

Submission to the Parliamentary Justice and Electoral Select Committee

United Nations Convention on the Rights of Persons with Disabilities

Submitted by:

Tania Kingi
Kaiwhakahaere
Te Roopu Waiora Trust

PO Box 23420
Papatoetoe
Auckland

Phone: (09) 277 4513

Fax: (09) 277 6390

Email: tania.kingi@teroopuwaiora.org.nz

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Submitter:

Te Roopu Waiora Trust, with a philosophy of 'placing the choices and direction of life back into the hands of whanau with disabilities' is a unique service targeting Maori disability communities in the Auckland region. *Founded and governed* by whanau with a range of impairments, the trust provides generic disability information, advocacy and support to Maori individuals, whanau and communities experiencing sensory, physical and intellectual disabilities. Waiora has evolved and expanded its role of providing disability information and advice to now include engaging whanau with Maori communities, providers, agencies and government. With less than 10 full time staff and a current database of 2000 whanau, Waiora works through strong partnerships and extensive community support to develop a number of unique and innovative projects.

In addition to supporting issues raised by whanau with disabilities, the Trust draws its knowledge for this submission as representatives and members of:

1. DIAS – member of the Auckland Disability Information Advisory Services Collective
 2. POU – Maori governance committee for the Counties Manukau DHB
 3. Tamaki Ngati Kapo Inc: Auckland Maori community of vision impaired/blind members and whanau
 4. Mana Tangata Turi: Auckland Maori deaf community
 5. Arau Ora – Counties Manukau Maori health and disability collaborative network
 6. National Steering Group of Maori Disability Services – Executive committee member
 7. Tamaki Makaurau collective of Maori Disability Services – Executive committee member
 8. Aotearoa Whanau Carers Network – Executive committee member
 9. Te Ora o Manukau – intersectoral forum of Maori representatives from government, social, health, iwi and Maori organisations – Executive committee member
 10. Manukau City Council Disability Policies Steering Group
 11. CMDHB Maori Disability Plan Steering Group
 12. Tomorrow's Manukau Strategic Steering Group – intersectoral management forum
 13. Taikura Trust: Disability Needs Assessment & Service Coordination Agency – Board member
 14. Homai National School for the Blind – Board member
 15. Auckland Spinal Unit – Consumer Advisory Committee
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Te Roopu Waiora Trust supports ratifying the Convention through the Disability Bill that:

1. intends to amend legislative provisions that are inconsistent with the Convention
2. Amends the Human Rights Act 1993 to clarify the scope of its provisions enabling a person to refuse to accommodate a person's disability in certain areas of activities.

Persons with disabilities have routinely suffered discrimination in the job market, in schools and in receiving public services. This Convention will make sure that these people will no longer be ignored.¹

During the development of the Convention, it had been argued that people with disabilities were covered by existing human rights treaties, but the reality according to the United Nations, is very different.² This is consistent with issues raised by Maori disability communities that constantly identify:³

- Indigenous deprivation - lack of access to Maori language and knowledge particularly as residents of institutions (deaf schools, blind institutions, residential facilities for people with intellectual disabilities)
- Barriers to government services including inadequate policies and rigid service menus that have not included Maori specific needs or contributions
- Barriers to community services both cultural and non-cultural
- Lack of access to service and resource knowledge including health and disability supports
- Processes that assume sight, hearing, literacy and comprehension levels beyond many Maori disability communities
- Physical access restrictions to public facilities, both internally and externally
- Attitudinal discrimination and institutional racism
- Paternalism
- Under-utilisation by Maori of advocacy and grievance processes⁴

¹Akiko Ito, Division for Social Policy and Development, DESA, United Nations – Scoop Press Release, 5 May 2008

² ibid

³ Aggregate service data from Te Roopu Waiora Trust (2008)

⁴ Conversations with management from the NZ Health & Disability Commission (2007)

By ratifying the Convention, NZ is demonstrating a commitment to enact laws and other measures to improve disability rights to access and enjoyment of participation in society as non-disabled.

The convention also signals strengthening the rights of indigenous groups to express themselves as Maori experiencing disabilities. For many years the Maori deaf community and wider Maori society has suffered the indignity of sign language gestures that are culturally offensive and inappropriate. The Convention provides the platform for work started by Maori deaf in developing and progressing appropriate Maori sign language to be included in NZ Sign language.

However the Bill must go further to anchor the rights and provide protection for indigenous disability groups who continue to factor as the most deprived population in New Zealand. Policies, strategies and services targeting people with disabilities continue to assume that the needs of Maori disabled are automatically addressed through universal means. If this were the case Maori disability populations would not factor as they do across all socio-economic indices. According to the Ministry of Health report “Living with Disability – A Summary” published in February 2005, Maori experience disproportionate levels of disability as well as relatively high unmet service need. This report draws alarming conclusions for a population with the highest deprivation rates, the highest disability rates and highest unmet need (refer to Appendix One of this submission).

The Bill must therefore include support and protection of Maori disabled aspirations and eliminate methods that ignore Maori specific needs and/or references to the Treaty of Waitangi.

Authorities across all sectors acknowledge that the needs of whanau with disabilities have not adequately factored into policy development, planning or implementation of services. Furthermore it is difficult to identify the level of utilisation, resource **allocations** and rates of improvement and progression for Maori disability communities if authorities fail to adequately collect and analyse relevant statistical information.

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The logical argument by disability advocates that “*services that are accessible to whanau with disabilities are accessible to all*”⁵ has also suffered neglect across all sectors. Services refer to ~~compliance costs, insufficient workforce knowledge, other agencies being responsible, and/or difficulties locating resources as obstacles preventing inclusion of people with disabilities.~~ Few recognise the causal and dominant philosophies that influence repressive policy, service and decision making. It is at this level that the Bill is most useful in order to affect and support disability communities grow and lead services that improve their participation, wellbeing and enjoyment of life.

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Self Determination Efforts

Maori disability communities have struggled to secure support for initiatives that can only be described as innovative. For instance a collective effort from several Maori disability communities concerned with the lack of access to kaupapa Maori health services (there is still only one *qualified* trilingual sign language interpreter in NZ) has resulted in the development of an initiative to help improve access to whanau with disabilities by building accessible technology platforms. This includes:

- Mobile web cam conferencing (similar to video conferencing but portable): where interpreters are digitally projected into gatherings regardless of where they are in the country so Maori deaf in ‘real time’ can access information, participate in health promotions, hauora hui and a range of whanau ora activities
- Producing digital audio and visual formats to increase the methods of communication and range of information available to whanau with various impairments
- Storage and downloading accessible information via internet sites
- Reviewing and promoting voice activation programmes that allow whanau with limited limb use to access electronic and web based health information

It took three years to secure resources for this initiative after being referred back and forth numerous government agencies that have yet to work out, align and coordinate specific responsibilities for people with disabilities⁶. There are 10 government departments plus ACC that have a financial responsibility to the disability population⁷

⁵ Disability Empowerment Advocacy Support - DEAS (2003)

⁶ Incidentally this initiative has made the finals of the Whanau Ora Innovation Awards to be held by the Ministry of Health in September 2008 however the ability to attend remains a challenge for a disabled members of this initiative.

⁷ Office of Disability Issues, Navigation Project (2006)

with each its own criteria, policy structure, service menu and eligibility created in isolation.

Other initiatives developed by Maori disability communities still seeking funding and support include:

- Striving to establish the first Kohanga Reo in Aotearoa where tamariki and their whanau with disabilities or kaimahi with disabilities can participate with full supports and health services available
- Offering the first disability law service to whanau and their communities where demand is far exceeding resources
- Launching an intersectoral framework and outcome measurement tool that whanau with disabilities use to evaluate how well services across all sectors provide and respond to their aspirations and needs
- Establishing the first District Health Board Maori disability plan in Counties Manukau developed by the Maori disability community where implementation is monitored by whanau representatives, mana whenua and District Health Board management
- Researching and planning the first marae in the country designed entirely by whanau with disabilities. Much more than physical access, the concept of this marae will allow whanau with various impairments host hui and give back to society rather than being considered 'a needy population.'

These are a few examples of initiatives led by Maori disability communities in an effort to meet their own needs and improve their own level of wellbeing. The Bill should underpin these efforts and smooth the course of realizing the aspirations of indigenous disability groups and individuals. Besides the obvious if the Bill is not ratified, the campaign to achieve improved wellbeing among a population that is experiencing unacceptable disparity promises to be an arduous one.

Please note:

Te Roopu Waiora Trust would have preferred to present this submission in person however the timeframe was inadequate to allow organization of disability supports for its members. Please consider our requirements in future; particularly given the subject matter of this submission.

Māori Disability – A Population Overview

Taken from a recent and comprehensive Ministry of Health report⁸, the following describes the position of whanau with disabilities in the health and disability sector. National statistics have been included as regional data could not be located providing the same level of information.

All Māori

In 2001, an estimated 106,500 Māori living in households had a disability. This was 21 percent of all Māori living in households. By comparison, 19 percent of non-Māori living in household had a disability.

Adjusting for the different age profiles of the two populations, age-standardised rates of disability were higher for Māori (24,000 per 100,000 or 24 percent) than for non-Māori (16,700 per 100,000 or 17 percent).

Children

The disability rate for Māori children aged 0–14 was 15 percent. This was higher than the rate for non-Māori children (10 percent). Sixteen percent of Māori boys aged 0–14 reported a disability, compared with 13 percent of Māori girls in the same age group.

Adults

In 2001, among Māori adults living in households, the prevalence of disability was closely associated with age. Sixty-one percent of Māori aged 65 and over reported having at least one kind of disability, compared with 34 percent of Māori aged 45–64, 22 percent of Māori aged 25–44 and 13 percent of Māori aged 15–24. In contrast, 51 percent of non-Māori adults aged 65 and over had a disability, as did 24 percent of non-Māori aged 45–64, 13 percent of non-Māori aged 25–44 and 8 percent of non-Māori aged 15–24.

The pattern of disability for Māori in the oldest age group is similar to that for the 45–64 age group. These higher disability rates for older Māori reflect the greater incidence of disease and illness, which affect Māori from a younger age than the non-Māori population (Table 8.4 and Figure 8.6).

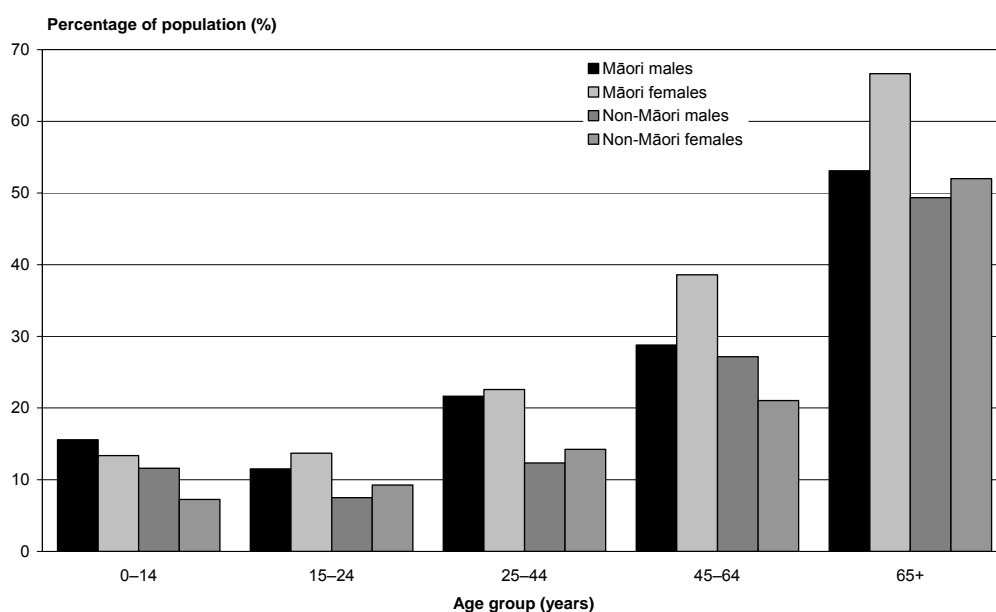
⁸ Ministry of Health (2004) Living with disability

Table 8.4: Rates of selected disability types, Māori and non-Māori aged 65 and over, living in households, 2001

Disability	Rates per 100,000	
	Māori	Non-Māori
Mobility	45,500	37,900
Agility	35,200	29,300
Hearing	24,400	22,000

Note: Data in Appendix Table 8.3B.

Figure1: Percentage of Māori and non-Māori people (adults and children) with disability living in households, by age and sex, 2001



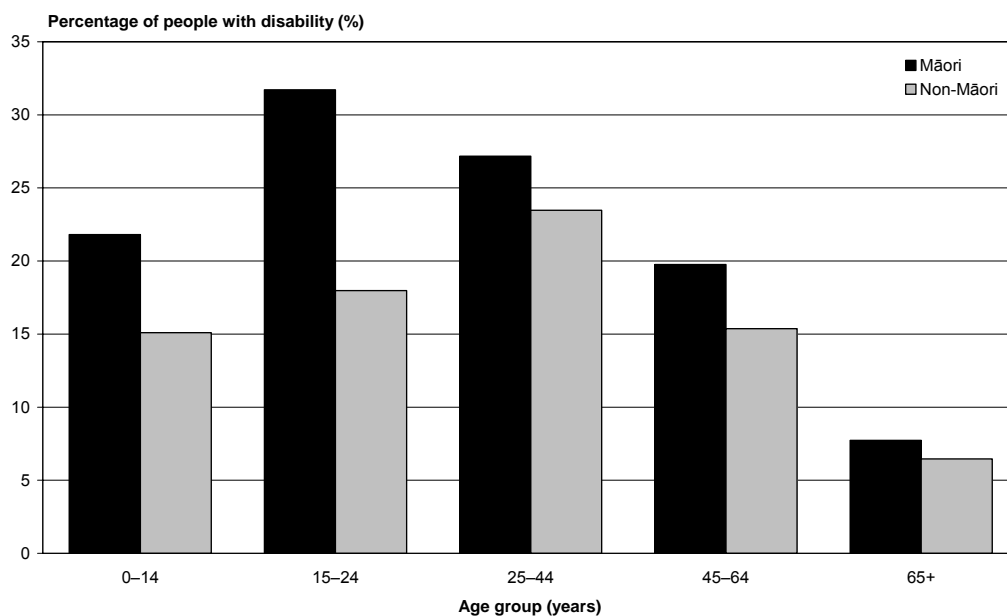
Unmet need for at least one type of health service

An estimated 24,200 Māori with disability living in households, 23 percent of all Māori with disability, reported an unmet need for some type of health service in the previous 12 months. This compares with 14 percent of non-Māori with disability living in households.

In particular, younger Māori with disability were more likely than their non-Māori counterparts to report an unmet need for health services. Thirty-two percent of Māori aged 15-24 with disability reported an unmet need, compared with 18 percent of non-

Māori with disability in this age group. Similarly, 22 percent of Māori children aged 0–14 with disability reported an unmet need, compared with 15 percent of non-Māori children (Figure 8.16).

Figure 8.16: Percentage of Māori and non-Māori with disability living in households who reported an unmet need for health services in the previous 12 months, by age, 2001



Source: Statistics New Zealand, 2001 Household Disability Survey

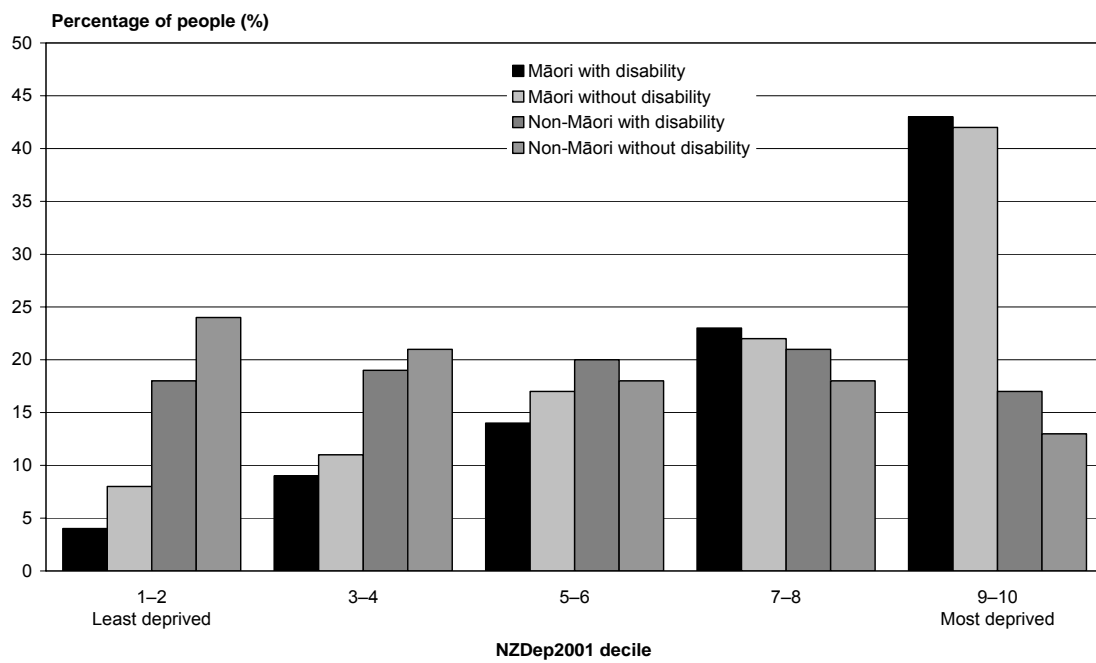
Note: Data in Appendix Table 8.29.

Socioeconomic areas

There are several explanations for the relatively high rates of disability among Māori, but a major factor is the high proportion of the Māori population with and without disability who are represented in the lower socioeconomic groups and the higher levels of social and material deprivation.

The difference in the proportion of Māori and non-Māori people with disability living in the most deprived areas is significant. For instance, 43 percent of Māori with disability lived in NZDep2001 areas 9–10; while only 17 percent of non-Māori with disability lived in these areas (Figure 8.17).

Figure 8.17: Percentage of Māori and non-Māori with and without disability living in households, by NZDep2001 area



Source: Statistics New Zealand, 2001 Household Disability Survey