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**The Unmet Legal, Social and Cultural Needs of Māori with
Disabilities**

A thesis

**submitted in partial fulfilment
of the requirements for the Degree
of**

**Doctor of Philosophy in Law and Māori and Pacific Development
Studies**

At the University of Waikato

by

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Abstract

There is little work done in the area of indigenous disability identity issues and how they are recognised in domestic and international human rights laws. The discourse of disability has always been based on social constructionism and without it, there is no identity. I discuss its relevance to indigenous (Māori) with disabilities and how the multiplicitous nature of the identity of “other” has a particular impact when indigenous, gender and disability are all identified from marginalised groups. I also explore the impact of westernised thinking around impairment, in particular the models of disabilities on indigenous well-being. The issues of family (*whānau*), *whakawhanaungatanga* (family relationships), interdependence (community) and collectivity identities central to indigenous thinking are largely ignored by law and policy, yet central to indigenous identity. This ignorance in policy has led to the disparities that continue to remain for indigenous persons with disabilities, particularly those from within thematic identity groups.

Keywords: Māori, disability, indigeneity, human rights, cultural rights, Māori health models, disability models

Dedication

**To Murray and Maureen Hickey, my adoptive parents, and Winnie,
my nana, who gave me the values and beliefs I hold strong today.
Thank you for your unconditional love. Although you are gone, you
are close to my heart.**

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This is an opportunity to place in writing a word of thanks for all of those who have been not only a part of this PhD thesis, but also a part of my life. Words are however, inadequate in that they can only capture a small part of my appreciation for all the influences shaping my thinking. I am acutely aware of those who have passed away from my life in the time prior to the commencement of my studies where their teachings and values have shaped my beliefs into what they are. I am also very aware of those close to me who have passed away during the completion of my thesis where they never had the opportunity in life to share this event. In particular, my adoptive mother, Maureen who, after years of pain and debilitating conditions racking her body, passed away in 2005. I am forever grateful to her for her continual love and dedication to me even when she did not always understand me.

Family is a term that can be broadly or narrowly applied and it is in my adoptive and birth families that I have found family and all that entails. They are the reason for me being here and the reason for my desire to conclude this chapter of my life. My oldest son Jamie, who I gave up at birth is another influence, as is my youngest son Josiah who has been in my life for 21 years. These experiences with these two young men have shaped my being as it has theirs and they have inevitably been in my thoughts and heart all these years. Life is not however, complete without friends. Erin my oldest and dearest friend, who has been with me in good and troubled times, who has often also not understood my journey, yet supported me, I say thank you.

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Whaia e koe ki te iti kahurangi; ki te tuohu koe, me maunga teitei

Seek the treasure you value most dearly; if you bow your head, let it be to a lofty mountain.

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Abbreviations

ACC – Accident Compensation Act (1972)

ADA – American Disabilities Act (1990)

CCS NZ Ltd – Crippled Childrens’ Society New Zealand Limited

CEDAW – Convention on the Elimination of all Forms of Discrimination against Women

CRPD – Convention on the Rights of Persons with Disabilities

DDA – Disability Discrimination Act (1995)

DPA – Disabled Persons Assembly

DPEPA – Disabled Persons Employment Promotion Act (1960)

DPCWA – Disabled Persons Community Welfare Act (1974)

DPI – Disabled Persons International

DRIP – Declaration on the Rights of Indigenous Peoples

EWCA – English Workmen’s Compensation Act (1897)

ECOSOC – United Nations Economic and Social Council

HDC – Health and Disability Commissioner Act (1990)

HRA – Human Rights Act (1993)

HRC – Human Rights Commission

ICCPR – International Convention on Civil and Political Rights

ICESCR – International Covenant on Economic, Social and Cultural Rights

IDA – International Disability Association

IDC – International Disability Caucus

IIDCWG – International Indigenous Disability Convention Working Group

MOH – Ministry of Health

NGOs – Non Governmental Organisations

NZDS – New Zealand Disability Strategy

OAPA – Old Age Pensions Act (1898)

ODI – Office of Disabilities

RRA – Race Relations Act (1971)

SSA – Social Security Act (1938)

TPK – Te Puni Kōkiri

UDHR - Universal Declaration of Human Rights

UK – United Kingdom

UN – United Nations

UNCROC – Convention on the Rights of the Child

WBU – World Blind Union

WCA – Workers Compensation Act (1900)

WDU – World Deaf Union

WHO – World Health Organisation

WIPA – Widows Pensions Act (1911)

WNSUP – World Network of Survivors of Psychiatry

WPA – War Pensions Act (1924)

Glossary of Māori words used in the text

NB: brief meanings only are provided here, and the reader should seek other sources for the full meaning of some of the complex ideas embodied in these terms. Thanks to Cilla Wehi for providing me a list of terms to utilise with my own.

<i>Āhua</i>	a person's appearance
<i>Aroha</i>	Love
<i>Atua (ātua plural)</i>	God or goddess
<i>Awa</i>	River
<i>Awhi</i>	Support
<i>Hapū</i>	sub-tribal group
<i>Hauā</i>	Disability (or could be interpreted as uniquely different)
<i>Hauā-tangata</i>	Person centred
<i>Hinengaro</i>	Mind, thought, intellect
<i>Iwi</i>	tribal group
<i>Kaitiaki</i>	guardian (s)
<i>Karakia</i>	Prayer
<i>Karanga</i>	ritual calling by women when a group enters the marae
<i>Kaumātua</i>	Elders
<i>kaupapa Māori</i>	project, research, or research method which incorporates Māori perspectives and values
<i>Kōrero</i>	speak, discuss; speech, discussion
<i>Korowai</i>	type of fine garment, with thrums on the body of the cloak
<i>Kuia</i>	respected female elder
<i>Mana</i>	Prestige
<i>Mauri ora</i>	Breath of life
<i>Maoritanga</i>	Old world
<i>Marae</i>	traditional gathering place for a hapū or iwi
<i>Mauri</i>	life principle
<i>Moana</i>	Ocean

<i>Pākehā</i>	New Zealanders of European descent
<i>Pakehatanga</i>	New world
<i>Raranga</i>	weaving; sometimes referred to as plaiting. This technique is used to make floor mats and baskets.
<i>Takatapui</i>	'intimate companion of the same sex'.
<i>tangata whenua</i>	in the context of the marae, the local people
<i>Tangi</i>	mourning ceremony
<i>Taonga</i>	treasured possession
<i>Tapu</i>	sacred, set apart
<i>Teina</i>	younger sibling or relation
<i>Te Ao Māori</i>	The Māori world
<i>Te Oranga</i>	Participation in society
<i>Tikanga</i>	what is correct, right and usual
<i>Tinana</i>	Body
<i>Tohunga</i>	Expert
<i>Toiora</i>	Healthy lifestyle
<i>Tupuna</i> (pl. <i>tūpuna</i>)	Ancestor
<i>Tūrangawaewae</i>	Home, place where one has rights of residence
<i>Waiata</i>	Song
<i>Waiora</i>	Healthy water
<i>Wairua</i>	Spirit, soul
<i>Whaikōrero</i>	formal speaking
<i>Whakapapa</i>	Genealogy
<i>Whakataukī</i>	ancestral saying
<i>Whānau</i>	family, extended family
<i>Whanaungatanga</i>	connecting through family relationships
<i>whare pūrakau</i>	house of learning
<i>whare wānanga</i>	house of learning
<i>Whenua</i>	Land

Introduction

I. General remarks

Certain types of disability are widespread, if sometimes unrecognised as such, within indigenous communities as a consequence of the long colonial experience. Poorer levels of general health, blindness from glaucoma and diabetes, and developmental disabilities contribute to the general social problems of the communities. Yet the social processes that disable indigenous people are rarely identified by disability services as a matter of concern for policy (Jakubowicz & Meekosha, 2002, p. 247).

In 1982 the World Program of Action for Persons with Disabilities was adopted by the United Nations General Assembly. Since then a Convention on the Rights of Persons with Disabilities has been developed and put into action a global plan of action to close the gaps for persons with disabilities. Prior to the 1800's, disability (formerly given the names of handicapped, crippled, deformed, decrepit and freakish) did not exist as a conceptualised identity until medicalisation and institutionalisation focused on excluding and segregating persons with disabilities from society. Prior to that time, disability was linked to conditions where those with disabilities were either absorbed into roles in the family and community or were ostracised or killed as outsiders

It is through disability activism that the discourse of disability developed. The focus of this paper is on indigenous peoples with disabilities as little is known of indigenous peoples with disabilities identity, in particular indigenous who have been colonised. Yet, there were clearly attitudes towards disability within indigenous populations as there are with all cultures, that give insight into how some impairments were accepted and others were not. While New Zealand disability policies acknowledge Māori, women, children and Pacific peoples with disabilities, in their statements and objectives, these policies are written with the concept of approaching disability monoculturally. Barille (2000, p. 209) outlines diversity and disability by stating that:

...throughout history there has always been cultural and regional inequity in understanding and treating people with disabilities. Inequity occurs when the social structures and spaces, social norms, culture and the tools of social interaction are constructed without taking differences, and therefore, equity, into account. Inequity, or the application of uniform standards, results in a singleton society built on the premise that everyone is the same and that those who are not must either learn to live within the structure established for the majority or perish. In extreme terms, from a disability standpoint, this notion of "sameness" would give everyone the same accommodations....Similarly, impairments are understood and experienced differently in different parts of the world, depending on the social, economic, and cultural interpretation of impairments and the availability of resources to eliminate disabling environments. One alternative is to acknowledge that "same" does not always mean "equal."....Also, it is important to validate the notion that each impairment is different from the other, and therefore, different solutions must be found to accommodate all individuals with diverse impairments so that they can fully participate in society.

In reviewing the literature for this thesis it was found that while health-related research was extensive, little related to indigenous persons with disabilities within a Polynesian context and with an emphasis on cultural identity and their relationships within their community. Little was found either in the area of disability discourse around the concept of indigenous cultural identity and living with impairments. Indigenous peoples with disabilities appeared to be a significantly invisible group in disability identity discourse particularly considering the impact of colonisation on them and their identity within legislation focusing on disability.

The quandary faced was how to engage in research around indigenous disability identity with little in the way of resources or networks catering specifically to this group. The few pieces of written research found gave little insight into impairment from an indigenous historical pre-colonial perspective. The research found describes Māori as viewing themselves as being disabled through colonisation (Kingi & Bray, 2000). This research did not delve into the specific

identity of being Māori with disabilities that are impairment-based rather than linked specifically to colonisation issues. This led to the conclusion that impairment has impacted heavily on indigenous disability identity, yet little progress has been made in this area of work due to the invisibility of indigenous with disabilities. Work done thus far focuses on Māori health models and not specifically on Māori disability identity (Ballard, 1994; Durie, 1994; Gething, 1995; Ratima et al., 1995; Durie, 2001; Collins et al., 2006). The preliminary research into this topic revealed that while policy appeared able to address one or two identities within its frameworks, it failed to take these issues into account collectively and simultaneously. Identifying with a singular identity is not realistic as most fit within two or more identity frameworks, yet disability policy reflects a singular approach to disability policy in that it applies a singular approach to the diverse range of identities reflected within the disability sector. Addressing the more complex nature of gender in relation to disability and multi-ethnic identities, and possibly even identifying within sexual minority identities creates difficulties for those trying to implement policy. It is easier for policy writers to address one or two issues than to try and address them all, despite the possibility of gaps existing. While research has examined health and income disparities for indigenous peoples and the disparities that exist for some within the disability identity paradigm, little research has been done to address the question of what impairment means to indigenous peoples.

Initial research suggests that anthropologists have identified the status of impairment in pre-industrial societies where evidence of impairment existing has been found within high ranks of society. This finding suggests that impairment did not always result in negative responses within those communities. This contrasts with current societal attitudes where, despite steps taken to prevent such reactions, negative and deficit language and attitudes are constantly used to place disability at a lower level of inclusion within society. This is because even those who have the ability to educate and influence those in power often use these same negative processes regarding disability. Disability is, however, a socially constructed identity and, in the past, was attributed to increasing medicalisation and institutionalisation of impairment leading to marginalisation for those whose impairments did not allow them to fit within the 'norms' of society.

Proponents of the social model of disability tell us that society has the disability while those with impairments are only disabled by the attitudes and structures adopted within society to create those barriers. Oliver (1984) would have us believe that persons with disabilities can self-define the impairments they live with and that the identity of impairment does not need to be medically constructed. To achieve this ability to self-identify within disability services in New Zealand, however, would not be possible as it is on a medical diagnosis confirmed by health professionals that services and equipment are funded. Laws and policies for disability in New Zealand are influenced by United Nations' instruments that have been developed over a period of 60 years. Disability rights are no exception. With the development of the Convention on the Rights of Persons with Disabilities, a move away from the medical model of disability into a rights based model of disability is possible. Although rights discourses originate from a philosophical framework, over the last 100 years they have begun to develop at a faster pace from theory into practice. Earlier versions of rights-based documents such as the Magna Carta already existed and, from these beginnings, the most exciting developments for persons with disabilities have been more recent within the history of rights-based law.

Even within the international human rights domain, gaps that existed after the implementation of the United Nations Universal Declaration of Human Rights (1948) are being challenged. The signing on 30 March 2007 of the Convention on the Rights of Persons with Disabilities and the ongoing discussions around the Declaration on the Rights of Indigenous Peoples are two examples of changes being made. While debate over the Declaration on the Rights of Indigenous peoples has dragged out for over 27 years with no sign of resolution, it exposes the tension between rights, culture and governments. The term culture has been used broadly within human rights discussion and the proposed Declaration is a step towards addressing the broader aspects; the Declaration may begin to put culture into perspective for those who identify culture in a more specific manner than is set out in the current instruments. The multiple and diverse nature of indigenous disability and gendered identities is the core theme throughout this

thesis. Originally the emphasis was on the legal frameworks but this has evolved into the incorporation of a multi-disciplinary approach.

II. Aims of Study

The main aims of this study are:

- (a) to identify the legal and institutional human rights and disabilities framework for law and policy that impacts on indigenous peoples with disabilities;
- (b) to provide an understanding of impairment from an indigenous perspective as opposed to the western-dominated discourse of disability currently used in policy in New Zealand;
- (c) to identify and understand the attitudes that exist towards Māori with disabilities and their communities; and
- (d) to provide a framework from an indigenous disability perspective for the delivery of services and supports for Māori/indigenous persons with disabilities.

III. Structure and Scope of Thesis

Definition Issues

This study focuses on the legal, social and cultural aspects of indigenous disability identity. Since the introduction of the medical and charity models of disability, the institutionalisation and medicalisation of disability have been a major focus for delivering services when someone identifies as living with the impacts of impairment. The social model of disability implemented through the New Zealand Disability Strategy (2001) aimed to address the attitudinal issues in society around disability. Objective 11 of the strategy outlines the objectives of the strategy for Māori with disabilities although it does not appear to have made any real difference for this group thus far, as chapters five and six will show.

Disability language is confusing and leads to many debates within the disability community; in particular, the recent debates on the United Nations Convention on

the Rights of Persons with Disabilities have caused some discussion on this issue. The New Zealand Human Rights Commission uses the term 'disabled person', while the Convention on the Rights of 'Persons with Disabilities' uses the term person with disabilities. Individuals involved in disability discussions over the years claim equal preference for both terms to describe disability. Morris (2001) argues also that the term 'persons with disabilities' is used in preference to 'disabled person' to emphasise the impairment created by barriers within society, placing the focus on describing the experience of discrimination and oppression (person with disabilities) rather than on the individual (disabled person) (Oliver, 1990; Morris, 2001).

Other terms such as 'someone who is challenged' or 'differently-abled' have also been mooted by those not comfortable with the term 'disability' as a label. All language around disability is socially constructed, as is the identity itself, and if the impairment proves to be something that could be removed in the future, then is it accurate to identify with a disability once cured? There is a problem with socially constructed identities in that they do not adequately address the issues facing that identity which, in some cases, may be eradicated through the contentious technological advancements that have occurred such as cochlear implants for the Deaf. For the purposes of this research, the term used is 'persons with a disability' which is the preferred current terminology within the international arena; it is used to make the paper readable without an ongoing interchange of terminology. It is possible that, if indigenous disability identity is understood from an indigenous perspective, then, in time, disability identity and language can develop using their own unique language and thinking of impairment within their communities.

IV. Structure of the Thesis

This research is an extension of my 2000 one-paper Masters thesis on '*Persons with Disabilities: Objects of Welfare or Subjects of Legal Rights? Closing the Gaps, Human Rights and Disabilities*'. This doctoral thesis contains seven chapters plus an introduction and conclusion. The chapters originally proposed have been amended slightly as the research progressed, making it clear that the

focus shifted from a purely legal perspective to a broader multi-disciplinary approach. Through the research and participant participation, knowledge developed around Māori disability identity that needed to be reflected in a more dominant way than previously perceived. A non-legal approach was not originally planned and, while there are three chapters outlining human rights, the Treaty of Waitangi and domestic legislation in relation to disability, the results of the research and findings meant a more in-depth analysis was required on identity, disability, health and well-being models.

V. The Chapters

Chapter one outlines the research and methodology of the thesis. The purpose of this research was to obtain information on attitudes from Māori in relation to indigenous disabilities identity and how attitudes impact, if at all, on the well being of Māori/indigenous peoples with disabilities and their access to their cultural communities. Chapter one sets out the methodology for the research and explores a mixture of archival and participant research to ascertain the historical, global and domestic situation for indigenous peoples and, in particular, Māori, with disabilities. While the research is from the perspective of Māori with a disability it has been extended to incorporate some indigenous disability identity research in the broader sense to look at similarities and differences that may be relevant for the identity of Māori with disabilities in law and policy.

Chapter two focuses on Māori (indigenous), gender and disability identities. While a focus on the citizenship status of Māori (indigenous) with disabilities was originally intended, research showed that little had been written which actually delved into the core aspects of the multiple issues of identity around being indigenous, female and living with disabilities. The under-development of indigenous disability gender identity discourse left a gap in the research and therefore it was decided to adapt the research to include these multiple factors that affect Māori with disabilities. The multiple identities of indigenous, disability and gender roles play a very important part in how law and policy has developed for these groups and without an exploration of these identities, the research could not continue in its original form. To gain an understanding of this topic, a focus on

indigenous and disability identity within a Maori context was discussed, while also taking into account gender identity discourse within the disability paradigm. Feminism and disability is a relevant field as research in this area has developed extensively in recent years, especially since disability became a part of academic identity research.

Indigeneity, gender and disability are all concepts discussed either on their own or more recently, together, yet little has been done to outline all of these identities and how they relate intersectionally. Barille (2000) and Morris (1993) discuss the difficulties of the multiple nature of marginalisation when one belongs to more than two marginalised identity groups. This difficulty of addressing the multiple marginalised identities collectively in law and policy remain relevant issues for Māori (indigenous) with disabilities. More specifically, Pacific and gendered disability identities within a westernised post-colonial construct are relevant when exploring Māori disability gendered identity in law and policy.

The findings of chapters one and two lay the foundation for chapter three which examines human rights law and instruments from a global perspective. As it is clear that multiple identities are important to the thesis in relation to being Māori with disabilities (and sometimes having the other gendered and age-related identities as another component of being Māori with disabilities), these needed to be explored within the international human rights frameworks. Several distinctive features of international human rights law and instruments are relevant to the issue of disability and indigeneity. Whilst grouped separately within international frameworks, indigenous and disability conventions are very inter-relational for those within the indigenous disability community because of the need for recognition of both in order to gain improved status within their own community and within 'mainstream' society.

The Universal Declaration of Human Rights (1948) may have catalysed a global focus on rights, yet gaps exist as evidenced by declarations and instruments developed since its inception. The proposed Convention on the Rights of Persons with Disabilities and the proposed Declaration of Indigenous Peoples' Rights aim to address these omissions in the Universal Declaration, yet it is argued that gaps

will still remain as long as the issue of multiple identities is not incorporated into their text. To explore the issue of identity in the working text of the Convention on the Rights of Persons with Disabilities and the Declaration of Indigenous Peoples' Rights a focus on each is explored separately in their own sub-sections. The issue of group rights along with collective rights is also explored in the context of being indigenous and a citizen, whereby individual identities are accorded their place within the human rights frameworks while collective identities are not seen as an entity having the same recognition of rights. The international discussion gives rise to the next step in this thesis which is to bring relevance to the finding within the context of the New Zealand society.

Chapter four examines the Treaty of Waitangi, its history, articles, principles and the current placement of the Treaty in relation to law and policy in New Zealand today. The Treaty is relevant to all Māori and it is the role that the Treaty plays in the life of Māori with disabilities that provides the main focus for this chapter. The tensions between rights and culture are discussed to explore whether or not the Treaty is rights-based and whether the Treaty has cultural and rights relevance today as in 1840. The role that the Treaty plays in the area of Māori disability identity is also discussed; the Treaty principles are applied in some disability policies, giving the Treaty a central role in shaping operational standards in disability policy.

In chapter five, which examines disability legislation in New Zealand, the focus is specifically on the areas of law that pertain directly to disability. While historically, disability in law has been objectified, and in conjunction with international human rights developments there has been an effort to bring disability identity into law as subjects of law. Laws such as the Disabled Persons Employment Promotions Act (1961) are designed to allow exemptions to minimum wage and employment law for persons with disabilities and were framed from a medical model of disability which placed persons with disabilities strongly within a medicalised, objectified framework. Human rights law such as the Human Rights Act (1993) provided a means of protecting persons with disabilities in that it provided for specific anti-discrimination protections, placing this group within the context of being subjects within the law. This move to give

status to persons with disabilities was the first step to removing the invisibility in law of persons with disabilities. Prior to these changes, the law was written as a means of protecting society from the issues of disability rather than of focusing on protecting the individual from the issues in society, such as prejudice, affecting them (Breslin, 2002; Quinn & Degener, 2002).

While legislation has been slowly reflecting the changes by addressing disability identity in the law, it is the policies that have been developing which show the greatest impact on disability in society. Although it is not legislation, the New Zealand Disability Strategy (2001) is also discussed in this chapter within the context of the impact it has had on law and policy in New Zealand. The Hansard Parliamentary debates show the diversity of opinion and understanding among parliamentarians who are often at odds with each other and their disability constituent base; this base is often still considered within the construct of objectification in law rather than having inclusion as subjects within the legal frameworks. While this chapter does not specifically address Māori with disabilities in the law, their identity as experiencing disabilities is the relevant focus of this chapter, leading to an exploration of law in New Zealand and how disability identity is reflected within it.

Chapter six is an exploration of disability, health and well-being models and how they relate to disability and, more specifically, to Māori with disabilities. This chapter was decided on as a result of the research findings which showed that little is known about Māori disability identity within disability models. The Māori health and well-being models also appear to place an emphasis on being Māori, with no clearly identified focus on Māori with disabilities. Some of this invisibility of Māori disability identity could be due to there being a distinct lack of work in this area. Whereas chapter two discusses Māori disability identity in the context of their visibility in disability models, chapter six focuses on Māori disability work from a professional Māori perspective rather than the Māori disability identity perspective. The disability movement has sought to establish a model that focuses on removing the barriers to this socially constructed identity and giving independence to the individual with disabilities; such a model is

clearly at odds with indigenous collective identity when addressing health and family issues.

Durie's *Te Whare Tapa Wha* (1982), Pere's *Te Wheke* (1984) and the Royal Commission on Social Policy's *Nga Pou Mana* (1988) models of health and well-being are the models most commonly implemented in Māori health and disability programs. The disability models have evolved from religious/charity-based models, where the person with disabilities is treated as someone to be pitied and cared for, to the social model of disability (Oliver, 1990; Corker et al., 2002) where the emphasis is on societal barriers created negative attitudes shifting the focus from the individual to society. The chapter discusses how to incorporate the concept of interdependency and collective identity with the disability models in which any concept other than independence is not considered as relevant to persons with disabilities. The difficulty with individual models such as the social model is that many indigenous persons with disabilities prioritise their identity as indigenous more highly than the identity of living with a disability. Family are also central to the wellbeing of Māori with disabilities and, while the Māori well-being models recognise this, westernised disability models do not place family as central to well-being for persons with disabilities. As neither disability models nor Māori health and well-being models give adequate visibility and accommodation to Māori with disabilities identity, another option needs to be considered.

Chapter seven brings together the findings of the previous chapters and identifies some core issues that need addressing if Māori with disabilities are to achieve more positive outcomes than those currently experienced. For Māori with disabilities to have representation that is equal to that of others with disabilities in New Zealand, some recommendations may be needed to implement changes. Central to Māori identity are the *whānau* in their lives and the effects on *whānau* and individual well-being when addressing disability issues in their community. *Whānau* are as relevant to the participants of this research as they are to all Māori. Māori often identify with the multiple concepts of identities generally such as with the identity of being Māori and experiencing disability. In the case of disability and Māori identity, disability is a compounding factor to Māori with

disabilities experiencing marginalisation and disparities compared to other Māori and non-Māori with disabilities.

Most participants with disabilities in this research desire inclusion in the community for Māori with disabilities. While inclusion is clearly desired, due to a lack of access, funding and understanding of this group, inclusion is often not the reality. As inclusion is a feature of the social model of disability in addressing society's attitudes to disability, it would appear reasonable to assume Māori with disabilities seek the same goals. It would also appear reasonable to assume that non-Māori with disabilities could benefit from frameworks that incorporate them at the centre of all health and well-being models along with service delivery. Non-Māori with disabilities also have family in their lives, therefore it can be concluded that any family-based focus would benefit all persons with disabilities not just Māori with disabilities.

The outcome of this thesis is to provide a better understanding of a largely invisible group where, despite some diversity work done on disability identity, indigenous disability identity remains largely under-researched. In exploring identity from a Māori/indigenous disability identity perspective, there is the opportunity finally to have reflected in policy an appropriate disability framework that addresses the cultural, social and legal issues for this group. Given that New Zealand has the largest Polynesian population in the world, it appears appropriate that a Polynesian influence be reflected in law and policy, regardless of ethnicity. While New Zealand law has its foundations in the Westminster common law principles, developments in areas of law such as disputes resolution where cultural components utilising customary legal principles are incorporated in restorative justice programs, the reality is different in the policy development on disability policy for Māori with disabilities. Despite New Zealand being a world leader in developing disability policy and recognising a range of thematic disability identities in law and policy, there is still the monocultural approach to how policy is implemented. While this thesis is focused specifically on the cultural, social and legal needs of Māori with disabilities, this work can be easily adapted into other diverse disability identities to allow for the ability to empower and embrace difference as a positive outcome of policy.

Embracing cultural diversity in policy does not mean rights have to be compromised. It is through the embracing of cultural diversity and the visibility of different identities in disability policy that a greater understanding of difference can result. The Treaty of Waitangi often gives rise to negative reactionary responses from those who do not fully understand its significance as a core foundational document in New Zealand. The Treaty of Waitangi for Māori with disabilities can be the key to inclusion for them and the key to understanding how to incorporate law and policy that adequately represents this group and reduces the gaps and disparities they currently experience. This thesis also opens a door to further research with a deeper exploration of Māori disability identity and, more specifically, how Pacific concepts can be embraced in disability policy that is relevant to New Zealand and its population.

Chapter 1: Introduction, research aims, questions and methodology

1.1 Introduction

This research is an extension of my one paper Masters thesis completed in 2000 titled *Persons with Disabilities: Objects of Welfare or Subjects of Legal Rights? Closing the Gaps, Human Rights and Disabilities*. While the original paper was a broad examination of the legal rights of persons with disabilities, it led me to ask about indigenous persons with disabilities and how they are identified in disability-specific law and policy. The purpose of this research was to obtain information into attitudes from Māori in relation to indigenous disabilities identity and how attitudes impact on the well-being of Māori/indigenous peoples with disabilities and their access to their cultural communities and mainstream society. The background for this study was gathered through a combination of archival and participant research to ascertain the historical, global and domestic situation for indigenous peoples and, in particular, Māori with disabilities. While the research focuses on Māori disability identity, through exploring indigenous disability issues from other settler countries, a similarity of experiences of indigenous with disabilities communities became apparent and some reference to this is made in chapters two and six.

1.2 Research aims, questions and hypotheses

As a Māori/aborigine woman with disabilities, my experiences and other research into disability issues generally led to the finding that any reference to disabilities from a settler-colonised, indigenous perspective is sparse and seldom from the indigenous disability perspective. Through undertaking this research a greater understanding of the indigenous disability paradigm could be created, resulting in an increasing awareness of the issues and needs as described by indigenous peoples with disabilities themselves and not from those who assume a knowledgeable role from an 'outside' or professional/expert perspective.

Working in partnership with Māori support persons who were fluent in *te reo Māori* (the Māori language) and in the knowledge of their *tikanga* (customs) for

the *rohe* (area) led to contact with participants who agreed to be a part of this study. This proved beneficial when visiting marae, as it enabled me to present the proposal to the community in a culturally and regionally appropriate way for the participants, resulting in the endorsement by the *kaumātua* (elders) who were present at the *hui* (meeting). These *kaumātua* went on to encourage their *whānau* (family) with disabilities to participate in the research. Without their support and acknowledgment, this research would not have obtained the information it did.

Not all participants were able to be reached through marae consultation as some have experienced isolation away from their *iwi/whānau/hapū* (tribe/family/sub-tribe) since birth or since their impairments became a source of exclusion for them. These participants were reached through a *pānui* (information sheet) being sent out to community disability networks derived from both Māori and mainstream throughout New Zealand. A diverse range of responses was received from those who have remained close to their cultural identity through to those who have not. The tables and comments documented in this chapter indicates that those who retain close cultural ties have, on average, a more positive outlook than those whose cultural ties have been broken.

The results of the research will be disseminated back to the participants on the completion of the work, either through *hui* or through one-on-one discussions. Copies of the thesis will be available to the participants, with a bound copy going to *Tainui iwi* in recognition of their support for this work. Community presentations and academic presentations will be delivered if requested by those interested in this work.

The original intent was to locate indigenous peoples with disabilities throughout the world who could respond to the research to enable a comparative analysis of similar and/or different experiences they may have of living with impairments. Due to the lack of funding obtained to support this research's original aim, I had to rely on the sparse archival evidence available to gain a global perspective and concentrated mostly on seeking Māori attitudes towards disability identity from a Māori with disabilities perspective. To establish the attitudes of Māori towards

disability, three objectives were developed to identify the issues around disability identity for Māori. The objectives proposed to achieve these results were:

1. To identify and recruit Māori with disabilities as participants throughout the country
2. To identify attitudes established by *whānau* towards their *whānau* members' impairment
3. To establish whether these attitudes are consistently positive or negative, or both towards Māori with disabilities.

In deciding on the research tools, the QRN6 student research program (NuDist) was used for coding and collating the results of the surveys and interviews. The NuDist program served as a method for coding the materials and provided the data set out in the tables in this chapter. The survey questions were designed with a mixture of both quantitative and qualitative questions and sent to the University of Waikato Law School Ethics Committee who approved the survey for distribution. The two different methodologies for the questions were designed to gain insight from the participants into their feelings/beliefs around attitudes and the impact of those attitudes on their lives. This style of questioning is consistent with indigenous research techniques. Ethnographic models of research and exploring post-colonial thinking around identifying as indigenous and with impairments appeared to be the appropriate process for this research in that these approaches embrace the concept of incorporating a *kaupapa Māori* (Māori concepts) research process which gives a different emphasis on what is important when researching with Māori. This process is outlined by Smith in *Decolonising Methodologies* (Tuhiwai-Smith, 1999).

Some of the disparities around impairments for Māori are the results of the relationship between the colonizer and the colonized (Tuhiwai-Smith, 1999). This is not a unique concept to Māori where the owner of the knowledge is perceived not to be the researcher but the participant who is imparting their knowledge to that researcher. In a conference in New Zealand in November of 2005, UNESCO (United Nations Economic, Social, Cultural Committee) described the process of collating information from Pacific peoples as the 'Pacific Way' and claimed that

research within a cultural context is what should be driving methodology (UNESCO, 2006). While I had the prepared questions, I was aware that by allowing the *kanohi ki te kanohi* (face-to-face) participants to share their stories throughout the interview, I would achieve greater participation from them and be better informed of the issues relating to impairment for Māori.

The experiences of Māori with impairments as Māori and as Māori living with impairments along with the Crown's policy development around impairment and disability, exemplifies the colonizers' role in policy impacting heavily on the colonized.

The colonizing of the other through discipline has a number of different meanings. In terms of the way knowledge was used towards the colonized worked in a variety of ways. The most obvious forms of discipline were through exclusion, marginalization and denial....Discipline is also partitioned, individuals separated and space compartmentalized. This allowed for efficient supervision and for simultaneous distinctions to be made between individuals (UNESCO, 2006).

As suggested, indigenous peoples have had little control over their own policies and identities since colonization. This colonial and post-colonial structuring of policy is impacting on Māori with disabilities and perpetuating the experiences of colonization. This situation is not helped when those Māori who do not have the experience of impairment further remove the process of self-determination from Māori with disabilities when they exclude this group from the process of consultation and decision making. Gonzales (2003) describes the impact of the post-colonial mind and awareness on post-colonial research. Gonzales states that:

It is from the cognizant place in the colonized mind that the post-colonial perspective is birthed. There is an awareness of colonization after having been woken from a hegemonic slumber. Often...this awareness does not erase the reality of the colonization occurring. Accordingly a post-colonial ethnography will do more than simply point out that colonization has taken place (2003, p.81).

Awareness is created that outlines in a post-colonial construction the issues in research from a colonised perspective. In considering indigenous applicable research, Gonzales outlined four points of post-colonial ethnography considered essential when carrying out indigenous research. These four points are: accountability, context, truthfulness and community (Gonzales cited in Clair, 2003). These four ethics are essentially about retaining one's credibility within one's community, being accountable to that community and making the research relevant to that community. Finally, these ethical considerations ensure that the researcher brings the results of that research back to their communities, thereby empowering them with the results derived from their own shared knowledge.

In this instance, community is an important factor when including Māori with disabilities as participants in their cultural community and considering what the implications for the participants are when trying to engage as a community member. This is consistent with the concept of the 'community' members defining and identifying themselves and the way they do this. This is also consistent with the ethnographic decision model (EDM) concept as it allows the community to engage in a way that ensures their safety. This enables the participants to guide the researcher, not the other way around.

Defining community research is as complex as defining community. For example, 'the community' is regarded as being a rather different space, in a research sense to 'the field'. Community conveys a much more intimate, human and self-defined space, whereas . . . the community itself makes its own definitions (Tuhiwai-Smith, 1999, pp.126-127).

Another consideration for this community is the sensitive or *whakamā* (shame/embarrassment) issues that may surround their identification with impairments. This was taken into account throughout the research process and was of paramount importance in safeguarding the dignity and respect of the participating individuals and their *whānau* connection;

One result of the negative stance, particularly in the investigation of sensitive topics, has been non-involvement by these communities, and in many cases this has served to further disadvantage them (Smith 1999; McLennon et al 2004). Disadvantages include isolation, reduced access to resources and services, and continued mistrust of and resistance to research and researchers, including Māori. While there are many success stories and some evidence of improvements in Māori wellbeing, it is often the case that the issues and concerns that affect Māori communities either continue to be dealt with ineffectively, in ad hoc ways that produce inaccurate findings, or they simply remain unaddressed. To take but one relevant example, health disparities between Māori and Pākehā have continued to grow, especially since the mid-1980s, despite decades of research and intervention. (Edwards et al, 2005, p. 89)

When research is undertaken among Māori, *The Law of Research: a Guide* states that the principles of the Treaty of Waitangi (Treaty) are the guiding ethical principles. These principles are outlined as:

- *Kawanatanga*: The Government has the right to govern and make laws.
- *Rangatiratanga*: Maori have the right to control their own resources.
- *Equity*: All New Zealanders are equal before the law.
- *Reasonable cooperation*: This is expected between the Government and Maori.
- *Redress*: The Government shall provide effective processes for resolving grievances in the expectation that reconciliation can occur.
- *Partnership*: The relationship between Maori and the Crown is akin to a partnership.
- *Good faith*: The parties have a positive duty to act in good faith towards one another.
- *Active protection*: The Crown has an obligation actively to protect Maori interests.
- *Consultation*: the Crown has a duty to consult with Maori to be properly informed. (Tipene-Matua & Dawson, 2003, p. 65)

These principles are problematic in that their interpretation may differ for Māori, depending on whether there is an emphasis on the Māori or English version of the Treaty. It is of note here that Māori mostly signed the Māori version thereby retaining their *kawanatanga* as they interpreted it. This interpretation by Māori may have been that the government did not have the right to govern and rule Māori. For the purposes of this paper, however, these are the principles as outlined in legal research and incorporated as the main principles currently identified for ethical research.

I acknowledge the limitations in identifying the Māori ethics in law and submit that, in taking these principles and applying a *kaupapa Māori* set of principles beside the legal principles as set out by Tuhiwai-Smith (1999), Gonzales (2003) and other indigenous researchers, I am able to take control of the research ensuring the participants are treated in a culturally appropriate manner that also considers their status (*mana*) and their rights to the information retrieved by the participant.

Kaupapa Māori is a research paradigm that recognises and accommodates the unique requirements of this project. As a response to traditional Western research paradigms it acknowledges the historical experiences that Māori have had with research. It goes further to provide possibilities for creativity and innovation within a framework that is responsive, reflective and accountable. (Dawson & Peart, 2003, p. 89)

In applying the kaupapa research there is also an acknowledgment that a clearer definition than that set out by the *The Law of Research: a Guide* is being considered when incorporating the principles. The definition as the *kaupapa Māori* outlines discussed, are also a part of this process. For example where the *Law of Research: A Guide* outlines equity as meaning that all New Zealanders are equal before the law, there is also a consideration of the understanding that, while this is true in theory and a desired goal where law applies to all equally, the reality for indigenous, and in particular, Māori is different. Disparities and inequalities exist in accessing particular services and support, which has led to the negative statistical representation of Māori in all areas of society.

The challenge facing Maori and other New Zealanders in the twenty-first century is to ensure that Maori share equally all the benefits of New Zealand life. Good health is partly dependent on the attainment of other social and economic advantages, and is certainly one of the most important of the benefits expected in national life (Lange, 1999, p. 269).

These issues are consistent with the development of post colonial ethics as outlined by Gonzales (2003) in her writings on ethics in post-colonial ethnography research. While aware of the colonial influences in the lives of the research participants, embracing a post-colonial ethnographic and narrative process is consistent with the conclusion that Māori with disabilities identity are heavily impacted on, and influenced by the colonial influences which impacted on the traditional pre-colonial construct of Māori with disabilities identity. Therefore, applying a *kaupapa Māori* perspective, while acknowledging the social structures that have created the Māori disability identity and the existing attitudes towards that identity today, is appropriate for this study.

A post-colonial ethnography, therefore, is not merely an act of defiance, but one of great courage, in that unlike pre-colonial awareness, there is now a sense of coexisting within social systems that may or may not still be fully or partially in the creative grasp of the colonial Fist. One's "buy-in" to the colonial systems of costs and rewards is tested. Does it determine what ones says or doesn't? Do we feign free expression when we are aware that we made explicit choices not to express something because of social implications? The ethics of a post-colonial ethnography must be able to provide a means for such obviously ambiguous readings to be made clearly (Gonzales, cited in Clair, 2003, p. 81).

To further develop the application of a *kaupapa Māori* framework for this study, the Health Research Council's paper on *kaupapa Māori* research guidelines, which sets out the principles of the Treaty of Waitangi as the guiding principles when undertaking research with Māori persons, was also utilised (Health Research Council of NZ, 1998). While this is an introductory paper for researchers involved in health research with Māori, it is an essential starting point

for any researcher who may wish to succeed in obtaining Māori participants consent for research.

There is little written around research on minority groups with disabilities including indigenous peoples with disabilities. While health research guidelines have been developing, little is talked of specifically around issues unique to indigenous persons with disabilities, such as the inability to attend *hui* or cultural events, their exclusion from their community or their isolation through institutionalization that may have been a factor in their invisibility within Māori society. Māori statistics show their experiences are very similar to other minority groups experiencing disabilities (Preston-Shoot, cited in Cooper, 2000, pp. 278-279):

There has been little research on community care for people from ethnic minority communities (Ahmed and Atkin 1996). In research and in practice, black disabled people are often excluded and forgotten (Begum, Hill and Stevens 1994)...Black disabled people are, moreover, likely to have significantly higher levels of unmet need.

Part of the problem for Māori with disabilities could be the tendency for policy analysts and law makers to view disability as homogenous in its identity, thereby denying an indigenous or cultural identity when accessing disability services. According to Preston-Shoot (cited in Cooper, 2000, p.279), barriers to access for minorities with disabilities include:

- lack of knowledge, including familiarity with concepts underpinning services
- a tendency to homogenize the experiences of all disabled people (Begum *et al.* 1994; Stuart, 1996) which privileges white perspectives on disability
- culturally inappropriate assessments and services, and experience of racism
- access barriers – information, transport, cost, language, stigma, fear
- over-reliance on families to provide care

- racist attitudes and stereotypes, and misrepresentation of people's needs
- under-developed policies
- short-term or inadequately funded specialist provision
- marginalization in community care planning and provisions

Critics may argue that heterogenous approaches do occur in law and policy regarding indigenous persons with disabilities purely through the mention of their ethnic identity in policy (i.e., categorising a section on Māori with disabilities). It can be argued that this does not remove the homogeneity that currently exists in such policy recommendations as set out in the New Zealand Disability Strategy (2001) and evidenced by the lack of uptake of services by Māori with disabilities and the lack of consultative inclusion of Māori with disabilities themselves.

When exploring Māori *tikanga* in relation to research, it was also relevant to look at the role of *kawānatanga* (government). To understand why *kawānatanga* is an important concept for Māori, it is imperative also to understand the relevance of indigenous knowledge and the ownership rights to that knowledge. If Māori do not have control over their knowledge and resources then they do not have control over researching and enhancing the well-being of Māori (Cooper, 2000). The debate is still continuing over the meaning of 'kawānatanga' and 'rangatiratanga' (sovereignty) and which definition is to be preferred. It can be argued that it is Māori (in this case, Māori with disabilities) who should have the right to define, and it is Māori who should have the right to make the decisions and implement those decisions as per their right set out in the Māori version of the Treaty; this discussion takes place in more detail in chapter four (Orange, 1987).

The right of indigenous researchers to control and maintain their cultural knowledge is set out in the *Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples (1993)* which was signed in Whakatane, New Zealand with two key recommendations relating to this research:

2.1 Recognise that indigenous peoples are the guardians of their customary knowledge and have the right to protect and control dissemination of that knowledge.

2.2 Recognise that indigenous peoples also have the right to create new knowledge based on cultural traditions.

It is these recommendations that have been contemplated throughout this research when considering a method of research that is of an appropriate indigenous manner. As already stated, it is intended that these research results be disseminated back to the participants and other stakeholders, as requested by the participants. This is consistent with the four ethical principles outlined by Gonzales (2003) and the Mataatua declaration (1993) recommendations, and is also consistent with *kaupapa Māori* research. In the New Zealand context, research ethics for Māori communities extend far beyond issues of individual consent and confidentiality. In a discussion of what may constitute sound ethical principles for research in Māori communities, Ngahuia Te Awekotuku has identified a set of responsibilities which researchers have when working with Māori participants. These are not prescribed in codes of conduct for researchers, but tend to be prescribed for Māori researchers in cultural terms:

1. *Aroha ki te tangata* (a respect for people).
2. *Kanohi kitea* (seen the face, that is present yourself to people face-to-face).
3. *Titiro, whakarongo...korero* (look, listen...speak).
4. *Manaaki ki te tangata* (share and host people, be generous).
5. *Kia Tupato* (be cautious).
6. *Kaua e takahia te mana o te tangata* (do not trample over the *mana* of people).
7. *Kaua e mahaki* (don't flaunt your knowledge) (Tuhiwai-Smith, 1999, pp. 119-120).

Where the questions allowed for a qualitative response to give the participant an opportunity to share their stories, these responses are reflected throughout the research. The narrative ethnographic style of data collection, identified broadly as

native ethnography because it is written by researchers who share the colonial and economic history and, in this case the experience of disability and attitudes, was used (Ellis & Bochner, cited in Denzin, 2003, p. 213). The ethnographic decision model, as outlined by Gonzales earlier in this chapter, was identified as an appropriate process for the design and analysis of the questions to ascertain and analyse certain behavioural/attitudinal behaviours linked to impairment for Māori. The ethnographic decision model, along with narrative data collection, is a consistent method appropriate for indigenous research as it utilizes open-ended interviews to gain the responses in order to understand behavioural process when faced with impairment within Māori communities. While it is true that ethnographic decision model researchers engage in this process to identify and build preliminary models, it is also more recently seen as a process that can effectively test a nationally representative sample.

Because of the intensive labor involved, EDMs have been necessarily restricted to relatively simple decisions in relatively small and homogenous populations. Recently, however, we found we could effectively test, on a nationally representative sample, our ethnographically derived decision models for whether or not to recycle cans and whether or not to ask for paper or bags at the grocery store (Weitzman, cited in Denzin, 2003, p. 289).

Because the ethnographic decision model process does not analyse what people are thinking, the narrative response was encouraged to gain insight into why people believed there were attitudinal problems with their diagnosis and if these attitudes were because of their impairment or 'other' factors. The narrative process was also a way of removing barriers of communication with participants in the hope that it would help them to answer the survey questions, albeit indirectly.

Researchers identify themes, describe them, and compare them across cases and groups. Finally, they combine themes into conceptual models and theories to explain and predict social phenomena (Weitzman, cited in Norman, 2003, p. 290).

The text analysis aided in identifying themes (tables 7-14). The narrative responses contained personal histories that were reflected throughout the study as they provided insight into the participants' emotions and feelings around living with impairments and the attitudes of others towards them. The participants (five) who provided face-to-face responses for the purposes of this study are identified as key informants as they provided more intensive responses to the qualitative questions which, while not differing from the information already gleaned from the written responses, did appear to confirm the responses reflected in the tables. This information was obtained by applying several techniques to the research questions and by validating the informants' cultural identities by allowing them to guide the interview and answer in a manner with which they were comfortable. Detailed comments made by participants around *whānau* coping and final comments are pasted throughout the chapters giving their response to situations discussed in those chapters. The comments are in no specific order and are not attributed to anyone so as to maintain the confidentiality of the participants who gave comments.

1.2.1 *Whānau* Coping

The responses to *whānau* coping were split into four sections: positive, negative, both positive and negative, and neutral. These comments provide insight into the feelings and emotions of the participants around attitudes of Māori towards their experiences of impairments. These two were listed independently of the tables due to the broad nature of their responses and the value their insights may offer to the different components of this study.

A widely used method for describing themes is the presentation of direct quotes from respondents --- quotes that lead the reader to understand quickly what it may have taken the researcher months or years to figure out (Weitzman, cited in Norman, 2003, p. 282).

The positive comments around *whānau* coping provided me with insight into what participants considered to be the factors in support given them by *whānau* to help them to cope with their impairment. The *whānau* appeared to offer all kinds of support and assistance to the individual. Where there was support, the participant

appeared to feel confident and positive around coping with their impairment. One participant outlined what their positive experience meant in relation to their *whānau* coping with the participant's impairment.

Make me comfortable and just give love & support when I have health problems (eg run baths, clean up my mess, read me my lectures notes or books, talk to me when I am not feeling good, make sure I take medication, go and buy the necessary personal items on demand, tell the doctors how bad my condition is for the month, miri miri my arms, hands & feet, don't allow me to carry heavy items) (female student participant with physical impairment).

The negative *whānau* coping comments provided insight into the feelings of the participants if their *whānau* are not coping. Most felt disconnected or isolated from their *whānau* along with expressions of anger and misconceptions around their impairment. While the participants experienced negative attitudes, some rationalised the behaviour by outlining what they see as the reason for their isolation from their *whānau* as described by one participant.

They don't have much if anything to do with me. I can understand this because they suffered terrible family disharmony as they grew up. (male participant with psychosocial impairment).

One participant made a simple statement that gave deep insight into their feelings around their *whānau* not coping.

Silently and alone (female participant)

Some participants believed their *whānau* had both negative and positive experiences with the majority of the participants reporting that while the *whānau* tried to cope, it was a lack of understanding and a frustration at seeing their *whānau* member not managing that created both the positive and the negative responses to their impairment. This insight into the support and anger expressed to the participants is outlined by one participant who stated:

Supportive, but gets hoha (angry) when I am not able to do my usual activities (wife with impairment).

Two participants indicated they had no insight into how their *whānau* coped with their impairment. They gave no rationale for this and it was not investigated further.

1.2.2 Final Comments – Summary Preview

Responses in the final comments section ranged from nothing, to some advice into how to disseminate the research information back to the community, and even an offer to become involved in assisting the researcher with the study. I note from the comments that Māori generally are not well informed about what is available to them in relation to entitlement funds and services for Māori with disabilities. One participant stated that:

I believe a lot of our people are not well informed when dealing with Government agencies and their entitlement (female participant).

Another participant also believed the questions should have included one identifying financial need of Māori with disabilities when trying to access their traditional cultures by stating that:

Also I think some of these questions should include whether they are able to keep in contact with their iwi/hapu financially when living away from their iwi, (eg living in the city but tribal affiliations in the East Coast etc, may be physical, financial burden going back home) (female participant).

Some participants stated they often received negative responses from the medical profession and did not like how they were treated by them as outlined by one participant who stated that:

In many ways you are like a human guinea pig in which doctors will try you on different medications or methods instead of getting to the right remedy. Sometimes they think you over-exaggerate the disability and tell you no-one can bleed that much and still be standing (male participant).

Other participants believed it was important to ensure they maintained a holistic approach and discussed the need for support to maintain their well-being. One participant identified the impact support has on their well-being by stating that:

I think the most important thing is to have a stable life style, secure housing (meaning you won't have to move) and if you need to have support, if you are lucky enough to have that from whanau then that is great. It has been my experience that mental health problems get too much for my family. You need to have more outside support and I feel incredibly blessed to have a fantastic community support worker. We are friends but not quite friends if you know what I mean. I have the luxury of being able to talk for a long time to my mental health case worker and I have who is considered the best psychiatrist in my area. My chiropractor is wonderful and my GP is also considered to be the best around (female participant).

Not everyone made a final comment; however those who commented were clear on how they believed attitudes impacted on themselves and other Māori with disabilities. Several of the participants stated that these issues were important to all Māori with disabilities and not just an issue for them personally. This collective caring and thinking of others with impairments reflects the concept of aroha for others, even though they are often disconnected from *whānau* and their traditional community. Māori with disabilities differ little in characteristics to Māori who do not experience impairments and in many ways they often think of others who are facing similar situations and still express themselves in a collective and indigenous way, despite their exclusion from their cultural community.

1.3 The Process

Two processes were used for information gathering. The first was to send out a *pānui* (information sheet) to as many disability networks and individuals as

possible, inviting Māori with disabilities (participants) from age 18 years to take part in the research via a survey, with a small number (five) randomly selected for *kanohi ki te kanohi* (face-to-face) interviews. The second step taken was, on invitation of several Māori with disabilities and their support networks (e.g. CCS Northland, People First Whakatane), to meet with them and their *whānau* to discuss the aims and objectives of the survey, and to outline how they could benefit from the results of the survey when completed. These strategies and the results of the findings from those who completed the survey are set out below.

1.3.1 Strategy One: Gathering the Information from Māori with disabilities

1.3.1.1 Recruiting participants

The expectation was that approximately 20 to 25 responses would be received based on the premise that Māori with disabilities are not visible within their community or society in general and that there might be reluctance for them to identify with an impairment, based on the attitude of being *whakamā* (embarrassed), which may add to the reluctance to participate in the research.

To overcome this possible barrier, the support of some Māori (including one fluent in *te reo* of the *Ngāti Porou iwi* who also had links to the *Waikato rohe*) who had access to the communities was engaged. Through this support and the *pānui* (See *Appendix 1*), 44 responses were received from Māori with disabilities. A total of 120 *pānui* were sent out to individuals and disability networks both mainstream and Māori. This response was higher than the ten percent response usually expected for research and, even more surprisingly, the responses were overwhelmingly from Māori with disabilities rather than their *whānau* and carers doing the surveys for them. While Māori with disabilities were the targeted group, previous research experience in this area indicated there would be a low response rate from this group.

Included in the *pānui* were:

- a) an introduction to me and my background and my reasons for conducting the research

- b) an invitation for Māori with disabilities and/or their supporters/carers to participate in the research
- c) an outline of what was required of the interviewer and interviewees and of their rights to withdraw themselves and their information from the research at any stage of the study, and
- d) researcher's contact details.

The *pānui* was sent out electronically, by mail send outs, and through visiting some marae by invitation to discuss the research and to distribute surveys with stamped addressed envelopes for their return. The participants were anonymous unless they responded as wanting to be considered for *kanohi ki te kanohi* interviews, in which case where they were to add their contact details which would remain known only to me. Those who were interested in participating further were given a consent form (*Appendix 2*) and were given time to ask any questions or clarify any issues prior to commencing the interview.

While it was originally intended to complete approximately six to eight *kanohi ki te kanohi* interviews, after five were completed, the information retrieved was no different from the written surveys that had been completed and it became apparent we had reached saturation of information. As no new information would be collated, the decision was made not to continue with any more interviews. This decision was based on existing research practices: where research is found to be similar to the written responses so that it would offer no new information, there is no need to continue the physical interviews as they could offer little added value.

While there has been a general reluctance by Māori with disabilities to participate in research (Nikora et al, 2005), coming with the lived experience of impairment through my own identity as a Māori woman with disabilities along with taking the time to visit some of the networks and bringing local members from their rohe who Māori participants knew, assisted me in gaining access to a community not easily reached by researchers in general. Including the *kaumātua* and *whānau* was also useful in that it gave the group the sense they were fully in control of the process.

1.3.1.2 Sample Characteristics

Forty-four Māori with disabilities responded to the *pānui*; the representation between men and women who responded was marginal in difference with 24 men and 19 women responding. There was one person who did not respond to this question. There was no intentional rationale for the gender split as participation in the research was voluntary and the onus was on the participant to respond voluntarily to the *pānui*. The number of respondents is reasonable, given some of the social attitudes attached to the issue of impairment among some Māori as described in this study.

The data coding was split into 11 specific headings, with demographic being the first; tables 1-7 outline the results of the demographics information. Tables 8 and 9 outline the response to the participant's coping with their impairment and if *whānau* are coping with the participant's diagnosis. Table 10 outlines *iwi* contact since diagnosis, while table 11 outlines if participants have been involved with their marae since diagnosis. Table 12 outlines attitudes from other Māori towards the participant's diagnosis and Tables 13 and 14 describe the participant contacts for health care (13) and for crisis contacts (14).

1.3.2 Demographics Tables

Table 1: Gender of Participants (n=44)

Gender	Number	Percentage %
Male	24	55
Female	19	43
Not identified	1	02
Total	44	

The sample shows a slightly higher number of men responded than women; although specific genders and ages were not sought for this study, men responded in greater numbers (55%) than women (43%).

Table 2: Age Range of Participants (n=44)

Age	Participant	Percentage
18-20	3	07
21-30	3	07
31-40	11	25
41-50	13	30
51-60	4	09
61+	10	22
Total	44	

The sample is generally representative of a wide range of age groups from 18 to over 61 year olds, with the largest groups being between the ages of 31 and 50 years of age (55%).

Table 3: Geographic location of Participants (n=44)

Geographic location	Client	Percentage
Urban	32	72
Rural	9	20
North Island	37	84
South Island	4	09
Outside NZ	2	04
No response	4	09

The majority of participants resided in the urban centres (72%) and North Island (84%) areas. Two participants responded from overseas (Australia).

Table 4: Employment Status of Participants (n=44)

Employment Status	Client	Percentage
Unemployed	27	61
Part time employment	0	0
Full employment	7	16
Unpaid/voluntary employment	7	16
No response	3	07

The majority of the participants (61%) identified as being unemployed with 16% identifying themselves to be in full employment and 16% identifying as being in unpaid and/or voluntary employment.

Table 5: Diagnosis (n=44)

Type of diagnosis	Client	Percentage%
Physical	12	27
Psychiatric	4	09
Sensory	1	02
Intellectual/learning	2	04
Medical/non-specific	19	43
Multiple diagnosis	8	18

** responses in this table do not total to 44 as 8 participants reported having more than one diagnosis.*

The majority of participants identified as having a medical/non specific diagnosis (43%), while the second highest group were those identifying with a physical diagnosis (27%), and 18% of the participants identified as having more than one diagnosis made.

Table 6: Doctor Diagnosed (n=44)

Doctor diagnosed	Client	Percentage%
Yes	40	91
No	4	09

91% of the participants were diagnosed by a doctor, while 9% were not diagnosed by a doctor.

Table 7: Length of time person has lived with diagnosis (n=44)

Length of time	Client	Percentage%
Under 10 years	27	61
More than 10 years	17	39

The majority of participants (61%) had lived with their diagnosis for less than 10 years.

1.3.3 Tables 8 to 14 *Qualitative Results*

Tables 8 to 14 outline the attitudinal aspects of being Māori with disabilities. These results, along with the qualitative responses are reflected throughout the paper where they are highlighted as they are required to represent the participants perspective on the subject matter relating to the information given.

Table 8: Coping with diagnosis (n=44)

Coping	Client	Percentage%
Yes	15	34
No	11	25
At times	18	41

34% of the participants stated they were coping with their diagnosis, 41% acknowledged they are coping at times and 25% of the participants stated they were not coping.

Table 9: Whānau coping (n=44)

Coping	Whānau	Percentage%
Yes	13	30
No	12	27
Sometimes	14	32
Absent	5	11

Participants reported that 30% of their *whānau* were coping with their diagnosis, 27% of their *whānau* were not coping, 32% of the participants reported their *whānau* were coping sometimes and 11% of the *whānau* were reported as being absent from their lives since their diagnosis.

Table 10: Iwi Contact (n=44)

Contact	Client	Percentage%
Satisfied with contact	27	62
Satisfied with lack of contact	11	25
Dissatisfied with contact	5	11
Other	1	2

The majority of participants reported they were happy with the level of contact with their Iwi (62%) while 25% of the participants were satisfied with the lack of contact.

Table 11: Marae Involvement since impairment (n=44)

Involvement	Client	Percentage%
Yes	15	34
No	23	52
Some day trips only	6	14

The majority (52%) of the participants reported they have not been involved with their *Marae* since their impairment was diagnosed with 14% saying they only visited their *Marae* on day trips.

Table 12: Attitude problems from other Māori towards your impairment (n=44)

Attitudes	Client	Percentage%
Yes	29	.66
No	11	.25
Both	2	.045
Unsure	2	.045

The majority of participants (66%) reported they had encountered attitude problems from other Māori towards their impairment.

Table 13: Contact for Health Care (n=44)

Contact	Client	Percentage%
Whānau	19	43
Doctor	34	77
Nurse	13	30
Māori disability/health provider	9	20
Hospital	7	16
Other providers	5	11
Other	6	14
Total	93	

** some participants gave more than one answer*

The majority (77%) of participants said they contacted their doctor with regards to their health care with the next highest contact being their *whānau* (43%) along with 30% contacting the Nurse for health care and 20% contacting a Māori health/disability provider. Participants often contacted more than one health care provider although the majority went to their doctor as the primary contact, there were some who sought other alternative networks for provision of their health care.

Table 14: Crisis Contact (n=44)

Contact	Client	Percentage%
Whānau	27	61
Doctor	33	75
Nurse	14	32
Māori disability/health provider	9	20
Hospital	3	7
Other providers	4	9
Other	5	11
Total	95	

** some participants gave more than one answer*

When participants had to deal with a crisis regarding their health, the majority (75%) would seek help from a doctor with their *whānau* (61%) being their second highest contact in an emergency regarding their health.

1.4 Summary

The research response exceeded my expectations in both the response rate and the results. No more than 20 survey returns were expected. It was also not expected that Māori with disabilities would be the overwhelming respondents. The response resulted in the final number of respondents totalling 44. While the original intent of the *kanohi ki te kanohi* interviews was to have six to eight interviews, they were stopped after five completed interviews. Saturation was reached when no new information was being obtained and therefore it was concluded that, for the purposes of this thesis, the information needed through the surveys and interviews had been obtained from these responses.

The results identified four clear attitudes around disability among Māori and helped to clarify some of the issues needing to be considered for Māori with disabilities in law and policy. By remaining close to an indigenous ethical framework for the research, and by identifying with the lived experience of impairments, a positive response was elicited when the *pānui* went out to the communities for participants.

The limitation of the research was that many of the participants requested help for their situation. Other than offering advocacy and information as to services available to them, this research was not in a position to help them with some of their issues if they were in an environment where access to support was difficult. This may partly be due to the lack of access to disability specific information and services for those within the rural communities around the Waikato and East Coast. Despite having a range of Māori health and disability services identified for these participants, few felt confident they could have their needs met and fewer still felt that they could break their isolation and exclusion from their cultural community because of attitudinal barriers that exist regarding their particular impairment.

Those participants who did have whānau support also identified the lack of information and access to disability specific services and equipment for the participant as a significant issue related to their coping. All the participants expressed a sense of being overwhelmed by the issues surrounding the disability and the needs left unmet due to multiple factors. The ignorance of members within their *whānau* and local community appeared to be an issue for most of the participants and appears to be the reason for the exclusion and isolation for some from their own *iwi*, *hapū* and *whānau*. Some had also experienced abuse from providers and whānau which still left an impact for them and created further isolation and exclusion as they struggled to manage their activities of everyday living with their impairments. While there was evidence of support from some with *whānau*, this appears to be the exception and not the norm. More extensive research may be able to explore this in further detail. While this result is outside the brief of this study, it is worthy of highlighting.

The results of this study show a need to further examine the issue of impairment and what that means for Māori with disabilities, the role of *whānau* and whether whānau have a role with Māori with disabilities. Finally, it could also be useful to examine why Māori with disabilities and their whānau do not actively pursue support and equipment that is specific to their disability needs. There may be other issues that arise as these areas are examined, but these are the initial factors I have identified from the results of my research.

Chapter 2: Māori with Disabilities Identity: Integrating the intersectional nature of Indigeneity, Disability and Gender Identity Frameworks

2.1 Introduction

They don't have much, if anything to do with me. I can understand this because they suffered terrible family disharmony as they grew up (male participant of research survey, 2004).

In recent years, disability discourse as an identity discourse has developed from the medical, social work and rehabilitation fields into what are now seen as identity-based critical fields of study, as are women's studies and queer-based studies. Disability models are discussed in detail in chapter six, although a background to disability identity is discussed further in this chapter to incorporate a more comprehensive picture of disability as an identity and the more recent work on identity issues when identifying with disability and other identities. The disability identity work has also begun to take an increasing recognition and knowledge of the diversity that exists within our different communities. With this increasing knowledge has also come an understanding of the complicated factors that have an impact on these different identity frameworks. The identity of indigenous people with disabilities is inextricably linked to ethnicity and gender status and yet little research has been carried out to explore these intersectionalities and their impact on the well-being of indigenous people with disabilities. Research undertaken to date has been from a provider's perspective and focuses on how to provide culturally appropriate services regarding the *health* status of indigenous peoples. Little analysis has been done from the position of identity around indigeneity and disability.

Ethnicity is also a contentious term when discussing disability identity, due to the monocultural¹ approach to disability identity in New Zealand policy (Office for Disability Issues: 2006). In the same way that eugenics theory was used to justify the termination of life of some persons with disabilities historically, ethnicity was

originally used to determine someone's characteristics as a justification of someone's 'perceived' inferiority or superiority (Geertz: 1963). The theory of polygenesis was based on a hierarchy of races where Caucasoids (Europeans) ranked higher than Mongoloids (Asians) and where Negroids and Aboriginals were ranked lower than both (Nelson, 2001). These racial stereotypes have since been discredited scientifically, yet its popularity and utilisation as a group descriptor remains. There are two approaches to ethnicity – primordial and situational. In discussing primordial ethnicity, Wetherell and Potter (1992) describe race as a purely biological determinant which also includes cultural, social and economic characteristics showing that primordial ethnicity and race are closely interconnected.

Situational ethnicity has the distinctive characteristics of identifying through cultural distinctiveness, self-identification and choice over biological connections. According to Weber (1968) ethnicity was regarded as a phenomenon to aid the process of group formation when seeking social, economic or psychological rewards. Weber believed that ethnicity and ethnic identity were affirmed by the belief in the common bond of individuals rather than the actual biological bond. In following Weber's argument surmised that people chose their ethnic identity to meet personal and collective needs. Barth (1969) however, argued that ethnicity was not strictly ascribed nor was it unchangeable. Barth believed individuals could claim different identities at different times, it depended on the situation within which they were identifying themselves.

In the New Zealand context, Statistics New Zealand (1993, 1996) has both situational and primordial ethnic concepts and defines ethnicity as an ethnic group or groups that people identify with or feel they belong to. Ethnicity is a measure of cultural affiliation, as opposed to race, ancestry, nationality or citizenship. Ethnicity is self-perceived and people can belong to more than one ethnic group. From this description it can be deduced that an ethnic group is made up of people who have some or all of the following characteristics:

- a common proper name
- one or more elements of common culture which need not be specified, but may include religion, customs, or language

- unique community of interests, feelings and actions
- a shared sense of common origins or ancestry, and
- a common geographic origin' (Statistics New Zealand, 2001, p 6).

For the purposes of this study, the statistics New Zealand definition is used as it effectively outlines ethnicity in both the biological sense and in the sense of self-definition where both are valid for Maori with disabilities who identify as Maori first, and those Maori with disabilities who identify as living with a disability first.

Maori ethnic identity is a continually evolving concept (Pearson, 1990; Broughton, 1992; Durie, 1995). While Maori maintained their connections to their land, sea and whanau, hapu links through such methods as whakatauki, there were multiple connections and identities maintained that changed according to the political, social, economic and geographical environments (Ballara, 1998). Historically the term Maori simply meant normal or usual and was not a term used by Maori to describe an ethnic identity (Barlow, 1991). The use of the term Maori to describe the indigenous inhabitants of New Zealand evolved around the time Europeans began arriving in New Zealand which was around 1810 (Belich, 1996).

The modern contemporary approach to Maori identity must consider the rural/urban tensions where the urban migration patterns of the 1960's have led to the spread of kinship ties going beyond the local environmental and economic patterns of the past. This has led to the inter-meshing of boundary, where interdependence and consciousness is constantly present (Pearson, 1994) Durie's (1995) Maori diverse realities framework is an appropriate tool when considering the fluidity of identity for Maori with disabilities within a contemporary environment, this model is discussed in detail in chapter six, however, it is worth mentioning here that in considering Maori with disability identity, the issues for Maori who do not have a direct experience of impairment is applicable to those who do have a direct experience. Taking into account the factors of impairment and now the term disability when applying an ethnic appropriate response to meet the requirements for Maori with disabilities, the State, despite years of addressing Maori ethnic identity in policy, is failing this group.

As the State became aware of Maori issues in policy, the Ministry of Maori Affairs adoption of the Tu Tangata philosophy in 1977, the State began implementing policies that considered Maori concepts leading towards the devolution of State involvement in all areas of service delivery for Maori such as developing Kohanga reo (Fleras, 1989; 1991) and Matua Whaangai². Inevitably, these community initiative programs were also expected to run on minimal state funding which has led to ongoing deficits in funding for such programs to remain operational. At the same time this was happening, the transfer of persons with disabilities from institutional to community assisted care was developing also putting financial responsibility onto the community programs with less onus on State support. For Maori with disabilities, the impact of both institutional and community care was dependent on their involvement with their whanau and with their community.

Taking into account the two approaches to ethnicity being both primordial and situational; primordial Maori ethnicity is where the permanence of the kin relationship is emphasised with the role of community, rituals, language and spirituality which are seen as the 'core' component to Maori 'traditonal' identity (Webster, 1995). Situational Maori ethnicity on the other hand is more fluid as Duries (1995) diverse realities of Maori discussion shows and allows for the ability to self identify. While these two have clear differences in their approaches to describing Maori ethnic identity, Karetu (1990) identifies a common link between both as being that of whakapapa which links individuals to a place, to ancestral links and to a particular group or groups within Maori society. Ihimaera (1998) identifies this as emphasising not only the blood links but also the community ties and relationships that exist with those links.

Within Maori disability identity are other impairment groups who identify as distinctive groups, while at the same time as living with impairments yet not identifying as living with disabilities. In other words they see their impairment identity and their ethnic identity as positive aspects of their selves while disability as an identity label is seen as a negative label (Padden, 1996). This argument by those of Deaf cultural identity to identify within a cultural identity is an evolving

concept and while older Deaf persons would once identify as becoming deaf through a particular experience of impairment, younger Deaf persons simply see their identity as one from a cultural perspective through a unique language and community identity. Deaf persons consider themselves to be a distinct, cultural identity and not a subculture within a culture, but equal to other cultural identities, hence the reason for the tensions that exist when trying to define culture within a Deaf contextual framework. To define culture for Deaf persons is to re-examine culture as a concept of ethnic identity, to define culture for Deaf Maori (or Maori Deaf) is to define Deaf culture also from an ethnic framework where neither fit under the current definitions. Deaf persons wanting to define culture for themselves are calling for a new definition of culture that will allow for their own specificity as Deaf persons without placing this identity within disability or as a subgroup of another group (Clifford, 1988; Padden, 1996):

In academic life, definitions of “culturally Deaf” are suspect as potentially stereotypic, but within the group they serve to reassure insiders and dismay outsiders. The reality of the “authentic” Deaf person is one that holds for just about any modern individual – it is an ideal. (Padden; 1996, 87)

The example of the discussion around Deaf culture outlines the difficulty of framing disability in a monocultural manner. In returning to the theme of this study, the New Zealand Disability Strategy (NZDS, 2001), does identify certain ethnic groups such as Maori and Pacific persons with disabilities, however, it does not apply an ethnic specific model to its objectives for these groups nor does it identify the specific issues for Maori Deaf exemplifying the assumption of one concept of disability throughout its recommendations. The NZDS does not seek to apply the policy recommendations from the perspective of, for example, Māori with disabilities, which would involve several components, including an interdependent approach to their well-being and social integration with their cultural communities. For more discussion on disability, health and well-being models see chapter six. For a discussion on how a more culturally appropriate approach can be applied, chapter seven outlines recommendations where this is detailed. The NZDS applies a mono-cultural approach to each of the groups outlined in its framework and not a diversity approach, recognising the collective

nature of indigenous culture which is, in part, an element recognised in their cultural identity. This section explores these issues from the disability identity which is socially constructed approach, and differs from a biological determinant, as impairment and attitudes around impairment are often a social construction defined by the community within which the individual resides (Li, 1999).

Disability offers a challenge to the representation of the body...it means that the disabled body provides insight into the fact that all bodies are socially constructed – that social attitudes and institutions determine far greater than biological fact the representation of the body's reality (Siebers, 2001, p. 737).

The results of the survey results for this research into Māori disability identity and well-being indicated a high degree of dysfunction or inability to be fully supportive of whānau members who identified as living with impairments. Another significant element of the survey is that most of those who responded or had a face-to face interview did not see themselves as having or living with a disability. The participants mostly viewed their place within their whānau and Māori society in general as an essential component of their well-being. The term 'disability' was not a term that Māori participants identified with. Their identity remained strong with the Māori community rather than with the disability community.

This finding could partially explain why few Māori with disabilities are involved within the disability sector, considering other factors affecting their lives as well. Or it could be that identity is more complex and multiple in nature than is identified when discussing disability discourse in New Zealand. This appears to be similar to other indigenous people with disabilities who do not define themselves through their impairment but through their indigenous identity.³ This is consistent with the findings in my own journeys globally: that indigenous people with disabilities who identify more strongly as people with disabilities than as indigenous peoples do so because of their disconnection from their families and cultural communities. Those with disabilities who were removed and institutionalised in infancy or at birth appear to have a greater disconnection with

their *whānau* links than those who were raised with their *whānau* and within their cultural communities. Some participants identified the lack of contact with their families as being significant, with four of them alluding to a fragmented relationship:

They don't... (male participant living alone)

They don't, I live in a special home....(male participant living in a disability provider home)

Hard... (male participant living alone)

Don't visit or anything... (female participant living alone) (Participants of research survey, 2004).

This chapter explores the diverse nature of identity, within the context of identifying as an indigenous person and living with a disability. The added discussions around sexuality and gender in the context of indigenous and disability identities provide some other perspectives to this discourse. While identity discourse can be discussed in a generic form, it is relevant for this research to position myself. All the identities I align with are within the context of already identified marginalised identities, which create the concept of multiple marginalisation. Because of those identities, the added sociological or environmental factors may further impede inclusion into society. It is also important for me to use this thesis to argue for an understanding of the diverse nature of identity and to consider if this is reflected when disability policy and law is developed that affects indigenous people with disabilities.

Identity is a shifting paradigm because of the constant movement between identities throughout our lives, depending on the context within which we are identifying ourselves. Once we identify, we place ourselves within a certain construct. When positioning within identity labels, multiplicitous experiences of marginalisation need to be accounted for in clarifying identity frameworks. While it is generally true that, during their lives, people move into and out of different identities with understandings and worldviews continually evolving.

I am not sure this is true for some who experience disabilities if their major experiences are institutionalisation, which limits their experiences with the

different communities that exist. It is the invisibility of disability identity within Māori/indigenous communities that creates the further multiplicity of marginalisation already experienced by indigenous people with disabilities. Barile (2000) asserts that it is the multiple minority status of persons of minority ethnic identity with disabilities (in her case as an Italian woman with disabilities living in Canada) that positions them into multiple minority discriminatory experiences with greater limitations and discrimination than those with a single minority status identity. Barile also asserts that it challenges ethnic minority people with disabilities who work collectively and as a group where they are forced to work as individuals, often in isolation from their ethnic and cultural communities.

She states that:

Even with membership in five or more 'groups' the individual does not necessarily get his or her needs met because the groups are designed to address a single, or double identification of minority status. The combination of disabilities, social or ethnic backgrounds, gender or sexual orientation differences are not addressed by the groups.... The challenge then is to use new analytical tools, or adapt existing ones, to emancipate those experiences of multiple levels of discrimination due to their multiple minority status. (Barile, 2000, 126-7)

The focus of this study is on indigenous disability identity and it is in terms of these concepts that identity is discussed. The discussion of gender and disability is appropriate also, due to the work done in this field which can contribute to a helpful framework of identity when exploring the issues for indigenous disability identity. It is this very complex, multi-valent and intersectional nature of identity that is discussed and expanded on when looking into indigeneity, disability, sexuality and gender discourses. I believe that no single identity holds a higher position over another when it comes to placing ourselves into a construct, although this discourse encapsulates how these are socially constructed within indigenous communities. Professor Ngahuia Te Awekotuku puts it succinctly when she states that:

Frequently, all the contradictions of my life are harrowing, but I refuse to reject any one facet of myself. I claim *all* my cultures, all my conflicts. They make me what I am; they will shape what I am becoming. (Te Awekotuku, 1984, p. 121)

2.1.1 Disability Identity: a Background

The distinction between impairment and disability lies at the heart of the social model...impairment is defined in individual and biological terms. Disability is defined as a social creation. Disability is what makes impairment a problem. For social modellers, social barriers and social oppression constitute disability, and this is the area where research, analysis, campaigning and change must occur. (Shakespeare, 2006, p. 34)

Disability identity standing alone has not existed outside of models of disability which are explored in chapter six. Impairment on the other hand has always presented as a medical diagnosis of a particular condition affecting an individual. Disability identity is socially constructed as an identity and is modern in that it evolved from the industrialisation of society with the impairment being the common denominator for that group. Impairment alone is confined to individual experiences of impairment such as blindness being the physical presentation of a medical condition yet, disability is more about experiences of marginalisation and discrimination. The history of disability in law is covered in chapter five with the disability models being outlined in detail in chapter six. The difficulty in acknowledging the identity of disability is that with impairment comes the loss of identifying positively about self and having to adopt an identity which has terminologies fixed in deficit language. Disability identity is linguistically specific in its formation which has been socially constructed. As a result disability identity is complicated in defining elsewhere as an identity of 'other'; as Galvin (2003, p.152) states:

...the interaction between knowledge and power which constitutes our identities, whether they be positive or negative, is mediated by language, that...because language is built on the process of "othering" it constitutes a

naming process which defines identity through difference. Our words are very powerful tools of representation which are accorded even more potency when they are taken for granted as transparent symbols of "reality".

The process of 'othering' is applicable to identities that fit outside the concept of what was perceived as natural and leads to the negative fears around disability identity (Foucault, 1988; Hughes, 2000) Brown (2002, p.41) states that:

For the development of disability culture, history of disabled people has an important role to play. History occupies a significant place in the formation of group identity. However, until recently, history of disabled people has been ignored.

Brown argues that disability identity history has been ignored except through the medical aspects of disability where attention is given to disability from an objectification of the individual's identity based on medical frameworks (Brown, 2002). As other aspects of disability identity such as feminism and disability have developed so has the understanding of disability as an identity (Corker & Shakespeare, 2002; Foucault, 1988; Garland-Thompson, 2002; Morris, 1991, 1993; Oliver, 1996).

2.2 Indigeneity: Being Indigenous, Colonised and Westernised

It is my view that the assumptions behind the phrase 'double oppression' make this an adequate starting-point. There has been minimal research to define clearly what is meant by this or any other concept of the black disabled experience....As a consequence, the phrase 'double oppression' is rather empty; rhetoric has replaced clear thinking...The predominant concept of disability – which I shall call the norm – is that it is regarded as a personal tragedy needing medical attention....The idea is vigorously challenged by the disability movement. Likewise, anti-racist writers challenge what has become the norm within the philosophy of 'the new racism'...New racism has replaced this rather straightforward form of prejudice and substituted a more sophisticated one. The idea is a response to the steady erosion of racist bigotry and practices that has been dominant. Rather than focusing upon skin colour,

new racism attempts to use culture as the marker of difference. (Swain & Finklestein, 1999, p. 93)

In New Zealand, indigenous people with disabilities also have the added issue of facing greater discrimination because of their lack of culturally appropriate services and their social economic placement within society. Added to this is the overall lack of appropriate supports from the State for all indigenous peoples. Until indigenous people receive appropriate support, indigenous people with disabilities cannot expect to see improvements in their own status.

..the Follow Up Report addressed the necessity of dealing with the serious problems of poverty, unemployment, social and geographical isolation, as well as inadequate living conditions. These conditions continued to contribute to the high incidence of disability among First Nations people. The Follow Up Report stated that the situation of First Nations people with disabilities is not likely to improve significantly until the situation of all First Nations people improves. The report also recognized that jurisdictional debates among government departments and among levels of government about who is responsible for providing services to First Nations people were creating incredible difficulties for people with disabilities, making it almost impossible, in some instances, to access services (Durst & Bluehardt, 2001, p.37).

This quote focuses on the discussion of identity in relation to indigenous women with disabilities where there is the unavoidable impact of 'triple jeopardy' and not simply a double oppressive component to these identities. The use of the term 'oppression' is not appropriate in this context as it holds a negative assumption that may not always be the case. 'Triple jeopardy', which also has an implication of negativity, has a slightly different emphasis. 'Jeopardy' implies that, while oppression may occur, all three identities have a historical foundation of marginalisation. Therefore, even if not oppressed by society, the identities alone have a component of marginalisation. With more than two marginalised identities already attached to the individual, if a third marginalised identity is added to the existing ones, then there is a triple impact of marginalisation which is very

difficult for the individual to avoid. This triple impact is identified as 'triple jeopardy' (Durst & Bluehardt, 2001).Ghai (2003, p.80), in describing colonisation and disability states that:

The colonised loses its entity as a subject in its own right and remains only what the coloniser is not. It is thus an erasure both out of history and all significant aspects of development.

The issue of disability as a subject being applied to indigenous people with disabilities is a problem. The perception of disability by indigenous with disabilities may differ to the perception of disability held by non-indigenous peoples. Despite society's believing indigenous people with disabilities have a disability, there may be a difference in perception between the health and disability professionals and indigenous peoples who may not see themselves as having a disability (Gething, 1995). Gething identified a lack of clear statistical analysis to the variants he found in the personal definition of what constitutes a disability between the professionals and the aboriginal peoples themselves. Obvious impairments such as amputations or severe physical impairments are easily defined as a disability; it is the hidden impairments such as intellectual/learning or psycho-social which are often not seen as a disability by indigenous peoples generally. Many of the disabilities that affect us later in life are considered to be a normal aspect of the life cycle and are therefore not singled out or isolated as belonging to the disability identity for those people. *"Disability is rarely seen as a separate issue, but is seen as part of problems which are widespread and a part of the life cycle"* (Gething, 1995, p.81).

In exploring the analogies that occur between different movements and oppressions, such as the social movements of feminism, gay and civil rights it is useful to question its necessity when exploring some of the complex nature of identifying within the disability spectrum. Shakespeare (2006, p. 41) states:

As social movements, women's liberation, gay rights, disability rights and anti-racism are similar in many ways. Each involves identity politics, each challenges the biologisation of difference, each has involved an alliance of

academia and activism. There are parallels between the theorisation of disability, and the theorisation of race, gender and sexuality, as the many citations of other oppressions within disability studies literature demonstrate. Yet the oppression which disabled people face is different from, and in many ways more complex than, sexism, racism and homophobia.

It is therefore, in the context of indigenous peoples with disabilities, also relevant to note the cultural diversity that exists, which affects the definition, interpretation and attribution of factors constituting a disability. As the issue of indigenous disability identity is a complex issue, while some comparisons can be made to other identity constructs, it is indigenous peoples with disabilities identity that remains the core theme of this study. Therefore it is from within this construct the discussions are primarily focused on. Therefore, if Maori Deaf wish to construct themselves not as a disability identity but as Maori who identify within the Deaf cultural framework, then it is their right to do so. The term 'disability' does not exist for some cultural groups, and therefore they do not consider attributing this identity to a group of people. What could be viewed as a disability today differs between the different cultural and tribal beliefs of indigenous peoples. What the dominant western ideology may define as a disability may not be the same for different indigenous peoples.

Culture, however defined, is not a static state, but the dynamic interaction of many forces, including interaction with other cultures. Western culture itself is undergoing constant change, in which the influence of Eastern philosophies cannot be ignored; it seems somewhat patronising to suggest that other cultures are immutable and should be preserved in some kind of time capsule. (Coleridge, 1993, p.150)

Because the diversity of understanding impairment exists within different cultural communities where, for example, some indigenous peoples hold to the belief that some impairments have a social or spiritual component which affects well-being and does not derive from a medical or physiological condition. Other indigenous communities sadly do not encourage the participation of their tribal members with disabilities, hence the exclusion and isolation that often occurs for some

indigenous people with disabilities. This also alludes to the diversity of experiences within indigenous communities towards disability as there is diversity of experiences within non indigenous communities. Kiyaga and Moores in discussing deafness in the sub-Saharan region stated that:

Given the diversity of sub-Saharan Africa, there are exceptions to any generalizations. Beliefs about deafness in African societies range from acceptance and protection to rejection, including considerations of infanticide. Some beliefs common to most nations in the region have the unfortunate effect of increasing the likelihood of isolation and marginalization of people who are deaf. Many traditional beliefs characterize deafness as a manifestation of a mysterious fate, perhaps God's will. Some societies pity children who are deaf and see them as burdens, dependent on their families and lacking the ability to be independent. This type of belief in the lack of capability of deaf children may by itself impede access to education. In other cases, cultural practices may result in the deaf child being hidden from public view because of familial shame over having a "handicapped" child who may bring misfortune upon the family. Such beliefs can lead to abuse, neglect, and abandonment, and deaf children's potential to contribute to the development of African nations is dismissed (Kiyaga & Moores, 2003, p.20).

An example of this exclusion for Māori with disabilities is the invisibility of identity leading to the lack of consideration where access is an issue. Some of the older marae have not been modernised or updated with ramps or sensory aids to assist anyone who has an impairment going to those marae. Some of the newer marae have addressed this with accessible toilets and bathroom areas and removing steps into the whare although there are still marae which have not, to date, been adapted. The Ministry of Health Māori Disability Services Directorate have a list of accessible *marae* which is posted on its website at: <http://www.moh.govt.nz/moh.nsf/indexmh/disability-maorisupport>. The Ministry of Health Māori Disability Services Directorate's *hui* held in Auckland in June 2006, was only one of three, which did not cover the country, so many out-of-town Māori with disabilities who did not have resources could not attend. The *Ngati Kapo* advocacy group for Māori who are blind also raised the issue of their

guide dogs on marae at *hui*, and objections were raised by the members of the local marae to having these dogs within the buildings. This is a common problem for *Ngati Kapo* members who assert their right to independence by having their guide dogs with them when they attend any *hui*. The objection to guide dogs on marae is often contentious with some citing the issue of allergic reactions to the dogs and other concerns. This opposition is not unique to one marae; it is an attitude that has prevailed for some time and not one that appears to be resolving in the short term. In 2007, five *hui* have been arranged at which Māori disabilities issues will be raised; at time of writing, only dates are mooted with venues to be advised. Concerns have been raised as to access issues and broader representation to include rural Māori with disabilities and other key stakeholders.

Defining indigenous as an identity is difficult, as there is no standard or fixed definition and indigenous experiences vary vastly between colonised communities and non-colonised communities. A working definition of indigenous peoples by the International Labour Organisation (ILO) gives an insight into the complexity of such an identity. Indigenous communities, peoples and nations are those which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing on those territories, or parts of them. At present they form non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal system. The United Nations working group have defined indigenous as consisting of one or more of the following factors:

- a) Occupation of ancestral lands, or at least of part of them;
- b) Common ancestry with the original occupants of these lands;
- c) Culture in general, or in specific manifestations (such as religion, living under a tribal system, membership of an indigenous community, dress, means of livelihood, lifestyle, etc.);

d) Language (whether used as the only language, as mother-tongue, as the habitual means of communication at home or in the family, or as the main, preferred, habitual, general or normal language);

e) Residence on certain parts of the country, or in certain regions of the world;

f) Other relevant factors.

On an individual basis, an indigenous person is one who belongs to these indigenous populations through self-identification as indigenous (group consciousness) and is recognized and accepted by these populations as one of its members (acceptance by the group). This preserves for these communities the sovereign right and power to decide who belongs to them, without external interference (UN Doc. E/CN.4/Sub.2/1994/2/Add.1).

While this is a difficult and convoluted definition, it highlights the complexity of identifying as an indigenous person. These are the same issues when indigenous persons identify as living with impairments. For the purposes of this research, given the context of Polynesian (namely Māori) identity, with the added issue of having been colonised, it could be said a group of characteristics as identified in this definition is a more appropriate concept than a definition, for this issue. The concept of indigenous identity cannot be a shortened or abbreviated definition as it would otherwise remove and dilute some of the intent behind the description of indigenous peoples, thereby making the argument less applicable to the group being discussed in this paper. Added to the identity of being a colonised indigenous person is the issue of whether or not this alone gives rise to the argument of having a triple jeopardy component. It could be argued that indigenous persons, as a singular identity, already experience higher rates of poverty and less probability of employment than non-indigenous people. Indigenous people with disabilities have the added pressure of worse statistics for them because their disability further impedes their opportunity to gain effective employment.

Full participation in society means having a full and meaningful involvement with economic, social and leisure activities. Unfortunately for many indigenous peoples, due to the economic factor this is denied. Indigenous people with disabilities face further marginalisation because as a person with a disability it is

highly unlikely they will be employed, or will even access their health and equipment needs to be able to participate in employment. Therefore they face the double jeopardy of both identities. In relation to statistics for Māori with disabilities in obtaining employment and identifying with an impairment, the latest trends and data of the Work in Progress report (2004-2005) show Māori have:

...the highest age-standardised rates of impairment. Compared with non-Māori they tend to have more severe impairments at younger ages. Māori are also more than twice as likely to report an unmet need for transport costs. Half of all disabled Māori had a total annual income of \$15,000 or less. Over a third had no educational qualification considerably higher than their non-Māori counterparts (Minister of Disabilities Issues, 2005, p. 81).

The report also found that 25 percent of Māori with disabilities who live in households had reported an unmet need for health services, (compared to 14% of non-Māori) which is significantly higher than the fourteen percent of non-Māori with disabilities who have reported an unmet need. It is reasonable to expect that if significant equipment and health needs are unmet, then a disparity will exist. It is also reasonable to assert this marginalised group would not be able to fully participate in society as per the objectives of the New Zealand Disability Strategy (2001). This is also consistent with Māori who do not identify with a disability whose health and employment statistics do not equal those of non-Māori. Having an unmet need was particularly high for younger Māori (15-24 years) where the rate was almost double that of their non-Māori counterparts. Fifteen percent of Māori with disabilities had an unmet need for special equipment, compared with 11% of non-Māori with disabilities' (Minister of Disabilities Issues, 2005).

Indigenous people, people with disabilities and women face numerous obstacles participating fully in society as indigenous people, as people with disabilities, and as women. This is despite programs set up over the years to address these issues and reduce the marginalisation. As indigenous peoples face marginalisation generally, it is not unreasonable to assume their participation in society is limited.

Unless indigenous people address the concerns of indigenous people with disabilities, there will continue to be multiple marginalisation, denying full access to cultural life and activities within their own communities for the members with disabilities at a much greater level than for other groups. When looking at the multiplicitous nature of identity in being indigenous, a woman, of lower economic status and living with a disability, It is appropriate to consider Spivak's statement, that:

...The pattern of domination is here determined mainly by gender rather than class. The subordinated gender following the dominant within the challenge of nationalism while remaining caught within gender oppression is not an unknown story. For the (gender-unspecified) "true" subaltern group, whose identity is its difference, there is no unrepresentable subaltern subject that can know and speak itself; the intellectual's solution is not to abstain from representation. The problem is that the subject's itinerary has not been left traced so as to offer an object of seduction to the representing intellectual...the question becomes, How can we touch the consciousness of the people, even as we investigate their politics? With what voice-consciousness can the subaltern speak? (Spivak, 1999, pp.272-3)

Religion is another strong component of Polynesian identity post-colonially. The Old Testament, in particular, plays a large part in influencing how Māori view Māori members of their *whānau* with disabilities, and the influences of the Bible account for the still active movements of *Ringatu* and *Ratana* which arose out of times of conflict and loss. When missionaries came into New Zealand, they brought with them a biblical teaching that opposed the practice of the *tohunga* and the belief in many *atua*, and involved a new process evidenced today in many practices that influence *Māori tikanga* such as *karakia* (reciting chants), *waiata* (song, chant, psalm), *himene* (hymns) and *whaikōrero* (formal speech, oratory).

Unlike the traders, who were motivated only by commercial gain, the missionaries were the cutting edge of colonisation. Their mission was to convert the Māori from heathenism to Christianity and from barbarism to

civilisation. Underlying this mission were ethnocentric attitudes of racial and cultural superiority (Walker, 2004, p. 85).

While it is true that Māori were affected by these new colonial influences, it could be that Māori also selectively and consciously took control and selected what appealed to them. Examples of this are the *Ringatu* and *Ratana* religions that began to thrive among Māori, combining the Old Testament Bible and traditional practice in their teachings. Whatever the case may have been, there is no mistaking that the missionaries became effective in changing pre-colonial beliefs by providing Euro/western medical care to Māori while teaching them the Bible. They challenged traditionally held beliefs of sickness and changed many ways of thinking in Māori culture, which still today has a mix of traditional and Christian beliefs. This has played a large part in the thinking around indigenous persons with disabilities today, in that religion, in particular the Old Testament, plays a part in the role of excluding indigenous people with disabilities from their cultural community (Elsmore, 1999). This influence still permeates Māori cultural identity, and it is this influence that continues to divide the thinking of Māori around impairment today.

2.3 Gender Identity within the Disability Paradigm

...emerging disabilities are known to be associated with race and income inequality. However not enough attention is being paid to the gender differences associated with these conditions. Various chronic conditions and disabilities affect men and women in different ways. The occurrence of certain chronic conditions such as asthma, diabetes, carpal tunnel syndrome, violently acquired spinal cord injuries and traumatic brain injuries, and HIV/AIDS, appears to be significantly related to gender. These conditions highlight the complex interplay of the social, economic and physical environment that affects their epidemiology and etiology. (McNeil & Kroll cited in Smith & Hutchison (ed) 2004, p, 287)

Gender plays a large role in our identity whether we are male, female, transgendered or inter-sexed. Our gender identity defines our roles within society, and disability's impact on gender is no different in attitude to those without disabilities. It has been my observation in the 15 years as an academic that a disability perspective within women's studies in New Zealand is not a prevalent or widely constructed discourse. In New Zealand, the women's studies conferences historically did not have a pro-active stance towards incorporating women with disabilities into their structures. Despite one-off responses on site to strong action by individuals or small groups of women with disabilities, the work was often not carried forward and entrenched, unless the women with disabilities themselves maintained an active role within those networks. This has led to small numbers of women with disabilities attending the conferences or participating in women's studies and, because of this isolation and clear exclusion of women with disabilities, few have maintained their communications with the networks, preferring instead to concentrate where their energy is best placed. This experience is not exclusive to women with disabilities as Maori and Pacific women have also expressed tensions raised around addressing cultural and diverse issues at women's studies conferences. Prejudice exists in all corners of society and with all forms of identity although experiences of prejudice and discrimination for some identities are greater than for others.

Feminist theory was not always accepting of the diversity within women's identity until the second wave and post-modernist theorists began to push forward the thinking from the perspective of 'other'. Feminist thinking about disability has been affected by the thinking that disability means someone having something 'wrong', which removes the concept of normality from the identity of being a woman and having an impairment. Women with disabilities are excluded from the larger social class of women and it is this exclusion that creates another identity of marginalisation based on impairment alone. Women of colour with disabilities face multiple experiences of marginalisation and exclusion from the larger social class of women because of their ethnic and impairment identities. To add to these the identity of being *takatāpui* (gay, lesbian, bisexual, transgendered, intersexed), indigenous, and living with impairments is to include three marginalised identities which have all been excluded historically from the larger social class of women.

Feminism is increasingly recognising the differences that exist for women and that being a woman is not a single identity.

Women often identify with multiple identity labels and hold multiple roles within those different identities. It is this multiplicity of identity that can, in some instances, give experiences for some groups that would appear to be marginalised. Yet, this multiplicity of identity does not, in itself, lead to marginalisation; for instance, being a woman of colour, a lesbian and a woman with disabilities does not in itself mean one is also marginalised. What matters is the social construction of these identities and how the person's community treats those identities. In other words, identity alone, however multiple, does not, in itself, create marginalisation. Other factors play a part in that marginalisation, such as socio-economic status and rights of inclusion within a community. In the case of women who identify as indigenous, as living with disabilities and also being takatāpui, the chances are they are also identified as living within a lower socio-economic group status and therefore their marginalisation is reinforced by holding further marginalised status identities. There is personal experience in seeing how disability can appear to frighten some feminists who do not identify with disabilities and while my identity as takatāpui, as indigenous and as a student have all been accepted, my identity of living with a disability has not received the same level of acceptance or acknowledgment by the wider feminist networks within New Zealand. In examining the rationale for this apparent discomfort of seeing disability within the feminist networks, there is a move by women to separate themselves and avoid stereotyping women with the images of being carers and holding mainly submissive roles. The isolation of women with disabilities has come from the historical stereotyping of women and their roles within society. Society, with the exception of a few women like June Opie, Helen Keller, Neroli Fairhall and Eve Rimmer,⁴ does not normally view women with disabilities as being mothers and lovers, having jobs and being independent people within their own right. Despite work on this issue, this attitude has not changed as society prefers to view women with disabilities as having a submissive, quiet and unassuming role where they are not seen or heard from unless it is with the permission of that society.

Societal response towards disabled women is of utter neglect and total submission. One can find this negative response in the media, which acts not only as a mirror of society but also as a catalyst of change – bringing in new ideas, values and modes of perception. (Hans & Patri, 2003, p. 79)

The added problem for women with disabilities is often their need to receive assistance with their care and support needs. This forces the recipient into a role of a subordinate and not into a role as an equal; their dependence is controlled not by them but by their care providers. In New Zealand, this is particularly the case in that those women with disabilities requiring support needs to be met by the State come under a system where the provision of care is dealt with by an agency and we must accept the carer provided through agencies. We are a small nation that is severely under-resourced in relation to carers for people with disabilities, and that situation does not allow client-controlled decisions around the services they need.

Any individual-based carer service exists either because the individual has the resources to effect this, or, in the odd exception to the rule, because this service has been negotiated with the disability services. This is, however, the exception and not the rule. Women with disabilities, already in isolation from their non-disabled peers, and often completely dependent on non-family carers, are subject to the risk of abuse and mismanagement. They have little ability to address this, as often there are not the choices to switch should they have a problem with their provider. Provider-based services are an extension of institutional care and it is this underlying construct which is creating a disempowerment of women with disabilities in relation to their care needs being met.

However, dependence – in the same sense of being helpless and subordinate – not only characterises institutional care but can also be part of the experience of living ‘in the community’...This means that a disabled person becomes dependent on unpaid care and the nature of the care will be determined by the nature of the relationship between the carer and the person cared for. (Morris, 1991, p. 143)

These behaviours towards the identities of being an indigenous takatāpui⁵ woman with disabilities are socially constructed, and it is this social construction that forges our thinking, our behavioural patterns and our status placement within society. In spite of some changes achieved in education and thinking along with the State and media power that influences society, we are caught up in the thinking that pervades our communities. Society is still generally wary of accepting disability and certain impairments in particular still face stigma and isolation because of their condition and not through the reality of the individual's own experiences and differences. A good example of this is the issue of community placement of people who experience psychological or intellectual impairments. Society still lives with the attitude of NIMBY syndrome, acronym for "not in my backyard". Despite housing reports from the Ministry of Social Development (2002) and the Mental Health advertisements in New Zealand with the theme of 'Like Minds; Like Mine', when some individuals with psychological or intellectual learning impairments attempt to be placed in the community it has to be done quietly or the community often objects and seeks to remove the individual from its midst.

Like disabled people, people who have experience of mental illness often have reduced housing options through factors such as discrimination when neighbours object to supported houses being established in their area. Consumers/tangata whai ora and providers report NIMBY syndrome as a common discriminatory feature of New Zealand society. (Pere, Gilbert & Peterson, 2003, p. 5)

I do not believe change will occur unless we embrace the concept of interdependence with those of our peers who do not identify with disabilities. This concept is relevant to indigenous/Māori persons with disabilities understanding the role of *whānau/whanaungatanga* (family/kinship) and of how interdependence works as a partnership and equal role for them. Isolation and exclusion are major problems, especially for women with disabilities, and not having the concept of *whanaungatanga* recognised in policy jeopardises the identity of indigenous women with disabilities. For this to change, interdependence in the form of empowerment or strengthening models is

important in order to achieve equal societal status with others in their community. The connotation of the term 'carer' also creates problems, as it has significantly contributed towards the marginalisation of people with disabilities.

The reality is that society does not want to see people with disabilities and if people do see them, they do not want them to be seen to be celebrating their identity, as disability is still viewed as a deficit identity, as something to be afraid of or as something to avoid at all costs. The reality is also that when society sees people with disabilities, especially those who do not fit the 'norm' of the physical structure viewed as ideal by at least many within western societies, it sees something it knows could happen to anybody, and there appears to be an aversion to including people with disabilities into daily life.

Thus disability is socially constructed through the failure or unwillingness to create ability among people who do not fit the physical and mental profile of 'paradigm' citizens. Failures of social support for people with disabilities result in inadequate protection from physical, sexual and emotional abuse, minimal opportunities for social learning and interaction, and many other disabling situations that hurt people with disabilities and exclude them from participation in major aspects of life in their societies (Wendall, 1988, p.41).

The complexities of these identities are not going to come together with any form of smooth, integrative ease, as discussing these identities within their own frameworks highlights the diversity that exists in separation. Putting these identities together only further highlights that diversity and complexity which comprise the nature of identity, if we are to define these within a contextual framework.

2.4 Disability and Body Image: Is it a Relevant Discourse in Indigenous Disability Research?

Traditionally, being a female, having a disability, or being of an ethnic identity meant being seen as dependent people, vulnerable, asexual, a curiosity, weak and

incapable of achieving anything of any value within society (Lifton et al, 2001; Morris, 1993; Thomas, 1997). Aristotle viewed women as mutilated men (Radke & Stam, 1994), while people with disabilities were often considered ‘freaks’ in the past, and placed on display as curiosities of nature. While this display of persons with disabilities is no longer accepted as a norm, it still appears, for example in the dwarf throwing contests in public bars such as in the Bahama Hut in Tauranga in 2003⁶. There is a continued fascination with the “different” or the “oddities of nature” which are publicised in the media for society to view and express an opinion on. It was not unusual for these ‘freaks’ to hail from a non-European society where their colour, gender and cultural markings set them apart from the mid-nineteenth century European society. They were placed into the same category as people with disabilities. This category was of having a genetically deficit component to their identity, as being incomplete and incapable of living within a “normal” society.

The exploitation of the South African Khoe-San woman, Saartje Baartman, as the ‘Hotentott Venus’ in the mid 1800s in Europe is just one such example of how race, gender and difference played a part in her being considered a ‘freak’. What were, in fact, her normal racial and ethnic characteristics were given the status of ‘freak’ and ‘outcast’, forcing her into a terrible existence as a display of curiosity for the Western world, where difference was considered inferior (Garland-Thompson, 2002). Baartman was sexualised in that it was her buttocks and genitalia that were displayed. Even after her death, Baartman was preserved for “scientific study”. This occurred also for persons with disabilities in that era.

Moreover, sexuality has often been folded into this process of objectification....Similarly, if more benignly, in 1863 P. T. Barnum arranged a wedding between midget performer Charles Stratton, who became “General” Tom Thumb, and Lavinia Warren....The wedding and marriage both downplayed Stratton’s sexuality by constructing a “wedding that looked like children imitating adults”....Barnums’ display of “Circassian beauties” on the one hand and Julia Patrana, a hirsute Mexican woman whom he dubbed “the ugliest woman in the World,” on the other, explicitly linked a freak

identity with the (putatively male) viewers sexual desire and standards of female pulchritude (Chinn, 2004, p. 197).

It is easier for society to understand the “illness” factor created within the medical paradigm as part of a disability identity. The idea of a psychological illness being a disability issue, rather than the condition being, for example, an outcome from the societal issues placed on young girls/women within society, appears to be easier to consider than the fact that some people appear to be deliberately engaging in behaviours that create impairments, and therefore their behaviours or practices could be considered deliberate mutilations creating impairments. The frisson of risk exists within society. The issue of body image and body beautiful are just as relevant to persons with disabilities, as they often face the media comparisons of what constitutes a “beautiful” body image, which is unattainable for some people with disabilities, where disfigurement or psychological body image is visual. Losing weight and having the “perfect” body does sometimes result in affected persons with disabilities engaging in bulimic or anorexic practices in the hope that they, too, can achieve what some able bodied women also want to achieve.

Marginalised by the exclusive hierarchy of appearance commonly known as “beauty” or “normalcy,”...each woman is excluded from the cultural center because her deviant bodily marks or configurations, as well as being black, poor, female, and – in some cases – old (Garland-Thompson, 2004, p. 249).

It is worth exploring in further research if some of these practices are purely an impairment issue, a cultural issue or an issue of what constitutes beauty within our society (Hayward, 2005)⁷. The issues between western cultures and non western cultures when disability is the theme is also clear as it is not easy to compare people with disabilities from developing nations with indigenous people with disabilities who have experienced colonisation and marginalisation both as indigenous and because of their impairments. This is because, while those in developing countries do have issues of well-being and poverty, they have entirely different political and social identities unique to that experience. Comparing colonised indigenous people with disabilities with their Western counterparts in

the same country is possible, however, as it is the differences between these two groups within the same political and social context that allows for a more realistic comparative analysis of why indigenous people with disabilities remain marginalised in a wealthy nation.

The difference in poverty experiences between developed wealthy nations and developing nations is an issue outside the scope of this research, and incorporates issues that go beyond the scope of indigeneity. To compare developing and developed nations, one would need to review the complexity of being a developing nation, the Western influences and histories with those nations and how impairment is viewed historically. Given that the financial infrastructures do not exist for many of these nations, is an issue. That is a thesis in itself and stands separately to this work, as the cultural differences are complex in nature and in experiences. This thesis is narrowly focussed on indigenous identity from within the Western-colonised context, and not all developing nations have that experience, which further reinforces the argument for disability and identity not being of a monocultural nature.

It is useful however to note that one area of interest regarding western and non westernised ideology is the concept of disability and body image which plays a part in disability identity and body image. This discussion is within the context of this thesis with its focus on body image and how it is seen from within the construct of disability, indigeneity, sexuality and gender-specific concepts. With the discussion of identity, it is also important and relevant to note the historical link to the eugenics movement, where disability, race, sexuality and gender identities outside the “norm” were considered better off being euthanized or sterilised than living a less-than-ideal existence, as framed by those making those decisions.

...we traced the horrors of sterilization and extermination programs in Germany as the Nazi government sought to eliminate hereditary forms of “disability” from the population everywhere....the actions of the Nazi regime were only one step removed from those of eugenicists throughout the Western world in the interwar period. (Branson & Miller, 2002, p. 153)

To argue that eugenics is not applied to certain groups today would be a mistake where as recently as August, 2006, the United Nations International Disability Caucus working group was still debating the rights of women and girls not to be sterilised on the grounds of disabilities. Even within the disability movement there is no agreement around whether girls and women with disabilities should not be sterilised which comes back to the eugenics discourse that has developed over the years. While males with disabilities are also sometimes sterilized, the focus has been placed on the girls and women with disabilities as their risk of getting pregnant is easily identified. This has been particularly contentious in instances where the girl or woman has been in an institutional environment, becomes pregnant and male staff have been implicated as the ones who have impregnated them. Disability is still a reason that some member states give as the rationale for pre-birth terminations of a foetus that carries a gene identified as not worthy of life.

In many countries across the world this practice continues to be debated and justified by governments, legal, medical and other professionals and even family members and carers as being in the 'best interests' of disabled women and girls. In reality the justification has more to do with eugenic fears, the best interest of the state, community or family and the social control of the unruly bodies of disabled women and girls. Of great concern to the disability rights movement is the absence of the voices of disabled women and girls who have been or may be affected by forced sterilisation⁸.

To further understand these issues within the identity framework, it is important to recognise that disability as a specific identity did not exist outside of the medical paradigm until activism brought disability identity into the realm of identity discourses. Chapter six outlines the background to disability models and how the way in which they developed is how disability identity began to develop also. For Māori with disabilities, their identity both as living with impairments and being Māori has never been formally recognised other than within a medical or health framework. Body Image as an issue is not specific to persons with

disabilities, although with the increasing focus on youth, fitness and body image in society, it

is valuable to note this for further possible research into disability and the body within Polynesian communities. Theorists such as Garland-Thompson (2002) Morris (1991), Meekosha (1998) and Ghai (2003) have provided excellent academic grounding on this subject matter, however more work is warranted that provides specific understanding of indigenous women with disabilities and their placement within their cultural, gender and impairment identities. In summary, Ghai (2003: 79-80) outlines the tensions that exist for Indian women with disabilities and the need to develop gender discourse of 'other' diverse groups within disability when she states that:

‘The omission of the concerns of disabled women reflects an historical practice that continues to render them as invisible by engaging in the very process of alterity’. The concept of alterity is sometimes a very palpable presence, while at other times only a significant trace in so far as it is implied in discussions of identity, domination and subordination....The colonised loses its entity as a subject in its own right and remains only what the coloniser is not. It is thus an erasure both out of history and all significant aspects of development. ‘

2.5 Summary

Identity as a term is not always understood when used and can often be deemed ineffectual when used glibly and liberally without an exploration of the term within the context it is meant for. While Maori is recognised in policy such as objective 11 of the New Zealand Disability Strategy (2001) the application of the objectives is addressed monoculturally not taking into account the cultural component of Maori identity and at the same time only marginally recognising the rights of Maori who have direct experiences of impairment. While multiple identities and, in the area of disability, impairment, may contain elements of marginalisation, it is not identity or impairment alone that creates that marginalisation. It is the circumstances or situations that create the experiences for the individual that exacerbate marginalising experiences for some and not for others. Being a woman of colour alone does not give one an automatic status of

marginalised identity; however, being a woman of colour who lives in a lower socio-economic situation and as a person with disabilities can. What happens then, when an individual is faced with multiple marginal identities? Their ability to be well, to have equity with others within one of more of their identities, and to achieve is severely compromised, hence the reason for disparities within certain identified marginalised groups and the risk of there being even greater experiences of marginalisation within multiple identity groups. It is clear that diversity of identity is an issue for those who have the role of defining disability identity within policy and procedures. For Indigenous peoples with disabilities, this is a particular issue and one that remains under developed in all areas of research and practise.

Chapter 3: International Human Rights Law and Instruments

3.1 Introduction

Rights-based issues within the international and domestic context are relatively new in legal terms. Even more recent is the development of disability and indigenous peoples' policy. Since the introduction of the Universal Declaration of Human Rights 1948 (UDHR), the United Nations (UN) has focused on treaties for groups requiring specific protection. The original Declaration did not take into account some of the inequality issues for certain minority groups such as indigenous and persons with disabilities who are identified as two specific groups excluded and marginalised because of their lack of acknowledgment as a specific group in need of protection. In relation to the rights of persons with disabilities, it is argued that this group is a minority that has not been easily included in previous human rights instruments.

In the context of equal rights, disabled people have until recently been a forgotten minority. Consequently, it was assumed... that an anti-discrimination statute which did not expressly mention disability or (health status) would probably not, in practice, be applied for the protection of disabled people. (Lawson & Gooding, 2005, p.87)

The developments around human rights and disability rights occurring at the United Nations in consultation with States, Non Governmental Organisations (NGOs) and individuals experiencing disabilities interested in seeing the proposed Convention on the Rights of Persons with Disabilities (CRPD) signed, ratified and implemented into international and domestic law and policy is explored. Within this discussion is an outlining of the impact any disability convention may have on indigenous persons with disabilities. It is my contention that indigenous persons with disabilities have been excluded from the development of the CRPD, due to a possible lack of support from their governments and the lack of financial resources. To understand how the CRPD is being developed, an historical overview of the status of persons with disabilities internationally is provided. The

overview is not specific to indigenous persons with disabilities who have experienced colonisation as this is discussed further in chapters two and five. Some of the overview will, however, highlight non-westernised developments as well as western/industrial State developments in law and policy. Specific to persons with disabilities is the notion of group/collective rights. Relevant to indigenous persons with disabilities is the discussion of universalism and cultural relativism which outlines the tension between cultural and cultural group rights as opposed to human rights being universally equal for all regardless of any cultural specific identity.

3.2 The United Nations Human Rights System

3.2.1 Origins

Civil society is an artificial creation which has no other purpose than to amplify natural freedom and equality. Although the theory of a state of nature has now been abandoned, the first words in the Universal Declaration of Human Rights clearly echo it: “All men are born free and equal in dignity and rights”, which is another way of saying that men are *by nature* free and equal...The freedom and equality of human beings is not a reality, but an ideal which has to be pursued, not an existence but a value, and not a being but a must (Bobbio, 1996, p.15).

Over time these theoretical frameworks have developed into the International Bill of Human Rights consisting of the Universal Declaration of Human Rights (UDHR) (*Appendix 5*), the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the International Convention on Civil and Political Rights (ICCPR). Whilst human rights legal frameworks are identified as new and evolving law, the precepts behind human rights are not new. As far back as Confucius, Socrates and Plato, what would now be called human rights concepts were being debated. These ideas are applied to human rights today. Over two millennia ago Confucius believed that it was through education that the values of rational, aesthetic, political, social, historical and transcendental qualities could be

cultivated among human beings, even commoners. (De Bary & Tu, 1998) Human rights as a construct dates back to classical Greece (Freeman, 2004).

The Athenians identified the right to provide protection against tyranny for the individual. The Romans expanded on this Athenian idea and used the concepts of reason and distinctions between the natural and rational ideal world, developing them into Roman law. Roman law was founded on the idea of rational natural law being applicable to all humans, as it was based on the rational world of ideas believed to be shared by all human beings. The basis of a series of universal moral principles derived from the nature of all things became an important aspect of the later philosophical developmental frameworks of human rights thought (Ishay, 2004).

The rise of human rights ideology derived from Europe in the seventeenth century where rights based-thinking had developed, not in the form of human rights as known today but in the form of particular customs and legislation. These early rights did not apply to all human beings but only those considered worthy of such rights such as upper class land owners or lords who were often the law enforcers of their time (Freeman, 2004). Grotius and Hobbes advanced the ideological frameworks of natural rights for human beings. These theorists further evolved the concept of the Athenians that every man had property in himself as an individual and as a human being and therefore held a natural right to self preservation (Freeman, 2004; Ishay, 2004). John Locke's work laid the foundation for the development of human rights theory which was later used to influence a burgeoning American nation. Locke's claim that every man had a right to life, liberty and property formed the basis of the American Constitution and was developed on the ideology of rational, equal and natural rights attributed to Christian principles (Donnelly, 2004).

Nozick coined the phrase "Lockean proviso" from Locke's "The Second Treatise of Government" which framed the belief in the right to protect oneself and one's property from tyranny (Nozick, 1974; Cox, 1982). The French Revolution was fuelled by concepts of equal rights. On August 26 1769, the National Assembly declared the rights of man, including freedom from arbitrary arrest, the

presumption of innocence and freedom of expression and religion. Thomas Paine, inspired by the French Revolution, formed his framework of universal and human rights for utilisation in radical reforms of that time. In the eighteenth century, with the rise of the middle classes and industrialisation human rights was given a stronger political focus.

These middle class individuals found new ways to argue against aristocratic classes and privilege through the concept of natural rights. This followed the earlier move in the seventeenth century of demanding rights for propertied European males and against the aristocracy. Since that time, those early arguments expanded the range of subjects recognized as having the right to hold natural rights (Donnelly, 1999). The concept of natural rights was heavily challenged already in the late eighteenth century with conservatives seeing these as too radical a concept in their egalitarianism; radicals became concerned at the fact that natural rights reinforced economic inequalities (Freeman, 2004).

3.2.2 The United Nations and the Universal Declaration of Human Rights

The impact of both wars, in particular the impact of war on over 100 million people in World War II through death or disablement of both civilians and soldiers meant that a global response was needed. As a result, the end of World War II saw the formation of the United Nations and the introduction of the Universal Declaration of Human Rights (UDHR). In 1945 the United Nations was formed to create a multi-nation body and in 1948 the UDHR was formally drawn up. Within its framework the philosophical works of human rights theory evolved from something general into something that would create legal frameworks to provide standards.

3.2.3 Two Covenants and Subsequent Conventions

The UDHR outlines in 30 articles, the range of human rights. The two Covenants were the codified result of the two sets of rights outlined in the UDHR. These covenants were made binding in order to concisely and clearly define the

universality of human rights as set out in the Declaration. These two Covenants were:

- the International Covenant on Economic, Social and Cultural Rights; and,
- the International Covenant on Civil and Political Rights. (Steiner & Alston, 2000)

The UDHR, and the two Covenants, along with the subsequent optional protocols, comprise the International Bill of Rights. The optional protocols are:

- Optional Protocol to the International Covenant on Civil and Political Rights which is designed to achieve the purposes of the International Covenant on Civil and Political Rights and provide means of implementation through instruments (Steiner & Alston, 2000); and,
- Second Optional Protocol to the International Covenant on Civil and Political Rights, aiming at the abolition of the death penalty, believing the death penalty to be a denial of human dignity and not conducive to the enhancement of human rights.

These covenants and protocols effectively bind states that have ratified them to compliance with the UDHR. Over 60 other human rights treaties outline the fundamental rights and freedoms set out in the International Bill of Human Rights. These treaties address the concerns of slavery, genocide, humanitarian law, the administration of justice, social development, religious tolerance, cultural cooperation, discrimination, and violence against women, refugees and minorities. Yet disability, until recently has been largely ignored. As well as the two International Covenants, there are four Conventions that address the issues of racial discrimination, torture, women and children, and are considered the basic human rights treaties. These are:

- The International Convention on the Elimination of All Forms of Racial Discrimination;

- The Convention on the Elimination of All Forms of Discrimination against Women;
- The Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; and,
- The Convention on the Rights of the Child (NZ Ministry of Foreign Affairs, 2003; Brownlie & Goodwin-Gill, 2002)

Of note to this study are Article 27 of the UDHR and Article 15 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) which give cultural rights a specific category, although the cultural rights appear almost as a secondary thought compared to the rest of the documents. The lack of importance placed on the ‘cultural’ component of the ICESCR is shown in that, while the term is broadly referred to, it is the economic and social rights that appear to be given priority (Alfredsson & Straropoulou, 2002).

3.3 Disability within the Human Rights Framework

Since World War II, the existence of human rights has been recognised in international law, and to varying degrees, in most domestic legal systems....Working from...concepts of prejudice and discrimination and recognizing how human rights are historically denied to others on the basis of certain recurring grounds, most of these national and international instruments make a ringing Declaration along the lines that “human rights shall not be denied on the basis of,” followed by a specific enumerated list that typically includes the grounds of race, ethnicity, national origin, and gender...the realities of racial segregation and violence all over the world that racial and ethnic minorities belonged to this new “human rights club,”... Disability, on the other hand, was not initially admitted into the club; the diminished opportunities and isolation of people with disabilities was seen as an inevitable consequence of their individual conditions and an issue for charity, not a matter of human rights being denied (Breslin & Yee, 2002, pp. 179-180).

There is currently no international document specifically addressing the rights of indigenous persons with disabilities; although the draft Declaration on the Rights

of Indigenous Persons seeks to address this, at the time of writing this study, the draft Declaration was not adopted.⁹ Therefore, New Zealand does not have an international obligation to implement disability-related legislation, although it has implemented some protections for persons with disabilities in domestic law such as the Human Rights Act (1993) and the Health and Disability Commissioner Act (1994), both of which are discussed further in chapter five. In its specific enumerated list, the UDHR does not identify persons with disabilities. The UDHR does, however, theoretically entitle ALL citizens to have civil, political, social, economic and cultural rights. The reality for persons with disabilities is, as noted, very different. The rights of individuals who experience discrimination based on their identity and as a specifically identified marginalised group were not considered when this Declaration was being developed.

The only specific reference to disability is Article 23 in the Convention on the Rights of the Child (UNCROC) (*Appendix 6*). This gives specific rights to children with a physical or mental disability to have certain protections which ALL children with disabilities should be able to access when wanting to obtain the same rights as children without disabilities. In contrast, the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW) (*Appendix 7*) offers no protection to women and girls with disabilities (Human Rights Commission, 2005). The United Nations did begin to address disability issues when, in 1971, it adopted two Declarations in response to the apparent disparities for some specific persons with disabilities. The Declarations are not binding, although they do give a reference point for Governments to acknowledge the rights of the group identified in these Declarations.

These Declarations are:

- The Declaration on the Rights of Disabled People 1975 (*Appendix 8*). This Declaration noted that every person with disabilities, regardless of their origins, nature and degree of impairment, has a fundamental right to be full citizens with their non-disabled peers (Cooper, 2000).
- The Declaration on the Rights of Mentally Retarded Persons 1971 (*Appendix 9*). Within this Declaration, mentally retarded persons (now

known as persons with learning/intellectual impairments) have, to the maximum degree of practicability, the same rights as other human beings (Cooper, 2000; Quinn & Degener, 2002).

Two other initiatives also implemented by the United Nations were:

- The Proclamation on the Full Participation and Equality of Disabled People in the Asia Pacific Region (*Appendix 10*); and,
- The World Programme for Action Concerning Disabled People 1983 (*Appendix 11*) (Cooper, 2000; Quinn & Degener, 2002).

In December 1993, the Standard Rules on Equalisation of Opportunities for People with Disabilities was adopted to align with the World Programme for Action through extending the focus on the equalisation of opportunities for persons with disabilities. The Standard Rules are made up of 22 rules which are divided into three categories:

- pre-conditions for equal participation;
- targets for participation; and,
- implementation measures (Cooper, 2000).

Two reports are of significance to the development of human rights and disability at the United Nations. The first Special Rapporteur, Erica-Irene A Daes, was commissioned to write a report titled “*Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder*” (1986).¹⁰ From this, the General Assembly on 17 December 1991 adopted a key resolution 46/119 called “*Principles for the protection of persons with mental illness and the improvement of mental health care*”. These principles are significant in that they show a departure from the traditional concept of liberty in the law with a new focus on positive treatment and the quality of treatment (Rosenthal & Rubenstein, 1993). In 1996, a second report was commissioned in which the Special Rapporteur, Leandro Despouy, reported to the Commission for Social Development on Disability that while the Standard

Rules had been proven to be useful tools for international efforts, there were gaps. Some of the drawbacks to the Standard Rules were that not all countries had fully implemented them and there is no legal obligation for them to report to the United Nations for monitoring or auditing of the effectiveness of implementation.¹¹

Despuoy noted that while other groups benefited from thematic conventions, persons with disabilities did not receive the same benefits. To counter this, Despuoy recommended that all treaty-monitoring bodies supervise their human rights treaties to include persons with disabilities with the recommendation that the Committee on Economic, Social and Cultural Rights be assigned to take the lead role to implement human rights for persons with disabilities. Until these reports, none of the UN instruments identified as relating to persons with disabilities were legally enforceable. The earlier findings of both Daes and Despuoy¹², which concluded that, a lack of inclusion of persons with disabilities within conventions, and the lack of enforceability, have led to the development of the CRPD.

The disability sector has mooted various points for the inclusion of persons with disabilities into human rights frameworks. Scholars such as Quinn (2002), Degener (2002), Cooper (2002), and Corker and French (1999) have argued for the inclusion of those with disabilities at a United Nations level. In 1999, Rehabilitation International (RI) presented to the United Nations a Charter for the Third Millennium after previous attempts to have a convention considered had failed. This latest attempt was the result of research by Rehabilitation International providing a more positive environment for the States to consider the proposal (Cooper, 2000. p.67). Many of these organisations, scholars and advocates came together in 2000 at a symposium on disability rights titled “From Principles to Practice” held by the Disability Rights Education Defence Fund (DREDF).

One hundred and sixty-seven lawyers and advocates with disabilities from around the world attended. At this symposium a decision was made to push for a Disability Convention. In line with other initiatives by disability-related NGOs and Governments, it was decided to develop a Convention on the Rights of

Persons with Disabilities (CRPD). In response to a report from the Office of the High Commissioner for Human Rights (OHCHR) in 2002, it was recommended that current mechanisms needed strengthening and a separate convention needed developing. An ad hoc committee was established by the Commission on Human Rights to draft the convention. At the UN ad hoc 8 meeting¹³ in August 2006, the CRPD (*Appendix 12*) was completed and on the 30th March 2007 it was approved by the General Assembly, and signed by 86 nations, with Jamaica being the first both to sign and ratify the Convention.

3.3.1 Disability as a Subject of Human Rights

Despite being one of the largest minority groups in the world encompassing 600 million persons (of which two out of three live in developing countries) disabled people have been rather ignored during the first three decades of the United Nations' existence (Degener & Quinn, 2000, p.7).

In law, persons with disabilities are commonly depicted as objects of welfare, health and charity programs and not as subjects of legal rights. Historically, the issue of disability as a subject of law has been included in social security and welfare legislation, health law and guardianship law, not as individuals with disabilities but as objects of that legislation. In the 1970s, it became clear to the United Nations that, despite a general acknowledgement that persons with disabilities have the same fundamental rights as all other citizens, this was not the reality (Breslin & Yee, 2002; Cooper, 2000).

The 1990s saw changes in some States¹⁴ where over 40 gave rise, through legislation, to more integrative and inclusive approaches to disability policy.¹⁵ Despite there being no specific mention of disability within the UDHR or the covenants, the rights of individuals with disabilities have since evolved from the United Nations Charter. This premise of rights is given in the Charter through the words, “a universal respect for, and observance of, human rights and fundamental freedoms for all without distinction....” This states that there is a universal respect, observance, human rights and fundamental freedoms for all, regardless of their background, colour, race, gender, or ability. Despite the development of the

charter and subsequent covenants, persons with disabilities still experience ongoing discrimination in several areas of their lives.

3.3.2 Other instruments relating to disability (including the International Labour Organisation)

Two Conventions of the International Labour Organisation (ILO) are also relevant in that they impacted heavily on employment legislation globally, New Zealand being no exception. These two Conventions were:

- Convention 111 Discrimination in Respect of Employment and Occupation 1958 (Convention 111); and,
- Convention 159 Vocational Rehabilitation and Employment (Disabled Persons) 1983 (Convention 159).

The ILO was founded in 1919 and became the first specialized agency of the UN in 1946. The ILO's aims and objectives are to formulate international labour standards through Conventions and Recommendations, to set minimum labour standards, to protect and provide equal opportunities and address all labour issues within the workforce. Some more recent examples, according to the ILO reports (ILO 2000, 2003 & 2005), have been changes in employment situations, giving rise to the legal scope of employment relationships not being in line with the realities of working relationships. For some persons with disabilities, this disparity between employment and working relationships has been a particular issue for well over 40 years.¹⁶ The more recent disparities in labour protection can be linked to a range of markers such as globalisation, technological advances and changes in organisational structuring of enterprise development.

These markers along with restructuring in a highly competitive environment have led to uneven impacts in some nations where labour markets are energised with employment growth and new types of work. The labour market has engaged its workers in diverse and selective ways. This includes the use of individual contracts, sub-contracting, self-employment and temporary employment to engage workers rather than traditional permanent positions for employees¹⁷. The result of this is that tensions between employees and employers have increased through

disputes and uncertainties in employment relations. The employment relationship is vague and ambiguous or the employers adopt methods to disguise their obligations to their employees (ILO, 2003).

This change in the labour market has exacerbated the risks of discrimination and inequality of opportunities for persons with disabilities such as in New Zealand where persons with disabilities are not well-represented in employment.¹⁸ Convention 111 which provides for protection for employees on the grounds of race, colour, sex, religion, political opinions, national extraction or social origin was introduced in 1958 to address the issue of discrimination and to address the concepts of rights within the UDHR. Convention 111 Article 5 (2) states that:

Any member may, after consultation with representatives of employers' and workers' organisations, where such exist, determine that the other special measures designed to meet particular requirements of persons who, for reasons such as sex, age, disablement, family responsibilities or social or cultural status, are generally recognised to require special protection or assistance, shall not be deemed to be discrimination.

Convention 159 (1983) was in response to a new understanding of rehabilitation needs of persons with disabilities, a follow-on from the "Vocational Rehabilitation (Disabled) Recommendation (1955)", and the "Human Resources Development Recommendation (1975)". The 1981 United Nations General Assembly International Year of Disabled Persons theme of 'full participation and equality' and the 'World Program of Action concerning Disabled Persons' were the catalysts to Convention 159. This provided new international standards which take into particular account the need to ensure equality of opportunity and treatment for all categories of persons with disabilities, in rural and urban environments to fully participate in employment and integration into the community. It was decided that a Convention was the next obvious step and in 1983 Convention 159 was introduced and supported by member States (Martz, 2002).

3.3.3 Some issues around disability at the International Level

While globalisation is strengthening the principles of democracy as a concept, it also creates a problem where majority rule overlooks the rights of minority groups. This raises the challenge of ensuring all social minorities have the same rights as the majority (Garcia, 2005). In recognising the globalisation of rights, it is also important now more than ever to recognise the rights of specific minority groups such as persons with disabilities and indigenous peoples. In the area of disability rights, several States have attempted to address this issue through various means. Canada and the United States of America were the first countries to adopt specific anti-discrimination laws and other human rights legislation for persons with disabilities in the 1990s as the global climate began to change in favour of including disability human rights concepts (Degener & Quinn, 2000). The organisation of American States (OAS) and the European Union (EU) have since passed strong equality legislation on disabilities with the OAS becoming, in 1999, the first inter-governmental organisation to have a binding human rights treaty on disability.¹⁹ This document is significant in that it is the first regional treaty to define disability-based discrimination. The diversity in how anti-discrimination law is applied globally could, arguably, reflect the varying levels of involvement by persons with disability in the law making processes where the laws are either strong or appear to be ‘toothless tigers’.

The diversity in law can be divided into four specific but different approaches when applying anti-discrimination law for persons with disabilities. These four approaches are:

- criminal law;
- constitutional law;
- civil law; and,
- social welfare law.

The criminal approach applies a punitive model to any breach of the disability anti discrimination legislation. One example of the criminal approach is the Australian Disability Discrimination Act (1992) (ADDA) in which sections 42

and 43 sanction the incitement of unlawful discrimination or harassment as an offence with a punitive sentence in the form of imprisonment or a fine. Most countries with this approach also have an element of civil or social law within their legislative frameworks. Luxembourg differs, however, in that its anti-discrimination provisions are exclusively in its criminal code, which makes it a criminal offence to discriminate against persons with disabilities.²⁰ The problem with the Luxembourg approach is that the perpetrator must have the intent to discriminate. If intention in the act of discrimination is absent, then a prosecution is not an option. While the criminal approach is punitive in nature, it does give substance to addressing discrimination against disability and giving some redress to the victim of the discrimination, at least in the form of making the perpetrator accountable through imprisonment or fines.

Of relevance to the **constitutional approach** is that several countries have adopted constitutional anti-discrimination provisions specifically designed to cover persons with disabilities. This approach has the distinctive feature of introducing affirmative action programs based on the premise that persons with disabilities cannot compete in the competitive mainstream environment (Cooper, 2000; Degener & Quinn, 2000). Examples of affirmative action policies are the quota systems used to provide representation of persons with disabilities in employment. Employment quotas were the common approach to protect persons with disabilities after World War II. Some African nations have applied this approach to ensure political representation of persons with disabilities in their constituency. Uganda has five seats reserved for representatives from the disability community. Malawi provides that the Senate include representatives of various interest groups such as disability and women. Kenya has taken this policy and used it to provide a seat in parliament for the political representation of persons with disabilities.²¹ Uganda's approach of including representatives of thematic groups into its political arena resulted in more than 2,000 citizens who identify as living with disabilities becoming elected officials at all levels from the parish to the district level by the year 2000 (Principles to Practice Symposium, 2000).

The constitutional approach would appear to be a preferable model to the criminal approach, in that it provides for greater inclusion of persons with disabilities into mainstream society along with entrenching the policy through constitutional means. The concern is that it could become outdated and untenable depending on the legal framework the country has in place. If there is no substantive element within the constitutional framework this could result in a broad and vague framework with the public sector having to comply with the private sector escaping the same need to comply at the same level (Degener & Quinn, 2000).

The **civil approach** differs from both the criminal and constitutional approaches in that it is more detailed in regards to its scope. The civil approach provides for a clearer and more concise method of applying disability legislation. Most of the civil laws also closely define what constitutes a disability and what constitutes discrimination or a discriminatory practice. Civil disability discrimination laws have provisions or enforcement mechanisms, as evidenced in the Americans with Disabilities Act (1990) (ADA). The ADA was tested in the case of ‘the Board of Trustees of the University of Alabama V Garrett, 531 U.S. 356 (2001), where the compliance issues of the State were tested in court. The court found that:

...the “reasonable accommodation” requirement of the ADA law failed the congruence and proportionality test even though there was a hardship exception to the accommodation requirement.

The court also said that:

Disability discrimination is rational in that hiring non-disabled employees would conserve scarce financial resources by avoiding the need for costly reasonable accommodations...and that states have rational reasons for violating the part of the ADA law banning policies that have a disparate impact on the disabled.

In summary, the court held that it was reasonable for employers to save financial resources by not having to employ employees with disabilities. The court also held that while reasonable accommodation under the ADA was unenforceable.

Employers have exemption from the ADA which has led to a culmination of disparate experiences for persons with disabilities. action to remove this aspect of discrimination against employees with disabilities. For persons with disabilities to take an action against an employer through the ADA, they must undertake expensive, lengthy court action which becomes punitive for the individual without the resources to take action through the court. This does raise an issue of cost for persons with disabilities already faced with the prospect of discrimination and loss of their employment. In Canada, the Andrews case, cited as ‘Andrews v. Law Society of British Columbia, [1989] 1 S.C.R. 143’, was significant in that it was the first case in Canada to deal with Section 15 (equality rights) of the Canadian Charter of Rights and Freedoms. This test case, sometimes known as the Andrews test, determined whether there had been a prima facie violation of equality rights. The Canadian Supreme Court when defining a general guarantee found that Section 15 was not a general guarantee of equality and that its only concern was with the equal application of the law. The court further stated that it should also be said that not all differences in treatment will result in inequality and that identical treatment may result in inequality, hence the relevance to disability.

The **social welfare approach** is a method chosen by some States to combat disability discrimination where, through traditional social welfare laws, the issues for persons with disabilities are addressed. In applying the welfare model, there tends to be a vague and broad interpretation of the law in that there are no specific protections for persons with disabilities outside of the medical, welfare, rehabilitation models being implemented (Degener & Quinn, 2000). Some countries have integrated both social welfare and civil rights laws such as the *Magna Carta* of the Philippines. However, in Title 1 Chapter I Sec 2 (b) there is a clear statement that clarifies the legislators’ intention to move from the medical model to the social model of disability. It states that, “Disabled persons’ rights must never be perceived as Welfare services by the Government.” Costa Rica and Spain also have discrimination provisions within social welfare legislation and civil rights laws, although discrimination provisions in welfare legislation tend to be less comprehensive and reform oriented. The shift from the medical model to the social or human rights model of disability tends to be less obvious in these forms of legislation.

Whilst persons with disabilities may find some protection in each of the four different approaches to law, it can be argued that the most comprehensive approach appears to be the civil rights approach. The difficulty in applying disability anti-discrimination legislation is that there is no universal approach thus fragmenting the ability to protect persons with disabilities.²² It is hoped that the recently signed CRPD provides uniformity of implementation of disability anti-discrimination legislation, bringing it into a human rights framework. Unless clearly defined and mandated by the States, the varied approaches to disability anti-discrimination law will remain as stated by Degener and Quinn (2002, p.35):

There is no current universal definition of disability based discrimination and no universal concept of equalization of opportunities of persons with disabilities. Definitions of discrimination rank from unjustified differentiation, over direct or indirect unfavourable treatment to detailed lists of discriminatory practices. However, it can be concluded that modern disability discrimination laws adhere to the principle of desegregation, deinstitutionalization and the duty to provide reasonable accommodations, which means to actively abolish structural discrimination. In addition to a strong definition of discrimination the law needs to provide clear and effective enforcement mechanisms in which disabled persons individually or as a group need to play a major role.

As the Canadian Charter of Rights and Freedoms, ss 1, 15 (1) states:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

To better understand some of the issues of equality for persons with disabilities it is relevant to understand the concept of equality. As stated previously, the Canadian charter did not give a general guarantee of equality. It was only concerned with the equal application of the law. Formal equality is a principle of equal treatment where individuals who are alike should be treated alike. It is a

principle that is applicable to individuals, whose right to be treated on their own merits can be viewed as a right of individual autonomy, or to a group, whose members seek the same treatment as members of other similarly situated groups. Formal equality as shown in the *Andrews v Law Society of British Columbia* case is granted where there is a legislative requirement to provide equal opportunities for person or persons regardless of characteristics or background. Whilst formal equality exists in legislation and policy the reality for certain sub groups such as woman, indigenous, children and persons with disabilities is that their experiences can differ from mainstream disability identity if one or more factors of marginalisation of their identity exists (see chapter two for further discussion of marginalisation of identity). The principle of formal equality requires that if two people are to be treated differently, some relevant difference between them must exist.

The principle of formal equality could also be argued as being a principle of the concept of universality and that all are equal, yet all may not be treated equally due to other marginalising factors such as gender, ethnicity and disability. Therefore it is my contention that two distinctly different discourses exist with the principle of formal equality. The first discourse is the one of being human. The other discourse is derived from how humans are treated. Analogising this concept to persons with disabilities, the first principle of all persons with disabilities being valued as human beings would apply; the second principle of how persons with disabilities are treated is dependent on their diverse identities which could conceivably create substantive inequalities (Donnelly, 1999; Yamin, 2005).

3.3.4 The Disability Convention

As outlined in 3.3 the viability of a Convention on the Rights of Persons with Disabilities (CRPD) has been vigorously debated for a long time. While there has been little analysis about the CRPD's development since the ad-hoc meetings began, international disability networks such as Disabled Persons International (DPI), World Network of Survivors of Psychiatry (WNSUP), World Blind Union (WBU), World Deaf Union (WDU) and others have collaborated to form, with the UN, the International Disability Association (IDA). The International Disability

Caucus (IDC), which also includes individuals and disability groups, grew out of these networks. Because of the lack of other written documentation to date, the information in this section is derived primarily from UN websites and the IDC official web group http://groups.yahoo.com/group/AdHoc_IDC/. This web group is significant in that it links UN delegates, international UN and non-UN affiliated disability groups and individuals with disabilities into consultation before, during and after each ad-hoc meeting in New York. In November 2001, the UN General Assembly passed resolution 56/168 and set up the ad-hoc committee to consider the proposals for a Convention on the rights and dignity of persons with disabilities.

The first ad-hoc session was held from 29 July to 9 August 2002. It was not until the appointment of Don McKay as chairperson in 2004 that substantial results were achieved, leading to the draft of the CRPD being presented to the UN for final editing and presentation to the General Assembly at the Ad Hoc 8 Session of 14 - 25 August and 5 December 2006. In 2004, the indigenous peoples with disabilities group became one of the IDC steering group members. Eight members of the IDC made up the steering group and, with indigenous, the women's caucus and the children's networks, argued for thematic articles specific to their identities to be included in the CRPD. Whilst articles for women and children were included in the body of the CRPD, the indigenous, minorities, people with disabilities in war zones, gay/lesbian/bisexual/transgendered and intersexed (glbti) persons with disabilities, minorities and groups of "other" identities were not. Some of those identities excluded from within the body of the CRPD have received mention in the preamble of the draft document. The relevant section of the CRPD preamble (p) expresses concern about:

...the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status....

This statement in the preamble recognises the complex nature of multiple or aggravated forms of discrimination based on identity other than disability identity

itself. This statement appears to seek inclusion into the CRPD for those groups/individuals who do not necessarily have equal access to the article rights set out in the Convention based on their disability identity alone. For example, indigenous peoples with disabilities who do not have the ability to have autonomy of decisions over their own social and cultural needs should be recognised in the CRPD so that they can argue the same rights as other thematic groups already recognised in the text. Examples of these thematic groups included in the Convention text are, as previously identified, women and children with disabilities who are also specifically mentioned in the preamble under (q) and (r) which states:

- q. Recognizing that women and girls with disabilities are often at greater risk, both within and outside the home of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation;
- r. Recognizing that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child.

This may lead to the question: if they are mentioned in the Preamble, why did the States then agree to also including them in a specific article in the body of the CRPD but not indigenous peoples or other marginalised groups with disabilities? Why is there no consistency in having all thematic groups included in the Convention? It is difficult to answer why some and not others have inclusion in the body of the CRPD other than it being too controversial. It does seem that some of the States appeared alarmed by the term 'self-determination' in the proposed article for indigenous peoples with disabilities. This was intended to provide for the right of indigenous with disabilities to determine their own disability needs and services. Some of this confusion could be due to the ongoing debates around the Declaration of Indigenous Peoples adopted by the Human Rights Council on the 26th June 2006.

Without official representation at the UN of indigenous peoples with disabilities, it was an issue that could only be articulated through the few indigenous peoples

with disabilities who were there in other roles and through existing ad-hoc networks such as the International Indigenous Disability Convention Working Group (IIDCWG) set up by concerned indigenous with disabilities to address the disparity of representation. This has led to a limited ability for certain minority groups to have representation and effective voices on the CRPD. For women and children, however, there is a clear acknowledgement of their marginalisation due to gender and age as outlined in their articles. The article (6) for women with disabilities states that:

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

Article 7 for children with disabilities states that:

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Articles 6 and 7 are the only two that specifically identify thematic groups in the text of the Convention, leaving the issues around marginalisation for other thematic groups unaddressed within the body of the text. Whether the mention within the preamble is sufficient will depend on the implementation and monitoring of the CRPD once it comes into force.

Outside of thematic representation other issues arose during the discussions of the delegates at the ad-hoc UN meetings with legal capacity being highly contested throughout the debates. Article 12 – ‘Equal recognition before the law’ provides the outline for how capacity is to be decided. The World Network of Survivors and Users of Psychiatry (WNSUP) was particularly vocal throughout the development of this article and were well represented as a group along with RI (Rehabilitation International) which works primarily with persons with intellectual/learning impairments. As a result of the strong debating and negotiation, the final draft states that:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The

safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

An unprecedented footnote was added at the ad-hoc 8 meeting to allow some States exclusion from compliance with this Article, but the IDC successfully had it removed at the final meeting on the 5th of December 2006.

Another major issue debated was the right to sexual and reproductive health. Article 25 on Health (a) states the requirement to:

...provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

The inclusion of 'of sexual and reproductive health' has been particularly contentious because of the opposition from some states, particularly those with strong religious connections such as where the Roman Catholic Church is influential. Some such countries have concerns that including the right to sexual and reproductive health for women with disabilities, could lead to an increase of abortions. For persons with disabilities, the debate is primarily about the right to have children, and access to their sexual and reproductive health needs rather than the right to abort, although the women's caucus has indicated it wants to have that right also if women with disabilities choose that option.

Division remains among negotiators of the CRPD as to whether it is necessary to include the issue of sexual and reproductive health in the document. The question should be: if women and men without disabilities have access to sexual and

reproductive health rights, then should not those with disabilities have access also? Why deny one group and not another based only on the impairments they live with? The IDC acknowledges the difficulties of this article and recognise it may lead to non ratification or ratification with reservations. If the Holy See, which has Roman Catholic religious representatives at the UN, and other anti-abortion groups succeed in having this reference to sexual and reproductive health needs removed, then it will mean women with disabilities will not have the equal access to sexual and reproductive health needs that was intended when this article was framed.

Articles 4 and 33, on obligations, monitoring and implementation set out a clear emphasis on consultation with persons with disabilities. It is hoped this will extend also to those marginalised identities with disabilities although no such obligation has been indicated within the body of the text.

3.4 Indigenous Rights at the United Nations

Whilst indigenous peoples are accorded the same rights as everyone else in the States in which they live, it has long been accepted that they also have certain rights to protection and promotion of their rights as indigenous persons. Customary and treaty rights are two examples of those specific protections for indigenous persons. One initial issue for indigenous persons is the difficulty of defining the term ‘indigenous’. Despite several attempts to precisely define ‘indigenous’, there has, to date, been no universally accepted definition. The differential treatments given to the different peoples have also created both conceptual and practical problems. Whilst indigenous peoples have moved to identify themselves separately from minorities, differential treatments of both identified groups ensure these disparities continue to exist.

The World Bank has argued that the changing contexts for indigenous peoples means their diversity cannot adequately be defined (Barsh, 1994). Therefore, it is not in narrowly defining indigenous peoples that a consensus can be found but in a set of characteristics that enables the development of the term ‘indigenous’.

This set of characteristics is identified in chapter two. The UN working group on indigenous peoples has since defined indigenous in the following way:

Indigenous communities, peoples and nations are those which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of societies now prevailing in those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop, and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions, and legal systems (Cobo, 1987, p. 31).

Whilst this is a definition used by the UN working group, it is not accepted by all parties. The rationale for the current preference for identifying specific characteristics of indigenous identity rather than a definition allows for the broader aspects of this identity to be considered. Along with this set of characteristics there is also the principle of self-defining one's identity, as set out in the ILO Convention 169. There it is specific to indigenous peoples, although others could use this to argue for their own right to self-define (Brownlie, 1992).

3.4.1 The Process Regarding the Draft Declaration of the Rights of Indigenous Peoples 1985-1999

The process for recognition for indigenous peoples has been an ongoing one for several decades. As far back as 1923 indigenous leaders such as T. W. Ratana and Haudenosaunee Chief Deskaheh approached the then League of Nations to ask for the right to self-govern, to live on their own land, and practise their own beliefs. These were denied them then, but the push for indigenous rights has not abated since (Corntassel & Hopkins Primeau, 1995; Brownlie, 1992; Barsh, 1996). In 1982, the Working Group on Indigenous Populations was established to oversee the promotion and protection of human rights for indigenous peoples. In 1985, the Working Group began drafting the Declaration on the Rights of Indigenous Peoples and after extensive consultation with indigenous groups the draft was

completed by the working group and the sub-commission on the Promotion and Protection of Human Rights in 1993. In 1999, the Commission on Human Rights took steps to establish a permanent forum which would review and make recommendations on the proposed Draft Declaration.

3.4.2 The Permanent forum

The Permanent Forum on Indigenous Issues was established by the United Nations Economic and Social Council (ECOSOC) resolution 2000/22 on 28 July 2000. This forum was given the mandate to "discuss indigenous issues within the mandate of the Council relating to economic and social development, culture, the environment, education, health and human rights." The Permanent Forum comprises 16 independent experts, who are each appointed to a term of three years as members with the ability to be re-elected or re-appointed for one extra term. Eight of the members are decided by the governments and eight are nominated by indigenous organisations from within their own regions. The government appointments are made up of the five regional groupings based on the UN model and the indigenous appointments are representative of the seven socio-cultural regions, with the aim of establishing a broad representation of the world's indigenous peoples. In 2002, the Secretariat of the Permanent Forum on Indigenous Issues was established by the UN General Assembly. The reason for establishing this role was to formalise the forum, create a source of information and co-ordination for the issues relating to the permanent forum and prepare annual reports for the members. One advantage of the appointment of the Secretariat for the Permanent Forum on Indigenous Issues is that they are able to participate at in-house meetings at the UN when required (Holder & Corntassel, 2002; Quane, 2005).

3.4.3 The current process

The core of the ongoing international debate continues to be the issue of self-determination from a group/collective rights perspective, although this has been only one of the many issues causing states to delay acceptance of the draft Declaration on the Rights of Indigenous Peoples. Governments had originally

expected to only have government representatives on the working group. When indigenous representatives were appointed, some States refused to work on the draft (Durie, 2003; Maaka & Fleras, 2005). Without self-determination it is argued, the identity of indigenous persons is at risk:

... a core right of self-determination that befits their generally shared avowal of sovereignty and nationhood. The degree to which such a right of self-determination is currently part of international law remains uncertain and controversial. There is, to be sure, no binding formal instrument that establishes such a right, or for that matter clarifies its scope, particularly in relation to...sovereign states within whose territory or territories such indigenous peoples and nations are situated...(Falk, 1997, p. 61).

Those States which have objected to the ratification and acceptance of the draft Declaration have done so on the grounds that the definition of indigenous peoples is too broad, hence the additional discussion as set out in chapter two on the characteristics of indigenous peoples. Chapter 3 outlines a discussion on self-determination. New Zealand, in particular, has opposed the proposed article 3 on self-determination, written in the Draft Declaration on the Rights of Indigenous Persons (*Appendix 13*) which states that:

Indigenous peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development

Other articles allude also to political self-determination from the indigenous perspective which could, in effect, place them at odds with the current governments who have assumed control of indigenous rights to the point where they have removed their political systems and political powers. The issue of self-determination is a barrier for post-colonial governments where they have become the majority and the indigenous have become the minority (Durie, 2000). The politics of indigeneity are intrinsically linked to the discussions of citizenship and identity, and it is in these debates that the issues of entitlement and equality of rights are often also raised. Durie (2003, p. 9) states that:

In effect the Declaration proposes that indigenous peoples should have access to the indigenous world with its values and resources, access to the wider society within which they live, access to a healthy environment, and a degree of autonomy over their own lives and properties. It looks forward as well as backward and is as much about development as restoration. It is also about the rights of individuals to participate in indigenous networks and the rights of indigenous groups – as tribes or collectives – to form polities within their own cultural context.

Durie is not alone in this contention of indigenous having the right to engage at all levels of society, with indigenous concepts having both legal and practical influence. The draft Declaration has yet again been delayed because of State refusal to accept that self-determination is a core aspect of indigeneity and that indigenous peoples have a right to live their lives according to their values and principles rather than those imposed on them. This is not to say that human rights is not also an intrinsic component of cultural rights.²³

It had been hoped that in December 2006 the draft Declaration on the Rights of Indigenous Peoples would finally be accepted (*Appendices 14 and 15*). This hope was diminished when on November 27 2006, a non-action resolution was put forward by the Namibian delegation which was supported by a majority at the United Nations General Assembly's Third Committee. The Declaration, which is still under decision by the Third Committee, must be considered by September 2007 at the 61st General Assembly where the States will again vote on the Declaration²⁴. The Namibian delegation's amended Declaration proposal has been supported by the majority of the States²⁵. Steps are being taken by indigenous organisations and States to resolve this impasse. There has been discussion as to the roles of the USA, Australia and New Zealand in opposing this Declaration's adoption. With New Zealand consistently opposing the Declaration, it is hardly surprising that there are tensions between the indigenous population and the Crown. Mr Andrew Begg (New Zealand Government representative) at the UN General Assembly's 60th Session on the 11 September 2005, Third Committee stated:

The draft text that has been under debate for over ten years is unworkable and unacceptable for many States, including New Zealand. It must be amended if a Declaration can be implemented as a standard of achievement. Failure to recognise this will effectively mean no Declaration. Let us all be absolutely clear about that, Mr Chairman...in elaborating the rights of one group of citizens, New Zealand cannot agree to a document that suggests there are two standards of citizenship or two classes of citizen.

In June 2006 it was reported that Don Mackay the Permanent Representative, NZ Permanent Mission to Geneva, stated that:

New Zealand cannot associate itself with this text which, despite our most strenuous efforts and genuine intentions, remains fundamentally flawed²⁶.

As stated earlier, the New Zealand Government does not support the Declaration as it is currently drafted and it has made its views clear on this matter. New Zealand has particular concerns at the potential for perceived inequality of law between indigenous and non-indigenous peoples should the Declaration be adopted. In its statement about the draft Declaration to the UN Commission on Human Rights in 2004, New Zealand representative Tim Caughley stated that *'In articulating the rights of one group, we have to be careful not to discriminate against other members of society'*²⁷. This statement clearly contradicts existing international legal protection of certain group rights such as the rights of women and children which is adopted without compromising the rights of others. The other contradiction with this statement is the issue of discrimination already experienced by indigenous peoples, the reason behind the draft Declaration on the Rights of Indigenous Peoples.

The New Zealand position on the draft Declaration remains unresolved at the time of submitting this study. Postscript: New Zealand registered its opposition to the draft Declaration. On 13 September 2007, Rosemary Banks²⁸, in an explanation of Vote to the General Assembly stated that:

“...In particular, four provisions in the Declaration are fundamentally incompatible with New Zealand’s constitutional and legal arrangements, the Treaty of Waitangi, and the principle of governing for the good of all our citizens. These are Article 26 on lands and resources, Article 28 on redress, and articles 19 and 32 on the right of veto over the State.”²⁹ (Banks, 2007, p.1)

Banks contends that the Crown’s position on Article 26 which gives the right for indigenous peoples to own and have provision made to own, use, develop and control lands and territories traditionally owned, occupied or used by them is problematic. She stated that “*For New Zealand, the entire country is potentially caught within the scope of the Article*” (Banks, 2007, p.1). It is government belief that all citizens both indigenous and non-indigenous will be unfairly targeted. This Article will require that all legally owned lands will be recognised and that such factors as ‘*customs, traditions and land tenure systems of indigenous peoples concerned will be ignored*’ (Banks, 2007, p.1). In addition, Banks argued that the provisions on redress and compensation, in particular those outlined in Article 28 were unworkable in New Zealand. This is despite provisions already made in New Zealand law such as *The Treaty of Waitangi Act (1975)* aimed at addressing Maori claims. The Government argument is that again, all citizens will be unfairly affected, including lands legitimately owned by others, thereby putting at risk the rights of legitimate land owners over indigenous rights and claims. New Zealand argued that it is impossible to address fully any compensatory claims that included the entire country where financial compensation was never the primary objective for most Maori seeking redress in New Zealand (Banks, 2007, p.2).

The final objection Banks raised was the issue of self-determination, particularly in regards to Articles 19 and 32(2). While New Zealand argues it is supportive of indigenous peoples exercising a democratic right to a decision-making process, it is argued that as Maori are a minority population (15%), Maori cannot be seen to be a majority decision-maker. Banks stated that with 17% of Maori as Members of Parliament, Maori are aptly represented in government (Banks, 2007, p.2).]

While this debate continues, there is still tension around giving collective rights to one group on a par with giving individual rights which is discussed more in section 3.4.4.. Until this tension is addressed and dealt with fully, collective rights will remain second to individual rights currently preferred by the State. With collective rights comes the concept of self-determination and, while collective rights alone may not be an issue, collective rights with the concept of self-determination attached to them, brings a different focus to the discussion.

3.4.4 Problems with Indigeneity: Group Rights and Self-Determination

Cultural groups are not undifferentiated wholes but associations of individuals with interests that differ to varying extents (Kymlicka, 1995, p. 236).

Chapter two of this thesis discusses indigenous identity in the context of disability and gender identities. While indigenous identity, including ethnic identity is a part of chapter two's discussion, this section concentrates more on the politics of indigeneity³⁰ and the concept of collective group rights as opposed to individual rights.

There are two difficult and distinct issues concerning indigenous group rights:

- 1) Collective/group rights; and,
- 2) Self-determination.

Both of these are distinct issues for indigenous peoples who will argue for dual-standing group rights. Generally indigenous peoples identify that collective and individual rights are mutually interactive and not in conflict with each other.. Rodolfo Stavehagen, the Special Rapporteur for Indigenous Peoples rights on the marginalisation of indigenous peoples, wrote to the Human Rights Commission in his *Report on the Situation of Human Rights and Fundamental Freedoms of Indigenous People* (2004, p.2) that:

‘Observing that indigenous peoples the world over are usually among the most marginalized and dispossessed sectors of society – the victims of perennial prejudice and discrimination – he recommends that States carry

out exhaustive reviews and, if necessary, reforms of their justice systems to better protect the rights of indigenous peoples. He....says that such reforms should include respect for indigenous legal customs, language and culture in the courts and the administration of justice; the full participation of indigenous people in justice reform; and the establishment of alternative justice mechanisms.’

Most humans interact at multiple levels, as citizens of the State, as individual members and as indigenous members of a group (Holder & Corntassel, 2002), to achieve this multiplicity of interaction with the experience of marginalisation as indigenous peoples, is difficult. This also outlines the difficulty of identifying indigenous peoples as individual entities while also attempting to address collective rights as a group entity. Jones examines group or collective rights from within the concept of moral subjectivity, that is, whether certain collectives or groups have independent standing on a par to individual members of the group. Jones contends that, when arguing the rights of collectives as right holders, we are actually arguing in the same way people argue whether foetuses, animals and future generations may become right holders (Jones, 1999). The issue that arises with this argument is whether we credit moral standing to groups in the same way we do individuals. If the answer is yes, then we can argue a group in the same way that we argue an individual is a right-bearing entity.

Human rights can be more than individual rights and can recognize collective rights within a human rights framework. Theorists argue there are two primary concepts to group and collective rights. These are *collective conception of rights* and *corporate conception* (Raz 1986; Shapiro and Kymlicka (1997). The collective conception of rights contends that group rights are bound through duties within the group where, according to Raz (1986) the interests of the group justifies the imposition of duties on individuals. This justification of duty upholding the interests for the good of the group overrides that of the individual which would not be justifiable within the group concept. Although the group itself must be able to stand significantly as an entity with group status and standing in order to be perceived as such, the group is not dispensable by choice nor is it

dependent on individuals solely for its survival but on the functioning collective as a group in the interests of that group.

Jones (1999) warns that upholding group rights, while valid in some contexts, is not always possible because of the risk of the abuse of the rights of individuals within that group. Jones (1999, p.92) argues:

“The corporate conception accords groups a status that is ultimate rather than derivative. Consequently, a potential for rivalry between groups arises that is both fundamental and ineliminable. In turn, that potential gives rise to the reasonable fear that individuals and their claim of right will be crushed beneath the greater weight of groups and their claims of rights.”

The core difference between collective and corporate concepts of rights is that while the collective concept of rights gives moral standing only to individuals who also hold the right as a group. The corporate concept gives rights only to the group, thereby overriding the individual right. The group is seen as a unitary entity with the right seen as the groups right and not the individuals rights within the groups. To enable collective/group rights there needs to be a clear understanding of what constitutes a collective group entitled to collective rights as not all groups would qualify as rights bearers. International and regional human rights and humanitarian law already provides reasonable recourse to the legal recognition of a variety of group rights, in particular the rights of indigenous peoples, persons with disabilities and minority rights. However, they cannot be recognised as a single entity, but taking into account the groups unique characteristics and presentation, it is possible to ensure the right of the collective while retaining the rights of the individual.

For indigenous peoples, their rights as individual entities are clearly protected as is their right as a group entity. The core issue however is not the question of citizenship which is clearly outlined for individuals and for groups as a concept in human rights, it is the issue of being recognised as a distinct collective entity with their own right to self governance, self identity, as a collective peoples and as having to bear the same consequences of carrying these rights³¹. To understand the argument of collective rights as indigenous peoples, there are two core

elements identified for such a claim by indigenous peoples: the right to self-determination (discussed further in this section) and the right to free prior and informed consent, consultation and participation. The New Zealand government, as already stated, argue these rights are already provided for under such legislation as the Treaty of Waitangi Act 1975 and that the consultation is sufficient. The Maori party, a minority party, which sits in opposition to the current Labour led government argue differently³².

The right to self determine and the right to free prior and informed consent, consultation and participation are a core component to indigenous collective rights. These concepts are the precursor to any issues related to the rights to traditional practices, lands, economic negotiations for the group, development and resources. This contrasts sharply to New Zealand's individualistic processes implemented in policy.

“Social policy in Western societies has evolved through a creative tension between the increasing recognition of individual civil, social and political rights and the assertion of group interests. Individualism – the belief that each person should be regarded as a rational and self-determining entity - is the central feature of the legal and political system that New Zealand inherited and adapted from Britain. While there have been critiques of the New Zealand state which stress collectivism, these have rarely had a significant and dominant influence on the overall direction of policy. However strongly argued, Maori, feminist, tagata-Pasifika, and class-based analysis of social policy have largely failed to convince government and electorate that individualism is but a guise for the group interests of property-owning male Pakeha.” (Cheyne.C. O’Brien. M et al, 1997, p. 146-7)

Any collective rights given to Maori have been done with limitations attached and to ensure a careful watch by crown entities such as the Maori Land Court and Te Puni Kokiri³³ which contravenes Article II of the Treaty of Waitangi allowing for the rights of Maori to manage Maori assets independently. It is these sorts of restrictions which contradict the claims of equality of citizenship status for Maori on a par with all citizens in New Zealand and provide the background to some of

the issues of discrimination and marginalisation already identified around indigenous peoples issues through the United Nations Human Rights Commission. For Maori, as stated earlier, collective rights and individual human rights are inter-relational and interchangeable with one another. Maori prior to the Treaty of Waitangi viewed individual rights and individual identities as existing only through group identities with a common ancestry and history (Davidson, 1992).

Some analysts on the other hand, point out that group rights cannot override individual rights (Donnelly, 1988; Marie, 1986; Nordenfelt, 1987). This argument is based on rights being human rights and therefore only ascribable to human individuals where a group is not deemed a human being but a collection of human beings who already have individual rights. This is already shown as denying the concept of self-determination which is a strong precept for minority indigenous peoples who identify as a collective wanting to collectively attain the right to self-determine their own rights as a group and not as individuals. Within a collective, the individual rights of the members remain individual rights, but the group rights can only be ascribed if the group deems itself to be a distinct collective with the right to self-determine rights for their members.

Sovereignty is conceptualised into two distinct and exclusive structures: internal (citizenship) and external (nationhood). Internal control of one's community is deemed to be sovereignty. These two concepts have been subjected to different interpretations with several indigenous groups adopting sovereignty as a part of their ongoing pursuit of increased autonomy and cultural preservation. The lack of a unified position among indigenous populations over the external construction of sovereignty is evident with the ongoing debates among the indigenous peoples in developed nations who focus on civil rights and the indigenous groups in the developing nations arguing for the right to 'develop' (Boldt, 1985; Maaka & Fleras, 2005). Boldt and Long (1985) argue that the use of the concept of sovereignty by indigenous groups only further perpetuates the legitimacy of the Western-European powers of authority and decision-making. The difficulty that also exists when discussing self-determination from an indigenous perspective is

that 'indigenous sovereignty' can have multiple meanings ranging from 'cultural integrity' to 'internal management'. Deloria (1979, p.26) contends that:

...the conflict over Indian sovereignty today originates in part because of the misconception held by the non-Indians with respect to social institutions and nationality.

While sovereignty is traditionally seen as a legal concept, Deloria (1979) has, in relation to indigenous peoples, conceptualised it to:

consist more of continued cultural integrity than of political powers and to the degree that a nation loses its sense of cultural identity, to that degree it suffers a loss of sovereignty (p. 26).

If Deloria's conceptualisation is to be accepted, then sovereignty becomes the set of cultural differences which relies on the development of a distinct community. The difficulty with this expanded concept, however, is it dilutes the meaning of sovereignty in international law. Corntassel and Hopkins-Primeau (1995, p.360) state that:

Invocations of self-determination and sovereignty cloud the issue of indigenous rights when it is unclear whether the term reflects the traditional international law interpretation, the notion of cultural integrity or another competing definition. The lack of clarity regarding the term's application can have the unintended effect of preventing solutions. If the language used in the draft Declaration and other subsequent legal documents is to be universal, then there must be terminological precision.

In other words, there needs to be greater clarity. Because of the confusion over sovereignty by both indigenous populations and member states, the Declaration of the Rights of Indigenous Peoples continues to be contentious. Not all indigenous populations want self-determination as international law understands, with expanded sovereignty being preferable to sovereign statehood (Corntassel & Hopkins-Primeau, 1995; Hannam, 1988; Koskenniemi, 1994). The Working Group on the Declaration of the Rights of Indigenous Peoples appears to have

been of the view that indigenous populations do not have a right of secession, although they do concur that indigenous communities have the right to self-management within the structure of the existing host state.³⁴

As to group rights versus individual rights in New Zealand, the constant drive by Māori as a collective for their right to self-determination has not abated since the signing of the Treaty of Waitangi (Brownlee, 1992, p.303). (See chapter four for more discussion on the Treaty of Waitangi). Group rights as opposed to individual rights is not just about self-determination. Language is a good example of this in that Māori language rights are accorded as a specific right of language to a collective group.

Recent legislative moves by the Labour Government have led to renewed and increasing calls for the right to self determination and the right of redress as long as legislation is drawn up that removes Māori (collective) rights of tribal title to land. In relation to the Foreshore and Seabed Act (2005), which was seen as a direct challenge to Māori, Durie (2003, p. 8) states that:

...at the heart of the debate about Māori representation and ownership of the foreshore and seabed, is the Māori opinion that being indigenous confers group rights that non-indigenous citizens do not have.

Durie's arguments would appear to support Jones' view of the collective group (in this case Māori) having the right to representation and ownership over and above individual rights although the reality for New Zealand Māori as examples is that 'external' sovereignty will not be possible due to their governments' reluctance to support this concept. Whether these rights should be conferred at an internal or external level is still being debated among indigenous populations but it is clear that the Declaration on the Rights of Indigenous Persons remains contentious as long as indigenous peoples are thought to call for the external sovereignty which nation states will not agree to. Clarification of what these levels of self-determination actually mean will provide a way forward to a long overdue Declaration being accepted if both parties are prepared to compromise their push

for external, as well as internal, sovereignty. Related to the issue of collective/group rights is the discussion of cultural relativism and universalism which are two rights based discourses directly relevant to this debate.

3.5 Universalism and Cultural Relativism

All human rights are universal, indivisible and interdependent and interrelated. The international community must treat human rights globally in a fair and equal manner, on the same footing, and with the same emphasis. While the significance of national and regional particularities and various historical, cultural and religious backgrounds must be borne in mind, it is the duty of States, regardless of their political, economic and cultural systems, to promote and protect all human rights and fundamental freedoms (Vienna Declaration and Programme for Action, 1993).

The issue of gender roles within culture is one clear example of the universalism versus cultural relativism debate between those who believe in upholding cultural identity and those who believe in the upholding of equal rights for all including women having the right to participate in society equally with men regardless of cultural backgrounds. The idea of equality, as well as the concept of cultural identity differs between cultures. Brems states that:

Cultural feminists are the antipodes of liberal feminists in that they stress women's difference from men rather than equality of the sexes. Real equality, as opposed to formal equality, takes this difference into account and values it. Various measures are proposed for the introduction of the female difference approach into the human rights system (Brems, 1997, p.138).

Who defines what is equal within a community and from within whose construct is this definition of equality derived? These are important questions to consider but there is no single answer. Messer (1993) wrote of the intransigent relationship between anthropology and human rights and listed five major rationales as to why anthropologists have remained largely uninvolved with human rights research and

formulations. The **first rationale** is anthropologists' preference to argue for the rights of collective groups, particularly the rights of indigenous persons. International human rights have only recently embraced the concept of collective rights for groups such as indigenous persons. The **second rationale** is that anthropologists have involved themselves in applied or action-orientated anthropology to improve the economic and political environment of smaller-scale societies. This latter claim involves the **third rationale** where anthropologists, whilst undertaking field research, have tended not to engage in critical analysis of political legitimacies of sovereign states and their actions. The **fourth rationale** is that, while anthropologists contribute heavily to socioeconomic, cultural and indigenous rights, the UN human rights groups continue to be dominated by legal theory. Finally, the **fifth rationale** claims that anthropologists have identified the limitations of the UN processes that do not go outside of the state to identify the human rights notions as well as the sources of violations (Messer, 1993). While human rights legal theory has continued to evolve, anthropological human rights arguments do not appear to have significantly progressed at the same rate.

3.5.1 Universalism

Universalists often accuse the relativists of making excuses through culture for the suppression of what are considered universal human rights. While relativists may argue there is no universal moral agreement in universal theory (e.g. Tilley, 2000; Perry, 1997), universalists counter that argument by claiming that some moral judgements are universal (Shestack, 1998; Nussbaum, 1997). Human rights entail a universalistic claim in referring to all human beings. This universalistic approach has, however, led to claims of the global dominance of a certain culture, that being the cultural imperialism of westernised states (Pollis et al, 1979). Is it a realistic claim to argue that the western construct only has limited applicability? It is an agreed fact that human rights as a legal concept is of western origin in that it was formulated originally in Europe and North America. This does not equate with the ideology of human rights being essentially and exclusively connected with western culture and philosophy, making it only available to Western societies. Human rights evolved as a concept partly through revolution and often faced considerable resistance from the representatives of western cultural and religious traditions (Hilpert, 1994).

The other argument against the assertion that human rights is a westernised concept is that human rights do not derive from, and are not entirely dependent on, westernized ideological frameworks. A radical pluralism has played a significant part in the conceptualisation of human rights (see chapter three for more discussion on human rights) (Rawls, 1993). Formulating a new social contract through the embracing of difference as a central element of human freedom is the key. Incorporating political recognition and legal protection for a person of diverse identity and difference, is treated in the same manner as a responsible agent entitled to equal respect. There is no avoiding the concepts of pluralism and multiculturalism from both within and between the states. To ignore these concepts is to face political risks leading to political disasters such as “ethnic cleansing”. Because of these political risks, human rights may offer the option of achieving basic agreements across the spectrum of ethnic, cultural and religious divides. Considering this, the universalism of human rights does not necessarily agree with the global imposition of a particular set of westernized values. Instead, human rights aims to provide universal recognition of pluralism and difference, the diversity of different values, cultures, identities and political beliefs whilst maintaining the potential of human integrity and personal dignity.

The risk of pure universalism frameworks is the risk of imperialism imposing a purely globalised construct while ignoring diversity. Some globalisation of rights provides for the opportunity to have basic emancipatory rights accorded within all human societies. When do human rights begin or when is a human accorded the status of human? The origins of human rights are explored in chapter three. People with disabilities are aware that they seldom gain citizenship status automatically on the basis of their impairment and therefore their identity as human is not always acknowledged and they do not qualify for human rights status because of their disability.

Eugenics is one example of how humans with the full rights of citizenship have culled those they regard as ‘other’ within their society and it is through such programs as Hitler’s ‘Aktion T4’ that persons with disabilities, gypsies, homosexuals, Jews and anyone outside of the realm of ‘human’ by laws created in

that time were killed (Kershaw, 2000). Eugenics as a concept was born out of a need to define 'normalcy' and the desire to cure any condition that deviated from that definition. As early as 800 BC the Spartans were deciding who lived and died when they killed the babies they considered too weak to live in their society and those nurtured considered worthy of rearing. Sir Francis Galton (1822-1911) coined the phrase 'eugenics' for the first time. Galton was a British psychologist who advocated for restrictions on the 'breeding of feeble-minded'. These practices were later codified into law (Gillham, 2001). Darwin theories of evolution were also pessimistic towards impairment and thought of disability as something to fear and shun. The work of Darwin became the basis for increasingly medicalised eugenics programs in the early to mid 1900s (Crook, 1994). People with intellectual/learning and psychosocial impairments were a particular focus of eugenics programs. The eugenics argument was also applied to different social classes and ethnic groups, dependent on the colour and status of the persons having these labels applied to them (Crook, 1994).

This belief never disappeared completely and resurged in popularity during the time of Hitler and World War II. It was in the medicalisation of disability that eugenics thrived through the routine experimentation and sterilisation of those considered 'feeble-minded' (Pfieffer, 1994). Hitler was not alone in his belief that persons with disabilities and certain ethnic and religious groups had no place in a society where any deviation from the majority concept of normal existed. The term 'racial hygenists' was used to describe those who removed those deemed unworthy of a place in society at that time (Kuhl, 1994). There is growing sympathy within ethics and philosophy discourse today for the 'humane euthanatizing' of those who are severely multiply impaired and it would appear that as technology develops that there is a drive to remove from the gene pool prior to birth those who are considered genetically disabled. These issues are relevant in that they underline just how human rights are defined and implemented according to values and how values are not evolving as much as some might have us believe (Singer & Kuhse, 2002).

In New Zealand there appears to be vestiges of a similar attitude towards persons with disabilities. The New Zealand courts appear to show leniency in cases where

persons with disabilities are killed in what is considered a mercy killing, as in the case of Eric Neil Smail who murdered his tetraplegic friend Keith McCormick (*R v Smail* [2006] BCL 925 CA 196/06). Smail stabbed McCormick six times in the neck, the one place his friend could feel. He received a lighter sentence than would otherwise be given with a 13 year non-parole period. Smail claimed he did this to save his friend from a 'tragic' life as a tetraplegic.

Cultural learning and the embracing and acknowledgment of the diversity of cultural identity will help us to move 'out' from a strictly relativist paradigm into a broader conceptualising of human rights. Feminism and post-colonial writers have contextualised the issues of difference where it is no longer enough to argue the role of women/colonised/people with disabilities or what is 'fair'. These concepts of 'fairness' must be challenged outside of the western paradigm and placed within the context in which 'fairness' is being challenged.

3.5.2 Cultural Relativism

Universalism and cultural relativism are important issues to explore in relation to this study. Universalism can be viewed unmistakably as a European concept and therefore anyone thinking outside of that construct will come into conflict with these ideals. Alford argues:

It is true that both the Western liberal tradition and the Chinese schools of thought previously discussed are concerned with promoting human dignity, but their respective ways of fostering it and their sense of purpose are different in important regards (An-Na'im, 1992, p.73).

Alford further stated that:

...different need not entail an absolute endorsement of one and total rejection of the other, nor a valueless and mindless relativism equating the two (AnNa'im, 1992, pp.73-74).

Without acknowledgements of diversity within the rights debate there is cultural imperialism. Universalists would argue that rights discourse must, in itself, be

open to diverse interpretations of rights in a world that is political and pluralistic and multicultural (Huntington, 1993). According to Rawls (1999), the key for succeeding in the human rights debate is achieving an “overlapping consensus” of the diverse identities, beliefs and cultures. Rawls asserts this term to mean there is a practical normative consensus on political and legal justice in a pluralistic democratic society. This can lead to a conclusion that taking a purely relativist approach provides the mechanism for recognition of difference within the human rights framework. To take a purely universalist approach is to provide for the concept of rights as overriding any cultural, religious or diverse aspects of a community. It is dangerous to assume homogeneity of anything in that oneness does not necessarily equate to equity. Goodhard states that:

The debate between relativists and universalists has created an essentialist conceptual framework that, like the debate itself, dominates the field. By "essentialist," I mean simply the view that cultures have fundamental or "essential" properties, among them their values and beliefs. By an "essentialist framework" I mean one that reduces most important theoretical questions about human rights to the core question of whether such an "essential" connection exists between a given culture and "universal" human rights doctrines (Goodhard, 2003, p.940).

The UN has not fully embraced the range of issues around cultural relativism. It has failed to place within its instruments, including the more recently drafted UN Convention on the Rights of Persons with Disabilities (August 2006), recognition of diversity of identity to address any issues of disparities and inequities³⁵. Universalism in relation to human rights has been challenged in that it is a form of imperialism or hegemony which opposes collectiveness common in non-westernized societies.

Universalism, for example, obligates respect for others as a matter of principle, but, for that very reason, arouses no curiosity about, or respect for, the otherness of others. On the contrary, universalism sacrifices the specificity of others to a global equality that denies the historical context of its own emergence and interests (Beck, 2004, p.430).

Underlying the constructs of universalism in human rights and cultural relativism is the right to choose and the freedom to make choices. Through rigidity of practices or beliefs, there is little scope for variants. Culture is not a static or solid concept but is fluid and constantly exposed to change. Prior to colonisation, the great voyage to *Aotearoa*/New Zealand brought about changes of cultural practices so that successful adaptation to a new environment could succeed, Colonisation also led to Maori cultural practices changing to meet its new environment. An example of this is how christianity is now entrenched in many Māori songs and practices on marae. The ability for cultural identities to diversify, amend, edit and change their practices according to new knowledge, whilst still maintaining core cultural and human rights values, will provide a way to achieve a human rights framework acceptable for most societies and communities. When aligning as an indigenous person with disabilities, there is also a strong cultural identity attached to this identity to give a voice within a particular human rights convention such as disability and indigenous UN instruments. This is to give recognition to the collective identity of a group and to give indigenous peoples opportunities to comply and meet the needs of a marginalised group within their community. The ability to adapt has already been shown through the ability to amend and change existing beliefs according to new knowledge gained. It is possible to again adapt and amend when needed in order to afford inclusion for those often excluded.

Disability identity within indigenous communities has already adapted practices through the introduction of colonisation and increasing scientific, medical and other healing skills brought to the community³⁶. This adaptation to change does not compromise cultural integrity; instead it would enhance and empower indigenous with disabilities. All human rights discourse derives from a relativist perspective, in that even though it is perceived to be dominated by the western ideal of individualism, which is in itself a relativist concept. Cultural ideals and thinking have inevitably influenced the development of universalism. The right to human rights and the right to a cultural identity (or identities, as the case often may be) are both fundamental to the rights discourse. The difficulty is bringing these two concepts together to find the key for a workable model that incorporates both within the human rights framework. Chapter 7 which provides

recommendations looks at what can be workable models when addressing issues in law and policy for indigenous persons with disabilities.

3.6 Indigenous People with disabilities

The difficulties appear to be compounded for indigenous persons with disabilities such as in the development of the Declaration on the Rights of Indigenous Persons whose health issues are identified but disability remains an unrecognised issue, and where indigenous persons with disabilities do not have an article in the CRPD, although they are mentioned in the preamble, this has not been developed further³⁷. Instead of having the ability to intervene in the planning stages of developing the CRPD, indigenous peoples with disabilities were excluded and are facing invisibility through the lack of recognition of their identity as a specific marginalised group within an already marginalised group. Indigenous with disabilities are a group not characterised as equal through their exclusion as an identity within the proposed Conventions and through their own multiple marginalisation. This is a problem specific to indigenous peoples with disabilities who have been colonised, although aspects of exclusion may also exist for “other” indigenous because of their identity as persons with disabilities being classed as invalid alongside their peers. While little is written on indigenous disability identity, work has been extensive in the area of colour and disability (Lawson & Gooding, 2005).

Therefore, as indigenous persons with disabilities are not included as a specific group in the text of the CRPD, achieving equality has become more difficult as compared with their non-indigenous peers with disabilities, as they are inequitable in status and recognition. Given the statistics which show indigenous as being among the poorest of the poor (Quane, 2005), it makes sense to conclude that indigenous persons with disabilities would be highly represented in those statistics. For further discussions on the intersectionality of various identities, refer to chapter two of this thesis.

3.7 Summary

Whilst steps are being taken at the international level to ensure persons with disabilities have human rights, there are still the outstanding issues of self determination and collective rights for indigenous persons with disabilities. It is promising to see the development of anti-discrimination policy where persons with disabilities have gone from being objects of the law to subjects within the law. With the removal of paternalism and medical model approaches in human rights instruments, persons with disabilities may now be able to see a decrease in their isolation and exclusion from mainstream society. Indigenous peoples with disabilities, however, still have to contend with the issue of exclusion and fragmentation culturally, while their social standing in the community further exposes their disparate experiences. This is despite various programmes designed to address these issues. Discussion around collective rights versus individual rights must also be visible in disability policy as it is an important concept, not only for indigenous persons, but also for other marginalised groups that identify as experiencing specific discrimination based on their identity, both as persons with disabilities and as a member of another minority group. The discussion of universalism and cultural relativism is also pertinent to this discussion as it outlines the tensions that exist between cultural considerations and human rights as a universal concept relevant to all without regard to cultural specificity.

Inevitably, the international impact of the CRPD will affect domestic practices in New Zealand. The CRPD has, within its preamble, mention of minority groups for inclusion such as indigenous peoples with disabilities, and while it does not recognise specific marginalising issues for this group, it does recognise their rights within the context of disability. The Declaration on the Rights of Indigenous peoples, will also impact on indigenous persons with disabilities as their issues are the same as those of indigenous who do not experience disabilities, although their marginalisation status within an existing marginalised group will be greater. .

Chapter 4: The Treaty of Waitangi and Disability

4.1 Introduction

This chapter briefly explores the Treaty of Waitangi with a specific focus on how Māori with disabilities are identified through its application to policy involving Māori with disabilities. While the Treaty of Waitangi is a unique document for the New Zealand environment, the broader concept of customary law applies to this issue as well as to the issue of indigenous rights in international law and therefore it is pertinent to begin this chapter with a brief discussion of customary law. This is followed by an overview of the Treaty of Waitangi, explaining the articles in both the English and Māori text which differ within at least two of the articles. A focus on the Treaty of Waitangi Act (1975) and the development of the Treaty principles into policy, including health and disability policy, is explored to consider the impact this has for Māori with disabilities. The rationale behind providing this historical overview is that while it is an extensively explored subject, in the context of Maori with disabilities, there is no work on how the Treaty may or may not directly impact on them. One piece of legislation particularly affected by the Treaty of Waitangi is the New Zealand Health & Disability Act 2000 which is discussed in more detail in chapter five. Chapter three introduces the concept of collective/group rights outlining briefly some of the tensions in human rights discourse between individual and collective group rights when exercising human rights principles. Chapter three also outlines the tensions that exist in the discourse of cultural relativism and universalism. The Treaty of Waitangi, its articles and principles in the context of Māori with disabilities are the focus of this chapter which attempts to utilise the Treaty to apply effective, inclusive law and policy around disability in New Zealand. Chapter four is not an attempt to analyse the already extensive collation of work on the Treaty of Waitangi, it is to introduce into the discourse a perspective pertinent to Maori with disabilities as an identity in disability policy where the Treaty can be applied.

4.2 Customary Law

Customary laws emerge spontaneously as a consequence of cooperation induced by reciprocities. Reciprocity, in fact, provides the basis for recognition of duty or obligation under customary law. Cooperation does not require collective (governmental) action. Furthermore, the rules of obligation recognized under all the customary law systems that have existed have always focused on individual rights, including the right to private property. That has been the basis for customary laws from primitive societies through the Middle Ages, and for all the remnants of such law that exist today (Benson, 1990, p.26).

Customary law is central to the identity of indigenous peoples, local and other traditional communities as this governs many aspects of their lives in their communities. Customary law has also greatly influenced the development of post-colonial law in settler communities. Customary law can best be described as established patterns of behaviour objectively verified within a particular social setting. Generally, customary law exists when a certain legal practise is observed and the relevant parties consider it to be law. In international law, customary law refers to the legal norms developed by states over time through customary exchanges. These exchanges can be based on friendly negotiation or acts of aggression. Some of the principles of customary law have achieved strength of acceptance through compelling law thought to have overall acceptance by states. Customary law is distinguishable from Treaty law where explicit obligations exists between nations and are agreed upon in an attempt to codify pre-existing customary law (Smith, 1993; De Sousa Santos, 1984; McDade, 1986; McHugh, 2004). The practice and support of customary law within the indigenous communities is of importance to indigenous peoples, it is often the nucleus for the preservation of a community's cultural identity. Indigenous peoples have pushed for varying aspects of having their customary laws and values to be recognised beyond their own communities and applied in law generally (McHugh, 1987). Within the discussion of customary law is also the issue of rights within a cultural context.

4.2.1 Rights and Culture

Some considerations are needed for the Treaty to fit within human rights frameworks per se as it could be seen to be an argument based on a cultural identity versus an argument based on human rights. A cultural right is the right to practise customs, beliefs, attitudes, values, laws, traditions, language and moral guidelines that give a distinct identity to a community. Some aspects of a cultural identity may be shared by other cultures and some are distinctly different; cultures can exist within cultures which creates the multiplicitous nature of identity as for most other identity-based frameworks. (See chapter two) Cultural right is a human right and therefore the Treaty of Waitangi could be construed to be culturally framed and a rights-based treaty. For further discussions on human rights frameworks and culture, see chapter three

Culture, ethnicity and human rights...are complex and heavily inter-related issues that impact significantly on international relations...Culture, ethnicity and human rights are all fluid concepts. They are ever-changing. They progress and regress. Cultural and ethnic interpretation differs from generation to generation as each seeks to make sense of their surroundings and adapt accordingly. Human rights too are exposed to societal change (Wilkinson, 1997, p.27).

Vincent claims there are three duties when applying human rights. These are the duty to avoid depriving others of these rights; the duty to protect from deprivation; and the duty to aid those whose rights have been deprived (Vincent, 1986). Culture does not necessarily conflict with these human rights duties, although the interpretation of cultural ideology may sometimes be in conflict³⁸. Culture sometimes conflicts with human rights principles and cultural values of a particular group within the cultural community such as over gender issues. Cultural and human rights advocates often clash if their ideologies are in opposition in what is often termed cultural relativism versus universalism. The concepts around universalism and cultural relativism is set out in chapter three as it directly relates to human rights. It is however, through understanding the basic principles of both that a common ideal can be found, providing human rights as rights everybody should have because of their very humanity. Such rights can be

found when still retaining cultural identity and values that embody our identity as individuals and collectively.

As already identified, friction can arise between the concepts of cultural relativism and universalism³⁹ where the upholding of one's cultural identity and values clash with addressing any abuses of human rights within cultural settings. Some cultural practices could be construed as oppressive from within their own communities towards members such as women and peoples with disabilities and how their roles might be defined within their cultural environment. Human rights and cultural rights are inextricably linked, despite those advocating for cultural rights arguing against certain aspects of human rights. It is impossible to separate the two, yet there are continual attempts to do this. While the discussions of collective/group rights and universalism and cultural relativism from within the context of human rights is in chapter three, it is important to note that culture and human rights are interlocking concepts that may have a relevance in the discussion of the Treaty of Waitangi, given the differences of interpretations as to its intentions at the time of signing.

4.3 The Framework of International Law

As outlined in chapter three and under customary law in this chapter, rights as Maori fits within both the human rights framework, and, since 1840, the Treaty of Waitangi. Within the context of civil and political rights compliance with international law depends heavily on a State's legal system, its courts and other legal entities. International law is the body of law that governs the conduct of States, and provides certain rights to individuals within those States (Steiner & Alston, 2000). However, for those who have experienced colonisation, it is arguably less effective. Ishay states:

State rule [in settler countries] differed substantially from state rule in the mother countries. Parliamentary democracies in the mother countries could afford to make concessions to the subordinated classes in civil society, in exchange for their acceptance of the prevailing capitalist form of production....State rule in the colonies however, was different. Though the

colonies may have adopted some economic and cultural aspects of the hegemonic core, they were less able to adopt its political models. There the Europeans used the coercive apparatus of government to suppress dissent, while using control over education and the press to help legitimize colonial rule.(Ishay, 2004, p.336)

International law also has no overarching authority such as the United Nations that dictates or governs the State and its breaches or perceived breaches of international law against citizens. This lack of an authority that oversees all States and their compliance with international law is the reason why some believe that international law is not truly law. Some see it instead as a series of opinions that States can 'choose' or 'opt' to accept or dismiss. It is this lack of State acceptance of an authority that is part of the problem when dealing with issues, even when the United Nations tries to direct or sanction a State. If a directive is ignored, there is little the UN can do to enforce that directive. The other problem is when a State has already taken on the governance role within a country, the citizens therefore have limited rights under the State as citizens of the State occupying that territory. This onus on State responsibilities differs from those of citizens, who are required to act on directives given to them by the courts of the land (Leckie, 1998; Skogly & Gibney, 2002; McLean, 2003). Therefore, while international law applied to this agreement may identify the general principle of *pacta sunt servanda* (pacts must be respected) as applicable to the Treaty of Waitangi, it is seen only as an opinion and not a directive. States can refuse a directive from the International Court of Justice if it chooses to.

Customary law is made up of rules that a State has explicitly agreed to comply with. The United Nations considers customary law along with the general principles of international law to be the primary sources of international law (Steiner & Alston, 2000). Article 38 (1) (b) of the International Court of Justice lists the sources of international law as:

- (a) international conventions, whether general or particular, establishing rules expressly recognized by the contesting States;
- (b) international custom, as evidence of a general practice accepted as law;

- (c) the general principles of law recognised by civilized nations;
- (d) ...judicial decisions and the teachings of the most highly qualified publicists of the various nations, as subsidiary means for the determination of rules of law (Steiner & Alston, 2000, p. 69).

The rule of customary law is derived from the consistent conduct of States who act from the belief that the law has required them to act in a certain way. The evidence of State practice such as the introduction of national legislation and compliance with UN General Assembly resolutions shows the intent of the State. The second ingredient is if the state practises through a sense of obligation *opinio juris et necessitatis*. The behaviour of the State must be supported by a significant number of States and not rejected by that significant number of States (Rosenne, 1984). The rule of conventional law binds only those States that have expressly agreed to it. As discussed in chapter three, conventions are instruments of law to which States become signatories. Conventions usually apply only to the States that ratify them, with the weakness showing when a country is apparently in breach of Conventions ratified by a significant number of States and they are not signatories to that convention. Treaties come under international law and include such doctrines as the Vienna Convention on the Law of Treaties (1969).

As the sources of New Zealand law are derived both from common law and statute, it is reasonable to surmise that the status of international law is dependant on there being admission through either the common law or through recognition within statute. Therefore, unless the international law on treaties is recognised through either source the State is not compelled to comply with international instruments. New Zealand has enacted United Nations' conventions into statute through such legislation as the Human Rights Act (1993), the Health and Disability Commissioner Act (1990) and the Bill of Rights Act (1990). All of these pieces of legislation have reference to the conventions that are relevant and set the framework for these conventions being applied in New Zealand.

International law is clearly a part of New Zealand law and therefore the general principles of international law applies. International law is incorporated into domestic law through Parliament and not through the courts. The reality is that

domestic legislation such as the New Zealand Bill of Rights Act (1990) has incorporated the obligations under international conventions, namely the International Covenant on Civil and Political Rights. Of relevance is that for States such as New Zealand who have ratified it, the Optional Protocol to the Covenant allows scrutiny by the Human Rights Committee. It is standard for the courts of most common law countries such as New Zealand to utilise decisions of national courts and relevant authorities when interpreting human rights legislation. Cook, P in *Tavita v Minister of Immigration* at 267 noted New Zealand's ratification of the Optional Protocol by stating that:

...the United Nations Human Rights Committee is in a sense part of this country's judicial structure, in that individuals subject to New Zealand jurisdiction have direct rights of recourse to it.

While New Zealand law incorporates international obligations in domestic law, the question remains whether the government is consistent when it comes to legislation governing Māori autonomy. As the discussion on the Declaration on the Rights of Indigenous Peoples shows, New Zealand is reluctant to support full autonomy for Maori, which inevitably includes Maori with disabilities.

The discussion on the Declaration of Independence, the Treaty of Waitangi, its articles and principles outlines the core principles and beliefs applicable at the time of the signing of both the Declaration and the Treaty. It is therefore relevant to have a discussion on the Treaty to consider whether it is relevant to incorporate the principles of the Treaty of Waitangi into law and policy affecting Māori, and in relevance to this study, Māori with disabilities.

4.4 The Treaty of Waitangi

4.4.1 Background to International Law including Treaty Law within a New Zealand Context

The Treaty of Waitangi was a response to the growing issues of lawlessness among the British in New Zealand, increasing settlement interest from the French and a desire to purchase lands to develop settlements for United Kingdom

migrants. Māori were not aware of the impact these Europeans would make (Christie, 1997; Consedine, 2005; Durie, 1995; Kawharu, 1989; King, 2003; McHugh, 1991; Orange, 1997; Renwick, 1991). In 1835, 35 Northern chiefs and a total of 52 Chiefs gathered to sign a Declaration of Independence at Waitangi, in response to rumours that the French were taking an interest in New Zealand. The Declaration of Independence had four components. Although the declaration was written up in English it was Māori who, at that time, had sovereignty in New Zealand. Therefore it appears a reasonable assertion that the Declaration of Independence, taken into account with the Treaty of Waitangi, clarifies Māori understanding of sovereignty given the information/knowledge they had been exposed to at that time. This knowledge differs greatly from that of the English negotiating with Māori as they had developed the notion of sovereignty and its rules surrounding cession over a longer period of time and in the context of European law (Christie, 1997; Consedine, 2005; Durie, 1995; Kawharu, 1989; King, 2003; McHugh, 1991; Orange, 1997; Renwick, 1991).

The four components of the declaration were:

- 1) to declare the independent state of the United Tribes of New Zealand;
- 2) to give all sovereign power to the hereditary chiefs and heads of tribes and state that no other legislative power be allowed to exist in New Zealand;
- 3) that the Chiefs meet every year to make laws for peace and good order of the country; and,
- 4) a request for the King of England to watch over and protect New Zealand from all attempts at denying its independence (Consedine, 2005).

French interest in New Zealand continued to be of concern to the British and on February 6 1840, the Treaty of Waitangi was signed at Waitangi, although most Maori signatories signed after that date, and the majority preferring to sign on the Māori version of the text but not the English version of the Treaty. This is significant in that, since the signing, there have been issues of differing interpretation between the Māori and English versions with *kawānātanga* and *rangatiratanga* being the most contentious (McHugh, 1991; Orange, 1991). McHugh (1991, p.3) states:

The most obvious and fundamental problem relates to the question of what it was that the chiefs were ceding....In any event, the Maori version of the Treaty ceded the kawanatanga to the Crown, leaving the chief's rangatiratanga. The shade of difference between the two was too subtle to be depicted, as in the English version, as a simple cession of sovereignty. Kawanatanga, on the other hand, was a transliteration into Maori of 'governor' whereas rangatiratanga described the customary authority of the chiefs over their own people.

Māori who signed the Treaty expected to have a shared relationship of authority with the British Crown in that the Crown authority would have governorship over its own people, the settlers and itinerants, while the chiefs retained their chieftainship with all their autonomy intact. Māori did not sign the Treaty expecting to lose either their autonomy or chieftainship.

It is likely that those Maori who signed the Treaty expected a new relationship with Britain based on shared authority....For Maori the Treaty was not only a written document but also a spoken agreement (Consedine, 2005, p. 90).

Māori expectation of retaining their sovereignty is not unreasonable in that Māori did not believe they would lose their autonomy. To understand the relevance of the Treaty of Waitangi it is important to remember that, in international law, a treaty is a binding agreement. The European negotiators of the Treaty knew to adhere to the principles of treaty law which were, at that time, part of customary international law that applied the general principles of treaty law. In the 1840s, disputes began over the interpretation of the Treaty with settlers arguing that Māori would eagerly recognise and embrace the Crown's right of pre-emption and therefore be supportive of having their land sold to the Crown (Orange, 1997). Māori viewed this differently in that they neither recognised nor embraced the Crown's right of pre-emption. In contrast, the Treaty was viewed in the Māori context as a way of formalising their relationship with the British and provide the formalised system of protection for themselves, their resources and their right to autonomy (Turner, 2002; Kawharu, 1995).

4.4.2 The Treaty of Waitangi and the Treaty Articles

In the Treaty, the Crown (State) and Māori entered into a binding agreement that consisted of three written and one oral statement:

Article 1: (English version) The Chiefs of the Confederation of the United Tribes of New Zealand and the separate and independent Chiefs who have not become members of the Confederation cede to Her Majesty the Queen of England absolutely and without reservation all the rights and powers of Sovereignty which the said Confederation or Individual Chiefs respectively exercise or possess, or may be supposed to exercise or to possess over their respective Territories as the sole sovereigns thereof.

(Māori Version) Ko nga Rangatira o te wakaminenga me nga Rangatira katoa hoki ki hai i uru ki taua wakaminenga ka tuku rawa atu ki te Kuini o Ingarani ake tonu atu - te Kawanatanga katoa o o ratou wenua.

Article 2: (English version) Her Majesty the Queen of England confirms and guarantees to the Chiefs and Tribes of New Zealand and to the respective families and individuals thereof the full exclusive and undisturbed possession of their Lands and Estates Forests Fisheries and other properties which they may collectively or individually possess so long as it is their wish and desire to retain the same in their possession; but the Chiefs of the United Tribes and the individual Chiefs yield to Her Majesty the exclusive right of Pre-emption over such lands as the proprietors thereof may be disposed to alienate at such prices as may be agreed upon between the respective Proprietors and persons appointed by Her Majesty to treat with them in that behalf.

(Māori version) Ko te Kuini o Ingarani ka wakarite ka wakaae ki nga Rangitira ki nga hapu - ki nga tangata katoa o Nu Tirani te tino rangatiratanga o o ratou wenua o ratou kainga me o ratou taonga katoa. Otiia ko nga Rangatira o te wakaminenga me nga Rangatira katoa atu ka tuku ki te Kuini te hokonga o era wahi wenua e pai ai te tangata nona te Wenua - ki te ritenga o te utu e wakaritea ai e ratou ko te kai hoko e meatia nei e te Kuini hei kai hoko mona.

Article 3: (English version) In consideration thereof Her Majesty the Queen of England extends to the Natives of New Zealand Her royal protection and imparts to them all the Rights and Privileges of British Subjects.

(Māori version) Hei wakaritenga mai hoki tenei mo te wakaetanga ki te Kawanatanga o te Kuini - Ka tiakina e te Kuini o Ingarani nga tangata maori katoa o Nu Tirani ka tukua ki a ratou nga tikanga katoa rite tahi ki ana mea ki nga tangata o Ingarani (Orange, 1997; Consedine, 2005; Walker, 2004; King, 2003).

The main differences between the two versions of text are:

Article 1: Māori believed under this article the Queen was to retain her leadership of the British while Māori retained their tribal sovereignty (rangatiratanga) and their rights to own their land unless they chose to sell it. The Māori version reflects the Māori interpretation, not the British. The British, on the other hand, had interpreted article one to mean they would have control of their British subjects, but would also establish a government to keep law and order via a British legal system. The British believed this would protect Māori interests.

Article 2: Māori believed they had full retention of their tino rangatiratanga (full sovereignty, chieftainship) rights over their land, their villages, property and treasures. In the British text, Māori leaders and the people both collectively and individually were promised “exclusive and undisturbed possession of their lands and estates, their forests, fisheries and other properties”. Yet, in the British text, Māori had ceded their right to sell and determine their land rights by giving to the Crown the exclusive right to purchase their land. Māori had agreed to give the right to buy land to the Crown but only if Māori wished to sell the land freely and without coercion.

Article 3: The English text appeared consistent with the Māori text in this article (Kawharu, 1995).

Two clergymen (Bishop Pompallier and William Colenso) recorded a discussion at the signing of the Treaty which involved giving Māori the right to retain their customary law and having religious freedom. Hobson subsequently agreed to the following statement that was read to the Chiefs prior to the signing of the Treaty: “E mea ana te Kawana ko nga whakapono katoa o Ingarani, o nga Weteriana, o

Roma, me te ritenga Maori hoki e tiakine ngatahitia e ia”. This translates to: “The Governor says the several faiths (beliefs) of England, of the Wesleyans, of Rome, and also the Maori custom shall alike be protected by him.” (Law Commission, 2001) This discussion may have influenced the chiefs in signing the Māori version of the Treaty as it indicated an intention to honour Māori customs and autonomy.

4.5 The Government

Since at least the mid-nineteenth century, English lawyers have recognized only two sources of law. These are Parliamentary Acts (also known as statutes or legislation) and the common law or judge-made law. Our legal system is based upon the English fixation with those ‘positive’ sources of law. This positivism, as it is known, means the New Zealand legal system does not acknowledge or enforce any ‘natural rights’ except to the extent they have been incorporated into positive law by statute or the common law...The legal source of Maori rights, then, is not the Treaty of Waitangi itself, but the statutory or common law means through which these rights have or may become part of our legal system. These statutory and common law sources will determine the character of the primary rule. (McHugh; 1991, p. 11)

For the New Zealand Government, the Treaty and its principles remain a controversial issue. Historical refusal to formalise in law the Treaty in New Zealand has been at the foreground of some of that controversy. In *Wi Parata v Bishop of Wellington (1877)*, Prendergast CJ held that Māori were found at the time of colonisation to be without any form of civil government or any established system of law. Prendergast CJ found Māori to be ‘primitive barbarians’ with no political entity capable of being granted autonomy. The Treaty was therefore held to be a ‘simple nullity’. Prendergast CJ further concluded that as no legal entity existed for Māori, s. 4 of the Native Rights Act 1865 cannot call what does not exist into being and therefore no such body of customary law existed. Essentially, in making this decision Prendergast CJ denied ancient *iwi* and *hapū* laws, customs and institutions, with the effect being the Treaty disappeared from the landscape. It was not until the 1970s with a resurgence of Treaty discourse through

legislation such as the Treaty of Waitangi Act (1975) that the Treaty position was again challenged to any great extent.

Development in law incorporating principles of the Treaty has continued to evolve inequitable status for Māori in health and social economic statistics remains (Crengle et al, 2005; Davis, 2002; Dew and Davis, 2005; Ministry of Health, 2002). Any gains for Māori have often been overridden by these underlying issues that remain in many communities. For Māori, the Treaty is a vital link for any redress they seek. If the Treaty is severely weakened through international or domestic law, then the likelihood of that redress also weakens. If the Treaty and principles are removed, what is left for indigenous peoples in *Aotearoa*? The future development of the Treaty will depend on its legal standing within law and how entrenched that is. Opinions of the Treaty have varied from having no relevance to it being central to the development of New Zealand law. The core issue is the fact that Māori are dependent on the will of the Government.

Although there have been flickerings of judicial interest, there has been no sustained attempt to give the Treaty of Waitangi *independent* legal status...its “legal” status is dependent on the willingness of the Government acting through the legislature to give it status (Spiller, 2001, p.183).

While it is widely discussed that Māori have never ceded sovereignty, there is still no agreement on how the Treaty should be recognised. The New Zealand Government has enacted legislation to incorporate settlement of Treaty grievances and has developed principles applied in law and policy, yet it has never formalised the Treaty itself as the founding document of this country⁴⁰. This section outlines some of the government processes developed to incorporate Treaty principles.

4.5.1 The Treaty of Waitangi Act 1975

The Treaty of Waitangi Act (1975) (ToWA) was introduced and the Waitangi Tribunal was established to make recommendations on claims bought by Māori in relation to unresolved breaches of promise by the Crown. The ToWA originally had limited powers although it was amended in 1985 to investigate historical

treaty breaches from 1840 and increase the Tribunal membership. The membership was increased further through another amendment in 1988. The Treaty of Waitangi Amendment Act 2006 amends section 6 of the ToWA and was enacted to set the closure date for submitting all historical claims to the Waitangi Tribunal at 1 September 2008. Other legislation that governs the Waitangi Tribunal in its operations are the Commissions of Inquiry Act 1908, the Treaty of Waitangi (State Enterprises) Act 1988, and the various legislation that give effect to Treaty claim settlements such as the *Tainui* and *Ngāi Tahu* settlements.

4.5.2 The Principles of the Treaty

The Treaty ‘principles’, although not defined in the 1975 Act, were developed through the work of the Waitangi Tribunal, the Government and the New Zealand Māori Council. The defining case in giving an interpretation of principles of the Treaty was the State Owned Enterprises case by the New Zealand Māori Council when Cook P noted that the principles of the Treaty of Waitangi had come into common use in recent years (*New Zealand Māori Council v Attorney General* [1987] 1 NZLR 641). There are various interpretation of these principles and differences of opinion as to their definition and application. The Court of Appeal in 1987 stated that the principles provide protection, partnership and participation while still giving the Crown the right to govern. In 1989, the Labour Party defined the principles and these were modified a year later by the National party to be:

- principle of government (kawanatanga)
- principle of self-management(rangatiratanga)
- principle of equality
- principle of reasonable co-operation between iwi and government
- principle of redress. (Consedine, 2005, p.121)

The New Zealand Māori Council (1987) introduced its version of principles which are:

- The duty to make good past breaches of the Treaty
- The duty to return land for land
- That the Maori way of life would be protected

- The duty to consult Maori
- That the parties would be of equal status
- That priority would be given to Maori values with regard to taonga (Stenson, 2004, p.21-22).

These principles are constantly evolving and will continue to do so as long as the ability to incorporate the Treaty principles into law and policy exists although they would be more effectively protected if the Treaty were entrenched.

4.5.3 Use and Effect of the Principles in General

The complexities of Treaty jurisprudence in general and of the meanings associated with rangatiratanga in particular have resulted in varying degrees of recognition and provision of the Treaty in law and policy...It is widely accepted that the Treaty does have a place where lands, forests, fisheries, and other environmental resources are concerned, even if knowing what it is seems unclear given the current political climate. But where social matters are concerned, the Treaty is even more obscure. Neither Crown nor Maori perspectives are clear or singular regarding how the Treaty generally, let alone the specific provision of rangatiratanga ought to be considered. (Kawharu cited in Belgrave et al.; 2005, p.105)

Since the decision in the State-Owned Enterprises case, the principles of the Treaty have been incorporated into other legislation and policies. The Treaty principles are incorporated in one form or another in over 40 pieces of legislation. Examples of legislation incorporating the Treaty principles are the Conservation Act 1987, the Resource Management Act 1991, the Local Government Act 2002 and the Land Transport Management Act 2003. However, while there is mention of the Treaty principles in these pieces of legislation, they are easily removable (Spiller, 2001) for the signing of the Treaty in 1840, the constitutional role of the Treaty is still being contested. While the Crown continues to argue that Māori ceded sovereignty, giving Māori demanding tino rangatiratanga no rights of self-determination, the issues of whether Maori ceded sovereignty and which version of the Treaty applies (Durie, 1995; Lashley, 2000; Kawharu, 1995; Orange, 1997; Walker, 1997; Consedine, 2005).

This chapter also explores issues for Māori with disabilities, as well as non disability Māori issues. The issue of autonomy is pertinent to all Maori and not only for Māori with disabilities given that Maori as an identity are deemed citizens within a state and not as a Nation. Even when approval and funding is given services are regulated by the Crown, Māori, in some cases, have a type of de-facto autonomy from the Crown when Māori *iwi* authorities are able to exercise their power within the dictates of State law such as the Fisheries Act (1996) where certain rights are accorded certain *iwi*. This example, along with other processes given to Māori, however, still reflects colonial and post-colonial impositions for Māori. The problem that exists for Māori today when seeking autonomy in decision making over their own resources is their de-facto relationship with the Crown. Where legislation such as the Fisheries Act (1996) and the Resource Management Act (1991) state that consultation must occur with Māori over resources, it is at the discretion of the Crown.. This process of giving Māori some restricted rights in legislation is paternalistic towards Māori and their decision-making. The Fisheries Act (1996) has for instance allowed for kaitiaki over customary fishing rights; however, the structure for implementing this in practice is still governed by the Crown, with Māori working within the legislative framework.

4.5.4 Current Questioning of Principles

As stated earlier the principles are constantly under review by the Crown. When ex-National opposition leader Don Brash made his speech in Orewa, New Zealand in 2004, he was not alone in his criticism of the Treaty of Waitangi and its principles. Cabinet Minister Trevor Mallard was also calling for a ‘one law for all’ policy and argued that all New Zealanders, including Māori, are monocultural with no differences in treatment or representation. These arguments have created some tensions and disagreement among Māori and non-Māori not always agreeable. .

Durie (1995) and Consedine (2005) argue that it is through understanding both the Māori and the Crown positions on the Treaty that an agreement on the treaty

principles can be made. In 2005, as a means of reducing some of the ignorance, the Government set up a road show displaying the Treaty and information about the Treaty to go around New Zealand and educate New Zealanders. It could be argued that New Zealanders are less ignorant about the Treaty than they were 20 or even 10 years ago, although Don Brash admitted after his Orewa speech in 2004 that he had never read the Treaty or anything about it. In 2006, Doug Woolerton of the New Zealand First Party introduced a bill called the 'Principles of the Treaty of Waitangi Deletion Bill' (deletion bill). It went through the first reading and, although it was removed at the second reading, introducing such a bill signifies an ongoing threat to the Treaty of Waitangi and its principles. The rationale for the deletion bill was because, according to Mr Peters, the leader of New Zealand First:

- the principles had been inserted by Parliament and not Maori. Despite political representation of Maori in Parliament, Maori MPs often have to comply with party policy even if they oppose these policies
- the principles have never been defined, leading to judges setting a definition still not formally set out in legislation
- there is ongoing debate and litigation as to the relevance of the Treaty principles and their meaning; and the principles are preventing Maori and non-Maori from finding true resolution over these matters (<http://www.nzfirst.org.nz>).

The intent behind the bill was to give the Treaty historical status only rather than its current status and to pre-empt any constitutional review. Where the focus on the Treaty and its principles is in the future will depend on any constitutional review and how New Zealand's future position is decided. The Treaty is for both Māori and Pakeha, although Māori do not have the majority of numbers in the population and therefore will need to rely on partnerships with other stakeholders to the Treaty to be made central to any constitution. Partnership implies equality of power and decision-making. It is argued by Maori that partnership is not equal because of their minority status to those they are supposedly in partnership with, making them vulnerable to inequitable power relationships resulting in threats to their autonomy with such legislative moves expressed in this section⁴¹.

4.6 The Treaty and Māori with Disabilities

How can the Treaty of Waitangi be utilised specifically for Māori with disabilities? The relevance to Māori with disabilities lies within the interpretation of the Treaty articles. It is relevant to consider how these articles are applied in practice to Māori with disabilities. The reality for Māori in New Zealand is that they have limited authority and will not regain full sovereignty with the right to self government at a level equal to that of the Crown (see chapter three where levels of autonomy are discussed in further detail). If the Crown was, however, prepared to share power in partnership with Māori then it could provide an answer to some of the health and social economic problems plaguing Māori society today. This can be both an empowering or disempowering experience for Maori with disabilities, dependent on their relationship with those who make the decisions around disability policy.

It would appear that Maori policy has simultaneously contributed and detracted from the empowerment of Maori people. At times, Maori policy has worked to improve the lives and life-chances of Maori; at other times, it seems to be at odds with Maori interests by espousing ‘national interests’ at the expense of Maori rights...The role of the state in enhancing rangatiratanga rights is equivocal; on the other hand, state policy has bolstered Maori customary rights as entrenched in Article 2 of the Treaty, especially through Crown settlements; on the other, however, policy initiatives condone a commitment to individualism and corporatism, neither of which are immediately compatible with collective rights. (Fleras and Spoonley; 1999, p.147)

For Māori with disabilities, their ability to be self autonomous in all aspects of their lives and to gain full active inclusion within society and within their own community lies in exploring the relevancy of the articles of the Treaty as a foundation for arguing for this right. This discussion is also relevant when taking into account the discussion on levels of autonomy, as set out in chapter three. Article one, which guaranteed Māori their right to their own tribal sovereignty, is the key issue for Māori with disabilities who can argue the same rights as Māori without disabilities, regardless of their impairment identity. Māori with

disabilities currently have little or no autonomy in their own Māori-specific disability services (for further discussion see chapter six).

Māori with disabilities are not able to easily access Māori services. The Ministry of Health Maori Disabilities directorate have tried to address this disparity. However, as they do not fund whanau as caregivers or cultural support, Maori with disabilities struggle to have some of their needs met that do not fit within the narrow definition of what constitutes a need by the Ministry of Health. They may also have become disconnected from their tribal authority and have little or no contact with Māori, which further reduces their ability to exercise their independence as Māori with disabilities. Māori with disabilities who were research participants stated a desire to come under a Māori-run service, but expressed hesitation to do this for a myriad of factors. Issues such as their own disconnection from their *whānau*, their community, and living in an urban environment which is not in their own tribal area because they cannot access disability services at home, were some of the reasons for not going to a Māori-led service. Chapter seven on recommendations explores solutions to these gaps identified throughout this study.

The Māori text of article two of the Treaty of Waitangi gave Māori their full sovereignty and chieftainship rights over their land, villages, property and treasures, which is consistent with article one. Yet Māori with disabilities, as shown in chapters three and six of this work, clearly do not have autonomy or sovereignty of services, are not given broad inclusion throughout their tribal groups and do not have the ability to self-determine their needs in their own way. Through combining the intent of both articles one and two, autonomy can be achieved for Māori with disabilities, and is addressed in chapter seven. . Chapter six outlines how the NZDS has given autonomy to Māori providers to provide services for Māori with disabilities, yet as outlined in that chapter, Māori with disabilities are not given the autonomy to decide service delivery for themselves. It can therefore be argued that, without autonomy or their ability to determine their own service delivery needs for themselves in a culturally appropriate manner, they are not able to take advantage of the guarantees of articles one and two of the Treaty of Waitangi. Autonomy in this context could be understood as

having the capacity to alter one's personal environment using resources and information to allow us to make choices around our own concerns and those close to us such as family members. Therefore the autonomy of Māori with disabilities can be understood as being their ability to be self-determining in their lives.

Any discussion of autonomy for Māori is always countered by the different arguments for separatism: that we are all one, therefore the law must be the same for all. The flaw in this argument is that equity must exist for all to be equal within the law. The articles guarantee Māori that right of autonomy. Article three promised Māori the full protection of the Crown. For Māori with disabilities, if articles one and two are not being complied with then article three is at risk of being compromised. The Westminster legal system which New Zealand law is founded on may not necessarily be the best process for Māori. The process is formal, often oppressive and has led to Māori being the largest population group within New Zealand prisons. (Ministry of Justice, 1999) It would appear to also be an issue for Māori with disabilities as, being a marginalised group within an already marginalised group, any impact on the general Māori population will impact further on them.

Article four, which is informal and would provide a further argument for Māori sovereignty and the right to enjoy customary and religious rights when placed into the context of the other three articles, article four is very relevant as it gives Māori the right to practise *rongoa*, traditional spiritual practices, and exercise their customary law in areas impacting on them.

The Tohunga Suppression Act 1907 was introduced by Sir Apirana Ngata to wipe out charlatan *tohunga*, in particular, to remove such influences from leaders such as Rua Kenana on Māori (Webster, 1979). This Act was never intended to remove true *tohunga* practices although, in reality, it impacted greatly. It was enacted to remove those considered a risk to the community, due to the introduction of substances such as alcohol. While there is an increase in *rongoa* practices in some tribal areas such as services in the Kirikiriroa health clinic, or the Morrinsville Maori health services, again these have changed and have inevitably evolved with new knowledge acquired since colonisation. The introduction of new techniques

and knowledge has not always been negative for Māori. New medical knowledge has some benefits in providing improved care and improved the quality of *rongoa* practices for Māori. Rural Māori communities such as in the Waikato, East Coast and Northland have maintained their *tohunga* practices. Te Whanau a Apanui have set up a health clinic within their region that incorporates conventional medical as well as traditional *rongoa* services using *tohunga* and other healers to meet the broader needs of its clients. The original *tohunga* practices are, however, developing with new knowledge introduced into the practice of healing and, as a result, applying a variety of practices to present day communities. Kirikirioa Marae, Te Puna Pounamu in Christchurch and Te Puna Oranga in Hamilton are some examples of services that provide Māori traditional healing (*Rongoa Māori*) which includes an assortment of traditional and healing styles. These services include *rongoa rākau* (herbal remedies), *mirimiri* (physical therapies, including massage), *karakia* (spiritual healing and rituals), variants of cultural and spiritual support, and counselling (Durie, 1998).

For Māori with disabilities, the right to have access to their spiritual and customary practices is paramount to their well-being as it can easily complement modern medical interventions. Although in many cases for Māori where medicines are not working, the *rongoa* such as *mirimiri* or using indigenous plants for healing can be complementary to existing practices, the access to *karakia*, traditional music and the *reo* in relation to healing can also help not only the physical but also the spiritual and emotional well-being of the individual and their *whānau*. This is consistent with chapter six which outlines Māori well-being models being mooted and holistic models currently being encouraged when dealing with health and disability issues for society in general. Where the emphasis was once on the medical model of health and disabilities, there are now holistic models of health and well-being which need to incorporate cultural identity to adequately address the existing disparities for Māori with disabilities.

4.7 The Principles of the Treaty of Waitangi in Disability Policy

Apart from mental health policy, little disability work has developed on Maori with disabilities in policy. Disability policy generally is impacted by legislation such as the New Zealand Public Health and Disability Act 2000 that

acknowledges treaty principles. Treaty principles are gaining increasing recognition in health and disability policy where, over the years, different health and disability networks have been implementing the treaty in their frameworks. An example of this is where the Mental Health Foundation (MHF) incorporated the Māori version of the treaty into its practice frameworks and adapted its policies which were derived from the TU-Hanz: A Treaty understanding of Hauora in *Aotearoa*-New Zealand, Health Promotion Forum of NZ 2002. The MHF expressed the following article statements:

Ko te Tuatahi – Article One- Kawanatanga

Achieve Maori participation in all aspects of mental health promotion.

In practice this means meaningful Maori participation at all levels of the organisation, with a priority being given to Maori participation at decision-making and management levels.

Ko te Tuarua –Article two- Tino Rangatiratanga

Achieve the advancement of Maori health aspirations

This requires action towards the achievement of Maori health aspirations as determined by Maori. It involves the organisation creating and resourcing opportunities for Maori to exercise tino rangatiratanga over Maori health

Ko te Tuatoru – Article three-Oritetanga

Undertake mental health promotion, which improves Maori health outcomes

In practice this means prioritising of mental health promotion action which will bring about positive health outcomes for Maori. (Health Promotion Forum of NZ, 1999)

The principles that have developed in some policies and those identified by the Māori Council, if applied as intended, can be effective and inclusive for all. If properly done, the opportunities to reduce disparities and encourage equity for Māori, including marginalised groups within Māori such as Māori with disabilities exists. If these principles are removed, Māori with disabilities risk greater inequity than they already experience. For Māori with disabilities, the risk of increasing their experiences of inequality will deepen the disparities, becoming almost impossible for them to overcome.

4.8 Impact/Effect of the Principles of the Treaty of Waitangi on Disability Policy

While Māori with disabilities are identified as a marginalised group in such documents as the NZDS, the office that addresses disability issues (Office of Disabilities Issues - ODI) does not directly address issues pertaining to Māori with disabilities. Te Puni Kokiri (TPK) is the government mandated advisor to the NZDS on Māori disabilities issues. There has been some recent discussion of disbanding TPK, which would lessen the ability to have Māori with disabilities represented on any policy affecting them as there is no Maori authority mandated by Maori with disabilities to represent this group in disability policy. Objectives for Māori with disabilities are identified within the Ministry of Health's Māori Disability Directorate or placed under health within TPK, which will also not necessarily address the issues/needs unique to this group. There is a gap in representation from Māori disability advocates and this failure to identify core people for consultation exposes flaws in the current process of working with ODI, TPK and the MOH Māori Disability Services Directorate. Recommendations to address the issue of representation and inclusion of Māori with disabilities at all levels of disability work are outlined in chapter seven.

In reviewing the annual progress reports, little has been done by the ODI or the Ministry of Disabilities Issues to constructively inform of change for Māori with disabilities since the introduction of the NZDS (see chapter five). This is due to the lack of formal advocate consumer Maori disability networks led and mandated by Maori with direct experiences of disabilities. Ngati Kapo a Maori group run by, for and about Maori with visual impairments are one exception, however, they have a narrow focus (visual impairment only) and Maori with disabilities identity is not included in their communications with government organisations. The reports completed show Te Puni Kōkiri as reporting that it is complying, yet whatever is being achieved on paper by both TPK and ODI, Māori with disabilities have yet to see any obvious changes as shown in the annual ODI reports. In 2001, a first progress report as required by the New Zealand Public Health and Disability Act 2000, section 8 was completed (Minister for Disabilities Issues: 2001). This report outlined the progress of the disability strategy for Māori

as per the actions set out in the NZDS objective (11) aimed at promoting the participation of Māori with disabilities.

The issue here is that Māori with disabilities must have a key role in developing and implementing disability strategies for Māori with disabilities. Objective 22 does not specifically target Māori with disabilities in the same way it does other disability identities in the NZDS. The omission of the term ‘Māori with disabilities/disabled Māori’ in the objectives for implementing objective 11 allows for a broader interpretation. Objective 11 is aimed at utilising the expert/professional/medical model of disability in its implementation of services to Māori with disabilities which is outlined in more detail in chapter six. The Crown, in acknowledging the Treaty of Waitangi as the founding document of New Zealand, agrees that Māori also have an important role in developing and implementing disability strategies for Māori. In 2001, TPK reported that it would identify what barriers hindered full participation of Māori with disabilities in society by 28 June 2002 (Te Puni Kokiri, 2001). There was no mention of the results in any following progress reports by ODI that have been published by them or TPK. In the 2002-2003 progress report by ODI (Ministry for Disabilities: 2004), TPK reported under each action with statements such as those in 11.1.

Te Puni Kōkiri has representation on an interagency group working with the Office for Disability Issues within the Ministry of Social Development on the review of payment and support of family caregivers of disabled people. Te Puni Kōkiri’s advice has included:

- ensuring there is a sufficient collection of information, specifically data on Māori ethnicity
- a request to put forward Māori representatives for consultation
- contacting Te Puni Kōkiri’s Regions and Operations General Manager to request whether its regional offices can assist with consultation
- the nomination of appropriate Māori facilitators to assist with the consultation.

Te Puni Kōkiri has also contributed to work led by the Office for Disability Issues to develop a draft framework for coherent services and support on an equitable basis for all disabled people, based on a whole-of-government and

life-cycle approach, and consistent with the principles of the New Zealand Disability Strategy. Te Puni Kōkiri's advice on this work focused on the following areas:

- difficulties for rural Māori accessing services
- consultation with Māori
- gathering consistent data on disability populations, in particular disabled Māori

Five years on there is still no formal recognition of *whānau* as caregivers of Māori with disabilities, so despite identifying some of the key issues for this group, no action appears to have stemmed from the recommendations made.

The 2004-2005 ODI report states that:

The 2001 Disability Survey shows that, of all groups, Māori have the highest age standardised rates of impairment. Compared with non-Māori, they tend to have more severe impairments at younger ages. Māori are also more than twice as likely to report an unmet need for transport costs. Half of all disabled Māori adults living in households had a total annual income of \$15,000 or less. Over a third had no educational qualification; considerably higher than their non-Māori counterparts. The survey found nearly a quarter of disabled Māori living in households reported an unmet need for some type of health service (compared with 14% of non-Māori). Having an unmet need was particularly high for younger Māori (15-24 years) where the rate was almost double that of their non-Māori counterparts. Fifteen percent of disabled Māori had an unmet need for special equipment compared to 11% of disabled non-Māori (Office for Disabilities Issues, December 2005, p.85).

The statistics clearly show no significant improvement for Māori with disabilities, despite the previous annual reports indicating claims to identify and promote the inclusion of Māori on all issues for Māori with disabilities. Nowhere in any of this work is there a statement calling for the inclusion of Māori with disabilities. It is also relevant to note that TPK has not posted any work plan for the implementation of the New Zealand strategy for July 2006 to June 2007. In the

July 2005 to June 2006 work plan, TPK did note that it would work with Māori (not specifically Māori with disabilities) in the following ways:

The Te Puni Kōkiri Disability Strategy enables the organisation to identify barriers for disabled people and complements Objective 11 of the Disability Strategy which promotes participation of disabled Māori in all areas of life.

All our strategic documents are driven by our vision of a fully inclusive society, in which being disabled, no less than being Māori, is no barrier to the achievement of human potential. (Te Puni Kokiri, 2006, p.3)

Whilst this statement appears to be fully inclusive, there is a risk of absorbing Māori with disabilities within the broader work plan, further marginalising, isolating and making invisible an already marginalised group. Māori with disabilities are not well reflected in Māori society generally, but TPK's objectives outlined in their statement, does not address these issues. The effect of any strategic document may be minimal with regards to the disability issues for Māori because it is largely ignored now. The impact of marginalisation and disparities, however, will be the same for Māori with disabilities as for others in relation to health and well-being if their rights to autonomy of decision-making about services are ignored. Attempts in 2006 and 2007 have been made by the director, of the Ministry of Health Māori Disability Services Directorate, working with TPK, DPA and some other disability providers such as CCS who have engaged with Māori with disabilities through a series of *hui* designed to reach the community. Although evidence for this assumption is lacking, TPK is involved in this networking through the MOH.

4.9 Conclusion

While indigenous identity and collective/group rights have relevance to the Treaty chapter, they were placed in chapters two and three because of the unexplored issues in relation to Maori disability identity discourse and within the human rights frameworks. It is noted that ethnicity, identity and rights are interlinked into the discussion of the Treaty, however, this thesis is not to provide a broad overview, it is to provide a direct focus on a specific subject matter being

indigenous/Maori with disabilities. In summary, the Treaty of Waitangi articles and later developed principles are very relevant to Māori with disabilities if this group is identified and acknowledged as the core stakeholder when developing and implementing law and policies for and about Māori with disabilities. The Treaty has been incorporated into health and disability policies generally while disability services are still establishing those principles into practice. A lack of understanding of the Treaty of Waitangi and its relevance remains in many sectors of New Zealand society. The main weakness in implementing the Treaty is its compromised status within New Zealand's current legal system and the lack of understanding by many sectors of New Zealand society, including those working within disability disciplines. Another weakness is the inability of Māori generally to have an equal power-sharing relationship with the Crown which would give them partnership status and the ability to act in their own capacity as Māori and as self-determining peoples within their services and communities. These weaknesses are impacting severely on all Māori, but even more so for marginalised identities within Māori identity such as Māori with disabilities because of their invisibility within their own communities and society in general. Until these issues are addressed, Māori with disabilities remain at risk of marginalisation and face inequitable futures as compared with their non Māori counterparts.

Chapter 5: Disability legislation in New Zealand

People with disabilities and those concerned for social justice have identified inclusion as the key to achieving equality and fair treatment. (Corker & Shakespeare, 2002; Oliver, 1996-2002; Quinn & Degener, 2002; Saucier, 2002; Swain, Finklestein et al, 1993) The concept of inclusion goes beyond the notion of tolerance, assimilation or integration. Inclusion contains within it the idea of celebrating diversity, developing flexible social policy...equality and respecting all people. This means that for a person to be accepted as a full member of the community, issues of race, gender, sexuality or ability. At the same time full membership requires that the differences which may result from historical disadvantage, or from the way in which people are currently situated, must be taken into account and regulated in a manner which results in substantive equality. An inclusive society will not be “colour blind” and will not be “neutral” to the varying features which may be described in terms of gender, race, sexuality and ability. Rather, the inclusive society will take account of these factors where, in so doing, equality can be promoted and justice achieved (Jones & Marks, 2000, p.2).

5.1 Introduction

Other than the medicalising and objectifying of disability in law, disability has, in the past, been largely ignored as a subject worthy of inclusion from a disability/human rights angle. The invisibility of persons with disabilities in law as subjects meant that discrimination could continue as long as persons with disabilities were not involved in the decision-making process. It was through the construction and implementation of a human rights model of disabilities that the notion of persons with disabilities as ‘subjects’ began to evolve.

A powerful link can be forged between the “social construct” model of disability and the human rights perspective on disability. Society has ignored or discounted the difference of disability in regulating the terms of entry into and participation in the mainstream, thus excluding – or effectively excluding –10 per cent of any given population. This is not

merely irrational from an economic point of view; it also violates the inherent dignity of all human beings (Quinn & Degener, 2002, p.20).

Many States such as Australia, The USA, the UK, Canada, South Africa, Kenya, Israel include disability rights within their human rights legislation rather than specifically within a disability law. Disability-specific discrimination law has developed in several nations through utilising the American Disabilities Act (1990) (ADA) and/or Standard Rules as the model law. New Zealand applies the Standard Rules which can be seen as a soft law model that can work if taken seriously by Governments. Any country that has implemented disability legislation has done so with the lobbying and involvement of persons with disabilities who have actively sought the development of such law. It is through this activity that disability legislation has been implemented which has resulted in the removal of 'pity' laws, the result being a shift from the national to the international disability policy such as the ADA (Breslin, 2002, p. 21).

This chapter explores domestic legislation within the New Zealand context and the placement or needs of disability within law. This is not an exhaustive summary as it focuses primarily on legislation that directly impacts on people with disabilities within the legal framework. Legislation is being updated constantly to reflect the new language used in the disability discourse, although attitudinal issues of the legal profession have remained largely unaddressed where, for example, there are no courses at a post graduate level in the tertiary sector on disability within a New Zealand legal framework. Work in the area of attitudes towards disability within the law has not been explored to any extent in New Zealand and remains an unknown area. To analyse, the disability movement is at the level feminist and civil rights for persons of colour was at in the last forty years.

“Over the last several years, disability studies has moved out of the applied fields of medicine, social work, and rehabilitation to become a vibrant new field of inquiry within the critical genre of identity studies. Charged with the residual fervor of the civil rights movement, Women’s Studies and race studies established a model in the academy for identity-based critical

enterprises that followed, such as gender studies, queer studies, disability studies, and a proliferation of ethnic studies...Even though disability studies is now flourishing in disciplines such as history, literature, religion, theatre, and philosophy in precisely the same way feminist studies did twenty-five years ago, many of its practitioners do not recognize that disability studies is part of this larger undertaking that can be called disability studies (Garland-Thompson cited in Smith & Hutchison ed., 2004, p. 73).”

While disability as an identity or discourse remains largely unaddressed in legislation, work is being done to address legislation to include persons with disabilities. To understand the development of domestic legislation, it is important to understand the evolution of the international movement in the promotion of disability within a human rights paradigm, and the extent to which international treaties and covenants reflect impairment, if at all, which is covered in chapter three.

5.1.1 Historical Background to New Zealand Disability Law

Historically, disability legislation in New Zealand focused on the development and functioning of state provision for those with disabilities, which is consistent with the charity and medical models of disability where those deemed unable to care for themselves through impairment would be cared for by the state. Legislation positioned persons with disabilities as objects of the law rather than as subjects within the legal framework. With industrialisation in the 1800s came an increase in the incidence of disability and an emphasis on productivity and the ability to work. As a result, it became increasingly difficult to apply common law on these issues so legislation such as The Workers Compensation Act (1900) (WCA), which was the first piece of legislation to formalise pensions for disability in New Zealand, took shape. The Old Age Pensions Act (1898) (OAPA), legislated prior to the WCA, was an early example of a disability pension if one considers age as an impairment. It was designed to provide for those who, through age-related disabilities, were unable to continue work and is the forerunner to the superannuation pension that exists today.

The WCA derived from European laws such as the English Workmen's Compensation Act (1897) (EWCA) and developed new pensions and legislation for those who, through no fault of their own, could not provide for themselves. The Widows' Pension Act (1911) (WiPA) and the War Pensions Act (1915) (WPA) are some examples of the pensions and legislation that evolved from the WCA. The Social Security Act (1938) (SSA) provided a categorisation of medical conditions and introduced the term 'sickness' as a term for disability, further emphasising medicalisation and the 'object' status of persons with disabilities in law. Personal injury, however, continued to be problematic, and following the Royal Commission on Compensation for Personal Injury headed by Justice Woodhouse (the Woodhouse Report), the Accident Compensation Act (1972) (ACC) was introduced. While the original ACC Act has been amended and changed many times, it still creates a disparity between accident-related impairments and medical-related impairments, with invalid benefit recipients significantly disadvantaged compared with the often more financially enriched ACC recipients. The Disabled Persons Community Welfare Act (1974) (DPCWA) was aimed at providing better provision for financial and other assistance in respect of persons with disabilities. The DPCWA also provided for the support of voluntary organisations and private organisations concerned with providing facilities for the community welfare, sheltered employment, training, and day care of persons with disabilities. This piece of legislation has been revised several times yet, essentially, continues to be based in the old charitable/medicalised discourse of the time as discussed in chapter six.

This historical paternalism shown in common law and this earlier legislation held that incapacity was permanent and there was no shift in the incapacity of the individual. The current law, however, recognises the continuum of change and how incapacity varies in nature as well as experience, showing a gradual shift from the medicalisation of persons with disabilities to recognising the need to become more inclusive of this group as subjects within the law, worthy of the same protections as those without impairment. Certain impairments such as intellectual, psychosocial⁴² or dementia-related conditions are singled out as being a specific group where legal capacity may be an issue. The assumption in law is changing, with the perception that only some with disabilities may need to be

under a legislative arm of protection but not the majority, as previously believed. An example of assumption of disability in the case of Māori with disabilities where capacity may be an issue is in the Māori land court information brochures which still allow for the exclusion of “Maori with mental disabilities” within whānau trusts as trustees and decision makers which does not give an objective test on the issue of capacity but instead relies on the family and the Maori Land Court to decide (Ministry of Justice and Ministry of Maori Development, 2002). Unless the Maori Land Court has specific experience and expertise in deciding capacity based on impairment, then it is not the best place to make this decision.

5.2 Disability Law in New Zealand: Are Persons with Disabilities Objects or Subjects within the Law?

As already outlined in chapter three, several countries have adopted specific legislation for persons with disabilities. These include Zambia, Zimbabwe, Israel and the United States of America.⁴³ In the UK, the Disability Discrimination Act (1995) (DDA) was extended in 2005 to place a duty on all public sector authorities to promote disability equality⁴⁴. While New Zealand has not developed such disability-specific legislation to protect the rights of persons with disabilities and incorporating all law into one, it has developed several pieces of legislation specific to an issue for persons with disabilities such as discrimination. The Human Rights Act (1993) and the Health and Disability Commissioner Act (1994) (discussed in more detail later in this chapter) are two examples of legislation in New Zealand that give certain protections to persons with disabilities against discrimination. This section explores these and other pieces of legislation and policy specific to disabilities in New Zealand.

5.2.1 Disabled Persons Employment Promotion Act (1960)

The ILO conventions, which are outlined in detail in chapter three, had a particular impact on disability employment legislation in New Zealand, namely the Disabled Persons Employment Promotion Act 1960 (DPEPA), in that they allowed exemptions through legislation from equitable employment conditions for persons with disabilities. Whilst this legislation was originally planned to

rehabilitate war veterans, sheltered workshops for persons with intellectual and other severe impairments used the DPEPA to set up and provide work for them below the minimum wage rate. In 2000, the Department of Labour reviewed vocational services where individuals, families and disability/vocational organisations were consulted. In 2002, the government strategy 'Pathways to Inclusion' was developed as a five-year implementation plan to expand the opportunities for work, study, leisure and skill development not previously given a priority for those who were in sheltered employment schemes. The scheme was funded to the amount of \$27 million dollars, aimed at implementing the Pathways plan (Department of Labour, 2001). Over 700 hundred submissions and feedback from 58 meetings occurred, with a core of submissions coming from families, individuals and disability organisations. According to Wendy Wicks, the Disabled Persons Assembly (DPA) national policy researcher, the submissions showed overwhelming support to change the DPEPA which allowed exploitative work practices and low wages that created inequalities in the workplace (DPA Bites, April/May 2005). Hansard reports that in the Parliamentary debates during May 2005, the first reading for the repeal of the DPEPA was held which would make it consistent with a changing environment and meet the human rights frameworks developing in New Zealand and globally. On 26 May 2005, Dyson was reported in the Hansard reports as stating that:

The benefits of repealing the Act are as follows. People with disabilities employed in sheltered workshops will be entitled to the same employment conditions, rights, and entitlements as all other New Zealanders, including minimum wages and entitlement to statutory holiday provisions. We will have legislation that is compliant with the Human Rights Act of 1993 and the New Zealand Bill of Rights Act 1990. The repeal of existing legislation is consistent with international conventions, particularly ILO Convention 111 Concerning Discrimination in Respect of Employment and Occupation, of 1958, which was ratified by New Zealand in 1983, and there will be significant action towards achieving objective 4 of the *New Zealand Disability Strategy*. Most important, there will be transparency, consistency, and fairness in the application of wage and holiday legislation for all New Zealand workers.⁴⁵

The National and Act opposition parties, however, strongly opposed any repeal, stating that cost to the government agencies and providers would preclude any benefit to persons with disabilities seeking employment opportunities. Simon Powell (National) spoke of his concerns as to the cost on the government and employers, responding to Dyson's speech in this way:

...All this means one simple thing, and that is that those people who look to seek work, who have disabilities, and wish an occupational opportunity, will not get it if this legislation is put in place, because the compliance costs contained in the legislation have not been measured...The one thing that is clear...is that those costs will fall directly on the Government agencies and providers concerned. If that lessens the opportunity for those people with disabilities to start down the career path they wish to choose, that cannot be good news for the so-called inclusive society that this Minister wishes us to see. There will immediately be direct costs to those Government agencies and providers because they will have to comply with the Minimum Wage Act, they will have to comply with the Holidays Act, and they will, as is noted in the statement of regulatory costs, face substantial compliance costs⁴⁶.

Heather Roy (Act) noted also Act's opposition and stated that:

We know that in the past some of these workers have been exploited, but certainly my experience in the more recent past has been that they are not exploited. We know that some workers earn well above the minimum hourly wage, but most are paid \$50 on top of their invalids benefit, for 33 to 35 hours of work a week. They are allowed to earn up to that sum without being taxed, or up to \$80 before their benefit is reduced. That is part of the problem. The fact is if they earn over \$80 they are penalised for working, and that, of course, provides no incentive for any sheltered workshop employer, or any other employer, to pay them more....Certainly, nobody should be left to sit at home and be dished out money by the Government for doing nothing at all. In this respect, disabled workers, many of whom are intellectually disabled, have

been showing many, many New Zealanders a very fine example for a long period of time. So ACT New Zealand is very much opposed to the introduction of this bill⁴⁷.

The assumptions attached to the value of those with intellectual/learning impairments and their willingness to work in the sheltered environment was evident within the parliamentary debates, showing little consideration to their value in society, instead focusing on the financial cost to society. Paul Adams (United Future) summed up MPs' attitudes on the issue of disability by stating that:

...When dealing with the Disabled Persons Employment Promotion (Repeal and Related Matters) Bill, we are dealing with a bill concerning probably the least-understood group in this nation. I, for one, am thankful every day when I wake up for the abilities I have. I went through a season, just a few weeks ago, when I lost the hearing in one ear. It is amazing what a difference it makes....When we deal with the disabled, we are dealing with a wide-ranging group of people. They are often in a situation not through any choice of their own. Yet they are still human beings just like you and me, and they deserve the respect of society. They deserve to be cared for by society, and a person who has worked alongside them finds that it makes him or her a bigger person on the inside. That is so much so that each year my children have been sent to assist at disabled camps. If we are honest, those of us who have all of our abilities sometimes are uncomfortable or even awkward alongside those who are seriously disabled. Every disabled person is normally also part of a family⁴⁸.

Gary Williams (CEO of DPA NZ Ltd) has argued that any move to deny equity of employment for persons with disabilities is a denial of fundamental human rights as enshrined in articles 23 and 24 of the UDHR (DPA Bites, April/May 2005). The argument that persons with disabilities are unable to work equally productively as persons who do not experience disability is fundamentally flawed and the assumption of lower productivity is not necessarily a fact. The debate as to whether the DPEPA should be repealed continues with parliamentary debates

on the 21st March 2007 in which Ruth Dyson (Minister for Disabilities Issues) asked that the bill be read for a third time. Dyson stated:

Repealing this outdated legislation is part of a package of wider changes aimed at ensuring that the voice of disabled people in New Zealand is heard and acted upon... All submissions on the legislation supported the intent of the repeal, although some submissions expressed concerns about its implementation. Some submitters were worried that the move to paying the minimum wage would force some sheltered workshops to close. The intention of the repeal is not to close sheltered workshops; that has never been its aim. But, yes, the legislation will mean change....The repeal will mean that all sheltered workshops will have to pay everyone they employ at least the minimum wage—unless an individual worker has an exemption. It will also mean that all people who work in sheltered workshops will have access to holiday and sick leave entitlements—all the conditions that every other New Zealand worker enjoys. By repealing the Act, disabled New Zealanders will finally be valued for what they can do, rather than be defined by the place in which they work⁴⁹.

Dr Paul Hutchison (National Party) responded, expressing his opposition to the passing of the bill:

The National Opposition does want to see disabled people enabled so that they have a real choice in what they can do, like anyone else, according to their ability and capacity. We agree with the general philosophy behind the New Zealand Disability Strategy and Pathways to Inclusion. We agree that disabled people should not be patronised by central or local government. I was surprised when I heard the Minister say that this legislation ensures that disabled workers are no longer underpaid for their work, because unfortunately it does nothing of the sort. It is this practical reality that the Minister refuses to acknowledge....I remain deeply concerned that successive Labour Governments tend to bring in changes without carefully ensuring that the practical details are attended to. In this legislation that has very clearly happened, both to the detriment of disabled people's aspirations as well as to the detriment of the workshops they work in.

Hutchinson then went on to argue the case against the repeal of the DPEPA by claiming pressure has been put onto organisations such as IHC (now renamed IDEA) by Dyson to have this legislation repealed. Hutchinson argued that he had evidence to show the CEO of IHC wrote to the parents of a client in response to their concerns as to whether IHC had become too politically correct and if it was true that service providers must comply with Government expectations, standards and policies. Hutchinson stated that he believed the funding that providers receive comes with a cost. Hutchinson believes the DPEPA will ensure working clients are no longer in situations suitable to them or their needs. He also believes clients with disabilities to be incapable of working at a level warranting minimum wage pay for their labour. New Zealand First, the Greens and the Māori Party all rebutted National's stand in favour of repealing the legislation. Te Ururoa Flavell (Māori Party-Waiariki) gave a very good analysis of disability for Māori when, on 21st March 2007, he showed support for repealing the DPEPA in Parliament:

For much of the history of this country, people thought that the best way to care for people with disabilities was in institutions, separated from their communities and focused on their disabilities, with their opportunities defined and restricted by the services they could access. For disabled Māori, the marginalisation of being disabled as well as being Māori saw them surrounded by a whole host of professionals but segregated from their marae and whānau, and from their right to find real work for real pay.... Disability rates for Māori adults are higher than disability rates nationally. We know that one-third of Māori aged between 45 and 64 years report a disability, compared with one-quarter of the total population in that age group. So there are more of us....⁵⁰

The third reading of the DPEPA took place on the 21st March 2007 with 71 ayes and 50 noes. The repeal of this legislation is key to the disability community in that it will finally recognise the equal participation of persons with disabilities in society and give inclusion as full citizens worthy of equal treatment in law. For persons who identify as living with intellectual/learning impairments, the repeal of the DPEPA is more significant in that it stops the exploitation of their labour and gives value to their work which has often been done without payment.

5.2.2 The Protection of Personal Property Rights Act 1988

The Protection of Personal Property Rights (PPPRA) Act (1998) takes the principle that there is a presumption of competence, as set out in s 5 (a) and (b) which states:

Presumption of competence – For the purposes of this Part of this Act, every person shall be presumed, until the contrary is proved to have the capacity –

- (a) To understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare; and
- (b) to communicate decisions in respect of those matters.

For the PPPRA to have relevance for someone deemed to have incapacity to act on their own behalf, each application must first provide proof of incompetence. It is not sufficient simply to provide a medical diagnosis. Certain impairments have, in the past, provided for an automatic assumption of incompetence, but this no longer applies as the complexities of the differing levels of competency are increasingly understood. The courts, however, do tend to revert back to their traditional paternalistic and sometimes medical model approaches and legal understandings of what constitutes competency with no requirement to update their own knowledge around impairment⁵¹. This leads to the perpetuation of prejudices and assumptions of society which are prevalent within our legal system. Disability discourse is not necessarily well understood by those who practise law as there are no compulsory training programs on disability identity at undergraduate level in any disability field of law. This can lead to any understanding of a disability perspective being self learned and relying on the legal professional's own knowledge of impairment. Representing persons with disabilities, based on the practitioner's own assumptions, is not necessarily the best training tool for lawyers who act on behalf of clients requiring specialist knowledge of their condition.

Nevertheless, in the PPPRA an individual deemed not to have capacity under the Act has their own rights protected within this legislative framework. This Act has two primary objectives specified in section 8:

- 8 (a) To make the least restrictive intervention possible in the life of the person in respect of whom the application is made, having regard to the degree of that person's incapacity; and
- 8 (b) To enable to encourage that person to exercise and develop such capacity as he or she has to the greatest extent possible.

While 8 (a) is open to interpretation or even mis-interpretation based on the practitioner's own bias and understanding of impairment, 8 (b) does appear, in theory at least, to try to allow the individual deemed to not have capacity to participate in any decision affecting them, although the wording does appear vague and open to a variety of interpretations. Whether this is happening in reality is a matter for those presiding over individuals who come under the PPPRA and those supporting them in their care. The PPPRA does not act in isolation of other legislation; it interlinks with legislation such as the Intellectual Compulsory Care Act (2003) (ICCA). This inter-linking of legislation enables the courts to consider a matter on a case-by-case basis, taking into account the legislative needs while singling out certain impairments for care and protection. The PPPRA does not specify which impairments are considered relevant for consideration under its framework as it must consider each case on the evidence presented. The Act does not assume particular impairments, intellectual disability, mental health status or dementia, as the only components to consider capacity. This is consistent with rights-based models and the social model of disability discussed in chapter six. Not all those with intellectual impairments, psychosocial conditions or dementia-related conditions will need to be held under this Act; as with all impairments, variations of ability exist and this fact must be considered when reviewing any application.

5.2.3 Health and Disability Services Act 1993

In response to the cervical cancer inquiry of 1987 (the Cartwright enquiry), the Health and Disability Services Act (HDSA) (1993) was introduced by the National-led Government in 1992 to develop the framework for reforming New Zealand's publicly-funded health system and secure improved health and disability support services for all New Zealanders. The Act was also designed to establish, under section 7, ethics committees through the Ministry of Health, along with a separation of the responsibility for the provision of those services from funding and purchasing. The ethics committees were able to come under this legislation, providing them with a mechanism for accountability. This Act is also an example of the dramatic changes to health and disability funding by the government in that it was also in line with the user pays system then being implemented. The intent of section 7 was to provide a mechanism for enforcing human rights principles in health and disability services. Accountability is at the core of human rights, and without the mechanism of accountability the intent of the legislation is ineffective.

5.2.4 Human Rights Act 1993

The Human Rights Act (HRA) (1993) was significant for persons with disabilities in that this piece of legislation included, for the first time in New Zealand law, persons with disabilities specifically as a group in need of protection against discrimination. The HRA replaced the previous Race Relations Act (1971) (RRA) and the Human Rights Commission Act (1977) (HRCA). This is significant in that it led to the placement of persons with disabilities as the subject within the law and not medicalised or placed in as an object of the law. Disability was introduced as a new prohibited ground of discrimination under section 21 (1) (j) of the HRA. The World Health Organisation (WHO) led the way to defining disability which was later used in section 21 (h) of the HRA:

(h) Disability, which means---

- (i) Physical disability or impairment
- (ii) Physical illness
- (iii) Psychiatric illness
- (iv) Intellectual or psychological disability or impairment

- (v) Any other loss or abnormality of psychological, physiological, or anatomical structure or function
- (vi) Reliance on a guide dog, wheelchair, or other remedial means
- (vii) The presence in the body of organisms capable of causing illness

This Act also became a significant breakthrough for advocates of disability rights in New Zealand. Statistics NZ (2002) had found that:

A total of 743,800 New Zealanders reported some level of disability in 2001, an increase of 41,800 since 1996–1997. However, the overall disability rate of 1 in 5 has not changed. Twenty percent of people living in households reported a disability, compared with 97 percent of people living in residential facilities...(Statistics NZ, 2002, p.15).

Given these statistical findings, it shows that the number of those who identify with impairment under the definition of what constitutes a disability is not an insignificant number of citizens and therefore legislation is important to their inclusion in society. In 2005, the Human Rights Commission, in consultation with key stakeholders, published an action plan which showed the legislation is not giving better protection to persons with disabilities. In other words, the anti-discrimination aspect of the HRA is seen as providing lower level of rights for persons with disabilities than for those who do not experience disability. Reasonable accommodation and how it is interpreted is part of the problem for describing discrimination regarding persons with disabilities. In the *Daniels & Orr v Attorney-General* [2003] 2 NZLR 742 case, reasonable accommodation was the focus of the case where a group of parents with children with special needs sought a judicial review of the Government decision to introduce a policy of mainstreaming. The parents argued that treating everybody the same led to discrimination against children who needed differential treatment. The courts disagreed and argued that discrimination was when there was a failure to treat the children the same rather than the failure to treat children with disabilities differently. A settlement was later reached between the parents and the Government although the issue of clarifying reasonable accommodation remains

an issue. In 2004, the Human Rights Commission addressed some concerns raised with implementation of the Act.

The failure of society at large to recognise the barriers it creates for disabled people and to actively consider how to accommodate their differences has led to some dissatisfaction with the HRA provision for 'reasonable accommodation'. Many of the consultation participants felt it provides a lower level of rights than for non-disabled people, and mocks the purpose of the Act by providing an easy 'escape clause' for non-compliance (Human Rights Commission, 2004, 81).

Despite the HRA and the New Zealand Disability Strategy (2001) being implemented and providing a framework for action to improve the lives of persons with disabilities, there has been a lack of progress to date. The HRC also noted a need for progress in implementing the objectives identified in its framework. Another critique of the NZDS was the need for better collation and reporting of data to monitor progress (Human Rights Commission, 2005). The Human Rights Commission (HRC) noted that with New Zealand's participation in the development of the CRPD at the UN, the visibility and status of persons with disabilities will be assured (see chapter three for further discussion).

5.2.5 Health and Disability Commissioner Act (1994)

The Health and Disability Commissioner Act (1994) (HDC) was passed in October 1995 and the Commissioner's Office was established in 1995. The Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations (1996) were enacted on 1 July 1996. These regulations were designed to have application for all forms of health and disability services and research. A nationwide advocacy service was established and at that time community organisations such as CCS, IHC and DPA worked in collaboration with the Commissioner to create greater understanding of the code and its implications for different individuals and groups accessing health and disability services. In 2003, the Consumer Advisory Group (CAG) was set up in response to criticisms made to the HDC for its failure to meet the concerns of persons with

disabilities over issues with health and disabilities service providers. Commissioner Ron Patterson has since formalised this group and is viewing this as a long term advisory network linking the Commission with the community representatives⁵². In consulting with the disability advisors, HDC has become aware of some of the issues pertaining to certain groups such as those with intellectual impairments and psychosocial conditions and their vulnerability if they make a complaint. While, health and disability issues for prisoners with disabilities is outside of the Commissioner's role, a question as to how prisoners with disabilities can receive safe and appropriate health and disability care whilst incarcerated is a subject worthy of further research.

5.2.6 The New Zealand Public Health and Disability Act 2000

The New Zealand Public Health and Disability Act (NZPHDA) (2000) was enacted on 14 December 2000, repealing and replacing the previous Health and Disability Services Act (1993) (HDSA), and amended and renamed the Health Sector (Transitional Provisions) Act (1993) (HS(TP)A), now called the Health Sector (Transfers) Act (1993) (HS(T)A). This repeal and amendment aimed to formally dissolve the former Health and disability services and the Health Funding Authority, changing and dividing the responsibilities to District Health Boards and the Ministry of Health respectively. This legislation is administrative in nature, and whilst not directly relating to the topic, it does have an indirect impact on persons with disabilities coming under the services of the district health boards.

5.2.7 Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (IDCC&RA) and the Criminal Procedure (Mentally Impaired Persons) Act 2003

The Intellectual Disability Compulsory Care Act (2003) (IDDC & RA) was introduced to work in conjunction with the Criminal Procedure (Mentally Impaired Persons) Act (2003) (CP (MIP) A). The IDCC&RA gives the court the power to order individuals with intellectual impairments who have been charged and convicted of a criminal offence that carries a prison term of compulsory care

and rehabilitation, into appropriate secure care facilities. Those who experience psychosocial conditions, and who are convicted of a crime that carries a prison term, are held under the Mental Health (Compulsory Care and Treatment) Act (1992) MH (CAT) A). Both pieces of legislation came into force in September of 2004. The IDDC&R allows the court to order compulsory care for up to three years, which is renewable by the Family Court if the offender's behaviour still poses a significant risk to the community. The Family Court can also direct whether the care recipient requires secure or supervised care. As people with intellectual and psychosocial impairments were previously held in prison, these new Acts allow for them to be transferred to a more appropriate facility that provides more appropriate services and supports reducing their risk of abuse or ill-treatment that has been the case in the past. In Parliament on the 21 October 2003 supporting the IDDC&R bill, Dr Linda Scott (National) stated that:

For someone who has an intellectual disability, going to prison is a very serious event. Those people are vulnerable, and are abused in a prison situation. I myself know of cases from when I was a geriatrician. I was seeing an elderly couple who were caring for their son. The mother had a stroke, and the father, who was in his 90s, died suddenly. This man, who was in his 40s, all of a sudden had all his supports removed. His behaviour deteriorated markedly. Once his behaviour had deteriorated he started committing offences, and he ended up in prison. It was a very unacceptable situation for such a vulnerable person. Under this bill, when such a person is found guilty he or she can be cared for in an appropriate facility that cares for people with an intellectual disability and gives 24-hour cover and care⁵³.

It is important to separate the two impairment identities under these Acts, as they are not the same. Those with intellectual disability, which is sometimes known as mental disability, are persons who have been diagnosed as being developmentally delayed. It is important to recognize that while their IQ levels are a factor, other aspects of their impairment(s) must be considered before addressing the issue of capacity. Psychosocial conditions are more commonly identified as psychiatric impairment and are not the same as an intellectual impairment.

The most difficult area to legislate is when legal capacity is not sufficiently clearly defined for the Courts to make a decision or where the assumption of incapacity exists for some persons with disabilities. This is similar to the PPPA where capacity is an issue that needs better clarification and understanding by the practitioners. This is particularly the case for those with intellectual impairment and those who experience a psychosocial condition. Whilst this legislation is aimed at providing protection for individuals with certain impairments from being incarcerated within a risky environment, it is, also in effect, targeting people with disabilities who are historically shunned, stereotyped and demonised because of the impairments they live with. It is difficult within the judicial system to provide a fair and equitably balanced system for intellectually impaired and those with psychosocial conditions if they do not fit into the parameters of either of these Acts. These pieces of legislation were hotly debated through community and individual submissions to Parliament by those who felt they would be most affected when the law was finally enacted. The main concern from the advocates of those with an intellectual impairment, such as DPA, was the issue of separating out the identity of those with intellectual disability and placing them under a specific legislation for the protection of society, which was initially seen as discriminatory and a move away from disability protections set out in the Human Rights Act (1990). With the advocacy of People First NZ, DPA and IDEA (formally IHC) consultation to air the concerns led to amendments so that the final bill was accepted and enacted. One of the challenges with the IDCC & RA is having disability service providers whose focus has been on community development and support now having to find ways to provide forensic support to those in their client base who come under the definition in this Act. As a result of this legislation, those who identify with intellectual impairment are being identified and considered for more suitable services through the Ministry of Health and appropriate agencies such as IDEA.

Mental health consumers who are incarcerated are still reporting difficulties in gaining access to support services. Those requiring appropriate incarceration are now able to access it, yet when they are deemed well enough to be released, there is still stigma for those individuals.

5.2.8 Other matters regarding the New Zealand legal system

The issue of capacity has been largely addressed through providing a means of protecting the individual and society when a criminal offence has occurred. In other respects, the process, by which persons with disabilities access to the judicial systems remains largely untouched. In 2006 the first Deaf person was called onto a jury for a hearing in a Christchurch court, yet there is an automatic exclusion right for those identifying with a disability when called up for jury service. Obtaining court documents in an accessible format is not yet possible, so that some blind/visually impaired colleagues and client have trouble receiving the information in a reasonable timeframe to enable them to convert the documents through technology in order to practice effectively for their clients. Kevin Murray, a blind law student in Christchurch who runs an advocacy service for persons with disabilities, often cites the difficulties he and other blind persons have with legal documents not being placed into an accessible format or not being available through electronic means. Blind/visually impaired persons who are trying to receive court documents do not get funded through legal aid applications for the documents to be transcribed into an accessible format, and while Deaf can get interpreters there are not enough of them trained to provide complex legal interpretation. Persons with intellectual impairments find the legal language difficult as many have low literacy skills⁵⁴ that exclude them from being able to fully participate in the legal process; the courts are not set up to accommodate their needs⁵⁵. Should the courts be able to accommodate the needs of those with disabilities, either practitioners or users of the legal system? If persons with disabilities are to be given full citizenship rights, then they should also have systems in place in all spheres of society, including legal, that are accessible and diverse enough in structure to meet their needs.

5.3 New Zealand Disability Strategy 2001: A Way Forward?

New Zealand began recognising persons with disabilities as subjects within law only when the HRA was enacted. Prior to this, there was little in the way of anti-discrimination rights specifically for this group. In 2000, the position for Minister for Disabilities Issues was created, with Ruth Dyson being the first Minister to hold this position. In 2001, in consultation with persons with disabilities,

providers and other interested parties, the NZDS was introduced into policy as a long-term plan to address the barriers experienced by persons with disabilities seeking inclusion into society. The NZDS includes 15 objectives to identify certain groups and issues pertaining to disability barriers such as education, employment, women, children and Māori and Pacific peoples with disabilities. The Office for Disabilities Issues (ODI) was set up in 2002 within the Ministry of Social Development. Gaps exist, such as with Māori with disabilities; until December 2005, Māori with disabilities had not been specifically included as a target group in any of the consultation processes despite there being positions set up to reflect Māori with disabilities on the new Disability Advisory Council. The December appointment was made without discussion with all Māori disability networks in New Zealand. The Ministry of Health's Māori disabilities director, Roger Jolly, has been informed of a database being developed by the Māori Development Research Centre which identifies both Māori with disabilities in the community and Māori leaders with disabilities in the hope this will improve communication and representation with Māori with disabilities.

Disability providers and government agencies still struggle to understand how to consult on disabilities issues, as evidenced by the slow departmental uptake of the policies (Human Rights Commission, 2005). In his annual report, DPA President Mike Gourley spoke of the gaps and slow progress on implementing the NZDS and the disappointment felt by persons with disabilities:

We are disappointed by continuing gaps in the reporting on implementation of the Strategy. In our view this reflects a quaint notion that disability is a charitable add-on, or aspect of social responsibility that does not sit within the strategic imperatives of government agencies. Nothing could be further from the truth. The Strategy points to a society that 'fully values our lives and continually enhances our participation'. To achieve this requires, at the very least, a public service responsive to our rights and needs as a population group (Gourley, 2004, p.1)

Mental health networks have strongly advocated inclusion through participation and consultation of survivors who have experienced psychosocial conditions, with

the added emphasis on consulting with their Māori consumers to develop policies specifically relevant to them. With this significant contribution, the policies being developed are better able to reflect that community's identity rather than some assumption-based policies defined by their providers without their involvement.

Another regional example of the representation of Māori with disabilities is where the *iwi/hapū* have taken leadership in this matter, such as in Te Whānau ā Apanui, Tūhoe and Ngāti Porou districts where Māori providers are directly consulting with their client base and work closely with whānau with disabilities to give them inclusion at all levels of their services. As a result, Māori with disabilities receive the benefit. This is evident with CCS NZ Ltd, who in 2006, appointed the first Māori Policy Manager to work specifically on Māori policy issues at the head office in Wellington. This position is the first in CCS to offer Māori policies and services in consultation with Māori through their membership of CCS and the *kaumātua* group established to oversee and advise on the Māori components of CCS.

5.4 Comparing New Zealand's Domestic Law with Commonwealth Partners

Any comparative analysis of New Zealand's progress in disability law is relevant when viewing some of the Commonwealth nations that have a similar legal framework to New Zealand, in order to compare the method and reasoning adopted by each of the countries where there is a similar system of law. All of these nations, despite their common status as Commonwealth members, vary in their expression of human rights for persons with disabilities. For instance, Canada and Australia have Federal and State Parliamentary systems whereas New Zealand has a one tier legal system (Cooper, 2000). Canada was the first nation in the world to give persons with disabilities equity as citizens within its constitutional law. In contrast, Australia has not yet done this (Cooper, 2000). For New Zealand, the challenge is to ensure that persons with disabilities have full participation as citizens in society and to make the current legislation effective for meeting the rights and needs of persons with disabilities. A way forward for disability law in New Zealand could be through the example of Canada who has

incorporated disability in their constitution. This is especially relevant given the CRPD signed by New Zealand recognising the unique position of persons with disabilities. While the New Zealand Government has resisted introducing a disability Commissioner or a Disability Act, instead preferring to opt for policies such as the NZDS, it is possible this position could change once the CRPD has finalised at the UN.

5.5 Conclusion

In summary, it is clear that the law has evolved in New Zealand in relation to disability issues within a legislative framework. What began as inadequate law reflecting a medicalised perspective so that persons with disabilities were not included in the consultation and development has evolved into substantial changes in how the law is drafted, as shown in the Human Rights Act (1993) in which disability is given a status in anti-discrimination law. While New Zealand has not followed the moves by some countries, such as Australia and Canada, who have implemented disability legislation, it has developed the New Zealand Disability Strategy (2001). The social model of disability is heavily influencing disability policy in New Zealand where attitudes are seen as disabling rather than the impairment.

The Human Rights Commission has been proactive in addressing concerns of persons with disabilities. The Commission's 2005 action plan showed that the current New Zealand legislation to address disability issues is inadequate and soft compared to other legislation. Recommendations were made, including the recommendation to support the CRPD discussed in chapter three. There has, however, been resistance by employers, sheltered workshop providers, the National Party, NZ First and Act towards some changes to legislation such as in the repeal process for the DPEPA where paternalism still has a heavy influence on the thinking of those purported to represent its citizens including persons with disabilities.

Another concern from disability advocates is the law practitioners who work with persons with disabilities and their training or lack of training on disability identity

so they can advocate from the disability perspective for their clients. The IDCC & RA has also raised controversies with the result being a process of providing more suitable services to those with intellectual/learning impairments who commit crimes. Central to setting up this legislation, however, has also been the issue of how that alternative secure care is provided and by whom. The result has been that where service providers such as IDEA once focused on community supports and services, they now have to focus also on providing secure care facilities for those who come within the parameters of this Act.

While change continues to occur in law, with some changes being implemented in a timely fashion, there are gaps such as there being no Disability Act. A rationale has not been given by the Government for there being no Act although the energy has been to focus on the conclusion of the CRPD signed by New Zealand on 30 March 2007. Persons with disabilities have expressed through advocates such as DPA their disappointment at the slow progress of these changes. The evolution of human rights law internationally that encompasses particularly the CRPD, is bound to impact on domestic legislation; however, as long as the paternalism remains at a government level it will take much longer than necessary. It is time for a highly visible political presence of persons with disabilities at all levels of government if change is to be achieved for persons with disabilities at all levels of society.

Chapter 6: Models of wellbeing and disability: Shifting the paradigms from the medical, charity and social models to the indigenous model of disability

The approach to disability which I propose to adopt suggests that disability is always an interaction between individual and structural factors. Rather than getting fixated on defining disability either as a deficit or a structural disadvantage, a holistic understanding is required. The experience of a disabled person results from the relationship intrinsic to the individual, and extrinsic factors arising from the wider context in which she finds herself. Among the intrinsic factors are issues such as: the nature and severity of her impairment, her own attitudes to it, her personal qualities and abilities, and her personality. Among the contextual factors are: the attitudes and reactions of others, the extent to which the environment is enabling or disabling, and wider cultural, social and economic issues relevant to disability in that society. (Shakespeare, 2006, pp 55-56)

6.1 Introduction

This chapter explores a Māori perspective on disability in relation to Māori health/well-being models and disability models used in New Zealand policy. The three most commonly referenced Māori models of health/well being used in health and disability policy are outlined, along with the two main disability models incorporated into New Zealand disability policy. Whilst it is acknowledged that there are many more models within both areas that have been developed for various purposes, the models chosen in this chapter are directly related to health and well-being for certain groups of Māori with certain disabilities. The medical and social models of disability are the two most utilised models in current policy in New Zealand and are therefore relevant to this discussion because of their direct impact on Māori with disabilities. The issues of debate here are whether any of these models are able to incorporate all aspects of Māori with disabilities identity and whether they can incorporate not only the individual identity status of Māori with disabilities but also the issues around their collective identity and interdependent aspect of that identity.

6.2 From Charity to empowerment: An Historical Overview of the Evolution of the Disability Models into the Social Model of Disability

Non-disabled Americans do not understand disabled ones. That was clear at the memorial service for Timothy Cook, when long time friends got up to pay him heartfelt tribute. “He never seemed disabled to me,” said one “He was the least disabled person I ever met.” pronounced another. It was the highest praise these non-disabled friends could think to give a disabled attorney who, at thirty-eight years old, had won landmark disability rights cases....But more than a few heads in the crowded chapel bowed with an uneasy embarrassment at the supposed compliment. It was as if someone had tried to compliment a black man by saying, “You’re the least black person I ever met,” as false as telling a Jew, “I never think of you as Jewish,” as clumsy as seeking to flatter a woman with “You don’t act like a woman. (Shapiro, 1993, p.3)

There are nine distinct disability models reflecting societal attitudinal changes as these models have developed. They are:

- Tragic/pity/charity model where persons with disabilities are seen as tragic victims. We often see this type of portrayal in fundraising advertising for disability organisations where a child with disabilities is used to induce people to give to the charity. Persons with disabilities are not seen as individual people with value but something to shun, pity, and be afraid of (Wendall, 1996; Shakespeare, 1999).
- Religious/moral model views disability as a punishment or infliction on the individual and/or family from an external force. Sometimes the disability inflicts a lower status on the whole family affecting their stand in their community. Psychosocial conditions may be seen as being the result of ‘evil spirits’. The disability is inevitably seen as the result of a sin or indiscretion caused by the individual and their family, hence the rationale for punishing, isolating or even excluding the individual and their family from their community (Clapton & Fitzgerald, 1997).
- Medical model argues that disability results from an individual’s physical or mental limitations. The disability is largely unconnected to the social or

geographical environments. It is sometimes referred to as the Biological-Inferiority or Functional-Limitation Model (Clapton & Fitzgerald, 1997; Campbell & Oliver, 1996).

- Expert/professional model is an arm of the medical model and is seen as the impairment being the identifying factor with the provider being the fixer of the situation with the fixee being passive and accepting of the paternalism imposed on them (Clapton & Fitzgerald, 1997).
- Rehabilitation model is another arm of the medical model, the disability seen as a deficiency with the only recourse of fixing the problem with the engagement of a professional (Clapton & Fitzgerald, 1997; Campbell & Oliver, 1996).
- Economic model is based on the level of or lack of productivity by persons with disabilities in the workforce. This is primarily policy framed around economic development and the role or lack of, of persons with disabilities (Charlton, 2000).
- Social model identifies disability as a consequence of environmental, societal and attitudinal factors (Campbell & Oliver, 1996; Oliver, 1999; Shakespeare, 1998, 1999; Corker, 2002, UPIAS, 1976).
- The customer/empowering model is the opposite of the professional/expert model with the professional working alongside the client and not making the decisions for the client (Oliver, 1996; Corker & Shakespeare, 2002).
- The rights-based model conceptualizes disability as a socio-political construct within a rights-based discourse and based on the social model of disability. The focus shifts from dependence to independence and bases itself within a political civil rights framework challenging ableism, racism and sexism (Breslin, 1998; Lawson & Gooding, 2005; Oliver, 1999; Shakespeare, 1998, 1999).

There are clear themes running through these models which show an evolution from the paternalistic, deficit and blaming approaches towards disability to a civil rights, empowerment approach with challenges to attitudes and inclusion of persons with disabilities into society (Clapton & Fitzgerald, 1997, Corker & Shakespeare, 2002; Oliver, 1996, 1999) . The approach of the rights-based model

while focusing on inclusion is individualistic, favouring independence over dependence without the acknowledgement of interdependence, a factor in indigenous identity is through interdependence and whanau relationships are healing and empowering and play a central role in the individuals well-being as illustrated by Lapsley, Nikora et al (2002).

These models are well researched; however, while New Zealand is promoting the social model of disability, service providers such as the disability support link which allocates carer hours to community based disability services still utilises the medical/rehabilitation/professional models when providing services to clients with disabilities, and the rights-based model when advocating for individuals with disabilities, not necessarily addressing the issues of collective identities such as indigenous persons with disabilities.⁵⁶ This chapter discusses the Māori models of well-being, the medical and social models prevalent in policy in New Zealand and their roles when addressing the issues around disability for indigenous persons with disabilities.

6.3 Māori Models of Well-being

There are no disability models for Māori disability identity. There are, however, several Māori health and well-being models (Nikora et al., 2004). The three most commonly known and utilised Māori health models are the *Whare Tapa Wha*, *Te Wheke* and *Nga Pou Mana* models. Other models used in developing the framework for promotion and monitoring of Māori health are *Te Pae Mahutonga* and *Te Roopu Awhina o Tokanui* Models. *Te Pae Mahutonga* (the Southern Cross) model was developed by Durie (ALAC, 2003) to provide a framework for Māori health promotion. The four components of this model are:

- Te Ao Maori *The Maori World* (Mauri Ora *Breath of Life*);
- environmental protection (*Waiora Healthy Water*);
- healthy lifestyle (Toiora); and,
- participation in society (Te Oranga) (ALAC, 2003).

These four elements provide significant steps towards good Māori health (ALAC, 2003). This model is utilised in providing psychosocial services, particularly in the field of alcohol and drug services. *Te Roopu Awhina o Tokanui* model was

developed at Tokanui Hospital in 1986 by a group of Māori health professionals.⁵⁷ This model was aimed, in particular, at providing good psychiatric nursing care to Māori mental health patients. The seven elements contained in this derive from the four elements of Durie's *Whare Tapa Wha* model. The remaining 5 elements are:

- Taha Whenua (environment);
- Taha Tikanga (compliance);
- Maoritanga (old world);
- Pakehatanga (new world); and,
- Taha Tangata (self) (Durie, 1994).

While these two models are designed for psychosocial, drug and alcohol services, they each have elements of the three more commonly used Māori health models. In reviewing *Te Whare Tapa Wha*, *Te Wheke* and *Nga Pou Mana*, it becomes evident that a problem exists in disability policy in relation to Māori when trying to define concepts within a *Pākehā*/Westernised disability framework. A framework for monitoring and measuring Māori well-being within a Māori conceptual paradigm could address this. The framework that was developed to provide such a measurement analysis within mental health is the *Homai Te Waiora Ki Ahau* framework (Palmer, 2002). The main objective of this measuring model is to identify any areas where a compromise of the components of Māori well-being models utilised in the services impacts on well-being. For instance, if *Taha Wairua* is affected, then the balance of the individual's well-being becomes compromised, reducing the ability of that individual to be well.

This methodological approach means that each item can be measured and understood with those whose *reo* skills are limited. The *Homai Te Waiora Ki Ahau* measurement tool applied comes from a Māori conceptual paradigm and therefore seeks a *kaupapa Māori* approach which is more appropriate when applying a Māori health framework. The *Homai Te Waiora Ki Ahau* measuring tool would be an appropriate tool in measuring the effectiveness of a disability service seeking

to meet the needs of Māori with disabilities and it is possible to go outside of the psychosocial paradigm to do this.

This theory, however, has to be tested in other areas around impairment and *kaupapa Māori* services for peoples with disabilities before there can be confirmation as to its effectiveness. The problem in relation to *whānau*, disability and well-being concepts is the lack of work so far that takes into account the construct of disability from within a Māori identity framework; while Māori health models are appropriate in measuring Māori well-being, they lack the inclusion factor when addressing the issues for Māori with disabilities. It is one thing to have the right terminologies and theories when trying to implement policy into practice; the reality of that implementation and results appear to be very different, thus demanding an investigation as to why Māori with disabilities are not achieving equity of health with non-Māori with disabilities. As identified earlier and discussed below, there are three main Māori health models utilised in services providing health and disability supports to Māori with disabilities.

6.3.1 *Te Whare Tapa Wha*

Te Whare Tapa Wha model, designed and outlined by Professor Mason Durie, is the most commonly cited model in Māori health and development policies. At a health *hui* in Palmerston North in 1982, Durie presented the *Whare Tapa Wha* model as a four-part framework resembling the four walls of a whare (house). This analogy was made to ensure strength and symmetry, thereby giving balance in the well-being of the individual and the community. The four dimensions are:

- Taha Wairua (the spiritual side),
- Taha Hinengaro (thoughts and feelings),
- Taha Tinana (the physical side); and,
- Taha Whanau (family) (Durie, 1994, p.70).

Te Taha Wairua is generally seen by Māori as the most important link for good health. *Wairua* provides a spiritual link to well-being and is seen as an interweaving construct with *whānau* and the environment. It is believed that, without a spiritual knowledge or awareness, one cannot be well and must

therefore be prone to illness. This spiritual belief is not necessarily linked to a formal church or religious order. It is a faith or belief in God or *Atua* which is a normal part of Māori identity. The *wairua* also links in with the environment and the ability to access historical, tribal lands important to one's identity and sense of well-being (Durie, 1994).

Te Taha Hinengaro focuses on the mind, encompassing expression and thoughts. Māori believe thoughts and feelings derive from within the individual. For Māori, health in relation to thoughts and feelings is interrelated with well-being. Everything is linked to the other. It is believed that illness, disability or disease is the result of a breakdown in the harmony of the individual and their environment, both through the physical compromise of well-being and a belief that there is a compromise. For example, if the environment is poisoned as in Taranaki with the dioxin issue, then no-one who is ill with the affects of dioxin exposure can achieve harmony or well-being until their environment has been restored to its previous state. This could be an issue where environmental influences are now impacting on the well-being of Māori. Conditions once rarely seen among Māori such as multiple sclerosis, are increasing and it could be because the environment since colonisation, along with industrialisation, has steadily poisoned New Zealanders. This is only a theory at this stage, although one that could be considered for further research. The saying *He taru tawhiti* (a thing from afar) is relevant to this issue and a reminder by *kaumātua* that diseases as known today did not exist prior to the exposure to European influences.

Thoughts and feelings for Māori are not about an emphasis on words; through the expression of feelings, an emphasis is placed. This difference of emphasis between words and emotions/feelings is often at odds with western thinking which values the concept of words over feelings. Māori do not make such a distinction. Māori generally prefer face-to-face (*kanohi ki te kanohi*) meetings where the visual gestures such as eye or facial movements add meaning to the words, rather than focusing on words alone and ignoring the visual effects. As Durie asserts, this explains why when Māori express feelings at *marae*, there is a lot of emphasis on the expressions of emotion with words, rather than on words alone (Durie, 1994). Emotional and physical expressions with weaponry, haka,

pukana or theatrical gesture, emphasise the message and can often, ironically, distort it as well. Such performances can vary from one iwi to another for example Tama Iti of Tuhoe compared to Scotty Morrison of Ngati Whakaue.

Te Taha Tinana (bodily health) is known in non-indigenous well-being models, although for Māori the emphasis is different in that there are certain bodily parts that are *tapu* or *noa*. The head is of particular importance and it is important to remember this when considering well-being of Māori, when in institutional care such as head injury rehabilitation centres, or in hospital undergoing even the most basic of treatments. Everyday functions such as eating, drinking, sleeping and defecating all have their own significance, requiring different rituals for maintaining an individual's well-ness (Durie, 1994). He further states that hospitalisation of Māori or the institutionalisation of severely disabled Māori are particular issues for Māori in relation to their well-being, as often the functions carried out for washing the body are done in the same room or space as feeding the individual. Food often removes *tapu* and induces *noa*; if this is ignored by carers, this becomes an issue that could invariably affect the well-being of Māori. It remains a contentious subject of discussion.

Health and body image are considered differently by Māori, which could explain the difficulties of having Māori change behaviours around lifestyle related-illnesses such as diabetes. *Whānau*, friends and clients who have diabetes-related impairments appear resigned to the illness factor of diabetes and the consequences of that diagnosis, and in many cases their behaviour towards diet and lifestyle may remain unchanged. It is imperative to consider how Māori view the body; obesity is not viewed as negatively as it is in society generally and slender bodies are not necessarily as valued as a well-rounded shape. Perhaps the prevention work is being targeted incorrectly. A successful campaign emphasising the impact of diabetes on people's children and grandchildren would provide a better attitudinal change than trying to target the individual themselves, as some Māori tend to not be persuaded through appealing to their own personal vanities (Durie, 1994). The face-to-face interviews also indicated a pattern where Māori tend to worry more about the well-being of their *whānau* and future generations than about their own well-being.

The fourth and final dimension of the *Te Whare Tapa Wha* model is *te taha whanau* which is about the family, including the extended family and its relationship with health. The family is central for the well-being of Māori, in that it is often the prime support system, not only physically but also culturally and emotionally. Not all Māori with disabilities have access to *whānau*. Until the early 1980s, Māori born with significant disabilities were often removed and placed into institutional care, perpetrating the stereotypes and myths around disability. This has become an issue for example in the transitioning of residents from Templeton institution which is now closing. The Ministry of Health is trying to place the 200 residents back into the community, but some families are not able or willing to take family members back (Human Rights Commission, 2005). In many cases, the parents have passed on, the resident is elderly and the siblings were not even aware of the existence of their brother or sister. Some relationships have been formed with family, some of which have ended in success, and some in failure. Some residents have no opportunity to ever be with family ever and are therefore being placed into community group homes. Templeton is just one example of a place or institutional facility replacing family or whanau for persons with disabilities in New Zealand.

While institutions are not as prevalent as they were prior to the move towards community care, persons with disabilities still experience a form of institutionalisation through community supports, funding allocations and community agencies with their own rules and regulations. Individuals with disabilities must comply with these rules if they wish to access services and supports from them. Māori with disabilities were as affected through institutionalisation as non-Māori with disabilities. In some cases, their impairment, no matter how small, was used to remove them from their families and to institutionalise them.⁵⁸ This institutionalisation, according to the participants, also created a fear and loathing within Māori around Māori with disabilities and it is this issue that still exists for the participants today, creating exclusion and isolation for Māori with disabilities. While younger Māori with disabilities are no longer taken away and placed into institutions, some informants suggest that the *whānau* member with the disability may still be blamed for any

imbalance or discomfort within the *whānau*. One young female participant (age 25) advised that she was constantly told she was the result of a *hara*⁵⁹ committed by a family member.

In discussion with other Māori with disabilities⁶⁰, it is common to find that the younger ones have often been taken in by their grandmothers and cared for. This has been despite opposition from *whānau*, due to existing negative attitudes towards disability generally⁶¹. The raising of the child with disabilities is consistent with some Māori attitudes towards children, in that parental rights are often secondary to the interests of the child. As times have changed so has *whāngai* concepts where it is no longer deemed as prevalent for grandparents to take on the role of caring for their grandchildren as much. So it could be construed that the grandmother takes on the parental role of the child in order to protect that child from any perceived misconceptions around their care, which is consistent for children if Māori *whānau* are allowed to proceed with *whāngai* arrangements which were common before colonisation. While *whāngai* is still prevalent in Māori communities, this practice has been affected by the Adoptions Act (1955) (AA) section 19 by which *whāngai* adoptions are not recognised as formal adoptions (see discussion further in this section). Some writers have reported that *Whāngai* and *whānau* concepts have undoubtedly been affected through legislation and policies around *whānau*. This may require further scrutiny (Ballard, 1994; Morris, 1994).

The other point in relation to *whānau* as primary supporters and carers of Māori *whānau* members with disabilities is that while this is seen as happening, disability support services do not formally recognise *whānau* as primary caregivers financially. If any care is given by *whānau* members, it is often voluntary, causing further fragmentation, poverty and inequality for *whānau* carers and their *whānau* with disabilities. This requires further investigation and interrogation of the available statistics on poverty and impairment. Māori Deaf are not allowed to use *whānau* for support with services, yet there are only two official tri-lingual interpreters in the whole of New Zealand so Māori Deaf are being denied their language through the New Zealand Sign Language which is in the English language and not in Maori. Māori Deaf are also unable to access their

language through the telephone relay service as it is only in English, even though Māori is an official language in New Zealand. Māori with disabilities and their relationship with their *whānau* is a complicated and contradictory relationship. On one hand, there is considerable *aroha* (love) and *awhi* (support) for a *whānau* member who has disabilities, and on the other hand, there is some ignorance or lack of understanding around many disability issues. Because of the lack of knowledge about resources available and a lack of resources which could provide culturally appropriate supports for Māori with disabilities and their *whānau*, gaps remain.

The second aspect of *Taha Whanau* is about identity and the sense of purpose. Māori see interdependency with *whānau* as the key to well-being for Māori. This is in opposition to the concept of independence being pushed by Western models for well-being and rights-based models for disabilities which is centred on individual human rights rather than collective human rights. There are often clashes with the cultural concept of interdependence, a concept which would suit Māori with disabilities well as independence often means isolation and exclusion. Interdependence on the other hand, encourages involvement and inclusion with *whānau*. Western models encourage independence through capitalism and individualism as the key to well-being, yet funding is individual and does not take into account broader needs such as *whanau* needs to support the individual with the impairment. For Maori with disabilities, independence is less desirable than interdependence which is about relationships within *whanau* units benefitting the *whanau* as a whole unit, not just the individual. The individual identity is linked in with the *whanau* characteristics and is an important feature even when negotiating disability needs with services and the individual *whanau* member with disabilities. ; ...*personal identity derives as much, if not more from family characteristics than from an occupation or place of residence* (Durie, 1994, p.73).

The *whānau* and tribal affiliations are given more relevance within *taha whānau* than qualifications and achievements. If individuals can link themselves to their *whānau* and are active within their *whānau* and tribal communities, they are more likely to be seen as having value, rather than value being given to their qualification and achievements as occurs in the non-Māori context. This is not to

dismiss one value over another as both carry their own inherent values benefitting for different reasons.

Integration is another theme Durie identified in the *Tapa Wha* model, in that individual health is dependent on the ability of the *whānau* to be well. This concept is not always clearly outlined in policy and is not clearly identified within disability policy. Although *whānau* are mentioned in policy, it is not as integrative or inclusive as would be considered by Māori for the well-being of the *whānau* member with disabilities.

6.3.2 *Te Wheke*

Another model of Māori health is the *Te Wheke* model which was discussed by Rangimarie Rose Pere at the Hui Whakaoranga in 1984. *Te Wheke* (the octopus) looks at Māori health mainly from a Māori family perspective. While this model relates to well-being within education, it is relevant to health and possibly disability well-being for Māori in that it is easily adaptable to the subject matter at hand. Each of the eight tentacles of the octopus contains a symbol of a particular dimension of health, with the body and head of the octopus symbolising the family unit. The tentacles attached to the head and body symbolise the inter-connection of each dimension as it relates to the family.

The different dimensions for well-being are:

- Wairuatanga (spirituality)
- Tinana (body)
- Hinengaro (mind)
- Whanaungatanga (family relationships)
- Mana Atua ake (ancestral link)
- Mauri (lifeforce)
- Whatumanawa (seat of emotions, heart, mind)
- Ha a koro ma a kuia ma (breath of life from forebears)

These eight dimensions can be described as having an interconnected relationship with the head and body which symbolises the family unit. Each dimension or tentacle is important in considering the well-being of the individual. The eyes of the octopus represent the *waiora* or well-being of the person, it is this, that can identify the state of the individual (Pere, 1985). Each tentacle has its own function or role within the octopus and, while each is independent, it is important to note the interdependence again with this model as with *Te Whare Tapa Wha*, in that each has an independent, yet connected, role to the *whānau* and the individual.

Wairuatanga is spirituality. Pere (1985) outlines *wairua* as denoting two waters, and the responses and feelings are important. The *wairua* addresses outside forces or forces beyond the physical realm of this world. To maintain good health, sustaining and nourishing one's spiritual well-being is important. This is not so much about religious belief, as about a spiritual identity Māori have always had and therefore it is not difficult for Māori to identify and understand spirituality from within their own perspective and upbringing (Pere, 1985). Māori spiritual concepts have undoubtedly been impacted through the introduction of Christianity, with aspects of those new beliefs affecting traditional beliefs and practices through the incorporation of Christian phrases in waiata such as in Whakaria Mai and in karakia where Christian prayer is often translated into Maori such as the Lords Prayer.

Tinana is the physical side/tentacle to the octopus. The concept of physical well-being is the same as *Te Whare Tapa Wha* model in that physical well-being is important to maintain good health. Catherine Love outlines tinana as the need to provide sustenance for the physical:

Aspects of this dimension include adequate nutrition, shelter, clothing, exercise, experience of physical contact, pleasure and pain. Maori society provides a number of avenues for physical expression of the spiritual, emotional and cognitive aspects of people within situations. Haka and waiata provide for the physical expression of a range of emotions, thoughts and desires. Karanga and whaikorero provide for the physical and verbal expression of *wairua*, acknowledgement of whakapapa connections, the pain of

losses, and the kaupapa that brings people together. In performing karanga and whaikorero, men and women are physically connected to, and stand between Papatuanuku and Ranginui. They stand on the earth that their ancestors stood on, breathe the air and view the skies their ancestors knew. Alternatively inside a whareniui, people are surrounded by physical representations of the ancestors and the history of the home people. The spirit of those who have gone on may be felt and acknowledged within the ancestral house. The house itself is often the embodiment of a tupuna, so people are symbolically contained within the body of the ancestor (Love, 2004, p. 61).

If these elements or practical applications supporting the physical body are interconnected spiritually and emotionally to the *whānau* and the environment, then Māori with disabilities are again disconnected as though the tentacle is not attached to them. Many persons with disabilities sense isolation and, as the participants in this research indicated, *whānau* did not cope and were often unable to meet the basic needs, thereby isolating whānau members with disabilities from their cultural activities and removing them from the everyday activities which are central to many Māori and to their well-being. The comments received around involvement with whānau were varied, with a lot of understanding as to the feelings behind *whānau* reactions to their impairments. One participant stated that:

They don't cope, they are angry I am so big (Male research participant).

Another interviewee described how, despite their fears towards amputations, whānau did try to understand and support their whānau member with impairments. They stated that:

We have had other whānau who have had parts cut off then die, they have their own fear but try (male research participant).

Another participant spoke of the isolation they experience from their whānau due to their having to live in an adapted home, and commented that:

They don't, I live in a special home (female research participant) .

A couple with both experience psychosocial conditions commented on how they cope with each other's condition when one becomes unwell and how the wife's mother keeps any of the issues to herself without sharing any concerns with other *whānau* members. The participant stated that:

My husband has Bi-polar Disorder too and he does cope when I get mentally unwell and I run things around the house. He does his best. Last time he got Psychiatric Emergency out to give me an assessment. By that time I needed to go into hospital. He makes noises about me taking on too much work that is backed up by my caseworkers. I do listen but I still want to take on the world. The rest of them, my Mum, etc, just leave things to him. They are elderly and can't handle the problems. My mother doesn't pass information to other members of my family but it more about what I am doing than my disability. For a long time she thought my mental illness was behavioural and could be fixed (female research participant, married couple).

Not all participants reported negative responses from *whānau*, although those who did report support commented that the *whānau* often did not understand, although their *whānau* members with disabilities is important to them, and they did all they could despite often inadequate funding or support services to keep their *whanaunga* as well as they could. Some of the participants commented that their *whānau* members would:

Make me comfortable and just give love & support when I have health problems (e.g. run baths, clean up my mess, read me my lectures notes or books, talk to me when I am not feeling good, make sure I take medication, go and buy the necessary personal items on demand, tell the doctors how bad my condition is for the month, miri miri my arms, hands & feet, don't allow me to carry heavy items) (female participant).

Participants also noted it was not always physical needs that were met by *whānau*, but also emotional support by being there to listen to or support in other ways they can. Two participants noted:

Alright, if I need someone I phone and they come and sit with me 4/5 hours (female participant).

and

They realize I have an illness and try to support me as much as possible (male participant).

I have a supportive sister. The rest are unsure but try to help by asking sister to explain things (female participant).

Participants also noted that while the *whānau* would try and support, it was also frustrating at times as it would often be misdirected or misunderstood support. One participant put it succinctly by stating that it was.

Ok, but sometimes frustrating (Participant survey feedback)

What is particularly striking about the participants' responses was that, although they had the love and support to be expected with Māori where *whānau* step in and do what they can, this support was not consistent for many or even in evidence for some. This support is considered informal and therefore not valued or given any financial consideration, despite the *whānau* member in some cases being a full-time care provider. The support was dependent on the financial well-being of those providing support, often becoming the cause of the frustrations and inadequacy of support. This lack of formal recognition of *whānau* support is not specific to Māori as all persons with disabilities face this problem when seeking primary support from *whānau* members. What differs for Māori with disabilities and their *whānau* is they clearly identify *whānau* as central to their well-being, whereas other persons with disabilities identify as living with impairments as their priority (see chapter two on identity).

Hinengaro is the emotional or feelings tentacle within this model and is also described as the mind. Durie's *Tapa Wha* identifies emotion and feelings along with verbal expressions as all interrelated, so that one cannot function properly without the other. Love (2004) describes Pere's *hinengaro* concept in this way:

The literal meaning of *hinengaro* is the hidden lady or female element. The term is commonly understood as referring to the mind, intuition and source of

thoughts, perceptions and some emotions. Pere (1988, 1991) associates this dimension with cognitive activities, lighter level emotion and intuition (Love; 2004, p.67).

The female element of *hinengaro* outlines the private nature of the mind and how it is intrusive to delve into that mind. This could explain why indirect questioning and the indirect way of expressing feelings and expressions are so prevalent among Māori. When I conducted the *kanohi ki te kanohi* (face-to-face) interviews, the *kaumātua* in particular were very indirect in their responses, yet the answers came as they were allowed the freedom to answer in their own way. The answers in the end were of more value, as what they shared came in the form of stories, which provided added value to the results. This is different to the Western thinking around communication which often requires direct response. This difference can often lead to misunderstanding of the answers, thinking and attitudes around impairment, particularly within psychosocial services. It is also important to note the *tapu* nature of the head where the mind is based. This *tapu* nature of the mind adds to the concept of why one needs to proceed carefully with Māori when addressing issues of the mind. Any intrusion into the mind could conceivably affect the well-being of the individual (Love, 2004; Pere, 1985; Durie, 1994).

Whanaungatanga is the tentacle that describes *whānau*, particularly the extended *whānau* and their relationship to the individual. Pere outlines *whanaungatanga* as:

...based on ancestral, historical, traditional and spiritual ties. It forms that strong bond that influences the way one lives and reacts to his/her kinship group, and Maori people generally. It is the area where one's aroha (the concept of giving, caring, sharing) is tested to the fullest extent. It is an area that poses many challenges for an individual who has to live in and out of two worlds. – one that is basically Polynesian and one that is basically Western. Whatever affects the kinship group, whether it be positive or negative, affects the individual, there are certain inbuilt obligations that the individual feels towards the group (Pere, 1985, p. 12).

Durie's *Tapa Wha* outlines whānau in a similar way; there is an interconnectedness or, as Durie puts it, interdependence between the individual and the *whānau*. The sense for Māori with disabilities in both *Te Whare Tapa Wha* and *Te Wheke* is the interconnectedness and the interdependency. Western models (such as the social model) emphasise the individual with disabilities and their independence. Interdependence is not such a western construct whereas, for Māori with disabilities, it is a normal process of working with *whānau*. Unfortunately, the fragmentation and dysfunction of *whānau*, as discussed in Durie (1988), is an issue for Māori with disabilities. As stated earlier, many were removed from *whānau* which those who were raised by their *whānau* experienced tension within the *whānau*.⁶² Some Māori with disabilities were removed as babies and adopted by non-Māori as *whāngai* adoptions were specifically not allowed in the Adoption Act 1955, s 19 and so the breakdown of *whānau* and *whanaungatanga* were being legally assisted.

19. Adoptions according to Maori custom not operative—

(1) No person shall hereafter be capable or be deemed at any time since the commencement of the Native Land Act 1909 to have been capable of adopting any child in accordance with Maori custom, and, except as provided in subsection (2) of this section, no adoption in accordance with Maori custom shall be of any force or effect, whether in respect of intestate succession to Maori land or otherwise.

(2) Any adoption in accordance with Maori custom that was made and registered in the Maori Land Court before the 31st day of March 1910 (being the date of the commencement of the Native Land Act 1909), shall during its subsistence be deemed to have and to have had the same force and effect as if it had been lawfully made by an adoption order under Part 9 of the Native Land Act 1909. (Adoption act (1955) s 19)

If this is the case, then that *whānau* well-being is compromised as the law worked to reduce the strength of *whānau* concepts as understood and implemented by Māori. It is encouraging to note that, while procedures and policies were put into place to remove *whāngai* as a formal means of care of children by extended

whānau, it was never eradicated with urban migration in the 1960s, and children with disabilities often remained in the country with relatives, usually grandparents. This removal of customary adoptions began further back in colonial legislation and, although not explicit, the assimilation and removal of Māori children did begin before the 1955 legislation through the Native Land Act 1873. Griffiths comments that:

Into this remarkably fluid arrangement, Western adoptions laws were introduced. It was a totally alien concept, contrary to the laws of nature in Māori eyes for it assumed that the reality of lineage could be expunged, and birth and parental rights irrevocably traded. At first Māori customary placements were recognised in law, but then wrongly equated with adoption. From 1901 it was required that they be registered to have status (Griffith; 1996, p.453).

Some of the Māori children with disabilities who could not be adopted were either fostered or placed in such institutions as Kimberley, Kingseat or Tokanui. Such institutions identified these children as having disabilities, with many Deaf reporting they were institutionalised and often treated as having a psychiatric condition; they report abuse by staff and a denial of the basics of care and attention all that children require to thrive well.⁶³ If Māori had had self-determination and complete control of their *whānau* well-being, much of this would not have happened. It can be argued that *whānau* and *whanaungatanga* are concepts impacted upon by the colonial laws and policies which broke down *whānau* as a concept, so breaking down or reducing the ability for well-being of Māori *whānau*.

Mana Atua ake, or ***Mana***, as Pere (1985, 1988, 1991) notes, can be described as having a link through the ancestral lines, through being gifted, or through the work done for their own people in their own ways and recognised by that group. Most Māori who do the work for their people do so humbly and without expectation of reward. *Mana* is also enforced with a strong identity within both the individual and throughout the group that individual identifies with such as their *iwi*, *hapū* and *whānau*. *Mana* is a difficult concept to define in English as to

define it as status is not completely accurate. *Mana* is about prestige and authority: Ngahaia Te Awekotuku defines *mana* in this manner:

Mana, like *tapu* is a pan-Pacific concept. It has layers and levels of meaning: primarily, it is about power and empowerment, about authority and the right to authorise. Charisma, personal force, social status, princely charm, leadership inherited or achieved are all forms of *mana*; it is a subjective human quality, measured by various means. Two of the most important were *mana whenua* and *mana tangata*...[which] reflects the importance of people, of the complex social and political relationships that secure a community's alliances and effective leadership; a successful chief would embody *mana tangata*. (Starzecka, 1996, p.27)

A lot of grassroots work undertaken by Māori is unpaid employment, often with an impairment of some nature, and yet their *mahi* or work is seldom valued or identified by society in general as the work is not seen as having a value, such is the nature of various voluntary endeavours by individuals. They do this work to keep themselves occupied, to meet the shortage of certain skills or needs within the community (ironically these same needs and skills are often not valued by society providing paid employment opportunities for persons with disabilities) and too often take on the role that disability services have failed or refuse to fill. This is particularly common with Deaf Māori whose children, siblings and parents often undertake the role of interpreter because the Deaf Association either cannot financially or physically, through a shortage of interpreters, meet the *whānau's* need. This work of interpreting is not given any financial value but it is an essential form of communication for Deaf who have no ability for independence without it.⁶⁴

Atua is the higher being, God or deity, depending on our beliefs. *Mana Atua* is the spiritual element of *mana*, which places the *mana* at a higher level than standing in its own right. *Ako* means to teach or to learn. Pere considered this tentacle with the emphasis on education; this could be extended slightly to include the education of Māori about persons with disabilities issues which is not something that is happening, at any depth within our community.

Mauri, the essence or life force, is another tentacle identified by Pere as essential to well-being for Māori. In her 1985 writings, Pere asked the question whether we consider the *mauri* of other living things, whether we respect, appreciate or care about our environment and the impact we have on other living things. In looking at environmental determinants as an example, in the case of dioxin, the Government is aware of its effects, yet still refuses to provide the tests or acknowledge fully those of us affected by this exposure. Our environment was damaged, affecting the well-being of our environment, mainly our *whenua* and our own life force. Everything we eat affects us if it comes from that *whenua* and the air we breathe; the animals we eat who have also been exposed, and our following generations may also face the effects of this poison we have had placed in us through no fault of our own.

Whatumanawa is the tentacle that refers to one's emotional side, the need to experience and to express fully, emotions. Grief, joy, anger and jealousy need to be fully expressed and this is often in conflict with the repressive nature of Western colonisation that does not, even today, encourage or support the full expression of one's emotions. There are a number of means by which emotion/feelings are fully expressed, for example, through such media as *haka* and *waiata tangi*. Any emotion that is fully expressed from the heart has more value than mere expression; it is the linking to the heart-felt emotions that gives the deep understanding of the concept of *whatumanawa*. For Māori with disabilities, where some impairments involve emotion, it is often difficult to express fully heart-felt emotions without being medicated or accused of being unwell.

Sometimes persons with disabilities are not 'expected' to behave in what is considered an 'appropriate' manner, which makes it difficult to achieve social integration into society. The same could be said for how society views Māori expressions of emotions. '*Ha a koro ma a kuia ma*' is literally translated to mean 'the breath of life from forebears', which is the final tentacle in Pere's *Te Wheke* model. This concept is about the continuity between the individual, the *whānau* and *hapū* or extended *whānau* living now and their relationship with those who

have gone before. There is no separation between those living and those who have passed on. It is often through society's ill-conceived disdain at Māori continual reference to past issues considered by some to have no relevance to the present time. For Māori there is no separation of the past and the present, making the past issues as relevant to today as it was in the past. This is not always possible for Māori with disabilities as access to our *whenua*, our *urupā* (gravesites) or to our community is not always possible because of barriers such as lack of ramps or refusal to allow guide *kurī* (guide-dog)⁶⁵ onto some *marae*. For Māori with disabilities, the ability to even access that continuity of relationship with the forebears, along with the living relationships, is often impeded by all of societies' lack of acknowledgement of this relationship Māori like to have with their past and present *whānau*.

A review of Pere's model, shows where the eight tentacles all have a role in the wellness of Māori with disabilities; it is apparent that these tentacles are often severed by non-Māori with disabilities and non-Māori generally who deny aspects of well-being for Māori with disabilities simply through denying them access to their *whānau*, *whenua*, *reo* and other elements that make up their identity as Māori. Both *Te Wheke* and *Te Whare Tapa Wha* contain elements of *whānau* and environment which are also key parts of Māori disability well-being.

6.3.3 *Nga Pou Mana*

In 1988 the Royal Commission on Social Policy described another set of values and beliefs – four supports, *Nga Pou Mana*, as pre-requisites for health and well-being. *Nga Pou Mana* is also a model which has interacting dimensions as its key to well-being. This model concentrates on the dimensions of *mana*, cultural integrity, a sound economic base and a sense of confidence and continuity. This model has a greater emphasis on the external environment and the significance of oral tradition as the stabilizing influence. Originally, *Nga Pou Mana* was to examine the foundations for social policies and social well-being. It is still able to have significance for health as it outlines four supports for social well-being:

- family (*whanaungatanga*)

- cultural heritage (*taonga tuku iho*)
- the physical presence (*te ao turoa*) and,
- an indisputable land base (*tūrangawaewae*)

The emphasis on environment is thought to have been influenced by the Waitangi Tribunal's decisions regarding claims around pollution of tribal waterways. These claims recognised that a clean environment is important for well-being (The Royal Commission, 1988). Given the issue already mentioned around dioxin exposure through spraying of land in the 1960s along with the manufacturing of the product 245T up until 1985 in Taranaki. It is a significant issue in that Māori being largely rural and working in factory environments, may have been exposed to such poisons. It makes sense that Māori could have been seriously affected by exposure to such chemical pollutants in the environment. As previously mentioned, there appear to be few studies looking at whether introduced chemicals have affected Māori physiology in any way. Human waste into the *moana* (ocean) and *awa* (river) is also an issue for many Māori and, while this practice has reduced, it has not been stopped completely around the country, still polluting and affecting the environment from whence Māori get their food. The Waikato River is an example of a polluted river (often from fall out from farms and factories adjacent to the river) and of a river that is also central to an *iwi* (*Tainui*). If the river is unhealthy then it makes sense the people who have a close affinity to that river are also likely to be unhealthy⁶⁶.

6.3.4 Comparing the Māori Models

The easiest way to compare *Te Whare Tapa Wha*, *Te Wheke* and *Nga Pou Mana* is through Table 15 (Durie, 1994, p.77):

Table 15: Māori health perspectives – three models

	<i>Whare Tapa Wha</i>	<i>Te Wheke</i>	<i>Nga Pou Mana</i>
Components	<i>Wairua</i> <i>Hinengaro</i> <i>Tinana</i> <i>Whanau</i>	<i>Wairuatanga</i> <i>Hinengaro</i> <i>Tinana</i> <i>Whanaungatanga</i> <i>Mana ake</i> <i>Mauri</i> <i>He a koro ma a kui ma</i>	<i>Whanaungatanga</i> <i>Taonga tuku iho</i> <i>Te ao turoa</i> <i>Turangawaewae</i>
Features	Spirituality Mental Health Physical Family	Spirituality Mental Health Physical Family Uniqueness Vitality Cultural Heritage Emotions	Family Cultural heritage Environment Land base
Symbolism	A strong house	The octopus	Supporting structures

As previously stated, no models specifically address the well-being of Māori with disabilities. Although the existing models can fit into the framework some of their structures could clash with the social model of disability preferred by the current Government in developing policy for persons with disabilities in New Zealand. To understand these possible clashes, its relevant to note that there appears to be an monocultural approach to disability in policy, and this further compounds the issues for Māori with disabilities. In saying this it is important to break down the social model and also look at an alternative model through concepts already published, such as the psycho-social multi-ethnic validity model first mooted by Forrest B. Tyler. The next section looks at these two models and then compares these with the Māori well-being models in the hope of identifying some commonalities to pursue for the well-being of Māori with disabilities.

6.4 Other Models/Frameworks

6.4.1 Psychosocial Transcultural Ethnic Validity Framework

Tyler (1996, p. 26) argued that:

Using scientifically based models and methods is a powerful way of figuring out the generality of psychological laws and of individual and cultural beliefs, and the significance of historical events. It can also identify the value bases and empirical strengths and limitations of alternative approaches to human endeavours....In basic areas, phenomena have been studied apart from their history or context, or both, in controlled laboratory settings. This approach has been considered to provide unbiased value free, and therefore more legitimate, truths. In contrast, psychologists in applied areas have explicitly and directly been concerned with the value (however measured) of specific effects and, even more directly, with accepting responsibility for producing those efforts. Until recently, both frameworks assumed that people's lives developed within a universal, homogenous context and an evolutionary perspective with regard to sociocultural and individual differences.

The models that have been developed around disability appear homogenous in nature, which is the reason why they still fail to meet the needs of persons with disabilities who fit outside the realm of the 'mainstream' or the majority the model is designed for. Those who are within what is considered a minority identity, or several minority identities, struggle to have their needs met in these models and this is because the identity as persons with disabilities is viewed within a universal, homogenous context. Anything outside of that context cannot be dealt with in the frameworks designed to address disability. Tyler's ethnic validity framework offers a solution to the problem of ethnic identity being ignored in disability models. Durie (1995) argued that Māori are diverse in their identities and there is no one reality or single definition that encompasses the range of Māori lifestyles. Durie also notes that while Māori realities are diverse, there are some common factors such as the socio-economic factors and urbanization which have had a direct impact on Māori well-being (Durie, 1995). It is this Māori diverse reality that Māori disability identity can fit into, where the commonality of

the experience of lower socio-economic status exists. It is also the reality that Māori women with disabilities often face the ‘triple jeopardy’ effect where, as Māori, they face disparities and as women they confront the inequality that still exists for women of colour in society. Finally, as disability, which is a part of their identities is not being met by the current models of disabilities, they face greater disparities than those who do not experience the multiple marginalisations that this group experiences. Durie (1995) found that:

Far from being homogenous Maori individuals have a variety of cultural characteristics and live in a number of cultural and socio-economic realities. The relevance of so-called traditional values is not the same for all Maori, nor can it be assumed that all Maori will wish to define their ethnic identity according to classical constructs. They may or may not enjoy active links with hapu or iwi, or other Maori institutions yet they will describe themselves as Maori and will reject any notion they are “less Maori” than their peers (Durie, 1995, p.15).

Durie’s Māori diverse realities framework appears similar to Forrest B. Tyler’s multi ethnic framework which helps to address the issue of variants within identity. The multi-ethnic framework further supports the Māori models of well-being in that it addresses the issues of the ecological components of multi-ethnic well-being as social, physical, personal and environmental (Tyler, 1996). This is similar to the *Nga Pou Mana* model which identifies the environment as interconnecting with *whānau*, the physical and the social networks for Māori to achieve well-being. These models do not appear to be incorporated in the social model of disability which is the framework behind the New Zealand Disability Strategy (2001). Tyler’s model also allows for those from ethnic diverse realities to define for themselves their needs and what constitutes well-being, which is consistent with Durie’s discussion on Māori diverse realities where Māori are diverse and unique as individuals as well as within the *whānau* and their environment.

6.4.2 Shifting Paradigms from the Medical to the Social to a Multi-ethnic Model of Disability

The experience of physical impairment is similarly constructed [within different cultural groups], as indeed is its incidence, which varies across societies and also within societies according to class, race, gender, occupation and geographical location. An individual's experience of a particular impairment must be placed within its social context. For instance, the actual course of a condition such as multiple sclerosis will be influenced by socio-economic factors, and the experience of associated impairments, for example loss of mobility or sight, will depend on factors such as an individual's economic resources and available services, all of which interact with other social constructs (class, race and gender in particular) (Swain et al, 1993, p.86).

6.4.3 Social and Medical Models of Disability: A Western Perspective?

From the nine identified models of disability emerge four themes that have historically influenced western policy around disability within western society. Such models as the moral/charity/religious, medical/expert/professional model and rehabilitation/social adapted model are the four themed models responsible for the objectifying of persons with disabilities in law and policy through stigmatising and medicalising disability and not viewing it as a social issue.

In the thousands of years of human existence before 1800, life for most exceptional people appears to have been a series of unmitigated hardships. The great majority of disabled persons had no occupation, no source of income, limited social interaction and little religious comfort. Conspicuously abnormal persons were subjected to superstition, myth and fatalism-especially fatalism. Their lives were seriously limited by widely held beliefs and superstitions that justified the pervasive prejudice and callous treatment (Davis, 1997, p.76).

The medical and social models are the two models currently in use in New Zealand. Although the medical model officially is not encouraged by the Ministry of Disabilities Issues, it is still utilised in that impairment is still medicalised when incorporating services for persons with disabilities.⁶⁷ As the medical and social models are the two most commonly applied models for disability policy in New Zealand, these are the focus for discussion within the context of Māori disability identity.

6.4.3.1 The Medical Model

Criticism of the medical model has led to changes, and there are increasing signs that services are moving away from medical control provided by the health service to social and welfare interventions provided in community services. The problem is, however, that this shift does not necessarily result in disabled people having greater control of their lives. On the contrary, community-based service providers generally have a wider perspective than their medical colleagues in identifying areas of disabled people's lives for their professional assessments and interventions. This may leave very little for disabled people to do without feeling that an expert is waiting in the background to intervene. In this respect experts are often encouraged to see the lives of disabled people in terms of problems to be solved and their role as providing solutions (Swain et al, 1993, p.15).

Disability was medicalised when the industrialisation of society created the 'problem' of where persons with disabilities were going to 'fit' once society no longer accommodated disability within the group or community structure of employment where cottage industries were, in the main, easily accommodating of disability (Oliver, 1990; Corker & Shakespeare, 2002; Garland-Thompson, 2004). Disability within this new society was suddenly viewed as a 'problem' so that 'labelling' and categorising of people became a normal process and the onus of the disability was placed on the individual and not on society as an issue. Doctors gained control of persons with disabilities; the concept of impairment as a sickness or disease was the norm whereby the individual was unable to achieve in

society. Segregation and institutionalisation of persons with disabilities were preferred to pertaining them within their home and community. Gooding describes the medicalisation of disability as a form of medical control over a group, specialising in removing their control and identity over their own bodies and lives.

The medicalisation of social ‘problems’ as a form of control has been powerfully analysed by writers such as Foucault and Illich. By ‘medicalisation’ I mean the perception that disability is first and foremost a problem of individuals, with the corresponding power that gives to the medical profession over disabled people’s lives. Whilst medical intervention can be entirely appropriate, for example in the treatment of a medical condition or the diagnosis of an impairment, it undoubtedly extends to a ridiculous degree....The medical profession came to hold great power over disabled people’s lives, both within institutions and outside them, through their function as gate-keepers of the welfare state (Gooding, 1994, p.18).

In New Zealand, if a person with a disability is deemed to be ‘unfit’ for work, they are entitled to apply for an “invalid’s’ benefit”. It is this language that further stigmatises and stereotypes persons with disabilities within the medical model (otherwise known as the ‘deficit’ model) of disability. If persons with disabilities are unable to be productive citizens, they are deemed ‘unfit’. If they wish to receive this benefit, they must submit to the medical scrutiny of a government-approved doctor. They are then able to receive a benefit that allows exemption from compulsory work requirements of many other benefits. Persons with disabilities are also forced to rely on the charity of organisations, the Government and individuals for their basic needs to be met. This has not significantly changed up to the present, despite the New Zealand Disability Strategy being implemented by the Government in 2001.

Ever since the days of the Poor Law, these two principles of social policy have been to some extent separate: a division has existed between those ‘outside’ the economic system, to whom only charity is owed, and those who are economically active and potentially viable, whom society must help in its own interest and as a matter of social justice (Blaxter, 1976, p. 2).

The New Zealand Disability Strategy (2001) which advocates the social model of disability has been in place for five years. However, to qualify for a welfare benefit, as mentioned earlier, a person with disabilities has to qualify using the medicalisation process of assessment and identification of their impairments. This medicalised process is not consistent with the social model of disability. Despite the social model being promoted for implementation of policy in New Zealand, society still has issues to address around how disability is perceived, as the medicalisation of persons with disabilities is still the dominant mindset within our community. This is evidenced by the public ongoing protests against new homes being set up in the community for people with intellectual and/or psychosocial impairments. Society still suffers from the 'NIMBY'⁶⁸ attitude when such supports are being set up within a local community. Access to disability equipment and supports is still often through doctors or other medical professionals, and the terminology has not changed significantly, despite international discourse in the language of disability having called for change for over 30 years. One example of this call for change is through a model known as the social model of disability (Swain et al, 2003).

6.4.3.2 The Social Model

The distinction between impairment and disability lies at the heart of the social model. It is this distinction that separates British disability rights and disability studies from the wider family of social-contextual approaches to disability –impairment is defined in individual and biological terms. Disability is defined as a social creation. Disability is what makes impairment a problem. For social modellers, social barriers and social oppression constitute disability, and this is the area where research, analysis, campaigning and change must occur. (Shakespeare, 2006, p.34)

Since the 1970s the disability movement in the USA and Britain, in particular, called for a change away from the medicalisation of disability to viewing this as an issue for society (UPIAS, 1976). In the 1980s Finkelstein began

to question the medical/deficit model of disability as a theoretical framework, arguing for a social discourse. Oliver (1993) took the work of Finkelstein and others in the disability discourse of the time and developed from these a social model framework still being implemented globally. For example, the New Zealand Disability Strategy (2001), recommending this model for its policy framework for disability in New Zealand as recently as 2001. Oliver's social model of disability is one which separates the experience or liability of impairment from the individual and instead places the onus of responsibility of access onto society (Oliver, 1996). The issue here is which societal model should be applied? The western and non-western constructs around rights within society differ greatly from each other. I believe Oliver's social model to be based on the premise of a westernised and individual rights-based society which is not the reality for some within different cultural paradigms. Where gender differentials still exist, for example, can society be expected to reflect the same changes as Oliver's social model framework reflects? Or do we seek to construct an appropriate culturally-based framework which addresses disability issues from within the cultural paradigm? The social model infers one dismissal of cultural and collective identity, privileging instead a western construct of individual rights.

Among the problems faced by disabled women is that they have not yet been integrated fully into either the disability movement or the women's movement. Even ardent campaigners for disabled people's rights are not always alive to gender issues. In the Middle East, for example, while general literature on disability in the region abounds, disabled women remain strangely invisible (Dambrough cited in Hans & Patri, 2003, p.158).

Hans and Patri (2003) raise a valid point in relation to cultural and gender identities along with disabilities, in that women and culture are strangely invisible as evidenced by many of the issues raised during the debate outlined in chapter three around diversity recognition in the CRPD.

Oliver's social model definition of disability contains three main elements: the presence of an impairment; the experience of externally imposed restrictions; and, self-identification as a disabled person (Oliver, 1996). Oliver used the term

‘disabled person’ as opposed to the term ‘person with a disability’, as he argued that language has an important role to play in determining one’s place within society and one’s own community. The issue here is with the terminology used around disability (describing Māori with disabilities/disabled Māori) which is discussed in chapter two on identity and language used among indigenous peoples as opposed to accepting the western notion and language of disability. Non-western discourse on disability is still emerging and it is difficult to find anything from a Māori or Pacific peoples’ perspective that outlines disability identity within these frameworks.

In the Western world, disability activism has led to an emergent field of disability studies, which is venturing to create theories that conceptualise disabled and non-disabled people as central, harmonizing parts of the whole universe (Ghai, cited in Corker & Shakespeare, 2002, p.95).

Colonised indigenous have long faced disparities greater than their non-indigenous counterparts within society. The issue of impairment as a distinct identity as previously established in earlier chapters, disability identity is a modern, and recently developed phenomenon and did not exist as a ‘problem’ until colonisation because disability as an identity construction did not exist. Introduced diseases made a great impact on the well-being of indigenous identity and created a new separate identity known today as disability. In the same manner as Māori, Native Americans also claim good health prior to their colonisation which has since left a life expectancy differential of around 28 years between the Native American and the non-indigenous North American citizen. This, they believe is a direct consequence of colonisation as impairment (while not defined or identified as such as an identity) existed among all communities, including indigenous, with no exception. In the same way as Māori with disabilities have come to believe, disability is not the primary focus for achieving well-being, but the issues that create disparities and impact on well-being which are the same today as they were when colonisation first impacted on indigenous peoples lives. Archambault (2001) identified this issue in the following quote:

Indian health was remarkable to early pioneers and chroniclers. Early Colonial sources testify to the extraordinary well-being and cleanliness among Native Americans, called 'savages' in the early period of continental USA. By the end of the 18th century it had notably diminished from its pre-Columbian wholeness (Archambault, cited in Marshall, 2001, p.4).

Within New Zealand's policy development, while the NZDS does incorporate the social model of disability, and identifies differences of equality/inequality within the disability sector for such groups as women, children, Māori and Pacific peoples, little has changed for these groups other than a theoretical recognition of their disparities with 'other' persons with disabilities within their communities.

In developing policy for Māori with disabilities, there is an assumption of homogeneity with no discussion around attitudes of Māori towards Māori with disabilities. There is also little attitudinal education of Māori towards disability and there is no discussion about the attitudes of Māori towards Māori with disabilities. It is this dearth of information that motivated the writing of this thesis. Durie's Māori diverse realities discussion does not include the broader identity of disability other than to mention impairment as a result of disease or illness. The notion of diverse realities for Māori with disabilities is important for breaking down the assumption of homogeneity of disability and of Māori identity which is discussed in chapter two. This homogenous approach in disability policy appears consistent with other contemporary political phenomena for example in the feminist movement in the 1970s all women were assumed to be of one identity and were later found, through the breaking down of feminist ideologies, to be as diverse as the rest of society. This was also the same for people of colour who, through civil rights actions, also showed the diverse realities from within.

Some of the difficulties for persons with disabilities stem from the argument by some for disability to be seen as a distinct cultural identity. Deaf have led a strong campaign for this as they base their cultural identity on being of a distinct linguistic minority whose language and culture is threatened by the implementation of the cochlear implant; implantation is seen by some as a colonial-type invasion of their identity as Deaf. Where society sees an

impairment, many with disabilities and, in particular, Deaf, see a cultural identity with its own beliefs, language, and structure defining it as a culture in its own right. Charlton positions this clearly below:

The modern world is composed of thousands of cultures, each with its own ways of thinking about other people, nature, family and community, social phenomena, and so on. Culture is sustained through customs, rituals, mythology, signs and symbols, and institutions such as religion and the mass media. Each of these informs the beliefs and attitudes that contribute to disability oppression. These attitudes are almost universally pejorative. They hold that people with disabilities are pitiful and that disability itself is abnormal. This is one of the social norms used to separate people with disabilities through classification systems that encompass education, housing, transportation, health care and family life (Charlton, 2000, p.25).

6.5 Shifting the Paradigm: A comparison of the Māori health models with the medical and social model of disability. Where do Māori with disabilities fit within their frameworks, if at all?

The meaning of impairment is a cultural issue, related to values and attitudes of the wider society. The visibility and salience of impairment depends on the expectations and arrangements in a particular society: For example, dyslexia may not be a problem until society demands literacy of its citizens. (Shakespeare, 2006, p. 35)

In 2001 the NZDS was created, introducing the social model into disability policy. This includes applying the social model of disability to Māori disability issues and it is within this context that I discuss its relevance, given that Māori health models were well recognised prior to the introduction of the social model. The social model of disability recognises society's attitudinal barriers towards disability; however, it does not address cultural specificity around impairment and, without this, it is difficult for Māori with disabilities to achieve full inclusion in their own community and society in general.

Is the social model of disability suitable for looking at certain groups within the community, given their existing marginalised status within society without disability as an identity? While the social model is being promoted within the policy development around disability, the issues for Māori with disabilities and the growing gaps they experience remain unresolved. For Māori with disabilities, the NZDS identified 7 actions to encourage the inclusion of this group into society. These actions are outlined below:

11.1 Build the capacity of disabled Māori through the equitable allocation of resources within the context of Māori development frameworks.

11.2 Establish more disability support services designed and provided by Māori for Māori.

11.3 Ensure mainstream providers of disability services are accessible to and culturally appropriate for disabled Māori and their whānau.

11.4 Train more Māori disability service provider professionals and increase the advisory capacity of Māori.

11.5 Ensure that Government funded or sponsored marae-based initiatives meet the access requirements of disabled people (and encourage all other marae-based initiatives to also meet those requirements).

11.6 Support training and development of trilingual interpreters for Deaf people.

11.7 Ensure Te Puni Kōkiri undertakes a leadership role in promoting the participation of disabled Māori (Minister for Disabilities Issues, 2001, p.28).

Language is an important consideration when reviewing these actions. If the objective of the social model is for the empowerment of persons with disabilities, then these actions do not provide the key to empowerment for Māori with disabilities as they discuss empowering Māori as the key to including Māori with disabilities into society. While Māori are encouraged to provide services for Māori with disabilities, nowhere is there the action that would encourage leadership development of Māori with disabilities, the expertise of the lived experiences of this group and their consultation to advise and educate Māori provider services on what their needs are and how to provide those needs. While 11.7 does talk of TPK providing leadership development of Maori with disabilities, to date, there has been no evidence available to the Maori disability community.

How can the capacity of Māori with disabilities be developed within Māori development frameworks if they are not brought into all of the developmental processes in a culturally appropriate manner? the professional/expertise model is being applied here and not the social model of disability, as claimed in the document. Have Māori with disabilities been identified and brought together, and where is their representation within *iwi*, *hapū* and *whānau* lines? It is argued that this is not the case. The decision by the Ministry of Disabilities Issues and the Office of Disabilities Issues (hereafter abbreviated as ODI) to elect *Ngati Kapo* (Blind Māori Association) to the role of the Māori representative group to the National Advisory Council without any consultation with broader Māori disability individuals and networks, for example, raises the issues of who speaks for whom on Māori disability issues, who is consulted and who makes these decisions.

The difficulty for Māori with disabilities is the lack of information going to Māori disability groups outside of *Ngati Kapo* which is an advocacy group for Maori who identify as blind or visually impaired. No system has been put in place to open up the opportunity for consultation and feedback, which makes this position relevant only to the group it represents and irrelevant to those wider Māori disability groups who are not included in the loop. There are concerns as to the process for this position. Given that the Māori models of well-being all identify *whānau*, *iwi* and *hapū* as the central core of Māori well-being, this decision-making process by the Government networks is contradictory to Action 11.2 of

the NZDS which identifies Māori development frameworks as the vehicle for the delivery of services to Māori with disabilities. Given the mandate given to TPK to take leadership of Objective 11 of the NZDS, it is better to apply action 11.7 of the NZDS and at least ensure Te Puni Kōkiri develops an appointments process and take on a leadership role, as outlined in this action. In this role, TPK would begin negotiating with Māori with disabilities as to how decisions are made affecting their lives and their representation on national and international networks. While the preference is for Māori with disabilities to manage their own leadership, as no Māori disability advocacy group outside of Ngati Kapo currently exists, then it falls on the mandated authority to begin the process with a view to handing this work over to the consumer and not the provider. The ODI role in deciding who represents Māori on their advisory team very strongly steeped in the colonial paternalism still evident in many aspects of service provision for Māori with disabilities because of the lack of consultation with Māori consumers with disabilities and their iwi, hapu, whanau. Not only are the decisions removed from users, but control over decisions is not even given to Māori with disabilities.

The current initiatives are far from reaching the goal of having Māori with disabilities at the decision-making centre of their identity. However, groups such as *Te Hunga Haua Awhina Roopu* and *Mana Tua a Kiri* are a beginning. Although it is not yet inclusive of *iwi* providers as it has not been proactive in encouraging Māori disability networks within its frameworks. Māori key informants on these issues have expressed a reluctance to complain or outline any concerns publicly about these services as they do not want to be seen to be putting Māori services down. If Māori with disabilities prefer a *whānau* member to be their carer, such carers are not paid to provide the service and there is an issue of monitoring, training and providing supports for both the individual and their *whānau* member carer. The question of the quality of services provided to Māori with disabilities needs addressing with solutions discussed under recommendations in chapter seven.

Action 11.3 appears to have been implemented in some disability services such as CCS NZ and IDEA (formally IHC) which have had many years of grassroots experience with persons with disabilities and their *whānau*. It would appear these

services are using their experiences and developing culturally appropriate services for their consumers and their *whānau* whilst utilising their members as key to their consultation teams. This is not to say that other services may be struggling to embrace the bicultural framework, as funding has been identified as an issue for some and the issue of biculturalism remains a contentious one in New Zealand as multi-cultural diversity demands attention.

As already identified, action 11.4 does not specifically call for Māori with disabilities to be trained into becoming Māori disability service provider professionals. It states only that Māori be trained, not Maori with disabilities. This can be a problem if there are no trainers with direct experience in understanding Māori disability identity as it is a largely under-researched area with little work done by, for or about Māori with disabilities. This is where disability research at tertiary level and, in particular, at post graduate level needs to be encouraged to understand and apply this action and improve services and understanding of issues for Māori with disabilities. Without this, there is a limited understanding and application, and the result is that Māori with disabilities receive support that is less trained and informed than support given to other persons with disabilities in New Zealand.

Action 11.5 is a desirable goal to strive for. However, the reality is that attitudes, even from within their own communities, such as some of those attitudes quoted throughout this paper from participants of this research sometimes prevent Māori with disabilities from being included in their community. Physical access is one of the more obvious barriers although, as earlier mentioned, those with other impairments also face barriers when trying to access *marae*. As a wheelchair user, I am constantly faced with access barriers. Unfortunately, most *marae* do not have the funds to provide access and it is not only access to the houses at the *marae*, but also to the toilets, the kitchens and sleeping quarters. This is a major issue as Māori become excluded if they are unable to participate with other Māori at *marae* and other *marae* based activities. Action 11.5 only provides for government-funded or sponsored *marae*-based initiatives to meet the access requirements of people with disabilities. It will take more than merely encouragement to make *marae* accessible; it requires money and, as disability

services are already under-funded, this is not likely to be an achievable goal in the short term.

The inability to make *marae* accessible is also due to a cost factor involved when having to comply with the accommodations needed to be disability-friendly, such as providing ramps, upgrading ablutions, installing fire safety/sprinklers, and setting up Deaf and blind-appropriate safety measures. *Marae* are often under-funded, and meeting the needs of disability goes beyond their capacity; although the need does not go away and creates a barrier in the future for any family member who may acquire impairments.

Regarding Action 11.6, money is required, as well as time. There are only two official trilingual interpreters in New Zealand for Deaf Māori Deaf already face increased marginalisation with the telephone relay service⁶⁹ not providing a service in the Māori language, and with the New Zealand Sign Language Act 2006 not providing for Māori sign language as a legally identified language in New Zealand. Tariana Turia (Māori Party) outlined her party's concern at the lack of Māori language in sign when debating at the second reading of the New Zealand Sign Language Bill in Parliament:

A particular concern that the Māori Party would like to see addressed and further advanced in legislation is the complete inability of the bill to address the issue of trilingual interpreters and to recognise trilingual interpretation—Māori, sign, and English. The number of trilingual signers is very few and far between. The Auckland University of Technology trilingual interpreting course was cut as part of the Government's so-called race-based funding cuts of 2004. It was yet another example of the ethnic targeting no-go zone promoted by the Government. The tragedy of this is that it denies Māori Deaf access into Māori hui where te reo is used. Māori Deaf have every right to understand the true meaning of the processes and kōrero that occur on the marae. Sign language interpreting helps bridge those communication gaps (http://www.hansard.parliament.govt.nz/hansard/Final/FINAL_2006_02_23.htm#_Toc129585411).

Despite the World Deaf Association identifying the right of indigenous Deaf to access their own language in sign, as with all other languages, indigenous Deaf access to their own language and culture is ignored by government. Māori Deaf are currently a fragmented and under-supported group who rely heavily on whānau members to be their voices when the services they are entitled to let them down⁷⁰. Without funding, it is doubtful Māori Deaf will break out of their exclusion and isolation within the short term. It takes several years for an interpreter to be fully trained in trilingual forms of communication and, although six scholarships were made available in 2006, they will not meet the urgent need for this community for several years to come. Action 11.7 calls for Te Puni Kōkiri to take on a leadership role in promoting the participation of disabled Māori. This is not currently happening for Māori with disabilities, although TPK in the annual reviews that have been completed in the two years since ODI came into being has been advising the ODI it is meeting the obligations of the NZDS.

Taking into account these actions and ODI's adherence to the social model, it would appear that the issues raised in this short account of the actions are in line with that approach. However, the issue is more complicated than this. Government policy contradicts Māori well-being generally; for example, where Māori with disabilities may have a preference for a whānau member to be their carer, there is currently no process in place to allow this to happen. The rationale behind not having *whānau* as carers is the risk of abuse to the individual, regardless of their ethnicity. This impacts all persons with disabilities who want to have *whānau*/family members as their care providers. This is not an insurmountable issue, however, as it is possible to provide training for the *whānau* carer, and monitoring of the situation is an issue that should apply to all carers; supports such as respite services should also be available for both parties, whether they are whānau members or not. The issue of financial abuse of Māori with disabilities by *whānau* could exist, given the voluntary nature of their relationship when caring and the general lower socio-economic status for them and their whānau. This could easily be remedied, however, if *whānau* were paid income as carers and did not have to rely on the invalid or sickness benefit of the *whānau* member with disabilities as their only means of support.

In the context of the NZDS the social model of disability already has the recognition of Māori with disabilities in objective 11. In order for Māori with disabilities to achieve better than current ODI and TPK reports suggest, it will take a series of recommendations aimed specifically at targeting Māori with disabilities and their community. Chapter seven outlines recommendations for giving Māori with disabilities full inclusion in society.

6.6 Summary

While Māori development frameworks have been identified as the key to well-being for Māori, these have not been incorporated into practice in regards to Maori with disabilities, as shown by the disallowing of whānau as paid carers and by the lack of Māori with disabilities training, support and involvement in the development and provision of disability services. There has also been a lack of consultation with *iwi*, *hapū*, *whānau* and TPK to consider how Māori with disabilities can make a valuable contribution to understand the issues of living with disabilities and as Māori members of society, largely due to the lack of Maori disability consumer advocacy networks and understanding of what constitutes Maori disability identity. While the social model is the one being mooted through the NZDS, the medical model is the one Māori appear to understand most in that, when issues of disabilities are raised, they often refer to the impairment more than to the issue of identity because of the nature of disability and labelling of such which depersonalises the identity further. There is also the issue of impairment where Māori are predominantly identified in medical-related impairments such as the consequences of diabetes, or poverty-related impairments due to colonisation, or accidents as a result of at-risk behaviours more than are identified through some of the more commonly identified forms of impairment with other groups such as Multiple Sclerosis. Disability has not traditionally been a separate identifying factor for Māori, yet colonisation, labelling and compartmentalisation of identity has meant that Māori with disabilities now have to find an identity where they can incorporate their Māori identity, while also identifying with an impairment which may bring exclusion from some activities and become isolating for them as Māori.

This issue of identity was discussed at length in chapter two. However, to understand Māori disability identity, it is relevant in this piece of work to understand why the religious/tragedy/charity and medical models are easier for Māori to relate to and why the social model is not seen in the same way. It is argued there is more commonality for Māori with disabilities in the application of Māori development/health frameworks, along with a consultative or strengthening model of advocacy to develop the leadership, inclusion and development of the Māori disability voice. Unless Māori health models (Durie, 1995; Pere, 1985; The Royal Commission, 1988) are adhered to and Māori with disabilities are consulted and included widely in the discourse outlined in the social model of disability, then objective 11 has no relevance for them. The social model is not applied to Māori, despite the actions outlined, and this fact is borne out by the lack of involvement of Māori with disabilities in disability training and in development of services and processes for Māori with disabilities (Office for Disabilities Issues, 2003)

Chapter 7: Final Discussions and Recommendations – New Ideas with Traditional Principles

7.1 Introduction

From discussions in previous chapters, my assertion is that Māori with disabilities expect to have representation within the disability sector on a par with non-Māori with disabilities. As the chapters developed, however, it became clear that this is not the case. Despite all the policy developing which appears on the surface to be inclusive of Māori with disabilities, the fact remains that Māori with disabilities are a disparate group with disability discourse reinforcing an assumption of disability as a homogenous identity. Disability models such as the Social model of disability do not incorporate the concept of ethnic identity when exploring disability as an identity and this poses a quandary for those who do not fit within mainstream disability identity frameworks. The reality is that Māori with disabilities continue to experience a lack of understanding of their identity as indigenous with disabilities. This group also experiences an under-representation in the mainstream disability sector and exclusion from society at a higher level compared to their non-Māori peers with disabilities. Māori with disabilities continue to be represented as a marginalised people within existing marginalised identities such as disability and gender identities. While some of the marginalisation issues are shared by other identities such as Māori or women who do not experience disabilities, there are some unique differences of marginalisation that are specific to being a minority (Māori with disabilities) identity within a mainstream (persons with disabilities) identity.

Chapter one identified, through responses from participants who are Māori with disabilities, who they are and how they view the attitudes of others, including whānau towards their impairments. This is important as it helps to understand the issues needing to be identified and raised for solution in order for Māori with disabilities to reduce the gaps they experience when seeking full enjoyment of life. Chapter two outlined how multiple identities are inter-related in experience, yet, not a marker of marginalisation if only viewed from a single identity. Identity,

as chapter two outlined, is a multiple concept and living with multiple marginalised identities is more common for Māori with disabilities than for non-Māori with disabilities. For Māori with disabilities, the issues of inclusion and full participation in society are as important as they are for all persons with disabilities, hence the relevancy of discussing international human rights instruments and inclusion for this group in chapter three.

In considering how to implement successful policy for Māori with disabilities, the Treaty of Waitangi is an important tool in relation to issues such as inclusion and participation. Chapter four outlines the Treaty, its principles and how relevant it is for Māori with disabilities where Treaty principles are already being used to reflect policy in the health and disability sectors. Legislation, as set out in chapter five, is another important tool for all persons with disabilities in New Zealand as it outlines how disability identities are to be treated and protected in domestic legislation. While not specific to Māori with disabilities, legislation discussed in this study is relevant to all persons with disabilities in that it has a general recognition of the identity, although is not necessarily specific to thematic groups within the general concept of disability.

While chapter two explored identity, chapter six outlined the models relevant to persons with disabilities as an homogenous group. In order to understand Māori with disabilities and their ability, or inability, to fit into disability models, it was also relevant to explore Māori health models. No Māori or indigenous disability model has, to date, been developed. In writing these chapters, a set of issues were identified and chapter seven is an attempt, through a series of recommendations, to provide solutions to some of the issues causing the ongoing disparities and negative statistics for Māori with disabilities.

7.2 Identifying the issues that need addressing for Māori with disabilities

The NZDS sets out the objectives for the different groups, with objective 11 focusing on Māori with disabilities. While these objectives promote Māori providers, there is no specific focus on this group having autonomy as Māori with disabilities. The best way to overcome this gap is to mandate a requirement for all

disability providers, in particular Māori disability providers, to consult and include Māori with disabilities at all levels of their services. This process will put the onus on all disability providers to include Māori with disabilities. To do this successfully, much ground work is also required.

No revolutionary or newly identified concepts are needed to reduce the disparities that exist for Māori with disabilities. Existing concepts within the Treaty of Waitangi and its principles can easily be adapted into policy for Māori with disabilities. The keys to reducing Māori disability disparities are the right of autonomy for Māori with disabilities wanting to have access to services appropriate to them and adaptability to include their *whānau* also, if this is their choice. The key concepts of interdependency and autonomy are pivotal to achieving positive outcomes for this group. There are, however, several commonsense approaches that can help this group achieve some form of parity with other persons with disabilities, and more importantly, to find acceptance and inclusion with Māori who do not identify as living with disabilities.

7.3 The Core Elements

The core elements required for Māori with disabilities to have parity with their counterparts and achieve positive outcomes in all areas of disability discourse are these:

- Government agencies, disability providers and Maori iwi health providers give Māori with disabilities autonomy in their decision making
- providing an appropriate *kaupapa Māori* structure of supports and services for the delivery of their services
- empowering Māori with disabilities through robust and transparent consultation and inclusion in all aspects of disability decision-making including in the development of policies and programs aimed at this group
- providing a framework with a focus on interdependency and independence to place the individual with disabilities at the centre of all decision-making for them and also provide for inclusion of *whānau* for Māori with disabilities if it is the individual's choice and,

- providing appropriate funding to incorporate the recommendations set out.

The key to addressing these core elements is to look outside the mainstream discourses of disabilities that developed in New Zealand policy and to incorporate a mixture of both traditional and non-traditional disability concepts that have a particular emphasis on Māori with disabilities. These core elements could also be adapted and utilised by other disability identities such as to Polynesian peoples, migrants, gay, lesbian, bisexual, transgendered and intersexed persons with disabilities who do not fit into or have full inclusion through mainstream disability frameworks to provide a bias free environment that incorporates diversity.

The exploration of traditional concepts for Māori with disabilities includes understanding and incorporating *kaupapa Māori* approaches to service delivery and a change in thinking around disability in language and in practice for this group. Whilst some services use the term “kaupapa Māori” or state their compliance with the “principles of the treaty”, these steps alone are not sufficient. Recommendations must be identified and developed to ensure systems are in place that recognise the place of Māori with disabilities in all areas of society, including their own communities.

7.4 Eight Recommendations

Eight main recommendations are identified to effect changes:

- 1) develop a Māori disability framework that incorporates the individual with disabilities at the core, this identity to be used when developing policies and delivering services and supports to Māori with disabilities;
- 2) challenge the language of “disability” and “impairment” from the western paradigm and develop Māori (indigenous) language and systems that are more appropriate to Māori with disabilities⁷¹;
- 3) define the concept “kaupapa Māori” service for Māori with disabilities and not accept the term alone as not sufficient. Whilst defining this concept, it is necessary to interpret the language sufficiently to ensure the concepts enhance effective and appropriate services and supports for this group;

- 4) provide a process by which Māori with disabilities have autonomy in their decision-making as individuals, as *whānau* and as members of the disability community.
- 5) develop an educational resource around Māori disability identity and awareness of this identity in policy at all educational levels (primary, secondary and tertiary);
- 6) establishing monitoring and auditing tools to ensure safety of implementation of service delivery for Māori with disabilities, including any *whānau* carers as providers of services to Māori with disabilities;
- 7) provide resources on a level equal with non-Māori with disability representatives to ensure equal participation of Māori with disabilities in representative roles on disability advocacy networks domestically, and internationally;
- 8) provide educational and employment opportunities in both the public and private sectors for Māori with disabilities to become leaders in Māori disability issues;

7.5 The Rationale for and the Implementation of these Recommendations

To successfully implement these recommendations reflections on the findings from the earlier chapters are incorporated throughout this chapter. It is important that rationale are provided to give a greater understanding as to the issues raised and why it is important for Māori with disabilities that a focus be placed on their impairment identity for inclusion in their community and in society generally.

7.6 The Recommendations in Detail

1) Develop a Māori disability framework that incorporates the individual with disabilities at the core, this identity to be used when developing policies and delivering services and supports to Māori with disabilities

A Māori disability framework is essential for developing a greater understanding of Māori disability identity and providing knowledge, along with a foundation for developing policies and delivering services and supports for Māori with disabilities. Chapter six outlined the existing disability models used in New

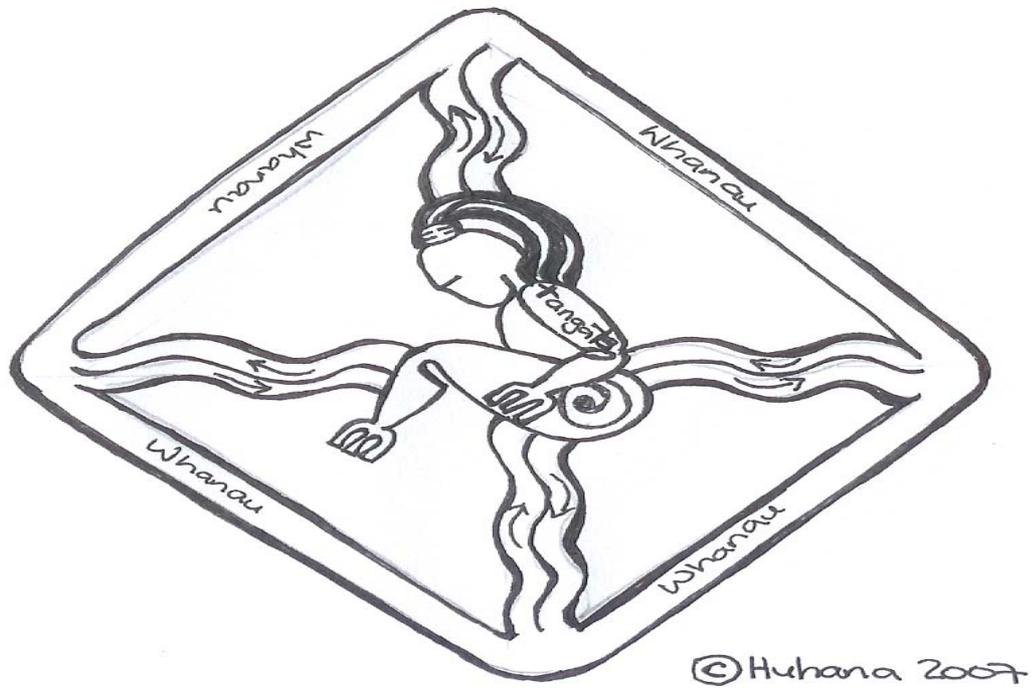
Zealand policies, along with the main Māori health frameworks. Chapter six also outlined the gaps in the models, with the suggestion that there be a *tangata*- (person) centred approach to any Māori disability identity framework. The term *Hauā Tangata* is mooted for this framework with the emphasis being on the term *Hauā* before *Tangata* to emphasise the theme of impairment as central to the subject and The *Tangata* being the person at the centre of the framework. *Hauā Tangata*-centred framework is therefore mooted as an appropriate framework for incorporating Māori disability identity into aspects of disability policy and delivery.

Symbolism plays an important part in the development of the framework when describing processes for Māori with disabilities. It is symbolism that led to the development of this framework to bring about the inclusion and successful delivery of services and supports for Māori with disabilities. This symbolism is also able to be adapted and explained to those with literacy problems, as well as to those with sensory impairments, in that any written explanation can be adapted to meet the particular needs of Māori with disabilities for information in a different way from general formats.

The '*Hauā Tangata* (person-centred)' framework is visually outlined in Figure 1 and shows four triangles linked together, with the *hauā tangata* in the centre, because of its shape and ability to apply equally the aspects of well-being (*Te Whare Tapa Wha*) as designed by Mason Durie. Durie's model is relevant in that well-being is central for Māori with disabilities, as it is for all Māori although it is not a sufficient model on its own. The *Hauā-Tangata* framework was also developed to place the individual with disabilities at the centre of the triangles, providing a vital link between and within each of the triangles. In the case of this framework *Hauā-Tangata* means person-centred or individually/uniquely person-centred, with the purpose of incorporating person-centred inclusion (an explanation of the term *hunga hauā* is set out in recommendation two). Māori with disabilities are not always consulted about their needs by providers and other services. This raises the need to develop an interlinking approach of multiple agencies involved in the individual's care and support whilst incorporating an overall link involving their whānau. Language and terminology are discussed

further under recommendation three where rationales and explanations of terminology are included.

Fig 1: The *hauā tangata*-centred framework for inclusion and service delivery



The *hauā tangata*-centred framework must be at the core of all disability services and policies for Māori with disabilities identity, regardless of whether they are Māori or non-Māori providers or services. Therefore, unless Māori are viewed as an identity in the centre of the decision-making about their service provision, and having a link to all aspects of their service delivery, the *hauā-tangata* centred framework does not work.

In Figure 1, the *hauā tangata* (individual with disabilities) is placed at the centre of the framework. This reflects their central placement in all decision-making. The waves going out from all sides of their body to the outer layer surrounding them is representative of the blood line between the individual and their *whānau*. Like a *korowai* (feather cloak), the *whānau* are as integral to the model as they are to individual in that they reflect and support the individual with disabilities by flowing to and from the central figure. The flow of the *whānau* link surrounding the individual represents the protection the *whānau* can offer and the support they

provide to the individual, while allowing the focus to be on the individual in relation to their needs.

Within the framework are four triangles which represent the health and disability providers; the individual is incorporated in the centre, surrounded by and linked to *whānau*. The concept of *whanaungatanga* (relationship/kinship) is strong in this framework, with providers of health and disabilities services not able to avoid the link between the individual and the *whānau*. Because the framework is adaptable, the four triangles surrounding the individual can also equally represent the four aspects of well-being. *Wairua*, *whānau*, *hinengaro*, and *tinana* can be placed in the four corners as the four aspects of what makes up *Te Whare Tapa Wha*. Within each of the four corners, some essential Māori concepts such as *mauri* (life principle), *mana* (prestige, authority, control, power, influence, status, spiritual power, charisma) and *āhua* (a person's appearance) can be considered also as they incorporate aspects of our humanity. These concepts are dependant on the individual identifying themselves, therefore they are not written into the framework as such; instead, they enable the ability of the individual to self-identify. The emphasis on these concepts in relation to the individual linking them to their own *wairua*, *whānau*, *hinengaro* and *tinana* also extends to the individual being able to name what and where that need or emphasis lies.

At the middle of the *hauā tangata* framework is the *tangata* (person) who, in most service delivery, is, in theory, identified as the centre of the process. This framework cannot exist without the *tangata* being the centre, hence the rationale for the *hauā tangata* framework. The red flowing in and out of the *tangata* represents the life essence (the *whānau*), with the blood flowing from the centre (often where the heart may lie) throughout each of the triangles, linking them to each other. An analogy to this is to have the consumer at the centre of the services with a presence at all levels of the service. This is consistent with the phrase in Māori:

E kore e taea e nga tinana ora te kōrero mo te hunga hauā.

(The able-bodied cannot speak for the disabled)

If the *hauā tangata* is not at the centre of the service and does not have a voice and presence throughout the service, then it is not correct to call a service ‘person-centred’. The *hauā tangata* framework is a simple system that removes the complexities of some existing models and applies a person-centred approach to the services that utilise this model. Having multiple agencies involved in the care of Māori with disabilities can often lead to services operating in a fragmented and isolated manner, which may cause an overlapping of service delivery. A limited service delivery may inevitably meet only one aspect of the individual’s need whereas a holistic approach addresses all aspects of their disability needs. This fragmentation leads to confusion, frustration and inappropriate or inadequate funding and implementation of services to persons with disabilities. In order to have a successful framework, however, there is also the need to ensure the services are working together with the individual, the *whānau*, the community and the other services relevant to the needs of the individual with disabilities. With the *whānau* wrapping itself around the entire framework like a cloak, linking directly to the individual and the decisions they make, this will provide a successful delivery of services to the individual and the *whānau* supporting them.

Weaving together the providers for good service delivery

The weaving process provides a symbolic description of the process of putting together successful services which, if done correctly, provides a strong foundation of support for the *hauā tangata* framework to properly develop for Māori with disabilities in service and policy delivery. It is important for all disability provider services and supports for Māori with disabilities to work together; failure to do this will, in effect, make the *hauā tangata* framework ineffective. Having services fragmented, working in isolation and overlapping each other does not provide an efficient use of money and resources for the benefit of Māori with disabilities and their *whānau*.

While a *korowai* can symbolise the *whānau*, the provision of health and disability services to Māori with disabilities can be likened to the weaving together of flax. It is important that providers, the community, support services, the *whānau* and individuals with disabilities work together to ensure quality service delivery for the needs of persons with disabilities. Just as in weaving, a design is developed,

the materials are sourced with careful consideration as to what is best for the item being produced, and the skills are applied in making the object that is appropriate to the need. Service delivery is no different in that all parties, including Māori with disabilities and their *whānau*, must be consulted, the gaps identified, and the best service to meet the needs also identified and sourced to ensure the delivery of quality and effective services to that person. Working together makes it possible to resource from a variety of sources and to communicate with each other allowing for inclusion and consultation with the individual and their *whānau*. Without such approaches, the individual with disabilities and their *whānau* face exclusion, lack of resourcing and no central involvement in the delivery of services impacting on their lives. To avoid the risk of having too large a number of representative groups vying for limited resources, incorporating a process of local, regional and national representation gives local iwi, hapu and interest groups autonomy as well as providing a core supply of representatives for a national caucus to provide national and international representation on behalf of Māori with disabilities issues.

2) Challenge the language of ‘disability’ and ‘impairment’ from the western paradigm and develop Māori (indigenous) language and systems that are more appropriate to Māori with disabilities

Language is a means of empowerment or disempowerment, and language used to describe Māori with disabilities is no exception. The important role of language in the identity as Māori, as with all persons with disabilities, cannot be emphasised enough. If we apply meaning to words outside of our own cultural identity, we are applying something that, when translated, may have different meanings than originally intended. A good example of these misconceptions that exist around impairment for Māori are the terms translated to mean disability. When first translated, the terms used such as ‘deformed’, ‘handicapped’, ‘crippled’ and ‘decayed’ were negative and stereotypical of the time when disability was seen as an illness or as something negative. When disability terminology is used today it is with negative words such as ‘disabled’, ‘disabilities’, and ‘mental illness’, which are terms that derive from the previous medicalisation of disability⁷². The reality is that even if we were to change the language away from terms such as ‘impairment’ or ‘disability’, negatively reinforced language remains for society to

continually link a particular thought or experience to. Bruggemann and Modellmog (2002) outline how identity is always viewed in relation to the body:

...it seems prudent to acknowledge that the risk of identity differs from performance to performance, in part because the performance of an identity is always read in relation to a body that might itself be read as either normal or deviant. For example, people who use wheelchairs, leg or arm braces, guide dogs or white canes, or who have physical "disfigurements," such as missing or shortened limbs, are almost always read—at least when encountering other people face to face—as disabled, regardless of their attempts to pass as able-bodied. Even this reading, though, can be a misreading of the complicated terrain of disabilities and disability identities. The individual in the wheelchair might be temporarily disabled, a condition that does not ordinarily mean that he or she has a disability identity....(Brueggemann, 2002, p.313).

For some, the impairment is permanent and for others it is temporary. Nevertheless, there is a perception attached to certain terms used to describe certain people within the community. These words, while used by the disability community as being preferable to the previous use of medicalised language, still carry negative connotations. Even the words 'impairment' or 'impair' imply something is less than or not right, compared to those who do not identify with these words. The term 'dis' is negative and, when added to the term 'ability', implies a lack of ability or capacity. Therefore, when disability is used to describe a group of a particular identity, it is implying there is something lacking by comparison with those who do not identify in that way.

As disability identity is socially constructed (see chapter two), society actively applies negative terms to this identity. Even disability models such as the social model of disability also use negative words to describe identity. This appears to be at odds with the philosophy behind this constructed identity. MacIntyre (1999) states that the starting point in examining the role of disability and dependence in our lives must begin with a "suspicion of ourselves". Despite new knowledge being essential in the creation of fully inclusive communities where persons with disabilities may live without prejudice or exclusion from those who do not

experience disabilities, this cannot happen until we acknowledge our own involvement with past constructions of disability that clearly impact negatively on our views of humanity. MacIntyre recommends we explore the meaning of human vulnerability and dependency. Of particular concern is the impact this terminology has on a group seeking to have full inclusion in society. It is very difficult to argue equality of inclusion if persons with disabilities are seeking to also have included in their labelling a term (disabilities) that implies a lack of ability, compared with those without disabilities. Of relevance to Māori with disabilities and their identity is the interpretation according to the beliefs of the time of colonisation (see chapter two) and how those beliefs still influence the thinking of Māori today. The Bible had a strong influence in that it was used to translate English into Māori.

...while the translation and distribution of the scriptures in the Maori language might have helped to avoid some errors of misinterpretation, and while it was the means by which the gospel was spread so widely and so quickly, ironically perhaps, it was a further reason for the rise of much misunderstanding of the Christian religion. This was inevitable, for in reading the words the Maori could only interpret them according to the experience of their own cultural background. Explanations from missionaries went only so far towards avoiding this problem (Elsmore, 1999, p.11).

Te Reo Māori commonly used in disability networks today to describe Māori with disabilities is 'Hunga hauā'. Māori translations of the disability services title is often used alongside the English title in disability services such as CCS NZ and *Ngaati Kapo* (Māori blind advocacy network). The use of the term 'Hunga Hauā' and the interpretation of that term is descriptive rather than literal because of the story-telling tendency of Māori when describing their impairment experience. The descriptive process describes the subject matter, so translating it into English can be difficult if it is not strictly adhering to a literal interpretation of the subject matter. While early Māori/English dictionary translations show "hunga hauā" to mean a group of people who are crippled, diseased, decrepit, decayed and deformed, it has since been used to mean Māori with disabilities. None of these

terms adequately address how Māori viewed disability in their society pre-colonially (Tauroa, 1990).

Another example of the descriptive nature of Māori disability language can be found in the *Ngaati Kapo* advocacy service for Māori with visual impairments: a *Ngati Kapo* member who is very active in blind issues globally as well as in New Zealand, has identified over 200 different terms for describing visual impairment. He has also stated that he does not support the term ‘hunga hauā’ as it is not applicable to visual impairment. In informal discussions Maaka, who is fluent in *te reo Māori*, has explained that for *kapo* (blind) issues, the way people define themselves is based on their experiences as to how their visual impairment came about: hence the reason for the varied differences in language used to describe their visual impairment the word for ‘blind’ alone is not enough to describe its entire history. It would appear this is similar for other impairments, in that the event or the experience that created the impairment is part of what gives it the label it has. This would be consistent with oral histories in that the event is the reason behind the story given for how something has occurred. Yet, in western discourse, this is not how disability is labelled. Part of the difficulty in trying to define or give a term to the impairment because of the event that caused that impairment is that there is no agreed umbrella term that fits disability neatly into labels, and therefore, the current terms are not able to identify descriptively. The other difficulty is the multiple impairments that many identify with, which gives other complicated and convoluted results when describing the impairment.

Due to the nature of disability services and funding and ongoing disagreements among Māori with disabilities as to the correct terminology, it is not currently possible to give a self-definition that is consistent with Māori or indigenous thinking around impairment. Any conformity of language could create a difficulty in categorising disability and therefore providing funding according to the impairment and not the individual. It is therefore suggested, for the sake of moving this discussion forward, that Māori with disabilities use an umbrella term such as ‘hauā Māori’ which can be understood and adapted to mean a group of Māori who are distinctly and uniquely different because of their impairments, yet remain as Māori first.

The term ‘Hunga hauā’ is contentious among some Māori because of the negative translations given early in the 19th and 20th centuries (Tauroa, 1990) where terminology for disability accommodated the thinking of that time. Māori with disabilities have been reluctant to engage with a disability identity as they do not identify with the terminology. It makes perfect sense to me that there is a reluctance to identify with disabilities as few would want to identify as being crippled, decrepit, decayed, diseased or deformed. There are those within the disability community who do seek to challenge these terms by accentuating their impairment through art or other forms of expression. These terms are highly negative and aimed at separating and excluding a certain group from their community. Ironically, Māori who participated in this thesis research do not appear to have an issue with using medical terminologies to define their impairment, which appears to be consistent with Maaka’s statements related to our oral tradition of describing significant events through using different terms relevant to those experiences. The impairments that occur for Māori are often medically based⁷³ and they appear comfortable in describing the medical aspects of their impairment. The issue of identifying within a community of people with disabilities is not something Māori with disabilities appear comfortable with. This could be because of the translations, along with disability as a social construct. Māori or indigenous generally did not need to develop a social construct around impairment to gain inclusion into their community (see chapter two on identity).

Language alone does not, however, explain why Māori with disabilities are sometimes excluded from their community. Language does partially explain why this group remains elusive in the disability networks. It is very difficult to locate representatives on disability committees from the Māori community, with some positions remaining unfilled or later appointed by the providers or government agency staff and not by the community which that position purports to represent. There are also few Māori with disabilities participating in the political arenas of disability issues, creating a silence that leads to an assumption of acceptance of the discourse around disability politics existing in New Zealand today. Even the disability-focused models that have been developed for persons with disabilities

contain a component of medical language or medical definitions which again make it difficult to take disability identity beyond the medical paradigm.

Indigenous language in relation to impairment can be more empowering in that the medical labelling is not an issue because Māori did not use terms to categorise people with impairments. For Māori, it is the experience of how the impairment occurred that informs them and their community, not labels. During informal discussions, linguists stated that the translation is literal rather than descriptive and suggested the term 'hunga hauā' could mean whatever we wish it to mean. It was also suggested that describing Māori with disabilities as Māori who are uniquely different is quite appropriate. The term 'uniquely different' suggests a more positive approach to the issue of the language describing impairment for Māori with disabilities. 'Hunga hauā' or 'uniquely different' is more positive language whilst still acknowledging the unique difference that is evident in the individual's appearance and experiences. This identity also removes the previous historical stereotyping of the impairments, allowing for the re-education of society to view impairment not as a negative identity to be shunned and isolated, but as an identity worthy of full inclusion in society. 'Hauā Māori' is also a term that can be broader in its interpretation than 'hunga hauā' and therefore provide an umbrella identity whilst allowing individuals and Māori disability networks to self-define according to their own experiences of impairment. Development of these terms needs to occur among Māori (indigenous) to allow for their own autonomy in deciding for themselves how they wish to identify. It is recognised that the use of medical terminology to define and categorise impairment need not be an issue other than for the relevant situations where having a medical diagnosis outlined is necessary. Disability services must also amend their protocols and policies to allow for the self-defining of identity within all disability communities. As it stands currently, unless a diagnosis is made it is very difficult to obtain disability services, equipment and support. Even the language used in government pensions, such as the 'Invalids benefit', is negative and forces individuals with disabilities who require financial support to apply using language that is outdated and inappropriate for the community, despite the government incorporating the social model through the NZDS in 2001 (see chapter six).

3) define the concept “kaupapa Māori” services for Māori with disabilities and not accept the term alone as not sufficient. Whilst defining this concept, it is necessary to interpret the language sufficiently to ensure the concepts enhance effective and appropriate services and supports for this group

To define ‘kaupapa Māori’ services for Māori with disabilities, it is important to fully understand what this entails. It is not enough to simply state that something adheres to ‘kaupapa Māori’ principles; it is important to understand these principles in the context of Māori disability issues. If Māori disability and language have not been understood, then how can *kaupapa Māori* services pertaining to this group be applied? It may even be worthwhile to consider reviving some of the positive pre-colonial beliefs/practices around impairment, whilst acknowledging that with colonisation also came new concepts around impairments that can develop further to incorporate Māori with disabilities fully back into their community.⁷⁴ Chapter four explored the Treaty of Waitangi, the articles and its principles, which is useful in exploring the practical implementation of *kaupapa Māori* services in the health and disability sector, as the principles have been applied to both fields by health and disability providers.

Te Rangihaeata, a disability services provider in Taranaki, successfully piloted a program which allowed for 200 clients to be individualised in their funding⁷⁵. The facilitator of this process did report back that only one client failed to be successfully funded through the individual funding package scheme⁷⁶. The rest benefited as it meant the client would be in charge of their own decisions around how that funding allocated to them would be spent. This meant that if a Māori member with disabilities wanted to attend a *hui* and needed their carer, they could work with their personal assistant to decide how they could best be supported with the funding allocated. The problem with providing this type of funding is that successful service delivery will require increased funding levels, compared to the current levels. If funding is not increased, then any individualised scheme is compromised because of lack of resources. The individual with disabilities does not currently have the autonomy to decide what is an appropriate funding or carer allocation for them. They are not involved in the discussions; they are simply

interviewed and the decision over their hours and support are made by the disability support services appointed to make such decisions.

To provide an appropriate *kaupapa Māori* service for Māori with disabilities, the process begins at the first point of contact with the individual with the disabilities. When first contact with the client/consumer is made, some initial issues need to be identified so that assessors who do the original assessment have the ability to apply an appropriate process for the individual. The next step is to ensure the interview process itself is decided on by the client with disabilities and to allow the involvement of anyone whom the individual with disabilities wishes to have involved, such as *whānau*, friends and *kaumātua*. This is consistent with what is stated, yet not always explained, when clients are approached for assessments.

The choice of providers is often limited to what is available in the community and not always appropriate to the individual's own wishes or needs. For Māori with disabilities in rural communities, finding a variety of providers is not always possible. Often the choice does not exist for certain groups requiring culturally appropriate choices, or even full provision of services for their care. Often the care is then left up to the *whānau*, who are not currently recognised as formal carer support persons by disability support services. *Kaupapa Māori* services recognise the role of *whānau* in the delivery of services to Māori with disabilities, especially in the rural sector where they may be the only people available to provide and so it is important to recognise this process for such service delivery. Already in practice is the example of the *kaupapa Māori* service delivery of Te Rangihaeata in Taranaki. There is ongoing training of *whānau* and other carer support staff by Māori with disabilities and others skilled in knowledge of care provision of persons with disabilities, to ensure that all parties are informed, involved and fully competent in providing a service to the client. The cultural component of disability must be incorporated in all service providers' training as Māori with disabilities utilise a variety of services dependant on availability and needs. It seems commonsense to conclude that, to have inclusion, systems and structures are needed that enable the support needed for that inclusion. Therefore, it appears quite reasonable that to have Māori with disabilities supported through *kaupapa Māori* processes there must be a process of enabling disability services and

supports appropriately. This was not the common experience of the participants to this research, which is of concern.

What does providing a *kaupapa Māori* service mean? Is it enough to have mainstream services such as CCS or Māori services within Mainstream services (bi-cultural units) put a Māori name on the headers, employ Māori staff and engage Māori *kaumātua* leadership? Or is more required? *Kaupapa Māori* has the added focus of identifying clearly a particular practice within any service. It also gives a focus to the services, identifying them as being Māori, thereby enabling Māori to choose and possibly even give some autonomy to Māori. It is clearly not enough to label something as kaupapa; it is about applying a truly Māori philosophical framework to the services being delivered and incorporating culturally appropriate structures which clearly differentiate from non-Māori services, clearly identifying from a culturally specific perspective.

Some Māori health providers already incorporate kaupapa Māori structures just as some also incorporate Treaty principles (see chapter four) into their service delivery. One example of this being done is *Te Manu Toroa* (Māori health services for the Western Bay of Plenty) in Tauranga which whose Mission Statement includes the following:

Mission Statement & Principles

To provide comprehensive, integrated community and Primary Health Care for Maori in the Western Bay of Plenty

To improve the life of our people through using the concept of Tangata Whenua determinants of health

The foundations upon which this will be achieved are our:

Fundamental PRINCIPLES AND CORE VALUES

Which are based on a belief that:

The Treaty of Waitangi, which recognises and guarantees Tino Rangatiratanga over the material, cultural and spiritual resources of Tangata Whenua must be endorsed and promoted,

The relationship between Te Manu Toroa and Te Whanau Poutirangiora a Papa will remain intact,

The Tino Rangatiratanga of each Whānau, Hapu and Iwi will be respected, Whakapapa, Whanaungatanga and Aroha shall be paramount.(www.temanutoroa.org.nz)⁷⁷

Other services appear to be embracing similar kaupapa principles which also have relevance to their own *iwi/hapū* area and therefore, whilst incorporating the principles nationally, they remain regionally distinct to that particular area, which is important for any principles to succeed. Mainstream services such as CCS NZ (Ltd) and, in Hamilton the LIFE Unlimited disability information service have included Māori within their mainstream services. These services are staffed by Māori to attend to the needs of Māori members using their services⁷⁸. They have also incorporated aspects of *kaupapa Māori*⁷⁹ through Māori units that are part of the mainstream, which could undermine their ability to be truly autonomous as Māori within the services. The current trend within some mainstream disability services is either to argue Māori-specific disability needs are completely irrelevant and secondary to the overall needs of all the disability community or to state they provide a bi-cultural service by employing ‘a Māori’ to oversee policies for Māori, engaging *kaumātua* and providing a unit for Māori staff to work with Māori clients.

This latter bi-cultural framework is a start in that it is better than having nothing. However, discrimination does still exist and the Treaty is also as contentious within disability networks as it is in non-disability networks. This is not to say the providers themselves are not supportive; however, the environment has to become friendlier towards Māori by ‘all’ (including the clients) within the services and not just by the staff or managers who implement the services. The other limitation with a bi-cultural framework is the lack of autonomy and decision-making by Māori unless they happen to be within a managerial framework and even then there are risks. It would appear more prudent to work towards an autonomous service by, for, and about Māori with disabilities, with the ultimate goal of having complete decision-making for this group taken over by this arm of the service. It is achievable for existing providers incorporate *kaupapa Māori* services by providing the opportunity for Māori to become consumers and central to the service as key stakeholders in all aspects of service development.

In the 1980s and early 1990s Native Americans, through the American Indian Organisation (AIO), identified four R's as the core cultural values shared within indigenous communities across generations. These four were identified as *Relationship, Responsibility, Reciprocity and Redistribution* (Harris & Wasilewski, 2004). Harris and Wasilewski argue that each of these core values manifests within itself a core obligation within indigenous societies.

- Relationship provides the kinship obligation, the sense of belonging and being related to people, our land and all that is within our environment. These things are all interrelated. All of these aspects of kinship are valued (Harris & Wasilewski, 2004, p.492).
- Responsibility is the community obligation this is where we know we each have an obligation or responsibility for all of those within our community, and all that is within our environment. We each have a role and responsibility for the fulfilment of that role (Harris & Wasilewski, 2004, pp. 492-493).
- Reciprocity is the obligation that involves the cyclical nature of our environment, for the environment such as the seasons are all cyclical and with those cyclical events come obligations. The environment is dependent upon everyone and is cyclical in nature (Harris & Wasilewski, 2004, p. 493).
- Redistribution is in sharing and having an obligation to share. This is about the redistribution of our resources. It is also about maintaining balance within relationships. It is about keeping the well-being of the *whānau*, community and environment by redistributing resources within the community. The basic principle of redistribution is not to accumulate wealth (not just financial, but including skills, time and energy) but to keep distributing around the community as needs arise. Each of these values is inter-related with each affecting the other both positively and negatively if not applied in a fair and balanced way (Harris & Wasilewski, 2004, p. 493).

These core values are consistent with Māori models of well-being (see chapter six) and consistent with the collective/community approach to service delivery that is mooted for Māori with disabilities. Having a *kaupapa Māori* provider service in the disability sector will not fail if appropriately implemented. It is not the *kaupapa Māori* service that is at risk; it is the lack of financial support, the lack of 'other' support from the disability sector and the lack of knowledge of what is needed to successfully incorporate *kaupapa Māori* supports for Māori with disabilities, although other persons with disabilities can also benefit as the service would be open for all who wish to come under such service, as is the case with Te Rangihaeata.

Given such an open approach to include all who wish to come into a *kaupapa*, providers could begin to see the benefits of incorporating such concepts as *whakapapa* (genealogy/ancestral lines), *whanaungatanga* (kinship relationships) and *aroha* (love) as the keys to improving the well-being and identity of all those who live with a disability. This process may eventually evolve into an indigenous-focused set of principles that differ greatly from the global trend, yet show success in their ability to empower and provide for the dignity and *mana* of all persons with disabilities in place of the current negative stereotyping around impairment that exists today.

Achieving such a unique model requires the acceptance of placing the *hauā tangata* person-centred framework firmly within all health and disability policy. In this way, empowerment and autonomy of the individual and their identity become normal practice for all health and disability services. The Pacific aspect of any service provision is achievable when providing the person-centred approach while also applying culturally appropriate supports throughout all levels of policy and delivery.

4) Provide a process by which Māori with disabilities have autonomy in their decision-making as individuals, as whānau and as members of the disability community

Autonomous decision-making will be beneficial, especially for persons with disabilities to whom, history shows, decision-making is not accorded. If all

persons with disabilities, in particular those within the disability networks who have histories of multiple marginal experiences linked to their multiple identities (see chapter two), are able to fully participate in all aspects of society as the NZDS proposed in 2001, then clearly disparities would reduce. As discussed in this thesis (see chapters five and six), this has not happened for Māori with disabilities simply because the NZDS objective 11 which addresses their issues for inclusion as per the social model of disability does not incorporate or insist upon *kaupapa Māori* principles which includes having their *whānau* involved in their decision making. Neither is there an onus on consultation with Māori with disabilities themselves.

It will take more than having Māori with disabilities represented on disability boards and trusts, or to have Māori with disabilities appointed on councils and other decision making positions within Government and non-government structures as these are western-constructed forms of representation and do nothing to encourage true *kaupapa Māori* representation within. Nor is it enough to have Māori who do not directly experience disabilities advocating and speaking for Māori with disabilities unless they are mandated to do so by Māori with disabilities. These need to be specific at both micro and macro levels, which means having local, regional and global representation, with autonomy and decision-making for that area remaining specific to that area. There must also be a national focus where appointments are made to a national representative body which then goes onto represent Māori with disabilities in the different representative . However, direct experience of disability alone is not enough as other skills are required in governance and other areas pertinent to the representation being sought. Such as possessing prior nursing qualifications when sitting on the nursing council representing Maori with disabilities on that board.

It also needs to be recognised that, while it is prudent to have a *kaupapa Māori* approach to the representation of Māori with disabilities, it is also important not to overlook some of the existing disparities within Māori disability networks. These disparities include under representation of Māori women, children and young people and those with certain impairments such as intellectual impairment and those with psychosocial impairments where there is greater ignorance or

marginalisation occurring both within society generally and within the wider Māori community. *Iwi*, *hapū* and *whānau* must also take responsibility to find a way to embrace and include their members with disabilities. Without inclusion in the wider Māori community, the isolation and fragmentation of their tribal/whānau members will not be addressed.

5) Develop an educational resource around Māori disability identity and awareness of this identity in policy at all educational levels (primary, secondary and tertiary)

As already identified in chapters two and six, disability is socially constructed and, along with language, is a continually changing concept. For acceptance of these changing concepts to disability identity and language, an educational element is required to promote an accepted umbrella term such as *hauā Māori*. Within the defining of an umbrella term there should be descriptive explanations of disability terms for Māori with disabilities. This strengthens the rationale for Māori with disabilities to define through story telling, describing their experience of how they acquired their impairment. Describing disability/impairment experiences within the Māori community must be incorporated into disability work to better understand impairment from the Māori perspective and not from the existing disability discourse. Māori with disabilities must be supported in developing their skills to impart their experiences to their community and educate *iwi*, *hapū* and *whānau* on Māori disability issues and experiences to break down some of the assumptions that are still prevalent throughout the community.

For there to be disability awareness at all levels of society, the teaching of the next generation must be given priority. It is recommended that disability discourse become a mandated subject throughout all areas of education. This will provide an ability to change thinking around impairment and challenge long-held assumptions and fear by some in society. Thematic groups such as indigenous, women, children, Pacific peoples, migrants and queer persons with disabilities must also have the right to be included in the training process in order to provide an understanding of diverse experiences of impairment.

Whilst training is needed to understand disability issues, this should be an evolving process, adapting to change as knowledge also adapts and changes. If regular review found that disability no longer characterised a marginalised or dispirited group, then training should be altered to include different aspects or issues around impairment as required. The decision to plan, implement and teach disability discourse must be in the hands of those with disabilities, with Māori with disabilities being able to teach their own issues to their own communities as well as to educate all society in mainstream processes.

6) Establish establishing monitoring and auditing tools to ensure safety of implementation of service delivery for Māori with disabilities, including any whānau carers as providers of services to Māori with disabilities

Monitoring and auditing tools are essential as aids in providing safety for persons with disabilities and their service/support networks. It is recommended these be developed to incorporate the role of *whānau* as carers and providers of services to Māori with disabilities. For the *whānau* to be a central part of the *hauā tangata*-centred framework for Māori with disabilities, it is important not only to mention them, but also to develop models of safety for *whānau* and the individual when they become the primary supports for their *whānau* member with disabilities. Training, auditing and monitoring is already developed for providing safe and effective care for persons with disabilities; it is simply a matter of ensuring *whānau* receive the same level of training and support as non-*whānau* caregivers.

Part of this process of ensuring good practice is also to accommodate the interdependent relationship Māori and other cultures/peoples with disabilities have with their *whānau*. The role of *whānau* is an important concept that has not been taken up adequately by policy makers when delivering services and supports to persons with disabilities. To successfully incorporate community is to redefine that community for persons with disabilities and to acknowledge that no individual can be truly independent as we all have a certain amount of dependency on something, someone or some process to make our lives possible. Interdependency is a good middle ground in that it neither removes the right to autonomy nor encourages complete dependency on others. Instead, interdependency allows for involvement of others to work in partnership along

with the individual with disabilities whilst still allowing that individual to have autonomy in their decision-making.

Interdependency does allow a role for the whānau in the lives of Māori with disabilities. The *whānau* role is increasingly being acknowledged as the key to providing good health care to Māori. For Māori with disabilities, this is the same need as other Māori and therefore any move to benefit whānau in their lives is a step towards benefitting them. How to define *whānau*, however, is another issue and how those definitions of whānau are applied in services involving Māori with disabilities is important when considering how whānau roles operate for this group. While *whānau* as a concept is a global concept known to all identities, for indigenous peoples, *whānau* take on a different aspect of identity in that despite globalisation and changes within the structures generally, *whānau* is still central to well-being and identity, yet whānau as official, equal partners in the lives of Māori with disabilities is still not formally incorporated in policies and services.

Harvey (2001) in addressing a conference on indigeneity, globalisation and diaspora in London observed that whānau is a concept carried globally by Māori even those who had since emigrated to places like London.

Not all Maori in Ngati Ranana are from the same *iwi*, tribe back home. Certainly they are not all of one whānau, family (even when we note that ‘family’ refers to the wide kinship collective which the Western term ‘extended’ implies is unnatural over against what we might otherwise call the ‘diminished’ kind predominating in modernity). But, while they are Ngati Ranana, they are whānau, they construct themselves weekly and annually as kin. Ancestors may be more than local, and Maori may be global, but here they find and/or create new intimacies. And as family they can receive guests, manuhiri, even academic ones. Some of this is familiar to Maori in New Zealand too, for example, those who are forming ‘urban *iwi*’ uniting Maori from beyond ‘this place’ and attempting not only to build community but also to be recognised as having rights under ‘the Treaty’ (of Waitangi) (Harvey, 2001, p. 4).

Whānau is therefore a globalised and a continually evolving concept with definitions being dependent on the context within which it is used (Te Roopu Whariki Research Group, 2005). In the Ministry of Health's Mental Health (Compulsory Assessment and Treatment) Act 1992, section 7(a) states that:

...requirement to consult with family/whānau outlines the obligations of the practitioners to consult with the whānau during the compulsory assessment and treatment process. Although this consultation is also dependant on the consent of the person for which the compulsory assessment and treatment order is applied to.

4.3 of the MOH guidelines outlines who is defined as family/*whānau* and states:

4.3 Who to consult

4.3.1 Defining family/whānau

People's definitions and understandings of family/whānau vary and are informed by people's cultural backgrounds and practices. Almost always, the most important perspective for defining family/whānau is that of the patient or proposed patient. The following definition is only one of many possible definitions, but the Ministry of Health recommends medical practitioners and responsible clinicians use it to help avoid confusion and for consistency across the country.

4.3.2 Recommended definition

Family/whānau means a set of relationships a patient or proposed patient defines as family/whānau. It is not limited to relationships based on blood ties, and may include:

- the spouse or partner of the patient or proposed patient
- relatives of the patient or proposed patient
- a mixture of relatives, friends and others in a support network
- only non-relatives of the patient or proposed patient.

A patient's or proposed patient's definition of family/*whānau* may differ from this recommended definition. If the patient or proposed patient is competent to decide who their family/*whānau* is, then their definition must be accepted. The Act requires compulsory notifications at various stages of the assessment and treatment process to welfare guardians and to principal caregivers. Such persons should be regarded as family/*whānau* for the purposes of consultation under section 7A, in addition to other family/*whānau* members.

Where there are disputes of who are considered *whānau* members of the person, the Ministry of Health guidelines applies. Section 4.3.4 of the guidelines outlines the process for any disputes including consultation with Māori workers to aid in the process. Other bodies such as the Ministry of Social Development and the Families Commission have defined *whānau* and its role in Māori communities with research developing clear pictures of how *whānau* are placed generally (Dallas, 2002; Ministry of Health, 2006; Collins & Hickey, 2006).

Ensuring a healthy role for the *whānau* in the lives of Māori with disabilities is not just about defining the *whānau*. As identified in the research survey results (see chapter one), there is currently a sense of isolation, lack of understanding and lack of support for *whānau* members of Māori with disabilities. There is a definite desire among *whānau* who are supporting *whānau* members with disabilities to continue to support them, yet a lack of resourcing and support appears to prevent them being fully effective in their roles. Even community care is not perfect, with resources not matching institutional funding levels, and when *whānau* are left to care for the one with the impairment, they are not recognised formally as carers, or are left to pick up the financial shortfall of costs associated with living independent lives. This situation is not unique to Māori with disabilities and their *whānau*; however, the impact on an already marginalised and financially stretched *whānau* serves to compound the issue to create a continual cycle of financial crisis.

Durie (1994) identified the need to include whanau as a core element which gives Māori balanced well-being. Pere (1985) also identified the importance of whanaungatanga in her "Te Wheke" model (see chapter six for further discussion

on these models). These are just two examples that show how important it is to include *whānau* as a central element in the lives of Māori if well-being is to be maintained. This need for *whānau* at the centre is the same for Māori with disabilities. The research results in chapter one found that the participants believed *whānau* held a greater importance than employment or any other aspect of their lives. This importance of *whānau* existed even for those who were taken away or institutionalised and for those whose *whānau* ignorance of their impairment led to exclusion.⁸⁰ The move towards developing significant policies for Māori with disabilities and their *whānau* is essential if they are to improve their well-being and reduce the disparities. Formalising *whānau* roles in policy and services will address this issue; however, it is important to remember also that Māori with disabilities must remain the centre of the decision-making in everything.

As already shown in chapter six, Te Rangihaeata has already provided *kaupapa Māori* services through a limited scheme with the Ministry of Health, allowing for *whānau* members to be formally recognised as care support persons for *whānau* with disabilities. While this is still not a formal policy for disability funders, it is a recognised preferred option for Māori with disabilities. Monitoring and auditing of services can be achieved through a third party where the client chooses their option of having *whānau* or non-*whānau* as their carer support persons. Alternatively the individualised funding already recognised in some cases can be managed by the individual and their *whānau*, with an independent body overseeing the supports to ensure safety for the individual and their *whānau* carer support person(s). Currently there is no provision for individuals to engage their *whānau* as care givers, which does not give the autonomy and empowerment sought by Māori with disabilities who wish to have the right to decide how their care is provided.

Another means of providing an appropriate monitoring and auditing tool for Māori with disabilities is to develop a local, regional and national caucus of Māori with disabilities and their supporters/*whānau* which would oversee the development of all representation, all policy and all processes regarding their needs. Currently it is out of the hands of Māori with disabilities to have autonomy

of decision making regarding representation. The isolation of non-representation is often more apparent for Māori with disabilities in that, while their identity generally does not work in isolation, the non-Māori systems do not acknowledge the collective decision-making and representation is safe and appropriate for Māori with disabilities. An example of this isolationary representation is DPA which has one position for a Māori representative, leaving them to become 'the' sole voice for all Māori with disabilities in that organisation. Of significant note is the Ministry of Health Disability Services Directorate's disability advisory group and the Office for Disabilities Issues Advisory groups who also have this 'sole' position, perpetrating a myth that individuals become the voice for their entire community, but often without their consultation. A national caucus can address these issues and provide a safe and appropriate structure for representatives put forward locally, regionally and nationally.

7) Provide resources of a level equal with non Māori with disability representatives to ensure equal participation of Māori with disabilities in representative roles on disability advocacy networks domestically, and internationally

In order to give autonomy to Māori with disabilities, it is essential that funding be on a par per capita with mainstream disability identities, given an overall shortage of funding of disability services generally, this is unlikely in the foreseeable future. The other aspect of providing full autonomy for those with disabilities is to ensure Māori with disabilities are at the centre of the decisions around their resourcing. Participation of Māori with disabilities in decision making is poor compared to participation by those with non-Maori (namely *Pākehā* New Zealander) disability identity. Understanding that disability representation is not only about impairment representation but also about representation of diverse identities within disability identity is the key to participation by those groups who have traditionally been under-represented. Māori with disabilities must be given the resources to implement local, regional, national and global representation of their identity and issues at all levels of society. At the United Nations ad-hoc meetings in New York (see chapter three) there was no official representation of any indigenous in the discussion of the CRPD. This is despite Jan Scown, the director of the Office for Disabilities at the two UN ad-hoc meeting in New York

in 2002, stating the need to include diverse disability identities in the consultation and implementation of the CRPD (see chapter three for more details of the UN ad-hoc meetings).

Despite there being no official representation throughout the CRPD process, the IIDCWG was formed by those concerned who identify as indigenous and with disabilities and the few who attended the ad-hoc meetings in other roles. This network tried unsuccessfully to have a specific article for indigenous with disabilities included in the body of the CRPD, although they did succeed in having their identity recognised in the preamble (see chapter three). It is of no value to Māori with disabilities to have organisations and NGO groups state they have the principles of the Treaty of Waitangi within their constitution and policies, if they deny partnership development of their Māori members in comparison to their non-Māori members. For there to be equality of representation and equal participation, it is recommended there be practical application to the Treaty of Waitangi concepts 'partnership', 'participation' and 'protection' as discussed in chapter four.

8) Provide educational and employment opportunities in both the public and private sectors for Māori with disabilities to become leaders in Māori disability issues

Whilst it has already been mooted that educational programs must be incorporated to provide a greater awareness of disability issues throughout the whole educational spectrum, it is also important not to neglect the non-educational sector such as employers, corporate and government agencies in the delivery of disability education. Employment opportunities need to develop; it is not enough to amend a disability benefit such as the 'Invalids benefit' to provide work plans for getting more beneficiaries with disabilities into work, and there needs to be practical consideration to making this happen.

Support services must be retained for workers with disabilities and equipment and resources must be made available, along with opportunities within government and corporate structures, to incorporate disability employment programs to increase the workforce identity of persons with disabilities. Affirmative action is

one way of ensuring that persons with disabilities are able to get into work. However, without constant evaluation and adaptation of any scheme, it could become a problem meeting quotas in the workplace with people lacking the skills or merit to do the job properly. Although its effectiveness is contentious, affirmative action has already been implemented for greater inclusion in society of women and people of colour through education and employment programmes aimed at increasing their participation (Rhoads et al, 2004; Anderson, 2005; Hucker, 1997). Affirmative action has inherent disadvantages such as the ability to create a tokenistic role, thereby becoming an ineffective tool for persons with disabilities. Any program for employment development must be in line with gaps identified, training support to fill those gaps and jobs that are not created for persons with disabilities to meet quota. The jobs need to be real jobs and value must be given to that employment.

Legislation is already in place to address discrimination against persons with disabilities. Chapter four outlined some of these laws. If the DPEPA is repealed, then recognising a fairer pay level for persons with disabilities in employment will become a reality. Enforcement of these laws is the key to providing safety mechanisms for persons with disabilities if addressing discrimination and inequality within the workforce. Providing mechanisms for employers to be positive towards the employment of persons with disabilities is another key to successful inclusion of this group in employment. These steps have not been adequate and require greater focus than there has been to date. On 11 April 2007 the New Zealand Herald and TVNZ reported that, while unemployment rates had gone down dramatically since 1999, there has been continued increase in the uptake of sickness and invalid benefits. Work plans are about to be implemented for sickness and invalid benefit beneficiaries (in October 2007) which are to be based on the assumption that all those with disabilities are required to find work. Although in reality there will always be some with disabilities whose impairment is of such severity as to make it impossible for them to work, some are trapped in a cycle of poverty and unemployment through barriers around impairment rather than an inability to work. As shown in chapters three, four, five and six, Māori with disabilities are over-represented in statistics for unemployment and health disparities, which strengthens the argument for providing mechanisms to engage

with Māori with disabilities and assist them towards independence in education and employment. Such action would reduce their dependence on state-funded supports.

Employment and education are the keys to enabling persons with disabilities to break any cycle of poverty induced through a life of dependency on disability pensions. These pensions are known in New Zealand as ACC benefits for those whose impairments have derived from accidents, sickness benefits for those whose impairments are temporary, and invalids benefit for those whose impairments are permanent. For Māori with disabilities, the goal of becoming financially independent is the same as for others with disabilities. The focus for Māori with disabilities is, however, slightly different in that the well-being of whānau has a greater level of importance over employment and education.

7.7 Concluding remarks

In summary, there are solutions to what can appear, on the surface, to be an overwhelming set of problems around reducing the disparities that exist for Māori with disabilities. The solution, however, involves a major shift in the current thinking around disability and around Māori with disabilities. The shift in thinking also involves changing policy and procedures to accommodate the differences that exist in order to give this group parity with all others. Language and whānau are very important for Māori with disabilities, not only because *whānau* have often been excluded from their lives as insignificant and secondary to their disability needs such as education or providing care, but also because *whānau* are an integral part of our identity where there is an interdependent aspect to this relationship.

Māori with disabilities deserve much better quality and delivery of services and supports from both Māori providers and mainstream providers and only by embracing and including them in all aspects of their decision-making can this goal of improvement be achieved. The hauā tangata person-centred framework can be an important tool in giving persons with disabilities the central focus in self-defining the concepts and issues as they see them. The framework has a structure

that can easily be added to and amended for the individual, giving them the ability to self-identify their issues rather than have to rely on others to do it for them. This also means the framework is not limiting as others have been for Māori with disabilities.

It has been easy over the years to identify the problems; however, without finding solutions, the problems remain and become overwhelming. We can make changes if our community is willing, empowered and resourced to ensure Māori with disabilities are supported and represented within *kaupapa Māori* frameworks. Autonomous decision-making for Māori with disabilities, resourcing, education and employment are some of the keys for them and their whānau to achieve better results than are currently evident.

Chapter 8: Conclusion

In concluding this study, I am drawn to the issues that evolved during the researching phase of this work. I began with having mooted this topic for a number of years yet with no clear direction as to how to proceed. As I explored my own issues within the New Zealand disability community, I found myself at odds with the disability networks around being Māori with disabilities. This was further compounded through the lack of other Māori involved with disability advocacy from the perspective of a consumer or user of services. I had the opportunity of being a member of the Māori Psychology Research Unit in the Department of Psychology at Waikato University where I undertook a literary review of the materials available around the issue of being Māori/indigenous with disabilities. This search discovered few materials that came from an identity perspective with the underlying issues of identifying as indigenous and living with impairments. Most of the disability identity constructed has been done from a non-indigenous disability perspective strong in sexuality and gender discourse, giving more validation to these identities rather than indigenous disability perspectives. I began to question the current development within New Zealand of disability policy when the introduction of the New Zealand Disability Strategy in 2001 does not appear to have improved the status of Māori with disabilities. Despite a series of objectives aimed at targeting certain thematic groups such as women, children, Pacific peoples and Māori with disabilities, the ongoing reports are not showing any significant changes for Māori with disabilities.

Māori with disabilities are not well represented in governance either; it is either their *iwi* representatives or mainstream disability advocates who take on these roles on our behalf without consultation or involvement of the Māori disability community. Any communication that does take place occurs in a fragmented way and not intersectionally. Māori with disabilities are consulted because of their impairment and the impairment group they identify with or on an *iwi* referral. *Iwi* are not specifically educated in the area of disability and, while some have established processes providing for representation of their Māori members with disabilities, some have not. With no consistency in policy for Māori with disabilities within *iwi* networks, and with the lack of education around their

identity and the issues pertaining to them specifically, Māori with disabilities remain on the outer rims of their *iwi*, *hapū* and *whānau* networks.

Māori disability identity is not explored or considered nor is the background to disability within indigenous communities prior to colonisation. Much of the pre-colonial information is lost because of the oral nature of our history. Except for fragments of information, it is not possible to gain an absolutely clear picture of how disability/impairment was addressed within the traditional Māori communities. Internationally, anthropological evidence suggests that impairment within pre-colonial, pre-industrialised societies was treated either with indifference or with the same attention as any other issue the community addressed. The detailed writings of the early missionaries helped to provide insight into the early patterns of society around addressing health and disability issues. While I concede that the construct of disability was not in existence when colonisation began to change traditional society in New Zealand, concepts of illness, health, and the older language used to describe disability helped me to unravel some of the information I needed to develop a fuller understanding of impairment identity for indigenous peoples with disabilities.

While health models and policy have developed, making them specific to target groups such as Māori, disability policy has only drawn from existing Māori health models to devise programs supporting Māori with disabilities in policy and service development. There has been no development of disability policy derived from an indigenous or Māori disability framework. This gap is causing problems both within the disability sector generally, within Māori disability provider networks and for Māori with disabilities. Māori with disabilities are as impacted upon by the developments of international human rights instruments as any others with disabilities are. I would argue that the impact for them is greater in that, as a specific group who have experiences of marginalisation in more than two of their diverse identities, they are exposed to greater issues of discrimination and marginalisation. Indigenous peoples with disabilities were not included in the debate on the proposed Convention on the Rights of Persons with Disabilities, which has led to their exclusion as a specific group within the Convention's proposed articles.

In the ad-hoc 2 meeting in New York (2002), Dr Jan Scown identified certain thematic groups open to increased discrimination as being women, children and indigenous peoples with disabilities. She also identified their need for inclusion into the convention, yet no strategy was developed to do this. The International Indigenous Disability Working Group was formed from the ad-hoc disability e-group where articles were developed and presented for inclusion in the convention. At ad-hoc 8 in New York (August 2006), the member states refused to adopt an article on indigenous peoples with disabilities, although they were mentioned in the preamble. This resistance to including indigenous and other minority groups into the Convention could be for two reasons:

- 1) Ad-hoc 8 had just completed a discussion on occupied nations when it turned to the issue of including the article on indigenous and other ethnic minorities with disabilities. As the debate on occupied states was hotly contested prior to moving to the next topic, this may have been a catalyst to the refusal to adopt the Venezuelan proposal for including indigenous peoples with disabilities in the Convention.
- 2) The current disagreement over self-determination that has occurred in the meetings regarding the Declaration on the Rights of Indigenous Peoples may have led to some member states believing that indigenous peoples with disabilities were seeking resolution of the same issue.

Neither of these issues could be addressed by any delegation of indigenous peoples with disabilities as they were not included in the debate unless they were representing unofficially or through other means such as being attached to an NGO network. The implication of the non-adoption of the proposed article on indigenous peoples with disabilities within the main body of the Convention is, at yet, untested as, at the time of writing this thesis, the Convention had not been ratified by the majority of countries. Women and children with disabilities also argued for inclusion through articles and it would appear they were acknowledged. This leads to the broader issue of the diversity of identity within the disability paradigm that appears at odds with the implantation of policy, as it could inevitably challenge the disability discourse as it has developed to date. The

laws and policy that have developed in New Zealand approach disability in an homogenous manner in that disabilities are grouped together to imply a sense of oneness, or a sense of collectiveness in disability, yet, in reality this could not be further from the truth. Stigmas exist with certain groups which are reflected in law, differentiating procedures for certain impairments as being of a greater importance than others. ACC policy differentiates accident-related impairments from medical impairments, with the invalid beneficiary being at the lower end of financial independence than someone on ACC benefits. Some with psychosocial conditions and intellectual impairments have certain capacity and legal limitations placed on them, depending on their behavioural abilities at different stages of their lives.

Māori with disabilities have shown little uptake of service delivery, supports and equipment, yet feature significantly in statistics around negative health and impairment rates. They are less likely to be in employment, and less likely to present in an economically viable situation. Despite these facts, little is done to address these gaps in service delivery and policy at this time. The issues for Māori with disabilities are compounding issues over identity, being one aspect of many for this group. The models identified in health and well-being, which do not specifically address impairment issues for Māori with disabilities are another issue. The models that exist are good models, yet limiting in that they are defined within the parameters of those models. Māori with disabilities can be placed within the existing models to provide service delivery, yet these models do not address the core underlying issues of isolation and exclusion experienced by those with disabilities who have fragmented whānau relationships.

Even with *whānau* relationships being central to their lives, Māori with disabilities and their whānau are further disadvantaged when *whānau* become informal unpaid care providers because the current system does not allow them to be formally recognised as carers. This informality for the whānau as carers sets up barriers, with some Māori with disabilities not accessing services due to their not wanting to have others in their homes and not wanting to be dictated to by providers. The lack of education on impairment issues for Māori is another reason

for the lack of uptake by Māori with disabilities and the lack of cohesive disability service delivery by them, for them.

Placing the impairment identity at the centre of Māori disability policy and service implementation is a solution to the gaps of involvement of Māori with disabilities in all levels of disability and Māori disability networks. This can be done by adapting the existing Māori health models which identify the core values within any framework needed, and by providing an avenue that allows Māori disability identity to be at the centre of any implementation of these services. The hauā tangata framework I have devised is person-centred, with impairment identity at the centre of all policy and service delivery frameworks. However, this model cannot operate in isolation as there is a community focus to this framework which I have outlined in the service delivery framework. This service delivery framework, if linked together properly, and if the services work together collectively, can hold up the *hauā tangata* framework and keep it well within its structure. These frameworks and their descriptive outlines are aimed at providing a visual explanation of these models in order to give a better understanding of the way these two can fit together and yet are isolated and fragmented when they do not have each other to rely on. This interdependency, having the hauā tangata person-centred framework placed within the service delivery framework, is reflective of how inter-connected they are and how, in isolation, they provide only partial benefit to either part.

Disability language is often frustrating for myself and others spoken to within the disability network. If, as disability networks, we are unable to find a solution to the dilemma of how to label ourselves, then we cannot expect policy writers and those involved in the decision-making process to know how to label disability identity. The English language dominates in the formation of disability identity, just as it dominates disability thinking along with the medical and social models of disability. Indigenous thinking around impairment is not necessarily consistent with disability thinking, and indigenous are not highly represented globally in political advocacy on disability issues. Domestically, this lack of representative diversity leads to the few representing the many and not necessarily in a manner that is beneficial to Māori with disabilities.

Representation depends entirely on how involved Māori with disabilities are in the process of determining that representation. If the process is decided without consultation, and representatives are decided on in a way that does not reflect a balance of representation or *kaupapa Māori* values, then the results may be ineffective for Māori with disabilities. The process for involvement determines the outcome, and until Māori with disabilities are fully included in a way they and their *iwi/hapū/whānau* (once educated on impairment issues for Māori) define that process to be, there will remain issues around impairment causing fragmentation and isolation for Māori with disabilities.

In summary, in exploring the core underlying issues of the identity of indigenous/Māori with disabilities, I am led to conclude that there is a great deal to be done to ensure parity with others within the disability, indigenous communities and within society generally. It does not help when the mainstream Māori/indigenous community and disability community are also experiencing marginalising issues with mainstream society, as it makes the journey ahead for Māori/indigenous with disabilities more difficult. It is, however, possible to gain equality with others in the disability community if a concerted effort is made to address the core underlying issues creating the disparities for all of these groups. It is not enough to recognise disparities within marginalised groups but not address them, to identify the issues yet ignore any solution that may improve their differences, nor to treat disability as a homogenous group. In acknowledging the diversity of identity among those with disability, it is possible to give visibility to a previously invisible group by giving them autonomy to establish their own identity in their own way.

In relation to disability identity being the subject of legislation, our laws and policies are under-developed, with the exception of the Human Rights Act (1993) which was designed to remove/reduce discrimination against disability as a specifically targeted group. However, as disability is a socially constructed identity, it is up to the individual to define impairment as the issue of discrimination which can, in the case of hidden impairments, mean 'outing' someone, further stigmatising them if their impairment is part of a group of

impairments that face greater discrimination than others. Although New Zealand has not developed post graduate discourse in disability, it is hoped that, as more persons with disabilities of diverse backgrounds explore their educational options beyond graduation, this will change. We are still in the early stages, however, with a long way to go before we can achieve the same knowledge of Maori disability discourse that the global world has already developed around impairment and difference.

Endnotes

¹ Monocultural in this context is defined as being one cultural identity or uniform in structure or composition throughout. This does not recognise the multi-valent nature of identity.

² For more information on Matua Whaangai programs go to <http://www.justice.govt.nz> or <http://www.cyf.govt.nz>.

³ Indigenous identity is defined in detail on page 49 of this chapter.

⁴ While these women have left their mark in our histories, they are the exception and not the norm, with women with disabilities still showing statistically as compared with their non-disabled counterparts.

⁵ Takatapui is a term adopted by the Maori members of the gay community. This term is translated to mean '*intimate companion of the same sex*'. And is derived from the love by tutanekei for his male friend Tiki. Tutanekei described Tiki as '*Taku hoa takatapui*'. For more information read Te Awekotuku in outlines (2003, p. 8).

⁶ The issue of dwarf-tossing became news when Brad Shipton was in the news for historical rape charges. In 2003, Mr Shipton owned the Bahama Hut where a variety of entertainment took place, including dwarf-tossing, which became controversial at the time. For more information see the New Zealand Herald archives which can be viewed at: <http://www.nzherald.co.nz>.

⁷ Hayward, B (2005) "Beauty" a New Zealand produced video which represents a woman with disabilities from the perspectives of her body and her disfigurement through dance, also Tee Corinne's work encompassing lesbian identity within her photography.

⁸ <http://www.wvda.org.au/steril3.htm>

⁹ [Postscript] on 13 September 2007 the draft Declaration on the Rights of Indigenous Peoples was adopted by the United Nations General Assembly with only Australia, New Zealand, Canada and the USA opposing its adoption.

¹⁰ United Nations publication, Sales No. E.85 XIV.9

¹¹ United Nations publication, Sales No. E.92.XIV.4.

¹² These two thematic reports helped shift the paradigm from medical to the human rights model of disability. These reports were also the first to recognise disability as a thematic subject within the human rights division of the United

Nations which, in turn, helped persons with disabilities to be regarded not merely as recipients of charity measures but as subjects of human rights (violations).

¹³ Ad-hoc is the latin phrase for “for this purpose” and is the official name given the meetings to discuss and develop the Convention on the Rights of Persons with Disabilities through the United Nations.

¹⁴ States is the United Nations term for Nations

¹⁵ See chapter two for discussion on identity, chapter five for discussions on legislation and chapter six for discussions on various models of disabilities.

¹⁶ See chapter five discussion on the ‘Disabled Persons Employment Promotions Act (1960)’ for further discussion about labour protections for some persons with disabilities in the labour force.

¹⁷ Whilst this is particularly so in New Zealand, there are examples as shown in the ILO document of 2003, throughout many of the Nation States where employment legislation exists around disability.

¹⁸ See Annual reports from the Ministry for Disabilities Issues Progress Reports 2005 and 2006 outlining the present situation and steps taken to amend any gaps existing for persons with disabilities.

¹⁹ The Inter-American Convention on the Elimination of all forms of Discrimination Against Persons with Disabilities. A.G. Res.1608. 29th session., O.E.A/Ser. PAG/doc. 3826/99 (1999) For the period prior to the new treaty, see Instituto Inerameri Canto de Derechos Humanos Los Derechos Humanos de la Personas con Discapacidad (Rodrigo Jimanes ed., 1996)

²⁰ Luxembourg Penal Code as of 1997

²¹ Mrs Florence Nayiga Sekabiro became the first person with disabilities to be elected in this seat and, when Kenya had its recent elections in 2005, she stood for re-election, this time for a general seat. She won, opening the way for another person with disabilities to enter parliament through the allocated seat.

²² See chapter six for discussion on models of disabilities.

²³ See chapter five for discussion on cultural relativism and universalism which outlines in more detail the issues of values in relation to human rights and culture.

²⁴ <http://www.iwgia.org>

²⁵ UN Document number: A/C.3/61/L.18/Rev1

²⁶ <http://www.converge.org.nz/pma/in220606.htm>

²⁷ Tim Caughley, New Zealand representative, CHR 61:item 15: Human Rights and indigenous issues, 11 April 2005. Caughley was responding to a rewrite of the draft Declaration submitted in 2004 by New Zealand, Finland, Norway, Iceland, Sweden and Switzerland. For further information on this matter go to <http://www.converge.org.nz/pma/in080306.htm>.

²⁸ New Zealand Permanent Representative to the United Nations.

²⁹ <http://www.mfat.govt.nz/media-and-publications/Media/MFAT-speeches/0-13-September-2007.php>

³⁰ Indigeneity in the context of this paper is a socio-political form of identity which might or might not be recognised. Chapter two explores ethnicity and indigenous identity as an identity construct, this chapter explores the political issues surrounding this identity.

³¹ See Commission on Human Rights, Sub-Commission on the Prevention of Discrimination and protection of Minorities, *Study on the problem of discrimination against Indigenous Peoples*, prepared by the Special Rapporteur Jose Mendez Cobo, E/CN.4/Sub.2/1986/87 Add 1-4; and Commission on Human Rights, Sub-Commission on the promotion and Protection of Human Rights, Prevention of discrimination and protection of indigenous peoples and minorities, *indigenous peoples and their relationship to land, Final working paper by the Special Rapporteur*, Mrs Erica-Irene A. Daes, E/CN.4/Sub.2/2001/21.ILO Convention No. 169, Article 13 also recognizes this relationship to the land.

³² For further information go to the Maori party website which holds parliamentary speeches made by their MP's. <http://www.maoriparty.com>.

³³ While the Maori Land Court and Te Puni Koriri address Maori issues, they are financed and overseen by the government.

³⁴ For further information see the proceedings from the 11th Meeting of the UN Working Group on Indigenous Rights, at 17, U.N. Doc. E/CN.4/Sub.2/1992/33

³⁵ To understand the United Nations on this issue, see chapter three for further discussion.

³⁶ See chapters two, three, five, six and seven for more discussion on this subject.

³⁷ In May 2006 at the Indigenous Peoples Forum held in New York, a member of the international Indigenous Disability Working Group (IIDCWG) successfully managed to obtain support from the forum for a Special Rapporteur report on

indigenous peoples with disabilities. As yet no further action has been taken to begin this process.

³⁸ For more discussion on cultural rights see chapter three.

³⁹ See chapter three for the discussion of collective/group rights and cultural relativism and universalism.

⁴⁰ [Postscript] This issue remains contentious with the NZ government opposing the Declaration on the Rights of Indigenous Peoples. See chapter three for more discussion on the Declaration.

⁴¹ [Postscript] Since the thesis was completed, the draft Declaration on the Rights of Indigenous Peoples was signed by many States except New Zealand, Australia, Canada and the USA who remain vehemently opposed to the declaration and the provision within it to give indigenous peoples rights of decision-making. For more discussion on this topic see chapter three.

⁴² At the Ad_hoc 8 UN meeting (August 2006), emphasis was placed on re-naming conditions known as mental illness and psychiatric illness with the preferred term psychosocial as a way of differentiating between intellectual impairment and those who have psychosocial experiences. This new term also recognizes that mental illness implies a thinking around 'illness' when many of those with psychosocial experiences are living 'well' lives.

⁴³ Zambia: Persons with Disabilities Act (1996) (Act No. of 1996); Zimbabwe: Disabled Persons Act 1992, Israel: Equal Rights for Persons with Disabilities Act 1998; Australia: Australian Disability Discrimination Act 1992; USA: Americans with Disabilities Act 1990.

⁴⁴ <http://www.drc.govt.uk>.

⁴⁵ http://www.hansard.parliament.govt.nz/hansard/Final/FINAL_2004_05_26.htm#_Toc75685887

⁴⁶ http://www.hansard.parliament.govt.nz/hansard/Final/FINAL_2004_05_26.htm#_Toc75685887

⁴⁷ http://www.hansard.parliament.govt.nz/hansard/final/FINAL_2004_05_06.htm#_Toc75685887

⁴⁸ http://www.hansard.parliament.govt.nz/hansard/Final/FINAL_2004_05_26.htm#_Toc75685887

⁴⁹http://www.hansard.parliament.govt.nz/hansard/Final/FINAL_2007_03_21.htm#_Toc162665021

⁵⁰http://www.hansard.parliament.govt.nz/hansard/Final/FINAL_2007_03_21.htm#_Toc162665021

⁵¹ See chapter six for discussion on paternalistic models of disability such as the medical model and the professional models of disability.

⁵² Discussion with key stakeholders involved in the HDC consumer advisory group reveals there is a consensus to make the advisory nature of the group permanent, with rotational appointments of two years for representatives to allow for the diverse range of representation needed in the disability area.

⁵³http://www.hansard.parliament.govt.nz/hansard/Final/FINAL_2003_10_21.htm#_Toc145227375

⁵⁴ Possibly due not only to their impairment creating learning difficulties; there could also be the issue of whether or not there is an assumption of inability to learn because of their impairment. Their literacy skills may be partly due to an inability to access an appropriate learning style to meet these needs.

⁵⁵ People First New Zealand is an advocacy rights group run by persons with intellectual disabilities about and for intellectual persons with disabilities; the group has been working with Judi Strid of the Health and Disability Commission to develop plain language documents of the HDC code for persons with intellectual disabilities and those who cannot read or write. The Office for Disabilities Issues has also printed a copy of its New Zealand Disability Strategy (2001) in plain language to specifically target those with disabilities whose literacy skills are lower than average.

⁵⁶ See chapter three for more details on group rights and self determination.

⁵⁷ (This establishment has since been closed and the residents relocated into the community).

⁵⁸ From personal discussions with a Nga Puhi woman who is Deaf and who was removed from her family to the Kelston school for the Deaf. She was not able to make contact with her family for many years.

⁵⁹ Hara – translated to mean a sin, a transgression.

⁶⁰ Members of *Te Hunga Haua Awhina Roopu* have often described their relationship with their grandparents as being very important to them.

⁶¹ Chapter two outlines more on the issue of attitudes and identity regarding disability and indigeneity

⁶² From discussion with a key informant, a young woman with disabilities who was raised by her grandmother which caused friction between the grandparents, resulting in the grandfather leaving. Her uncle also wrote a masters paper where he believed it was a *hara* that caused his niece's disability, causing further dissension within the *whānau*. She has a good relationship with the women in her *whānau* who all work together to support her and her partner and child, yet the men appear to struggle with her impairment.

⁶³ Based on personal conversations with several key informants now living independently and active in the People First movement which is an advocacy network by, about and for people with intellectual impairments. Also from conversations with adults whom I have worked with on a one-on-one basis dealing with the issues of abuse in psychiatric institutions when they were children and experienced rape and abuse by staff, along with threats of, and often the actual, electric shock treatment used to control behavioural trouble when the child/adolescent would play up after the abuse or rape allegedly occurred. Currently, legal actions are being taken against some of these institutions and their staff.

⁶⁴ From personal communication with Māori Deaf I have met and with whom I discussed the issues of communication for them as Māori and as Deaf Māori.

⁶⁵ *Ngaati Kapo* is an independent advocacy group for Māori who identify as blind and who advocate for *marae* to allow guide dogs onto *marae*. In June 2006 an issue arose at three national hui on disability in Auckland, Wellington and Christchurch where local *iwi* were concerned at having guide dogs on their *marae*. This issue is still under discussion at the time of writing.

⁶⁶ Landcare research (<http://landcareresearch.co.nz>) has submitted various reports on the state of the waterways in New Zealand, with Waikato being one of those waterways. In December 2006, Raglan experienced a broken sewerage pipe which caused sewerage to flow into the sea, affecting the shellfish. Other reports can be found at <http://www.nzherald.co.nz>.

⁶⁷ There is some evidence of this in correspondence with persons with disabilities over accessing disability support link services, where their impairment and not their social needs is the issue for allocation of resources.

⁶⁸ NIMBY = not in my back yard, is an attitude that is still evident when provider groups such as IHC or Pathways try to set up home environments for clients with these particular impairments. Society still struggles to accept certain groups of persons with disabilities and, in particular, those who are ‘stereotyped’ as being a danger to society such as those who live with psychosocial issues or intellectual impairments whose behaviour may have been deemed inappropriate by the society they live in.

⁶⁹ a telephone service providing telephone communication between Deaf and hearing persons shared through a third party who interprets the data from the specialised phone used by Deaf to hearing persons on the phone. This form of communication creates tensions when personal or intimate information is being

⁷⁰ Personal communications with Māori Deaf networks within New Zealand and with Markhu Johnson, the President of the World Deaf Association (2004-2006), in 2005.

⁷¹ For instance, the social model of disability identifies the individual within the framework. For frameworks to be successful in delivery to Māori, *whānau* need to be at the centre of the framework and not merely mentioned in them.

⁷² The CRPD has used the term ‘persons with disabilities’, placing the emphasis not on the individual but on their impairment, as opposed to the NZDS using the term ‘disabled person’ which places the focus more on the individual.

⁷³ For example diabetes or lifestyle-induced addictions such as drug and alcohol abuse or drug-induced psychosis, are all increasingly impacting since colonisation and the introduction of such substances and foods not suitable to Maori. For further information as to percentages go to <http://www.stats.govt.nz>

⁷⁴ Evolution of knowledge is not always positive, as has been the case around impairment for Māori with disabilities. Even the concept of institutionalisation, individualism and the removal from the concept of community care and support that existed also prior to colonisation have all been impacted by “different” attitudes and thinking that has impeded their social structures.

⁷⁵ Individualised funding is not currently allowed for service delivery for clients funded by the Ministry of Health disability services, although it has been piloted and has been argued for over a number of years, especially by those advocating for intellectual disability supports such as Lorna Sullivan, a disability advocate from Whakatane. On 13 April 2007, Minister for Disabilities Issues Ruth Dyson announced a plan to introduce, in consultation with the Carers Alliance group, a carer's benefit for those family members supporting family members with disabilities.

⁷⁶ This is information from a meeting between Peter and myself in June 2006 where he gave me some background to his services' successful trial of individualised funding and his hope to see individualised funding become a normal part of service delivery policy.

⁷⁷ To view their website outlining their service delivery to this community go to:
<http://www.temanutoroa.org.nz/>

⁷⁸ Rangi Manihera is the co-ordinator of the LIFE Unlimited Kaupapa Māori program in all its centres throughout New Zealand

⁷⁹ These *kaupapa Māori* principles are held within the Mission Statement and/or guiding principles aspect of their service information available to the public.

⁸⁰ See also <http://www.familiescommission.govt.nz/publications/index.php> for recent research developing within the Families Commission around *whānau*/families with disabilities.

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Appendix 1: Panui: Exploring indigenous identity for indigenous persons with disabilities

Panui

“Exploring indigenous identity for indigenous persons with disabilities”

Kia ora, koutou. *I am a Maori student with disabilities completing my PhD on what it means to be an indigenous person living with disabilities and what it means for indigenous persons living with disabilities accessing their community. The main aim of the project is to better understand what it means to live with disabilities for Maori with disabilities and their Whanau. This research will also look at how they are affected by their disabilities when trying to access their Marae and other cultural networks that are a part of their identity as Maori. It is hoped a better understanding of this identity will be the result of this research.*

We are inviting you and/or a designated carer of your choice to be part of a study involving interviews with indigenous people living with a disability.

Interviews

Participation will involve surveys for written completion, and a few will be chosen for face-to-face interviews, approximately 45-60 minutes long. Participants can choose to have a whanau or individual interview. We will be asking you questions on the types of needs you experience as a person who lives with a disability.

In order to ensure as wide a range of disabilities as possible is included, we have organised for interviews to be conducted using a variety of media. If you would, once you have completed the survey wish to take part in a face-to-face interview, please let the researcher know or you can contact the researcher Huhana at details listed below.

We will be asking you for your consent to audiotape the interview. The tapes will be destroyed after the research has finished.

By taking part in this interview you can be assured that:

- Your anonymity will be protected
- You may refuse to answer any question(s),
- You can withdraw at any time,
- You will not be identified in any way in the final report.

Should you need further information, please contact the researcher below:

Huhana Hickey (Ngati Tahinga) Waikato Iwi

PO Box 4467, Hamilton East

Ph: 078582686, mobile: 021 754033

Email: Sjh8@waikato.ac.nz

Appendix 2: Participant consent form: Exploring indigenous identity for indigenous persons with disabilities

PARTICIPANT CONSENT FORM

“Exploring indigenous identity for indigenous persons with disabilities”

- I have read the information sheet for this study and have had the details of the interview explained to me. I have had a chance to ask any questions that I may have had. My questions have been answered to my satisfaction and I understand that I may ask more questions at any time.

- I understand that I am free to withdraw from this interview at any time, or not to answer any particular questions in the interview. I agree to provide information to the researchers on the understanding that my anonymity will be protected.

- I give consent for the interview to be audio taped with the understanding that no full transcripts of the interviews will be made, and that these tapes are solely for the purpose of data collection and will be deleted.

Name: _____

Email: _____

Phone: _____

Signed: _____

Date: _____

Should you need further information, please contact either Huhana or her supervisors at the following contact details:

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Appendix 3: Survey Form

Maori persons with disabilities
Participant Demographic Information

- 1) Gender: Male ____ Female _____
- 2) Age: _____
- 3) Employment Status
____ Unemployed
____ Part time employment
____ Full employment
____ Unpaid employment/Voluntary
- 4) Do you live in a rural or urban area? _____
- 5) What town/city do you currently live in? _____

INTERVIEW SCHEDULE

I'm going to ask you some background and then your opinion about the care and support available, and finally what you see as your needs.

- 1) What is your disability/illness?
 - a) Is this how the medical profession describes your disability/illness?
 Yes
 No
- 2) How long have you had this Disability/illness?
 less than 10 years
 more than 10 years
- 3) How do you cope with your disability/illness?

- 4) How does your Whanau cope with your disability/illness?
- 5) How has your Whanau supported you since you began experiencing life with your disability/illness?
- 6) Do you live with the person who provides your carer support?
- 7) What is your relationship to this person i.e. whanau, friend, etc, agency?
- 8) Is this person your primary caregiver or is care shared with other people?
(Please state who?)
- 9) Are there other people or health/disability workers who also provide support or care for you?
- NO - - - - Please comment
- Yes ---- Please comment
- 10) Do you have contact with your Iwi/Hapu?
- 11) How do you feel about your contact (or lack of contact) with the Maori community?

Prompts:

- Satisfied with contact
- Satisfied with lack of contact
- Dissatisfied with (specify) -
- Other (give detail) -

12) Since identifying with your disability/illness, have you been able to return to Marae activities?

- If so, how?
- If not, why not?

13) Have you faced any attitude problems or opinions from other Maori since identifying with your disability/illness?

- NO - - - - Please describe why?
- YES - - - - Please describe why?

14) What do you believe are the reasons for the attitudes or opinions you have faced from other Maori about your disability/illness and disabilities generally?

15) Who do you contact for advice about accessing health/disability care?

- Whanau
- Doctor
- Nurse
- Maori health/disability provider
- Hospital
- Other people who provide care to people with similar disabilities/illnesses
- Other (specify) -

16) Who do you contact when there is some crisis?
(tick more than one if more than one is relevant for you)

- Whanau
- Doctor

- Nurse
- Maori health/disability provider
- Other people who provide care to people with similar disabilities/illnesses
- Hospital
- Other (specify) -

17) Do you believe you:

A) have the support you need to fully be a part of the Maori community; and

B) would this be different if you didn't have disabilities/illnesses to live with?

18) Is there anything else that would be helpful and anything else you would like to say?

Thank you for taking the time to fill this out.

If you would like to be considered for a face to face interview please add your name and contact details:

Appendix 4: Universal Declaration of Human Rights

Universal Declaration of Human Rights

Preamble

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people,

Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations,

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

Whereas Member States have pledged themselves to achieve, in cooperation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge,

Now, therefore,

The General Assembly,

Proclaims this Universal Declaration of Human Rights as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

Article 1

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Article 2

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

Article 3

Everyone has the right to life, liberty and security of person.

Article 4

No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

Article 5

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

Article 6

Everyone has the right to recognition everywhere as a person before the law.

Article 7

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

Article 8

Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

Article 9

No one shall be subjected to arbitrary arrest, detention or exile.

Article 10

Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights and obligations and of any criminal charge against him.

Article 11

1. Everyone charged with a penal offence has the right to be presumed innocent until proved guilty according to law in a public trial at which he has had all the guarantees necessary for his defence.
2. No one shall be held guilty of any penal offence on account of any act or omission which did not constitute a penal offence, under national or international law, at the time when it was committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time the penal offence was committed.

Article 12

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

Article 13

1. Everyone has the right to freedom of movement and residence within the borders of each State.
2. Everyone has the right to leave any country, including his own, and to return to his country.

Article 14

1. Everyone has the right to seek and to enjoy in other countries asylum from persecution.
2. This right may not be invoked in the case of prosecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.

Article 15

1. Everyone has the right to a nationality.

2. No one shall be arbitrarily deprived of his nationality nor denied the right to change his nationality.

Article 16

1. Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.

2. Marriage shall be entered into only with the free and full consent of the intending spouses.

3. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

Article 17

1. Everyone has the right to own property alone as well as in association with others.

2. No one shall be arbitrarily deprived of his property.

Article 18

Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

Article 19

Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 20

1. Everyone has the right to freedom of peaceful assembly and association.

2. No one may be compelled to belong to an association.

Article 21

1. Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.

2. Everyone has the right to equal access to public service in his country.

3. The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

Article 22

Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 23

1. Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.

2. Everyone, without any discrimination, has the right to equal pay for equal work.

3. Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.

4. Everyone has the right to form and to join trade unions for the protection of his interests.

Article 24

Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

Article 25

1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

Article 26

1. Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.

2. Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace.

3. Parents have a prior right to choose the kind of education that shall be given to their children.

Article 27

1. Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.

2. Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

Article 28

Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

Article 29

1. Everyone has duties to the community in which alone the free and full development of his personality is possible.

2. In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.

3. These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

Article 30

Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

<http://www.unhchr.ch/udhr/lang/eng.htm>

Appendix 5: Convention on the Rights of the Child

Convention on the Rights of the Child
Adopted and opened for signature, ratification and accession by
General Assembly resolution 44/25
of 20 November 1989
entry into force 2 September 1990, in accordance with article 49

Preamble

The States Parties to the present Convention,
Considering that, in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,
Bearing in mind that the peoples of the United Nations have, in the Charter, reaffirmed their faith in fundamental human rights and in the dignity and worth of the human person, and have determined to promote social progress and better standards of life in larger freedom,
Recognizing that the United Nations has, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status,
Recalling that, in the Universal Declaration of Human Rights, the United Nations has proclaimed that childhood is entitled to special care and assistance,
Convinced that the family, as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community,
Recognizing that the child, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding,
Considering that the child should be fully prepared to live an individual life in society, and brought up in the spirit of the ideals proclaimed in the Charter of the United Nations, and in particular in the spirit of peace, dignity, tolerance, freedom, equality and solidarity,
Bearing in mind that the need to extend particular care to the child has been stated in the Geneva Declaration of the Rights of the Child of 1924 and in the Declaration of the Rights of the Child adopted by the General Assembly on 20 November 1959 and recognized in the Universal Declaration of Human Rights, in the International Covenant on Civil and Political Rights (in particular in articles 23 and 24), in the International Covenant on Economic, Social and Cultural Rights (in particular in article 10) and in the statutes and relevant instruments of specialized agencies and international organizations concerned with the welfare of children, '
Bearing in mind that, as indicated in the Declaration of the Rights of the Child, "the child, by reason of his physical and mental immaturity, needs special

safeguards and care, including appropriate legal protection, before as well as after birth",

Recalling the provisions of the Declaration on Social and Legal Principles relating to the Protection and Welfare of Children, with Special Reference to Foster Placement and Adoption Nationally and Internationally; the United Nations Standard Minimum Rules for the Administration of Juvenile Justice (The Beijing Rules) ; and the Declaration on the Protection of Women and Children in Emergency and Armed Conflict,

Recognizing that, in all countries in the world, there are children living in exceptionally difficult conditions, and that such children need special consideration,

Taking due account of the importance of the traditions and cultural values of each people for the protection and harmonious development of the child,

Recognizing the importance of international co-operation for improving the living conditions of children in every country, in particular in the developing countries,

Have agreed as follows:

PART I

Article 1

For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.

Article 2

1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

2. States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.

Article 3

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.

3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

Article 4

States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention. With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international co-operation.

Article 5

States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.

Article 6

1. States Parties recognize that every child has the inherent right to life.
2. States Parties shall ensure to the maximum extent possible the survival and development of the child.

Article 7

1. The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents.
2. States Parties shall ensure the implementation of these rights in accordance with their national law and their obligations under the relevant international instruments in this field, in particular where the child would otherwise be stateless.

Article 8

1. States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.
2. Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity.

Article 9

1. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. Such determination may be necessary in a particular case such as one involving abuse or neglect of the child by the parents, or one where the parents are living separately and a decision must be made as to the child's place of residence.
2. In any proceedings pursuant to paragraph 1 of the present article, all interested parties shall be given an opportunity to participate in the proceedings and make their views known.
3. States Parties shall respect the right of the child who is separated from one or both parents to maintain personal relations and direct contact with both parents on a regular basis, except if it is contrary to the child's best interests.
4. Where such separation results from any action initiated by a State Party, such as the detention, imprisonment, exile, deportation or death (including death arising from any cause while the person is in the custody of the State) of one or both parents or of the child, that State Party shall, upon request, provide the parents, the child or, if appropriate, another member of the family with the essential information concerning the whereabouts of the absent member(s) of the family unless the provision of the information would be detrimental to the well-being of the child. States Parties shall further ensure that the submission of such a request shall of itself entail no adverse consequences for the person(s) concerned.

Article 10

1. In accordance with the obligation of States Parties under article 9, paragraph 1, applications by a child or his or her parents to enter or leave a State Party for the purpose of family reunification shall be dealt with by States Parties in a positive, humane and expeditious manner. States Parties shall further ensure that the submission of such a request shall entail no adverse consequences for the applicants and for the members of their family.
2. A child whose parents reside in different States shall have the right to maintain on a regular basis, save in exceptional circumstances personal relations and direct contacts with both parents. Towards that end and in accordance with the obligation of States Parties under article 9, paragraph 1, States Parties shall respect the right of the child and his or her parents to leave any country, including their own, and to enter their own country. The right to leave any country shall be subject only to such restrictions as are prescribed by law and which are necessary to protect the national security, public order (*ordre public*), public health or morals or the rights and freedoms of others and are consistent with the other rights recognized in the present Convention.

Article 11

1. States Parties shall take measures to combat the illicit transfer and non-return of children abroad.
2. To this end, States Parties shall promote the conclusion of bilateral or multilateral agreements or accession to existing agreements.

Article 12

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

Article 13

1. The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.
2. The exercise of this right may be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:
 - (a) For respect of the rights or reputations of others; or
 - (b) For the protection of national security or of public order (*ordre public*), or of public health or morals.

Article 14

1. States Parties shall respect the right of the child to freedom of thought, conscience and religion.
2. States Parties shall respect the rights and duties of the parents and, when applicable, legal guardians, to provide direction to the child in the exercise of his or her right in a manner consistent with the evolving capacities of the child.
3. Freedom to manifest one's religion or beliefs may be subject only to such limitations as are prescribed by law and are necessary to protect public safety, order, health or morals, or the fundamental rights and freedoms of others.

Article 15

1. States Parties recognize the rights of the child to freedom of association and to freedom of peaceful assembly.
2. No restrictions may be placed on the exercise of these rights other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order (ordre public), the protection of public health or morals or the protection of the rights and freedoms of others.

Article 16

1. No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation.
2. The child has the right to the protection of the law against such interference or attacks.

Article 17

States Parties recognize the important function performed by the mass media and shall ensure that the child has access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health. To this end, States Parties shall:

- (a) Encourage the mass media to disseminate information and material of social and cultural benefit to the child and in accordance with the spirit of article 29;
- (b) Encourage international co-operation in the production, exchange and dissemination of such information and material from a diversity of cultural, national and international sources;
- (c) Encourage the production and dissemination of children's books;
- (d) Encourage the mass media to have particular regard to the linguistic needs of the child who belongs to a minority group or who is indigenous;
- (e) Encourage the development of appropriate guidelines for the protection of the child from information and material injurious to his or her well-being, bearing in mind the provisions of articles 13 and 18.

Article 18

1. States Parties shall use their best efforts to ensure recognition of the principle that both parents have common responsibilities for the upbringing and development of the child. Parents or, as the case may be, legal guardians, have the primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern.
2. For the purpose of guaranteeing and promoting the rights set forth in the present Convention, States Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.
3. States Parties shall take all appropriate measures to ensure that children of working parents have the right to benefit from child-care services and facilities for which they are eligible.

Article 19

1. States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or

exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.

2. Such protective measures should, as appropriate, include effective procedures for the establishment of social programmes to provide necessary support for the child and for those who have the care of the child, as well as for other forms of prevention and for identification, reporting, referral, investigation, treatment and follow-up of instances of child maltreatment described heretofore, and, as appropriate, for judicial involvement.

Article 20

1. A child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State.

2. States Parties shall in accordance with their national laws ensure alternative care for such a child.

3. Such care could include, inter alia, foster placement, kafalah of Islamic law, adoption or if necessary placement in suitable institutions for the care of children. When considering solutions, due regard shall be paid to the desirability of continuity in a child's upbringing and to the child's ethnic, religious, cultural and linguistic background.

Article 21

States Parties that recognize and/or permit the system of adoption shall ensure that the best interests of the child shall be the paramount consideration and they shall:

(a) Ensure that the adoption of a child is authorized only by competent authorities who determine, in accordance with applicable law and procedures and on the basis of all pertinent and reliable information, that the adoption is permissible in view of the child's status concerning parents, relatives and legal guardians and that, if required, the persons concerned have given their informed consent to the adoption on the basis of such counselling as may be necessary;

(b) Recognize that inter-country adoption may be considered as an alternative means of child's care, if the child cannot be placed in a foster or an adoptive family or cannot in any suitable manner be cared for in the child's country of origin; (c) Ensure that the child concerned by inter-country adoption enjoys safeguards and standards equivalent to those existing in the case of national adoption;

(d) Take all appropriate measures to ensure that, in inter-country adoption, the placement does not result in improper financial gain for those involved in it;

(e) Promote, where appropriate, the objectives of the present article by concluding bilateral or multilateral arrangements or agreements, and endeavour, within this framework, to ensure that the placement of the child in another country is carried out by competent authorities or organs.

Article 22

1. States Parties shall take appropriate measures to ensure that a child who is seeking refugee status or who is considered a refugee in accordance with applicable international or domestic law and procedures shall, whether unaccompanied or accompanied by his or her parents or by any other person, receive appropriate protection and humanitarian assistance in the enjoyment of applicable rights set forth in the present Convention and in other international human rights or humanitarian instruments to which the said States are Parties.

2. For this purpose, States Parties shall provide, as they consider appropriate, co-operation in any efforts by the United Nations and other competent

intergovernmental organizations or non-governmental organizations co-operating with the United Nations to protect and assist such a child and to trace the parents or other members of the family of any refugee child in order to obtain information necessary for reunification with his or her family. In cases where no parents or other members of the family can be found, the child shall be accorded the same protection as any other child permanently or temporarily deprived of his or her family environment for any reason, as set forth in the present Convention.

Article 23

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.
2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.
3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.
4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

Article 24

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.
2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:
 - (a) To diminish infant and child mortality;
 - (b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
 - (c) To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;
 - (d) To ensure appropriate pre-natal and post-natal health care for mothers;
 - (e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic

knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;

(f) To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

Article 25

States Parties recognize the right of a child who has been placed by the competent authorities for the purposes of care, protection or treatment of his or her physical or mental health, to a periodic review of the treatment provided to the child and all other circumstances relevant to his or her placement.

Article 26

1. States Parties shall recognize for every child the right to benefit from social security, including social insurance, and shall take the necessary measures to achieve the full realization of this right in accordance with their national law.

2. The benefits should, where appropriate, be granted, taking into account the resources and the circumstances of the child and persons having responsibility for the maintenance of the child, as well as any other consideration relevant to an application for benefits made by or on behalf of the child.

Article 27

1. States Parties recognize the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development.

2. The parent(s) or others responsible for the child have the primary responsibility to secure, within their abilities and financial capacities, the conditions of living necessary for the child's development.

3. States Parties, in accordance with national conditions and within their means, shall take appropriate measures to assist parents and others responsible for the child to implement this right and shall in case of need provide material assistance and support programmes, particularly with regard to nutrition, clothing and housing.

4. States Parties shall take all appropriate measures to secure the recovery of maintenance for the child from the parents or other persons having financial responsibility for the child, both within the State Party and from abroad. In particular, where the person having financial responsibility for the child lives in a State different from that of the child, States Parties shall promote the accession to international agreements or the conclusion of such agreements, as well as the making of other appropriate arrangements.

Article 28

1. States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:

(a) Make primary education compulsory and available free to all;

(b) Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, and take appropriate measures such as the introduction of free education and offering financial assistance in case of need;

- (c) Make higher education accessible to all on the basis of capacity by every appropriate means;
- (d) Make educational and vocational information and guidance available and accessible to all children;
- (e) Take measures to encourage regular attendance at schools and the reduction of drop-out rates.

2. States Parties shall take all appropriate measures to ensure that school discipline is administered in a manner consistent with the child's human dignity and in conformity with the present Convention.

3. States Parties shall promote and encourage international cooperation in matters relating to education, in particular with a view to contributing to the elimination of ignorance and illiteracy throughout the world and facilitating access to scientific and technical knowledge and modern teaching methods. In this regard, particular account shall be taken of the needs of developing countries.

Article 29 General comment on its implementation

1. States Parties agree that the education of the child shall be directed to:

- (a) The development of the child's personality, talents and mental and physical abilities to their fullest potential;
- (b) The development of respect for human rights and fundamental freedoms, and for the principles enshrined in the Charter of the United Nations;
- (c) The development of respect for the child's parents, his or her own cultural identity, language and values, for the national values of the country in which the child is living, the country from which he or she may originate, and for civilizations different from his or her own;
- (d) The preparation of the child for responsible life in a free society, in the spirit of understanding, peace, tolerance, equality of sexes, and friendship among all peoples, ethnic, national and religious groups and persons of indigenous origin;
- (e) The development of respect for the natural environment.

2. No part of the present article or article 28 shall be construed so as to interfere with the liberty of individuals and bodies to establish and direct educational institutions, subject always to the observance of the principle set forth in paragraph 1 of the present article and to the requirements that the education given in such institutions shall conform to such minimum standards as may be laid down by the State.

Article 30

In those States in which ethnic, religious or linguistic minorities or persons of indigenous origin exist, a child belonging to such a minority or who is indigenous shall not be denied the right, in community with other members of his or her group, to enjoy his or her own culture, to profess and practise his or her own religion, or to use his or her own language.

Article 31

1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.
2. States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.

Article 32

1. States Parties recognize the right of the child to be protected from economic exploitation and from performing any work that is likely to be hazardous or to

interfere with the child's education, or to be harmful to the child's health or physical, mental, spiritual, moral or social development.

2. States Parties shall take legislative, administrative, social and educational measures to ensure the implementation of the present article. To this end, and having regard to the relevant provisions of other international instruments, States Parties shall in particular: (a) Provide for a minimum age or minimum ages for admission to employment;

(b) Provide for appropriate regulation of the hours and conditions of employment;

(c) Provide for appropriate penalties or other sanctions to ensure the effective enforcement of the present article.

Article 33

States Parties shall take all appropriate measures, including legislative, administrative, social and educational measures, to protect children from the illicit use of narcotic drugs and psychotropic substances as defined in the relevant international treaties, and to prevent the use of children in the illicit production and trafficking of such substances.

Article 34

States Parties undertake to protect the child from all forms of sexual exploitation and sexual abuse. For these purposes, States Parties shall in particular take all appropriate national, bilateral and multilateral measures to prevent:

(a) The inducement or coercion of a child to engage in any unlawful sexual activity;

(b) The exploitative use of children in prostitution or other unlawful sexual practices;

(c) The exploitative use of children in pornographic performances and materials.

Article 35

States Parties shall take all appropriate national, bilateral and multilateral measures to prevent the abduction of, the sale of or traffic in children for any purpose or in any form.

Article 36

States Parties shall protect the child against all other forms of exploitation prejudicial to any aspects of the child's welfare.

Article 37

States Parties shall ensure that:

(a) No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment. Neither capital punishment nor life imprisonment without possibility of release shall be imposed for offences committed by persons below eighteen years of age;

(b) No child shall be deprived of his or her liberty unlawfully or arbitrarily. The arrest, detention or imprisonment of a child shall be in conformity with the law and shall be used only as a measure of last resort and for the shortest appropriate period of time;

(c) Every child deprived of liberty shall be treated with humanity and respect for the inherent dignity of the human person, and in a manner which takes into account the needs of persons of his or her age. In particular, every child deprived of liberty shall be separated from adults unless it is considered in the child's best interest not to do so and shall have the right to maintain contact with his or her family through correspondence and visits, save in exceptional circumstances;

(d) Every child deprived of his or her liberty shall have the right to prompt access to legal and other appropriate assistance, as well as the right to challenge the

legality of the deprivation of his or her liberty before a court or other competent, independent and impartial authority, and to a prompt decision on any such action.

Article 38

1. States Parties undertake to respect and to ensure respect for rules of international humanitarian law applicable to them in armed conflicts which are relevant to the child.
2. States Parties shall take all feasible measures to ensure that persons who have not attained the age of fifteen years do not take a direct part in hostilities.
3. States Parties shall refrain from recruiting any person who has not attained the age of fifteen years into their armed forces. In recruiting among those persons who have attained the age of fifteen years but who have not attained the age of eighteen years, States Parties shall endeavour to give priority to those who are oldest.
4. In accordance with their obligations under international humanitarian law to protect the civilian population in armed conflicts, States Parties shall take all feasible measures to ensure protection and care of children who are affected by an armed conflict.

Article 39

States Parties shall take all appropriate measures to promote physical and psychological recovery and social reintegration of a child victim of: any form of neglect, exploitation, or abuse; torture or any other form of cruel, inhuman or degrading treatment or punishment; or armed conflicts. Such recovery and reintegration shall take place in an environment which fosters the health, self-respect and dignity of the child.

Article 40

1. States Parties recognize the right of every child alleged as, accused of, or recognized as having infringed the penal law to be treated in a manner consistent with the promotion of the child's sense of dignity and worth, which reinforces the child's respect for the human rights and fundamental freedoms of others and which takes into account the child's age and the desirability of promoting the child's reintegration and the child's assuming a constructive role in society.
2. To this end, and having regard to the relevant provisions of international instruments, States Parties shall, in particular, ensure that:
 - (a) No child shall be alleged as, be accused of, or recognized as having infringed the penal law by reason of acts or omissions that were not prohibited by national or international law at the time they were committed;
 - (b) Every child alleged as or accused of having infringed the penal law has at least the following guarantees:
 - (i) To be presumed innocent until proven guilty according to law;
 - (ii) To be informed promptly and directly of the charges against him or her, and, if appropriate, through his or her parents or legal guardians, and to have legal or other appropriate assistance in the preparation and presentation of his or her defence;
 - (iii) To have the matter determined without delay by a competent, independent and impartial authority or judicial body in a fair hearing according to law, in the presence of legal or other appropriate assistance and, unless it is considered not to be in the best interest of the child, in particular, taking into account his or her age or situation, his or her parents or legal guardians;

(iv) Not to be compelled to give testimony or to confess guilt; to examine or have examined adverse witnesses and to obtain the participation and examination of witnesses on his or her behalf under conditions of equality;

(v) If considered to have infringed the penal law, to have this decision and any measures imposed in consequence thereof reviewed by a higher competent, independent and impartial authority or judicial body according to law;

(vi) To have the free assistance of an interpreter if the child cannot understand or speak the language used;

(vii) To have his or her privacy fully respected at all stages of the proceedings. 3. States Parties shall seek to promote the establishment of laws, procedures, authorities and institutions specifically applicable to children alleged as, accused of, or recognized as having infringed the penal law, and, in particular:

(a) The establishment of a minimum age below which children shall be presumed not to have the capacity to infringe the penal law;

(b) Whenever appropriate and desirable, measures for dealing with such children without resorting to judicial proceedings, providing that human rights and legal safeguards are fully respected.

4. A variety of dispositions, such as care, guidance and supervision orders; counselling; probation; foster care; education and vocational training programmes and other alternatives to institutional care shall be available to ensure that children are dealt with in a manner appropriate to their well-being and proportionate both to their circumstances and the offence.

Article 41

Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of the child and which may be contained in:

(a) The law of a State party; or

(b) International law in force for that State.

PART II

Article 42

States Parties undertake to make the principles and provisions of the Convention widely known, by appropriate and active means, to adults and children alike.

Article 43

1. For the purpose of examining the progress made by States Parties in achieving the realization of the obligations undertaken in the present Convention, there shall be established a Committee on the Rights of the Child, which shall carry out the functions hereinafter provided.

2. The Committee shall consist of ten experts of high moral standing and recognized competence in the field covered by this Convention. The members of the Committee shall be elected by States Parties from among their nationals and shall serve in their personal capacity, consideration being given to equitable geographical distribution, as well as to the principal legal systems. (amendment)

3. The members of the Committee shall be elected by secret ballot from a list of persons nominated by States Parties. Each State Party may nominate one person from among its own nationals.

4. The initial election to the Committee shall be held no later than six months after the date of the entry into force of the present Convention and thereafter every second year. At least four months before the date of each election, the Secretary-General of the United Nations shall address a letter to States Parties inviting them to submit their nominations within two months. The Secretary-General shall

subsequently prepare a list in alphabetical order of all persons thus nominated, indicating States Parties which have nominated them, and shall submit it to the States Parties to the present Convention.

5. The elections shall be held at meetings of States Parties convened by the Secretary-General at United Nations Headquarters. At those meetings, for which two thirds of States Parties shall constitute a quorum, the persons elected to the Committee shall be those who obtain the largest number of votes and an absolute majority of the votes of the representatives of States Parties present and voting.

6. The members of the Committee shall be elected for a term of four years. They shall be eligible for re-election if renominated. The term of five of the members elected at the first election shall expire at the end of two years; immediately after the first election, the names of these five members shall be chosen by lot by the Chairman of the meeting.

7. If a member of the Committee dies or resigns or declares that for any other cause he or she can no longer perform the duties of the Committee, the State Party which nominated the member shall appoint another expert from among its nationals to serve for the remainder of the term, subject to the approval of the Committee.

8. The Committee shall establish its own rules of procedure.

9. The Committee shall elect its officers for a period of two years.

10. The meetings of the Committee shall normally be held at United Nations Headquarters or at any other convenient place as determined by the Committee. The Committee shall normally meet annually. The duration of the meetings of the Committee shall be determined, and reviewed, if necessary, by a meeting of the States Parties to the present Convention, subject to the approval of the General Assembly.

11. The Secretary-General of the United Nations shall provide the necessary staff and facilities for the effective performance of the functions of the Committee under the present Convention.

12. With the approval of the General Assembly, the members of the Committee established under the present Convention shall receive emoluments from United Nations resources on such terms and conditions as the Assembly may decide.

Article 44

1. States Parties undertake to submit to the Committee, through the Secretary-General of the United Nations, reports on the measures they have adopted which give effect to the rights recognized herein and on the progress made on the enjoyment of those rights:

(a) Within two years of the entry into force of the Convention for the State Party concerned;

(b) Thereafter every five years.

2. Reports made under the present article shall indicate factors and difficulties, if any, affecting the degree of fulfilment of the obligations under the present Convention. Reports shall also contain sufficient information to provide the Committee with a comprehensive understanding of the implementation of the Convention in the country concerned.

3. A State Party which has submitted a comprehensive initial report to the Committee need not, in its subsequent reports submitted in accordance with paragraph 1 (b) of the present article, repeat basic information previously provided.

4. The Committee may request from States Parties further information relevant to the implementation of the Convention.
5. The Committee shall submit to the General Assembly, through the Economic and Social Council, every two years, reports on its activities.
6. States Parties shall make their reports widely available to the public in their own countries.

Article 45

In order to foster the effective implementation of the Convention and to encourage international co-operation in the field covered by the Convention:

- (a) The specialized agencies, the United Nations Children's Fund, and other United Nations organs shall be entitled to be represented at the consideration of the implementation of such provisions of the present Convention as fall within the scope of their mandate. The Committee may invite the specialized agencies, the United Nations Children's Fund and other competent bodies as it may consider appropriate to provide expert advice on the implementation of the Convention in areas falling within the scope of their respective mandates. The Committee may invite the specialized agencies, the United Nations Children's Fund, and other United Nations organs to submit reports on the implementation of the Convention in areas falling within the scope of their activities;
- (b) The Committee shall transmit, as it may consider appropriate, to the specialized agencies, the United Nations Children's Fund and other competent bodies, any reports from States Parties that contain a request, or indicate a need, for technical advice or assistance, along with the Committee's observations and suggestions, if any, on these requests or indications;
- (c) The Committee may recommend to the General Assembly to request the Secretary-General to undertake on its behalf studies on specific issues relating to the rights of the child;
- (d) The Committee may make suggestions and general recommendations based on information received pursuant to articles 44 and 45 of the present Convention. Such suggestions and general recommendations shall be transmitted to any State Party concerned and reported to the General Assembly, together with comments, if any, from States Parties.

PART III

Article 46

The present Convention shall be open for signature by all States.

Article 47

The present Convention is subject to ratification. Instruments of ratification shall be deposited with the Secretary-General of the United Nations.

Article 48

The present Convention shall remain open for accession by any State. The instruments of accession shall be deposited with the Secretary-General of the United Nations.

Article 49

1. The present Convention shall enter into force on the thirtieth day following the date of deposit with the Secretary-General of the United Nations of the twentieth instrument of ratification or accession.
2. For each State ratifying or acceding to the Convention after the deposit of the twentieth instrument of ratification or accession, the Convention shall enter into force on the thirtieth day after the deposit by such State of its instrument of ratification or accession.

Article 50

1. Any State Party may propose an amendment and file it with the Secretary-General of the United Nations. The Secretary-General shall thereupon communicate the proposed amendment to States Parties, with a request that they indicate whether they favour a conference of States Parties for the purpose of considering and voting upon the proposals. In the event that, within four months from the date of such communication, at least one third of the States Parties favour such a conference, the Secretary-General shall convene the conference under the auspices of the United Nations. Any amendment adopted by a majority of States Parties present and voting at the conference shall be submitted to the General Assembly for approval.

2. An amendment adopted in accordance with paragraph 1 of the present article shall enter into force when it has been approved by the General Assembly of the United Nations and accepted by a two-thirds majority of States Parties.

3. When an amendment enters into force, it shall be binding on those States Parties which have accepted it, other States Parties still being bound by the provisions of the present Convention and any earlier amendments which they have accepted.

Article 51

1. The Secretary-General of the United Nations shall receive and circulate to all States the text of reservations made by States at the time of ratification or accession.

2. A reservation incompatible with the object and purpose of the present Convention shall not be permitted.

3. Reservations may be withdrawn at any time by notification to that effect addressed to the Secretary-General of the United Nations, who shall then inform all States. Such notification shall take effect on the date on which it is received by the Secretary-General

Article 52

A State Party may denounce the present Convention by written notification to the Secretary-General of the United Nations. Denunciation becomes effective one year after the date of receipt of the notification by the Secretary-General.

Article 53

The Secretary-General of the United Nations is designated as the depositary of the present Convention.

Article 54

The original of the present Convention, of which the Arabic, Chinese, English, French, Russian and Spanish texts are equally authentic, shall be deposited with the Secretary-General of the United Nations.

IN WITNESS THEREOF the undersigned plenipotentiaries, being duly authorized thereto by their respective governments, have signed the present Convention.

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Office of the United Nations High Commissioner for Human Rights
Geneva, Switzerland

Appendix 6: The Convention on the Elimination of All Forms of Discrimination against Women

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), adopted in 1979 by the UN General Assembly, is often described as an international bill of rights for women. Consisting of a preamble and 30 articles, it defines what constitutes discrimination against women and sets up an agenda for national action to end such discrimination.

The Convention defines discrimination against women as "...any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field."

By accepting the Convention, States commit themselves to undertake a series of measures to end discrimination against women in all forms, including:

- to incorporate the principle of equality of men and women in their legal system, abolish all discriminatory laws and adopt appropriate ones prohibiting discrimination against women;
- to establish tribunals and other public institutions to ensure the effective protection of women against discrimination; and
- to ensure elimination of all acts of discrimination against women by persons, organizations or enterprises.

The Convention provides the basis for realizing equality between women and men through ensuring women's equal access to, and equal opportunities in, political and public life -- including the right to vote and to stand for election -- as well as education, health and employment. States parties agree to take all appropriate measures, including legislation and temporary special measures, so that women can enjoy all their human rights and fundamental freedoms.

The Convention is the only human rights treaty which affirms the reproductive rights of women and targets culture and tradition as influential forces shaping gender roles and family relations. It affirms women's rights to acquire, change or retain their nationality and the nationality of their children. States parties also agree to take appropriate measures against all forms of traffic in women and exploitation of women.

Countries that have ratified or acceded to the Convention are legally bound to put its provisions into practice. They are also committed to submit national reports, at least every four years, on measures they have taken to comply with their treaty obligations.

The Convention, which entered into force on 3 September 1981, has, as of March 2004, 176 States parties.

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United Nations Division for the Advancement of Women
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Appendix 7: Declaration on the Rights of Disabled Persons

Declaration on the Rights of Disabled Persons

Proclaimed by General Assembly resolution 3447 (XXX) of 9 December 1975

The General Assembly,

Mindful of the pledge made by Member States, under the Charter of the United Nations to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,

Reaffirming its faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,

Recalling the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, the Declaration of the Rights of the Child and the Declaration on the Rights of Mentally Retarded Persons, as well as the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organisation, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and other organizations concerned,

Recalling also Economic and Social Council resolution 1921 (LVIII) of 6 May 1975 on the prevention of disability and the rehabilitation of disabled persons,

Emphasizing that the Declaration on Social Progress and Development has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

Bearing in mind the necessity of preventing physical and mental disabilities and of assisting disabled persons to develop their abilities in the most varied fields of activities and of promoting their integration as far as possible in normal life,

Aware that certain countries, at their present stage of development, can devote only limited efforts to this end,

Proclaims this Declaration on the Rights of Disabled Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

1. The term "disabled person" means any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities.
2. Disabled persons shall enjoy all the rights set forth in this Declaration. These rights shall be granted to all disabled persons without any exception whatsoever and without distinction or discrimination on the basis of race, colour, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth or any other situation applying either to the disabled person himself or herself or to his or her family.
3. Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.

4. Disabled persons have the same civil and political rights as other human beings; paragraph 7 of the Declaration on the Rights of Mentally Retarded Persons applies to any possible limitation or suppression of those rights for mentally disabled persons.

5. Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible.

6. Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthetic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration.

7. Disabled persons have the right to economic and social security and to a decent level of living. They have the right, according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation and to join trade unions.

8. Disabled persons are entitled to have their special needs taken into consideration at all stages of economic and social planning.

9. Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement which he or she may derive therefrom. If the stay of a disabled person in a specialized establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.

10. Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.

11. Disabled persons shall be able to avail themselves of qualified legal aid when such aid proves indispensable for the protection of their persons and property. If judicial proceedings are instituted against them, the legal procedure applied shall take their physical and mental condition fully into account.

12. Organizations of disabled persons may be usefully consulted in all matters regarding the rights of disabled persons.

13. Disabled persons, their families and communities shall be fully informed, by all appropriate means, of the rights contained in this Declaration.

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Office of the United Nations High Commissioner for Human Rights Geneva, Switzerland

<http://www.unhcr.ch/html/menu3/b/72.htm>

Appendix 8: Declaration on the Rights of Mentally Retarded Persons

Declaration on the Rights of Mentally Retarded Persons, G.A. res. 2856 (XXVI), 26 U.N. GAOR Supp. (No. 29) at 93, U.N. Doc. A/8429 (1971).

The General Assembly,

Mindful of the pledge of the States Members of the United Nations under the Charter to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,

Reaffirming faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,

Recalling the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, the Declaration of the Rights of the Child and the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organisation, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and other organizations concerned,

Emphasizing that the Declaration on Social Progress and Development has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

Bearing in mind the necessity of assisting mentally retarded persons to develop their abilities in various fields of activities and of promoting their integration as far as possible in normal life,

Aware that certain countries, at their present stage of development, can devote only limited efforts to this end,

Proclaims this Declaration on the Rights of Mentally Retarded Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.
2. The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.
3. The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.
4. Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.
5. The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.
6. The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offence, he shall have a right to

due process of law with full recognition being given to his degree of mental responsibility.

7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

<http://www1.umn.edu/humanrts/instree/t1drrmp.htm>

Appendix 9: Proclamation on the Full Participation and Equality of People With Disabilities in the Asian and Pacific Region

Proclamation on the Full Participation and Equality of People With Disabilities in the Asian and Pacific Region,

1. We the government leaders of ESCAP members and associate members recognize that:

- Every day in this region people are being disabled due to malnutrition and disease, environmental hazards, natural disasters, traffic and industrial accidents, civil conflict and war.
- As a concomitant of improvements in child survival, the numbers of children surviving with disabilities are increasing.
- As more people survive to older age, the numbers of elderly people with disabilities are rising.
- The living conditions of large numbers of people with disabilities, especially those in rural areas, need to be further improved.

2. We note that in Asian and Pacific societies, minimum care and service are, to a large extent, provided for people with disabilities in the traditional family and community context. However, much more must be done to enable persons with disabilities to develop their full potential so that they may live as agents of their own destiny in the rapidly changing economic and social conditions of the region.

3. Throughout the region, the opportunities for full participation and equality for people with disabilities, especially in the fields of rehabilitation, education and employment, continue to be far less than those for their non-disabled peers. This is largely because negative social attitudes exclude persons with disabilities from an equal share in their entitlements as citizens. Such attitudes also curtail the opportunities of people with disabilities for social contact and close personal relationships with others. The social stigma associated all too often with disabilities must be eradicated.

4. The built environment throughout much of Asia and the Pacific has been designed without consideration for the special needs of persons with disabilities. Physical obstacles and social barriers prevent citizens with disabilities from participating in community and national life. The various impediments to participation and equality are especially formidable for girls and women with disabilities. With improved attitudes, increased awareness and much care, we can build social and physical environments that are accessible for all, i.e., we must work towards a society for all. In this regard, we urge the free exchange of information.

5. We take pride in the fact that in economic terms, Asia and the Pacific is the fastest growing region in the world today. We are also aware that countries in this region are at different levels of development. We resolve that economic progress will also be reflected in the efforts that we devote to this extremely vulnerable social group in our societies: people with disabilities.

6. We welcome the adoption by the Economic and Social Commission for Asia and the Pacific of resolution 48/3 on the Asian and Pacific Decade of Disabled Persons, 1993-2002, as a catalyst for effective new policy initiatives and

actions at national, sub-regional and regional levels aimed at systematically improving the conditions of people with disabilities, who constitute approximately one-tenth of our total population, and for harnessing their full development potential.

7. We thus proclaim and pledge our joint commitment to translating into action in our respective countries and territories the ideals and objectives of the Asian and Pacific Decade of Disabled Persons, and confirm our continued endeavour in accordance with the United Nations Charter's affirmation of faith "... in the dignity and worth of the human person...."

- ESCAP: Dec. 3rd, 1996, Message from Mr. Edward Van Roy, Director of Social Development Division, ESCAP, Bangkok, Thailand
- ESCAP: Proclamation on the Full Participation and Equality of people with disabilities
- ESCAP: Commission Resolution 48/3 on the Asian and Pacific Decade of Disabled Persons, 1993-2002
- ESCAP: Agenda For Action For The Asian and Pacific Decade of Disabled Persons
- ESCAP: Targets and Recommendations for Implementation of the Agenda for Action for the Asian and Pacific Decade of Disabled Persons
- ESCAP: Gender Dimension of Implementation of the Agenda for Action for the Asian and Pacific Decade of Disabled Persons

<http://www.dpa.org.sg/ESCAP/proc.htm>

Appendix 10: Implementation of the World Programme of Action Concerning Disabled Persons and the United Nations Decade of Disabled Persons

A/RES/44/70

Implementation of the World Programme of Action Concerning

Disabled Persons and

the United Nations Decade of Disabled Persons

1995-1997 United Nations

78th Plenary Meeting

8 December 1989

Web Posted on: November 24, 1997

The General Assembly,

Recalling all its relevant resolutions, including resolution 37/52 of 3 December 1982, by which it adopted the World Programme of Action concerning Disabled Persons, and resolution 37/53 of 3 December 1982, in which it, inter alia, proclaimed the period 1983-1992 the United Nations Decade of Disabled Persons,

Recalling also its resolution 43/98 of 8 December 1988, and reaffirming all of the relevant provisions contained therein, in particular, the list of priorities for global activities and programmes during the second half of the United Nations Decade of Disabled Persons set forth in the annex to the resolution,

Taking note of Economic and Social Council resolution 1989/52 of 24 May 1989, in which the Council, inter alia, urged Member States, bodies and organizations of the United Nations system and intergovernmental and non-governmental organizations to provide all possible support to the awareness and fund-raising campaigns to give added momentum to the Decade,

Noting the important work currently being undertaken by the Sub-Commission on Prevention of Discrimination and Protection of Minorities on human rights and disability, which could serve as a useful basis for the continued efforts to ensure for disabled persons the enjoyment of human rights and fundamental freedoms,

Taking into account the concrete measures already carried out by the Governments of Member States, the bodies and organizations of the United Nations system and non-governmental organizations to implement the objectives of the World Programme of Action within the framework of the Decade, and recognizing that much more should be done at all levels to improve the living conditions of persons with disabilities,

Mindful that Member States bear the ultimate responsibility for the implementation of the World Programme of Action and that national disability committees or similar co-ordinating bodies play a crucial role in this regard,

Recognizing the pivotal role of the United Nations in promoting the exchange of information, experience and expertise and closer regional and interregional co-operation towards more effective strategies and policies to advance the status and welfare of persons with disabilities,

Stressing that the Centre for Social Development and Humanitarian Affairs of the Secretariat is the focal point within the United Nations for the implementation and monitoring of the World Programme of Action,

Noting with satisfaction the strengthening of the Disabled Persons Unit of the Centre through the generous financial support of some Governments,

Concerned that the Voluntary Fund for the United Nations Decade of Disabled Persons continues to suffer from a lack of sufficient contributions and that, unless this declining trend is reversed and the resource capacities of the Fund are strengthened, many priority requests may not be met and the implementation of the World Programme of Action will be seriously affected,

Mindful that, since developing countries are experiencing difficulties in mobilizing resources, international co-operation should be encouraged to assist in national efforts to implement the World Programme of Action and the objectives of the Decade,

Noting that the International Meeting on Human Resources in the Field of Disability was held at Tallinn, Union of Soviet Socialist Republics, from 14 to 22 August 1989 and that it adopted a nine-point strategy to promote the participation, training and employment of disabled persons, especially in developing countries,

Having considered the report of the Secretary-General,

- 1 Reaffirms the validity of the World Programme of Action concerning Disabled Persons;
- 2 Reiterates that for the second half of the United Nations Decade of Disabled Persons, special emphasis should be placed on the equalization of opportunities for disabled persons;
- 3 Urges Member States, intergovernmental organizations and non-governmental organizations concerned to translate into action at all levels, as appropriate, the priorities for global activities and programmes during the second half of the Decade, such as those set forth in the annex to General Assembly resolution 43/98;
- 4 Renews its invitation to all States to give high priority to projects concerning the prevention of disabilities, rehabilitation and the equalization of opportunities for disabled persons within the framework of bilateral assistance, as well as financial support to strengthen organizations of disabled persons;
- 5 Invites Governments to participate actively in the international co-operation with a view to improving the living conditions of disabled persons by encouraging professional experts, in particular disabled persons, in various aspects of rehabilitation and the equalization of opportunity, including the expertise of retired persons;
- 6 Requests the Secretary-General to assist Member States in establishing and strengthening national committees on disability issues and similar co-ordinating bodies and to promote and support the establishment of strong national organizations of disabled persons;

- 7 Also requests the Secretary-General to encourage all organs and bodies of the United Nations, including regional commissions, international organizations and specialized agencies, to take into account in their programmes and operational activities the specific needs of disabled persons;
- 8 Invites the Secretary-General, in connection with the feasibility study on the substantive, financial and administrative implications of alternative ways to mark the end of the Decade in 1992, called for by the General Assembly in its resolution 43/98, to request Member States, in consultation with organizations of disabled persons, to submit their comments to him by 28 February 1990 for inclusion in the background document to be discussed at the meeting of experts to be held at Helsinki in May 1990;
- 9 Requests the Secretary-General to strengthen the regional commissions to enable them to promote technical co-operation activities and the sharing of national resources for personnel training, the exchange of information, policy and programme development and research and the participation of disabled persons;
- 10 Invites the Secretary-General and Member States to involve disabled persons to a greater extent in United Nations programmes and activities, including the provision of employment opportunities, and to give particular attention to improving the situation of special groups as outlined in the World Programme of Action, emphasizing the need for social justice and the participation of these groups in each sector of the society;
- 11 Invites the Centre for Social Development and Humanitarian Affairs of the Secretariat to expand its close collaboration with intergovernmental and non-governmental organizations active in the field of disability, in particular organizations of disabled persons, and to consult with them on a regular and systematic basis on matters relating to the implementation of the World Programme of Action, with a view to ensuring that the results of the Decade become meaningful and lasting;
- 12 Notes with satisfaction the progress made by the office of the Special Representative for the Promotion of the United Nations Decade of Disabled Persons;
- 13 Calls upon Member States, national committees, the United Nations system and non-governmental organizations, especially organizations of disabled persons, to assist in a global information and fund-raising campaign to publicize the Decade through all appropriate means;
- 14 Recognizes the important role of non-governmental organizations, especially those representing persons with disabilities in the effective implementation of the World Programme of Action, in raising international awareness of the concerns of persons with disabilities and in monitoring and evaluating progress achieved during the Decade;
- 15 Requests the Secretary-General to ensure that contributions, in cash or in kind, related to the Decade are channelled into the Voluntary Fund for the United Nations Decade of Disabled Persons, while giving donors the option of earmarking contributions for special purposes;
- 16 Reaffirms that the resources of the Voluntary Fund should be used to support catalytic and innovative activities in order to implement further the objectives of the World Programme of Action within the framework of the Decade, with priority given, as appropriate, to programmes and projects of

- the least developed countries;
- 17 Invites Governments and non-governmental organizations to continue their contributions to the Voluntary Fund, and calls upon Governments and non-governmental organizations that have not yet done so to consider contributing to the Voluntary Fund so as to enable it to respond effectively to the growing demand for assistance;
 - 18 Requests the Secretary-General to bring the Tallinn Guidelines for Action on Human Resources Development in the Field of Disability, the text of which is annexed to the present resolution, to the attention of Member States, national co-ordinating mechanisms in the field of disability, organizations of the United Nations system, other intergovernmental bodies and non-governmental organizations concerned with disabilities;
 - 19 Requests the Secretary-General to report to the General Assembly at its forty-fifth session on the implementation of the present resolution;
 - 20 Decides to include in the provisional agenda of its forty-fifth session the item entitled "Implementation of the World Programme of Action concerning Disabled Persons and the United Nations Decade of Disabled Persons".

ANNEX

Tallinn Guidelines for Action on Human Resources Development in the Field of Disability

INTRODUCTION

1. The International Meeting on Human Resources in the Field of Disability, convened at Tallinn, Union of Soviet Socialist Republics, from 14 to 22 August 1989, having considered the situation of human resources development in the field of disability, particularly in developing countries, firmly believes that it is necessary to reinforce existing activities, as well as to undertake new and innovative ones, in order to promote the further development and continued progress of disabled persons.
2. Following the adoption of the World Programme of Action concerning Disabled Persons by the General Assembly, in its resolution 37/52 of 3 December 1982, there has been a growing need for higher priority to be given to the development of the human resources of disabled persons, with specific reference to education and training, employment, and science and technology. In this connection, the General Assembly, in its resolution 37/53 of 3 December 1982, proclaimed the period 1983-1992 the United Nations Decade of Disabled Persons, encouraging Member States to utilize that period as one of the means to implement the World Programme of Action.
3. The main objectives of the World Programme of Action are to promote effective measures for the prevention of disability, for rehabilitation and for the realization of the goals of full participation and equality for persons with disabilities. To accomplish these goals, due regard must be paid to education, training and work opportunities.
4. While it is acknowledged that the living conditions of the general population in developing countries urgently need to be improved, the objectives of the World Programme of Action call for the situation of disabled persons to be given special attention during the remainder of the Decade and beyond. Effective

implementation of the World Programme of Action will make an important contribution to the process of development of societies through the mobilization of more human resources.

5. While it is also acknowledged that a number of countries have already initiated or carried out activities within the framework of the World Programme of Action, further concerted efforts should be made to integrate the human resources development of disabled persons into intersectoral planning at the national level.

GUIDING PHILOSOPHY

6. Human resources development is a process centred on the human person that seeks to realize the full potential and capabilities of human beings. This process is fundamental to the concept of equalization of opportunities, in keeping with the goals of the World Programme of Action.

7. Through human resources development, disabled persons are able effectively to exercise their rights of full citizenship. As full citizens, they have the same rights and responsibilities as other members of society, including the right to life, as declared in international human rights instruments. They also have the same choices as other citizens in the social, cultural, economic and political life of their communities.

8. Because persons with disabilities are agents of their own destiny rather than objects of care, Governments and organizations need to reflect this perception in their policies and programmes. This means that disabled persons, as individuals and as members of organizations, should be involved in the decision-making process as equal partners.

9. The abilities of disabled persons and their families should be strengthened through community-based supplementary services provided by Governments and non-governmental organizations. These services should promote self-determination and enable disabled persons to participate in the development of society. Governments should recognize and support the role of organizations of disabled persons in enabling those persons to take charge of their own lives.

STRATEGIES

A. Participation of persons with disabilities

10. A statutory basis is required to enable disabled persons to participate as full citizens in decision-making at all levels of the planning, implementation, monitoring and evaluation of policies and programmes.

11. To facilitate the full participation of disabled persons and to enable them to exercise their rights as citizens, access to information is essential. To this end, all information has to be adapted to appropriate formats. These information formats may include Braille script, large print, audio-visual media and sign-language interpretation. Information channels should include television, radio, newspapers and postal services. Governments should work with organizations of disabled persons to identify appropriate information formats and channels to reach disabled citizens.

12. Governments should adopt, enforce and fund legally binding standards and regulations to improve access for persons with disabilities, ensuring that buildings, streets, and road, sea and air transport are barrier-free, architecturally

and in all other ways. Communication systems and security and safety measures should be developed and adapted to meet the needs of disabled citizens.

13. To facilitate the recruitment of disabled persons and to assist private-sector industries in hiring them, organizations at the national, regional and international levels, including the United Nations, should identify and maintain listings of qualified disabled candidates.

B. Strengthening of grass-roots initiatives

14. Local community initiatives should be especially promoted. Disabled persons and their families should be encouraged to form grass-roots organizations, with governmental recognition of their importance and governmental support in the form of financing and training.

15. Governmental and non-governmental organizations concerned with disability issues should allow disabled persons to participate as equal partners.

16. The efficient functioning of governmental and non-governmental organizations concerned with disability calls for training in organizational and management skills.

C. Promotion of an integrated approach

17. Overall national policy frameworks with supporting legislation should be developed.

18. The essence of an integrated approach is the inclusion of disability issues in all government ministries and at every level of governmental policy and planning. National co-ordination bodies, with linkages at the local, regional and interregional levels, should be established or strengthened. The membership of those bodies should include all government ministries, legislative committees and non-governmental organizations, particularly organizations of disabled persons. Those bodies should review existing policies, plans and programmes, identify existing and projected resources and monitor and evaluate the implementation of national policies.

19. National development programmes should include disability components.

20. Disabled women should be included in the existing national and regional programmes aimed at women.

21. At the level of service delivery, an integrated approach entails co-operation and referral among professionals working in organizational settings that provide educational, vocational, health and social services.

D. Promotion of education and training

22. The early years are critical in the overall development of a disabled child and for the fostering of positive attitudes towards the child. Specific programmes and training materials should be developed to address these needs during the formative infant and pre-school years.

23. Education at the primary, secondary and higher levels should be available to disabled persons within the regular educational system and in regular school settings, as well as in vocational training programmes. When such education is provided to deaf students, teachers and/or interpreters who are proficient in the indigenous sign language must be provided.

24. Special education programmes and schools that promote the indigenous sign language and the indigenous deaf culture must be available to deaf people. Deaf people should be employed in such programmes and schools.

25. Cost-effective alternatives to segregated school facilities should be developed and implemented by Governments at the national and local levels. These alternatives include special education teachers as consultants to regular education teachers, resource rooms with specialized personnel and materials, special classrooms in regular schools and interpreters for deaf students.

26. The education of disabled children should involve the co-operation and concerted efforts of health and social services, as well as of teachers and parents. It should provide support measures, such as technical aids, especially adapted pedagogical approaches, and incentives for teachers.

27. The content and quality of education and training should ensure the acquisition of skills that are economically viable and that provide opportunities for work. Career education and vocational training programmes should be available to ensure the transition of disabled students into the economic mainstream.

28. In addition to being offered formal skills training and education, disabled persons should be offered training in social and self-help skills to prepare them for independent living. Special efforts should be made to promote education and skills training for disabled girls and women, in both urban and rural areas.

29. General teacher-training curricula should include a course of study in skills for teaching disabled children and young persons in regular schools.

30. Each Government should have a national plan for training and employing an adequate number of health, education and vocational professionals in rehabilitation. Persons with disabilities should be recruited for such training and employment.

31. In fields such as education, labour, health and social services, law, architecture and technical development, which are often involved in the different aspects of rehabilitation, professional training should include training on the rights and needs of disabled people. Professionals in these fields should also be made aware of the resources available for disabled persons so that appropriate referrals can be made or services provided.

32. Appropriate technology should be considered essential for the utilization of available resources. This may include simple, universally available equipment, as well as computer technology.

E. Promotion of employment

33. Disabled persons have the right to be trained for and to work on equal terms in the regular labour force. Community-based rehabilitation programmes should be encouraged to provide better job opportunities in developing countries. Use should be made of the vocational services, guidance and training, placement, employment and related services that already exist for workers in general. On-the-job training may be more effective than conventional training.

34. General development programmes that provide loans, training and equipment for income-generating activities should include disabled persons.

35. Employment opportunities can be promoted, primarily, by measures relating to employment and salary standards that apply to all workers and, secondarily, by measures offering special support and incentives. In addition to formal employment, opportunities should be broadened to include self-employment, co-operatives and other group income-generating schemes. Where special national employment drives have been launched for youth and unemployed persons, disabled persons should be included. Disabled persons should be actively recruited, and when a disabled candidate and a non-disabled candidate are equally qualified, the disabled candidate should be chosen.

36. Organizations of employers and of workers should adopt, in co-operation with organizations of disabled persons, policies that promote the training and employment of disabled persons, including women, and non-disabled persons on an equal basis.

37. Policies for affirmative action should be formulated and implemented to increase the employment of disabled women. Governments and non-governmental organizations should support the creation of income-generating projects involving disabled women.

F. Provisions for funding

38. In general, funding should be allocated through regular sectoral budgeting systems. A national rehabilitation fund may be established to facilitate the employment or self-employment of disabled persons. This fund could be used to cover the costs of training, equipment and initial capital outlay.

39. Similarly, funds should be established for loans to small-scale pilot projects at the grass-roots level; such funds could be administered locally with the use of simple procedures.

G. Promotion of community awareness

40. To increase community understanding of the rights, needs and potentials of disabled persons, collaborative efforts with disabled persons and their organizations are required to develop and promote a flow of information using mass media, especially film, television, radio and print media. In particular, information for disabled persons and their families on all aspects of living with a disability should be as clear and uncomplicated as possible.

41. Community awareness programmes should include specific strategies for the prevention of disability. Government efforts aimed at early identification, intervention and prevention should be strengthened through community awareness and community involvement in programmes on disability.

42. Persons with mental disabilities (mental retardation or mental illness) or multiple disabilities are among the most stigmatized groups of citizens. They have the right to make choices, take risks, control their own lives and live in the community. Their adult status, abilities and aspirations must be respected and reinforced by their inclusion in decision-making, although many may need individual advocacy to be clearly understood.

43. It should be acknowledged that people with mental and multiple disabilities benefit from education, skills training and work opportunities. For many of these people, opportunities need to be individualized. Support is required to help them and their families to establish and maintain a positive life-style.

44. The World Programme of Action should be translated into all national languages, through governmental action. Braille, large print and simplified versions should also be made available by the appropriate media to ensure as wide a distribution as possible to all citizens, including disabled persons, their families, and non-governmental and governmental organizations.

H. Improving the methodology for human resources development

45. Policies and programmes for human resources development concerning disabled persons should be based on an assessment of their needs and resources as well as on the potential of existing development programmes and services to meet those needs. The implementation of such policies and programmes should be periodically monitored, with adjustments made to ensure effective implementation.

46. Evaluation should be built into programmes at the planning stage so that their overall efficacy in fulfilling policy objectives can be assessed. Persons with disabilities should play an active role in developing the criteria for monitoring and evaluation.

47. Increased attention should be given to services for people with hearing, speech, mental, intellectual or multiple disabilities.

48. The requirements of particular groups, such as disabled children, disabled women, the disabled elderly, disabled migrants and refugees, should also be recognized and met.

49. Governmental and non-governmental organizations should utilize recent developments in education through communications media, also known as distance education, which has been found to be an appropriate methodology in human resources development in the field of disability.

50. The local use of appropriate technologies for producing such items as wheel chairs, prosthetic devices and mobility aids, as well as aids for hearing and seeing, should take into account the technical, socio-economic and cultural conditions in the particular society. Each country should have a national system for the delivery of rehabilitation aids.

I. Regional and international co-operation

51. Training programmes in human resources development in the field of disability should be strengthened by collaborative efforts at the regional and/or subregional levels. Such programmes should be co-ordinated through existing intergovernmental and regional organizations, including those of disabled persons.

52. International development aid projects should include a component specifically aimed at supporting organizations of disabled persons and training their members. In addition, employment opportunities should be made available to disabled individuals within these projects.

53. All international development assistance programmes directed at macro-level planning and development, such as those in agriculture or education, should include a specific component ensuring the participation of disabled persons in such programmes.

54. At both the national and interregional levels, Governments should strongly support collaboration with non-governmental agencies in specific areas of disability, to ensure co-ordination and to prevent duplication of services.

55. Linkages between organizations of disabled persons in developed and developing countries should be strengthened. This can be done through the exchange of information, training and meetings to provide forums for disabled persons to share experiences on strategic approaches. Workshops and field studies should be organized to train trainers and the management personnel of organizations of disabled persons.

56. Implementation of these Guidelines relies on effective action at the national level. This action should be supplemented by concerted efforts at the international level, particularly on the part of the United Nations and its focal point for the implementation of the World Programme of Action concerning Disabled Persons, as well as relevant United Nations organizations and specialized agencies. National and international non-governmental organizations, in particular organizations of disabled persons, should be fully involved.

http://www.dinf.ne.jp/doc/japanese/intl/un_dinf/un_4470.htm

Appendix 11: Convention on the Rights of Persons with Disabilities

Preamble

The States Parties to the present Convention,

- a. Recalling the principles proclaimed in the Charter of the United Nations which recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world,
- b. Recognizing that the United Nations, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, has proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind,
- c. Reaffirming the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination,
- d. Recalling the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Convention on the Rights of the Child, and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families,
- e. Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,
- f. Recognizing the importance of the principles and policy guidelines contained in the World Programme of Action concerning Disabled Persons and in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in influencing the promotion, formulation and evaluation of the policies, plans, programmes and actions at the national, regional and international levels to further equalize opportunities for persons with disabilities,
- g. Emphasizing the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development,
- h. Recognizing also that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person,
- i. Recognizing further the diversity of persons with disabilities,
- j. Recognizing the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support,
- k. Concerned that, despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world,
- l. Recognizing the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries,
- m. Recognizing the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty,
- n. Recognizing the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices,

- o. Considering that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them,
- p. Concerned about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status,
- q. Recognizing that women and girls with disabilities are often at greater risk, both within and outside the home of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation,
- r. Recognizing that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child,
- s. Emphasizing the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities,
- t. Highlighting the fact that the majority of persons with disabilities live in conditions of poverty, and in this regard recognizing the critical need to address the negative impact of poverty on persons with disabilities,
- u. Bearing in mind that conditions of peace and security based on full respect for the purposes and principles contained in the Charter of the United Nations and observance of applicable human rights instruments are indispensable for the full protection of persons with disabilities, in particular during armed conflicts and foreign occupation,
- v. Recognizing the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms,
- w. Realizing that the individual, having duties to other individuals and to the community to which he or she belongs, is under a responsibility to strive for the promotion and observance of the rights recognized in the International Bill of Human Rights,
- x. Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities,
- y. Convinced that a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities will make a significant contribution to redressing the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities, in both developing and developed countries,

Have agreed as follows:

Article 1 – Purpose

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Article 2 – Definitions

For the purposes of the present Convention:

- "Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology;
- "Language" includes spoken and signed languages and other forms of non spoken languages;
- "Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;
- "Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;
- "Universal design" means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

Article 3 - General principles

The principles of the present Convention shall be:

- a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- b. Non-discrimination;
- c. Full and effective participation and inclusion in society;
- d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- e. Equality of opportunity;
- f. Accessibility;
- g. Equality between men and women;
- h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 4 - General obligations

1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

- a. To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
- b. To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
- c. To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;
- d. To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;

e. To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;

f. To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;

g. To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;

h. To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;

i. To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.

2. With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.

3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

4. Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.

5. The provisions of the present Convention shall extend to all parts of federal states without any limitations or exceptions.

Article 5 - Equality and non-discrimination

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

Article 6 - Women with disabilities

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

Article 7 - Children with disabilities

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Article 8 - Awareness-raising

1. States Parties undertake to adopt immediate, effective and appropriate measures:
 - a. To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
 - b. To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
 - c. To promote awareness of the capabilities and contributions of persons with disabilities.Measures to this end include:
 - a. Initiating and maintaining effective public awareness campaigns designed:
 - i. To nurture receptiveness to the rights of persons with disabilities;
 - ii. To promote positive perceptions and greater social awareness towards persons with disabilities;
 - iii. To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;
 - b. Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
 - c. Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;
 - d. Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

Article 9 - Accessibility

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

- a. Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
- b. Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures to:

- a. Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
- b. Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
- c. Provide training for stakeholders on accessibility issues facing persons with disabilities;
- d. Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
- e. Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
- f. Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
- g. Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
- h. Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

Article 10 - Right to life

States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

Article 11 - Situations of risk and humanitarian emergencies

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

Article 12 - Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest

time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Article 13 - Access to justice

1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Article 14 - Liberty and security of the person

1. States Parties shall ensure that persons with disabilities, on an equal basis with others:

- a. Enjoy the right to liberty and security of person;
- b. Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.

Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment

1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

Article 16 - Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation,

violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Article 17 - Protecting the integrity of the person

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

Article 18 - Liberty of movement and nationality

1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities:

- a. Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability;
- b. Are not deprived, on the basis of disability, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification, or to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement;
- c. Are free to leave any country, including their own;
- d. Are not deprived, arbitrarily or on the basis of disability, of the right to enter their own country.

2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.

Article 19 - Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 20 - Personal mobility

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- a. Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- b. Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
- c. Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;
- d. Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.

Article 21 - Freedom of expression and opinion, and access to information

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

- a. Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;
- b. Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
- c. Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
- d. Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
- e. Recognizing and promoting the use of sign languages.

Article 22 - Respect for privacy

1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.

2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

Article 23 - Respect for home and the family

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

- a. The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
- b. The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate

information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

c. Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

Article 24 - Education

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:

a. The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;

b. The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;

c. Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

a. Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

b. Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

c. Reasonable accommodation of the individual's requirements is provided;

d. Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

e. Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

- a. Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
 - b. Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
 - c. Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.
4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

Article 25 - Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a. Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c. Provide these health services as close as possible to people's own communities, including in rural areas;
- d. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- e. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Article 26 - Habilitation and rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

- a. Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
 - b. Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Article 27 - Work and employment

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:
- a. Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;
 - b. Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;
 - c. Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;
 - d. Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;
 - e. Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;
 - f. Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;
 - g. Employ persons with disabilities in the public sector;
 - h. Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;
 - i. Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;
 - j. Promote the acquisition by persons with disabilities of work experience in the open labour market;
 - k. Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.
2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

Article 28 - Adequate standard of living and social protection

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

- a. To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
- b. To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
- c. To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;
- d. To ensure access by persons with disabilities to public housing programmes;
- e. To ensure equal access by persons with disabilities to retirement benefits and programmes.

Article 29 - Participation in political and public life

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to:

- a. Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:
 - i. Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;
 - ii. Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;
 - iii. Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;
- b. Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:
 - i. Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
 - ii. Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

Article 30 - Participation in cultural life, recreation, leisure and sport

1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:

- a. Enjoy access to cultural materials in accessible formats;
- b. Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;
- c. Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic

and intellectual potential, not only for their own benefit, but also for the enrichment of society.

3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.

4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:

- a. To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;
- b. To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;
- c. To ensure that persons with disabilities have access to sporting, recreational and tourism venues;
- d. To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;
- e. To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

Article 31 - Statistics and data collection

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

- a. Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
- b. Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Article 32 - International cooperation

1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:

- a. Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;
 - b. Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;
 - c. Facilitating cooperation in research and access to scientific and technical knowledge;
 - d. Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.
2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.

Article 33 - National implementation and monitoring

1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.
2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.
3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

Article 34 - Committee on the Rights of Persons with Disabilities

1. There shall be established a Committee on the Rights of Persons with Disabilities (hereafter referred to as "the Committee"), which shall carry out the functions hereinafter provided.
2. The Committee shall consist, at the time of entry into force of the present Convention, of twelve experts. After an additional sixty ratifications or accessions to the Convention, the membership of the Committee shall increase by six members, attaining a maximum number of eighteen members.
3. The members of the Committee shall serve in their personal capacity and shall be of high moral standing and recognized competence and experience in the field covered by the present Convention. When nominating their candidates, States Parties are invited to give due consideration to the provision set out in article 4.3 of the present Convention.
4. The members of the Committee shall be elected by States Parties, consideration being given to equitable geographical distribution, representation of the different forms of civilization and of the principal legal systems, balanced gender representation and participation of experts with disabilities.
5. The members of the those meetings, for which two thirds of States Parties shall constitute a quorum, the Committee shall be elected by secret ballot from a list of persons nominated by the States Parties from among their nationals at meetings of the Conference of States Parties. At persons elected to the Committee shall be

those who obtain the largest number of votes and an absolute majority of the votes of the representatives of States Parties present and voting.

6. The initial election shall be held no later than six months after the date of entry into force of the present Convention. At least four months before the date of each election, the Secretary-General of the United Nations shall address a letter to the States Parties inviting them to submit the nominations within two months. The Secretary-General shall subsequently prepare a list in alphabetical order of all persons thus nominated, indicating the State Parties which have nominated them, and shall submit it to the States Parties to the present Convention.

7. The members of the Committee shall be elected for a term of four years. They shall be eligible for re-election once. However, the term of six of the members elected at the first election shall expire at the end of two years; immediately after the first election, the names of these six members shall be chosen by lot by the chairperson of the meeting referred to in paragraph 5 of this article.

8. The election of the six additional members of the Committee shall be held on the occasion of regular elections, in accordance with the relevant provisions of this article.

9. If a member of the Committee dies or resigns or declares that for any other cause she or he can no longer perform her or his duties, the State Party which nominated the member shall appoint another expert possessing the qualifications and meeting the requirements set out in the relevant provisions of this article, to serve for the remainder of the term.

10. The Committee shall establish its own rules of procedure.

11. The Secretary-General of the United Nations shall provide the necessary staff and facilities for the effective performance of the functions of the Committee under the present Convention, and shall convene its initial meeting.

12. With the approval of the General Assembly, the members of the Committee established under the present Convention shall receive emoluments from United Nations resources on such terms and conditions as the Assembly may decide, having regard to the importance of the Committee's responsibilities.

13. The members of the Committee shall be entitled to the facilities, privileges and immunities of experts on mission for the United Nations as laid down in the relevant sections of the Convention on the Privileges and Immunities of the United Nations.

Article 35 - Reports by States Parties

1. Each State Party shall submit to the Committee, through the Secretary-General of the United Nations, a comprehensive report on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard, within two years after the entry into force of the present Convention for the State Party concerned.

2. Thereafter, States Parties shall submit subsequent reports at least every four years and further whenever the Committee so requests.

3. The Committee shall decide any guidelines applicable to the content of the reports.

4. A State Party which has submitted a comprehensive initial report to the Committee need not, in its subsequent reports, repeat information previously provided. When preparing reports to the Committee, States Parties are invited to

consider doing so in an open and transparent process and to give due consideration to the provision set out in article 4.3 of the present Convention.

5. Reports may indicate factors and difficulties affecting the degree of fulfilment of obligations under the present Convention.

Article 36 - Consideration of reports

1. Each report shall be considered by the Committee, which shall make such suggestions and general recommendations on the report as it may consider appropriate and shall forward these to the State Party concerned. The State Party may respond with any information it chooses to the Committee. The Committee may request further information from States Parties relevant to the implementation of the present Convention.

2. If a State Party is significantly overdue in the submission of a report, the Committee may notify the State Party concerned of the need to examine the implementation of the present Convention in that State Party, on the basis of reliable information available to the Committee, if the relevant report is not submitted within three months following the notification. The Committee shall invite the State Party concerned to participate in such examination. Should the State Party respond by submitting the relevant report, the provisions of paragraph 1 of this article will apply.

3. The Secretary-General of the United Nations shall make available the reports to all States Parties.

4. States Parties shall make their reports widely available to the public in their own countries and facilitate access to the suggestions and general recommendations relating to these reports.

5. The Committee shall transmit, as it may consider appropriate, to the specialized agencies, funds and programmes of the United Nations, and other competent bodies, reports from States Parties in order to address a request or indication of a need for technical advice or assistance contained therein, along with the Committee's observations and recommendations, if any, on these requests or indications.

Article 37 - Cooperation between States Parties and the Committee

1. Each State Party shall cooperate with the Committee and assist its members in the fulfilment of their mandate.

2. In its relationship with States Parties, the Committee shall give due consideration to ways and means of enhancing national capacities for the implementation of the present Convention, including through international cooperation.

Article 38 - Relationship of the Committee with other bodies

In order to foster the effective implementation of the present Convention and to encourage international cooperation in the field covered by the present Convention:

a. The specialized agencies and other United Nations organs shall be entitled to be represented at the consideration of the implementation of such provisions of the present Convention as fall within the scope of their mandate. The Committee may invite the specialized agencies and other competent bodies as it may consider appropriate to provide expert advice on the implementation of the Convention in areas falling within the scope of their respective mandates. The Committee may invite specialized agencies and other United Nations organs to

submit reports on the implementation of the Convention in areas falling within the scope of their activities;

b. The Committee, as it discharges its mandate, shall consult, as appropriate, other relevant bodies instituted by international human rights treaties, with a view to ensuring the consistency of their respective reporting guidelines, suggestions and general recommendations, and avoiding duplication and overlap in the performance of their functions.

Article 39 - Report of the Committee

The Committee shall report every two years to the General Assembly and to the Economic and Social Council on its activities, and may make suggestions and general recommendations based on the examination of reports and information received from the States Parties. Such suggestions and general recommendations shall be included in the report of the Committee together with comments, if any, from States Parties.

Article 40 - Conference of States Parties

1. The States Parties shall meet regularly in a Conference of States Parties in order to consider any matter with regard to the implementation of the present Convention.

2. No later than six months after the entry into force of the present Convention, the Conference of the States Parties shall be convened by the Secretary-General of the United Nations. The subsequent meetings shall be convened by the Secretary-General of the United Nations biennially or upon the decision of the Conference of States Parties.

Article 41 - Depositary

The Secretary-General of the United Nations shall be the depositary of the present Convention.

Article 42 - Signature

The present Convention shall be open for signature by all States and by regional integration organizations at United Nations Headquarters in New York as of 30 March 2007.

Article 43 - Consent to be bound

The present Convention shall be subject to ratification by signatory States and to formal confirmation by signatory regional integration organizations. It shall be open for accession by any State or regional integration organization which has not signed the Convention.

Article 44 - Regional integration organizations

1. "Regional integration organization" shall mean an organization constituted by sovereign States of a given region, to which its member States have transferred competence in respect of matters governed by this Convention. Such organizations shall declare, in their instruments of formal confirmation or accession, the extent of their competence with respect to matters governed by this Convention. Subsequently, they shall inform the depositary of any substantial modification in the extent of their competence.

2. References to "States Parties" in the present Convention shall apply to such organizations within the limits of their competence.

3. For the purposes of article 45, paragraph 1, and article 47, paragraphs 2 and 3, any instrument deposited by a regional integration organization shall not be counted.

4. Regional integration organizations, in matters within their competence, may exercise their right to vote in the Conference of States Parties, with a number of votes equal to the number of their member States that are Parties to this Convention. Such an organization shall not exercise its right to vote if any of its member States exercises its right, and vice versa.

Article 45 - Entry into force

1. The present Convention shall enter into force on the thirtieth day after the deposit of the twentieth instrument of ratification or accession.

2. For each State or regional integration organization ratifying, formally confirming or acceding to the Convention after the deposit of the twentieth such instrument, the Convention shall enter into force on the thirtieth day after the deposit of its own such instrument.

Article 46 - Reservations

1. Reservations incompatible with the object and purpose of the present Convention shall not be permitted.

2. Reservations may be withdrawn at any time.

Article 47 - Amendments

1. Any State Party may propose an amendment to the present Convention and submit it to the Secretary-General of the United Nations. The Secretary-General shall communicate any proposed amendments to States Parties, with a request to be notified whether they favour a conference of States Parties for the purpose of considering and deciding upon the proposals. In the event that, within four months from the date of such communication, at least one third of the States Parties favour such a conference, the Secretary-General shall convene the conference under the auspices of the United Nations. Any amendment adopted by a majority of two thirds of the States Parties present and voting shall be submitted by the Secretary-General to the General Assembly for approval and thereafter to all States Parties for acceptance.

2. An amendment adopted and approved in accordance with paragraph 1 of this article shall enter into force on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment. Thereafter, the amendment shall enter into force for any State Party on the thirtieth day following the deposit of its own instrument of acceptance. An amendment shall be binding only on those States Parties which have accepted it.

3. If so decided by the Conference of States Parties by consensus, an amendment adopted and approved in accordance with paragraph 1 of this article which relates exclusively to articles 34, 38, 39 and 40 shall enter into force for all States Parties on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment.

Article 48 - Denunciation

A State Party may denounce the present Convention by written notification to the Secretary-General of the United Nations. The denunciation shall become effective one year after the date of receipt of the notification by the Secretary-General.

Article 49 - Accessible format

The text of the present Convention shall be made available in accessible formats.

Article 50 - Authentic texts

The Arabic, Chinese, English, French, Russian and Spanish texts of the present Convention shall be equally authentic.

In witness thereof the undersigned plenipotentiaries, being duly authorized thereto by their respective Governments, have signed the present Convention.

Source: Annex 1, Final report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities [A/61/611 - PDF, 117KB]

***Appendix 12: Convention (No. 169) concerning Indigenous and Tribal Peoples
in Independent Countries***

**Convention (No. 169) concerning Indigenous and Tribal Peoples
in Independent Countries**

**Adopted on 27 June 1989 by the General Conference of the International
Labour**

Organisation at its seventy-sixth session

entry into force 5 September 1991

[status of ratifications \(ILO database on International Labour Standards\)](#)

The General Conference of the International Labour Organisation,

Having been convened at Geneva by the Governing Body of the International Labour Office, and having met in its seventy-sixth session on 7 June 1989, and

Noting the international standards contained in the Indigenous and Tribal Populations Convention and Recommendation, 1957, and

Recalling the terms of the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, and the many international instruments on the prevention of discrimination, and

Considering that the developments which have taken place in international law since 1957, as well as developments in the situation of indigenous and tribal peoples in all regions of the world, have made it appropriate to adopt new international standards on the subject with a view to removing the assimilationist orientation of the earlier standards, and

Recognising the aspirations of these peoples to exercise control over their own institutions, ways of life and economic development and to maintain and develop their identities, languages and religions, within the framework of the States in which they live, and

Noting that in many parts of the world these peoples are unable to enjoy their fundamental human rights to the same degree as the rest of the population of the States within which they live, and that their laws, values, customs and perspectives have often been eroded, and

Calling attention to the distinctive contributions of indigenous and tribal peoples to the cultural diversity and social and ecological harmony of humankind and to international co-operation and understanding, and

Noting that the following provisions have been framed with the co-operation of the United Nations, the Food and Agriculture Organization of the United Nations, the United Nations Educational, Scientific and Cultural Organization and the

World Health Organization, as well as of the Inter-American Indian Institute, at appropriate levels and in their respective fields, and that it is proposed to continue this co-operation in promoting and securing the application of these provisions, and

Having decided upon the adoption of certain proposals with regard to the partial revision of the Indigenous and Tribal Populations Convention, 1957 (No. 107), which is the fourth item on the agenda of the session, and

Having determined that these proposals shall take the form of an international Convention revising the Indigenous and Tribal Populations Convention, 1957,

Adopts this twenty-seventh day of June of the year one thousand nine hundred and eighty-nine the following Convention, which may be cited as the Indigenous and Tribal Peoples Convention, 1989:

PART I. GENERAL POLICY

Article 1

1. This Convention applies to:

(a) Tribal peoples in independent countries whose social, cultural and economic conditions distinguish them from other sections of the national community, and whose status is regulated wholly or partially by their own customs or traditions or by special laws or regulations;

(b) Peoples in independent countries who are regarded as indigenous on account of their descent from the populations which inhabited the country, or a geographical region to which the country belongs, at the time of conquest or colonisation or the establishment of present State boundaries and who, irrespective of their legal status, retain some or all of their own social, economic, cultural and political institutions.

2. Self-identification as indigenous or tribal shall be regarded as a fundamental criterion for determining the groups to which the provisions of this Convention apply.

3. The use of the term "peoples" in this Convention shall not be construed as having any implications as regards the rights which may attach to the term under international law.

Article 2

1. Governments shall have the responsibility for developing, with the participation of the peoples concerned, co-ordinated and systematic action to protect the rights of these peoples and to guarantee respect for their integrity.

2. Such action shall include measures for:

(a) Ensuring that members of these peoples benefit on an equal footing from the rights and opportunities which national laws and regulations grant to other members of the population;

(b) Promoting the full realisation of the social, economic and cultural rights of these peoples with respect for their social and cultural identity, their customs and traditions and their institutions;

(c) Assisting the members of the peoples concerned to eliminate socio-economic gaps that may exist between indigenous and other members of the national community, in a manner compatible with their aspirations and ways of life.

Article 3

1. Indigenous and tribal peoples shall enjoy the full measure of human rights and fundamental freedoms without hindrance or discrimination. The provisions of the Convention shall be applied without discrimination to male and female members of these peoples.
2. No form of force or coercion shall be used in violation of the human rights and fundamental freedoms of the peoples concerned, including the rights contained in this Convention.

Article 4

1. Special measures shall be adopted as appropriate for safeguarding the persons, institutions, property, labour, cultures and environment of the peoples concerned.
2. Such special measures shall not be contrary to the freely-expressed wishes of the peoples concerned.
3. Enjoyment of the general rights of citizenship, without discrimination, shall not be prejudiced in any way by such special measures.

Article 5

In applying the provisions of this Convention:

- (a) The social, cultural, religious and spiritual values and practices of these peoples shall be recognised and protected, and due account shall be taken of the nature of the problems which face them both as groups and as individuals;
- (b) The integrity of the values, practices and institutions of these peoples shall be respected;
- (c) Policies aimed at mitigating the difficulties experienced by these peoples in facing new conditions of life and work shall be adopted, with the participation and co-operation of the peoples affected.

Article 6

1. In applying the provisions of this Convention, Governments shall:
 - (a) Consult the peoples concerned, through appropriate procedures and in particular through their representative institutions, whenever consideration is being given to legislative or administrative measures which may affect them directly;
 - (b) Establish means by which these peoples can freely participate, to at least the same extent as other sectors of the population, at all levels of decision-making in elective institutions and administrative and other bodies responsible for policies and programmes which concern them;
 - (c) Establish means for the full development of these peoples' own institutions and initiatives, and in appropriate cases provide the resources necessary for this purpose.

2. The consultations carried out in application of this Convention shall be undertaken, in good faith and in a form appropriate to the circumstances, with the objective of achieving agreement or consent to the proposed measures.

Article 7

1. The peoples concerned shall have the right to decide their own priorities for the process of development as it affects their lives, beliefs, institutions and spiritual well-being and the lands they occupy or otherwise use, and to exercise control, to the extent possible, over their own economic, social and cultural development. In addition, they shall participate in the formulation, implementation and evaluation of plans and programmes for national and regional development which may affect them directly.

2. The improvement of the conditions of life and work and levels of health and education of the peoples concerned, with their participation and co-operation, shall be a matter of priority in plans for the overall economic development of areas they inhabit. Special projects for development of the areas in question shall also be so designed as to promote such improvement.

3. Governments shall ensure that, whenever appropriate, studies are carried out, in co-operation with the peoples concerned, to assess the social, spiritual, cultural and environmental impact on them of planned development activities. The results of these studies shall be considered as fundamental criteria for the implementation of these activities.

4. Governments shall take measures, in co-operation with the peoples concerned, to protect and preserve the environment of the territories they inhabit.

Article 8

1. In applying national laws and regulations to the peoples concerned, due regard shall be had to their customs or customary laws.

2. These peoples shall have the right to retain their own customs and institutions, where these are not incompatible with fundamental rights defined by the national legal system and with internationally recognized human rights. Procedures shall be established, whenever necessary, to resolve conflicts which may arise in the application of this principle.

3. The application of paragraphs 1 and 2 of this Article shall not prevent members of these peoples from exercising the rights granted to all citizens and from assuming the corresponding duties.

Article 9

1. To the extent compatible with the national legal system and internationally recognised human rights, the methods customarily practised by the peoples concerned for dealing with offences committed by their members shall be respected.

2. The customs of these peoples in regard to penal matters shall be taken into consideration by the authorities and courts dealing with such cases.

Article 10

1. In imposing penalties laid down by general law on members of these peoples account shall be taken of their economic, social and cultural characteristics.

2. Preference shall be given to methods of punishment other than confinement in prison.

Article 11

The exaction from members of the peoples concerned of compulsory personal services in any form, whether paid or unpaid, shall be prohibited and punishable by law, except in cases prescribed by law for all citizens.

Article 12

The peoples concerned shall be safeguarded against the abuse of their rights and shall be able to take legal proceedings, either individually or through their representative bodies, for the effective protection of these rights. Measures shall be taken to ensure that members of these peoples can understand and be understood in legal proceedings, where necessary through the provision of interpretation or by other effective means.

PART II. LAND

Article 13

1. In applying the provisions of this Part of the Convention governments shall respect the special importance for the cultures and spiritual values of the peoples concerned of their relationship with the lands or territories, or both as applicable, which they occupy or otherwise use, and in particular the collective aspects of this relationship.

2. The use of the term "lands" in Articles 15 and 16 shall include the concept of territories, which covers the total environment of the areas which the peoples concerned occupy or otherwise use.

Article 14

1. The rights of ownership and possession of the peoples concerned over the lands which they traditionally occupy shall be recognised. In addition, measures shall be taken in appropriate cases to safeguard the right of the peoples concerned to use lands not exclusively occupied by them, but to which they have traditionally had access for their subsistence and traditional activities. Particular attention shall be paid to the situation of nomadic peoples and shifting cultivators in this respect.

2. Governments shall take steps as necessary to identify the lands which the peoples concerned traditionally occupy, and to guarantee effective protection of their rights of ownership and possession.

3. Adequate procedures shall be established within the national legal system to resolve land claims by the peoples concerned.

Article 15

1. The rights of the peoples concerned to the natural resources pertaining to their lands shall be specially safeguarded. These rights include the right of these peoples to participate in the use, management and conservation of these resources.

2. In cases in which the State retains the ownership of mineral or sub-surface resources or rights to other resources pertaining to lands, governments shall establish or maintain procedures through which they shall consult these peoples, with a view to ascertaining whether and to what degree their interests would be prejudiced, before undertaking or permitting any programmes for the exploration

or exploitation of such resources pertaining to their lands. The peoples concerned shall wherever possible participate in the benefits of such activities, and shall receive fair compensation for any damages which they may sustain as a result of such activities.

Article 16

1. Subject to the following paragraphs of this Article, the peoples concerned shall not be removed from the lands which they occupy.
2. Where the relocation of these peoples is considered necessary as an exceptional measure, such relocation shall take place only with their free and informed consent. Where their consent cannot be obtained, such relocation shall take place only following appropriate procedures established by national laws and regulations, including public inquiries where appropriate, which provide the opportunity for effective representation of the peoples concerned.
3. Whenever possible, these peoples shall have the right to return to their traditional lands, as soon as the grounds for relocation cease to exist.
4. When such return is not possible, as determined by agreement or, in the absence of such agreement, through appropriate procedures, these peoples shall be provided in all possible cases with lands of quality and legal status at least equal to that of the lands previously occupied by them, suitable to provide for their present needs and future development. Where the peoples concerned express a preference for compensation in money or in kind, they shall be so compensated under appropriate guarantees.
5. Persons thus relocated shall be fully compensated for any resulting loss or injury.

Article 17

1. Procedures established by the peoples concerned for the transmission of land rights among members of these peoples shall be respected.
2. The peoples concerned shall be consulted whenever consideration is being given to their capacity to alienate their lands or otherwise transmit their rights outside their own community.
3. Persons not belonging to these peoples shall be prevented from taking advantage of their customs or of lack of understanding of the laws on the part of their members to secure the ownership, possession or use of land belonging to them.

Article 18

Adequate penalties shall be established by law for unauthorised intrusion upon, or use of, the lands of the peoples concerned, and governments shall take measures to prevent such offences.

Article 19

National agrarian programmes shall secure to the peoples concerned treatment equivalent to that accorded to other sectors of the population with regard to:

- (a) The provision of more land for these peoples when they have not the area necessary for providing the essentials of a normal existence, or for any possible increase in their numbers;

(b) The provision of the means required to promote the development of the lands which these peoples already possess.

PART III. RECRUITMENT AND CONDITIONS OF EMPLOYMENT

Article 20

1. Governments shall, within the framework of national laws and regulations, and in co-operation with the peoples concerned, adopt special measures to ensure the effective protection with regard to recruitment and conditions of employment of workers belonging to these peoples, to the extent that they are not effectively protected by laws applicable to workers in general.

2. Governments shall do everything possible to prevent any discrimination between workers belonging to the peoples concerned and other workers, in particular as regards:

(a) Admission to employment, including skilled employment, as well as measures for promotion and advancement;

(b) Equal remuneration for work of equal value;

(c) Medical and social assistance, occupational safety and health, all social security benefits and any other occupationally related benefits, and housing;

(d) The right of association and freedom for all lawful trade union activities, and the right to conclude collective agreements with employers or employers' organisations.

3. The measures taken shall include measures to ensure:

(a) That workers belonging to the peoples concerned, including seasonal, casual and migrant workers in agricultural and other employment, as well as those employed by labour contractors, enjoy the protection afforded by national law and practice to other such workers in the same sectors, and that they are fully informed of their rights under labour legislation and of the means of redress available to them;

(b) That workers belonging to these peoples are not subjected to working conditions hazardous to their health, in particular through exposure to pesticides or other toxic substances;

(c) That workers belonging to these peoples are not subjected to coercive recruitment systems, including bonded labour and other forms of debt servitude;

(d) That workers belonging to these peoples enjoy equal opportunities and equal treatment in employment for men and women, and protection from sexual harassment.

4. Particular attention shall be paid to the establishment of adequate labour inspection services in areas where workers belonging to the peoples concerned undertake wage employment, in order to ensure compliance with the provisions of this Part of this Convention.

PART IV. VOCATIONAL TRAINING, HANDICRAFTS AND RURAL INDUSTRIES

Article 21

Members of the peoples concerned shall enjoy opportunities at least equal to those of other citizens in respect of vocational training measures.

Article 22

1. Measures shall be taken to promote the voluntary participation of members of the peoples concerned in vocational training programmes of general application.
2. Whenever existing programmes of vocational training of general application do not meet the special needs of the peoples concerned, governments shall, with the participation of these peoples, ensure the provision of special training programmes and facilities.
3. Any special training programmes shall be based on the economic environment, social and cultural conditions and practical needs of the peoples concerned. Any studies made in this connection shall be carried out in co-operation with these peoples, who shall be consulted on the organisation and operation of such programmes. Where feasible, these peoples shall progressively assume responsibility for the organisation and operation of such special training programmes, if they so decide.

Article 23

1. Handicrafts, rural and community-based industries, and subsistence economy and traditional activities of the peoples concerned, such as hunting, fishing, trapping and gathering, shall be recognised as important factors in the maintenance of their cultures and in their economic self-reliance and development. Governments shall, with the participation of these peoples and whenever appropriate, ensure that these activities are strengthened and promoted.
2. Upon the request of the peoples concerned, appropriate technical and financial assistance shall be provided wherever possible, taking into account the traditional technologies and cultural characteristics of these peoples, as well as the importance of sustainable and equitable development.

PART V. SOCIAL SECURITY AND HEALTH

Article 24

Social security schemes shall be extended progressively to cover the peoples concerned, and applied without discrimination against them.

Article 25

1. Governments shall ensure that adequate health services are made available to the peoples concerned, or shall provide them with resources to allow them to design and deliver such services under their own responsibility and control, so that they may enjoy the highest attainable standard of physical and mental health.
2. Health services shall, to the extent possible, be community-based. These services shall be planned and administered in co-operation with the peoples concerned and take into account their economic, geographic, social and cultural conditions as well as their traditional preventive care, healing practices and medicines.
3. The health care system shall give preference to the training and employment of local community health workers, and focus on primary health care while maintaining strong links with other levels of health care services.

4. The provision of such health services shall be co-ordinated with other social, economic and cultural measures in the country.

PART VI. EDUCATION AND MEANS OF COMMUNICATION

Article 26

Measures shall be taken to ensure that members of the peoples concerned have the opportunity to acquire education at all levels on at least an equal footing with the rest of the national community.

Article 27

1. Education programmes and services for the peoples concerned shall be developed and implemented in co-operation with them to address their special needs, and shall incorporate their histories, their knowledge and technologies, their value systems and their further social, economic and cultural aspirations. They shall participate in the formulation, implementation and evaluation of plans and programmes for national and regional development which may affect them directly.

2. The competent authority shall ensure the training of members of these peoples and their involvement in the formulation and implementation of education programmes, with a view to the progressive transfer of responsibility for the conduct of these programmes to these peoples as appropriate.

3. In addition, governments shall recognise the right of these peoples to establish their own educational institutions and facilities, provided that such institutions meet minimum standards established by the competent authority in consultation with these peoples. Appropriate resources shall be provided for this purpose.

Article 28

1. Children belonging to the peoples concerned shall, wherever practicable, be taught to read and write in their own indigenous language or in the language most commonly used by the group to which they belong. When this is not practicable, the competent authorities shall undertake consultations with these peoples with a view to the adoption of measures to achieve this objective.

2. Adequate measures shall be taken to ensure that these peoples have the opportunity to attain fluency in the national language or in one of the official languages of the country.

3. Measures shall be taken to preserve and promote the development and practice of the indigenous languages of the peoples concerned.

Article 29

The imparting of general knowledge and skills that will help children belonging to the peoples concerned to participate fully and on an equal footing in their own community and in the national community shall be an aim of education for these peoples.

Article 30

1. Governments shall adopt measures appropriate to the traditions and cultures of the peoples concerned, to make known to them their rights and duties, especially in regard to labour, economic opportunities, education and health matters, social welfare and their rights deriving from this Convention.

2. If necessary, this shall be done by means of written translations and through the use of mass communications in the languages of these peoples.

Article 31

Educational measures shall be taken among all sections of the national community, and particularly among those that are in most direct contact with the peoples concerned, with the object of eliminating prejudices that they may harbour in respect of these peoples. To this end, efforts shall be made to ensure that history textbooks and other educational materials provide a fair, accurate and informative portrayal of the societies and cultures of these peoples.

PART VII. CONTACTS AND CO-OPERATION ACROSS BORDERS

Article 32

Governments shall take appropriate measures, including by means of international agreements, to facilitate contacts and co-operation between indigenous and tribal peoples across borders, including activities in the economic, social, cultural, spiritual and environmental fields.

PART VIII. ADMINISTRATION

Article 33

1. The governmental authority responsible for the matters covered in this Convention shall ensure that agencies or other appropriate mechanisms exist to administer the programmes affecting the peoples concerned, and shall ensure that they have the means necessary for the proper fulfilment of the functions assigned to them.

2. These programmes shall include:

(a) The planning, co-ordination, execution and evaluation, in co-operation with the peoples concerned, of the measures provided for in this Convention;

(b) The proposing of legislative and other measures to the competent authorities and supervision of the application of the measures taken, in co-operation with the peoples concerned.

PART IX. GENERAL PROVISIONS

Article 34

The nature and scope of the measures to be taken to give effect to this Convention shall be determined in a flexible manner, having regard to the conditions characteristic of each country.

Article 35

The application of the provisions of this Convention shall not adversely affect rights and benefits of the peoples concerned pursuant to other Conventions and Recommendations, international instruments, treaties, or national laws, awards, custom or agreements.

PART X. FINAL PROVISIONS

Article 36

This Convention revises the Indigenous and Tribal Populations Convention, 1957.

Article 37

The formal ratifications of this Convention shall be communicated to the Director-General of the International Labour Office for registration.

Article 38

1. This Convention shall be binding only upon those Members of the International Labour Organisation whose ratifications have been registered with the Director-General.
2. It shall come into force twelve months after the date on which the ratifications of two Members have been registered with the Director-General.
3. Thereafter, this Convention shall come into force for any Member twelve months after the date on which its ratification has been registered.

Article 39

1. A Member which has ratified this Convention may denounce it after the expiration of ten years from the date on which the Convention first comes into force, by an act communicated to the Director-General of the International Labour Office for registration. Such denunciation shall not take effect until one year after the date on which it is registered.
2. Each Member which has ratified this Convention and which does not, within the year following the expiration of the period of ten years mentioned in the preceding paragraph, exercise the right of denunciation provided for in this Article, will be bound for another period of ten years and, thereafter, may denounce this Convention at the expiration of each period of ten years under the terms provided for in this Article.

Article 40

1. The Director-General of the International Labour Office shall notify all Members of the International Labour Organisation of the registration of all ratifications and denunciations communicated to him by the Members of the Organisation.
2. When notifying the Members of the Organisation of the registration of the second ratification communicated to him, the Director-General shall draw the attention of the Members of the Organisation to the date upon which the Convention will come into force.

Article 41

The Director-General of the International Labour Office shall communicate to the Secretary-General of the United Nations for registration in accordance with Article 102 of the Charter of the United Nations full particulars of all ratifications and acts of denunciation registered by him in accordance with the provisions of the preceding Articles.

Article 42

At such times as it may consider necessary the Governing Body of the International Labour Office shall present to the General Conference a report on the working of this Convention and shall examine the desirability of placing on the agenda of the Conference the question of its revision in whole or in part.

Article 43

1. Should the Conference adopt a new Convention revising this Convention in whole or in part, then, unless the new Convention otherwise provides:

(a) The ratification by a Member of the new revising Convention shall ipso jure involve the immediate denunciation of this Convention, notwithstanding the provisions of Article 39 above, if and when the new revising Convention shall have come into force;

(b) As from the date when the new revising Convention comes into force this Convention shall cease to be open to ratification by the Members.

2. This Convention shall in any case remain in force in its actual form and content for those Members which have ratified it but have not ratified the revising Convention.

Article 44

The English and French versions of the text of this Convention are equally authoritative.

* This is a direct link to the ILO ILOLEX database. Ratification information is updated daily.

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Office of the United Nations High Commissioner for Human Rights

Geneva, Switzerland

<http://www.unhchr.ch/html/menu3/b/62.htm>

Appendix 13: Draft Declaration on the Rights of Indigenous Peoples

Appendix 13: Draft Declaration on the Rights of Indigenous Peoples

Sixty-first session

Third Committee

Agenda item 68

Report of the Human Rights Council

Armenia, Bolivia, Bosnia and Herzegovina, Cameroon, Congo, Costa Rica, Croatia, Cuba, Cyprus, Denmark, Dominican Republic, Ecuador, Estonia, Fiji, Finland, France, Germany, Greece, Guatemala, Haiti, Hungary, Latvia, Liechtenstein, Lithuania, Mexico, Panama, Paraguay, Peru, Portugal, Slovenia, Spain, Switzerland and the former Yugoslav Republic of Macedonia: revised draft resolution*

Working group of the Commission on Human Rights to elaborate a draft declaration in accordance with paragraph 5 of General Assembly resolution 49/214 of 23 December 1994

The General Assembly,

Guided by the purposes and principles of the Charter of the United Nations, in particular the principles of self-determination of peoples, respect for the territorial integrity of States and good faith regarding the fulfilment of the obligations assumed by States in accordance with the Charter,

Taking note of the recommendation of the Human Rights Council contained in its resolution 1/2 of 29 June 2006, by which the Council adopted the text of the United Nations Declaration on the Rights of Indigenous Peoples,

Recognizing that the situation of indigenous peoples varies from country to country and from region to region,

1. *Expresses its appreciation* to the Working Group of the Commission on Human Rights for the work done in the elaboration of a draft declaration on the rights of indigenous peoples and to the Human Rights Council for the adoption of the text of the United Nations Declaration on the Rights of Indigenous Peoples;
2. *Adopts* the Declaration as contained in the annex to the present resolution.

* Text recommended by the Human Rights Council for adoption by the General Assembly (see *Official Records of the General Assembly, Sixty-first Session, Supplement No. 53 (A/61/53)*).

Annex

United Nations Declaration on the Rights of Indigenous Peoples

The Human Rights Council,

Affirming that indigenous peoples are equal to all other peoples, while recognizing the right of all peoples to be different, to consider themselves different, and to be respected as such,

Affirming also that all peoples contribute to the diversity and richness of civilizations and cultures, which constitute the common heritage of humankind,

Affirming further that all doctrines, policies and practices based on or advocating superiority of peoples or individuals on the basis of national origin, racial, religious, ethnic or cultural differences are racist, scientifically false, legally invalid, morally condemnable and socially unjust,

Reaffirming that indigenous peoples, in the exercise of their rights, should be free from discrimination of any kind,

Concerned that indigenous peoples have suffered from historic injustices as a result of, inter alia, their colonization and dispossession of their lands, territories and resources, thus preventing them from exercising, in particular, their right to development in accordance with their own needs and interests,

Recognizing the urgent need to respect and promote the inherent rights of indigenous peoples which derive from their political, economic and social structures and from their cultures, spiritual traditions, histories and philosophies, especially their rights to their lands, territories and resources,

Recognizing also the urgent need to respect and promote the rights of indigenous peoples affirmed in treaties, agreements and other constructive arrangements with States,

Welcoming the fact that indigenous peoples are organizing themselves for political, economic, social and cultural enhancement and in order to bring an end to all forms of discrimination and oppression wherever they occur,

Convinced that control by indigenous peoples over developments affecting them and their lands, territories and resources will enable them to maintain and strengthen their institutions, cultures and traditions, and to promote their development in accordance with their aspirations and needs,

Recognizing that respect for indigenous knowledge, cultures and traditional practices contributes to sustainable and equitable development and proper management of the environment,

Emphasizing the contribution of the demilitarization of the lands and territories of indigenous peoples to peace, economic and social progress and development, understanding and friendly relations among nations and peoples of the world,

Recognizing in particular the right of indigenous families and communities to retain shared responsibility for the upbringing, training, education and well-being of their children, consistent with the rights of the child,

Recognizing that indigenous peoples have the right freely to determine their relationships with States in a spirit of coexistence, mutual benefit and full respect,

Considering that the rights affirmed in treaties, agreements and constructive arrangements between States and indigenous peoples are, in some situations, matters of international concern, interest, responsibility and character,

Considering also that treaties, agreements and other constructive arrangements, and the relationship they represent, are the basis for a strengthened partnership between indigenous peoples and States,

Acknowledging that the Charter of the United Nations, the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights affirm the fundamental importance of the right of self-determination of all peoples, by virtue of which they freely determine their political status and freely pursue their economic, social and cultural development,

Bearing in mind that nothing in this Declaration may be used to deny any peoples their right of self-determination, exercised in conformity with international law,

Convinced that the recognition of the rights of indigenous peoples in this Declaration will enhance harmonious and cooperative relations between the State and indigenous peoples, based on principles of justice, democracy, respect for human rights, non-discrimination and good faith,

Encouraging States to comply with and effectively implement all their obligations as they apply to indigenous peoples under international instruments, in particular those related to human rights, in consultation and cooperation with the peoples concerned,

Emphasizing that the United Nations has an important and continuing role to play in promoting and protecting the rights of indigenous peoples,

Believing that this Declaration is a further important step forward for the recognition, promotion and protection of the rights and freedoms of indigenous peoples and in the development of relevant activities of the United Nations system in this field,

Recognizing and reaffirming that indigenous individuals are entitled without discrimination to all human rights recognized in international law, and that indigenous peoples possess collective rights which are indispensable for their existence, well-being and integral development as peoples,

Solemnly proclaims the following United Nations Declaration on the Rights of Indigenous Peoples as a standard of achievement to be pursued in a spirit of partnership and mutual respect:

Article 1

Indigenous peoples have the right to the full enjoyment, as a collective or as individuals, of all human rights and fundamental freedoms as recognized in the Charter of the United Nations, the Universal Declaration of Human Rights and international human rights law.

Article 2

Indigenous peoples and individuals are free and equal to all other peoples and individuals and have the right to be free from any kind of discrimination, in the exercise of their rights, in particular that based on their indigenous origin or identity.

Article 3

Indigenous peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.

Article 4

Indigenous peoples, in exercising their right to self-determination, have the right to autonomy or self-government in matters relating to their internal and local affairs, as well as ways and means for financing their autonomous functions.

Article 5

Indigenous peoples have the right to maintain and strengthen their distinct political, legal, economic, social and cultural institutions, while retaining their rights to participate fully, if they so choose, in the political, economic, social and cultural life of the State.

Article 6

Every indigenous individual has the right to a nationality.

Article 7

1. Indigenous individuals have the rights to life, physical and mental integrity, liberty and security of person.
2. Indigenous peoples have the collective right to live in freedom, peace and security as distinct peoples and shall not be subjected to any act of genocide or any other act of violence, including forcibly removing children of the group to another group.

Article 8

1. Indigenous peoples and individuals have the right not to be subjected to forced assimilation or destruction of their culture.
2. States shall provide effective mechanisms for prevention of, and redress for:
 - (a) Any action which has the aim or effect of depriving them of their integrity as distinct peoples, or of their cultural values or ethnic identities;
 - (b) Any action which has the aim or effect of dispossessing them of their lands, territories or resources;
 - (c) Any form of forced population transfer which has the aim or effect of violating or undermining any of their rights;
 - (d) Any form of forced assimilation or integration by other cultures or ways of life imposed on them by legislative, administrative or other measures;
 - (e) Any form of propaganda designed to promote or incite racial or ethnic discrimination directed against them.

Article 9

Indigenous peoples and individuals have the right to belong to an indigenous community or nation, in accordance with the traditions and customs of the community or nation concerned. No discrimination of any kind may arise from the exercise of such a right.

Article 10

Indigenous peoples shall not be forcibly removed from their lands or territories. No relocation shall take place without the free, prior and informed consent of the indigenous peoples concerned and after agreement on just and fair compensation and, where possible, with the option of return.

Article 11

1. Indigenous peoples have the right to practise and revitalize their cultural traditions and customs. This includes the right to maintain, protect and develop the past, present and future manifestations of their cultures, such as archaeological and historical sites, artefacts, designs, ceremonies, technologies and visual and performing arts and literature.
2. States shall provide redress through effective mechanisms, which may include restitution, developed in conjunction with indigenous peoples, with respect to their cultural, intellectual, religious and spiritual property taken without their free, prior and informed consent or in violation of their laws, traditions and customs.

Article 12

1. Indigenous peoples have the right to manifest, practice, develop and teach their spiritual and religious traditions, customs and ceremonies; the right to maintain, protect, and have access in privacy to their religious and cultural sites; the right to the use and control of their ceremonial objects; and the right to the repatriation of their human remains.
2. States shall seek to enable the access and/or repatriation of ceremonial objects and human remains in their possession through fair, transparent and effective mechanisms developed in conjunction with indigenous peoples concerned.

Article 13

1. Indigenous peoples have the right to revitalize, use, develop and transmit to future generations their histories, languages, oral traditions, philosophies, writing systems and literatures, and to designate and retain their own names for communities, places and persons.
2. States shall take effective measures to ensure this right is protected and also to ensure that indigenous peoples can understand and be understood in political, legal and administrative proceedings, where necessary through the provision of interpretation or by other appropriate means.

Article 14

1. Indigenous peoples have the right to establish and control their educational systems and institutions providing education in their own languages, in a manner appropriate to their cultural methods of teaching and learning.
2. Indigenous individuals, particularly children, have the right to all levels and forms of education of the State without discrimination.
3. States shall, in conjunction with indigenous peoples, take effective measures, in order for indigenous individuals, particularly children, including those living outside their communities, to have access, when possible, to an education in their own culture and provided in their own language.

Article 15

1. Indigenous peoples have the right to the dignity and diversity of their cultures, traditions, histories and aspirations which shall be appropriately reflected in education and public information.
2. States shall take effective measures, in consultation and cooperation with the indigenous peoples concerned, to combat prejudice and eliminate discrimination and to promote tolerance, understanding and good relations among indigenous peoples and all other segments of society.

Article 16

1. Indigenous peoples have the right to establish their own media in their own languages and to have access to all forms of non-indigenous media without discrimination.
2. States shall take effective measures to ensure that State-owned media duly reflect indigenous cultural diversity. States, without prejudice to ensuring full freedom of expression, should encourage privately owned media to adequately reflect indigenous cultural diversity.

Article 17

1. Indigenous individuals and peoples have the right to enjoy fully all rights established under applicable international and domestic labour law.
2. States shall in consultation and cooperation with indigenous peoples take specific measures to protect indigenous children from economic exploitation and from performing any work that is likely to be hazardous or to interfere with the child's education, or to be harmful to the child's health or physical, mental, spiritual, moral or social development, taking into account their special vulnerability and the importance of education for their empowerment.
3. Indigenous individuals have the right not to be subjected to any discriminatory conditions of labour and, inter alia, employment or salary.

Article 18

Indigenous peoples have the right to participate in decision-making in matters which would affect their rights, through representatives chosen by themselves in accordance with their own procedures, as well as to maintain and develop their own indigenous decision-making institutions.

Article 19

States shall consult and cooperate in good faith with the indigenous peoples concerned through their own representative institutions in order to obtain their free, prior and informed consent before adopting and implementing legislative or administrative measures that may affect them.

Article 20

1. Indigenous peoples have the right to maintain and develop their political, economic and social systems or institutions, to be secure in the enjoyment of their own means of subsistence and development, and to engage freely in all their traditional and other economic activities.
2. Indigenous peoples deprived of their means of subsistence and development are entitled to just and fair redress.

Article 21

1. Indigenous peoples have the right, without discrimination, to the improvement of their economic and social conditions, including, inter alia, in the areas of education, employment, vocational training and retraining, housing, sanitation, health and social security.
2. States shall take effective measures and, where appropriate, special measures to ensure continuing improvement of their economic and social conditions. Particular attention shall be paid to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities.

Article 22

1. Particular attention shall be paid to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities in the implementation of this Declaration.
2. States shall take measures, in conjunction with indigenous peoples, to ensure that indigenous women and children enjoy the full protection and guarantees against all forms of violence and discrimination.

Article 23

Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions.

Article 24

1. Indigenous peoples have the right to their traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals. Indigenous individuals also have the right to access, without any discrimination, to all social and health services.
2. Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right.

Article 25

Indigenous peoples have the right to maintain and strengthen their distinctive spiritual relationship with their traditionally owned or otherwise occupied and used lands, territories, waters and coastal seas and other resources and to uphold their responsibilities to future generations in this regard.

Article 26

1. Indigenous peoples have the right to the lands, territories and resources which they have traditionally owned, occupied or otherwise used or acquired.
2. Indigenous peoples have the right to own, use, develop and control the lands, territories and resources that they possess by reason of traditional ownership or other traditional occupation or use, as well as those which they have otherwise acquired.

3. States shall give legal recognition and protection to these lands, territories and resources. Such recognition shall be conducted with due respect to the customs, traditions and land tenure systems of the indigenous peoples concerned.

Article 27

States shall establish and implement, in conjunction with indigenous peoples concerned, a fair, independent, impartial, open and transparent process, giving due recognition to indigenous peoples' laws, traditions, customs and land tenure systems, to recognize and adjudicate the rights of indigenous peoples pertaining to their lands, territories and resources, including those which were traditionally owned or otherwise occupied or used. Indigenous peoples shall have the right to participate in this process.

Article 28

1. Indigenous peoples have the right to redress, by means that can include restitution or, when this is not possible, of a just, fair and equitable compensation, for the lands, territories and resources which they have traditionally owned or otherwise occupied or used, and which have been confiscated, taken, occupied, used or damaged without their free, prior and informed consent.
2. Unless otherwise freely agreed upon by the peoples concerned, compensation shall take the form of lands, territories and resources equal in quality, size and legal status or of monetary compensation or other appropriate redress.

Article 29

1. Indigenous peoples have the right to the conservation and protection of the environment and the productive capacity of their lands or territories and resources. States shall establish and implement assistance programmes for indigenous peoples for such conservation and protection, without discrimination.
2. States shall take effective measures to ensure that no storage or disposal of hazardous materials shall take place in the lands or territories of indigenous peoples without their free, prior and informed consent.
3. States shall also take effective measures to ensure, as needed, that programmes for monitoring, maintaining and restoring the health of indigenous peoples, as developed and implemented by the peoples affected by such materials, are duly implemented.

Article 30

1. Military activities shall not take place in the lands or territories of indigenous peoples, unless justified by a significant threat to relevant public interest or otherwise freely agreed with or requested by the indigenous peoples concerned.
2. States shall undertake effective consultations with the indigenous peoples concerned, through appropriate procedures and in particular through their representative institutions, prior to using their lands or territories for military activities.

Article 31

1. Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions.
2. In conjunction with indigenous peoples, States shall take effective measures to recognize and protect the exercise of these rights.

Article 32

1. Indigenous peoples have the right to determine and develop priorities and strategies for the development or use of their lands or territories and other resources.
2. States shall consult and cooperate in good faith with the indigenous peoples concerned through their own representative institutions in order to obtain their free and informed consent prior to the approval of any project affecting their lands or territories and other resources, particularly in connection with the development, utilization or exploitation of their mineral, water or other resources.
3. States shall provide effective mechanisms for just and fair redress for any such activities, and appropriate measures shall be taken to mitigate adverse environmental, economic, social, cultural or spiritual impact.

Article 33

1. Indigenous peoples have the right to determine their own identity or membership in accordance with their customs and traditions. This does not impair the right of indigenous individuals to obtain citizenship of the States in which they live.
2. Indigenous peoples have the right to determine the structures and to select the membership of their institutions in accordance with their own procedures.

Article 34

Indigenous peoples have the right to promote, develop and maintain their institutional structures and their distinctive customs, spirituality, traditions, procedures, practices and, in the cases where they exist, juridical systems or customs, in accordance with international human rights standards.

Article 35

Indigenous peoples have the right to determine the responsibilities of individuals to their communities.

Article 36

1. Indigenous peoples, in particular those divided by international borders, have the right to maintain and develop contacts, relations and cooperation, including activities for spiritual, cultural, political, economic and social purposes, with their own members as well as other peoples across borders.
2. States, in consultation and cooperation with indigenous peoples, shall take effective measures to facilitate the exercise and ensure the implementation of this right.

Article 37

1. Indigenous peoples have the right to the recognition, observance and enforcement of treaties, agreements and other constructive arrangements concluded with States or their successors and to have States honour and respect such treaties, agreements and other constructive arrangements.
2. Nothing in this Declaration may be interpreted as to diminish or eliminate the rights of Indigenous Peoples contained in treaties, agreements and constructive arrangements.

Article 38

States in consultation and cooperation with indigenous peoples, shall take the appropriate measures, including legislative measures, to achieve the ends of this Declaration.

Article 39

Indigenous peoples have the right to have access to financial and technical assistance from States and through international cooperation, for the enjoyment of the rights contained in this Declaration.

Article 40

Indigenous peoples have the right to have access to and prompt decision through just and fair procedures for the resolution of conflicts and disputes with States or other parties, as well as to effective remedies for all infringements of their individual and collective rights. Such a decision shall give due consideration to the customs, traditions, rules and legal systems of the indigenous peoples concerned and international human rights.

Article 41

The organs and specialized agencies of the United Nations system and other intergovernmental organizations shall contribute to the full realization of the provisions of this Declaration through the mobilization, inter alia, of financial cooperation and technical assistance. Ways and means of ensuring participation of indigenous peoples on issues affecting them shall be established.

Article 42

The United Nations, its bodies, including the Permanent Forum on Indigenous Issues, and specialized agencies, including at the country level, and States shall promote respect for and full application of the provisions of this Declaration and follow up the effectiveness of this Declaration.

Article 43

The rights recognized herein constitute the minimum standards for the survival, dignity and well-being of the indigenous peoples of the world.

Article 44

All the rights and freedoms recognized herein are equally guaranteed to male and female indigenous individuals.

Article 45

Nothing in this Declaration may be construed as diminishing or extinguishing the rights indigenous peoples have now or may acquire in the future.

Article 46

1. Nothing in this Declaration may be interpreted as implying for any State, people, group or person any right to engage in any activity or to perform any act contrary to the Charter of the United Nations.

2. In the exercise of the rights enunciated in the present Declaration, human rights and fundamental freedoms of all shall be respected. The exercise of the rights set forth in this Declaration shall be subject only to such limitations as are determined by law, in accordance with international human rights obligations. Any such limitations shall be non-discriminatory and strictly necessary solely for the purpose of securing due recognition and respect for the rights and freedoms of others and for meeting the just and most compelling requirements of a democratic society.

3. The provisions set forth in this Declaration shall be interpreted in accordance with the principles of justice, democracy, respect for human rights, equality, non-discrimination, good governance and good faith.

Appendix 14: Namibian Delegation Proposal to the United Nations on the Declaration on the Rights of Indigenous Peoples

DECISION ON THE UNITED NATIONS DECLARATION

ON THE RIGHTS OF INDIGENOUS PEOPLES

(DOC. ASSEMBLY/AU/9 (VIII) ADD.6)

The Assembly:

1. **TAKES NOTE of the United Nations Declaration on the Rights of Indigenous Peoples adopted by the United Nations Human Rights Council on 29th June 2006;**
2. **REAFFIRMS Resolution AHG Res-17/1 of 1964 in which all Member States of the Organization of African Unity pledged to respect borders existing on their achievement of national independence;**
3. **EXPRESSES concern at the political, economic, social and constitutional implications of the Declaration on the African Continent;**
4. **REAFFIRMS the United Nations General Assembly Resolution 1514 (XV) of 14 December 1960 concerning the Declaration on the granting of independence to colonial countries and peoples;**
5. **WELCOMES the efforts by the international community to address the rights of indigenous peoples and EXPRESSES full support and solidarity with indigenous peoples of the world;**
6. **WELCOMES ALSO the decision of the United Nations General Assembly to defer consideration and action on the Declaration to allow for further consultations on the numerous matters of fundamental political and constitutional concern, amongst the most important of which are questions about:**
 - a) **the definition of indigenous peoples;**
 - b) **self-determination;**
 - c) **ownership of land and resources;**
 - d) **establishment of distinct political and economic institutions; and**

e) **national and territorial integrity.**

7. **AFFIRMS that the vast majority of the peoples of Africa are indigenous to the African Continent;**
8. **DECIDES to maintain a united position in the negotiations on amending the Declaration and constructively work alongside other Member States of the United Nations in finding solutions to the concerns of African States;**
9. **MANDATES the African Group at the United Nations in New York to continue to ensure that Africa's interests in this matter are safeguarded;**
10. **ALSO DECIDES to remain seized of the matter.**

Appendix 15: Discrimination (Employment and Occupation) Convention

**Discrimination (Employment and Occupation) Convention (ILO No. 111),
362 U.N.T.S. 31, entered into force June 15, 1960.**

The General Conference of the International Labour Organisation,
Having been convened at Geneva by the Governing Body of the International Labour Office, and having met in its forty-second session on 4 June 1958, and
Having decided upon the adoption of certain proposals with regard to discrimination in the field of employment and occupation, which is the fourth item on the agenda of the session, and
Having determined that these proposals shall take the form of an international Convention, and Considering that the Declaration of Philadelphia affirms that all human beings, irrespective of race, creed or sex, have the right to pursue both their material well-being and their spiritual development in conditions of freedom and dignity, of economic security and equal opportunity, and
Considering further that discrimination constitutes a violation of rights enunciated by the Universal Declaration of Human Rights,
Adopts this twenty-fifth day of June of the year one thousand nine hundred and fifty-eight the following Convention, which may be cited as the Discrimination (Employment and Occupation) Convention, 1958:

Article I

1. For the purpose of this Convention the term "discrimination" includes:
 - (a) Any distinction, exclusion or preference made on the basis of race, colour, sex, religion, political opinion, national extraction or social origin, which has the effect of nullifying or impairing equality of opportunity or treatment in employment or occupation;
 - (b) Such other distinction, exclusion or preference which has the effect of nullifying or impairing equality of opportunity or treatment in employment or occupation as may be determined by the Member concerned after consultation with representative employers' and workers' organisations, where such exist, and with other appropriate bodies.
2. Any distinction, exclusion or preference in respect of a particular job based on the inherent requirements thereof shall not be deemed to be discrimination.
3. For the purpose of this Convention the terms "employment" and "occupation" include access to vocational training, access to employment and to particular occupations, and terms and conditions of employment.

Article 2

Each Member for which this Convention is in force undertakes to declare and pursue a national policy designed to promote, by methods appropriate to national conditions and practice, equality of opportunity and treatment in respect of

employment and occupation, with a view to eliminating any discrimination in respect thereof.

Article 3

Each Member for which this Convention is in force undertakes, by methods appropriate to national conditions and practice:

- (a) To seek the co-operation of employers' and workers' organisations and other appropriate bodies in promoting the acceptance and observance of this policy;
- (b) To enact such legislation and to promote such educational programmes as may be calculated to secure the acceptance and observance of the policy;
- (c) To repeal any statutory provisions and modify any administrative instructions or practices which are inconsistent with the policy;
- (d) To pursue the policy in respect of employment under the direct control of a national authority;
- (e) To ensure observance of the policy in activities of vocational guidance, vocational training and placement services under the direction of a national authority;
- (f) To indicate in its annual reports on the application of the Convention the action taken in pursuance of the policy and the results secured by such action. Article 4

Any measures affecting an individual who is justifiably suspected of, or engaged in, activities prejudicial to the security of the State shall not be deemed to be discrimination, provided that the individual concerned shall have the right to appeal to a competent body established in accordance with national practice.

Article 5

1. Special measures of protection or assistance provided in other Conventions or Recommendations adopted by the International Labour Conference shall not be deemed to be discrimination.

2. Any Member may, after consultation with representative employers' and workers' organisations, where such exist, determine that other special measures designed to meet the particular requirements of persons who, for reasons such as sex, age, disablement, family responsibilities or social or cultural status, are generally recognised to require special protection or assistance, shall not be deemed to be discrimination.

Article 6

Each Member which ratifies this Convention undertakes to apply it to non-metropolitan territories in accordance with the provisions of the Constitution of the International Labour Organisation.

Article 7

The formal ratifications of this Convention shall be communicated to the Director-General of the International Labour Office for registration.

Article 8

1. This Convention shall be binding only upon those Members of the International Labour Organisation whose ratifications have been registered with the Director-General.

2. It shall come into force twelve months after the date on which the ratifications of two Members have been registered with the Director General.

3. Thereafter, this Convention shall come into force for any Member twelve months after the date on which its ratification has been registered. Article 9

1. A Member which has ratified this Convention may denounce it after the expiration of ten years from the date on which the Convention first comes into force, by an act communicated to the Director-General of the International Labour Office for registration. Such denunciation shall not take effect until one year after the date on which it is registered.

2. Each Member which has ratified this Convention and which does not, within the year following the expiration of the period of ten years mentioned in the preceding paragraph, exercise the right of denunciation provided for in this article, will be bound for another period of ten years and, thereafter, may denounce this Convention at the expiration of each period of ten years under the terms provided for in this article.

Article 10

1. The Director-General of the International Labour Office shall notify all Members of the International Labour Organisation of the registration of all ratifications and denunciations communicated to him by the Members of the Organisation.

2. When notifying the Members of the Organisation of the registration of the second ratification communicated to him, the Director-General shall draw the attention of the Members of the Organisation to the date upon which the Convention will come into force.

Article 11

The Director-General of the International Labour Office shall communicate to the Secretary-General of the United Nations for registration in accordance with Article 102 of the Charter of the United Nations full particulars of all ratifications and acts of denunciation registered by him in accordance with the provisions of the preceding articles.

Article 12

At such times as it may consider necessary the Governing Body of the International Labour Office shall present to the General Conference a report on the working of this Convention and shall examine the desirability of placing on the agenda of the Conference the question of its revision in whole or in part.

Article 13

1. Should the Conference adopt a new Convention revising this Convention in whole or in part, then, unless the new Convention otherwise provides:

(a) The ratification by a Member of the new revising Convention shall ipso jure involve the immediate denunciation of this Convention , notwithstanding the

provisions of article 9 above, if and when the new revising Convention shall have come into force;

(b) As from the date when the new revising Convention comes into force this Convention shall cease to be open to ratification by the Members.

2. This Convention shall in any case remain in force in its actual form and content for those Members which have ratified it but have not ratified the revising Convention.

Article 14

The English and French versions of the text of this Convention are equally authoritative.

The foregoing is the authentic text of the Convention duly adopted by the General Conference of the International Labour Organisation during its forty-second session which was held at Geneva and declared closed the twenty-sixth day of June 1958.

IN FAITH WHEREOF we have appended our signatures this fifth day of July 1958.

<http://www1.umn.edu/humanrts/instree/n3ilo111.htm>

***Appendix 16: Vocational Rehabilitation and Employment (Disabled Persons)
Convention Discrimination (Employment and Occupation) Convention***

**C159 Vocational Rehabilitation and Employment (Disabled Persons)
Convention, 1983**

Convention concerning Vocational Rehabilitation and Employment (Disabled Persons) (Note: Date of coming into force: 20:06:1985.)

Convention:C159

Place:Geneva

Session of the Conference:69

Date of adoption:20:06:1983

Subject classification: Disabled Persons

Subject: Employment policy and Promotion

See the ratifications for this Convention

Display the document in: French Spanish

Status: Up-to-date instrument

The General Conference of the International Labour Organisation,

Having been convened at Geneva by the Governing Body of the International Labour Office and having met in its Sixty-ninth Session on 1 June 1983, and

Noting the existing international standards contained in the Vocational Rehabilitation (Disabled) Recommendation, 1955, and the Human Resources Development Recommendation, 1975, and

Noting that since the adoption of the Vocational Rehabilitation (Disabled) Recommendation, 1955, significant developments have occurred in the understanding of rehabilitation needs, the scope and organisation of rehabilitation services, and the law and practice of many Members on the questions covered by that Recommendation, and

Considering that the year 1981 was declared by the United Nations General Assembly the International Year of Disabled Persons, with the theme "full participation and equality" and that a comprehensive World Programme of Action concerning Disabled Persons is to provide effective measures at the international and national levels for the realisation of the goals of "full participation" of disabled persons in social life and development, and of "equality", and

Considering that these developments have made it appropriate to adopt new international standards on the subject which take account, in particular, of the need to ensure equality of opportunity and treatment to all categories of disabled persons, in both rural and urban areas, for employment and integration into the community, and

Having decided upon the adoption of certain proposals with regard to vocational rehabilitation which is the fourth item on the agenda of the session, and

Having determined that these proposals shall take the form of an international Convention,

adopts this twentieth day of June of the year one thousand nine hundred and eighty-three the following Convention, which may be cited as the Vocational Rehabilitation and Employment (Disabled Persons) Convention, 1983:

PART I. DEFINITION AND SCOPE

Article 1

1. For the purposes of this Convention, the term disabled person means an individual whose prospects of securing, retaining and advancing in suitable employment are substantially reduced as a result of a duly recognised physical or mental impairment.
2. For the purposes of this Convention, each Member shall consider the purpose of vocational rehabilitation as being to enable a disabled person to secure, retain and advance in suitable employment and thereby to further such person's integration or reintegration into society.
3. The provisions of this Convention shall be applied by each Member through measures which are appropriate to national conditions and consistent with national practice.
4. The provisions of this Convention shall apply to all categories of disabled persons.

PART II. PRINCIPLES OF VOCATIONAL REHABILITATION AND EMPLOYMENT POLICIES FOR DISABLED PERSONS

Article 2

Each Member shall, in accordance with national conditions, practice and possibilities, formulate, implement and periodically review a national policy on vocational rehabilitation and employment of disabled persons.

Article 3

The said policy shall aim at ensuring that appropriate vocational rehabilitation measures are made available to all categories of disabled persons, and at promoting employment opportunities for disabled persons in the open labour market.

Article 4

The said policy shall be based on the principle of equal opportunity between disabled workers and workers generally. Equality of opportunity and treatment for disabled men and women workers shall be respected. Special positive measures aimed at effective equality of opportunity and treatment between disabled workers and other workers shall not be regarded as discriminating against other workers.

Article 5

The representative organisations of employers and workers shall be consulted on the implementation of the said policy, including the measures to be taken to promote co-operation and co-ordination between the public and private bodies engaged in vocational rehabilitation activities. The representative organisations of and for disabled persons shall also be consulted.

PART III. ACTION AT THE NATIONAL LEVEL FOR THE DEVELOPMENT OF VOCATIONAL REHABILITATION AND EMPLOYMENT SERVICES FOR DISABLED PERSONS

Article 6

Each Member shall, by laws or regulations or by any other method consistent with national conditions and practice, take such steps as may be necessary to give effect to Articles 2, 3, 4 and 5 of this Convention.

Article 7

The competent authorities shall take measures with a view to providing and evaluating vocational guidance, vocational training, placement, employment and other related services to enable disabled persons to secure, retain and advance in employment; existing services for workers generally shall, wherever possible and appropriate, be used with necessary adaptations.

Article 8

Measures shall be taken to promote the establishment and development of vocational rehabilitation and employment services for disabled persons in rural areas and remote communities.

Article 9

Each Member shall aim at ensuring the training and availability of rehabilitation counsellors and other suitably qualified staff responsible for the vocational guidance, vocational training, placement and employment of disabled persons.

PART IV. FINAL PROVISIONS

Article 10

The formal ratifications of this Convention shall be communicated to the Director-General of the International Labour Office for registration.

Article 11

1. This Convention shall be binding only upon those Members of the International Labour Organisation whose ratifications have been registered with the Director-General.
2. It shall come into force twelve months after the date on which the ratifications of two Members have been registered with the Director-General.
3. Thereafter, this Convention shall come into force for any Member twelve months after the date on which its ratification has been registered.

Article 12

1. A Member which has ratified this Convention may denounce it after the expiration of ten years from the date on which the Convention first comes into force, by an act communicated to the Director-General of the International Labour Office for registration. Such denunciation shall not take effect until one year after the date on which it is registered.
2. Each Member which has ratified this Convention and which does not, within the year following the expiration of the period of ten years mentioned in the preceding paragraph, exercise the right of denunciation provided for in this Article, will be bound for another period of ten years and, thereafter, may denounce this Convention at the expiration of each period of ten years under the terms provided for in this Article.

Article 13

1. The Director-General of the International Labour Office shall notify all Members of the International Labour Organisation of the registration of all ratifications and denunciations communicated to him by the Members of the Organisation.
2. When notifying the Members of the Organisation of the registration of the second ratification communicated to him, the Director-General shall draw the attention of the Members of the Organisation to the date upon which the Convention will come into force.

Article 14

The Director-General of the International Labour Office shall communicate to the Secretary-General of the United Nations for registration in accordance with Article 102 of the Charter of the United Nations full particulars of all ratifications and acts of denunciation registered by him in accordance with the provisions of the preceding Articles.

Article 15

At such times as it may consider necessary the Governing Body of the International Labour Office shall present to the General Conference a report on the working of this Convention and shall examine the desirability of placing on the agenda of the Conference the question of its revision in whole or in part.

Article 16

1. Should the Conference adopt a new Convention revising this Convention in whole or in part, then, unless the new Convention otherwise provides-

(a) the ratification by a Member of the new revising Convention shall ipso jure involve the immediate denunciation of this Convention, notwithstanding the provisions of Article 12 above, if and when the new revising Convention shall have come into force;

(b) as from the date when the new revising Convention comes into force this Convention shall cease to be open to ratification by the Members.

2. This Convention shall in any case remain in force in its actual form and content for those Members which have ratified it but have not ratified the revising Convention.

Article 17

The English and French versions of the text of this Convention are equally authoritative.

Cross references

Recommendations:R150 Human Resources Development Recommendation, 1975

Recommendations:R099 Vocational Rehabilitation (Disabled) Recommendation, 1955

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Appendix 17: 2001 Disability Survey Snapshot 1 (Key Facts) - Media Release

2001 Disability Survey Snapshot 1 (Key Facts) - Media Release

Embargoed until 3pm — 19 April 2002

New Zealand Disability Survey Snapshot 1

Key Facts

This snapshot presents a selection of findings from the 2001 New Zealand Disability Survey, the second national survey on disability conducted by Statistics New Zealand. The survey provides an overview of disability in New Zealand. It covers people living in households and residential care facilities. The results are comparable with those from the 1996–1997 Disability Survey.

Summary

The results from the 2001 survey show that:

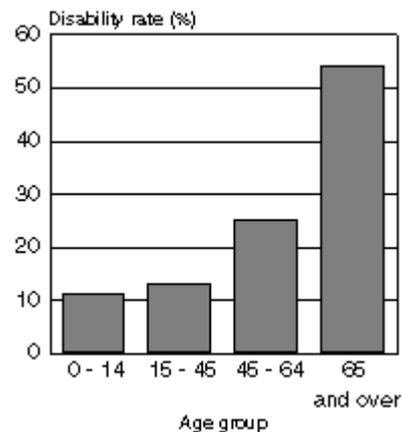
- One in five New Zealanders has a disability.
- Disability increases with age.
- The majority of disabled people have more than one disability.
- Physical disabilities are the most common type of disability; two-thirds of disabled people reported a physical disability.
- The number of people with mild disabilities has decreased and the number with moderate disabilities has increased.
- The number of people with disabilities living in intellectual disability units and mental health facilities has decreased.

1. Who has a disability?

- A total of 743,800 New Zealanders reported some level of disability in 2001, an increase of 41,800 since 1996–1997. However, the overall disability rate of 1 in 5 has not changed.
- One in five Māori have a disability, the same as for the total New Zealand population. The disability rate for Pacific peoples is 1 in 7.
- Disability increases with age. Eleven percent of children (0 to 14 years) have a disability, compared with 13 percent of adults aged 15 to 44 years and 25 percent of adults aged between 45 and 64 years. More than half (54 percent) of people aged 65 years and over reported having a disability.
- For Māori adults, the disability rates are higher than the national rates. One-third of Māori aged 45 to 64 years reported a disability compared with one-quarter of the total population aged 45 to 64 years.

- Sixty-one percent of Māori aged 65 and above reported a disability, compared with 54 percent of the total population in this age group.
- The disability rate for Māori children is 15 percent, which is also higher than the national rate for children (11 percent).
- More females reported disabilities (384,900) than males (358,900). However, the overall disability rate for males and females is the same.
- More than half (52 percent) of urban dwellers aged 65 and over living in households have a disability, compared with 45 percent of their rural counterparts. At other ages the rate of disability does not vary between people living in urban and rural areas.

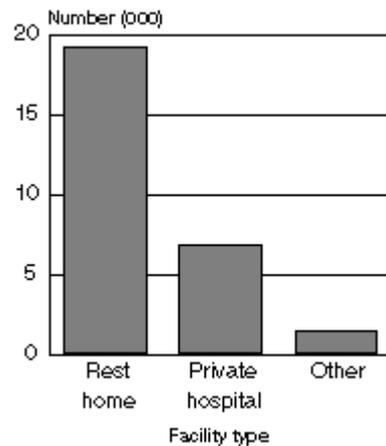
Disability Rates by Age Group



2. Where do people with disabilities live?

- Four percent or 27,300 people with disabilities live in residential facilities; the remaining 96 percent live in households.
- The majority of people with disabilities in residential facilities (70 percent) live in rest homes.
- Approximately 200 disabled people in residential facilities were living in intellectual disability units in 2001, compared with an estimated 1,700 in 1996–1997.
- The number of people with disabilities living in mental health facilities has halved, from 1,000 in 1996–1997 to around 500 in 2001.

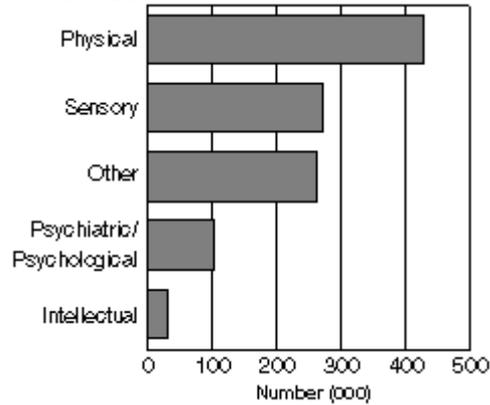
Disabled People by Facility Type



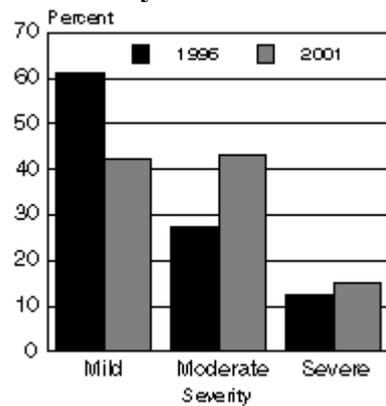
3. What types of disabilities do they have?

- The majority of people with disabilities have more than one disability. Forty percent of people with disabilities have a single disability.
- People living in residential facilities are more likely to have multiple disabilities. Ninety-six percent of disabled people living in residential facilities reported more than one disability compared with 59 percent of disabled people living in households.
- Physical disabilities remain the most common type of disability. Sixty-six percent of adults with disabilities reported some kind of physical disability (431,000). Sensory disabilities were the next most common, affecting over 40 percent (272,800).
- The leading cause of disability is a disease or illness (40 percent), followed by an accident or injury (30 percent).
- Forty-two percent of all disabled adults are mildly limited by their disabilities. A further 43 percent are moderately affected, and the remaining 15 percent are severely limited. In 1996–1997, just over 60 percent of the adult disabled population were mildly affected, 28 percent were moderately affected and 12 percent had severe limitations. Severity is defined by the level of assistance required.
- One-third (207,200) of disabled adults living in households reported that they use special equipment.
- Twelve percent (77,100) of disabled adults living in households reported an unmet need for some type of special equipment.

Disability Type for Adults with Disabilities



Severity of Disability for Adults with Disabilities



More information

This is the first in a series of nine snapshots providing key information from this survey. The titles and dates for these snapshots are listed below. A technical report containing information about how the survey was conducted, and tables from the 1996–1997 and 2001 surveys, will be published on 30 May 2002. The technical report from the 1996–1997 survey, 'Disability Counts', is available free on the Statistics New Zealand website: www.stats.govt.nz.

2001 New Zealand Disability Survey Snapshots

Release date	New Zealand Disability Survey Snapshots
19 April 2002	2001 Disability Survey Snapshot 1: Key Facts
7 May 2002	2001 Disability Survey Snapshot 2: Māori
17 May 2002	2001 Disability Survey Snapshot 3: Pacific Peoples
5 June 2002	2001 Disability Survey Snapshot 4: People in Residential Care
17 June 2002	2001 Disability Survey Snapshot 5: Children

25 June 2002	2001 Disability Survey Snapshot 6: Sensory Disabilities
11 July 2002	2001 Disability Survey Snapshot 7: Physical Disabilities
24 July 2002	2001 Disability Survey Snapshot 8: Intellectual Disabilities
2 August 2002	2001 Disability Survey Snapshot 9: Psychiatric and Psychological Disabilities

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END

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<http://www2.stats.govt.nz/domino/external/pasfull/pasfull.nsf/web/Media+Release+2001+New+Zealand+Disability+Survey+Snapshot+2+Maori?open>

New Zealand Disability Survey Snapshot 2

Māori

Summary

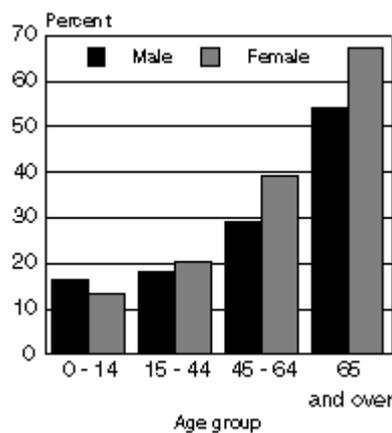
- One in five people of Māori ethnicity has a disability.
- Māori boys (0 to 14 years) are more likely to have a disability than Māori girls.
- Physical disabilities are the most common type of disability reported by Māori adults.
- Disease or illness is the most common cause of disability for Māori.
- Māori adults with disabilities are less likely to be in the labour force than Māori adults without disabilities.
- There are few Māori with disabilities in residential care.

1. Who has a disability?

- An estimated 107,200 Māori reported having a disability in 2001. This means one in five Māori has a disability. The disability rate for all New Zealanders is the same.

- Disability increases with age. Fifteen percent of Māori children (0 to 14 years) reported a disability, compared with 19 percent of Māori aged 15 to 44 years and 34 percent of Māori aged 45 to 64 years. Just over 60 percent of Māori aged 65 and over reported having a disability.
- Sixteen percent of Māori boys (0 to 14 years) reported a disability, compared with 13 percent of Māori girls in the same age group.
- At older ages the disability rates are higher among females than males. Nearly 30 percent of Māori men aged 45 to 64 years reported a disability, compared with nearly 40 percent of Māori women of the same age group.
- Half of Māori adults with disabilities were partnered. This is on par with the proportion of the total Māori adult population who were partnered (52 percent).

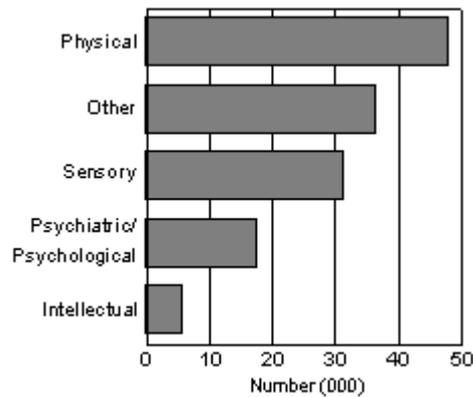
Māori Disability Rates by Sex



2. What types of disabilities do Māori have?

- Nearly 60,000 disabled Māori (55 percent) reported having more than one disability.
- Physical disabilities were the leading type of disability reported by Māori adults. Almost 48,000 (61 percent) reported this type of disability. 'Other' disabilities were the next most common, affecting 46 percent (36,400). 'Other' disabilities include speaking, learning and remembering disabilities.
- The majority of disabled Māori children (53 percent or 15,000) reported a disability classified as 'other'. This included children with speaking limitations, learning and developmental difficulties and children requiring special education due to a limitation. Sensory disabilities and chronic health problems were also common, each being reported by over one third of Māori children with disabilities (approximately 10,000).
- Forty-three percent of Māori with disabilities were mildly affected by their disability. Forty percent were moderately affected, and the remaining 16 percent were severely limited in their activities.
- The most common cause of disability was a disease or illness, reported by over 40,000 Māori (39 percent). The next most common cause was an accident or injury reported by nearly 30,000 (28 percent).

Disability Type for Māori Adults in Households



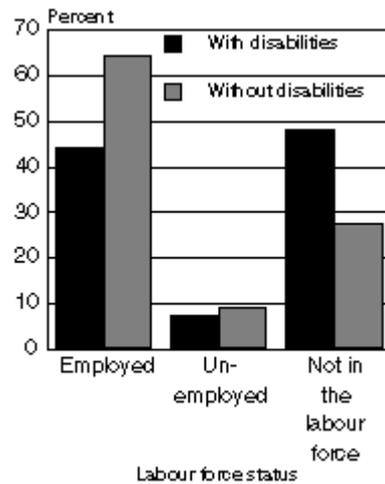
3. How are the lives of Māori with disabilities affected?

Unless otherwise stated, the numbers in this section relate to Māori living in households.

- Māori adults with disabilities were less likely to be in the labour force than those without disabilities. An estimated 48 percent of Māori adults with disabilities were not in the labour force. This means they were neither 'employed' nor 'unemployed and actively looking for work'. In contrast, 27 percent of Māori adults without disabilities were not in the labour force at the time of the 2001 Population Census.
- Māori with disabilities were also less likely to be employed than Māori without disabilities. Of those who stated their labour force status, 44 percent of Māori adults with disabilities (nearly 35,000) were employed, compared with 64 percent of Māori adults without disabilities (approximately 156,000).
- Sixty percent of disabled Māori adults had a total annual income of \$15,000 or less (38,200), compared with 44 percent of Māori adults without disabilities (95,100). This reflects the difference in the labour force situation of Māori adults with and without disabilities, as shown in the statements above.
- Almost 30 percent of Māori adults (22,400) reported using some type of special equipment related to their disability. Seventeen percent of disabled Māori adults (13,000) reported an unmet need for some type of special equipment.
- Twenty-three percent of Māori adults with disabilities reported an unmet need for some type of health service (18,000). This is on par with the proportion of disabled Māori children who reported an unmet need for some type of health service (22 percent or 6,200).
- Two percent of disabled adults living in residential facilities were Māori. This is in part due to the fact that Māori are highly concentrated in the younger age groups and the majority (92 percent) of disabled people in residential facilities are aged 65 and over. In 2001, approximately 4

percent of New Zealanders aged 65 years and above were Māori (2001 Census of Population and Dwellings).

Māori Labour Force Status



More information

This is the second in a series of nine snapshots presenting a selection of findings from the 2001 New Zealand Disability Survey. The survey provides an overview of disability in New Zealand. It covers people living in households and residential care facilities. The results are comparable with those from the 1996–1997 Disability Survey.

The next snapshot, "New Zealand Disability Survey Snapshot 3: Pacific Peoples", will be published on 17 May 2002. A technical report containing information about how the survey was conducted, and tables from the 1996–1997 and 2001 surveys, will be published on 30 May 2002. The technical report from the 1996–1997 survey, "Disability Counts", is available free on the Statistics New Zealand website: www.stats.govt.nz.

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