and equal enjoyment of all human rights by disabled people.

CRPD is the minimum standard

DPA uphold the CRPD as the minimum standard for our participation in society.

Partnership with DPOs

The implementation of the CRPD depends on a partnership between DPOs and the Government. This is highlighted in Article 4.3 which says governments shall consult closely with and actively involve disabled people, including disabled children, through their representative organisations.[[1]](#footnote-1) This partnership goes beyond just consulting with disabled people.

**CRPD on equality and non-discrimination**

Aspects of the CRPD that are particularly relevant to this petition:

1. The CRPD’s General Principles[[2]](#footnote-2):

* Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
* Non-discrimination
* Full and effective participation and inclusion in society
* Respect for difference and acceptance of disabled people as part of human diversity and humanity
* Equality of opportunity
* Accessibility
* Equality between men and women
* Respect for the evolving capacities of disabled children and respect for the right of disabled children to preserve their identities.

1. All disabled people are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law[[3]](#footnote-3)
2. All disabled people have a right to respect for his or her physical and mental integrity on an equal basis with others[[4]](#footnote-4)
3. All disabled people have an equal right to live in the community, with choices equal to others, and States Parties shall take effective and appropriate measures to facilitate full enjoyment by disabled people of this right[[5]](#footnote-5)
4. The Government is required to take effective and appropriate measures to eliminate discrimination against disabled people in all matters relating to marriage, family, parenthood and relationships[[6]](#footnote-6)

The NZ Health and Disability Amendment Act 2013

# This Amendment Act is discriminatory

*“It is discriminatory – a breach of human rights – that under ministry policy outside caregivers can be paid to look after their children, but family members cannot”.[[7]](#footnote-7)*

The Disabled Persons Assembly NZ Inc. and 1,491 others state the Health and Disability Amendment Act 2013 is discriminatory.

It limits the choices of adult disabled people to choose their family members as their paid carers.

It limits our right to judicial review.

The New Zealand Court of Appeal affirmed that the Ministry of Health’s policy of not allowing adult disabled people to use family members as their paid support people constituted unjustifiable discrimination.[[8]](#footnote-8)

This unjustifiable discrimination is on the basis of family status. Whilst the Human Rights Act’s protections appear less explicit on disabled people’s right to choice in our support services, disabled people are nonetheless, central to this issue.

In direct response to the Court of Appeal’s decision the government passed the New Zealand Health and Disability Amendment Act 2013 on 17 May 2013.

This Bill was passed under urgency[[9]](#footnote-9) despite their being significant human rights implications, and the Attorney General reporting it was inconsistent with the right to judicial review and potentially inconsistent with the right to freedom from discrimination.[[10]](#footnote-10)

The Health and Disability Amendment Act 2013 provides for discrimination of paid family carers in:

* the (lower) rate of pay
* limiting the amount of hours per week they may work, and
* prohibiting some family members from providing such services.[[11]](#footnote-11)

## The Act imposes a lower pay rate for family carers

The Health and Disability Amendment Act 2013 imposes a payment system with a lesser pay rate for family than is offered to non-family members using a different delivery system.

Support people who are family members are paid at the rate of the minimum wage.[[12]](#footnote-12) This is less than what is paid to non-family support people.

## The Act limits the circumstances in which family members can be paid

Under the Health and Disability Amendment Act 2013 the Government policy states that a family or whānau member cannot be employed as a support worker if that would mean they would be working more than 40 hours a week in total.[[13]](#footnote-13)

This is discriminatory. There are many people who work 40 plus hours per week.

If the reasoning behind this is to mitigate the risk of family members providing poor levels of care that would more appropriately be addressed within the Ministry’s checking and monitoring systems.

## The Act limits the category of family member that can be paid (e.g. parents but not spouses)

Under the Health and Disability Amendment Act 2013 the Government policy prohibits a disabled person from having a paid support person who is their husband, wife, civil union partner or de facto partner.[[14]](#footnote-14)

## The Act limits the right to judicial review

The Health and Disability Amendment Act 2013 ousts the Human Rights Commission’s jurisdiction and removes any potential domestic remedy for unlawful discrimination relating to family care policy.

This means that people are unable to make complaints of unlawful discrimination about family care policy to the Human Rights Commission, and no proceedings may be commenced or continued in any court in relation to discrimination of family care policy.[[15]](#footnote-15)

Effectively, the judiciary’s role as protector of individual citizen’s to ensure they are being treated in accordance with the laws of the land has been removed.

# Disabled people are central to this issue

This submission is presented from the perspective of disabled people. Disabled people are central to this issue.

This issue is about services to disabled people. Services that enable our participation in our family, whānau, community and society on our own terms.

Disabled people have made countless calls for disability support services to be person-centred and responsive to our individual needs and preferences.[[16]](#footnote-16)

Disabled people have a right to choice in the services they receive.

The sometimes poor and sub-standard nature of disability service provision, policies and frameworks has been highlighted in a number of reports, including the 2008 Parliamentary *“Inquiry into the quality of care and service provision for People with disabilities”.[[17]](#footnote-17)*

Historically, disability support and services have been heavily steeped in paternalistic and charity approaches. Thanks to the civil rights, women’s rights and disabled people’s rights movements’ things have moved on.

The Health and Disability Amendment Act 2013 is based on old and out-dated principles. The Act states:

*“The purpose of [this amendment act] is … to affirm the principle that, in the context of the funding of support services, families generally have primary responsibility for the well-being of their family members.”[[18]](#footnote-18)*

The policy related to the Health and Disability Amendment Act has also referred to family carers as ‘natural supports’.[[19]](#footnote-19) The implication here is that family members should provide unpaid support because they are family.

There are limits to the ‘natural support’ of families. It is not the norm that families live with a disabled family member who has high or very high needs.

The Government has an obligation to provide services and supports to disabled people based on their individual levels of need.

As such, government services assess disabled people for an allocated amount of support person hours.

The number of hours of support needed, and the disabled person’s level of need, does not diminish because the person providing those services is a family member.

Natural support from families occurs over and above the allocated support service hours, and should not be seen to reduce the disabled person’s level of need.

Put another way, a disabled person’s support needs do not change depending on who is providing those support services.

# Māori **disabled** people

Māori disabled people have raised this discrimination as a cultural issue.

Te Puni Kokiri expressed concern that the Health and Disability Amendment Act 2013 does not fully comply with the principles of the Treaty of Waitangi.[[20]](#footnote-20) As it restricts payment to some family members it may disproportionately affect Māori people. Whānau care is an expectation within whānau relationships.[[21]](#footnote-21)

Māori disabled people have said they want to be able to have their whānau as their paid carers, and have raised this as a Treaty right and a right to autonomy.[[22]](#footnote-22)

Similar issues are likely to arise for other cultural and language groups, including Pasifika disabled people and Asian disabled people who may find employing a family member as their support person is the culturally appropriate thing to do.

# Challenging the Government’s concerns

## Concerns about costs

One of the key arguments of the Government in developing the Health and Disability Amendment Act 2013 was ensuring the costs of paying family members as support people was sustainable[[23]](#footnote-23) and managing fiscal and litigation risks arising from this policy change.[[24]](#footnote-24)

Concerns about costs seem to have been poorly analysed.

The Court of Appeal noted that the Ministry of Health had only provided rough estimates of the costs if the Ministry paid parents of disabled children to care for them. These estimates varied from a low $17 million to a high of $593 million.[[25]](#footnote-25) As this issue is only about ***adult*** disabled people, making the calculation based on disabled children raises questions.

The Ministry of Health admitted it did not know how many disabled people would take up the option of using family members as their paid carers and the court commented that the Ministry’s concerns could be overstated.[[26]](#footnote-26)

Some of the costs of paying family members as support people will be nil. This will be in cases where a disabled person is already accessing an allocated amount of support people hours. The allocated hours and costs would be the same if they then choose to pay a family member instead of a stranger.

The Government allocated, from Vote Health, $23 million per year to implement its Funded Family Care policy in 2013.[[27]](#footnote-27) One year on, the evidence shows there has been no opening of the floodgates that the Government feared.[[28]](#footnote-28)

Actual figures

Since its inception on 1st October 2013, uptake of the new Family Funded Care (FFC) policy for paying some family members as support people to some disabled people has been significantly lower than calculated.

As at the end of September 2013, **155** people are receiving FFC to pay family members as their support people.

This is approximately **10% actual take** up as compared to the budgeted up take of 1,600 people.

To DPA’s knowledge, of the $23 million per annum budget for FFC we believe only about $6 – 8 million has been spent in the first year.

The number of people receiving FFC in the box above has been sourced from Crown Law.

## Monitoring service quality

The Government expressed concern about the ability to monitor the quality of services provided by family members as paid carers, and about the potential consequences on families.

Given that the Ministry of Health will already have in place systems for monitoring support services, these concerns seem overstated. If those systems needed to be adjusted in any way they should be addressed in the changing or strengthening those monitoring systems.

Furthermore, ACC might provide useful advice on ensuring systems can effectively monitor services provided by family members.

## The consequences on families

The Government also expressed concern about the consequences of families becoming reliant on the disabled person for income.

This risk is likely to be small. It seems unreasonable to limit the choices of all disabled people with high and very high needs because of the risks that a small number might be ***seen*** to become dependent on the disabled person for income.

This concern is further refuted on the bases that the Government should not determine a disabled person’s support funding based on any assumed negative aspects of this becoming a significant source of income for a family member.

Many beneficiaries are dependent on their benefits but they know that if certain conditions are not met they risk losing those benefits. Similarly, a paid family support person could risk losing their payments if they do not meet the required quality and monitoring standards, or if the disabled person decides to choose a non-family member to be their support person.

The important point is that if the disabled persons chooses to use a family member as their support person no policy should state this is wrong or limit those choices.

Any actual or perceived risks in paying family members as paid carers should be managed within the Ministry of Health’s assessment and monitoring systems. For example, ensuring any necessary checks on the disabled persons choices and quality of services being provided.

It is also important to note that there are some situations where there is a lack of available, appropriate or qualified support people in the community, meaning disabled people may sometimes need to turn to family members for their support services. Situations might include, people living in rural areas, or when a regular support person is sick or on other unplanned leave (eg: bereavement leave), and an appropriate or acceptable replacement cannot be found in time.

## ACC do it

An overlooked point in these arguments is that the Accident Compensation Corporation (ACC) pays family members to be support people.

People under ACC, who are injured or disabled by injury, are able to use family members as their support people in the same way they may use non-family members. People who are disabled from birth or from a health condition are not. Thus, the Health and Disability Amendment Act 2013 further discriminates against people based on the cause of their disability.

The fact that ACC do not differentiate between family and non-family support brings into further question the Government’s arguments not to do it.

ACC also seems an obvious resource in terms of helping the Government develop any new systems required for managing the Government’s concerns around implementing a policy of paying family support people.

# Case studies

These case studies are based on real life people living in New Zealand now. Details have been changed to protect privacy.

**Kathy & Mike**

Kathy worked as a caregiver for 15 years, including working with many disabled people. Kathy’s husband, Mike, has MS and requires more care now than he once did. Mike’s personality is quiet and he can find social interactions with strangers stressful. Mike wants Kathy to be his main support person, and Kathy wants to do this. Kathy is well qualified to do this work and knows that her doing this will reduce her husband’s stress levels, and thus the stress levels in their home.

**David**

David is a 30-something senior digital artist in a creative design company. He has two pre-school age children with his wife, Sally. David also has Cerebral Palsy. He uses an electric wheelchair and receives support person funding to pay for support workers to assist him in undertaking daily personal tasks including eating, showering and toileting at home and at work.

In most situations David prefers to use support workers who are not family members. However, there are times when he would like to use his wife as his paid support person, with her agreement. Examples include during family holidays in Australia or other intimate family times such as a family funeral or wedding.

**Ron, Mark and Janet**

Ron cares for his two adult children, Mark and Janet, who are intellectually/learning disabled. Both require personal care and home help in their daily lives, one more than the other, for things like eating, dressing, showering and toileting.

Being a carer for his children is hard work, some days the children’s physical and behaviour management needs are more than others.

Ron does the work because he loves his children. He’s also the best skilled person to do it.

There is no denying Mark and Janet are living a good life. Thanks to a dedicated Dad who understands their needs and desires.

# Support from key sectors

Large sections of the disability sector are united on this issue, including families and carers.

Below is a list of organisations and high profile people who have commented in support of repealing the Health and Disability Amendment Act 2013.

Human Rights Commission

The Human Rights Commission has consistently urged the Government to repeal this legislation. The Commission has expressed concern that rather than fixing a previous inequality the Act regularises a further inequality for disabled people and their families.[[29]](#footnote-29)

New Zealand Law Society

The New Zealand Law Society criticised the Health and Disability Amendment Act 2013 and the manner in which it was passed.[[30]](#footnote-30)

Prominent lawyers

Leading lawyers have criticized this Act, including Professor Andrew Geddis.[[31]](#footnote-31)

Carers New Zealand

Carers NZ has promoted DPA’s petition for the repeal of this Act.

Carers NZ, the national peak body for family caregivers, and the NZ Carers Alliance of 45 national not for profits, support the repeal of the NZ Health and Disability Amendment Act 2013.[inserted after sent]

UN Committee on the Rights of Persons with Disabilities

The UN Committee on the Rights of Persons with Disabilities queried the New Zealand Government on this Amendment Act during New Zealand’s first examination under the CRPD in September 2014.

The Committee’s Concluding Observations on the initial report of New Zealand expressed concern that this Amendment Act reversed the court decision by denying carers pay to some family members, and concern that the Act prevents some family members from making complaints of unlawful discrimination with respect to Government’s family care policy.[[32]](#footnote-32)

# The opportunity to put it right

Now is the opportunity to provide equality to Kathy & Mike, David and Ron and his adult children (see above) and the many others like them.

Now is the opportunity to remove the unnecessary limitation on our right to judicial review.

Most of us will experience disability at some point or care for someone with a disability.

In the over 65 age group, 60 percent of people have a disability. The baby-boomers have only just started moving over into this age category. The numbers of people with disabilities and long-term health conditions is going to rise sharply in the immediate future.

This is about future-proofing our legislation and policies.

Thank you for considering Disabled Persons Assembly NZ Inc. written submission outlining the petition to repeal the Health and Disability Amendment Act 2013.

DPA request an opportunity to meet with you to speak to this submission.

Sincerely



Rachel Noble

Chief Executive

1. United Nations Convention on the Rights of Persons with Disabilities, Article 4.3 [↑](#footnote-ref-1)
2. United Nations Convention on the Rights of Persons with Disabilities, Article 3 [↑](#footnote-ref-2)
3. United Nations Convention on the Rights of Persons with Disabilities, Article 5.1 [↑](#footnote-ref-3)
4. United Nations Convention on the Rights of Persons with Disabilities, Article 17 [↑](#footnote-ref-4)
5. United Nations Convention on the Rights of Persons with Disabilities, Article 19 [↑](#footnote-ref-5)
6. United Nations Convention on the Rights of Persons with Disabilities, Article 23 [↑](#footnote-ref-6)
7. Stuff, Waikato Times. “A Family Affair” (28 May 2012). The parents argument. Accessed on 27 November 2013 at: <http://www.stuff.co.nz/waikato-times/life-style/waikato-focus/6999202/A-family-affair> [↑](#footnote-ref-7)
8. Submission of the New Zealand Human Rights Commission to the Eighteenth session of the Human Rights Council; New Zealand’s Second Universal Periodic Review. (2013). “Report on New Zealand’s Human Rights Performance.” (17 June 2013). P 8. [↑](#footnote-ref-8)
9. Meaning there was no opportunity for select committee review. [↑](#footnote-ref-9)
10. New Zealand Law Society: Human Rights and Privacy Committee. (June 2013). “Submission to the Eighteenth session of the Human Rights Council. Shadow Report to New Zealand’s Second Universal Periodic Review.” 17th June 2013. P 5. [↑](#footnote-ref-10)
11. New Zealand Health and Disability Amendment Act 2013, Section 70D. [↑](#footnote-ref-11)
12. Ibid. [↑](#footnote-ref-12)
13. Ministry of Health website, “Funded Family Care Questions and Answers”. Accessed on 21 November 2014 at: <http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/funded-family-care/funded-family-care-questions-and-answers> [↑](#footnote-ref-13)
14. Ministry of Health website, “Funded Family Care Questions and Answers”. Accessed on 21 November 2014 at: <http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/funded-family-care/funded-family-care-questions-and-answers> [↑](#footnote-ref-14)
15. Human Rights Commission (2014) “Consideration of New Zealand’s initial report under Article 35 of the Convention on the Rights of Persons with Disabilities: Response to List of Issues”. Submission of the New Zealand Human Rights Commission to the 18th session of the Human Rights Council; New Zealand’s Second Universal Periodic Review. P 3. [↑](#footnote-ref-15)
16. Convention Coalition Monitoring Group. “Disability Rights in Aotearoa New Zealand 2012: A report on the Human Rights of Disabled People in Aotearoa New Zealand. (2012). P 30.; New Zealand Government Cabinet Paper. “Choice in Community Living.” Accessed on 18 June 2014 at <http://www.health.govt.nz/system/files/documents/pages/choice-in-community-living.pdf>; House of Representatives. (2008). “Inquiry into the quality of care and service provision for people with disabilities: Report of the Social Services Select Committee.” Forty-eighth Parliament (Russell Fairbrother, Chairperson) September 2008. [↑](#footnote-ref-16)
17. House of Representatives. (2008). “Inquiry into the quality of care and service provision for people with disabilities: Report of the Social Services Select Committee.” Forty-eighth Parliament (Russell Fairbrother, Chairperson) September 2008. [↑](#footnote-ref-17)
18. New Zealand Public Health and Disability Amendment Act 2013, Part 4A Family care policies, Section 70A(1). [↑](#footnote-ref-18)
19. Cabinet Paper. Minister of Health. (11 December 2012) “Paid Family Carers Case: Proposed Response”. Office of the Minister of Health. Cabinet Social Policy Committee. P 3. [↑](#footnote-ref-19)
20. Cabinet paper. Minister of Health. (8 May 2013) “New Zealand Public Health and Disability Amendment Bill 2013: Approval for Introduction”. [↑](#footnote-ref-20)
21. Ibid. [↑](#footnote-ref-21)
22. DPO’s (2014) “New Zealand Disabled Person’s Organisations Report to the United Nations Committee on the Rights of Persons with Disabilities on New Zealand’s Implementation of the Convention on the Rights of Persons with Disabilities. 31st July 2014”. Report prepared by the Disabled Person’s Assembly NZ Inc. P 13. [↑](#footnote-ref-22)
23. Stated in the “Purpose” of the NZ Health and Disability Amendment Act 2013. Part 4A, Section 70A(1). [↑](#footnote-ref-23)
24. Cabinet paper. Minister of Health. (8 May 2013) “New Zealand Public Health and Disability Amendment Bill 2013: Approval for Introduction”. P 1. [↑](#footnote-ref-24)
25. Stuff news (2012) “Appeal court’s landmark disability decision” 14 May 2012. Accessed on 19 November 2014 at: <http://www.stuff.co.nz/national/health/6917209/Appeal-courts-landmark-disability-decision> [↑](#footnote-ref-25)
26. Ibid. [↑](#footnote-ref-26)
27. Cabinet Paper. Minister of Health. (11 December 2012) “Paid Family Carers Case: Proposed Response”. Office of the Minister of Health. Cabinet Social Policy Committee. [↑](#footnote-ref-27)
28. Stuff, Waikato Times. “A Family Affair” (28 May 2012). The parents argument. Accessed on 27 November 2013 at: <http://www.stuff.co.nz/waikato-times/life-style/waikato-focus/6999202/A-family-affair> [↑](#footnote-ref-28)
29. Submission of the New Zealand Human Rights Commission to the Eighteenth session of the Human Rights Council; New Zealand’s Second Universal Periodic Review. (2013). “Report on New Zealand’s Human Rights Performance.” (17 June 2013). P 2. [↑](#footnote-ref-29)
30. New Zealand Law Society: Human Rights and Privacy Committee. (June 2013). “Submission to the Eighteenth session of the Human Rights Council. Shadow Report to New Zealand’s Second Universal Periodic Review.” 17th June 2013. P 5 & Appendix B P iii. [↑](#footnote-ref-30)
31. Pundit Blog by **Professor Andrew Geddis**, “I think National just broke our Constitution” (17 May 2013). Accessed on 24 June 2014 at: <http://pundit.co.nz/content/i-think-national-just-broke-our-constitution> [↑](#footnote-ref-31)
32. United Nations. Convention on the Rights of Persons with Disabilities. Committee on the Rights of Persons with Disabilities, (2014) “Concluding observations on the initial report of New Zealand”. Adopted by the Committee at its twelfth session (15 September – 3 October 2014). CRPD/C/NZL/CO/1. P 2. [↑](#footnote-ref-32)