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The Convention on the Rights of Persons with Disabilities
and its implications for the health and wellbeing of
indigenous peoples with disabilities

Minerva Concepción Rivas Velarde

March 2014

A thesis submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy

Sydney Medical School

University of Sydney
AUTHOR’S DECLARATION

This is to certify that:

I. this thesis comprises only my original work towards the Doctor of Philosophy Degree
II. due acknowledgement has been made in the text to all other material used
III. the thesis does not exceed the word length for this degree.
IV. no part of this work has been used for the award of another degree
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Signature(s):

Name(s):
Minerva Concepcion Rivas Velarde

Date:
March 2014

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Dedication

I would like to dedicate this thesis to all the participants who contributed to it. Thanks for your trust, your time and your support in making this happen. I hope this and further publications can contribute to alleviate inequalities and to disseminate indigenous peoples’ knowledge around the world.

También quiero dedicar esta tesis a mi familia, que me han dado su ejemplo y apoyo para seguir adelante en mi carrera académica. En Memoria a mi Papá Ricardo Rivas y su espíritu de lucha, espero mi trabajo contribuya a tu legacía, a mi hermano Ricardo Rivas-Velarde por sus mensajes de aliento. ¡Gracias tía Jass por tus porras y tu gran apoyo! Sobre todo quiero dedicarle esta tesis y el largo trayecto que representa a mi Mamá, Minerva Velarde, gracias por ser un ejemplo para mí. Por compartirme de tu fe, tu fuerza y sobre todo tu buen humor y dulzura cada que lo he necesitado.

Y finalmente quisiera expresar mi más profundo agradecimiento y dedicar esta tesis a mi esposo, el compañero y motor mi vida Hernán Costanzo. Gracias por el ‘animo, valor, coraje’ que me brindas. Por todos los chistes, los chocolates y los abrazos con los que cubriste esta tesis hasta final, je t’ aime!

[Translation: I would like to dedicate this thesis to my family, for their example and support in pursuing a career in academia. To the memory of my father Ricardo Rivas and his fighting spirit, I hope my work contributes to your legacy in Michoacán. To my brother Ricardo, thanks for his encouraging messages. Many thanks to my aunt Jass Rivas for cheering me up from a distance and always supporting me! Most of all, I would like to dedicate this thesis, and the long journey of work and commitment]
that it represents, to my mother Minerva Velarde, Thank you for being a role model to me. Thanks, Mom, for sharing with me your faith, your strength, your great sense of humour and more than all your kindness.

Finally I would like to express my deepest gratitude and dedicate this thesis to my husband Hernán Costanzo, my support and driving force in life! Thanks for the singing autumn of ‘energy, bravery, courage’, for all the jokes, the chocolates and the hugs that sustained my long hours of work on this thesis.]
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I would like to express my sincere gratitude to my supervisors, as I would not have reached this point without their support. Thanks to all my three supervisors Professor Patricia O’Brien, Professor Trevor Parmenter and Dr. Clive Aspin and David Longton for reading drafts and making editorial suggestions. I would particularly like to thank Professor Patricia O’Brien for her continuous support with my PhD: I will always treasure your mentorship and guidance prior to and during my PhD. Apart from my primary supervisor I also would like to express my gratitude to Professor Trevor Parmenter and Dr. Clive Aspin for their encouragement, insightful comments, and challenging questions. Trevor, although you joined this team towards the end of the journey, your engagement, commitment and wisdom made up for the times when you were not there.

I also would like to thank the Poche Centre for Indigenous Health, Kylie Gwynne, Kim Szerdahelyi, Vita Christie and former members, Professor Ngiare Brown, Dr.Tara Walker and Dr.Michael E. Otim. Thanks for being so supportive of my research and for offering me a welcoming and beautiful environment in which to work on my PhD (and where I almost moved in).

Thanks also to the Centre of Disability Studies, where with colleagues and fellow PhD candidates we shared great memories over the years! To Sydney Medical School and the Learning Centre and especially to Dr. George Ridgway for his kind support of my journey! To the World Health Organisation Department of Health and Human Rights and the Department of Social Determinants of Health, to Dr. Eugenio del Villar, Daniel Albrecht Alba and Helena Nygren-Krung and especially to Dr. Tom Shakespeare for your great support and encouragement. The Social Work
Department at the Mexican Institute for Social Insurance, The National Institute of Statistics and Geography (INEGI), National Institute for Social Development, The Mexican Council for Development and Inclusion of Persons with Disabilities; Radio de la Meseta Purepecha, Association for Indigenous with Disability in Patzcuaro Michoacán. In New Zealand, thanks go to the Ministry of Health and Te Roopu Taurima and in Australia, to Brewarrina’s Aboriginal Medical Services and the local hospital. Thank you very much for having faith in my work and for welcoming me into your work spaces, networks and teams.
Abstract

This thesis explores how the expressed health needs of indigenous peoples with disabilities resonate with the mandate of Article 25 ‘Health’ of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The perceptions of indigenous peoples with disabilities are investigated, regarding their access to, and expectations of, health care. Their views are compared to those of health workers, senior bureaucrats and United Nations delegates.

A qualitative approach was taken to the research presented in this thesis, framing the research methodology on indigenous enquiry. An exploratory case study approach was taken to compare three jurisdictions: Australia, Mexico and New Zealand. The data collection techniques used involved semi-structured interviews, focus groups and field notes. It presents the views of 50 participants including 18 indigenous persons with disabilities, 19 health workers, 10 decision makers and 6 United Nations Delegates. Data gathered were verbatim-transcribed and analysed using N-vivo10, following case study analysis guidelines and the incorporation of grounded theory tools.

The findings suggest that the health needs of indigenous peoples with disabilities are largely underserved and misunderstood by health departments. Specialised and preventive health care for those with disabilities was found to be particularly problematic. Poverty, discrimination and disenfranchisement emerged as being the possible major determinants of the ill health experienced by indigenous peoples with disabilities. The discourse of all groups of participants within the three case studies suggested that the CRPD mechanisms must substantially improve engagement with
indigenous peoples in order to impact positively on their health. The relevance of the CRPD to indigenous peoples was perceived to be very limited due to the lack of input of indigenous peoples into its development, implementation and monitoring mechanisms both domestically and internationally. This lack of representation was seen as a manifestation of ongoing colonisation, which remains the greatest barrier to improving the life and health of indigenous peoples.

A lineal model representing the health experiences of indigenous peoples with disabilities and the role of the CRPD and Article 25 emerged from the findings. Such a lineal progression indicates that greater political disenfranchisement relates to worsening health outcomes, whilst honouring indigenous people’s right to self-determination enhances health. The data collected suggest that to gain better health outcomes for indigenous peoples with disabilities it is necessary to foster practices that build resilience. These include creating a dialogue on health, disability and rights. By having a voice that translates into visibility across the CRPD mechanism, indigenous peoples with disabilities can move towards emancipation.

The findings of this research advocate the need to build capacity and rights literacy among across indigenous peoples with disabilities, particularly with respect to the CRPD, in order to enhance its impact on the health of indigenous people. A legitimate redistribution of resources and decision-making in response to the expressed health needs of indigenous peoples with disabilities is needed if the vision of the CRPD is to be realised in relation to Article 25.
Glossary and Use of Key Terms

The following glossary presents key words utilised through this thesis. Similarly it helps clarify a position regarding the use of language, outlining the rationale behind selected terms. It also provides a translation of indigenous words utilised by either participants or the literature quoted in this research.

<table>
<thead>
<tr>
<th>Key Terms</th>
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<tbody>
<tr>
<td>Indigenous peoples</td>
<td>The style guide of the Poche Centre of the University of Sydney suggests the use of capital letters in the use of the word indigenous, however the United Nations Declaration on the Rights of Indigenous Peoples (DRIP) uses the term ‘indigenous peoples’. Therefore this thesis complied with the DRIP.</td>
</tr>
<tr>
<td>Disability or disabilities</td>
<td>Disabilities is the term most commonly used in legislation in Australia. It is also the term used in The Convention on the Rights of Persons with Disabilities. However disability scholarship prefers the term ‘disability’. In this thesis the term will be used according to the literature that is being referred to.</td>
</tr>
<tr>
<td>Users or users of health care</td>
<td>This term will always be used to</td>
</tr>
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</table>
indicate indigenous peoples with disability.

<table>
<thead>
<tr>
<th>Abbreviations</th>
<th>Meaning</th>
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<tbody>
<tr>
<td>IMSS</td>
<td>Instituto Mexicano del Seguro Social: Mexican Institute of Social Insurance</td>
</tr>
<tr>
<td>IMSS Oportunidades</td>
<td>Health and social development programme supported by the Mexican Institute of Social Insurance</td>
</tr>
<tr>
<td>Purepecha</td>
<td>Indigenous peoples inhabiting the Purepecha plateau located between the Mexican state of Michoacán and Colima. Purepecha originally referred to the Purepecha language spoken by them.</td>
</tr>
<tr>
<td>EZLN</td>
<td>Ejército Zapatista de Liberación Nacional (EZLN): The Zapatista Army of National Liberation</td>
</tr>
<tr>
<td>Blackfella</td>
<td>An abbreviation of ‘black fellow’</td>
</tr>
</tbody>
</table>

**Glossary of Māori words used in the text**

<table>
<thead>
<tr>
<th>Māori word</th>
<th>Meaning</th>
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<tbody>
<tr>
<td>Iwi</td>
<td>Tribal group</td>
</tr>
<tr>
<td>Hapū</td>
<td>sub-tribal group</td>
</tr>
<tr>
<td>Kura Kaupapa Māori</td>
<td>Māori language immersion school</td>
</tr>
<tr>
<td>Pākehā</td>
<td>New Zealanders of European descent</td>
</tr>
<tr>
<td>Powhiri</td>
<td>Māori welcome</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>----------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>Taha wairua</td>
<td>Intellect and emotions</td>
</tr>
<tr>
<td>Taha hinengaro</td>
<td>The human body</td>
</tr>
<tr>
<td>Taha whānau</td>
<td>Human relationships</td>
</tr>
<tr>
<td>Tangi</td>
<td>Mourning ceremony</td>
</tr>
<tr>
<td>Te reo Māori</td>
<td>Māori language</td>
</tr>
<tr>
<td>Whakapapa</td>
<td>Genealogy</td>
</tr>
<tr>
<td>Whānau,</td>
<td>Extended family</td>
</tr>
<tr>
<td>Whanaungatanga</td>
<td>Connecting through family relationships</td>
</tr>
<tr>
<td>Whare</td>
<td>House</td>
</tr>
<tr>
<td>Whare wānanga</td>
<td>House of learning</td>
</tr>
</tbody>
</table>
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Chapter One: Introduction

Globally, indigenous peoples have made many significant contributions to the diversity and richness of civilizations and cultures, which constitute the common heritage of humankind (The United Nations Permanent Forum of Indigenous Peoples, 2012). However, indigenous peoples have been significantly affected by colonisation, contributing to inequalities linked to ill health, high rates of poverty, lack of access to food, unsustainable living and disenfranchisement (Levi & Maybury-Lewis, 2010).

Historically, indigenous peoples suffered enormously after contact with western cultures. Such contact resulted in a reduction in the indigenous population and is associated with the loss of traditional wisdom and knowledge (Kuppe, 2009). In modern times, the effects of colonisation with respect to governance have been addressed by legal actions taken by either the United Nations Council on Occupied Territories or domestic governments, however, social disparities remain an issue (International Labour Organisation, 2005). Poverty has been linked both as a cause and an effect of disability, which may be triggered by inadequate medical care and poor preventative health. An over-representation of ill health and disabilities among indigenous peoples is leading to a vicious circle of marginalisation. Specific attention targeted at both people with disabilities and indigenous peoples is required to stop this cycle, giving them the right to the highest attainable standards of health (Hunt, 2004). Socio-economic disadvantage and a lack of political representation, as well as historical and systematic discrimination, all highlight the need for indigenous
peoples with disabilities to be covered by adequate legislation and relevant health policies.

A number of major United Nations social development initiatives, such as the 1995 World Summit for Social Development, the World Summit +5 and the Millennium Development Goals (United Nations General Assembly, 2005), have been implemented to address social equity and poverty, but they all failed to incorporate disability as a mainstream issue and to address its over-representation in marginalised populations. This failure was recognised by Mexico, which then became a catalyst for change, taking the lead in advocating the rights of persons with disabilities within the international community at the World Conference Against Racism, Racial Discrimination, Xenophobia and Related Intolerance, held in Durban, South Africa in 2001 (United Nations General Assembly, 2001).

Mexico proposed a convention based on a social development approach. This was given a greater welcome by the member states of the United Nations than previous non-binding documents, such as, the United Nations General Assembly (1975), the Principles for the Protection of Persons with Mental Illness (1991) and the World Program of Action for Disabled Persons (1993). In December 2001, the United Nations General Assembly established an ad hoc committee to consider proposals for such a Convention. A very significant contribution was made by Mexico, which advocated a paradigm shift from non-binding international standards to formally binding legal obligations for those states that became party to the outcomes of the work of the ad hoc Committee. This is now known as the Convention on the Rights of Persons with Disabilities (United Nations, 2006) – see Appendix A.

The Convention on the Rights of Persons with Disabilities (hereafter referred to as}
CRPD) mandates that United Nation member states should respect the inherent dignity, individual autonomy (including the freedom to make independent choices) and independence of persons with disabilities. The CRPD does mention indigenous peoples in the preamble; however indigenous peoples are not included as a protected group within the binding text of the Convention, even though indigenous peoples are disproportionately represented among peoples with disabilities worldwide (Braithwaite, Carroll, Mont, & Peffley, 2009; Mégret, 2008; Wiley, 2009). This exclusion within the binding text could be seen as a legal barrier, as it is through international law that greater protection has been achieved for indigenous people’s rights (Pasqualucci, 2006) Therefore, it is relevant to explore the mandate that international conventions, such as the CRPD, have for improving the lives of indigenous peoples with disabilities and, for the purposes specifically of this thesis, the right to health as outlined in Article 25 of the CRPD.

Indigenous peoples have the highest morbidity and mortality rates worldwide and the lowest rates of access to health services among national populations (Smylie, Anderson, Ratima, Crengle & Anderson, 2006; Wilson & Richmond, 2009). Standardised negative social outcomes worldwide for indigenous groups raise several questions, including: are indigenous peoples with disabilities accessing health services and how are indigenous peoples’ health needs met? What are the commonalities and differences across international boundaries of how the health needs of indigenous peoples with disabilities are met? How do their needs resonate with the CRPD? What are the implications for policies and practices for nation states in the implementation of Article 25, Health, CRPD as they affect indigenous peoples with disabilities?
1.2 The protection of the right to health for indigenous peoples with disabilities

Indigenous peoples today are still struggling to overcome the injustices stemming from colonisation. As a result they are currently experiencing major violations of their basic civil and political rights, including the right to receive culturally adequate health care (Cooke, Mitrou, Lawrence, Guimond, & Beavon, 2007; Kuppe, 2009).

The fulfilment of human rights for indigenous peoples requires a strong monitoring system that enhances the voice of the population against discrimination. The uniformity of indigenous peoples’ health disparities within indigenous groups could be interpreted as a manifestation of Freire’s (1970) ‘culture of silence’ where colonised and disempowered groups have been subjected to silence by the powerful elite. European colonisation generated societies with extremely high degrees of inequality, and resulted in poor health outcomes of indigenous peoples across the globe (Penn, 2008). This raises two questions regarding the status of indigenous peoples with disabilities: firstly, whether the mechanisms of rights protection, such as the CRPD, are responding to those who need it the most; and secondly, how could the CRPD be utilised to enhance the health of indigenous peoples with disabilities?

The uniformity of the international struggles of indigenous peoples for the fulfilment of the right to health suggests shared patterns of oppression. The literature distinguishes two types of colonial settlement. Settler colonial states are states where settlers constituted the majority of the population and dominated the social institutions – examples of these types of settlement are Australia and New Zealand. A second type has been termed non-settler colonial states: an example is Mexico, where the prevalence of intermarriage between settlers and local tribes-peoples led
to a new group of peoples called Mestizos who formed the majority and controlled local institutions (Frankema, 2010).

1.3 Aims of the research

This research has examined the health experiences of three different colonised indigenous populations, which were selected to explore the following questions: what are the expressed health needs of indigenous peoples with disabilities in Australia, Mexico and New Zealand and how do they compare with the mandate of Article 25 of the CRPD? These three countries provide variation across different types of settlements and levels of legal protection of indigenous peoples, which were instrumental to an analysis of how the expressed health needs of indigenous peoples have been met. Mexico led in the creation of the CRPD and is a non-settler colonial state whose constitution recognises itself as a pluricultural country. Australia is a settler colonial state without constitutional recognition of its indigenous peoples. New Zealand is a settler colonial state in which the indigenous peoples signed a treaty with the British Crown at the time of colonisation to protect their sovereignty. These three countries are signatories to the convention, they all have also ratified it, but just two, Australia and Mexico, have ratified its optional protocol. The optional protocol is also an international treaty that strengthens the CRPD; it protects the rights of persons with disabilities by creating additional avenues of communication and accountability. It stabilises individual communication, allowing people with disabilities to bring petitions to the CRPD Committee, which is a body of independent experts monitoring the implementation of the Convention. The optional protocol also gives the committee the authority to undertake enquiries into grave or systematic violations of the Articles of the Convention. Ratification refers to concrete actions by
member States that show their commitment to undertaking legal rights and obligations mandated in the Convention or the Optional Protocol (CRPD, 2006)

As an indigenous scholar, I have been influenced by Smith (1999) in the methodological construction of this study. She is an indigenous researcher, who has indicated that indigenous research needs to be driven by indigenous priorities, meaning priorities directed by indigenous peoples, which should promote the development of the indigenous community, as an acknowledgement of indigenous sovereignty and self-determination. Smith’s writing resonates with Hegel’s (1896) proposition of how oppressed minorities seek solidarity as an avenue to emancipation. Similarly, Marxists and neo-Marxists, such as Fanon (1994), have continued to frame many explanations of the experiences of indigenous peoples in a discourse of class formation. Indigenous peoples seem to be isolated, not just from social protection but also from the social system as a whole, due to a lack of indigenous statistics arising from censuses and government surveys (Buvinic & Mazza, 2005). Similarly, the complex challenges of defining and identifying indigenous populations have been reinforced over the years due to their invisibility and lack of participation in society and in policy-making.

Contemporary Human Rights Treaties such as the CRPD are positioned to overcome these historical challenges and to promote a civil rights and anti-discrimination approach to disability. Specifically Article 25, which covers ‘Health’, is aimed at changing the negative attitudes and barriers towards people with disabilities across health systems. Therefore, the research described here is aimed at informing indigenous policies and practices in meeting the requirements of the optional protocol in relation to Article 25 of the CRPD (United Nations, 2006).
1.4 Thesis outline

This research was undertaken to explore how the expressed needs of indigenous peoples with disabilities have been met in comparison with Article 25 of the Convention on the Rights of Persons with Disabilities. Chapter One, Introduction, provides an overview of the research. It presents a general introduction to the historical issues affecting the health of indigenous peoples with disabilities, the aims of the study and the indigenous values that have underpinned its implementation and analysis. Chapter Two, Contextual Issues, contains an analysis of the relevant literature on the political, historical and environmental contexts that affect the health of indigenous people with disabilities in Australia, Mexico and New Zealand. These include the relationship between colonisation, social oppression and the underlying social determinants of health.

Chapter Three, Understanding Disability from an Indigenous Perspective, includes an analysis of the conceptualisation of disability and indigenous health. Here, disability scholarship is explored to obtain a deeper understanding of the life experiences of indigenous peoples with disabilities. The emancipatory nature of such scholarship is utilised in order to examine how the CRPD could fulfil the health needs of indigenous peoples with disabilities.

Chapter Four, Methodology, outlines the epistemological construction of this study. The research questions are further explored and a logical argument is given for the selection of the comparative approach of three exploratory case studies (Yin, 2009). Addressing the importance of indigenous methodologies in decolonising the creation of knowledge, this chapter provides an analysis of the literature relevant to
indigenous epistemology. It also gives the reader the clear rationale behind the sample of participants by describing the logical process that led to their selection, recruitment and ongoing engagement with the research. Chapter Five, *Research Findings*, contains a compilation of the findings from the case studies of Australia, Mexico and New Zealand. An in-depth analysis of the themes and relationships emerges as each case study is presented. The expressed health needs of indigenous peoples are compared and triangulated with the discourse of health workers, senior bureaucrats and United Nations delegates within each country, as they relate to the mandate of Article 25 of CRPD.

Chapter Six is a *Cross-Case Analysis of the Three Case Studies*. In it the similarities and differences between the cases are presented, showing the patterns, themes and relationships that have emerged cross-sample. In this chapter the findings of the three case studies are unified to examine the factors that play a role in perpetuating or alleviating the health problems of indigenous peoples with disabilities.

In Chapter Seven, *Discussion and Conclusion*, the grass roots of health inequities that have emerged as part of this study are discussed, and they are traced back to colonisation and its ongoing effects. A legitimate way to overcome these inequalities, such as by utilising the CRPD, is addressed. The chapter describes the process through which the analysis of the data was transformed into a linear model looking at what has occurred in the past, the present and in the future, where the health needs of indigenous peoples with disabilities can be met through affordable care, early identification and intervention, as well as accessible services with assured insurance.

In this chapter the reader is also provided with a review of the lessons learnt and challenges encountered in conducting research in this field. Guidelines are offered
for future research and for implementation in New Zealand, as well as in all member
states that have ratified the CRPD of Article 25 of CRPD for indigenous people with
disabilities, including Australia and Mexico.
Chapter Two: Contextual Issues

2.1 Introduction

This chapter examines the literature that has contributed to our understanding of how the right to health, as framed by the Convention on the Rights of Persons with Disabilities (CRPD), could alleviate the expressed health needs of indigenous peoples with disabilities. Firstly, the current health discrepancies between indigenous and non-indigenous peoples are exposed. Who ‘indigenous peoples’ are, for the purpose of this research, is established and a position on race and social theory is framed.

Secondly, the social and historical factors influencing the health experiences of indigenous peoples with disabilities are examined, drawing on examples from the indigenous peoples of Australia, Mexico and New Zealand. The relationship between poor health and indigenous people’s access to health services in all three countries is well illustrated. Colonial practices are also discussed with respect to their contribution to negative health outcomes for indigenous peoples worldwide. Core elements are examined from the historical perspective of the effects of the dominant colonial hegemony, highlighting disenfranchisement, poverty, discrimination and the limited representation of indigenous peoples in the development of human rights treaties.
2.2 Health discrepancies

Globally, from birth indigenous peoples worldwide are more likely to suffer ill health and disabilities (The Organisation for Economic Co-operation & Development (OECD), 2012). Ill health and the lack of health services are strongly related to a high rate of disability among indigenous peoples. The World Report on Disability produced jointly by the World Health Organization and World Bank (2011) states that people with disability experience a narrower margin of health. For indigenous people with disabilities this becomes exacerbated due to social exclusion and racism, factors further restricting access to health services and rehabilitation. Increases in cardiovascular diseases, mental illness, cancers, and respiratory illnesses observed in all parts of the world are expected to have a profound effect on the prevalence of disability among indigenous peoples (Albala & Corvalan, 2011; BeLue, Okoror, Iwelunmor, Taylor, Degboe, Agyemang & Ogedegbe, 2009; Gracey & King, 2009; Kritharides, Brown, Brieger, Ridell, Zeitz, Jeremy, Tonkin, Walsh, & White, 2010; Ohenjo, Willis, Jackson, Nettleton, Good & Mugarura, 2006; Vos, Barker, Begg, Stanley & Lopez, 2009). Disability-related Illnesses are disproportionally more prevalent within indigenous communities (Gracey & King, 2009).

Table 2.1 depicts an overview of the relevant health indicators. It shows that indigenous peoples from Australia, Mexico and New Zealand have systematically reported poorer health outcomes, such as lower life expectancies, higher infant mortality and a higher prevalence of disability. In general, the health outcomes of indigenous peoples within each of the countries selected have been negatively reported. Indigenous peoples often have the highest rates of morbidity and mortality, and the lowest rates of access to health services nationally (Yoshika, 2010).
Table 2.1 Key health indicators for disabilities

<table>
<thead>
<tr>
<th>Country</th>
<th>Australia</th>
<th>Mexico</th>
<th>New Zealand</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability prevalence</td>
<td>Nationally, half (50%) of Aboriginal and Torres Strait Islander people aged 15 years and over (adults) had a disability or a long-term health condition in 2008. Around one in twelve (8%) had a profound or severe core activity limitation.</td>
<td>31.9%. of the Purepecha population, indigenous population from Mexico selected for this study, has some sort of impairment in comparison with 6.1% prevalence in the non-indigenous population</td>
<td>Across the Māori population, the prevalence of disabilities is 16.1% against 14.4% for the non-Māori population; in rural New Zealand it is higher at 16.9%.</td>
</tr>
<tr>
<td>Population</td>
<td>Aboriginal and Torres Strait Islander people</td>
<td>Purepecha</td>
<td>Non-indigenous</td>
</tr>
<tr>
<td>Mean life expectancy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>women</td>
<td>72.9</td>
<td>82.6</td>
<td>72.9</td>
</tr>
<tr>
<td>men</td>
<td>67.2</td>
<td>78.7</td>
<td>67.2</td>
</tr>
<tr>
<td>Mean Infant mortality</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>rates</td>
<td>3.6</td>
<td>2.5</td>
<td>16.77</td>
</tr>
</tbody>
</table>

Systematic negative outcomes can be linked to a history of inadequate health policies (Dickert, Emanuel, & Grady, 2002; Krahn & Campbell, 2011). It is, therefore, important to explore what has been responsible for the patterns of health and well-being in populations, and how these patterns have resulted in the health patterns of indigenous peoples. Defining what ‘indigenous peoples’ are has been challenging for policy-makers and social scientists. Having a clear set of guidelines establishing who indigenous peoples are today will lay the foundations for analysing the major questions within this study. Specifically, how are the expressed needs of indigenous people with disabilities being met in comparison with the mandate of Article 25 of the CRPD?

2.3 Who are indigenous peoples?

Defining who indigenous peoples are has proved to be challenging for the UN, as some member states have been reluctant to recognise their existence within their territories (Escárcega, 2010). As indigenous peoples are so diverse, an official definition of ‘indigenous’ has not been adopted for use in any UN body (Levi & Maybury-Lewis, 2010; Yoshioka, 2010). Historically, one of the most quoted definitions was published in 1986 by the UN Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, who in his report on the Problem of Discrimination against indigenous wrote:

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. 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 system. (Martínez-Cobo, 1986, p. 7)

This definition influenced the modern understanding adopted by the UN Permanent Forum on Indigenous Issues (2007). The World Bank (2007) has developed Operational Directive 4.10, which proposes the following guidelines for the recognition of indigenous peoples:

- Self-identification of indigenous persons at the individual level, and accepted by the indigenous population as a community member;
- Historical continuity with pre-colonial and/or pre-settler societies, strong links to territories and surrounding natural resources;
- Distinct social, economic or political systems, distinct language, culture and beliefs, form non-dominant groups of society; and
- Serve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities. (World Bank, 2007)

However, these two positions taken by Martinez-Cobo (1986) and the World Bank (2005) with respect to the definition of indigenous peoples have not been universally accepted. Kymlicka (2008) stated that the concept of indigenous peoples as ‘descendants of the original non-European inhabitants of lands colonized and settled by European powers’ (p. 8) oversimplifies the term ‘indigenous’ and needs to be re-examined. Kymlicka’s interpretation reflects the need to think about the development of indigenous peoples and what it means to be indigenous today.

One of the strongest elements of both of the definitions above is an emphasis on
self-identification, which has been central to the human rights treaties that have been written to protect the rights of indigenous peoples, such as the UN Declaration on the Rights of Indigenous Peoples (2007) and the International Labour Organisation Convention (No 169) concerning Indigenous and Tribal Peoples. Both defend the right of indigenous peoples to self-identify freely. The approach taken by these two documents addresses the need to empower indigenous communities.

As an indigenous scholar, I concur with Escárcega (2010) who stated that:

Indigeneity has to be recovered, nurtured, protected, and reproduced and has to be understood as a process for social justice, rights, and decolonization in which indigenous peoples raise consciousness of themselves as ‘peoples’ with rights and the need to transform the system and structures that deny them peoplehood (p.4).

Self-identification implies empowering individuals to claim a social, cultural, and political identity. It entails a right to belong to an indigenous group, honouring its ancestral history and acknowledging a transcendental link.

In Australia, Mexico and New Zealand being indigenous means self-identifying, belonging to a community and ultimately adopting a political identity that reflects unity as a political group (Mora, 2007; Sanders, 2002; Suárez, 2005). Studies of indigenous self-identification in young adults in urban Australia found that self-identifying as Aboriginal is accompanied by reflecting on what it means to ‘look’ Aboriginal (Kickett-Tucker, 2009; Lumby & McGloin, 2009; Paradies, 2006). Lumby and McGloin (2009) stated that holding identifiable physical markers has ‘incited disputes about who can claim Aboriginality, both from within Aboriginal communities where identity regulation is enforced through the absorption of [historical] colonial
discourses, and from outside’ (p.32) This confirms Delgado and Stefancic’s (2011) statement that indigenous race was once utilised to delimit and define indigenous peoples, but today it is seen more as a social than a biological construct. However, the spiritual and transcendental role of blood connections cannot be overlooked, but care should be taken to avoid biological determination, as it is often attached to racial discrimination.

Defining indigenous peoples has serious implications for governance accountability. Data on indigenous peoples are not captured adequately in official statistics, often increasing the ‘invisibility’ of indigenous people and reinforcing their exclusion (Bhopal, 2008; Vos et al., 2009; Yoshioka, 2010).

Variations between countries in approaches to the measurement of the size of their indigenous population could be seen to be related to a country’s ideology, national history and indigenous advocacy. As a result, cross-country instruments for census/survey work may be reporting differing and incomparable data. Variations between Australia, Mexico and New Zealand are described below, as well as how measurement methodology has changed with time.

- The Australian Bureau of Statistics requests self-identification as follows – ‘Is the person of Aboriginal or Torres Strait Islander origin? Or are persons of both Aboriginal and Torres Strait Islander origin?’ (Australian Bureau of Statistics, 2012).

- The Mexican National Institute of Statistics and Geography (Instituto Nacional de Estadística) (INEGI) determines the size of the indigenous population with data based by respondents declaring an ability to speak an indigenous language. From 2010 INEGI has incorporated self-identification in its census
questionnaire (Instituto Nacional de Estadística, 2012)

- Statistics NZ has offered census respondents the option of census forms in Māori since 1996. Its questionnaire is also based on self-identification, asking whether the respondent identifies her/his biological ancestry to be Māori (Statistics New Zealand Tātakura Aotearoa, 2010)

These differences, therefore, illustrate that caution should be exercised when interpreting statistical data on indigenous populations. To exemplify this issue the Mexican National Institute of Statistics and Geography reported a difference of 1.2 million between those who speak an indigenous language and those who self-identify as indigenous. These data have serious implications for health as AID funding is often allocated depending on where vulnerable populations are located. Therefore, international attention should be focused on understanding the construction of the term, ‘indigenous’.

2.3.1 Theoretical construction of race and indigeneity

Race-based discrimination experienced by indigenous peoples worldwide highlights the need to understand the implications of the concept of race and racism. Thus several studies have shown the negative effect that race has on the health of indigenous peoples (Anderson, Crengle, Leialoha Kamaka, Chen, Palafox & Jackson-Pulver, 2006; Bramley, Hebert, Tuzzio, & Chassin, 2005; Durie, 2003; Smedley, Stith, & Nelson, 2009). Current disparities in health outcomes between indigenous and non-indigenous peoples reflect racial inequity, with race seen as a social rather than a biological construct (Delgado & Stefancic, 2011). Thus biological categories superficially distinguished by ‘colour’ have no scientific validity and no explanatory value in social science (Modood, Berthoud, & Nazroo, 2002). However,
world history has been racialised, and a racial hierarchy exists even in the postcolonial present (Tate, 1997).

Fujiura and Drazen (2009) have contributed to the analysis of the concept of race and ethnicity, stating that disability scholarship is a long way off understanding these concepts. They disqualified numerous studies constructed on the core logic that differences exist between racial and ethnic groups. Instead they proposed a much more valuable approach concentrating on identifying differences in life experiences. Balcazar, Suarez-Balcazar, Taylor-Ritzler, & Keys (2010) concurred with this view claiming that differences across races or ethnic groups will only have value if they contribute to addressing indigenous peoples’ needs in the race to alleviate disparities, such as health inequities.

I. Racism

Ignoring the influence of race entrenchment contributes to the establishment of racial subordination (Thomas, 2000). In general ‘racism’ and ‘racialisation’, which both mean the categorisation of people on the basis of their ‘race’ or ‘ethnicity’, have been related to ill health. As a phenomenon embedded in contemporary society, racism has stopped people from accessing social services, such as health (Goldberg, 1992; Thomas, 2000).

Balcazar et al. (2010) stated that racism and its legacy have been difficult to eradicate; instead race-based inequity has grown, influencing rates of morbidity, mortality, and prevalence of well-being across socially disadvantaged groups (Ford & Airhihenbuwa, 2010). For instance, racism has fostered social deprivation, which continues to affect the health of indigenous peoples (Anderson et al., 2006; Paradies, Harris, & Anderson, 2008) and it is necessary to understand the strong
influence that race has on people living with disability and on related social institutions, such as health care. Henry, Houston, and Mooney (2004) have argued that racism is embedded in Australian health care and ‘represents one of the greatest barriers to improving the health of the Aboriginal and Torres Strait Islander people’ (p. 517) Similar issues have been raised in New Zealand where Harris, Cormack, Tobias, Yeh, Talamaivao, Minster, and Timutimu (2012) provided evidence that racism may be a major determinant of ill health for Māori people. In keeping with this negative trend, Campos-Navarro (2010) also demonstrated the detrimental effects that institutional racism has had on indigenous health over many years in Mexico.

The UN Declaration on the Elimination of All Forms of Racial Discrimination (1965) defined racism as referring to hierarchies or doctrines of superiority based on racial differentiation. The UN also stated that racism could be alleviated though the implementation of non-discrimination legislation. However, it is important to highlight that traditionally international public law has defined discrimination by focusing on determining the legality of a State's treatment of foreigners. Historically, international law has not set out mandates to regulate the state's treatment of its own nationals and can be seen, therefore, as indifferent to whether a state might discriminate against a particular ethnic, religious or other group (McKean, 1970). This is of concern, particularly when indigenous peoples have been historically discriminated against by colonial law and by policies that restricted their rights, such as the right to health and all that this implies in terms of access to services (Anderson, 2007).

Public health has inadequately addressed the complexity with which structural racism influences health disparities (Ford & Airhihenbuwa, 2010). Social inequity experienced by indigenous peoples remains a severe problem with limited policy
interventions implemented to date. It has been recognised, however, that the negative effects of racism on the ill health of indigenous peoples go beyond the health system, and encompass broader systems of social oppression, which arise from poor ratings among indigenous peoples on what are considered to be the social determinants of health.

2.4 Social determinants of indigenous health

Social determinants of health are key social indicators that have an influence on the health and wellbeing of individuals (Marmot, 2005). Health is connected with a whole range of social determinants, from having enough available and affordable food, to being able to access a health system freely and obtain medications, to having information on preventing illness, to the availability of adequate housing and safe working conditions enabling people to earn fair salaries. The social determinants of health are the conditions in which people are born, grow, live, work and age, including the health care system (World Health Organisation, 2013). There are gross inequalities in health between countries and within the populations of Australia, Mexico and New Zealand. For example, life expectancy at birth varies by more than 10 years between indigenous and non-indigenous Australian people (Australian Institute of Health and Welfare, 2012); eight years between Māori and non-Māoris in New Zealand (Statistics New Zealand, 2012); five years between Purepecha and non-indigenous peoples in Mexico (Instituto Nacional de Estadística, 2012).

Social factors such as social class will lead to an understanding of disease causation and possible links between social position and disease risk. Disease causation is intrinsically linked to lifestyle and discrimination (Marmot, Kogevinas, & Elston, 1987). Social factors, such as poverty, impact strongly on the livelihoods of
indigenous peoples with disabilities. However measuring the ramifications and the extent of the impact of poverty remains a challenge due to the lack of robust data mostly from low and middle income countries; and on hard-to-reach populations, such as indigenous peoples (Groce, Kett, Lang, & Trani, 2011).

2.4.1 Disease distribution: social determinants of health theory

The framework for social determinants of health theory includes three main theoretical directions, which are not mutually exclusive, and inclusive of: psychosocial approaches (Martikainen, Bartley, & Lahelma, 2002); social production of disease/political economy of health (Krieger, 2001); eco-social theory and related multi-level frameworks (Krieger, 1994). These theoretical approaches utilise the three core concepts of: (1) ‘social selection’, or social mobility; (2) ‘social causation’; and (3) life course perspectives. Each of these concepts and associated pathways strongly emphasises the role of ‘social position’, which is found to play a central role in the acquisition of social determinants of health and the infringement of their inequities (Solar & Irwin, 2010).

Diderichsen (2004) elaborated on a critical hypothesis on the inference of social position on health status. This hypothesis concurs with Marmot (2005) who posited that social position works as a mechanism of social inequity. The social context in which every individual lives is part of the social stratification and gives a person a particular position in society. This position will determine any health-damaging conditions and risk. These authors claim that an individual’s future health will depend upon what the associated material resources are that go with a person’s position.

Contemporary societies have been fostering unfair and avoidable differences in health particularly within indigenous and non-indigenous populations (Carson,
Dunbar, Chenhall, & Bailie, 2007). The World Health Organisation (2002) stated that the primary purpose of health systems is to promote, restore or maintain health. However, this ideal, which was established more than 10 years ago, remains unreached for indigenous peoples with disabilities (Bramley et al., 2005; Montenegro & Stephens, 2006). The worldwide deprivation of health care for indigenous populations reflects inadequate policies and structures that have failed to resolve the issue of health inequity for indigenous peoples.

Marmot (2005) suggested that, to address inequalities in access, more effort has to be put into the control of major diseases and poverty. He also stated that major infectious diseases, as well as non-communicable diseases, both physical and mental, are linked with poverty in material conditions. Marmot’s thesis suggests that the level of poverty experienced by indigenous peoples mirrors the level of ill-health reported. Non-communicable diseases are particularly high amongst indigenous peoples (Albala & Corvalan, 2011; The Lancet, 2012; Vos et al., 2009). These pathologies very often are caused by and are aggravated by poor preventive care. Inequality of health among indigenous people demonstrates the urgent need to understand and analyse and respond effectively to social phenomena, such as the gap in life expectancies, and their over-representation in negative social outcomes including disability.

2.4.2 Inequity and severe poverty among indigenous peoples

Maru, Fletcher, and Chewings (2012) suggested that indigenous people are more likely to suffer poverty, with poverty strongly linked as both a cause and an effect of disability and any associated ill health (Grech, 2009; World Health Organization, 2011b). The intersection of severe ill health and the over-representation of poverty
and disability in indigenous peoples, makes the need to respond with a comprehensive approach at a grassroots level evident, in order to alleviate systematic poverty traps.

The literature on poverty (Grech, 2009; Groce et al., 2011; Hunt, 2006; Peiyun & Gina, 2009; World Health Organization, 2008) has reported on human capital outcomes as determinants of poverty among indigenous peoples. Indigenous peoples have been disadvantaged historically in terms of key human capital indicators (health and education). Human capital investments have been less effective in improving the living standards of indigenous peoples than of non-indigenous peoples (Hall & Patrinos, 2006). Lack of investment in raising the standards of indicators, such as health and education, has led to significant differences in earnings, thereby leading to the status of poverty (Levi & Maybury-Lewis, 2010).

In contrast to limitations in human capital, indigenous peoples are rich in social capital. Social capital refers to the institutions, relationships, and norms that shape the quality and quantity of a society’s social interactions and cultural assets and must be discussed in relation to indigenous health and wellbeing (Woolcock & Narayan, 2000). Social capital, which is defined as traditional community values, is often referred to as the only productive capital that minorities have in abundance (Woolcock & Narayan, 2000). Although indigenous peoples possess rich cultures, often accompanied by strong community values, this richness of social capital does not help to promote indigenous socioeconomic advancement (Patrinos & Skoufias, 2007).

It is widely believed, and in some cases well documented, that indigenous peoples
are the poorest of the poor in terms of income. This is the case particularly in Mexico (Hall & Patrinos, 2012), New Zealand and Australia (Grech, 2009; King, Smith, & Gracey, 2009), where disadvantage among indigenous peoples is well documented, and where poverty leads to the lack of opportunity to have an adequate standard of living and ultimately equity in health care.

From the social determinants of health perspective, relief of poverty will reduce inequalities in health across both indigenous and non-indigenous populations (Marmot, 2005). Equality and non-discrimination are akin to the concept of health equity, which Hunt (2008) saw as focusing on the individual rather than social differences, and proposed that equity is ‘equal access to health-care according to need’ (p. 85). He complemented this statement by stating that inequity can be defined by how it translates into living and working conditions.

For indigenous peoples, poverty and disability are exacerbated by historical disenfranchisement, racism and discrimination. In Australia, Mexico and New Zealand racism has been implicitly or explicitly named as the root cause of the extreme socio-economic and health disadvantages experienced by indigenous peoples (Australian Reconciliation Convention, 1997; Ford & Airhihenbuwa, 2010; Harris, Tobias, Jeffreys, Waldegrave, Karlsen, & Nazroo, 2006; Larson, Gillies, Howard & Coffin, 2007). So it is important to explore the role that social factors play in reinforcing poverty and poor health outcomes for indigenous peoples with disabilities.

2.5 The role of colonisation in shaping indigenous health

Colonialism ranks as one the most influential processes in human history (Horvath, 1972). However, some commentators believe that western scholars have failed to
understand this phenomenon (Horvath, 1972; Kuppe, 2009; Reeskens & Hooghe, 2010). They have argued that colonialism has significantly influenced the way in which society is configured and that it has shaped the disadvantages experienced by indigenous peoples due to negative and discriminatory practices. Defining the exact extent to which colonial practices have affected indigenous people has been challenging to social scientists. Social scientists have defined colonisation from various perspectives, which are compared below.

2.5.1 Defining colonialism

Key social scholars have attempted to define colonialism (Fanon, 1978, 1994; Peterson, 1998) by taking into consideration its social cultural and economic elements. However, the scholarship of colonialism is greatly affected by moral judgements that Horvath (1972) argued hinders the theoretical understanding of the concept, seen ‘either as a praiseworthy endeavour undertaken by fine gentlemen with the purpose of saving the wretched, the savage, the unfortunate, or as a dirty business engaged in by evil people’ (p. 45).

In an effort to define colonialism an examination of its core elements follows. Firstly, colonialism has been described as a form of domination (Horvath, 1972; Marx, 1853, 1867a, 1867b; Naved, 2008), with power over relationships between coloniser and indigenous peoples. For Marx (1853) colonialism was a contemporaneous characteristic of capitalism. Horvarth (1972) elaborated on this statement, concurring on its dimension of domination, but adding elements such as time, social movements and the intentions of colonisers to remain in conquered lands. He then expanded on colonialism as a form of domination in which significant numbers of settlers migrated permanently to the colony from the colonising power, bringing with them a system of
imperialist domination.

A second element identified as part of colonisation is the link between primitive accumulation and capitalism. Marx saw colonialism as a consequence of capitalism, which has been linked to an understanding of contemporary neoliberalism (Kelly, 2011). Contemporary societies and their economic systems and structures are strongly dictated to by Neoliberal economic trends. Neoliberalism evolved from primitive accumulation and feudalism where, according to Kelly, capitalism and other systems of domination had been driven by a process of economic exploitation. Neoliberal ideology is described today by its strong ‘glorification of individual choice, markets, and private property; as an extreme individualist conception of society’ (Kotz & McDonough, 2010, p. 2) and a society guided by a free-market where capital accumulation is at its core. These systems have shaped what today some indigenous authors, such as the Māori activist Maria Bargh (2007), have referred to as the postcolonial empires of neoliberalism. This link creates a connection between current social inequity and past systems of domination imposed by colonial states.

Marx (1853) discussed the effects that colonial powers exercise on colonised populations. These included the disruption of social order and personhood. In defining colonialism, Marx’s definition of economic exploitation addressed how colonialism converted living people into dead labour (‘enslavement and entombment’) and how it turned human beings into a mere attribute of themselves. Hence, for indigenous peoples he coined the term ‘black skins’, where indigenous peoples were deprived of their human rights, and he wrote:

The discovery of gold and silver in America, the extirpation, enslavement and entombment in mines of an indigenous population of that continent, as well as the beginnings of the conquest and plunder of India, and the conversion of
Africa into a preserve of the commercial hunting of black skins, are all things which characterize an era of capitalist production. (Marx, 1867, p.450).

In his writings Marx outlined the accumulation of valuable goods and the commercial hunting of ‘black skins’ as the drive for colonialism. He specifically referred to Spanish and British colonies and to the exploration of indigenous peoples as an element of colonialism. This is an explicit and in-depth observation encompassing the social, economic and cultural devastation of indigenous peoples carried out by colonial primitive accumulation. Marx (1867a) saw this as being directly related to the accumulation of capital. For Marx, money transformed into capital and capital generated ‘surplus-value’, forming more capital.

By definition colonialism implies exploitation, inequality and violence. From Marx’s exposition, colonialism and ethics are powered by ‘vile interests’. Naved (2008) supported Marx’s conclusion, as he concurred that colonial practice equates with an immoral treatment of a people guided by sheer brutality. Moral and philosophical views are now explored further exclusively from an indigenous perspective.

2.5.2 Defining colonialism from an indigenous perspective

Indigenous and non-indigenous authors agree that colonialism has led to exploitation, inequity and violence (Barker & Murray, 2010; Burman, 2009; Engerman & Sokoloff, 2005; Lange, Mahoney & Vom, 2006). Oppression and its ongoing effects, which remain in indigenous populations today, are central to the indigenous definition of colonialism (Battiste, 2011). One of the main differences between definitions of colonialism put forward by indigenous and non-indigenous authors is that indigenous scholars define it as a concept that is alive and has an ongoing impact on the lives of indigenous peoples. The link between colonialism and
brutal immorality has been a matter of concern for many scholars. Anderson et al. (2006) focused on ongoing colonial practices and the atrocities faced by Aboriginal and Torres Strait Islander peoples. Similarly, the Australian-based study by Short (2010) described the same phenomenon as disenfranchisement and genocide. Paradies et al. (2008) saw the current social exclusion of members of Aboriginal communities as an ongoing effect of colonialism. The resilience of indigenous peoples to overcome colonisation has also been stressed (Kirmayer, Dandeneau, Marshall, Phillips & Williamson, 2011; Maru et al. 2012; McLennan, 2009; Van Cott, 2004). These authors linked this with what it means to be an indigenous person; gaining strength from ‘the environment, the importance of collective history, the richness of traditions, as well as individual and collective agency and activism’ (Kirmayer et al., p. 84).

Anderson (2007) recalled the effect of colonialism on the land-bonds of indigenous communities. He stated that land-bonds encompass a whole life view incorporating the cyclical concept of life-death-life through their relationship with the land (National Aboriginal Health Strategy, 1996). Anderson pointed out that where the ties with the land have become weakened as a consequence of colonialism, cultural and familial ties have remained strong to combat such loss.

The Latin American indigenous literature takes a different approach to defining and discussing colonialism. Some Latino and non-Latino scholars focused on the effects of colonialism (Burkholder & Johnson, 2001; Hernández, 2010; Penry, 2008). From his work in Bolivia, Burman (2009) described colonisation as a strange (yaqha) subject encompassing a strange state of worry, stress, fear, envy, individualism and neglect of native spirits in the landscape.

A different viewpoint, which amalgamates the Australian and Latin-American
perspectives, was proposed by Durie (1998) who discussed colonialism from a Māori perspective. The devastating effects of the British colonial period in New Zealand resulted in the disruption of the crucial bond with the land and the natural environment (Durie, 1998), a key feature of indigeneity (Kirmayer & Valaskakis, 2009). This point reinforces Anderson’s views (2007) on land-bonds and the importance of these to indigenous culture and health.

2.5.3 Effect of colonialism

European colonisation generated societies with extremely high degrees of inequality (Engerman & Sokoloff, 2005; Penn, 2008). Some indigenous peoples, such as the Māori, protected their sovereignty by negotiating the Treaty of Waitangi (Durie, 1998). ‘Sovereignty refers to the Māori ability to determine their own destiny and to do so from the basis on their land and fisheries’ (Awatere, 1984, p. 10). Other indigenous peoples, such as the Purepecha from Mexico, did not fare so well, surrendering to the coloniser and consenting to adapt their governance and beliefs (Martinez-Cortes, Rubi-Castellanos, Vilchis-Dorantes, Luna, Coral, Canto-Cetina, Salazar-Flores, Munoz-Valle, Sandoval-Mendoza, Gamero-Lucas, & Rangel-Villalobos, 2010). Worse are others, such as the Australian, Aboriginal and Torres Strait Islander people, who were not even recognised as inhabitants of their own land under the principle of terra nullius (Banner, 2005).

*Terra nullius* – ‘as unowned land’ was applied to the colonisation of Australia by the British Crown. Under British colonial law, Aboriginal Australians were not perceived to have any rights to the land they had occupied for 50,000 years (Muller, 2003). Colonisation accordingly gave ownership of the entire continent to the British government (Banner, 2005). The principle of un-owned land or *terra nullius* was
described by Borch (2001) as a sinister presumption. It became an ominous idea for social science scholars, as it denies the existence of indigenous peoples’ communities prior to the arrival of the colonisers. As social scientists, each time we theorise on the formation of social institutions, such as colonies and their systems, we should be asking: who used to occupy this place, this space, this land? Social science needs to reflect human diversity in its production of knowledge (Borch, 2001; Connell, 2007). Acknowledging the original owners of the land could be enhanced by empowering the voices of indigenous people by honouring their interpretation of colonisation and respecting current legal frameworks, such as human rights treaties and conventions, such as the CRPD.

Domination, power and oppression are crosscutting concepts that emerge from both indigenous and western literature (Burman, 2009; Frankema, 2010; Lavallee & Poole, 2010). Colonialism invariably comprises two-way relations between the coloniser and colonised (Cooper & Stoler, 1997; Lange et al. 2006). The type of colonial settlement has influenced the cultural, economic and governance protocols surrounding indigenous peoples today and the question of whether there is any correlation between types of colonialism and the health outcomes experienced by indigenous groups remains unanswered (Lange et al. 2006).

2.5.4 Different types of colonial settlement

The indigenous groups selected for this study (Aboriginal and Torres Strait Islander, Purepechas and Māori) exemplify the different types of colonial settlement. Australia and New Zealand represent settler colonial states and Mexico was a non-settler colonial state.

Within the first type, the settler colonial state, it is relevant to establish whether the
settler population constituted the majority and as such dominated institutions (Anderson et al. 2006; Frankema, 2010). In Australia and New Zealand colonisers represented the majority of the population and dominated institutions. However, there is a difference between the two with the existence of the Treaty of Waitangi in New Zealand. New Zealand signed the Treaty of Waitangi in 1840 with the Crown and this safeguards the sovereignty of the Māori people. The Treaty of Waitangi gave the British Crown rights to govern and to develop a British settlement, while the Crown guaranteed the Māori full protection of their interests and status, and full citizenship rights (Treaty of Waitangi Tribunal, 2012). In contrast, Aboriginal and Torres Strait Islander people in Australia have historically been substantially restricted in their civil and land rights (French, Vince, & Saunders, 2003). Application of the terra nullius principle led to their self-determination and political status being affected. Progressively, Aboriginal and Torres Strait Islander people have achieved some recognition of their rights (Anderson, 2007). Aboriginal and Torres Strait Islander people and the Māori are examples of two variations of settler colonial states, whilst Mexico represents the second type.

Mexico is a non-settler colonial state. Here, the prevalence of intermarriage between settlers and local tribes-peoples led to a new group of people called the Mestizos who constitute the majority and control local institutions. Mestizo was the name for those who were of mixed blood between the indigenous population and the settlers (Bello, 2011). This phenomenon created three social groups in Mexico, colonisers, Mestizos and indigenous peoples.
2.6 Summary

In placing the study in context, it is important to look at the relationship between social determinants of health and the impact of colonisation leading to rights infringement for indigenous peoples.

Indigenous peoples are greatly affected by poverty globally. To improve the health outcomes of indigenous peoples with disabilities, care must be taken to acknowledge the effect that poverty, discrimination, lack of education and unemployment rates have on their health. Disability has been identified as a cause and consequence of poverty with current policy responses failing to address this poverty trap.

With this as a background, it is timely, considering the introduction of the CRPD, that a trajectory of health for indigenous peoples with disabilities should be examined from the perspectives of the people themselves. To hear from indigenous people with disabilities is part of honouring indigenous peoples’ self-determination, which is a part of ensuring their wellbeing.
Chapter Three: Understanding Disability from an Indigenous Perspective

3.1 Introduction

This chapter portrays the philosophical approaches undertaken in studies of disability towards indigenous knowledge. The emancipatory principles of disability studies frame an exploration of indigenous world views regarding health and disability. The social model of disability, the international classification of functioning, and a human rights-based model are utilised as part of the theoretical framework underpinning this study. An historical account of the fulfilment of the human rights of indigenous peoples is provided below, exploring the evolution of their human rights, citizenship and sovereignty. This chapter develops an understanding of how a human rights-based approach to disability, inclusive of access to health care services and support, will achieve a better quality of life for indigenous people with disabilities

3.2 Disability from an indigenous perspective

Research into disability is aimed at providing an analysis of the juxtaposition of the social characteristics that impact on disabled people’s life experiences; such as race, historical background, gender, legal status and racial hierarchy (Tate, 1997). The present study is aimed at contributing to the discourse on disability from an indigenous perspective, an area about which there is very little known (Hollinsworth,
Meekosha claimed that writings on disability have mainly come from the ‘Northern’ countries raising the question: do disabled people in the ‘Southern’ countries share the same issues and ideas? By ‘Southern’, non-dominant and/or colonised social groups are meant. She recalled the work of Connell (2007) who argued that social scientists are trained to produce their work from metropolitan, liberal and bourgeoisie institutions, referring to high income countries (The World Bank, 2013), or as Meekosha terms them ‘Northern’. In relation to this premise Connell stated,

Social science is, at best, ambiguous democratic. Its dominant genre pictures the world as it is seen by men, by capitalists, by the educated and affluent. Most important, they picture the world as seen from the rich capital-exporting countries of Europe and North America - the global metropolis (p. VII)

This statement challenges my understanding of social sciences that was gained from studying across a range of white middle-class educational institutions in Mexico, Ireland and now Australia. Prior to undertaking this study of indigenous issues associated with health and disability I was not fully aware of the impact of the processes of colonisation, colonialism, and neo-colonial power on the lives of disadvantaged people in the ‘global South’ (Connell, 2007). My views now, however, concur with those of Meekosha who claimed that the hegemonic global north has ignored the production of knowledge from the global south. Colonial practices led by the global north have been pointed out as being responsible for the high rates of preventable disabilities in the global south. However, causation is only one part of the issue. It is equally important to understand how disability is seen in the global south, particularly by indigenous people. Failing to do so will allow one dominant group (the non-indigenous people) to continue theorising illegitimately about others,
without acknowledging these people’s viewpoints or lived experiences.

Disability discourses are now examined as a means of exploring what is known about disability from an indigenous perspective. This examination will start by presenting the impact of the medical model, followed by other theoretical models that have been developed in response, including that of the social model, leading to a discussion of the Scandinavian model of disability.

3.2.1 The medical model

From the late 19th century, the medical model of disability was the dominant approach taken to disability, defining disability as a characteristic of the person, directly caused by disease, trauma or other health conditions (WHO, 2001). Disability was viewed as a deficit within the individual that should be adjusted or changed. Within the medical model problems arise from fixed deficits within the body with disability being seen to be linked intrinsically to loss and tragedy (Smith, 2010).

Social theorists of disability have argued in response that the medical model is underpinned by the domination of the medical profession. Such domination is not new to indigenous groups as they can be traced back historically to the Christian conquests of indigenous peoples. It is important to remember that the dominant voices of the European and North American debates on issues of disability grew out of Judaeo-Christian ethics and philosophy (Miles, 1995). This philosophy was transferred to colonial settlements, which were dominated by religious ideologies of benevolence, charity and compassion for those people less fortunate than oneself. For most Christian traditions, disability was frequently associated with ‘sin’ and wrong-doing. For indigenous peoples, this oppressive view was exacerbated by being indigenous, which in itself was a reason for discrimination for Christian
colonisers, particularly as indigenous peoples were often not acknowledged as citizens in their own land (Moyn, 2010). In elaborating the meaning of oppression as it affected indigenous peoples, it is important to note the role that assimilation policies played in trying to adapt Indigenous peoples to western paradigms. Such polices may be compared with the medical approach that aimed to ‘fix’ disabled people to fit into society (Armitage, 1995; Meekosha & Dowse, 1997).

3.2.2 Moving away from the medical model to the social model of disability.

The social model was a new approach to disability, initiated in the UK, which challenged the medical model of disability. The differences between the social model of disability and the medical model are that the medical model takes a biological essentialist approach; ‘essentialist’ refers to the way in which the medical model sets out a number of biological attributes that define disability (Hughes & Paterson, 1997). The medical model interprets disability as a deficiency and establishes differences between disabled and non-disabled people that cover biological and sometimes psychological characteristics. In comparison, the social approach counteracts this “essentialism by demonstrating how it is that exclusionary policies, environmental barriers and a process of social oppression which create the category of disability” (Shakespeare, 1996, p. 103).

Table 3.1 below, adapted from Smith (2010), summarises the interpretation of both the social and medical model interpretation of disability.
<table>
<thead>
<tr>
<th>Interpretation</th>
<th>Understanding of Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical Model</strong></td>
<td></td>
</tr>
<tr>
<td>Full-essentialist individual deficiency interpretation</td>
<td>Disability is caused by fixed medical characteristics that inevitably infer a life of deficiency and abnormality</td>
</tr>
<tr>
<td>Part-essentialist individual deficiency interpretation</td>
<td>Whilst disability is caused by the above medical characteristics, these can be partially alleviated by changes in the social environment, so as to enable some degree of ‘normal living’</td>
</tr>
<tr>
<td><strong>Social Models</strong></td>
<td></td>
</tr>
<tr>
<td>Politics of disablement interpretation.</td>
<td>Disability is caused by social practices that systematically exclude impaired people from the activities of ‘normal citizens’</td>
</tr>
<tr>
<td>Social construction of disablement interpretation.</td>
<td>Disability is caused by the way impairment is defined and associated with characteristics that are necessarily assumed to have a negative impact on personal identity, development and fulfilment.</td>
</tr>
</tbody>
</table>

Adapted from Smith (2010, p 22)
The social model has not been uniformly accepted by the disability community. Barker and Murray (2010) challenged the social model criticising it for a philosophy that was not culturally specific. Their criticism is relevant when one considers that the social model does not address how indigenous groups with disability define or perceive disability, let alone the impact of colonisation and its consequences on what it means to be disabled. The majority of research and scholarship on disability has arisen from local and national groups coming together to combat different forms of social oppression (Barker & Murray, 2010). An example of this is the work of the British Union of the Physically Impaired Against Segregation (Union of the Physically Impared Against Segregation, 1976), which has worked to raise and resolve issues of accessibility. Similarly, in the USA, people with disabilities, their families and advocates joined forces to create a civil rights approach to disability that saw disability appraised as a social minority (Blanck, 2011).

Shakespeare and Watson (2001) criticised Oliver and Zarb’s (1989) work on the social model on the basis of the lack of consideration given to its impact on people with intellectual impairments, people with complex health needs and/or diverse cultural backgrounds. As a result, they claimed that the original model was no longer of use at the beginning of the twenty-first century. They revisited the social model and posed a challenge for it to include not only social and environmental oppression leading to the experience of disability, but also the impact of physical impairment arising from people’s bodies. Drawing on their critique, Shakespeare and Watson (2001) suggested a new model, and defined disability as a complex dialectic of biological, psychological, cultural and socio-political factors. The inclusion of cultural factors in this model is very relevant to understanding the impact that disability can have on the lives of indigenous peoples. It provides a theoretical framework through
which the effects of oppression and colonisation may be analysed in relation to disability.

The social model (Abberley, 1987; Oliver, 1983 1984; Oliver & Zarb, 1989) has also been influential in advancing the understanding of disability and has been used to underpin new models and frameworks of disability such as the International Classification of Functioning, Disability and Health (Üstün, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003).

3.2.3 Disability studies

Disability studies have emerged over the last quarter of a century generating three main traditions of enquiry, one in the United Kingdom, a second in the United States of America, and a third in Scandinavian countries (Shakespeare, 2012). The United Kingdom’s tradition, the social model of disability, was generated in a framework of strong political engagement by disabled activists and academics. Its focus was on identifying that disability arose from a form of social oppression inclusive of financial, social, physical and environmental barriers, rather than being part of the pathology of the person. The emphasis of this approach was on barrier removal (Oliver, 1984, 1996). Although this was not specifically written about in relation to indigenous groups, the concept that disability was not within the person and of an individual deficit nature, but rather arose from social, financial and environmental oppression resonates with Meekosha’s (2008) writings on ‘Southern’ discrimination and disempowerment.

In comparison, the North American approach views disability as a part of the overall civil rights movement, with disability perceived as another example of a disadvantaged or minority group alongside African Americans, Women, Gays and
Lesbians. This approach argues that disabled people should be party to decision-making processes on policy and law on the basis of their claims of being an oppressed group. Proponents of this minority group strategy argue that it gives “disabled people a basis upon which to claim for certain adjustments to the environment (e.g. access to public buildings), instead of having adjustments imposed” (Liggett, 1988, p. 271). Disability as a minority issue has a similar trajectory to that of the Civil Rights Campaign for equality associated with race and ethnicity (Barnes, Oliver & Barton, 2002), in comparison to disability. Disability studies in the United States of America have their premises based on a socio-political analysis of disability (Linton, 1998).

A further model comes from the Nordic countries, which have a relational model, borrowing from the barrier-free principle of the UK approach. However, in Scandinavia the social relational model of disability has been more closely linked to the welfare state than to radical disability movements (Söder, 2009). The Scandinavian approach has its discourse centred on the principle of citizenship equality, which encompasses the ‘basic principles and values of the Scandinavian welfare states’ (Kristiansen & Traustadóttir, 2004, p. 6). This model advocates that it is the responsibility of the state to guarantee equal rights and opportunities for all citizens.

Nevertheless Scandinavian scholars have engaged in a critique of how the welfare state has failed to accommodate the needs of indigenous peoples (Häikiö & Hvinden, 2012), such as the Sami People (the indigenous peoples from far northern Norway, Sweden and Finland). These scholars state that the welfare model reinforces standardised policies and practices and overlooks special measures and ultimately the idea of equity.
The social model, the rights model and the Scandinavian relational model of disability all place an emphasis on identifying what the root cause of oppression is, commonly identified as the domination of the medical profession (Oliver, 1983; Oliver Zarb, 1989). This domination has influenced the way health services have been planned and delivered to indigenous people with disabilities. A critique of the ‘bio-psycho-social model’ embedded in the International Classification of Functioning, Disability and Health (ICF) promoted by the World Health Organisation follows with some discussion on alternative discourses that are relevant to understanding disability relating to indigenous groups.

### 3.2.4 Redefining disability

The International Classification of Impairment, Disability and Handicap (ICIDH) was originally put forward to the World Health Assembly in 1980 to describe the effects of chronic conditions and the long-term effects of rehabilitation, while at the same time offering a conceptual framework for information management between state members (World Health Assembly, 1980). In 1980 this document described disability using three dimensions – Impairment, Disability and Handicap as described below:

Within the model **Impairment**: was seen in the context of health experience as any loss or abnormality of psychological, physiological or anatomical structure or function.

**Disability**: was any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being.

**Handicap**: a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on
age, sex, and social and cultural factors) for that individual. (WHO 1980, p.3) See figure 3.1 for a graphic illustration of the uni-directional relationship between all three components of the model.

![Disease > impairment > disability > handicap](image)

**Figure 3.1 The International Classification of Impairment, Disability and Handicap (ICIDH) Model**

(WHO, 1980)

The 1980 model of the ICIDH was severely criticised by people with disability and by professionals who pointed out that this document inadequately recognised the environmental barriers in the creation of disability. ‘People were also concerned about the linear and unidirectional connections among the elements of the ICIDH model (Rosenbaum & Stewart, 2004, p. 7). The framework was primarily a biomedical approach to disease which Bickenbach, Chatterji, Badley, and Üstün (1999) believed was undermined by ‘the subtle ambiguity of language used’ (P.1175). The definitions of ‘disability’ and handicap’ were considered to be conflictive. Secondly, they saw that the ICIDH failed to consider the role the environment played in triggering or reducing the nature and extent of disability. Thirdly, a criticism was made by Simeonsson, Lollar, Hollowell and Adams, (2000) for the model not taking on the perspective of lifespan. Barnes and Mercer (1997) went further indicating that the development of the model had also failed to engage with academics with a lived experience of disability.
Although significant progress was achieved with the ICIDH, these concerns led WHO to conduct a comprehensive international consultation, which led to the publication of the CIDH-2 in 1999. The development of this document included recommendations from a series of global field tests that were intended to refine the draft ICIDH-2, started in 1996. The field test consists of ‘alpha test’ (1996), ‘beta test 1’ (1997) and ‘beta test 2’ (1998). In this version the dimensions were changed from disability, impairment and handicap to body, activity and participation. The overall aim of the ICIDH-2 classification was to ‘provide a unified and standard language and framework for the description of human functioning and disability as an important component of health’ (WHO, 1999 p. 7). More importantly, this version also reflected a change in the conceptual framework as it portrayed the principles of a biopsychosocial model (Bickenbach, 1999). The new dimensions of the draft ICIDH-2 document were:

**Body:** functions, structure and Impairments: Body functions are the physiological or psychological functions of body systems. Body structures are the anatomical parts of the body such as organs, limbs and their components. Impairments are problems with body function or structure presenting as a significant deviation or loss.

**Activity:** is the performance of a task or action by an individual. Activity limitations are the difficulties an individual may have in the performance of activities.

**Participation:** is an individual’s involvement in life situations in relation to health conditions, body functions and structure, activities and contextual factors. Participation restrictions represent the problems an individual may have in the manner or extent of involvement in life situations (WHO, 1999, p.6).

Over the years following ICIDH-2 (1999) the international community has embarked
on a comprehensive exploration of the level of detail required to portray these new dimensions. In 2001 the World Health Assembly endorsed the International Classification of Functioning, Disability and Health, which reflected a philosophical shift, promoting an instrument that ‘moved beyond looking at the consequences of diseases and viewing functioning as a component of health’ (Üstun, Chatterji, Bichenbach, Kostanjsek & Scheider, 2003, p. 556). The International Classification of Functioning, Disability and Health, known more commonly as the ICF, describes and measures health and disability; it ‘provides a description of the situation with regards to human functioning and serves as a framework to organise this information’ (World Health Assembly, 2001, p. 5). Global acceptance of the ICF relied on a comprehensive process of consensus.

In the ICF disability is defined as:

‘An umbrella term for impairments, limitations of activity and restrictions in participation. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, Down’s syndrome or depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social support’ (World Health Organization, 2011b).

This definition has been endorsed by all the member states of the World Health Assembly. It is the only international framework through which disability has been defined and it provides an international framework for the measurement of disability. The following figure represents the ICF model of disability
Figure 3.2 The model of disability that is the basis of ICF

WHO, 2001

The ICF definition and approach to disability emphasised the effects that the environment has on people’s level of functioning, which is particularly important for people living in the low income bracket and so is relevant to indigenous people with disability. The ICF Framework addresses the role of health in a broader context than its predecessors, the ICIDH (1980) and ICIDH-2 (1999). The ICF Framework incorporates environmental factors such as discrimination and negative attitudes to disability. The ICF ‘puts the notions of ‘health’ and ‘disability’ in a more comprehensive framework’.

Member states perceived that “the ICF not only addressed western concepts but had a worldwide cultural applicability” (Stucki, 2005, p. 734). This is of particular importance as the previous frameworks, the ICIDH and ICIDH-2, were seen as limited. The limitations of ICIDH 2 were exposed in an Australian study on disability among Aboriginal and Torres Strait Islander communities designed to examine the relevance of the concepts of disability to indigenous people, using the ICIDH-2 as a possible framework. The study was conducted in two communities located in Northern Australia. The results illustrated that disability was a difficult concept to discuss with Aboriginal and Torres Strait Islander people, as they did not understand
the concept and had differing views on what being disabled meant (Senior, 2003). Although environmental factors were included within the ICIDH-2, Senior, (2003) pointed out that lack of knowledge of the community and the inability to incorporate the beliefs of the local culture were severe limitations of this framework.

The first global report on disability published by the World Health Organisation and the World Bank (2011), aimed to inform member states of the current prevalence of disability across the world, as well as the challenges faced by people with disability regarding access to health care, rehabilitation, education, employment, and support services. The report highlighted the role that the CRPD could play in improving the lives of people with disability throughout the world. It stated that persons with disability in the world are over-represented within negative social and health indicators (World Health Organization & World Bank 2011).

3.2.5 Disability and indigenous peoples with disabilities

It has been well documented that indigenous communities find the term disability alien and somewhat contradictory to their traditional beliefs about impairments (Connell, 2011; Hickey, 2008; King, 2010). More than 10 years ago Ariotti (1999) conducted a study in Western Australia showing that the Anangu people, rather than seeing impairments, celebrated uniqueness and accepted the diversity and difference within humanity. Today Meekosha (2011) has urged academics and policy-makers in Australia to listen to indigenous peoples’ concepts of disability, as that of the Anangu people is absent from current policy and legislation.

In keeping with the outcomes of this study of the Anangu people, the Māori community in New Zealand also reported a need for disability to be constructed in a more positive and integrated fashion than it is within Western scholarship (Fitzgerald,
Māori people see the nature of humanness as a unique interrelated phenomenon, which connects past, present, and future, through land attachment and spiritual being. These explain a unique concept of humanity, with interrelation at its core. As such, inter-dependency between heritages, time and space cannot be easily transferred to the western conceptualisation of humanity. This ancestral Māori conceptualisation embraces difference and uniqueness, therefore disability is a natural part of being (Hickey, 2008). This approach opens up a major divide between it and the non-indigenous concept of disability. Indigenous enquiry incorporates non-empirical and non-generalisable dimensions.

Gotto (2009) explored the ways in which people with intellectual disability were integrated into indigenous communities in Mexico. Within groups such people were valued and respected members, who were recognised for their contribution rather than for their impairments.

Overall, indigenous traditional beliefs work to welcome people as people first, with a reluctance to identify them as different, or disabled, which is in keeping with Shakespeare (1996) who prudently stated that having an impairment may be a common experience, and being disabled is the specific social identity of a minority. Being disabled to some extent has been rejected as a concept by indigenous people. Watson (2002) has also argued that this discrepancy is not exclusive to indigenous peoples and the use of the term ‘disability’ has not always been welcomed by non-indigenous groups. She published an article entitled “Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person”: Identity and disability’ (2002), in which she challenged the concept of identity within disability scholarship and argued that ‘disabled’ people share one important attribute: they are all subject to oppression. The label ‘being disabled’ acts as a categorical
classification. However, according to Watson (2002), whether disabled people identify themselves as such is unknown.

Barker and Murray (2010) explained that for some indigenous people the determination of normalcy in wellness and health is dependent on whether the individual is in balance with his/her spirituality, family, social connections and ancestral attachment to the land. This acknowledgedment of indigenous needs is inter-connected with a responsiveness to cultural needs, which relates to cultural competency. Meeting the needs of indigenous people has been limited to looking at outcomes, as opposed to building an academic theory/discourse that is relevant to disability based upon the experiences of indigenous people (Bickenbach, 2009).

In view of the emphasis placed on culture within indigenous groups, the development of a constructivist approach to disability is relevant. An indigenous constructivist approach to disability would incorporate both the culture and life experiences of indigenous people within the postcolonial era. (Snyder & Mitchell, 2007). From an epistemological view the construction of a discourse on indigenous disability must challenge the traditional western construction of disability knowledge (Meekosha, 2008; 2011). Smith (1999) similarly has discussed the ‘regimes of truth’ situated within a particular cultural social system that needs to be ‘decolonized’. In this context an indigenous approach to disability must confront the epistemology of the western approach to research that concentrated on positivism rather than the research of a participatory nature.

Hickey (2008) remarked on the importance of indigenous Identity. She used the concept of ‘othering’ (Foucault, 1972) to describe how disabled indigenous identities have been perceived negatively by non-indigenous people. Foucault (1972) first introduced the concept of ‘othering’, which arose from working with vulnerable
people who were seen as ‘other’ rather than as having any value. The lack of knowledge production on how disability is perceived within indigenous communities is another aspect of ‘othering’ and indigenous discrimination (Creamer, 2009). In support of this behaviour as being discriminatory, Lavallee and Poole (2010) argued that knowledge of indigenous people’s systems and beliefs has been disregarded. They strongly supported the view that disability scholars need to recognize that indigenous peoples have their own knowledge systems that can augment, extend and contribute to contemporary disability enquiry.

A constructivist approach to understanding the nature and ontology of disability (ways of being for indigenous people with disability) will provide a significant contribution to disability studies. Indigenous scholars have argued that a western knowledge and understanding of universal human rights cannot explain or represent indigenous thinking. Indigenous epistemology should lead both the researcher and any scientific enquiry aiming to represent legitimately the lived experiences of indigenous peoples with disabilities. To understand the lived experience of disability and the conceptualisation of disability from an indigenous perspective, it is important to acknowledge the cultural and social context in which people with disabilities have lived and continue to live in.

### 3.3 Human rights and their historical links with indigenous peoples

Indigenous peoples currently experience three levels of injustice: they are trans-generational victims of historic colonisation; they are politically disenfranchised; and their cultural diversity is not officially recognised. In turn, indigenous peoples struggle for the recognition of their specific rights, in order to overcome the injustices they are currently experiencing (Bhopal, 2008; Casey, 2008; Dodson, 1994; Kuppe, 2009). In
order to mitigate this, there is a need for human rights to develop at an international level in order to establish a better role for indigenous people with disabilities. Human rights as a construct dates back to classical Greece (Brown, 1997). The Greek concept of human rights, as well as the Roman development and Hobbs’ approach to natural law, were not responsive to indigenous peoples (Ishay, 2008; Pasqualucci, 2006) They were instead highly focused on the principle of self-preservation of the state, which as a concept has been heavily criticised for the effects that it could have on minorities such as indigenous peoples (Marx, 1853).

The concept of humanitas or ‘humanity’ as conceived by the Greeks also excluded foreigners, women and slaves, whereas contemporary concepts of humanity have a premise that all humans possess a profound and inherent dignity. This moral principle underlies the philosophical frameworks of contemporary human rights (Ishay, 2008)

Marx (1853) challenged the concept of what we call ‘human rights’ and particularly the idea of universalism. He believed that as the implementation of human rights relies on the State, their universal application can be interrupted by the effects of oppression on minority groups. According to Marx, rights should promote emancipation of the oppressed and social equity. Marx built his thinking on the Rights of Man (Declaration of the Rights of Man and Citizen, 1793) and his framework was developed from natural law theory (Marx & Engels, 1965). As an indigenous woman, I concur with Boyd’s (2009) interpretation, in defending that Marx could well have simply criticised the Declaration of the Rights of Man and Citizen, however, he engaged in a critique of the philosophy underpinning the Declaration, stating that, if rights were to be authentic they should promote emancipation.

Marx (1867b) also acknowledged that the political freedom of the individual relied on
the protection of the state. If self-determination (indigenous people claiming their sovereignty) is to occur, political states need to do more than develop enabling legislation. Without states ‘cleansing’ themselves of self-interest, Marxists would claim that indigenous peoples will not be free of oppression from the ‘colonial state’. This principle portrays the complexities of legitimising indigenous sovereignty and it may not be in the best interests of the ‘colonial state’ to recognise it fully.

If human rights are to promote the equity and respect of indigenous sovereignty, they also need to be of an emancipatory nature (Marx, 1867a). However the universalism of human rights has not been responsive to indigenous peoples globally. The idea of universalism is also limited by other philosophical trends such as cosmopolitanism. This theory refers to the ‘multiplicity of ways in which the social world is constructed’ (Delanty, 2006, p. 27), and is very critical of the universalism of human rights. Fine (2009) argues that the real world does not operate within a universal framework; instead this author sees a divide between western thinking and indigenous culture. It is of interest to reflect on this argument given current inequities regarding the fulfilment of the human rights of indigenous peoples with disabilities. It is apparent that universalism is an aspiration, far from the reality experienced by indigenous peoples as the western understanding of human rights has, so far, failed to acknowledge the experience of colonisation and disenfranchisement (United Nations General Assembly, 2007; Wiessner, 2011; Yotti’Kingsley, Townsend, Phillips & Aldous, 2009).

European colonisers forced indigenous peoples to appeal to the western concept of universalism in arguing that the rule of the law should be equitable for them. It was not until 1945 that anti-colonialists framed their cause in the language of rights to sovereignty (Moyn, 2010). Indigenous people have been sorely mindful that western
humanism had not been sympathetic to them. Pasqualucci (2006) reaffirmed this:

> Indigenous communities in the western hemisphere are increasingly relying on international law for enforcement of their human rights. When there are no domestic laws that recognise indigenous rights, or such laws exist but there is no political will to enforce them, indigenous peoples in the Americas may turn to the Inter-American human rights system. Consequently, the Inter-American Court of Human Rights and the Inter-American Commission on Human Rights have developed a progressive case law in this area. (p.282)

Pasqualucci (2006) illustrated how indigenous peoples rely on international treaties, rather than domestic legislation, to pursue the fulfilment of their human rights, such as the right to the highest attainable standard of health. In keeping with this argument it is important to see how domestic and international law and policy have responded to the health needs of indigenous peoples with disabilities in different countries.

### 3.3.1 Past and present right to health for indigenous peoples

The countries selected (Australia, Mexico and New Zealand) have ratified the majority of the international human rights treaties that protect the right to health (Office of the United Nations High Commissioner for Human Rights, 2008). However, within the three countries, indigenous peoples have had significantly poorer health outcomes in comparison with non-indigenous populations (as addressed in Table 2.1). The World Health Organization (2005) stated that poor health indicators within indigenous populations are produced due to progressive under-investment in the indigenous infrastructure and amenities, with resultant disproportionate levels of poverty and poor living conditions. The WHO through the Rio Political Declaration on
Social Determinants of Health (World Health Organization, 2011a) has urged state members to work towards health equity, and to foster international cooperation to alleviate inequalities. There are an estimated 300 to 370 million indigenous peoples in the world today, with 69 million comprising roughly 5000 distinct groups, and speaking roughly 4000 distinct languages. Whilst historically Indigenous peoples had access to huge swathes of the world’s surface, today they possess the legal right to use only 6% of the land on the planet, and in many cases this right is partial or qualified (Cook & Sarkin, 2009). Such a discrepancy is indicative of the inequalities, particularly those associated with land rights, experienced by indigenous people (Rowley, O'Dea, Anderson, McDermott, Saraswati, Tilmouth, Roberts, Fitz, Wang, Jenkins, Best, Wang, & Brown, 2008; Watson, 2007). Globally, it has been strongly suggested that enjoying land rights would have a positive impact on the health of indigenous peoples (Altman, 2012; Burgess, Johnston, Bowman & Whitehead, 2005a; Burgess, Johnston, Bowman & Whitehead, 2005b; Watson, 2007; Yotti’Kingsley et al., 2009). Aboriginal and Torres Strait Islander people maintain a strong belief that the continued association with and caring for ancestral lands is a key determinant of health (Burgess et al., 2005b).

3.3.2 Is the struggle for indigenous health rights in Australia and New Zealand different from that in Mexico?

It is clear that indigenous people worldwide suffer from poor health outcomes, which are related to disenfranchisement, colonisation, poverty and discrimination (Anderson et al., 2006; Frenk & Gómez-Dantés, 2011; Rowley et al., 2008; The Lancet, 2012). The countries selected for this study are representative of a variation in approaches to health policy and law regarding indigenous peoples. Relevant laws
and policies affecting the health of indigenous peoples with disabilities are outlined below for each of the three jurisdictions.

I. Australia

During the last 40 years, Australia has made advances with respect to indigenous affairs. However, equity has not yet been achieved by Aboriginal and Torres Strait Islander people. The creation of social policies that pursue indigenous self-determination versus the earlier policy of ‘assimilation’ is gaining power in the political agenda (Dockery, 2010). Lessons have been learned from the atrocities experienced by Aboriginal and Torres Strait Islander people, such as relocation into cattle stations and reserves; the ‘stolen generation’, where children were removed from families by the state; and emergency interventions in the Northern Territory (Dodson, 2007; Johns, 2008), where curfews were implemented and alcohol was banned.

In recent years, moves to recognise human rights, including for Aboriginal and Torres Strait Islander people, have had an influence in shaping domestic indigenous policies. In 2006 the Australian Human Rights and Equal Opportunity Commission with a group of indigenously-driven non-governmental organisations started the human rights-based ‘Closing the Gap’ campaign, aimed at reducing the disparities in life expectancy between indigenous and non-indigenous Australians. This campaign led to the creation of the National Indigenous Health Equality Summit in 2008. Arising from this summit the Council of Australian Governments (COAG) committed to:

- closing the life expectancy gap within a generation;
- halving the mortality gap for children under five within a decade; and
Outcomes from the National Indigenous Health Equality Summit also highlighted the need to embrace a new partnership between indigenous and non-indigenous Australians. The preamble of the document states that working in partnership is the only way to solve indigenous inequity and inequality.

In 2008 the Australian Prime Minister Kevin Rudd offered a formal apology to the Aboriginal and Torres Strait Islander people for the ‘stolen generation’ on behalf of the Australian government (Rudd, 2008). While the apology ignited hopes of new efforts to address indigenous disadvantages, “five years after, the direction of policy on indigenous affairs still remains unclear” (Dockery, 2010, p. 316). While partial progress has been achieved in areas such as life expectancy and school enrolments, Aboriginal and Torres Strait Islander people remain over-represented in negative social outcomes, such as ill health and disability rates (NDIS, 2008).

To address disability, care and support, the Australian government commissioned a national report to provide an effective response to the support needs of Australians with disability and their families. The Report was produced by the Australian Productivity Commission, which is the Australian Government's independent research and advisory body on a range of economic, social and environmental issues affecting the welfare of Australians. The report recommended the introduction of the National Disability Insurance Scheme (NDIS). This scheme was aimed at providing insurance cover for all Australians in the event of significant disability.

The funding of this insurance scheme gives individuals support packages tailored to their individual needs, people could choose their own disability
service provider, ask an intermediary to assemble the best package on their behalf, cash out their funding allocation and direct the funding to areas of need (with appropriate probity controls and support), or choose a combination of these options (Productivity Commission, 2011, p. 5).

The Disability Care and Support Report highlighted the significant unmet need for disability support services in Australia, and that this has been the case for decades (Productivity Commission, 2011). The report also pinpointed that disability rates are alarmingly high among Aboriginal and Torres Strait Islander people and it also linked the rates of disability with economic disadvantage and social segregation as follows:

‘Indigenous Australians have high rates of disability but access relatively few services or support schemes. The consequences of this are compounded by broad socio-economic disadvantage and the geographical isolation that many indigenous Australians experience’ (2011, p. 532).

Although the NDIS guarantees flexibility and a greater choice, particular attention is to be given to those indigenous communities where services are not available, professionals are insufficient and provision of adequate housing is restricted. The Productivity Commission stated their concern for the need for a comprehensive and inter-agency indigenous approach to disability issues,

While the NDIS is (by definition) primarily focused on offering support to people with a disability, it does not directly address the underlying issue of the relatively high rate of disability among indigenous Australians. The causes of this lies in the socio-economic disadvantage and marginalisation experienced by many indigenous Australians and the risk factors to which they are exposed. While the NDIS will have a role in funding early intervention and
prevention approaches, it is not a panacea for broad indigenous disadvantage. Addressing indigenous disadvantage is an issue for all of Australian society and requires an ongoing cooperative approach from all levels of government and the Australian people (both Indigenous and non-Indigenous) more generally (Productivity Commission, 2011, p. 560).

In furthering the Productivity Commission’s message that indigenous inequities can only be resolved through co-operation, the introduction of the NDIS alone will not be sufficient to close the gap for Indigenous people associated with the social determinants of health, including education, employment, housing and leisure. Government departments associated with these areas need to create cooperative strategies, as isolated practices have shown limited results in the past. In targeting the health needs of Aboriginal and Torres Strait Islander people, the Australian Department of Health and Aging is creating the National Aboriginal and Torres Strait Islander Health Plan. This document began to develop in 2012 with a round of online consultations throughout Australia. The Plan has underlying principles aimed at creating a strategy that increases accessibility of health services and the appropriateness of service delivery. More importantly, it establishes, as a priority, that health and support systems need to ensure cultural diversity, rights, views, values and expectations of the Aboriginal and Torres Strait Islander people and that these are respected in the delivery of culturally appropriate health services (Department of Health and Ageing, 2012).

In 2013 the Australian Government adopted the National Aboriginal and Torres Strait Islander Health Plan, 2013-2023. At the core of this document is an acknowledgment of the racism and social disadvantages affecting the health of indigenous peoples. Social determinants of health and cultural healing are acknowledged as being core
to the good health of indigenous Australians. A very important feature of this plan is that it honours the UN Declaration on The Rights of Indigenous Peoples by stating that: ‘It adopts a strengths-based approach to ensure that policies and programmes improve health, social and emotional wellbeing as well as resilience whilst promoting behaviours for positive health’ (Australian Goverment, 2013, p. 4)

II. Mexico

The Mexican constitution has been amended to recognise that Mexico is a pluricultural country built upon the land originally inhabited by indigenous peoples (Cámara de Diputados del h. Congreso de la Unión Mexico, 2013), who are now referred to as the original land owners. This reform, apart from reflecting a shift in the ethos and philosophy of Mexican legislation, has produced several improvements in the delivery of justice and in the recognition of the rights of indigenous communities in Mexico. These improvements include: the translation of federal legislation into several indigenous languages; public education delivered in indigenous languages; and more importantly the recognition of the sovereignty of indigenous people. The Supreme Court has created a special protocol, which acts for those who face cases involving indigenous peoples or indigenous communities (Suprema Corte de Justicia, 2013). This protocol outlines special procedures for the protection of the self-determination and sovereignty of indigenous peoples within the entire country.

This constitutional reform, recognising that Mexico is a pluricultural country, is the result of a long fight by Mexican indigenous peoples and activists. This fight involved various social and political mechanisms, but one of the most influential movements emerged in 1994 in Chiapas, Mexico. The Zapatista Army of National Liberation EZLN (Mora, 2007; Reyes & Kaufman, 2011) was an indigenous armed movement
led by El Sub-Comandante Marcos (Mora, 2007; Reyes & Kaufman, 2011). They laid claim to respect for self-determination and for sovereignty of indigenous peoples in Chiapas and in the rest of Mexico.

Two years after this armed conflict began, the Federal government, led by Ernesto Zedillo Ponce de Leon and The Zapatista Army of National Liberation (Ejército Zapatista de Liberación Nacional, EZLN), signed the Tratado de San Andres in 1996. In this treaty the state compromised in order to respect the rights of indigenous peoples with the following principles:

- Recognise indigenous peoples within the Constitution;
- Work in partnership with indigenous communities;
- Tackle poverty and social isolation of indigenous peoples;
- Protect the cultural, economic, civil and political rights of indigenous peoples;
- Support the creation of an indigenously driven health service;
- Recognise and legitimise the self-determination and sovereignty of indigenous peoples in Mexico. (Gobierno Federal y el Ejercito Zapatista de Liberacion Nacional, 1996).

This treaty was designed to bring peace to the region by dealing with the root cause of the conflict, which was a lack of indigenous sovereignty (Arsenault, 2010). Unfortunately for Mexico’s indigenous peoples, the reforms approved by the National Congress in 2001 failed to recognise the San Andres agreements, thereby only giving a partial solution to their claims (Barcenas, Balderas & Sauceda, 2002)

The Zapatista Army of National Liberation (EZLN) demanded that an Independent indigenous health system be established aimed at overcoming the difficulties that
indigenous peoples faced in accessing health care. Social barriers were highlighted, such as cultural, linguistic and racial discrimination, lack of affordability and inadequate service delivery (Amoroz Solaegui, 2011). The health issues addressed by the EZLN were not exclusive to Chiapas, Southern West Mexico; such problems were generalisable to the rest of the indigenous population. In other states the EZLN led the way to create a strong indigenous movement, such as in Michoacán, Central West Mexico, where Purepechán (the indigenous group selected for this study) organisations joined the EZLN’s campaign to resolve their civil and political issues (Martínez, 2010).

Many have criticised the legitimacy of the EZLN (Tello Díaz, 2000). However, regardless of ethical issues and atrocities, the armed conflict led by the EZLN did bring the isolation, disadvantage and oppression experienced by the indigenous peoples in Mexico to the public’s attention. The high rates of ill health and disability currently present among indigenous communities are a reflection of this (Frenk and Gómez-Dantés, 2011; Knaul, González-Pier, Gómez-Dantés, García-Junco, Arreola-Ornelas, Barraza-Lloréns, Sandoval, Caballero, Hernández-Avila, Juan, Kershenobich, Nigenda, Ruelas, Sepúlveda, Tapia, Soberón, Chertorivski & Frenk, 2012). However, the outcome of such a conflict has led to the current amendments to the Constitution that recognise the overall rights of the indigenous peoples.

In relation to the health needs of indigenous people in Mexico, like the general population they fall under the general access and delivery of the legal framework of health laws (Camara de Diputados del H. Congreso de la Union, 2009b) that regulates health service delivery and access to the right to health. However, it does not stipulate special measures or anti-discrimination safeguards for indigenous peoples. This law lacks strategies to engage with the reality of indigenous people
being without appropriate health services. Nevertheless, the law recently created (The Inclusion of Persons with Disability; Camara de Diputados del H. Congreso de la Union, 2009a, in Articles 1 and 6) pinpoints the indigenous people’s needs for special consideration with respect to health, social assistance, and social development. It creates a blueprint for equity regarding health service delivery (Prieto, 2012). This piece of legislation mandates that the state should promote, protect and guarantee the fulfilment of the human rights and liberties of people with disabilities, ensuring their full inclusion in society with respect to equality and equal opportunities (2009a).

III. New Zealand

Māori peoples from New Zealand are the only indigenous group, from the three countries selected for study here, which signed a treaty with the colonisers to protect the sovereignty of their people. The Treaty of Waitangi (Te Tititi of Waitangi) was agreed and signed by representatives of the British Crown and over 500 Māori chiefs in 1840. Not all Māori tribes were party to the original treaty, but it is now applied to all Māoris as official policy (Stevenson, 2008). In 1975 The Treaty of Waitangi Act set up the Waitangi Tribunal to make recommendations on claims brought by Māori peoples regarding unresolved breaches of the promises by the Crown. The Treaty principles were developed by the Waitangi Tribunal in 1975. The New Zealand Māori Council was responsible for the interpretation of the principles of the Treaty. However, there are various interpretations of these principles and differences of opinion as to their definitions and applications (Hickey, 2008b). To solve such discrepancies in 1989, the New Zealand Labour Government announced the principles upon which it would act when dealing with issues arising from the Treaty of Waitangi. These principles were:
(a) The principle of government or the kawanatanga principle: Article 1 gives expression to the right of the Crown to make laws and its obligation to govern in accordance with constitutional process. This sovereignty is qualified by the promise to accord the Māori interests specified in Article 2 an appropriate priority;

(b) The principle of self-management (the rangatiratanga principle);

(c) The principle of equality;

(d) The principle of reasonable cooperation;

(e) The principle of redress: The Crown accepts a responsibility to provide a process for the resolution of grievances arising from the Treaty.

(Waitangi Tribunal, 1995).

Contemporary Māori and Pakeha (non-Māori) academics along with law-makers claim that the principles are constantly evolving and will continue to do so until the Treaty principles are embedded into all New Zealand law and policy (Wyeth, Derrett, Hokowhitu, Hall & Langley, 2010). Māori identity, practices and rights, as all cultures, were and are constantly undergoing renegotiation, change and development. Nevertheless, Joseph (2011) argued that New Zealand law has frozen Māori sovereignty rights. For example, with respect to Māori education, relegating and returning Māoris to a ‘hunter gatherer lifestyle’; such a lack of recognition is seen as inappropriate for contemporary Māori development.

Protocols that recognise the principles of the Treaty with a view to improving the health and wellbeing of Māori (Ministry of Health, 2013) have been developed. In 2002 ‘The Korowai Oranga: Māori Health Strategy’ was created. This strategy decides the direction of Māori health development in the health service and disability
sector. The strategy provides a framework for the public sector to take responsibility for the part it plays in supporting the health status of whānau (family) (Ministry of Health, 2002). A decade on, in 2012, the health indicators (Statistics New Zealand 2012) pointed out that Māori with disability were ‘still left behind’ and to respond to this issue Whāia Te Ao Mārama, The Māori Disability Action Plan, was created following a national consultation with Māori with disability over all New Zealand regions (Associate Minister of Health and Māori Disability Leadership Group, 2012). From the consultation priorities, strategies and evaluation benchmarks were established. The National plan entitles Māori with disabilities to:

- Greater personal leadership;
- Choice and control over disability supports accessed;
- Acceptance of Māori diversity and disability experience;
- Respect for Māori cultural values and preferences;
- Roles for Māori disabled people within their whānau (family) and their communities of choice (Associate Minister of Health and Māori Disability Leadership Group, 2012, p. 3).

The Māori Disability Action Plan (2012) has led to change in the delivery of Māori Health. It could be argued that when comparing New Zealand to Australia and Mexico the difference in outcome is related to the Māori signing the Treaty of Waitangi with the British Crown. However, Māori with disability remain one of the most disadvantaged social groups in New Zealand (The Lancet, 2012).

### 3.3.3 International legal protection of the right to health

The health of individuals and communities requires more than medical care, as indicated by the positive effect that self-determination and land rights have on
indigenous peoples’ health outcomes (Rowley et al., 2008; Watson, 2007). International human rights law puts into effect the right to the highest attainable standards of physical and mental health as an inclusive right, not only extending to timely and appropriate medical care, but integrating with it social determinants of health. In the last decade, states, international organizations, international and national human rights mechanisms, courts, civil society organizations, academics, and many others have begun to explore what the right to the highest attainable standard of health care means and how it can be put into practice (Hunt & Backman, 2008a). In the context of the existing gap in life expectancy between indigenous and non-indigenous peoples it is important to reflect on the laws, policies and the implementation of the right to health for indigenous populations. It is also imperative to reflect on what indigenous people themselves say are the right standards and to collect information on where these standards are being infringed.

Health and human rights are related in three main ways: the positive and negative effects on health of the promotion, neglect, or violation of human rights; the effect of health on the delivery of human rights; and the effects of public-health policies and programmes on human rights (Gostin; Gruskin, Mills & Tarantola, 2007). The relationship between health and human rights is stated explicitly in the preface to the WHO’s constitution, which establishes that health is the ‘state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity’ and ‘the highest attainable level of health is the fundamental right of every human being without distinction of race, religion, political belief, economic or social condition.’(WHO, 2005, p1) The WHO Constitution was drafted in 1946, and the latest amendment regarding its description of health dates back to 2005, after the Declaration of Alma-Ata adopted in 1978 at the International Conference on Primary
Health Care (World Health Organisation, 1978). The declaration urges member states to protect health as a fundamental human right under the premise of ‘Health for all’. Both instruments affirm the right to the highest attainable standard of health alongside the Ottawa Charter of Health Promotion of 1986 (The International Conference on Health Promotion, 1986). The latter charter stabilises the legal connection between public health and human rights (Hunt & Backman, 2008a). Furthermore, the Declaration on the Rights of Disabled Persons in 1975 raises concept of the need for legal protection regarding the right to health for persons with disabilities.

The Universal Declaration of Human Rights (UDHR) in Article 25 protects the right to an adequate standard of living in the event of disability. It frames disability within a medical discourse widely used in the post-war era (Stein, 2007a). In 1950 the General Assembly and the UN Economic and Social Council considered a report on the ‘Social rehabilitation of the physically handicapped’ (UN, 1950). This document focused on adapting the person rather than fostering an inclusive society. (World Health Organization, 2008). Furthermore, The International Covenant on Economic, Social and Cultural Rights Article 12 (ICESCR, 1966) covers the right of everyone to the enjoyment of the highest attainable standards of physical and mental health, protection of freedoms, entitlements and state obligations. Within this covenant a significant change towards a more comprehensive understanding of health and disability was achieved.

The freedoms encapsulated the right to the highest attainable standards of health include the freedom to refuse medical treatments, including those for sexual and reproductive health, and freedoms from cruel, inhumane and degrading treatments. These components of the International Covenant on Economic, Social and Cultural
Rights (ICESCR) are particularly relevant for people with disability. Data around these issues are often under-reported among the population of people with disability (Bodeker, 2008; Rosete, 2011). Taboos around sexuality are still the cause of major human rights violations for people with disability (Shakespeare, 2000), particularly among indigenous peoples with disability due to a lack of awareness, gender inequity, segregation, disempowerment and inefficient mechanisms for reporting such infringements (Meekosha, 2006; Richardson, 2000). The ICESCR also established the principles of non-discrimination and equity of access. Non-discrimination is a key principle in achieving equity for indigenous peoples with disabilities. Human rights mechanisms require specific attention to be paid to vulnerable groups such as migrants, women, children, persons with disabilities. The constant exclusion, discrimination and rights deprivation that people with disabilities were experiencing (Grech, 2009; Groce et al., 2011; Stein, 2007b) was recognised by the General Assembly of the United Nations in 2001. The creation of a Convention that specifically protects the rights of peoples with disabilities, enhances their voice and outlines special measures required addressing. This culminated in the development of the Convention on the Rights of Persons with Disabilities (2007), which will be discussed in the next section.

3.4 The creation of the Convention of the Rights of Persons with Disabilities

The story of the Convention of the Rights of Persons with Disabilities (CRPD) can be traced back to the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, held in Durban, South Africa, in 2000. The Mexican delegation urged member states to create a convention that would protect
the rights of persons with disabilities. The Mexican President, Vicente Fox, reiterated his proposal at the 56th meeting of the UN General Assembly. This was outlined as follows:

‘To consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination and taking into account recommendations of the Commission on Human Rights and the Commission for Social Development.’ (General Assembly, 2001, p. 5).

The General Assembly of the UN adopted the Convention of the Rights of Persons with Disabilities (CRPD) and its associated optional protocol on December 13, 2006. At its opening ceremony on March 30, 2007, 81 nations and the European Union signed the CRPD. The Convention came into force on May 3, 2008. The CRPD negotiations are reputed to have involved the highest level of civil society participation of any human rights treaty. The CRPD is the first UN human rights treaty to be adopted in the 21st century. Its principals are outlined in Article Three as follows:

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.

The CRPD is the first binding human rights instrument of the UN to explicitly address disability. Its 50 Articles provide legal protection for people with disabilities, establishing accountability systems to monitor the signatory countries on their action towards the progressive realisation of the mandate of the Convention. Its articles include abolishing laws that constitute discrimination (Article 4); equal rights for women and girls with disabilities (Article 6); the protection of children with disability (Article 7); the control of financial affairs as well as having equal access to bank loans, credit and mortgages (Article 12); protection of the right to live independently as well as being included in the community (Article 19); the right to education (Article 24) and access to the social and pedagogical support needed for pupils. It also protects the right to health (Article 25) and rehabilitation (Article 26). Finally through Articles 34 to 39 a Committee made up of independent experts, the Committee on the Rights of Persons with Disabilities, receives periodic reports from States and parties on the progress made in implementing the Convention.

The Convention sets out the legal obligations of States to promote and protect the rights of persons with disabilities, which are not new rights (McCallum, 2010). The CRPD was a response to the fact that although pre-existing human rights conventions offered considerable potential to promote and protect the rights of persons with disabilities, in practice this was often not achieved, with persons with disabilities being denied their human rights globally and being kept on the margins of
society.

The CRPD was a response to the absence of an international treaty expressly for protecting people with disabilities (Stein, 2007b). The CRPD is the first legally enforceable UN instrument specifically directed at the rights of persons with disabilities (Lord & Stein, 2008). The preamble of the CRPD acknowledges indigenous peoples as a vulnerable group, who are subjected to multiple or aggravated forms of discrimination.

An optional protocol was also adopted in relation to the CRPD recognising the ‘competence of the committee to receive and consider communications from or on behalf of individuals or groups of individuals subject to its jurisdiction who claim to be victims of a violation by that State Party of the provisions of the Convention’ (Optional Protocol to the Convention on the Rights of Persons with Disabilities Article 1, 2006, p.1). The faculties of the protocol protect only citizens in those countries that have ratified it, the member states can file a communication to the Committee, but not before exhausting national remedies.

CRPD Article 25, Health, mandated that signatories to the convention promote people with disability enjoying the highest attainable standards of health. It read as follows:

(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 (CRPD, 2006, p. 18)

Article 25, provides a framework urging signatory countries to respond to the health needs of persons with disability. Article 25 urges member states to address and take action on ‘health care often not being accessible or available to persons with disabilities on an equal basis with others because of factors like inaccessibility and even denial of treatment based on a disability’ (Lord, Suozzi & Taylor, 2010, p. 565). People with disability have many unmet health and rehabilitation needs (Tomlinson, Swartz, Officer, Chan, Rudan & Saxena). Based on international trends it could be argued that indigenous peoples with disability are facing a double barrier to enjoying their right to health.

The transformative vision of the CRPD relies on its legislative power to promote
change in disability law and policy at the domestic level (Lord & Stein, 2008). Other disability scholars emphasise the paradigm shift embedded in its principles and Articles (Quinn, 2010). Kayess and French (2008) stated that the CRPD gave opportunities for a higher degree of public participation by people with disabilities than any other human rights treaties. However, Kayess and French’s statement has been challenged from the indigenous viewpoint. Hickey (2008b) argued that indigenous persons with disabilities were excluded from the development of the CRPD. Reasons given included a possible lack of support from their governments, a lack of financial resources and fears of losing focus due to the political complexities behind the acceptance and representation of indigenous people. Nonetheless, the CRPD does reflect a particular historical moment. To date, Hickey’s early views are complemented by those of Meekosha (2011) who elaborated on the implementation of the CRPD and the potential benefits that it may have for indigenous peoples upon its development and implementation:

Disabled people in the South mobilised for the introduction of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which was initiated by Mexico. The countries of Latin America are now playing a leading role in motivating other countries to ratify and implement the CRPD (Meekosha, 2011, p. 670).

Human rights treaties, such as the CRPD, need concrete responses within domestic systems to allow them to function (Beco, 2009). The CRPD mechanisms need a clear understanding of indigenous needs and priorities to be documented from an indigenous perspective. Member states are mandated to submit reports under Article 35 ‘Reports by States Parties’. In April 2013 the Committee on the Rights of Persons with Disabilities (2013) responded to the initial mandatory progress report presented
by Australia. In the final recommendation the Committee urged Australia to present disaggregated data regarding the rates of disability among Aboriginal and Torres Strait Islander people, as well as taking action on non-discrimination and the health of indigenous peoples with disability. The report submitted by the Australian government (2010) with respect to Article 25 did not include any data or mention indigenous people with disability. This omission was also observed with other Articles within the Australian initial report (The Australian Government, 2010). Mexico and New Zealand have also presented their initial CRPD country reports mandated by Article 35. The official responses to these have not yet been released. However, the reports are available to the general public electronically through the website of the Committee (Office of the High Commissioner for Human Rights, 2013). The Mexican report did not mention any special consideration of indigenous peoples with disability, whilst New Zealand highlighted the urgent need to respond to the health needs of Māori with disabilities. It is clear that the international community through discussions at the CRPD recognised that being indigenous and disabled can lead to layers of discrimination, oppression, isolation and disempowerment. Such issues have been raised in several of the review sessions, such as the 9th session in which the Disabled Peoples Organisation (DPO) urged the committee to examine the alarming rates of infanticide among indigenous new born females (Organizaciones de Personas con Discapacidad de Paraguay, 2013). Also the 10th Session of the Damian Griffis, First Peoples Disability Network Australia (FPDN) enquired about the major disadvantages faced by Aboriginal and Torres Strait Islander people with disabilities (Australian Disabled Peoples’ Organisations, 2013). The Committee also made it evident through its recommendations that the implementation of the CRPD can contribute to alleviating the inequity, segregation and lack of access to health
services experienced by indigenous peoples with disabilities. Therefore, in keeping with the expressed need of indigenous people for self-determination (Andersen, 2010; Awatere, 1984; Calma, 2004), it is timely that the voice of indigenous people with disability should be heard in relation to their health needs and what they see as the implications of the implementation of the CRPD.

3.4.1 Linking up social context and human rights of indigenous peoples with disability and scholarship

Justice in the form of social equity has not yet been attained by indigenous peoples. The over-representation of indigenous populations among people with disability worldwide (Bhopal, 2008, Yoshioka, 2010), combined with their high levels of poverty and ill-health (Gracey & King), the lack of reliable disaggregated data and restricted participation in health governance (Hickey, 2008), supports the urgent need to respond to the needs of indigenous peoples with disability. This challenge is being taken up within this study. Up until now race-based inequity remains a challenge to public health, as well as to other fields such as disability studies. The urgent need to listen to what indigenous peoples have to say is reinforced by the lack of representation of an indigenous discourse in disability studies (Balcazar et al., 2010; Delgado & Stefancic, 2011; Dunbar, 2008; King et al., 2009; Yoshioka, 2010).

3.5 Background to the enquiry: towards the fulfilment of the right to health for indigenous peoples with disability

As an indigenous scholar who was raised in the state of Michoacán Mexico, I grew up seeing extreme poverty, ill health, discrimination and a highly marginalised Purepecha community. A disproportionately high number of people with disability
among the Purepecha was always evident. As I grew up, I followed the Zapatista Army of National Liberation (Ejército Zapatista de Liberación Nacional, EZLN) including their claim for justice and sovereignty (Gobierno Federal y el Ejercito Zapatista de Liberacion Nacional, 1996). I left Mexico to pursue further education, completed a research degree and worked in Europe for four years, returning to Mexico to work on health awareness in indigenous communities. After my postgraduate studies at Trinity College, Dublin, I co-ordinated a research project across Europe (funded by the Irish Government) to identify how people with disability were being included in the evaluation of residential care. As a result I interacted with governments, health departments; international NGOs, human rights bodies and research institutions across eight member countries of the EU. Whilst working on this project I was often reminded, by comments made by participants, of the leadership that Mexico had demonstrated in the creation of the CRPD (United Nations General Assembly, 2001). However, when I revisited Mexico, although I had seen the potential of the CRPD to act as a catalyst for change in improving the lives of persons with disability across many countries (Committee on the Rights of Persons with Disabilities, 2013; Kayess & French, 2008; Quinn, 2009), I found that the situation for indigenous peoples with disabilities appeared to be unchanged.

This observation was made even more potent upon my realisation that in other countries there had been growing participation of indigenous peoples’ representatives in intergovernmental discussions (Lawrence, 1994). Nevertheless, the work of the UN, through the Permanent Forum of Indigenous Issues and the ILO 169 Convention, in stressing human rights issues as they relate to indigenous peoples, has not yet achieved equity. There remains a lack of real improvement in their living conditions globally (Bhopal, 2008). The historical/cultural contexts of
colonisation and cultural dislocation, and the resultant inter-generational trauma (Australian Association of Social Workers, 2008; Dodson, 2007; Duran & Duran, 1995) needs to be addressed in order to understand the poor health outcomes for indigenous peoples.

The alarming rates of ill-health and social disadvantage amongst indigenous peoples have continued despite an improved understanding of the social and health determinants behind these conditions (McLennan, 2009). Dispossession of land and culture, discrimination and disruption of kinship ties are factors contributing to greater levels of disability among indigenous communities (Australian Disability Services Commission, 2006). Evidence exists that such factors have also affected and shaped the lived experiences of people with disabilities, along with their experience of being different from non-indigenous peoples (Barker & Murray, 2010; Bhopal, 2008).

In the preamble of the CRPD, indigenous peoples are acknowledged to be a vulnerable group. In general, in the CRPD the highlighted purpose is to address the continuing social exclusion of disabled persons. As indigenous peoples have experienced layers of social exclusion, member states are obliged to engage with indigenous communities and respond to their needs. However, this group is not listed in the binding text of the CRPD, and is limited to being recognised in the Preamble. If the Convention is to respond to the lives of all persons with disabilities (Lord & Stein, 2009), indigenous people need to be more fully recognised, particularly where health is concerned, in order to achieve fuller participation and inclusion. All member states need to engage with indigenous people with disabilities and listen to their needs (Harpur, 2010).
3.5.1 Research problem

In response to the reviewed literature and the problems this has raised with respect to the health of indigenous people with disabilities, this study aims:

To describe the health experiences of indigenous peoples with disability, drawing comparisons with and implications for the mandate of Article 25 of the United Nations CRPD.

The secondary aims are to:

a) Identify the perceptions of indigenous peoples with disabilities as to how their health needs are being met.

b) Analyse the commonalities and differences across international boundaries as to how the health needs of indigenous people with disability are being met.

c) Compare how indigenous people’s self-expressed health needs resonate with Article 25 ‘Health’ of the United Nations CRPD.

d) Investigate the implications of the health status of indigenous people with disabilities for the policies and practices of UN Member States with reference to the implementation of Article 25 of the CRPD.

Overall, this study will provide an international comparative exploration of Article 25, which will inform indigenous policy and practice as to how they could meet its requirements in association with its optional protocol. This study will take a qualitative approach, which will be outlined in Chapter Four.
Chapter Four: Methodology

4.1 Introduction

This chapter presents the rationale behind the qualitative methodological approaches taken in the thesis. The aim of the thesis is to investigate the health experiences of indigenous peoples with disability, drawing comparisons with and implications for the mandate of Article 25 of the United Nations CRPD.

A qualitative approach was chosen, as it aids in revealing the personal insights and views held by disabled Indigenous peoples. The views of Denzin and Lincoln (2008) and Smith (2007) regarding indigenous enquiry framed the research methodology decided upon for this study. As the aim of this research was to enhance the voice of indigenous participants a case study approach (Yin, 2008) utilising grounded theory strategies (Charmaz 2003, Corbin & Strauss, 1990,1994) was selected, coupled with participatory indigenous methodologies (Barker & Murray, 2010; Pennycook, 2002).

The exploratory approach followed Yin’s (2008) case study design utilising a set of qualitative techniques including semi-structured interviews, focus groups and observation strategies. An informal, conversational style of data collection eliminated power relationships between participants and researcher, interviewee and interviewer (Denzin & Lincoln, 2008).

The research design of this study is a response to a global call for an emancipatory approach to indigenous research (Denzin & Lincoln, 2008b; Fanon, 1994; Freire, 1970; Hickey, 2008a; Smith, 2006). Researchers from minorities, such as indigenous non-western and non-English-speaking scholars, have joined together to call for the creation of methodologies that query dominant groups and their traditional creation
of knowledge. This thesis takes a participatory and indigenous methodological approach to research and is aimed at highlighting the voices of indigenous peoples by examining their lived experiences with respect to accessing their rights to health as framed by the CRPD (2006).

4.2 Conceptual approach

4.2.1. Decolonising knowledge though an emancipatory approach to research

Many non-western and non-English-speaking scholars have expressed the need for a methodological approach that puts the voices of indigenous peoples and other minority groups at the forefront (Lincoln & González, 2008). Indigenous epistemology stresses the importance of participating in the creation of knowledge on an equal basis. Smith (2007) stated that research, ‘is not just a highly moral and civilized search for knowledge; it is a set of very human activities that reproduce particular social relations of power’ (p.117). She elaborated upon the link between research and power, by claiming that research in its broadest sense is an organized scholarly activity that is deeply connected to power. As a means of bridging this power divide Lincoln and González (2008) explored how western and indigenous scholars could contribute to ‘decolonise’ methodology and research. They suggested five elements when designing and conducting research, which have impacted upon my choice of methodology. These elements include:

a) working bilingual data;

b) considering non-Western cultural traditions;

c) multiple perspectives in texts;

d) multi-vocal and multilingual texts; and
e) technical issues to ensure accessibility. (Lincoln & González, 2008, p. 785).

These elements break with the ‘insider-outsider’ paradigm of research that assumed that the researcher was an ‘outsider’; that is an ‘outsider able to observe without being implicated’ (Smith, 1999). The fact that I am an indigenous Mexican in the eyes of the international indigenous community (The United Nations Permanent Forum of Indigenous Peoples, 2012) legitimizes my involvement as a facilitator of this research. Of note this latter forum has called for improvements to the health of indigenous peoples. My position as an indigenous researcher is reinforced by my lived experience in Michoacán Mexico. Therefore, a participatory approach was taken where I met or corresponded with indigenous leaders in all three selected countries prior to collecting the data. Overall their advice was

- to be flexible;
- to listen to the voices of indigenous groups;
- to honour their differences;
- to seek the truth in what is common and what makes them the same and different from one another;
- not to impose my thinking on the issues raised.

Arising from these consultations I looked for a way to capture how the lived experiences of the indigenous groups were associated with their health experiences.

**4.2.2 Advantage of qualitative research**

A qualitative approach was chosen as this gives insight into how the world is viewed by the research participants. Corbin and Strauss (2007) argued that qualitative research presents an opportunity to connect to the lived experiences of people
through data collection techniques that involve the person responding to how they have experienced the issues under discussion.

Finding a single definition of qualitative research is challenging, as it is used across a large range of disciplines and fields of enquiry (Denzin & Lincoln, 2007). In response to this challenge, Yin (2011) offered a set of characteristics that define qualitative research, rather than a single definition, including:

1. studying the meaning of people’s lives, under real-world conditions;
2. representing the views and perspectives of the people in a study;
3. covering the contextual conditions within which people live;
4. contributing insights into existing or emerging concepts that may help to explain human social behaviour;
5. striving to use multiple sources of evidence rather than relying on a single source alone (Barker & Murray, 2010).

In applying Yin’s views to indigenous research, qualitative approaches offer the chance to engage deeply with indigenous peoples’ realities and perceptions of the world.

Qualitative research has been criticised, however, by those within disciplines that have their origins in positivism, (Corbin & Strauss, 2008; Denzin & Lincoln, 2007), such as the experimental sciences of physics, chemistry, economics, and physiology. These have been hailed within research circles ‘as the crowning achievement of Western civilization’ (Denzin & Lincoln, 2007, p. 100). Positivism, with its emphasis on experimentally based science, is constrained to statistical outcomes that hinder hearing the world view of disempowered social minorities. A major criticism of qualitative research is that its thematic findings cannot be...
generalised beyond the sample of participants. In response, qualitative researchers would argue that it does enable theoretical generalisation. This means that qualitative researchers strive to gain and produce concepts and explanations that can be used in understanding the social world. Qualitative research is intensive in the collection of varying types of data in which people's opinions, insights and perceptions are gathered, compared and interpreted, leading to carefully constructed outcomes.

Qualitative research techniques are not new to those working with indigenous groups. For example, in the early 1920s the Chicago School used ethnography to study what Denzin and Lincoln (2008a) have described as the study of ‘the other’, the exotic and less civilised (p.18). In recent times ethnography has been used to observe, participate and record how the lives of ‘others’ have been challenged. This has led to the introduction of participatory research where vulnerable people themselves are central to how, when and where data are collected. Smith (2007), a Māori scholar argued that qualitative research, in particular participatory research, enables research that engages in multiple layers of struggle across multiple sites. She argued that, it involves the ‘unmasking and deconstruction of imperialism and its aspect of colonialism, in its old and new formations alongside a search for sovereignty; for reclamation of knowledge, language, and culture; and for the social transformation of the colonial relations between the native and the settler’ (p. 88).

Denzin and Lincoln (2008b) also elaborated on the use of qualitative techniques for indigenous inquiry. They stated that the set of interpretative practices utilized by qualitative research enhances critical discourse and ultimately emancipation. In keeping with the principles of emancipation Smith (1990) claimed that re-interpretation though rewriting and ‘re-righting’ the position of indigenous peoples
within the production of new knowledge is an important part of decolonising academia. The tools utilised to collect qualitative data include interviews, focus groups and field notes, as they create the space for collaborative dialogical work (Denzin & Lincoln, 2008). Critical qualitative research, ‘places research participants in scenarios where the researcher and participants can share, be critical and through this dialogue empowerment can occur’ (Denzin & Lincoln p. 5).

In this research qualitative techniques were used to portray the voices of indigenous people with disability, with the aim of capturing their narratives and discourses regarding their health needs. Also McLean (2012) argued that a qualitative approach reduces the distance between those with and without the lived experience of disability.

4.2.3 Grounded theory

The data collected within this study were analysed using grounded theory techniques. Grounded theory requires an analytical process of comparison and analysis that starts with the data collected. Kendall (1999) claimed that ‘grounded theory can be traced to the Chicago School of Sociology and the development of symbolic interactionism during the period between 1920 and 1950’ (p.743). However, this methodology gained its academic validation though the work of Corbin and Strauss (1990b, p. 12) who stated that ‘Grounded theory means theory that was derived from data, systematically gathered and analysed through the research process’.

4.2.4 Grounded theory and indigenous perspectives

Grounded theory was of particular importance for this research, as it enabled indigenous perspectives to be heard. Denzin (2007) argued that indigenous
grounded theory connects research to the struggles for liberation, which empower indigenous peoples to ‘challenging the status quo, rebuild leadership, restore environments and revitalize language culture and communities’ (p. 457). Nevertheless, Denzin also acknowledged the complexity and difficulty of achieving these outcomes with grounded theory. He stated that indigenous peoples have been seriously disempowered by western research. He urged researchers to use grounded theory to promote emancipation, self-determination and empowerment. He also made it clear that ‘grounded theory without modification will not work’ (Denzin, p. 456). He stated that the focus that grounded theory puts into obtaining data and analysing basic underlying social process may not respect the significance that social justice has to indigenous peoples. It was then suggested that grounded theory methodologies ‘must be localized to recognised customs, culture and social organisation’ (Denzin, p. 461).

In keeping with Denzin’s recommendations on the use of grounded theory design, the research described here was open to modifications that reflected the inclusion of local practices, cultures and beliefs, such as:

- Māori - Hui and blessing (Sinclair, 1990);
- Aboriginal and Torres Strait Islander people - message stick and group culture (Mathews, 1897)
- Purepecha - prayers, and food-sharing rituals (Gutierrez-Nuno, 1996).

4.2.5 Use of analytical tools

The data analysis in this thesis was guided by Corbin and Strauss (2007) who stated that ‘being an analyst means asking questions and thinking of all the range of possible answers which help us to take the role of the other so that we can better
understand the problem from the participants’ perspective’ (p.132). These tools were complemented by an indigenous perspective which critically pursues the voice of indigenous peoples with disabilities challenging at every step the ‘underlying structures and taken-for-granted ways of organizing, conducting, and disseminating knowledge’ (Smith, 2007, p. 88). The following analytical tools, described by Corbin and Strauss (2007), were used in both data collection and in analysis.

1. **Constant comparative method:** This technique refers to the researcher seeking similarities and differences by analysing data to compare it with other incidents. This also includes a theoretical comparison which refers to a deeper analysis of the concepts, events and narratives. It requires thinking more abstractly about what the concepts, events or narratives share and how they differ.

2. ‘**Flip-flop technique**’: In analysing the data it was useful to utilise what Corbin and Strauss term the ‘flip-flop technique’, and describe as a process in which the researcher turns the concept ‘inside out’ or ‘upside down’ (Corbin & Strauss, 2007, p.79). This technique helped to test assumptions and relationships within the data collected here.

3. ‘**Waving red flags**’ Corbin and Strauss advised keeping enough distance by ‘waving red flags’ when a researcher believes that they ‘always’ arrive at the same explication or if they are aware of a relevant phenomenon that ‘never’ appears. The waving of such ‘flags’ is an indication that further analysis should take place. ‘Waving red flags’ assisted me in reflecting on my own biases as an indigenous scholar and in analysing the data rigorously.

4. **Theoretical sampling:** In using grounded theory techniques the researcher attempts to generate new theories, and in order to maximise the
opportunities to develop new concepts theoretical sampling is recommended. It is a method of data collection based on concepts/themes derived from the data. So ‘theoretical sampling is a response to the data rather than a methodological feature stabilised before the research begins’ (p.144). It takes place once the research categories have reached a point of saturation, meaning ‘when no new data are emerging’ (p.143). The researcher identifies gaps in the data that need to be tested to construct a theory. Theoretical sampling arrives at a point when sufficient data has been collected to construct a well-grounded theoretical argument to the research question. It is important to recognise the research limitations and to address the possible need for further exploration.

5. Diagrams and memos are recommended in the implementation of grounded theory (Corbin & Strauss, 2007, Yin, 2011). Diagrams facilitate the graphic analysis of hierarchies, chronologies and other types of organisation and relationship across data. Yin (2011) stated that the memos ‘help track the coding process and provide reminders about possible refinements as well as tentative thoughts about the relationships among codes and the potential clustering of codes into categories and themes’ (p. 310)

Yin recommended utilising these memos and diagrams, which could take many forms, such as a personal journal, to assist with the ongoing analysis of the data. In Appendix B an example of a memo and its diagrammatic interpretation that I developed throughout the analysis stage may both be seen.

4.3 Research design

The literature review revealed that the health needs of indigenous peoples with disabilities have not been served. It has been recognised that ill health is influenced
by several elements outside of the health system, such as poverty, education, employment and access to adequate housing. Countries which are signatory to the CRPD have achieved differing results on the implementation of the right to health (Ministry of Health, 2013; The Lancet, 2012; World Health Organization, 2008). With respect to indigenous peoples, the limits and responsibilities of implementing the right to health arising from the CRPD go beyond any written documents and social structures. The complexities created in studying a phenomenon whose limits cannot be clearly defined is better met by using case study methodology (Yin, 2008). The following section provides a detailed rationale behind the choice of this methodology.

4.3.1 Exploratory case study approach

An exploratory case study research design was selected as the most appropriate way to portray and compare and contrast the health of indigenous peoples with disabilities across a range of countries. Although techniques such as ethnobiography or ethnography (Clifford & Marcus, 1986) and life stories (Lavallee, 2009) were considered, these anthropological techniques limited the response to the aims of this study. Ethnobiography, life stories or ethnography would provide insider views into the lives of indigenous people; however, such approaches would not capture the full picture of how the right to health, as mandated by the CRPD, has been fulfilled, promoted and monitored to date. The special features of an exploratory case respond more acutely to the research questions asked here.

Yin (2008) urged the researcher to comply with a ‘clear purpose when this methodology [case study] is applied, as well as [using] a criteria by which an exploration will be judged successful’ (2008 p. 30). He also recommended, as part of a case study approach, remaining within feasible limits, advice which was heeded by the choice of this methodology, as the boundaries of the phenomenon of health do
not clearly overlap with many different aspects of people's lives. Yin elaborated further in describing exploratory case studies as a tool to 'facilitate the analysis of interventions, which do not have a clear single set of outcomes' (p. 27) that were predicted, thereby making an exploratory case study a well suited methodology for this thesis.

The research components, following Yin's protocol, that have guided the exploratory design of this study are outlined in Table 4.1 below.
Table 4.1 Case study components in keeping with Yin’s protocol

<table>
<thead>
<tr>
<th>1. Research question</th>
<th>What are the health experiences of indigenous peoples with disability and how do they compare with the mandate of Article 25 of the United Nations CRPD?</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Proposition</td>
<td>Poor health outcomes of indigenous peoples with disability are influenced by oppression due to discrimination, racism, historical disenfranchisement and other factors related to colonisation. Recognition of sovereignty and self-determination has a positive influence on the health of indigenous peoples with disability.</td>
</tr>
</tbody>
</table>
| 3. Units of analysis  | • Access to health care  
                        | • Health needs of indigenous peoples with disabilities  
                        | • Human Rights based approach to health  
                        | • Implementation of Article 25 (Health) |
| 4. Logic linking the data to the proposition | The research design pursues discovering emerging patterns from the data. Locating findings and building explanations across cases, between the groups of participants and between the multiple case studies selected for this study. |
| 5. Criteria for interpreting the findings | Identifying and addressing patterns and rival explanations within the findings. |
This protocol was aimed at illuminating and comparing and contrasting the unique experiences of three different countries’ indigenous history and current reality arising from Article 25 of the CRPD. As a result, multiple case study methodology (Yin, 2008) was adopted for the purposes of reporting and analysing information from the three countries.

4.3.2 Selection criteria

This section outlines the criteria considered for the selection of each case study.

I. Overall criteria for selection of the case studies

In this study the following criteria were used to select the countries and indigenous communities:

a. Signatory countries to the CRPD

b. Countries that have been colonised
   i. Variation in type of colonial settlement
   ii. Variation in the way in which sovereignty of their indigenous peoples has been/or not been recognised.

c. Countries that currently recognised the existence of their indigenous peoples

d. Variation in geographical settings

e. Indigenous communities with an interest in the study.

Australia, Mexico and New Zealand were selected for this study. The variation and parallels within these countries allowed for the identification of facilitators and
barriers to meeting the health needs of indigenous peoples with disability. These three countries are all signatories to the CRPD, they have a shared history of colonisation, and they each recognise the existence of indigenous peoples. However, the recognition of indigenous sovereignty, as outlined in the review of the literature, varies between them. New Zealand signed a Treaty with the British Queen in 1840, protecting Māori sovereignty. Mexico has just recently recognised the pluricultural nature of its country in their constitution. Today, Article 2 of the Mexican Constitution protects the sovereignty and self-determination of indigenous peoples. In comparison Australia does not recognise the legal sovereignty of Aboriginal and Torres Strait Islander people. To support the selection made, an outline of each country’s history associated with the criteria is provided below.

II. Characteristics of the research sites: history, differences and commonalities.

Australia: The geographic location for the indigenous community studied was Brewarrina, situated in a remote rural area in Northern New South Wales. The population in 2011 was 1911 inhabitants, with an estimated indigenous population of 63.6 per cent, according to the Australian Bureau of Statistics (2012). The original land owners are the Ngemba people. The Brewarrina Ngemba Billabong was declared an indigenous Protected Area in November 2010 and it has a strong indigenous cultural tradition. From 1876 to 1967 the Ngemba Billabong was the Brewarrina Aboriginal Mission for local Aboriginal people whose land was taken by European settlers for grazing cattle.

Colonisation took a very particular and unique direction in Australia which was not applied either to previously conquered territories or to those conquered subsequently. It was not until 1901 that the six self-governing colonies collectively
became the states of the Commonwealth of Australia. Then, a decision was made not to include Aboriginal people in the census and the Commonwealth took control over some Aboriginal affairs under constitutional arrangements (Natoli, 2011). A referendum gave the Aboriginal people citizenship in 1967, and the 1976 Northern Territory Land Rights Act provided the basis upon which Aboriginal and Torres Strait Islander people could claim land rights based upon traditional occupation. It was not until 1992 that The Mabo v. Queensland decision by the High Court of Australia recognised native title in Australia for the first time (‘Mabo and Others v. Queensland’, 1992; Russell, 2005; Stephenson and Ratnapala, 1993).

**Mexico** – The geographic location chosen was Michoacán, Central West Mexico. The indigenous community that participated was located in ‘Zona lacustre de Patzcuaro’ one of the four Purepecha regions, all of them classified as semi-rural settings. The region is defined by six towns that have an estimated 87,794 inhabitants mostly populated by Purepecha people (Instituto Nacional de Estadística, 2012).

**Colonisation** The Purepechas were one of the few groups that resisted the Aztec expansion prior to the Spanish Conquest (Michelet 2001). When the Spanish crown invaded Michoacán, the ‘Irecha’ recognised the inability of the Tarascos to confront the Spanish invasions. The ‘Irecha’ decided to comply with the demands of the Spanish crown, including that of evangelising the clans. Tarascos were knowledgeable and respected warriors who eventually became servants of the Spanish crown. Purepechas helped the Spanish to invade other territories, such as Colima, throughout the period of colonisation (1520-1821). Recently the sovereignty of indigenous peoples and pluriculturalism have been recognised in the constitution (Cámara de Diputados del h. Congreso de la Unión Mexico, 2013).
**New Zealand** – The geographical location was in Manukau City, South Auckland, an urban setting on the North Island of New Zealand. The Māori population of this area ranks first in size out of the 73 districts in New Zealand, containing 8.4 percent of New Zealand's Māori population (Statistics New Zealand 2012). New Zealand's Māoris make up 15% of the population.

**Colonisation** - The British began to colonize New Zealand a few decades after they did Australia, but they did not treat New Zealand as *terra nullius*; instead they signed a treaty explicitly recognizing the Māori as owners of the land (Banner, 2005). The Treaty of Waitangi was signed in 1840 between the representatives of the British Queen and over 500 Māori chiefs. According to the 2012 New Zealand census statistics, 673,500 of the 4,433,898 inhabitants self-identified as Māori. Māori people came to New Zealand via canoe from Polynesia 700 years ago.

**4.4 Methods of data collection selected**

**4.4.1 Overview of types of data**

Yin (2011) described four differing types of data collection that contribute differently to the development of a case study. These four methods are: ‘interviewing and conversing, observing, collecting text and contents; and lastly recording your feelings’ (p.131). The exploratory and participatory nature of the research design resonated with collecting stories and narratives about people's health. The voices and the words utilised by indigenous peoples were core to answering the research questions and similarly the discourse of health workers, bureaucrats and UN delegates involved in health services and/or the development and implementation of the CRPD. Yin recommended interviewing and conversing with participants when the researcher values ‘the reality of what people say’ (p.132). Therefore, semi-structured
qualitative interviews and focus groups were selected as a means of gaining insight into the realities of how the health needs of indigenous peoples were being met from a variety of sources. Incorporated into this approach was field observation (Van Maanen, 2011), which was concentrated on documenting ‘the tone of the data collected as well as concerns, background information and personal posturing’ (Van Maanen, p. 179).

I. Semi-structured interviews

Semi-structured interviews allow the researcher to communicate with participants in a conversational fashion capturing the views and ways in which people get meaning out of their experiences (Rabionet, 2011). Qualitative interviews are ‘negotiated text, a site where power, gender, race, and class intersect’ (Denzin & Lincoln, 2008, p.48), providing an insider’s view, which is relevant to the research questions; for example, the role of affordability in accessing health care.

In keeping with the principles of decolonising indigenous knowledge, Yin’s (2011) methods of enquiry best allowed the use of indigenous narrative techniques (Lavallee, 2009). Such techniques include sharing stories, and narrative interviewing, allowing the researcher to be flexible as well as to conduct a purposeful interview, although Denzin and Lincoln (2008) argued that qualitative interviews can lead to an imbalance of power within the interviewer/interviewee relationship. Feminist literature (Reinharz, 1993) responded to this unequal relationship by inviting the researcher to connect with the interviewee by opening up her/himself, engaging in and pursuing a long-term trusting relationship. Feminist-based interviewing propounds that ‘the goal of finding out about people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the
interviewer is prepared to invest his or her own personal identity in the relationship’ (Oakley, 2003, p. 252). In view of this study being focused on marginalised groups and the proposed emancipation by the CRPD, a feminist approach to interviewing was required, rather than a positivist approach where the researcher is detached within the interview process in order to retain objectivity. However, to safeguard in such engagement the researcher also incorporated a process of reflexivity using self-reflection.

O’Brien and Murray (2008) defined reflexivity as a ‘mechanism of the research process by which the researcher is forced to evaluate and self-evaluate regularly’ (p. 95). My own process of self-reflection was assisted by debriefing sessions with local indigenous leaders who were not interviewed and with research supervisors and colleagues with expertise in the area. The way in which I reflected was influenced by the work of Malterud (2001), who wrote that reflexivity ‘starts by identifying pre-conceptions brought into the project by the researcher, representing previous personal and professional experiences, pre-study beliefs about how things are and what is to be investigated’ (p. 483).

II. Focus groups

Focus groups were also utilised, seen by Denzin and Lincoln (2008a) as a means of opening up the insiders’ view, allowing both consensus and opposition arguments among participants in order to understand the complex issue of how indigenous peoples gain their right to access health following years of marginalisation. Yin (2011) supported this approach as a good way of making participants feel comfortable, as in a group they may be more likely to express themselves. Kamberelis and Dimitriadis (2008) proposed that focus groups are a pedagogical, as
well as a political and interpretative methodology. Focus groups allow for the emergence of dynamics that open up possibilities for constructing effective stories and as a pedagogic tool are a space for political struggle and social transformation. Finally, First Nations people from Canada recognised sharing circles as an indigenous research method, and welcomed focus groups as a variation (Lavallee, 2009). This could be compared with the Māori *Hui*, where people gather to share and discuss issues similarly to in a focus group. However the *Hui* is also used for group problem-solving and resolution, as well as for ceremonial, official or celebratory purposes (Sinclair, 1990). People-gathering for ceremonial and problem-solving purposes is also embedded in Aboriginal and Torres Strait Islander people’s cultures and community rituals. (O'Donnell, 2010).

**III. Field notes**

From his work in the field of ethnography, Clifford (1990) stated that it was difficult to systematically or definitively describe field notes. Within this study field notes were utilized to capture feelings, informal conversations that took place around the interviews, reflective thinking after interviews; and other narratives arising within the field work visits, such as myths and personal stories that participants shared with the researcher. Clifford’s understanding of field notes was complemented by Patton (2005) who saw them as a means to organise a narrative description helping to illustrate themes, allowing the researcher to contextualise the text of the interviews and the dynamics between the researcher and the interviewees.

**4.5 Coding**

The first step in analysing the data was to organise it. Yin (2011) also refers to this process as one of ‘disassembl(ing) your data’ (p. 186). The process of analysis was
done separately for each case study followed by a cross-case analysis. This process was assisted by N-vivo10 qualitative data analysis software developed by QSR International. This software facilitates the analytical modelling and graphing of the data (Bazeley & Jackson, 2013). The use of N-vivo10 facilitated the detailed analysis of the large pool of data collected.

The organisation of the data collected complies with a system of coding described by Corbin and Strauss (1997), who propounded that there are different stages to break down, organise, investigate and reflect on in the data; firstly by open coding, followed by axial and finally selective coding. Each of the three case studies, covering Australia, New Zealand and Mexico were coded separately, and followed by cross-case analysis.

Within the analysis of the three case studies open coding was first applied, with transcripts read several times before the coding started. This stage of coding is defined as ‘the analytical process through which concepts are identified and their properties and dimensions are discovered in data’ (Corbin & Strauss, 1990, p. 101). N-vivo10 was utilized in a line by line process of open coding.

Open coding was followed by the application of axial coding. (Kendall, 1999) stated that, ‘whereas open coding fractures the data into categories, axial coding puts the data back together by making connections between the categories and sub-categories’ (p.745). Corbin and Strauss (2008) defined this stage as reassembling, This term was shared by Yin (2008) who wrote about a process of disassembling and reassembling data in using case study methodology. For Yin (2011) axial coding ‘goes into a higher conceptual plane, whereby themes or even theoretical concepts start to emerge’ (p. 191) At this stage the reseacher is able to identify the group of participants who contributed the most for each coded category. In other words it is
possible to compare and contrast the strength of coded categories between participant groups. Corbin and Strauss (1990) stated that open and axial coding may show up some rather blurry differences and that the formation of categories is not a straightforward exercise and as an analytical process it may not follow a lineal patter:

‘In axial coding, categories are related to their subcategories to form more precise and complete explanations about phenomena. Although axial coding differs in purpose from open coding, these are not necessarily sequential analytic steps, no more than labelling is distinct from open coding. Axial coding does require that the analyst has some categories, but often a sense of how categories relate begins to emerge during open coding.’ (p.124)

As part of axial coding, I looked at relationships, hierarchies, explanations and contradictions across the data using diagrams and other means of visualisation. Categories were re-analysed with codes being moved from one category to another, until the formation of categories was strong and showed sound correlations. The refinement of axial coding was guided through the research and sub-questions.

Figure 4.1 exemplifies one of the categories analysed with subcategories and relationships. This figure was compiled with real data from this study to indicate how the analysis carried out explored the relationships between codes and patterns generated.
Figure 4.1 Composition of theme: poverty theme

Moving analysis to the third category of coding, termed ‘selective coding’ was achieved when the analysis of the axial codes revealed core categories. Selective coding refers to a ‘process by which all categories are unified around ‘core’ categories and categories that need further explication are filled-in with descriptive detail’ (Corbin & Strauss, 1990a, p. 14)

Refining the analytical process occurred by questioning the interpretation of the data, by conducting a series of theoretical questions that were posed to understand the cause of an event, testimony or experience though the eyes of the participant. Corbin and Strauss (2008) recommended analysis of the data through various theoretical lenses in exploring a variety of possible interpretations of the data and the relationships that emerged. In this study different questions were posed throughout the stages of the coding process. However, selective coding forced the researcher to
explore the data more deeply using various theoretical lenses. As an example of the use of such lenses the process that scrutinised one of the categories will now be presented. Arising from the category of poverty the following question was asked of the data: what is causing an overrepresentation of poverty in the sample of users of health services? The literature on social determinants of health had pointed out a correlation between ill health and poverty.

In using Corbin and Strauss’s (1990) grounded theory principles, this example shows the reader how a critical and conscious exploration of the data used different theoretical lenses. The social determinants framework (Tanahashi, 1978) was used to explore why health services were not reaching the people they should serve. Through a comparison of Tanahashi’s model with that of the overall theme and sub-themes of poverty the following preliminary assumptions and potential theoretical concepts emerged:

I. Being indigenous with a disability was correlated with being poor and ill.

II. There was a significant mismatch in the concept of health and wellbeing evident through the ineffective relationship between user, health services and health governance.

III. The mismatch between health policies and health delivery are triggering ill health across all indigenous peoples with disabilities.

Selective coding is a stage of deep analysis of the data that allowed me to identify the core categories that represented the central phenomena of the study. This stage required me to revisit every memo, note and initial interpretation to find the correlation and the connexion between the axial themes. The outcomes of a constant comparison of the discourses from the different groups of participants in
each case study then enabled the core themes to be triangulated both within and across the three case studies.

Theoretical integration of the data was achieved after scrutinising comparisons within the categories and sub-categories within the codes. Theoretical integration is facilitated by identifying a core category or central category. A central category is described by Strauss and Corbin (2007) as one that appears to have the greatest explanatory relevance and the highest potential out of all of the other categories together (p. 104).

4.6 Construct validity

Validity is core to research. Scholarship in any field without validity is worthless as it will lead to false findings. Corbin and Strauss (2007) discussed other concepts such as ‘truth’ ‘rigour’ and ‘credibility’. However I feel that the need to define the ‘truth’ seems like dogmatism and I prefer the term ‘credibility’. However, I do stress the need rigorously to evaluate the processes and outcomes of qualitative research. Glaser (1992) stated that grounded theory needs specific criteria in order to assess its credibility by assessing its workability, relevance and modifiability. These characteristics are now outlined. First, workability refers to ‘whether the set of integrated and conceptually plausible grounded hypotheses sufficiently account(s) for the main concern of the participants’ (Charmaz, 2003, p. 193). In comparison relevance assesses what is important for participants, apart from academic interest. Whist modifiability refers to how the generation of theory is constantly modified as new data can always be integrated generating new hypotheses.

Yin (2011) described a less complex definition of validity as, ‘properly collected and interpreted data, so that the conclusions accurately reflect and represent the real
world that was studied’ (p.239). Yin described a ‘validity checklist’ developed by Maxwell (2009) that provided a detailed list of tasks providing a guide to ensure that validation was checked upon and ongoing within a study. These tasks included: 1) intensive involvement with the data, done by various readings of the material, in depth knowledge of the trends, relationships and themes created; 2) rich data, which could be backed up with vast amounts of data collected at each site; 3) respondent validation, following this requirement precisely proved to be unrealistic for the present research. Therefore, adequate modifications were implemented for this task. Respondent validation was modified, owing to significant issues such as low literacy among the group of indigenous peoples with disabilities, with most not having access to electronic communication. The time and expertise required to hold one-to-one validation processes was unrealistic according to indigenous leaders who supported this research. Also, the resources available did not allow the researcher to return to the remote and rural sites for validation. Furthermore other groups of participants such as health workers, senior bureaucrats and UN delegates were often time-restricted. This issue represented a challenge, however the indigenous leaders who supported the research did validate the findings from each research site. A draft was sent to them for consideration and this was a way of overcoming the difficulties faced across groups.

Continuing with the check list: task 4) searching for discrepant evidence and negative cases, was carried out by corroborating information, looking for different explanations across the data, as well as triangulating and gaining reflections from supervisors; 5) triangulation was completed among groups of participants within each country and across each country as well as by 6) comparison. All of these items are compatible with the requirements of Corbin and Strauss (2007) for the
implementation of grounded theory and the notion of quality research.

For this study particular attention was paid to using triangulation to, ‘corroborate a finding with evidence from two or more different sources’ (Yin, 2011, p. 313) Comparison according to Yin refers to ‘compar(ing) explicitly the results across different settings, groups, or events’ (Yin, p. 79). Triangulation took place between participant groups including, where appropriate, users of health services, health workers, senior bureaucrats and UN delegates from the same research site and then across countries. Selective core categories within sites and across countries emerged from the data following a deep process of analysis.

4.7 Data collection

4.7.1 Overview

For three of the four groups of participants semi-structured interviews were conducted with indigenous peoples, Senior Bureaucrats and UN delegates participating through interviews, while health workers were part of a focus group. (See interview/ focus groups schedule Appendix C and Information sheets Appendix C and Consent Forms Appendix D). The data collection started in New Zealand in October - November 2011, followed by Mexico January- March 2012 and Australia initiated in March and continued in September-October 2012. Description of the data collection with each group follows:

For indigenous peoples: Semi-structured, qualitative interviews took place in a location selected by the participants, which ranged from private houses, community centres or meeting rooms at community health services. Access to this location was facilitated by indigenous leaders who advised the researcher. An interview protocol
which was followed within people’s homes was that the researcher was accompanied by a third person and the interviewee could also have a support person present. People who decided to take part in the interview were then asked to sign a consent form, ensuring both confidentially the right to withdraw at any stage of the interview.

*Senior bureaucrats and United Nations Delegates* had their protocol dictated by their availability of time; they informed the researcher of the most convenient time and location for them. They all signed a consent form, with one senior bureaucrat from Australia not allowing tape recording. All senior bureaucrats and UN delegates were asked to sign a consent form to participate in a semi-structured interview. Two participants who participated via teleconference signed their consent form electronically.

*Health workers* who took part in the focus groups also signed a consent form. The focus groups were arranged in locations that were convenient and conformable for participants. On one occasion a health worker was not able to reach the focus group location at the agreed time, therefore the research was conducted during a separate session with him.

Participants who expressed an interest were free to withdraw at any point without the need to provide any explanation. Two out of the 19 expected participants did withdraw on the day of the interview in New Zealand. They did not arrive at the venue due to parallel events held by the organisation supporting this study, ill health and issues with transportation; and in Mexico participants withdrew their interest due to family difficulties. One participant died unexpectedly. Overall, the reasons for not attending included poor health, death and family difficulties.
4.7.2 Research participants

The selection of participants for this research was aimed at pursuing a comprehensive analysis of the health needs of indigenous peoples with disabilities, covering the parameters as outlined in Article 25, Health, CRPD. The selection was aimed at comparing the perspectives of indigenous peoples with disabilities, with: health workers who delivered services to them; bureaucrats who decided on policies and programmes within respective governments; and finally with UN delegates who advocated both domestically and internationally the implementation of the CRPD. See Figure 4.2

![Figure 4.2 Relation of research participants with CRPD](image)

4.7.2 Sampling technique

For case study methodology, non-probability sampling is commonly applied as it allows for the identification of those who hold particular profiles and/or who have experience that is relevant to the research questions (Zhong, 2009). Stehman (1999) pointed out that, ‘the non-probability sampling technique has been termed purposive
sampling as it allows the researcher to select participants that fit a particular criterion that matches the research question’ (p. 2429). For this study this sampling technique allowed the researcher to select participants who could provide an insider (Denzin & Lincoln, 2007) view of: living with a disability (indigenous participants); the provision of health care (health care workers); development of policy (senior bureaucrats) and advocacy (UN delegates). In qualitative research the samples are likely to be chosen in a deliberate manner in order to ‘use those that will yield the most relevant and plentiful data, given [the] topic of study’ (Yin, 2011, p. 88). The purposive selection criteria for each group is outlined below, and was designed to capture the views of key informants who also have an influence on the way in which Article 25 is designed to meet the needs of people with disabilities.

4.7.3 Participant groups

In each country, as depicted in Figure 2, four groups of participants were recruited:

**Indigenous people with disabilities**

Six indigenous people with disabilities were interviewed at each research site. The purposive criteria for selection covered

- People who identified themselves as indigenous;
- A range of different types of disability;
- A cross-section of genders;
- A spread of geographic locations;
- People who were interested in participating.

**Health workers**
Within each research site between five and ten health professionals, such as clinicians, social workers and community workers, were invited to participate in a focus group. The following criteria guided recruitment:

- Health workers working directly with indigenous people with disabilities;
- Health workers who worked at the same site/community/town as users of health services who were interviewed;
- Health workers being available for interview considering their high workloads and constraints on their time.

**Senior bureaucrats**

Three senior bureaucrats were interviewed within each country’s research site. The following criteria guided recruitment. Participants had:

- Responsibility for the implementation of the UN CRPD at either federal or state level;
- A leadership role in their department.

**United Nation Delegates**

Two UN delegates were interviewed within each country. The following criteria guided recruitment:

- Participants who were delegates for their country at the New York UN meetings for negotiating the passing of the CRPD;
- Ongoing commitment to advocating the implementation and or monitoring of the CRPD in their respective countries.

Table 4.2 shows a profile of the participants from each country.
Table 4.2 Description of participants and geographic locations

**Brewarrina, Australia**

<table>
<thead>
<tr>
<th>Profile</th>
<th>Number</th>
<th>Gender</th>
<th>Geographic location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous users of health services</td>
<td>6</td>
<td>4 Male</td>
<td>Rural Remote</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 Female</td>
<td></td>
</tr>
<tr>
<td>Health workers focus group</td>
<td>5</td>
<td>5 Females</td>
<td>Rural Remote</td>
</tr>
<tr>
<td>United Nations Delegates</td>
<td>2</td>
<td>1 Male</td>
<td>Urban</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>Senior Bureaucrats</td>
<td>4</td>
<td>1 Male</td>
<td>Urban</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 Female</td>
<td></td>
</tr>
</tbody>
</table>

**Total Participants 14**

**Michoacán, Mexico**

<table>
<thead>
<tr>
<th>Profile</th>
<th>Number</th>
<th>Gender</th>
<th>Geographic location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous users of health services</td>
<td>6</td>
<td>5 Male</td>
<td>Semi-rural</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 female</td>
<td></td>
</tr>
<tr>
<td>Health professional (interviewed separately)</td>
<td>1</td>
<td>1 Male</td>
<td>Semi-rural</td>
</tr>
<tr>
<td>Health workers focus group</td>
<td>7</td>
<td>7 Females</td>
<td>Semi-rural</td>
</tr>
<tr>
<td>United Nations Delegates</td>
<td>2</td>
<td>2 Male</td>
<td>Urban</td>
</tr>
<tr>
<td>Senior Bureaucrats</td>
<td>3</td>
<td>3 Male</td>
<td>Urban</td>
</tr>
</tbody>
</table>

**Total Participants 19**

**Northern Auckland, New Zealand,**

<table>
<thead>
<tr>
<th>Profile</th>
<th>Number</th>
<th>Gender</th>
<th>Geographic location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous users of health services</td>
<td>6</td>
<td>3 Female</td>
<td>Urban</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 males</td>
<td></td>
</tr>
<tr>
<td>Health workers focus group</td>
<td>6</td>
<td>3 males</td>
<td>Urban</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 females</td>
<td></td>
</tr>
<tr>
<td>United Nations Delegates</td>
<td>2</td>
<td>1 Female</td>
<td>Urban</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 Male</td>
<td></td>
</tr>
<tr>
<td>Senior Bureaucrats</td>
<td>3</td>
<td>Male</td>
<td>Urban</td>
</tr>
</tbody>
</table>

**Total Participants 17**
Identification (ID) codes comprising five parts were given to each participant. These ID codes were used to report the findings, with the aim of protecting participants’ anonymity. The first letters indicated the groups of participants: U = health care users; HW = health worker; SB = senior bureaucrat, UN = United Nations delegate. The subsequent letters indicated the country: A = Australia; MX = Mexico and NZ = New Zealand. The next letters showed the participation type: I = Interview; FG = focus groups. The gender of the participant was indicated by: M = male or F = female. Finally each participant was given a number. An example of an ID code is U.

A. IM9

4.7.4 Recruitment process

I. For indigenous groups

Participants were initially approached to engage in the research study by a key indigenous leader or by an organisation that supported the research. The researcher liaised with the leaders and relevant organisations. Once information was obtained they facilitated the contact with the relevant community to initiate recruitment.

Direct contact was initiated with indigenous service representatives, elders and other relevant organizations by the Poche Centre for Indigenous Health, University of Sydney, Australia; the Mexican Institute of Social Insurance (IMSS), Mexico; and the Te Roopu Taurima, New Zealand. All these organisations distributed information sheets inviting potential participants to an information session on the research. (See Appendix D for information sheets). Additionally, where organisations knew of people who would prefer to talk face-to-face about participating in the research the respective organisations arranged for them to be visited by a representative of their
organisation.

The specifics of recruitment across indigenous groups in each country were that in Australia informative home visits were arranged by a representative of the site staff. After the first approach the researcher travelled to Brewarrina to introduce herself and the study. After meeting and discussing with the researcher those interested in participating informed a Brewarrina representative who visited them after the researcher left.

In Mexico a representative of the Mexican Institute for Social Insurance (IMSS) (public hospital) called a public meeting to give information about the research by putting up flyers in the public square in Patzcuaro. This meeting was led by an indigenous leader and a representative of the IMSS. Potential participants attended an information session and those interested in participating informed an IMSS representative after the session. With this information the researcher and the IMSS representative arranged interviews and focus groups sessions.

In New Zealand the meeting was a *hui*, where people assembled at a *wharenui* (meeting place). It was led by a Māori elder who provided information. People interested in participating in the study informed the Te Roopu Taurima representative after the session

**II. Recruitment of health professionals**

The Poche Centre for Indigenous Health, the MISS and Te Roopu Taurima invited health professionals to an information session on the research, as well as sending information electronically, which was the preferred method.

Once some expressions of interest had been collected the researcher and the representative of each institution established a date and location for the focus group.
A proposed date was send out and those who were interested in taking part in the study confirmed their availability with the site representative. Prior to the session information sheets were distributed, they were printed and read on the day prior to reviewing and signing consent forms.

III. Recruitment of senior bureaucrats

The Centre for Disability Studies, University of Sydney, contacted representatives from Australia and New Zealand, whilst the Mexican Institute of Social Insurance contacted representatives from Mexico. General information was provided electronically. Those interested were invited to contact the researcher to obtain more information and to arrange an interview. Most of the interviews were face-to-face except if there were difficulties, when a teleconference call was offered to participants.

IV. United Nations Convention representatives

The Centre for Disability Studies approached UN CRPD delegates from the three participating countries: Australia, Mexico and New Zealand. A letter containing the relevant information about the research was sent (Appendix F).

Those interested in participating contacted the researcher directly to arrange an interview, as indicated on the invitation letter

4.8 Transcription

The data analysis began following the first round of interviews. All interviews were verbatim transcribed and analysed using Nvivo 10 software, which was dedicated to analysing qualitative data and developed by QSR International (2013). Transcription of the interviews allowed the researcher to become familiar with data and to create a
platform for analysis (Davidson, 2009). Verbatim transcription was used which means 'the word-for-word reproduction of verbal data, where the written words are an exact replication of the audio-recorded words' (Davidson, 2009, p. 38). However, Poland (2003) argued that this could be problematic as a text may not reflect non-verbal communication, expressions and other forms of expression that could alter the meaning of the text transcribed. He emphasised the need to look at the trustworthiness of the transcript and to 'be mindful of the limitation of this media to portray the full flavour of the interview' (Poland, 2003, p. 274). Therefore, the feelings, impressions and the context of interviews complementing the transcript were captured by the researcher’s field notes.

Verbatim transcription was used with the field notes to revisit the data and review the impressions and the exact words used by participants, comparing and contrasting the words, discourse and general narratives between participants. Most of the interviews and focus groups that took place were fully transcribed. When audio-recording was not consented to, the researcher captured information with notes during and after sessions, where possible documenting the exact words, phrases and expressions. These notes were seen as raw transcripts, and they were treated differently from field notes, as when they represented an exact reproduction of the expressions used by participants they were treated as transcripts, and therefore captured in n-vivo and coded.

Transcription and analysis was carried out in the participants’ own language, either English or Spanish, in order to capture their voices using their own words and expressions as well as the expression of their own culture. Lincoln and González (2008) support such an approach as it contributes to decolonising the research processes and practices. Words in te reo, Aboriginal languages, Purepecha and
Spanish were found throughout the research and explained in the glossary. The bilingual researcher translated from Spanish to English for the purposes of presenting the data in this thesis.

### 4.9 Ethical guidelines

Ethical approval to conduct this research was sought from the Human Research Ethics Committee of The University of Sydney and when it was approved it was given the research protocol No: 09-2011 / 13883 (See Appendix E).

In keeping with the guidelines on conducting research on indigenous populations, ethical approval was also obtained from the Aboriginal Health and Medical Research Council Protocol No. 851/12 (See Appendix F). The Human Research Ethics Committees in New Zealand and the Mexican Institute of Social Insurance were happy to validate the approval of the University of Sydney and did not require the presentation of an ethics approval application.

Several discussions were held about the question of offering financial compensation to participants. The guidelines for research into Aboriginal Health (Aboriginal Health and Medical Research Council of NSW, 1998) establishes that Aboriginal communities must be central to the development and execution of any research. Smith (1999) stated that indigenous research must be guided by indigenous values. With this as a framework it was decided that sharing the research findings would be more valuable than any financial compensation for participating. Indigenous leaders advised that payment could be viewed as patronising and disempowering. They considered payments to promote the old western research model where indigenous people were utilised. Due to the prevalence of poverty and substance abuse among the indigenous community, as reported by Dickert, Emanuel & Grady (2002), money
was seen as an unnecessary influence.

Sharing findings accessibly would allow people to have a clear understanding of the project’s outcomes with a view to empowering the participating indigenous users. The study outcomes will give indigenous communities the opportunity to compare their situation with that of other indigenous peoples with disabilities.

4.10 Summary

This chapter has presented a detailed explanation of the methodological approach selected for this research, as well as the techniques used to collected data and the analytical instruments. The advantages that a case study methodology (Yin, 2010) offers in understanding the health experiences of indigenous peoples with disabilities, in addition to the role that health workers, senior bureaucrats; UN delegates and domestic law plays in shaping such experiences has been illustrated. The data collection techniques selected includes semi-structure interviews and focus groups. Data analysis was carried out by integrating open, axial and selective coding as well as grounded theory techniques. The use of such grounded theory techniques responded to the need to produce theories that could contribute to understanding health issues across indigenous populations with disabilities, by promoting indigenous emancipation, self-determination and empowerment.
Chapter Five: Research Findings

5.1 Introduction

This chapter presents the findings in three sub sections, for Australia, Mexico and New Zealand. The interviews and focus groups conducted for each case study were verbatim transcribed and analysed using N-vivo10. Grounded theory tools were also used for examining data sets, as outlined in Chapter Four, with open, axial and selective coding carried out (Strauss & Corbin, 2008). Each case study provides the picture that emerged from analysing the expressed health needs of indigenous peoples with disability within each jurisdiction. Such an analysis benchmarked indigenous people’s discourse with respect to health with the mandate of Article 25 of the CRPD. The views of indigenous peoples with disabilities were triangulated with those of health workers, senior bureaucrats and UN delegates. In this chapter the particulars of each case study are scrutinised, providing the grounding for a further in-depth discussion of the commonalities and differences between the case studies (see Chapter Six: Cross-Case Analysis).

5.2 Australia

5.2.1 Introduction

The findings that emerged from the case study conducted in Australia are presented in this section. The process by which the research was conducted uncovered several outcomes relevant to the findings. The senior bureaucrats were mostly based in Sydney, but their contribution reflected their experiences of working in Aboriginal health across the whole of Australia. It also of importance in describing the findings that two out of the three senior bureaucrats self-identified as being Aboriginal. The
UN delegates stated that they were very strong advocates of all indigenous peoples’ right to health throughout Australia, particularly indigenous peoples with disabilities.

5.2.2 Overview of case study

Four core themes, which are presented in Figure 5. 1, emerged from the Australian case study. These were, specifically: indigenous identity, social determinants of health, over-provision versus under-provision of health services; protection of the rights of Aboriginal and Torres Strait Islander people with disabilities. Each theme is presented in this chapter along with sub-themes arising from triangulation of the interview data across the four participant groups. The following codes will be used to present supporting quotations within the text. The first letter indicates the groups of participants: U = users of health care; HW = health workers; SB = senior bureaucrat, UN = United Nations delegate. The next letter indicates the country: A = Australia. The subsequent letters provide the type of participation: I = Interview, FG = focus group. The gender of the participant will be indicated as M = male or F = female. Finally each participant has been given a number. ID codes will, therefore, appear as, for example, U. A. IM9.
5.2.3 Identity

I. Overview of the theme

Indigenous identity emerged as a strong sub-theme that influences all aspects of Australian Indigenous people’s health and social lives. It covers aspects such as, the meaning of being a ‘blackfella’; the relationship between culture and health and the Aboriginal and Torres Strait Islander people’s perceptions of disability.

II. Being a ‘blackfella’

Being a ‘blackfella’ was often the expression used to self-identify as an Aboriginal and Torres Strait Islander person. Acknowledging their identity as a ‘blackfella’ was very important for health care users. The importance of identity was also recognised by health workers, senior bureaucrats and UN delegates. Self-identification as an indigenous Australian person was linked with wellbeing. It acknowledged people’s history, their elders and their attachment to the land. It was also stated that self-identification as a ‘blackfella’ required resilience, as it was a way of standing up to the
history of oppression. Resilience emerged as intrinsic and underlying to the discourse throughout participant’s descriptions of what it means to be a ‘blackfella’ with a disability. They associated their indigenous Australian identity with concepts of power, strength and unity. They also described such concepts as being an inherent part of who they are or as expressed by one user of health care, ‘as part of their blood’.

Respondent: ‘I’m Aboriginal. I’m a full blood Aboriginal.’

Interviewer: ‘What does it mean to be Aboriginal?’

Respondent: ‘Oh, black power.

U. A. I M6

Being a black or a ‘blackfella’ was a common way of self-identifying as an indigenous Australian. It also represents a political stance and a way of indigenous peoples attaching themselves to the land and history of Australia. References were made to physiognomy, skin colour and blood ties. Being a black or a ‘blackfella’ was also a way of saying, ‘I am not white’, hence comparing themselves with Europeans. Indigenous participants showed a sense of pride and honour in self-identifying as Aboriginal and Torres Strait Islander people and/or ‘blackfellas’, distancing themselves from being white.

Well I’m proud of it. Very proud of being an Aboriginal woman. Black woman.

That’s all I can say. I’m very proud to be a black, Aboriginal.

U.A. I F5

The majority of the health care users, however, linked being indigenous with negative words such as ‘Abos’, which is a highly pejorative and disrespectful Australian term. The use of this term by Aboriginal and Torres Strait Islander people can also be viewed as a glimpse of internalised racism. A negative feeling, however, arose from
the potential negative consequences of publically stating that part of their identity was indigenous. This feeling was linked to the negative history of abuse and negligence experienced by the indigenous peoples in Australia.

...like there’s a voluntary Aboriginal identifier on the Medicare card. There’s not unreasonably a suspicion, oh why do we want to record that we’re Aboriginal on Medicare. Once the government’s got information about who we are and whether or not we’re Aboriginal, you know, what’s to stop negative policies arising from that?

SB. A. F 3

Indigenous participants perceived a difference between the ‘white fella’ and the ‘blackfella’. However, from an indigenous perspective this was not seen to get in the way of them relating to one another.

Between the white fellas and the blackfellas there’s a different attitude that’s all, but we get on good.

U. A. I M4

Cultural factors, such as language, were very important to participants when discussing Aboriginal and Torres Strait Islander affairs. The lack of indigenous languages, as well as a lack of their promotion, was perceived as a sorrowful loss. Non-indigenous participants recognised the value in acknowledging Aboriginal and Torres Strait Islander people’s languages. They considered such languages to be a part of the cultural heritage of indigenous people and their use in public and official events a way of respecting and honouring their history. The lack of importance given to indigenous languages in Australia was compared to other jurisdictions, such as New Zealand, where indigenous language is viewed to be important.
I was in the New Zealand Parliament giving a talk and we began [with] the Māori language and people were very serious about it, whereas in Australia we begin a meeting by honouring the land but after that nothing.

UN. A I.M1

In the narratives of indigenous users of health care, identity was often linked to blood-ties, history, colonisation and community life. For indigenous users, being part of the community involved being part of social and cultural activities, but this did not always extend to the health system. Indigenous health care users tended to perceive health services as alien, distant and something that they did not want to be involved with. Whilst health workers corroborated this perspective, they also added that cultural differences had led Aboriginal and Torres Strait Islander users to mistrust the services offered. They saw this detachment from health services as part of a cultural divide. Lack of appreciation of indigenous culture is exemplified in the quote below.

I think there’s something about Aboriginality in that ... they want to live for today. That is an identified thing about indigenous cultures.

HW.A.FG1

Health care users and health workers both described a strong cultural divide that discourages indigenous peoples with disabilities from using health services.

III. Health and culture

Cultural heritage also shaped the way in which Aboriginal and Torres Strait Islander people positively expressed how they felt about their lives. When indigenous users of health care were asked about their health, they were positive, regardless of its seriousness. Such attitudes were severely criticised by health workers and seen as being a denial of their needs.
Interviewer: ‘How would you consider your health?’

Interviewee: ‘This is the way I am. I am just happy

U.A.I M6

Such positivity was interpreted by health workers as indifference:

It is because they can’t feel it or see it, it’s insidious. If he’s got blood pressure, he can’t feel it, you know. And you also, you ask him, when you are doing a health assessment or something, you ask them are you well or have you got any illnesses: “No, I’m fine”.

A minority of the users of health care expressed an interest in accessing traditional medicine, stating that mobility restrictions hindered their use of it with them often having to go and find it in the wild. Health workers viewed traditional medicine as complementary to western medicine, whereas UN delegates and senior bureaucrats saw it as a cultural right and called for traditional health care to be extended beyond traditional interventions to include cultural activities aimed at enhancing well-being.

No. I haven’t been to any of them [traditional healers], mates of mine have been around but I don’t get out much.

U.A.I M4

Like there’s a few that will just go out and get the bush plants from out in the bush for pain…We don’t discourage it, but we don’t use it as part of our clinic.

HW.A.FG1

Health and the provision of health services were strongly related to culture. The relationship was evident in cultural protocols, such as addressing the role of traditional medicine, and in the delivery of health care.
IV. Perception of disability by Aboriginal and Torres Strait Islander people

The perceptions of Aboriginal and Torres Strait Islander people of what constitutes disability covered three areas: firstly, users of health care distanced themselves from the concept of disability, being reluctant to refer to themselves as disabled. Disability was perceived as an alien concept, often associated with a third person who faced bigger challenges than themselves, or with not being able to do something.

Interviewer: ‘Would disability be a word that the Aboriginal people use? Or do they use another word?’
Respondent: ‘I don’t know. First time I heard of it.’
Interviewer: ‘Do you consider yourself as having a disability?’
Respondent: ‘No. Well, if I can’t work no good to me. I’m finished. That’s about all I can say about the place. It’s not the place, it’s just me, I can’t work.

U.A.I M4

Secondly, disability was seen to be ‘normalised’ due to the high prevalence of impairments. Within indigenous communities, these were particularly associated with hearing loss due to poor living standards and with intellectual disability due to foetal alcohol syndrome

Well 80 per cent did we pick up with kids with hearing loss… I think it was 50, yeah. A huge problem.

SB.A.I F1

It’s a fine line sometimes. Who has got a disability and who hasn’t got a disability, I mean a learning disability …

HW.A.FG1
Thirdly, cultural beliefs and historical views impacted on how disability was perceived. Historical viewpoints indicated that in nomadic times people with disabilities did not survive trekking across country, hence from that perspective it represented a relatively new phenomenon which needed recognition within rural, remote and urbanised lifestyles.

Disability didn’t exist. Either they just don’t make it, because that’s just the way it was, culturally for us. Coming from my ancestors, from my grandfather and where he came from, he walked out of the desert, the Great Sandy Desert to come into Fitzroy, and people had to be strong to keep up with them walking, you know, to Fitzroy. No disability. So it’s that whole how do we mentally change our attitudes and deal with people with special needs.

SB.A.I F2

The spiritual beliefs surrounding disability led to it being viewed as a punishment not only for the individual but for the family.

It is recognised that some disabilities come from accidents or whatever else, but those beliefs also is to do with the spirit world and something that you might have done or your family has done is your punishment that you, you know, may have a disabled child or mental health issues is they have done something wrong, disrespected a custom. Cause we still practise our cultural practices.

SB.A.IF1

Self-identifying as an indigenous person is very important to indigenous peoples, although they fear the negative consequences of such identification. There is a strong cultural divide between how Aboriginal and Torres Strait Islander people and health
workers view what constitutes disability and health, which is influenced by both spiritual and historical factors.

5.2.4. Social determinants of health

I. Overview of the theme
The findings with respect to the influence that social aspects beyond health care had on determining the health of indigenous peoples with disabilities in Australia are now presented. These included political, economic and physical social determinants, such as social disadvantages related to disenfranchisement, geographical location, housing and accommodation, education, employment, discrimination, violence and substance abuse. Substance abuse was particularly relevant, as it was perceived by health workers and senior bureaucrats to be the cause of high levels of disability amongst the indigenous communities across Australia, including Brewarrina. Health workers contributed significantly to this theme, due to their close interactions with users of health care and their familiarity with the everyday issues faced by Indigenous people.

II. Social disadvantages related to disenfranchisement
Senior bureaucrats and UN delegates claimed that the social disadvantage faced today by Aboriginal and Torres Strait Islander people, including ill health, were the consequences of a long history of colonial oppression. Social oppression, geographical isolation and lack of access to social and legal protection were identified as shaping the current disadvantages faced by indigenous peoples. They stated that such circumstances have been particularly damaging to those with disabilities and to their access to primary and specialised health care.

If I have a disability and I have economic resources, I can take care of my
disability or my child’s disability. So …denial over the first 200 years of Australia’s post-colonial history means people (indigenous) are impoverished, people are sick, people are imprisoned, people have low educational achievement, they die earlier, they live with disabilities that are not detected efficiently.

SB.A.IF3

Health workers, senior bureaucrats and UN delegates elaborated on the challenging environment faced by indigenous peoples with disabilities in suggesting that such circumstances have pushed indigenous Australians into a lifestyle that they described as ‘survival mode’. This construct refers to a sense of ‘living for the day’. These participants believed that the ‘survival mode’ is a strategy used by indigenous peoples to cope with severe poverty on a daily basis. They also linked this construct to a history of disenfranchisement, consequences of colonisation and oppression.

It’s a matter of survival for every family member. So whether you’ve got a disability or not, you just move along. That family member gets taken along.

SB.A.IF1

This concept of a survival mode of living was also evident from negative self-perceptions of the indigenous users of health care. A sense of worthlessness and disengagement with community life, including health-related activities, permeated the discourse of users. Their skills, knowledge and experiences, or in other words their human capital, did not give them a sense of self-worth. Feelings of worthlessness, of being discriminated against and being ignored were described, indicating a poor sense of their own human worth, as well as a devaluing of their knowledge and their social and personal attributes. Social and domestic violence was woven through their
dialogue. Health workers equated the need to deal with violence on a daily basis with the reasons that indigenous users focused on the ‘now’, rather than attending to preventative and/or mental health issues.

The negative perceptions that users of health care believed about themselves are illustrated below:

No-one will have me.

U.A.I.F1

When you are out, they treat you like I don’t know what.’

U.A.I.F5

Oh just because I’m in a chair, they see me differently.

U.A.I.M16

Survival living was exacerbated in remote rural communities where disabled services are often not available. Distance and segregation were given as negative influences against indigenous people improving their access to health care and hence their quality of life.

III. Impact of geographic location on the health of Indigenous people with disability

Geographical location was one of the constant challenges faced by users of health care as reported by senior bureaucrats, who indicated that distances within remote rural communities had led to inaccessible health care. The lack of an infrastructure in remote rural communities had a particularly negative influence on indigenous people with physical impairments being able to access medical appointments.
Health workers elaborated extensively on this, by focusing on the lack of availability of specialised professionals and resources in their area, including difficulties in mobilising patients to regional health care services. Such mobilisation, according to senior bureaucrats and UN delegates, was not supported by government policy with a mandate to respond to the challenges of living in rural and remote areas. Users of health care reinforced the difficulties and sense of isolation of those inhabiting rural and remote locations, emphasising that staying close to their families and land was very important regardless of the potential deprivation of services.

Oh they treat me good here (Brewarrina) in hospital, but when you are out (Sydney), they treat you like I don’t know what.

U.A.IF5

Probably in bigger centre, we don’t actually have access to occupational therapists, physiotherapists, any allied health, we hardly ever get any of them visit Brewarrina. They go on numbers, but Brewarrina a small community, so by the time you get your numbers, those people could have left or passed away.

HW.A.FG1

Health workers and senior bureaucrats argued that attracting health staff to, and retaining them in, rural and remote areas had been a major challenge affected by cost of services. ‘Flying in-flying out’ was often the only option available for delivering specialised services; however, irregularities with patient adherence or difficulties in finding professionals often hindered the delivery of this service. Additionally, ‘flying in –flying out’ has been heavily criticised for its short stays, as opposed to promoting ongoing engagement with the community.
We built accommodation for visiting specialists, because it was really hard to get them to come to remote communities. We built some units, which now attract dentists, nurses and doctors, cause they’ve got a good home to stay in while they are there; they usually come for three months.

SB.A.IF1

Building trust and engagement between health workers, other professionals and the local indigenous community was highlighted as very important. Staff in Brewarrina often came from the local areas and claimed that their identity and understanding of the community made them more effective in their jobs. They believed that good knowledge of the traditions and politics of the community helped them to deliver their services in a more culturally appropriate manner.

It’s cultural safety. Feeling safe in your cultural identity. I don’t think we have that problem so much here because 60 or 70 per cent of the staff here are indigenous, and you are not going to come into this health service and not be able to find someone who you feel comfortable with.

HW.A.FG1

Retaining health personnel was pointed out as being very difficult, as once staff gained skills they tended to pursue better paid positions in major cities. The rotation of personnel was an ongoing challenge faced by managers in remote rural clinics and hospitals.

They have to go away for placements, clinical placements and blocks to uni (university), but the majority of their units are done by distance And then most people that go away and go to uni, they don’t come back.
Lack of access to a specialised infrastructure, care and staff created negative barriers to the available health outcomes in Brewarrina. The specific issues relating to locating accommodation are covered in the next section.

IV. Housing and infrastructure

According to health workers, senior bureaucrats and UN delegates, inadequate housing emerged as a major challenge, which has arisen from unhealthy, overcrowded conditions fostering illnesses and leading to impairments, violence and social conflict. Health workers reported that efforts to provide adequate housing tended to be rejected by the indigenous users of health care, causing tensions. Their different perspectives are illustrated by the quotations below:

So many other people live in the house. They don’t want people coming through. They are having a damn good time and they are happy to be living with 15 in there with no flooring. There might have been floor in there but they rip it up.

HW.A.FG1

This is the way I am [live] I am just happy

U.A.I M6

Health workers indicated that they were not in a strong position to challenge indigenous users’ acceptance of overcrowding for fear of being considered judgmental. Additionally, restrictions on the availability of housing in the community led to people being kept in hospital longer than necessary. Senior bureaucrats reinforced the housing issues, indicating that finance from the state and federal government had been limited, inadequate and misused with no improvement in
people’s living arrangements resulting.

There was something like 23-25 people in a three-bedroom house in the town, trashing the government housing in town because there is just too many people.

SB.A.I.F1

Housing and the associated social dynamics arising from overcrowded living arrangements had a profound effect on the health of users. Such effects included an increase in the risk of substance abuse and violence.

V. Violence and substance abuse

Although violence and substance abuse are two separate issues, they were often linked by health workers and senior bureaucrats. Violence was described in terms of overrepresentation of Aboriginal and Torres Strait Islander people in the criminal justice system and high rates of domestic violence among them. Domestic violence was reported to have a major effect on the injuries acquired, particularly to the brain and spinal cord, resulting in disabilities. Violence was also identified as a hindrance to accessing health care because of its effects on a family’s dynamics being linked with recurrent substance abuse

One fellow he’s in a wheelchair, he’s drinking all the time… Drinking all the time and in a wheelchair you know. That’s a bad warning you know

U.A.I. M2

We have the highest rates of alcohol consumption. We have the highest rates in the Northern Territory of violence. We have the highest rates of sexual assault. This is the reality of it.
A second issue was raised with respect to the policy responses to substance abuse. Senior bureaucrats and health workers claimed that Foetal Alcohol Spectrum Disorder (FASD) affects a large proportion of indigenous communities in Australia, but has not been recognised as a disability. Thus, all the funding and support attached to a diagnosis of a significant disability has not been accessed by indigenous families with a member with FASD.

Cause I’m just thinking about one young fella who I know has a physical disability because the mother was drinking…. The FASD should not be looked at any different, so it is a disability, whether it’s physical, mental, it could be cognitively, because it’s the well-being of a person. If you are not functioning very well here in your brain, well you don’t function very well anyway.

Senior bureaucrats linked substance abuse with a history of oppressive social policies that have implications for ill health.

And the policy has been, we'll try and breed Aboriginal people out; that was forced. Or okay, we’ll let them drink themselves to death, give them alcohol. If not, then rations, which [in the past] was a scoop of tea, a scoop of sugar, white bread.

Policy responses to substance abuse based on alcohol restrictions were highly controversial; most senior bureaucrats saw them as manipulative, referring to the double layer of vulnerability faced by people who were both substance-dependant
and part of an oppressed social group. The high rates of chronic alcohol dependency made this cohort extremely vulnerable to political manipulation.

…that is going to be happening which began on the 1st of July, on Monday. People who are picked up three times for drinking too much will be required to do mandatory rehab, rehabilitation. If they abscond from that then … it is sort of criminalisation. It’s a social problem, an illness. Now you are going to have a criminal record.

SB.A.IF1

In addition to the high exposure to violence and substance abuse, users of health care in Brewarrina were greatly deprived of educational and employment opportunities, which are discussed below as social determinants of health.

VI. Lack of education and employment for indigenous peoples with disabilities

The education of indigenous peoples with disabilities was found to be significantly restricted in Australia. UN delegates and senior bureaucrats claimed that the current low literacy rates and lack of provision of education was evidence of the violation of indigenous peoples’ right to education. Senior bureaucrats also highlighted the lack of efficiency and adequate support for disabled students across the education system. These views were corroborated by users of health services as none of them had received a full basic education, hence a big proportion of the interviewees did not possess basic literacy skills.

Nah. When I was out …I didn’t have education. Used to get flogged around all the time, all the time and when I came home here I took it out on my people […] I said I’m not mad.

U.A.I.M2
Just when we are talking about disabilities as well, a lot of our children have hearing and lots of infections in their ear and they can’t hear. So in the education system as well, where you have [indigenous] kids going to school and leaving with very low literacy and numeracy levels.

SB.A.I.F2

This lack of access to education, apart from its implications for health care, was also identified as a hindrance to employment. Most users of health care reported that living on the disability pension in addition to being out of employment never worked, although the value given to employment was not very high.

I can’t, I can’t get up that’s all, can’t work.

U.A.IM4

Respondent: ‘Can I work? No. No I don’t work.’

Interviewer: ‘Have you thought about it?’

Respondent: ‘No.

U.A.IM6

A minority of the users were carers and found this home-based role to be more productive than joining the outside work force.

I just thought I’d so some things for my family you know that’s all.

U.A.IM2

Discrimination and racism were associated with employment, particularly within the narratives of indigenous users of health care.

No the whites, yeah the whites are getting slack. Yeah that has quietened down, the work has quietened down…white people get the jobs …Yeah.
Lack of access to education and employment represented a barrier to indigenous users gaining an awareness of and information about their own health and what was available for their families. Isolation and discrimination also emerged as large obstacles to healthy living. The role of discrimination is explored further in the following section.

VII. Discrimination: fears of white people and racism

A fear of discrimination and racism were strong elements within the indigenous Australian and non-indigenous participants’ discourses. These concepts were often linked to negative historical policies such as the stolen generation, the high death rates of indigenous people in custody, and sexual abuse of children in Christian missions and boarding schools. Indigenous users related how they had experienced differential treatment, particularly concerning the attitudes of non-indigenous people

Good. I know white people, don’t like them, but it’s good to be Aboriginal.’

Interviewer: ‘Do you think Aboriginal people get treated differently than non-Aboriginal people?’

Respondent: ‘Sometimes, sometimes’.

Interviewer: ‘Like in hospital?’

Respondent: ‘Everywhere darling, everywhere.’

Discrimination was reinforced by other participating groups, indicating that it is a big
issue that has not been resolved by Australian laws, policies and practices. Health workers and senior bureaucrats saw the fear of such discrimination as the basis upon which indigenous people avoided seeking medical care. The White Australia Policy, although officially in the past, also surfaced as a reminder of racism:

    You shouldn’t force white medicine on them or whatever without understanding that, you know, their culture and the stolen generation has made them paranoid about all that sort of thing.

    HW.A.FG1

    This country was founded on a white Australia policy so very strong racial views in this country. I think they add to the difficulties of Indigenous Australians.

    UN.A.I.M1

All the negative responses to the social determinants indicators given above combine to cause poor access to health care. A combination of these social issues, negative attitudes and discriminatory policies represent a hindrance to improving indigenous people’s health.

5.2.5 Over-provision versus under-provision of health services

I. Overview of the theme

This theme covered the findings that health care for indigenous users was not available, affordable and/or culturally sensitive. The contributions from users of health care and health workers are dominant within this theme and these are reinforced with respect to regulations and policies according to the dialogue of UN delegates and senior bureaucrats.
II. Is it too much?

The question of whether too much is invested in the health care of indigenous peoples was constantly raised by health workers. They supported the UN perspective of over-allocation of services, seeing service delivery as more of a burden than a benefit. Their argument relied on the notion that resources tended to be wasted. They elaborated on the issues of having ‘too many’ health specialists visiting and/or approaching patients.

Overdoing it. They are overloading (health) funding … Than what is really needed… But it’s like here in Bree (Brewarrina), there is umpteen dozen different organisations here, and really people are almost sort of vying for business because there is so many different organisations.

HW.A.FG1

Health workers also identified over-funding laws causing a high fluctuation in ‘fly-in-fly-out’ specialists, which made patients more reluctant to get involved with health services as they felt over-scrutinised, further stating that having too much is not always positive. They believed that people were ‘spoilt’ beyond their health provision entitlements.

I mean there is so many governments and groups, organisation schools they will offer so much to them… If somebody comes up here and they are very judgemental and trying to be strict with them, they will never go back to that person again.

HW.A.FG1

Although health workers stressed that there was an over-service in some areas, they conceded that there was also a huge need for more specialised health services for
people with disabilities:

We don’t actually have access to occupational therapists, physiotherapists, any allied health, we hardly ever get any of them visiting Brewarrina. So a lot of that, that’s lacking and we have to manage.

HW.A.FG1

In support of the health workers’ opinions, the majority of users of health care reported being fairly satisfied with the level of care. However, they all pointed out unmet health needs, such as acquiring health aids and seeing a medical specialist for their impairments.

My eye is a bit blurry at times, a big bit, not the best for me I’ll put it that way.
Yeah wouldn’t mind a pair of glasses."

U.A.IF1

Interviewer: ‘Have you attended any rehabilitation services?’

Respondent: ‘Nah. No, it’s only a little town. They don’t come out this far.

U.A.IM6

From the discourses on health services it was clear that specialised services, such as rehabilitation services, were not available for people with disabilities. All responses pointed to an urgent need to consider the ‘waste’ of resources that contrasted sharply with a severe lack of specialised health care. In the next section a more detailed analysis of barriers to accessing health services is presented.

III. Support in accessing available services

Patients (users of health care) getting to health facilities emerged as a constant challenge in Brewarrina. Health workers stated that support to get to medical services
is essential but not always utilised. They described this support as a ‘pick up’ service that collected patients from their house and returned them after the consultation. In discussing their role in Brewarrina, health workers raised the issues of health services needing to be prepared to be flexible as the patient may not always be ready to attend, often wishing to re-schedule or to cancel at the last minute. As a result they felt that significant efforts need to be made to remind patients of appointments with visiting doctors and availing themselves of follow up consultations.

You do the referral here, you do everything. Which means organising transport and all those other things...everything is free. They don't pay for anything. And they even get picked up. They pay for nothing health wise, nothing.

HW.A.FG1

The following quotations from users of health services indicate how they have benefitted from this type of support.

Well I only went to Sydney three or four times when I had to go to a doctor, for my leg and arm. Cause I had a friend there that used to work for them [Health Service employee] and used to drive me down.

U.A.IM3

Usually someone comes with me... because they are told to do it so... no only joking. No it's nice to be in with the company.

U.A.IF1

Health workers reported that they felt a lot of unfair pressure to deliver health care tasks beyond what they should be expected to do. This sometimes resulted in users not gaining access to services and also to medication being owed to workers who were stretched in other areas.
I think we probably worry because we know we are getting judged and we’ve got to do it, we’ve got to do our job. That’s probably why we worry more about it than they do, but you worry about individual people. You know, you sort of, you think oh I wish that one would do that, and you do worry about them.

HW.A.FG1

In the next section specific barriers to, and facilitators of, the delivery of primary health care are examined.

IV. Primary health care

According to health workers and senior bureaucrats, primary health care was not utilised to its full capacity and preventive care was not prioritised. Health workers stated that challenging environments interfered with people accessing health care. They stated that users prioritised emergencies and not following up cardiac treatments or improving their diets, for example.

They have a fear of dying, but not preventing...The majority, they leave their medications, they don’t fill their dosage or anything for weeks after and they are suffering from high blood pressure and headaches and bad migraines. Something else like priority, something in the family, it just takes priority straight away over.

HW.A.FG1

On the contrary, users of health care reported accessing primary care and were positive about it with long-term relationships were reported

Interviewer: ‘When do you see the doctor?’
Respondent: ‘Every Friday, Mondays.’
Interviewer: ‘Every week?’
The narrative of health workers indicated that the availability of primary health services was not so much of an issue as was the lack of specialised services. These include rehabilitation, including occupational therapy, which are explored in the next section.

**V. Rehabilitation and specialised health care**

Usually rehabilitation services were not available for the general population in rural and remote areas. This was confirmed by all users and health workers with the latter group being concerned for those users who required rehabilitation to curb the ongoing effects of disability and to avoid, where possible, the development of co-morbidities.

Users would have to move to a bigger town to access rehabilitation services on a regular basis. Moving away from their family, however, was perceived as impacting negatively on a patient’s wellbeing. This perspective was reinforced strongly by senior bureaucrats.

**Interviewer:** ‘Have you attended any rehabilitation services?’

**Respondent:** ‘Nah. No, it’s only a little town. They don’t come out this far.

[to get rehabilitation] people have had to go and live in Alice Springs for up to six to twelve months, away from home, the loneliness.
Rehabilitation services are generally inaccessible in remote rural locations such as Brewarrina. Furthermore, transportation and the frequency of rehabilitation treatments required made it very difficult for users to access such services. The gaps in the services provided and the social environment have a strong relationship with the common health problems and medical conditions, which will be explored in the following section.

VI. Common health problems and medical conditions

The health outcomes of most indigenous peoples with disabilities were particularly poor due to both communicable and non-communicable diseases. Health workers described severe problems with cardiovascular disease and its co-morbidities, particularly renal failure and blindness. Also, loss of hearing due to ear infections and injuries related to violence, as well as the prevalence of FASD, were highlighted as being problematic. In relation to FASD, senior bureaucrats pointed out that a major issue was the lack of official data on its prevalence, but their empirical experience linked it as being co-morbid with intellectual disability in Aboriginal and Torres Strait Islander people. They claimed that until the severity of the problem is addressed, indigenous people living with FASD will not receive the support needed.

"I think at this stage Australia doesn’t really understand the problem [FASD] that we have, even from a public health perspective. I think Australia is behind where other countries are. Something we don’t understand our problem and so therefore we don’t recognise it as a disability."

SB.A.I.F2

The co-morbidity between disability and certain health conditions was recognised and unmet needs for resources were identified. Gaps were also perceived in the areas of sexual and reproductive health care, as discussed in the next section.
VII. Lack of access to sexual health services

The majority of the indigenous Australian users of health care reported that sexual health services were not available to them. This meant not having access to the routine health tests appropriate to their age and gender, such as those for sexually transmitted infections, for prostate cancer and pap tests. This lack of availability is evident from these brief quotations:

Interviewer: ‘Men’s health service?’
Respondent ‘No’.

U.A.IM2

Interviewer: ‘In the services do you get any men’s health attention in the hospitals? Men’s health?’
Respondent: No.

Interviewer: Have they ever tested you for prostate cancer?
Respondent: No.

U.A.IM6

Health workers, however, argued that these services were available on the same basis as for everybody else and maintained that engagement with reproductive health services, particularly contraception, was particularly low within the community in general. A connection was made with potential child welfare benefits (associated with a temporary policy in which the Australian Government was giving a ‘baby bonus’ of $5,000 to mothers of newborns).

Some of the young, thank goodness they don’t get that $5,000 now. But some of the young boys were encouraging the girls to get pregnant so that they could buy a car or a motorbike or something like that. And they would get
pregnant.

Cultural practices could be harmful to sexual and reproductive health. Senior bureaucrats identified that such practices included circumcision of male adolescents, a practice taking place as a part of an ‘initiation’. Details of the safety of this practice were not provided, however it was understood that this ritual occurs in remote rural areas and is conducted by elders of the community.

Well initiation ceremonies I guess is when young boys become men... Usually it's when they are starting to get to 10, 11, 12, it varies, and it's the uncles of the boy that usually have the, are in control of what happens. If the child has a disability it is said to go doctor way, they get to the doctor, and it's about circumcision really.

Sexual and reproductive health needs were reported to be under-served. Lack of effective engagement with indigenous people with disabilities was accompanied by negative preconceptions towards people’s sexual and reproductive health, as well as potential harm due to cultural practices.

Where sexual and reproductive health services were available, their delivery was not successful. Further issues within the health system affected indigenous peoples with disabilities negatively. Such gaps and limitations within the structure of the Australian health system will now be examined.

**VIII. Gaps within the health system**

Senior bureaucrats pointed out that obtaining specialised disability support and health care involved several referrals to general practitioners and specialists, with long
waiting lists and inappropriate out-of-pocket expenses. This process imposed significant structural, economic and practical barriers upon indigenous peoples with disabilities.

His GP refers him to a paediatrician, before your first consultation you need to pay $200 for the assessment. So he’s a low income, low education, person who has a 12-year-old daughter with behavioural and learning difficulties that haven’t been assessed, diagnosed and treated.

SB. A.IF3

Such observations were reinforced by health workers’ frustrations with the demands of an unrealistic bureaucracy.

The barriers are, we’ve said they need to ramp the house and all those things, but they won’t put them there. Bureaucracy won’t put them there because he hasn’t had the OT assessment or because the house is not in his name.

HW. A.FG1

Senior bureaucrats stated that some of the services available to users of health care services were highly inappropriate, failing to acknowledge the cultural background and oppressive history of indigenous people with disability.

I’ve got a (family member) who is 48 and she’s got an intellectual disability and she got sent away to a place for children like her when she was eight years old and she’s been in care since then, living in Perth. It’s just like the stolen generation thing.

SB.A.IF2

Gaps and barriers within the health system exacerbated the lack of access to health
care. Historical, practical and economic constraints prevented indigenous peoples with disabilities from getting the health care, including the preventative and specialised care needed. Denial of these verges on infringements of human rights, which is the focus of the next theme.

5.2.6 Protection of the rights of Aboriginal and Torres Strait Islander people with disabilities

I. Overview of the theme

This theme elaborates on the reporting mechanism embedded in the CRPD and the need for official recognition of Aboriginal and Torres Strait Islander people within the Australian constitution. It covers findings relating to the need to promote an awareness of human rights and the use of existing jurisprudence and legal frameworks, such as the Mabo v. Queensland case.

The perspectives of UN delegates and senior bureaucrats dominated this theme due to their engagement with political issues; the contribution from health workers and users of health care was relatively moderate. Users were mostly unaware of their official human rights and the implications of these for their health, although their discourse often reflected issues raised by both senior bureaucrats and UN delegates.

II. A long journey of legal recognition

Senior bureaucrats and UN delegates believed that the first issue to be overcome by Aboriginal and Torres Strait Islander people is their legal recognition as original owners of the land. Senior bureaucrats reported that Aboriginal and Torres Strait Islander people often quoted the phrase ‘we are not plants’ referring to their status before the 1967 referendum. This phase articulates a history of colonial genocide, disenfranchisement and social oppression, which was supported by indigenous
senior bureaucrats and UN delegates. Their discourse covered civil, political and land rights. They argued the need for a treaty to recognise Aboriginal and Torres Strait Islander people's sovereignty and rights as a means of overcoming the history of oppression and giving self-determination back to Aboriginal and Torres Strait Islander people.

No treaties. Australia was settled as *terra nullius*, a land without people. I was born in 1967. Up until 1967 Aboriginal people were flora and fauna. They weren’t counted in the Census as people. So you can look at me and my lifespan.

SB.A.IF3

There’s been very few constitutional changes since it was set up in 1921. Yeah but I think the Aboriginal people on the platform (of constitutional recognition) are working really hard to try and change that because I mean we’ve got two legs and arms and that and we are not a plant.

SB.A.IF2

A second area illustrating the current oppression of indigenous peoples is the major ongoing violation of their basic civil and political rights, such as lack of citizenship and its implications for public political participation and ultimately land rights.

I remember my (relative) worked for that. I remember growing up seeing my family going with the tin, to get some tea, milk and sugar – that was what they worked for. And that was happening in the 70s….right up until the 70s. So I guess we are just starting. But there is too few of us at the moment.

SB.A.IF1

Professor Dodson did a whole Australia-wide in getting our (constitution)
recognising indigenous people, because we were under the flora and fauna, so
…I mean that was a huge thing that was going around.

However, this discourse of oppression was alleviated to an extent by the legal
recognition of native land rights. The senior bureaucrats and UN delegates defended
this as a most powerful way of improving the health and wellbeing of indigenous
people. They celebrated how the decision of the High Court of Australia, Mabo v.
Queensland in 1992, recognised legally that native title existed for all Indigenous
people in Australia prior to the arrival of the British Crown. This decision has
transformed history for indigenous peoples who look to a better future.

Land rights are central to all indigenous people and where indigenous people’s
lives have improved it’s been when they’ve had control of land. Although we
have had land rights legislation in Australia for 20 years, the land rights system
has not been very good and there have not been good outcomes for most
indigenous people.

Contrary to the hope ignited by Mabo, a minority of the users were aware of the long
historical fight for land rights and reported sorrowfully their loss of hope of ever
enjoying such entitlements now or in generations to come.

You know a lot of people go upside down and everything. So you don’t want to
hear about it (fight for land rights) because you think that nothing really
happened.
Although land rights were perceived as a legitimate and influential way of improving Aboriginal health, it was also recognised that the political representation of Aboriginal and Torres Strait Islander people needed to be strengthened.

III. CRPD and advocacy to protect the rights of Indigenous Australians.

The CRPD was considered to be of major importance for Aboriginal and Torres Strait Islander people. Senior bureaucrats and UN delegates claimed that indigenous peoples are over-represented amongst people with disabilities in Australia and worldwide. Although indigenous peoples are mentioned in the preamble of the CRPD as a protected population, this position could have been stronger if there was an Article on indigenous peoples or if they were mentioned within the binding text. The discourse of senior bureaucrats and UN delegates suggested that the international community is raising awareness of the protection of the rights of indigenous peoples. However, they believed that greater legal protection is unlikely to be obtained in the short-term, due to the ‘confictive’ nature that the ‘indigenous’ concept has within international law. UN delegates elaborated further, stating that colonial states are not keen to recognise indigenous sovereignty. Furthermore, the existence of occupied territories is an unresolved issue within the UN and such political tension interferes with discussions of native rights, indigenous rights and land rights of any nature or located anywhere. Additionally, the UN delegates in this study perceived that there was a lack of political will amongst the Australian delegation, as well as other member states, to recognise indigenous peoples’ rights.

Australia tried to get recognition for indigenous groups. A lot of the times their issue got hijacked. There was support, not strong enough support to get it up into the Convention and in the end we only got it into the preamble…I think it’s interesting, I mean the indigenous position is very complex and there needed
to be recognition, so it was good. We were able to get it up in the preamble, but it could have been stronger.

Whilst the CRPD was negotiated UN delegates reflected that indigenous groups tried but failed to create an Article that addressed the need for their own protection and support. However, since the approval and enforcement of the CRPD, its mechanism has made indigenous issues visible.

My understanding is that there was to be during the negotiations of the Convention an attempt to have a clause or Article in the convention dealing with indigenous persons with disabilities but that was not taken into account. However in a number of dialogues that we have had with countries and we’ve only had three so far, we have had discussions about indigenous persons with disabilities.

UN delegates argued that the reporting mechanisms within the CRPD, have helped or could help to protect indigenous peoples with disabilities. Its potential to do this will be explored in the following section.

**IV. Implementation of CRPD will protect indigenous rights**

UN delegates stated that the implementation of the CRPD will enhance the recognition of indigenous peoples’ issues and the protection of their right to health. They claim that the shadowing reports are a powerful tool for advocacy. They also stated that the Committee on the Rights of Persons with Disabilities highlighted the urgent need to respond to the needs of indigenous peoples with disabilities, and in its response has mandated member states, such as Australia, to provide information on
the health of their indigenous peoples. They claimed that this mandate has set up a precedent through which the Committee and NGOs involved in the shadow report could urge member states to present data on indigenous health, therefore providing visibility and enhancing accountability. This process was perceived to be an effective way of promoting an ongoing relationship between indigenous peoples with disabilities and The Committee on The Rights of Persons with Disabilities.

(Indigenous groups) have got funding now both in New South Wales and at a federal level. So I think they have got greater potential now to get results from the CRPD than say five years ago. They have been active in the process of the shadow report.

UN.A.I.F1

Using the mechanisms embedded within the CRPD, however, remains a challenge. It was recognised that although positive legal changes have been achieved in recent years, the implementation of the principles and mandates of the CRPD is still problematic.

There is definitely room for reform and there needs to be greater improvement in terms of the mechanisms that are available to support people with their legal capacity.

UN.A.I.F1

The CRPD addresses the right to self-determination, the right to culture and the right to the highest attainable standard of health care, which all address the needs of indigenous people with disability, so long as responses to it are made with cultural sensitivity.
I think one can use the Articles (Article 30 Culture) of the convention in those areas, culture, education, health, employment, right to a family, right to marry, as involving delivery in an indigenously sensitive manner or indigenously appropriate manner.

UN.A.M1

The reporting mechanisms within the CRPD were identified as powerful instruments for the advocacy, promotion and legal protection of indigenous rights, although in terms of governance the full implementation of such a mandate remains a challenge. Further challenges raised concerned indigenous communities and the concept and acceptability of the CRPD within them. The following section reviews the incorporation of indigenous worldviews into the CRPD.

V. CRPD and indigenous worldview

UN delegates stated that attention should be paid to the theoretical basis of the CRPD. This was raised in relation to indigenous peoples’ approach to disability. It was perceived that the values of the social model of disability (Kayess & French, 2008; Oliver, 1984) as portrayed in the CRPD, needed to accommodate indigenous concepts of disability. UN delegates defended this by stating that the CRPD has been able to bring together the lived experiences of disability from culturally and socially diverse perspectives including high-income countries and the ‘developing’ world. This capacity to unify could also protect indigenous peoples’ views on disability.

That was the reason it got support, because it was able to bring developing countries along with it. There was still tension between Europe and the industrialised, other industrialised countries and the developing countries in supporting the convention. The West wanted a traditional non-discriminatory
model. It’s a hybrid convention as a result. It contains both social development and non-discrimination mechanisms.

Most users of health care reported a very limited or no understanding at all of the concept of rights and, therefore, of the CRPD, although the need for respect was recognised.

Interviewer: ‘What do you understand by human rights?’

Respondent: You’ve got to respect people aye, don’t care what colour they are, you’ve got to respect them.

Although the CRPD is a western construct, it is a unifying document that could extend its ability to protect to indigenous peoples with disabilities across Australia.

5.2.7 Summary

This study indicates that there is a need to acknowledge the effects of colonisation upon Aboriginal and Torres Strait Islander people. Poor health outcomes and high rates of disability were linked to a history of social oppression. Being indigenous, or a ‘Blackfella’, appears to have a strong influence on people’s health. Being indigenous increased the probability of experiencing ill health and living with a disability.

Being a ‘Blackfella’ is often utilised as self-identification by Aboriginal and Torres Strait Islander people. This phrase is also utilised politically to show reliance and great pride in being an indigenous Australian. However, appreciation of indigenous human capital and self-esteem was generally low. The combination of these two factors often led to social isolation and disengagement amongst indigenous communities, which was then correlated with a lack of hope and a ‘survival mode’ of
living; this was perceived as a coping mechanism in very challenging environments.

Social factors, outside of the health system, greatly affected the health of Aboriginal and Torres Strait Islander people. People living in Brewarrina were less likely to receive any specialised health services or rehabilitation. Additionally, users of health care reported high levels of unemployment and lack of education and housing that put them at risk of contracting diseases as well as a high prevalence of violence and substance abuse. Racism and prejudice, embedded within the legislation and history of Australia, were perceived to be still major factors in causing a fear of discrimination by indigenous Australians, which led to a thwarted relationship between users of health care and health services.

The availability of primary health was reported as sufficient, but poorly utilised by its users. Health workers stated that the level of support required by users of health care could be overwhelming for under-staffed health settings. This understaffing plus a lack of ability to retain well-trained personnel imposed further constraints on remote rural areas, which resulted in health workers having to improvise in under-resourced and challenging environments.

There was a high prevalence of disabilities, from cardio-vascular diseases and FASD to injuries acquired as a result of domestic violence, which was triggered by a lack of preventive medicine and specialised care. Other areas such as sexual and reproductive health were reported to be inefficient.

The CRPD has been perceived to be particularly important for Aboriginal and Torres Strait Islander people, due to an over-representation of indigenous peoples with disabilities requiring and restructuring the health services. It became evident that health is connected with all aspects of community life. The comprehensive approach
of the CRPD was seen to provide a strong legally binding framework through which to address the root causes of ill health, thereby working towards protecting the rights of indigenous peoples with disabilities to the highest attainable standards of health in Australia.

5.3 Mexico

5.3.1 Introduction

In this section the findings regarding the case study conducted in Mexico are presented. The five core themes that have emerged from the data analysis are discussed. In the first theme the Mexican roots of the CRPD are explored; the second theme is focused on poverty and its relationship with accessing health care. Within the third theme the health needs of the Purepechas in Riviera del Lago are presented. Here the point of contact with the health system is analysed, as well as the most common health conditions and the provision of medication and disability-specialised health care. The health needs of indigenous people with disability were strongly related with cultural practices and traditional medicine. The fourth theme is pluralism in Mexico; the relationship between wellbeing and the pluricultural nature of Mexico was analysed (see Figure 4.3.1).
It is important to note that, as outlined in Chapter 4, a health worker was interviewed outside of the focus group as he was not able to arrive at the focus group meeting on time. However, given his long-standing role in the community and his insider knowledge (not shared by any other health practitioner in the area) a semi-structured interview was conducted with him. This contribution comes under the ID code of (MD).

5.3.2 Mexico and the CRPD

I. Overview of the theme

Mexico was the country that originally proposed the idea of an internationally binding treaty to protect the rights of persons with disability. The UN delegates and senior bureaucrats interviewed all played a role either at the domestic or the international
level. As a result, their narratives are dominant in documenting the reasons why Mexico promoted the development of the Convention, while the discourse of health workers and users of health service showed little or no awareness of the Convention,

II. Mexican government’s engagement with the Convention

UN delegates and senior bureaucrats confirmed that the CRPD coincided with the election of Vicente Fox as Mexican President in 2000. Fox brought about a revolutionary transition within Mexico, moving the country from a one-party dominant regime with the Institutional Revolutionary Party (PRI) having ruled the presidency and senate in Mexico for more than 70 years. Fox’s support of the CRPD was perceived to be a political strategy to create a historical landmark in Mexico and to give Mexico a profile in the eyes of the international community. UN delegates described the CRPD as a political flag for a democratised Mexico.

The new government was interested in building a country based on equity of access, without discrimination, without any type of exclusion, with no physical barrier, so that all Mexicans were able to have a dignified life, as they are entitled to. A committee was created and with this mandate the claim was made at the UN.

UN. MX. I M2

UN delegates and senior bureaucrats stated that Gilberto Rincon Gallardo, a Mexican politician with the lived experience of disability, played a very significant role in the legitimisation of the CRPD proposal within the international community. They also highlighted the role that NGOs in Mexico played in representing people with disabilities and in advocating for the CRPD. They were also liaising strategically with organisations outside the country.
I was participating in the process. I was working in the office of promotion representation and of persons with disabilities. It was a project from the last administration where we organised 500 different NGOs.

UN. MX. I M1

Although the CRPD was seen as a reflection of political change focused on the rights of minorities such as people with disabilities, this was not inclusive of indigenous peoples, as will now be explored.

III. Addressing social inequity of indigenous peoples

In addressing the need to alleviate social inequity UN delegates and senior bureaucrats stated that President Fox was responsible for presenting the Convention as a solution to a problem faced not only by middle and low income countries, but becoming more relevant to high income countries. Vicente Fox was recognised for his role in framing the Convention in terms of social justice and economic development, whilst other countries saw it as promoting social inclusion and accessibility.

Europe did not want our Convention. They actually arrived with another convention because they concentrated on the theoretical side of it. They were fighting for different things. But practically (in low income countries) there is a lot to be done.

UN. MX. I M1

Fox’s emphasis on the UN Convention being grounded in social justice was reflected in health workers’ statements that indigenous peoples were over-represented amongst those with ill health, poverty and ultimately disability. Senior bureaucrats and UN delegates stressed that the need to address this indigenous overrepresentation did not have enough political support to be heard easily within the context of the debate at the UN. The recognition of indigenous issues was highly controversial due
to the international tensions associated with indigenous land rights and the lack of recognition of indigenous sovereignty.

Look when we were negotiating the creation of the convention, there was a moment when things turned ugly. This happened when we started talking about sexuality and indigenous peoples. Everyone was saying ‘you don’t talk about those things’, cannot talk about indigenous rights with the international community

UN. MX. I M1

UN delegates and senior bureaucrats stated that the lack of political will due to country-based conflicts was exacerbated by the vacuum of disaggregated data on indigenous peoples. The lack of reliable data excludes indigenous peoples from protection and participation in society. Indigenous peoples had been denied the right to participate democratically in Mexico.

Our democracy must open up without restriction to the participation of indigenous peoples. We must enhance laws and policies that protect the history and spirit of our indigenous brothers and sisters.

UN. MX. I M2

Data from indigenous populations gets updated every 10 years, but we have the Census for general data, and today we have indicators measuring self-identification and language, but this is very recent. We know municipalities that speak indigenous languages, more or less, but we don’t have disaggregated data for them.

SB. MX. IF4

UN delegates and senior bureaucrats said that collecting data allowed them to develop and monitor support. They highlighted the need for data on indigenous
peoples and also on persons with disability. The potential of the CRPD to solve this problem was identified by the Mexican delegation. One of many unique features of the CRPD is that it mandates the collection of data on disabled people. Article 31 of the CRPD requires states party to it to ‘collect appropriate information, including statistical and research data’ in order to create and implement policies that give effect to the Convention. The Article also outlines the standards to be used for the collection, maintenance and use of this information (Stein and Lord, 2010). UN delegates and senior bureaucrats believed that this was a step towards the democratisation of social policy and a way of making invisible populations visible.

It was the synergy behind the convention. But we wrote Article 31 here. Everything about information and we commented on the rest of the articles. But unfortunately policy-makers do not take it seriously but that’s the solution.

SB. MX. IF4

UN delegates believed that the international community does not know how to deal with people with disability who also belong to ethnic minorities, such as indigenous peoples, and elaborated on the ineffective manner in which Mexico has dealt with its own Indigenous population. In their narratives they elaborated on faulty government systems that segregated this population and the need for political protection of indigenous peoples.

The National Commission for Indigenous Peoples does not even have the technical capacity to deal with the population with disability; they turned the issue to the National Disability Council. The Council turned the issue back to them because they don’t know what to do!

UN. MX. I M1
Systematic exclusion of minorities among populations with disability has to be solved at the federal level as well as the state level. It is a chain of disadvantage because we don’t have effective laws and policies in place, although the constitution has changed, and we now have the Convention. This change is not enough.

SB.MX.I M5

Mexico has very recently amended its constitution to recognise itself as a pluricultural country. UN delegates and senior bureaucrats saw this change as a response to the history of political and social oppression of indigenous peoples. The changes in the constitution were perceived very positively, however they saw the need to design policies in line with such changes. They believed that a way to evaluate the implementation of these changes is by monitoring the access to social services, as well as recognising indigenous sovereignty and customary laws within the Mexican legal system.

To be a system based on justice we have to recognise inequity. By recognising it, it will also alleviate it. Indigenous peoples must enjoy the protection of justice as well as access to social services such as education. They often face discrimination due to the lack of recognition in historic regulation, language and social systems. The recent changes in the Constitution must be used to address this discrimination and solve it as the only way to work towards equity.

UN.MX. I M2

UN delegates and senior bureaucrats reported witnessing ongoing struggles and violations of basic human rights, some of which occurred within the health system. The fight for fundamental rights such as the right to life, deinstitutionalisation, legal capacity and reproductive rights seems to be contentious for people with disabilities
in Mexico. These areas are core principles of the CRPD. Such ongoing violations are not uncommon in other contexts, such as in Europe (Quinn, 2009). UN delegates and senior bureaucrats talked about their experiences in facing or finding out about major violations to people’s fundamental rights. It became evident that in some cases action was taken, whereas in others no legal investigation was mandated. This indicates a lack of responsibility and a tolerance of abuse contrary to their legal duties. They reported that anecdotal and personal information received regarding the violation of fundamental human rights was treated very casually.

There is a severe mismatch in the policies promoted by the Mexican government and their implementation. There is a need to straighten the monitoring system to be able better to evaluate the progressive realisation of such policies and laws. The following section will elaborate on issues specific to the mandate of human rights and its operation in health delivery.

IV. Human rights and health practice

The groups most informed about the Constitution and CRPD were the bureaucrats and UN delegates with health workers and indigenous people with disabilities indicating a lack of understanding about such changes. However, the narratives of these latter two groups validated the notions of inequity raised by the bureaucrats and UN delegates.

UN delegates and senior bureaucrats recognised that there was a trend towards greater recognition of indigenous rights. They stated that there was a new movement that needed to be reinforced with effective policies. They also stated that laws and policies had in the past tended to ignore indigenous rights. The issue of disseminating the new legislation was addressed, as well as the need to engage with indigenous
peoples more effectively. Health workers and users of health services admitted having minimal or no understanding of the idea of human rights and/or of legal entitlements. A minority of the users of the health service had an educated opinion about human rights.

We are now talking about the rights of indigenous peoples. I think, well… they don’t trust us. Because we have seen discrimination, great disparities in the way they are treated.

HW. FG 1

Interviewer: ‘Have you heard about the Convention on the Rights of Persons with Disabilities?’
Interviewee ‘No’
Interviewer: ‘Have you heard about human rights?’
Interviewee: ‘Well I know there have been some talks but I have not been there. So no, I have not actually heard about it.

U.MX.I 5

Health workers and users of health services focused on everyday struggles faced within the health services. Although health workers had limited awareness of changes in the constitution or of the existence of the CRPD, their narratives elaborated on their experiences of working in under-resourced services. They related the practical conflicts arising from inefficient systems of government funding, as well as the inability to attend to patients with whom they were unable to communicate.

Many people would be able to go to the other hospitals and that would allow us to dedicate our medication and resources to people who are not entitled to any
other service, but at the end of the day they come here and we have to provide services even if it means we are leaving other people out.

Health workers talked about some indigenous users of health services having a limited understanding, or what they considered to be a misunderstanding, about what constituted human rights. They believed that some claims were more to do with guarding their territory than gaining access to better health.

‘They get hold of (the idea of rights) that is to say “because you have to do something for me” like it was an obligation. It is not like that...they are abusive, I think that’s why they act in certain ways. Like “don’t mess with me” “do not come over to my territory, this is mine! Don’t make yourself welcome”.’

However, the perception that indigenous people with disability did not have an understanding of rights was contradicted by them, as illustrated in the following quotations:

People with a disability have rights. We have the right to be included within the community, and to receive services like everyone else.

It’s to speak up when we are being treated unfairly or there is something wrong. We have to defend ourselves. It’s like that is it not? This is what I understand.

It’s to respect someone.
In the literature on the right to health for indigenous people a significant link has been found between racial discrimination from health workers and poor health outcomes (Harris, Cormack, Tobias, Yeh, Talamaivao, Minster & Timutimu, 2012). Comparing the findings of this research with this link assists in the analysis of the attitudes of health workers. Their understanding of human rights, on occasion, showed an antagonistic position toward indigenous peoples, along with a limited appreciation and/or respect for indigenous values and traditions.

You may some indigenous peoples around, like in the markets. They are quite abusive, they think that everything has to be given to them, it's because the government is supporting them, but I believed they are out of place, they are not well informed.

HW.MX.FG1

Health workers acknowledged, however, that inter-cultural training had been put in place to create awareness of human rights including indigenous rights and the rights of persons with disabilities.

Last year we had some training regarding the rights of indigenous peoples. The course was called ‘interculturality’, within it we talked about how to empower people about their rights as we interact with them.

HW.FG.1

Health workers also reported having done some training on disability; however, they had no information on or understanding of CRPD. In response to this, the UN delegates and senior bureaucrats believed that the lack of dissemination and implementation could be traced back to its centralisation within the Mexican
There is a federal law and states have overlooked the specific action that they have to be taking to protect persons with disabilities, according to the CRPD.

SB.MX. I. M4

The narratives of the participants showed recognition of the challenges brought about by the introduction of the CRPD. In the next section the impact of poverty on accessing health care for indigenous peoples with disabilities is covered.

5.3.3 Struggles for fulfillment of human rights in a context of poverty

I. Overall view of the theme

The right to health is recognised in the Mexican Constitution of 1983, yet it has been denied to the majority of the population (Knaul, González-Pier, Gómez-Dantés, García-Junco, Arreola-Ornelas, Barraza-Lloréns, Sandoval, Caballero, Hernández-Avila, Juan, Kershenobich, Nigenda, Ruelas, Sepúlveda, Tapia, Soberón, Chertorivski, & Frenk, 2012). The research findings presented here indicate that inequities in Mexico have a significantly negative impact upon access to health care for indigenous peoples, including Purepechas. Purepechas suffer from poorer health outcomes than the general non-indigenous population (Frenk, 2012; Instituto Nacional de Estadística, 2012). There was a consensus across all the participating groups that poor health outcomes among indigenous people with disabilities was associated with: a lack of education; a lack of job opportunities and development; inadequate housing; disenfranchisement; discrimination; disempowerment and the increased vulnerability of these communities. In effect, these are what are commonly referred to as the social indicators of good health (Marmot, 2005) and they were deemed to be not readily visible within the indigenous population. The description of
social deprivation reported by the users of health care with disabilities is validated within the Mexican data set by the perceptions of health workers, senior bureaucrats, and UN delegates.

II. Link between poverty and disability

It was stated that people with disabilities faced much more severe barriers to health care than their non-disabled peers. All participants acknowledged, from their differing angles, the crucial role that poverty plays in trying to construct equity for indigenous peoples with disability. UN delegates and senior bureaucrats focused on the poverty faced by individuals with disability, whilst health workers highlighted the financial limitations within the health system. In comparison, indigenous peoples with disability described the influence of both:

> I would pay the doctor, were the charity that God provides me with (referring to earning begging).

U.MX.IM4

> In Mexico if you think about disability, it’s a discussion about severe poverty.

UN.MX.IM1

All participating groups believed that poverty has a major role on indigenous health. This was corroborated by the narratives of users, which described severely restricted access to health care, as well as no social assistance and an inability to afford specialised services privately due to poverty. These responses to the different areas of their health affected by poverty are examined in the following sections.

III. Unreported indicators regarding ill health

The information on Indigenous health in the Michoacán region where Purepecha
were interviewed is scattered. There was no systematic database documenting health outcomes over time, or currently, within specific communities. The information available via the Census, health system and anecdotal practice reflected the overrepresentation of indigenous people within the population suffering from ill health, including the high incidence of indigenous people with disabilities that could have been prevented, and with congenital disabilities. Health workers stressed that there is very little known about this dimension of ill health among the indigenous peoples.

We have measured poverty nationally…we know that people with disability are over-represented in catastrophic expenditure in health, this data arouse by from the National Census, we know Indigenous are most vulnerable

SB.MX. IM4

We have a major issue regarding indigenous health, not just in Mexico exclusively. Responding to indigenous health involves various government agencies, and between everything else, disability is not a priority when you face those levels of poverty.

SB.MX. IF3

The degree of poverty experienced by indigenous peoples was common knowledge to the UN delegates, senior bureaucrats and health workers. These three groups of participants showed awareness of how underreported these indicators of ill health for indigenous peoples were. In this next section the burdens that lack of insurance and low incomes represent for indigenous peoples with disabilities will be discussed.

IV. Household catastrophic expenditure on health care

Household catastrophic expenditure on health care refers to ‘individuals having to
invest more than 30% of their household income in health care’ (Xu, Evans, Kawabata, Zeramdini, Klavus & Murray, 2003). Most users of health care interviewed reported having no access to comprehensive social insurance; but a minority were protected by ‘Seguro Popular’. ‘Seguro Popular’ is a system of social protection introduced during Vicente Fox’s government. It is a scheme of funded health care for families, who had been previously excluded from social health insurance (Frenk, González-Pier, Gómez-Dantés, Lezana &Knaul, 2006).

All of the users of health care within this research project were excluded from traditional health insurance schemes (IMSS, ISSSTE and private schemes). The IMSS and ISSSTE would normally cover those employed by a registered company. Most of the indigenous users interviewed were not covered by these, as they were part of the non-salaried population. They were all either self-employed or permanently out of the labour market. Health care for indigenous peoples with disabilities relied on families paying out-of-pocket expenses, especially for primary health services and medicines.

They vast majority of people with disability are poor people, often working in high risk activities like construction, agriculture, mechanics or as carpenters. But those are very risky activities and things happen and they are not protected financially, and they have not got insurance.

SB.MX. IM5

I did not (have insurance), but know I have ‘Seguro Popular’ because my wife had a baby and we signed up.

U.MX.IM5

The limitations of comprehensive health insurance negatively affected the capacity of
users of health care to obtain medication, preventive care and ongoing health services such as rehabilitation. Poverty reaches 51.3 % of the population in Mexico, meaning that over half of the country lives on an income of $1.25 US/day or less. Indigenous peoples with disability are over-represented amongst those facing extreme poverty, meaning those with an income of less than a $1.00 US/day (World Bank, 2013). Having a family member with a disability with great need for health care burdens families by impacting upon their limited financial capacity. The negative effects of catastrophic expenditure have a negative effect upon other members of the family.

I tried to explain to her, we don’t have money at the moment, but we’ll be fine.

She cried, I talked to her we’ll go to Morelia and get your medicines.

U.MX.IF6

Health care expenditure emerged as something that added to the impoverishment of the households of indigenous people with disability. Limited access to other social services, such as education, also caused financial constraints and social immobility.

V. Lack of access to education

The lack of education of indigenous people with disability emerged as a major theme throughout the data. All four participating groups agreed that indigenous peoples with disability are extremely poorly represented within the education system in Mexico. Different rationales were put forward to explain this negative trend. UN delegates and senior bureaucrats related this issue to financial constraints, whilst health workers related it to the fact that families prioritise educational opportunities for their non-disabled members and their disabled member had the role of carer prioritised over access to educational opportunities.
The senior bureaucrats and the UN delegates related the lack of access to education to the financial constraints caused by poverty. Their narratives stated that people with disabilities in Mexico have been segregated from the education system for many years. Such segregation was considered to be more potent amongst the indigenous peoples. They perceived that the costs involved in accessing an education stopped indigenous people from doing so. The cost referred to expenses such as those involved with transportation. They also stated that available resources put up barriers at the school level and prevented the inclusion of people with disability. The limited availability of teaching tools and resource development specifically for students with disabilities was not encouraging for the participation of students with disability in mainstream education. However, senior bureaucrats and UN delegates saw education as a means of overcoming poverty, leading to greater political representation by and social mobility of indigenous peoples, including those with disability. They also raised the point that where there was financial assistance for their disabled children families took advantage of it to help meet the overall needs of the family.

A condition to be part of the ‘Progresa’ (social development programme) is to be enrolled in primary school so the family get some funding, access to health insurance and so on; it’s of great benefit to people!

The relationship between education, disability and poverty is exemplified below.

There are a few of us [people with disabilities] at the council, we didn’t go to school, because we cannot even get there, or we have parents that are overprotective, or the transport for us is very expensive, we are hardworking people but in general terms very poorly educated. I am the 0000.1 percent of the population.
There were three children in that family one of them came to school … and they said ‘my mother has nothing to give us and I cannot have breakfast before coming to school’. A scholarship was allocated to this family for six years which was all her primary school years; I thank God we have that funding for families.

This theme of sharing resources from scholarships and other government social development schemes was more important to users of health services than their concerns about access to education; their first priority was to support their family’s overall needs.

Dad was unwell, so I left school to look after him, my mother was there, but she encouraged me to stay at home as the teacher would not mind.

Users and health workers agreed that indigenous people in Mexico tend to express the view that they are more appreciated at home than within the education system. This trend was carried over into other areas such as employment, with the vast majority of users of health care working informally within the family. The repercussions of this on acquiring health protection through employment will now be explored.

**VI. Employment and access to health**

There was a connection between employment and health in various spheres: firstly as described above, the accessing of health insurance though worker protection; secondly, by the provision of financial capacity, and lastly as a facilitator of social inclusion. This relationship between health and employment emerged from the
discourse of all groups of participants. UN delegates and senior bureaucrats were aware of the need to develop policies and laws that foster the inclusion of people with disabilities in general. They were concerned about the limitations of such legislation in rural and remote communities where most of the indigenous population in Mexico live. Elaborating on this concern, health workers were aware of the great need for indigenous people to be employed in the area. They perceived employment to be a way of achieving the financial capacity for people with disability to gain greater access to services. These views were reaffirmed by indigenous peoples who reported feeling disempowered, discriminated against and devalued with respect to employment in the wider community.

Health cannot be thought of outside having a dignified job, with good remuneration. There is also no future or space for democracy if there is not promotion of the economic development of every member of society.

UN.MX.1M2

I applied for the job, submitting all the documents required, even including an application form with a photo as they asked. They told me that they have not received my documents and that I did not comply with the application procedure correctly. I guess they ripped it up and threw it away. They think that we are not trustworthy people, they don’t like people like us [people with disability].

U.MX. IM5

Users of health care felt that the possibilities of working formally outside of their family situation were limited. The fear of discrimination and lack of engagement with the wider community could be linked with this attitude. Being outside of employment was also related to the denial of the insurance protection provided by employment and of the benefit of having a regular income. The fear of discrimination went beyond
employment and was seen as a widespread systemic issue discussed in the following section.

VII. Discrimination within and outside the health system

Discrimination played a very strong role in the discourse of all groups of participants. UN delegates and senior bureaucrats addressed the issue of the double layers of discrimination experienced by an Indigenous person with a disability. They addressed the influence that discrimination has had on accessing health care and other social services. One of the senior bureaucrats interviewed expressed negative attitudes towards indigenous peoples, which were shared by the majority of the health workers interviewed. A minority of the health workers, however, opposed this point of view and addressed the need for health personnel to work without prejudice; these polar positions are exemplified below.

We have a problem with indigenous people because they are ignorant, that’s where everything starts. Who is going to reach those communities of ignorant people...they often believe that they cure themselves. They think that everything is in your mind.

SB.MX.IF2

There are various doctors who have a humanist approach to health delivery, they showed empathy to people with disability. But there are more who do not care... they don’t want to see them because they think they are wasting their time.

MD. MX I M1

Discrimination associated with being indigenous, living with disability and gender was
reported. All participants put forward the notion that women were particularly disadvantaged. The narratives obtained from UN delegates, senior bureaucrats and health workers provide an overview of the issues faced by indigenous women in general. This perception was corroborated by the fact that most participants interviewed were males, as often woman have to seek approval to engage in any social activity, such as attending the information sessions and the interview. The two females interviewed attended the interview with a member of their family. They both reported having experienced domestic violence and demonstrated fearful attitudes towards males.

Discriminatory attitudes towards indigenous people with disability were found both within and beyond the health system. Women were particularly affected by the issue of discrimination, which was exacerbated by domestic violence. Of relevance to this is the issue of housing, covered in the next section.

**VIII. Housing and transport**

Inadequate housing conditions emerged as a core barrier to health care. Housing issues included dangerous housing arrangements, remote locations and inaccessible facilities. All groups of participants contributed to this sub-theme; however, the discourse of users of health services and their narratives of poor housing and the constraints imposed on them by requiring accessible transportation were dominant. Housing and accessible transportation were often linked; however, they both presented particular challenges independently. Users of health services were affected by inadequate housing arrangements due to poverty. Risks included faulty settings - their accommodation was often unsafe to be inhabited - generally it was located in highly dangerous surroundings and was very isolated. Transportation was described as costly and not often available to users of health services. The complexities of
moving from their residence to medical facilities often prevented accessing health services.

Yes, it hurts, I was injured over here, it happened like 5 years ago, a pile of rock fell through the roof in the house we used to live in.

U.MX.IM4

I go to the clinic by the lake, once there sometimes they tell you that you have to come back tomorrow for another think, or to get medications. I feel bad because I cannot come back.

U.MX.IM2

The combination of poor housing and inaccessible transportation imposes a barrier to accessing health services. These two elements typify social determinants of poor health. In the next section the ways in which poverty is reinforced by a lack of political action are addressed.

IX. Political instability and the need to rely on NGOs for health care

According to senior bureaucrats and UN delegates the political instability of Mexico played a major role in the lack of creation and implementation of laws to protect indigenous peoples with disabilities. Such instability affects all areas of social services including health care. They stated that each time the government changed, new governments tended to dismiss previous protections and impose new agendas. They related the struggle to implement the CRPD and other health care strategies such as the ‘Seguro Popular’ to the fact that they are creations of previous governments, and regardless of their efficiency, new governments are not willing to give them any weight or funding. Indigenous users of health care corroborated this view, and reported relying on NGOs for the provision of health care, prosthetics, wheelchairs and other social services.
When they left (last government) there was a vacuum on the topic and now they are against us and you say well ‘how could this be so bad?’

UN.MX.IM1

With the communal radio and the support of the NGO we got a wheelchair and I went and delivered it myself.

U.MX.IM1

Social factors outside of the health system imposed serious barriers to the health care of indigenous peoples with disability. Those geographical, physical and social barriers had a strong relationship with poverty. Most of the indigenous peoples with disability interviewed did not have comprehensive health insurance; and the cost associated with their specialised health needs represents a major financial burden to their families. Education, housing and employment were also lacking, with discrimination also having a negative influence on people’s confidence in accessing health care.

5.3.4 Health needs of Purepecha people with disabilities in Rivera del Lago in Michoacán.

I. Overview of the theme

Indigenous peoples expressed the view that the current coverage by the Mexican health system has not completely fulfilled their health needs. Firstly, they highlighted areas in which urgent action is required such as reproductive health, obesity-related illnesses and early interventions. Secondly, they stated the need to understand indigenous people’s health values with respect to traditional medicine and cultural views on disability. Indigenous peoples in Riviera del Lago also reported major issues due to the lack of effective communication with health personnel. The narratives of
users of health care services and health workers dominated this theme. The views of users and senior bureaucrats give an insider’s view into the decision-making processes behind the allocation of funds. The UN delegates contributed modestly to this theme (see the sub-themes covered in Figure 4.3.4 Health needs of Purepecha people with disabilities in Rivera del Lago in Michoacán).

II. The first point of contact for Purepecha people

Most health workers and senior bureaucrats stated that indigenous people tended not to access primary health care regularly at ‘western’ health services. Primary health care referred to basic or general health care provided by family practices, paediatricians, internal medicine and gynaecologists. Health workers stated that tertiary health care or specialised consultative care is more likely to be the first point of contact with the health system for indigenous peoples. However, this trend did not appear where pluricultural settings were available, as the people tend to be more engaged. Pluricultural health settings refer to health services where traditional healing has been incorporated and users of the clinic may pay for health care by trading for it by carrying out general maintenance or gardening. The discourse from health workers based in pluricultural health settings indicated that indigenous people engaged very well in all the health centre’s activities; such activities included public talks on health and community life. It is important to clarify that pluricultural health settings are generally located within indigenous communities, and practitioners are willing to travel to see their patients, whereas mainstream services are located in towns and cities where medical personnel are less likely to provide home visits. Pluricultural settings achieve engagement beyond the addressing of health issues, as they invite people to collaborate on the maintenance of the building, gardening and other services.
They come here to weigh their children, to get vaccines and so on, they also take care of the botanic garden as a means of payment. People do not pay but contribute somehow to the clinic, by cleaning and so on.

MD.MX.IM1

They come if they have appendicitis and they are dying with pain, or have a problem with the vehicle as those people generally die, as it’s difficult! They would say ‘please doctors’, but what can you do when the vesicle has exploded! They should come before that, but they don’t.

HW.MX.FG1

Primary health care and preventive care provided by western medical settings tended not to be utilised by indigenous peoples with disabilities other than for major emergencies. Pluricultural settings were perceived as being much more effective in terms of creating early and long-lasting engagement with indigenous users of health care. This and various other positive outcomes of such a setting will now be outlined.

III. Pluricultural health settings

Pluricultural settings were mainly set up by the Mexican Institute of Social Insurance (IMSS) more than two decades ago. The aim was to provide access to health care to uninsured people living in rural remote communities. As they developed various indigenous elements were incorporated into this type of health provision. IMSS Oportunidades’ unique feature is the incorporation of traditional medicine. IMSS guidelines on the use of traditional remedies for general practitioners have been published in a manual of cultural protocols and it has also been a vehicle for delivering training to traditional practitioners. The outcomes of this programme were perceived very highly by all groups of participants. The extent of the coverage of IMSS opportunities is limited, however, senior bureaucrats and UN delegates stated
that strategies have been put in place to reproduce this model and expand it over more regions in Mexico.

We provide the research behind these concepts so medical practitioners understand what is actually true. For example, for maternal health people in Oaxaca gave opossum soup to women. We investigated and found out that opossum soup is actually very rich in calcium and iron so it’s very good for women who just gave birth.

SB.MX.IF3

Pluricultural settings were seen as an effective response to the cultural and health needs of indigenous peoples. Traditional practitioners emerged as being central to the mediation between communities and western medicine, as illustrated bellow.

IV. Traditional healer practitioners

The majority of users of health services stated that they tended to rely on traditional medicine for their health care. The decision was based firstly on geographical proximity, as most of the traditional medical men were available to indigenous peoples with disability within their home location. Secondly, the costs of these services were often minimal and the traditional medicines prescribed were more accessible and affordable. Thirdly, users reported having long-standing relationships with traditional medical practitioners, as they were often community members.

I prefer traditional medicine, because of what happened to me. I have high blood pressure, diabetes, since I take traditional medicine I’m much better, it is just good for me. It’s not like the other medication is, fix you something but it damage you something else.

U.MX.IM1
Health workers and senior bureaucrats were aware of the lack of trust, people’s preferences for traditional healers and the lack of connection with communities. The government had used small strategies in order to incorporate traditional practitioners into mainstream services with positive results. Senior bureaucrats urged Congress and other political organisations to roll out this model of cooperation.

The traditional midwife will come and receive training with the doctor, they received information, courses and now they come regularly to the medical services. They bring back information from the community, and we bring them some financial support.

MD.MX.I M1

In Paracho (Town in the Purepecha region) the government set up a rehabilitation clinic with a general practitioner and a traditional healer, people went there to see the traditional healer not the GP. The GP actually quit, and you need a medical professional to be responsible so that service was closed down.

SB.MX.I M5

Most health professionals reported an indifference to the lack of trust that indigenous peoples have towards health personnel. Their overall attitudes were discriminatory although they did acknowledge the efficiency of traditional medicine.

Talking about indigenous health is such an interesting topic, but they don’t see it that way, they don’t want to see it, that we have a different concept of health more positive, they have to change the way they think, we can’t force them, but they are wrong.

HW.MX.FG1
Although pluricultural settings and traditional practitioners have achieved successful relationships with indigenous communities, reporting efficient adherence, their coverage and implementation remain limited. Some of the most needed health services and interventions were not covered by the provision offered by these, meaning that indigenous communities are in severe danger.

V. Most needed health services

Users of health services reported their serious concerns about obesity, gastrointestinal disorders, maternal health and rehabilitation and the prevalence of chronic degenerative illnesses was particularly high. Additionally, the majority of users reported never having had a reproductive health consultation or discussing sexual and reproductive health with medical personnel. Health workers corroborated this perception that people with disabilities in general had a reluctance to talk about reproductive health. However, they also brought up the risk of sexual abuse faced by people with intellectual disability.

Interviewee: ‘She cannot get married or have boyfriends or anything, that’s not for her.’

Interviewer: ‘(NAME) do you know anything about sex or women’s health?’

Interviewee: ‘She knows a little, because they (Interviewee and her sister) watch Casos (a Mexican soap opera) and she knows, that she does not have to talk to strangers, or let them touch her, or get into people’s cars, or even get money or anything like that.

U.MX.IF3

Sexual health was clearly a very complex area and health workers reported that reproductive health tended not to reach female patients if it was only available from a male doctor. Staffing constraints did not always allow for female doctors. Sexual
health for people with intellectual disability was highly stigmatised and health workers tended to infantilise its intended recipients.

She wants to hug men, and she had an obsession with males in general, and she'll complain and say that it hurts (genitalia), so we came up with a strategy: we all have magic dust, and when she talks about it we tell her that we have the magic dust and all the pain will go away.

HW.MX.FG1

This paying inadequate attention to sexual and reproductive health was connected with problems of maternal mortality in the Purepecha region, as well as the violence and abuse suffered by indigenous women with disability. Women were particularly vulnerable, relying on the approval of husbands/fathers/male relatives to assist the doctor. Senior bureaucrats stated that action was being taken in response to this problem.

It’s is a very hard issue, it’s hard for people to care for their family member with a disability and then once they mature and are at a reproductive age, it is easier to deny it than face it. We have produced some informative materials and there are people working with communities, but it’s hard.

SB.MX.IM1

Indigenous people stressed the need for their views regarding health provision to be respected. Overall, traditional healing is welcomed more than western medicine by indigenous peoples and senior bureaucrats stated that combining them is the most effective way of engaging with indigenous communities. Health workers, however, reported their reluctance, and a negative attitude, towards engaging with indigenous
beliefs about health. It appeared that the pluricultural mandate by the Mexican constitution is not representative of practices across the health system, or of the attitudes of health workers and some senior bureaucrats. The vision of pluriculturalism will be analysed further in the following theme.

5.3.5 Mexico as a pluricultural country

I. Overview of the theme
The need to recognise indigenous cultural health rights emerged as a core theme within this research. Being Purepecha and talking about identity was a very powerful discourse among users of health care. Senior bureaucrats and UN delegates believed that recent changes to the constitution must be used to refine health care policies and practices. Indigenous people’s health disadvantage needs to be resolved by creating policies that reflect the pluricultural ethos of Mexico. Within this theme the role of the Purepecha identity is discussed, along with the perceptions of health and disability of the Purepecha people. The call that participants made to incorporate their views on health policy into the mandate of Article 2 of being a pluricultural country is also elaborated upon. Also, elements attached to contemporary Purepecha identity are illustrated.

II. Being Purepecha today
Being Purepecha and recognised as a member of the Purepecha community was very important to indigenous peoples with disability. They acknowledged that language, tradition and intermarriage have influenced the Purepecha Community in Patzcuaro. However, indigenous identity was utilised more like a political flag, in defining being Purepecha as having a strong attachment to the land, family, cultural traditions and community life. Their narratives acknowledged race, language and
geographical location as part of their identity with a strong focus on a sense of belonging.

I am Purepecha, indigenous Purepecha a race of indigenous peoples, with long standing tradition...the community would not reject you they welcome you.

UN delegates and senior policy-makers reinforced the political and legal importance that self-identification has in contemporary Mexico. They also acknowledged the long history of social struggle that indigenous peoples have faced to obtain legal recognition under Mexican law. They believed that these legal entitlements are far from being enjoyed by every indigenous person in Mexico. They highlighted the need to transform these legal principles into practice by the democratic representation of indigenous peoples. They elaborated on the legal and political influence that indigenous peoples’ self-determination and sovereignty have on the design and delivery of services by the state.

Indigenous peoples have been discriminated against and encounter very serious barriers to accessing the justice system and other social protections, the constitutional recognition of their, language, traditions and customary law must bring equity. I really hope this brings equity and social justice.

The concept of being indigenous was based on preconceived and limited definitions by senior bureaucrats, but this does reflect the way in which indigenous identity has been treated within the Mexican system.
A population was considered indigenous if peoples stated that they had an indigenous language spoken at home but now we also have indicators for self-identification.

Senior bureaucrats recalled the process achieved by Sub-Comandate Marcos and the EZLN. They referred to the leadership and the capacity to utilise the domestic and international community to bring the topic of indigenous sovereignty back to being priorities of the Mexican government. They distanced themselves from the notion of violence, but they recognised the legitimacy of their claims and the need to foster indigenous leadership.

What we need is people in Congress who will fight and defend indigenous peoples; people who have indigenous roots, family connections, someone who has a personal connection, but it is greatly complicated.

Being Purepecha was related to a sense of belonging to the Purepecha community. Being Purepecha was viewed as a political flag; a way of establishing a connection with the land and the people and of taking a social position. Indigenous people addressed the changes and influences that Purepechas had historically undergone, and equally how the legal perception of indigenous identity had changed within the Mexican government.

The participation of indigenous peoples politically in policy-making was perceived as the most effective way of responding to the needs of indigenous peoples. Participants recalled the positive effects that indigenous leaders had had on Mexican society, referring to particular leaders such as Sub-Comandante Marcos and his movement.
advocating indigenous rights.

Respecting indigenous rights and the mandate of the Constitution was also related to the translation of such rights into culturally adequate medical care and the views of indigenous people on health and disability. The expectations and barriers in this field will now be explored.

III. How Purepecha people see disability and health

The data that emerged from interviews and focus groups indicated that there was a major mismatch between the perceptions of users of health services and health workers. This lack of understanding extended to the indigenous concept of holistic health and disability. Users of health services stated that resolving the spiritual cause of their impairment was very important and helped with alleviating its physical symptoms. Although aware of the medical causes of their impairments, they placed great importance on looking at the spiritual healing aspect of them.

It was probably because of the eclipse, we had an eclipse when I was pregnant, and this thing happened. But my husband drank a lot and she is the seventh of ten children...Who knows! But I love her and people have to accept that she is like that.

U.MX.IF3

Most users of health services focused on their contribution to their families and communities and not on their impairments. An ability to contribute in some way to their family and community allowed them not to be viewed as disabled. Some participants stated that having impairments placed limitations on their abilities to do certain things, but they were not disabled as they could to do other things.
Disability, it's like when people tell you that you cannot do a thing! But not here (own community) people don't tell you that, they'll help you if you are struggling, and that’s it! They (community members) don’t want me to feel bad, they just help me and that’s it. This is just normal it is the way I am.

U.MX.IM5

The term disability was not only controversial for users of health services; senior bureaucrats also described how difficult it had been to design an instrument to measure and define disability nationally and internationally. They acknowledged that the international community had taken cultural differences into consideration, incorporating them into the recommendations made by the Washington group (The Washington Group on Disability Statistics was formed as a result of the United Nations International Seminar on Measurement of Disability to The World Health Organisation). They stated that the logistics of the application of such a recommended statistical instrument are unrealistic given the financial constraints on the application of the Mexican census. The census is the only instrument for measuring disability nationally. Senior bureaucrats are aware of the severe limitations on capturing statistics on disability within indigenous peoples.

We know culture is culture and indigenous culture differs from mainstream Mexican thinking. The Washington group’s advice added 18 indicators more to the standard group of indicators regarding disability in order to understand responses of people, it is called a cognitive test… But with our time and constraints with the census we can do that.

SB.MX.IF4

Senior bureaucrats also stated that the difficulties in defining and reporting disability affect the allocation of funds for indigenous people with disability. Disability tends to
be severely underreported and this is exacerbated by the way in which the indigenous population is measured. Until very recently the indigenous population were those who reported speaking an indigenous language. Since 2011 (INEGI, 2011), the census also asks for self-identification.

Well if you are to allocate resources for example in IMSS Oportunidades...because we are looking to put the funds where they are needed, but disaggregated data regarding vulnerability of those population was not available.

**SB.MX.IF4**

Cultural differences between users of health services and health workers have negative effects on communication, although it is known that pluricultural settings and practices are more effective. The lack of official data on indigeneity and disability has hindered the allocation of resources. Although methods of data collection have been modified, their implementation remains limited. This gap in the available information is related more to bureaucracy and the infrastructure and is not representative of the strong sense of indigenous identity that emerged from the users of health care.

**5.3.6 General summary**

Participants within this case study in Mexico perceived that the fulfilment of the CRPD will contribute to achieving a better quality of life for indigenous peoples with disabilities. Senior bureaucrats and UN delegates highlighted the challenges that must be addressed in order to comply with the principles of the CRPD; these include Article 31 on statistics and data collection. They also referred to the implementation of recent constitutional amendments to enforce non-discrimination law and policies.
Senior bureaucrats and UN delegates also described the CRPD as a political strategy initiated by Vicente Fox in order to engage minorities with his new government. This was viewed positively, although it attracted greater resistance from other political parties. They strongly agreed that indigenous peoples need a greater representation within policy-making organisations if change is to be achieved.

The majority of the health workers demonstrated a lack of understanding of indigenous cultural health practices. Their discourses often referred to indigenous cultural practices in a derogatory manner. However, some health workers who worked in pluricultural clinics were welcoming of them and worked in collaboration with traditional healers. This strategy was described as successful and effective in achieving long-term engagement with indigenous communities, as they offered convenient and affordable care. In using this model health practitioners and traditional healers exchange practices and knowledge in order to provide health care to communities. This group demonstrated a very limited awareness of human rights in general and none at all of the CRPD.

Similarly, users of health care reported a limited awareness of human rights and particularly regarding CRPD. They reported that they faced major challenges due to poverty, discrimination and lack of representation. The narratives of this group often referred to the social barriers imposed by their financial limitations. They are highly unlikely to have formal employment, a full basic education or to be protected by insurance schemes. Most of them relied on financial support from families to receive health care.

Being recognised as Purepecha was very important for these indigenous peoples and they defined this identity on the basis of social and political affiliation rather than on
racial determination.

5.4 New Zealand

5.4.1 Introduction

In this section, the findings from the case study conducted in New Zealand are presented. The level of social deprivation varied across the three selected countries which in turn led to the diversity within each sample, with the New Zealand sample having people with a higher level of education and professional employment. Data collection took place in Auckland, Wellington and Dunedin. Most senior bureaucrats and UN delegates were based in Wellington; users of health care were interviewed in both Auckland and Dunedin; health workers were interviewed in Auckland.

An important differentiating factor between New Zealand, Australia and Mexico was the representation of Māori at the political and bureaucratic levels. A significant proportion of the senior bureaucrats and UN delegates were Māori. Additionally, most users of health care were members of advocacy groups as well as human rights and anti-discrimination movements, such as internal self-advocacy movements (Te Roopu Taurima) and the Nationwide Health and Disability Advocacy Service. Also, a significant proportion was highly educated with a profound understanding of human rights and of the CRPD. The views of Māori participants across all the groups tended to be very similar, particularly on the issues of sovereignty, and of Māori identity and culture. This could be interpreted as an ideological trend driven by promoting the respect of the rights of Māori. However, different approaches, concepts and levels of awareness were identified.

Another difference between New Zealand and the other countries sampled is that Māori health issues are high on the political agenda. Most participants showed great
concern for Māori social deprivation and particularly for those with disabilities. All groups of participants reported dissatisfaction with the way in which Māori issues had been addressed in the past. In contrast with the other two case studies none of the participants referred disrespectfully to Māori or Māori culture. The data analysed led to the identification of four major themes. The first theme covers the relationship between Māori sovereignty and the health of Māori with disabilities. In exploring Māori sovereignty the participants’ views focused on the implementation of the Treaty of Waitangi and the effect that this has had on fostering improvements to Māori health. The second theme refers to the relationship between social deprivation and colonisation and the third theme covers the availability, accessibility and affordability of health care. The fourth theme indicated how the CRPD could be used to improve the health outcomes for Māori with disabilities. Figure 5.4.1 provides a graphical representation of the themes covered.

Figure 5.3 The presentation of the findings of this case study covered four core themes
5.4.2 Māori sovereignty and health of Māori with disabilities

I. Overview of the theme

The health of Māori with disability was strongly related to Māori sovereignty. This relationship implies a need to encourage the New Zealand health system to be respectful of Māori self-determination and sovereignty. Within this theme Māori engagements with public political life and the role of Māori in decision-making within the health system are also explored. The Treaty of Waitangi was central to the discourse of all participants, as it was considered to be the most important legal document for Māori. All participating groups contributed to this theme, but a proportion of highly educated Māori within the four groups dominated the narrative, offering a representative viewpoint.

II. Promoting Māori sovereignty

All participants from the four groups acknowledged the need to respect and observe the principles of the Treaty of Waitangi with reference to and including the health system. They all supported the proposition that if the quality of Māori life is to be improved, the fulfilment of the Treaty must be translated into social equity. All the Māori and non-Māori believed that the Treaty principles must be embedded in all legislation to prevent them being breached. Users commented on the abuse of the Treaty as this was related to loss of land and the effect of this on citizenship.

Once you had lost the land you became less of a citizen [even though] the Treaty was signed.
Bureaucrats acknowledged that the Treaty could be safeguarded with the introduction of the Treaty of Waitangi Tribunal.

We have a process to rectify Treaty breaches over the years through the Treaty of Waitangi Tribunal. There are a couple of claims to the Tribunal saying that successive government policies have undermined Māori ability to be sovereign people or to be treated equally as other New Zealanders.

SB.NZ.IM4

Māori sovereignty is considered to be at the centre of all Māori civil, political and economic rights. Senior bureaucrats, UN delegates and health care workers linked social inequity with a long-standing history of inefficient engagement by government with Māori sovereignty and the Māori community. They emphasised that fostering the involvement of Māori across all levels of decision-making within the health care system will be the most efficient way of achieving successful policies. Some Māori believed that current structures of governance, including decision-making within the health system, were more of a hindrance and that the answer lay in self-determination. This position was held across all participating groups and was strongly expressed by both users of health care and by senior bureaucrats.

The key thing is getting organisations to change the way that they see people, see their issues and greater open mindedness in being able to accept that the system doesn’t know the answers necessarily... so let us determine our own solutions, be self-determining, so that's what Māori are saying.

SB.NZ.I.M2

An alternative viewpoint was expressed by some Māori senior bureaucrats who
claimed that although Māori have recourse to protection under the Treaty this often had not been put into operation, resonating with earlier colonial practices.

Māori pretty much lost their ability to make money, to do the resources, to live independently, to function in their own way and that took 20 years, it wasn’t until the late 1880s that the wars stopped and that was all over the Treaty breaches. The Treaty breaches started in 1842, two years after the Treaty was signed and then the first arguments started against the British.

Participants from the four groups of participants believed that the New Zealand Government has an obligation to foster Māori sovereignty and self-determination, as non-compliance is seen as undermining the mandate of the Treaty of Waitangi. Most participants claimed that New Zealand’s recent history demonstrated a lack of commitment to honouring the Treaty, pushing Māori affairs outside of the political agenda, thereby fostering inequity. A sense of renaissance of the Māori culture and inner strength appears to be powering up the rallying of Māori towards equity, as outlined below.

III. Māori resilience and their ‘renaissance’

Resilience was a characteristic of the history of the Māori people and their fight for sovereignty, and of the way in which they had overcome social oppression and illness. Māori elaborated on their construction of resilience and linked it with their pride, history and ancestral ties, which have helped people to focus on recovering the sovereignty of their land and overcoming social deprivation. Within the four groups of interviewees, Māori participants linked their own capacity to cope with oppression and
abuse with the ‘Māori renaissance’. This was described as a cultural and political movement that pursued the resurrection of Māori culture and sovereignty, with a rebirth following a long and negative history of oppression.

They’ve held onto their stories, their way of life in the face of I suppose cultural oppression and for over a century and a half there has been an emerging renaissance I suppose, an unstoppable movement …unstoppable.

Māori users of health care and policy-makers reported that they have to fight social and political oppression on a daily basis, in order to re-establish Māori sovereignty. The narrative of participants revealed a sense of pride in being Māori.

I describe myself as being Māori because I’m brown skinned. A lot of people talk about it’s the worst of black people, there’s a lot of racists out there, in our society. They should accept people for who they are. Yeah move on with life and help other people out like myself. I describe it as well I’m proud to be Māori, I’m proud of my culture. Yeah it’s good.

The renaissance of Māori was also attached to the re-configuration of what it means to be Māori today, which will be examined next.

IV. Māori identity and health

Being Māori today has a social and political meaning. Being Māori was associated with blood ties; ancestries and with a socio-cultural approach to life. Being Māori was
also often associated with ‘being brown’ and with the te reo Māori language. Māori participants believed that their identity had been shaped by their whānau, iwi, hapū and their whakapapa. Intergenerational relationships and a strong sense of belonging were core elements of Māori identity.

I’m Māori, but because of my grandparents and their grandparents, cause they’re a mix. Our ancestors, they were full-blooded Māori. You get Māori today, we are mixed.

U.NZ.IM2

Identity and self-identification were related to the right to self-determination. Māori from each group of participants stated that the right to self-determination was a priority. Users of health care stated that being respected, acknowledged as a Māori and being able to enjoy their culture freely was important. Māori values were reported to be a fundamental part of Māori health and wellbeing.

Māori health has to be looked after in a Māori way, Māori services understand people and their whānau.

HW.NZ.FG1

Being seen as individuals but also their families, their tribe or their mob or their group that they belong to is central to who they are.

SB.NZ.IM3

Respect for, and acknowledgement of, Māori identity was raised within the four groups of participants. Nevertheless, there is a limited cultural understanding of various aspects of Māori, such as their views on disability. Participants reported that there is a lack of information available to health providers on the Māori discourse on
disability, which will be now discussed.

V. Māori discourse about disability

The users of health care stated that the Māori philosophy on disability is different from that of non-Māori. They see impairments, whether physical, sensory or intellectual, as part of people’s individual uniqueness, and not as something unnatural, disabling, or pathological. They stated that the uniqueness of each person is celebrated in Māori culture and argued that people’s bodies, minds and spirits are part of a continuum going beyond their temporal existence. This view was compared with Durie’s (2004) concept of the ‘Te Whare Tapa Wha’; a construct comparing good health to the four sides of a house and prescribing a balance between spirituality (taha wairua), intellect and emotion (taha hinengaro), the human body (taha tinana) and human relationships (taha whānau)’ (p.183)

Users of health care believed that the terminology used by health professionals and disability services is problematic as it does not acknowledge Māori health views. Users of health care did not identify themselves with the word ‘disability’, describing its use as alien to them, some even find the term offensive. However, they addressed their impairments and challenged the term disability and its imposition on the Māori community. They interpreted disability as a western construct and a current manifestation of ongoing colonisation, if they were to comply with it.

As a Māori woman well I don’t identify myself as disabled. I find that word a negative, disgusting deficit word. I don’t know why anybody would want to dis my ability, it’s that simple. Especially the fact that I’ve achieved so much in my life.

U.NZ.IF1
Acceptance, integration and inclusion do not seem to be an issue for those with impairments within the Māori community. Those with disability reported feeling more included in their Māori community, sensing a different attitude towards their impairment outside of their whanau. Even non-Māori interviewees stated that inclusion for people with disability is better executed among Māori communities than across non-Māori communities.

Across Māori, blindness was more accepted...as you are, you weren’t tried to be cured of that. See (it) an integral part of who we are and not something we necessarily want to change.

SB. NZ.IM1

Furthermore, impairments were linked to cultural practices. In some cases senior bureaucrats and UN delegates showed their concern that traditional beliefs could lead to negative attitudes surrounding people with disabilities, but this did not emerge from the users. The cultural aspects or causes of their impairments were seen as a natural process. They indicated that it was important for them to understand the cultural aspects and causes of their impairment.

I remember there was a wee boy who was born and lived for maybe seven years and he was seen as a gift to his whanau but his mum would say he was always meant to be here for a reason and I always felt sorry for him because I thought you’re just here to be you.

U.NZ.IF4

Users of health care did not identify as people with a disability, they were not welcoming to or positive about embracing such terminology. Cultural meanings of health and disability were perceived by many to be better expressed in te reo Māori.
Language was seen as a fundamental instrument for transferring Māori knowledge, and it was argued that the importance of it was not always honoured. Further insights into this argument are provided in the section below.

VI. The role of language

Te reo Māori is an official language in New Zealand. Its recognition is linked to the projection of a Māori world view as this may not always be encapsulated when translated into English. Māori participants highlighted the need to be able to speak and learn te reo Māori. They also stated that it is essential to use te reo Māori to transfer traditions and cultural practices relating to health and disability. Māori users of health care involved in advocacy said that te reo was a tool for engaging effectively with Māori in a way that legitimised Māori sovereignty. Language was described by all Māori as being at the heart of Māori culture, social rituals and ultimately of community development and social justice.

Article 30, (CRPD) absolutely I can see that they talk about culture. Think they talked about language quite strategically because of our own language that we want to hold onto as well as sign obviously.

Honouring the Treaty of Waitangi was seen as a way of overcoming Māori social disadvantage. In honouring the treaty, participants referred to the importance of Māori values protected in the Treaty such as the use of Te Reo and respect for Māori views on health. Their identity as Māori people was very important for Māori; it meant a connection with their ancestries, pride in their history and a political affiliation. As a political group Māori have recently recovered strength – termed the Māori renaissance as noted above. However, it was perceived that in general Māori are far
from achieving equity, and systemic social disadvantages still result in alarming rates of ill health.

5.4.3 Social determinants of health

I. Overview of the theme

Within this theme health and colonization are addressed. The effects that the social context has on dictating the health of Māori with disabilities is elaborated upon, including: the lack of access to education, housing, employment and of official statistics. Māori and non-Māori participants linked social deprivation with colonization.

II. Experience of colonisation

Most Māori from the four groups and some Māori and non-Māori senior bureaucrats described colonisation as being devastating and disruptive to the crucial bond that indigenous people have with their communities and their land. They stated that although the Treaty of Waitangi protected Māori people from colonisation, the current disadvantages faced by Māori reinforce its ongoing effects. Recovering from colonisation was connected with recovering land rights. Māori participants within all groups emphasised that the right to own Māori Land, was linked to their whakapapa (Genealogy) and e reo Māori.

The Māori and non-Māori participants claimed that the negative effects of colonisation included: population decrease, ill health, discrimination, land disposition, unemployment and poverty. The senior bureaucrats addressed the urgent need explicitly to acknowledge colonialism within legal frameworks along with other areas of non-discrimination legislation and policy in New Zealand. This proposal was seen as a way of recognising the negative social, economic and political effects that colonialism had on Māori people. This point was supported by Māori who often
reported feeling oppressed by a non-Māori government. In discussing the attitude towards Māori a senior bureaucrat summed up its effects:

There are different issues around Māori, they experience both racism and something I describe as colonialism, which is a word we don’t use in the discrimination sense to the same extent. We don’t put colonialism alongside racism, sexism, disablism, those things and I think it’s not just an impact on an individual, it’s enduring, it’s ongoing the effect of that.

SB.NZ.IM1

Another issue raised by senior bureaucrats was how current health policies have been patchy and inconsistent, lacking full recognition of Māori cultural identity and land rights. Māori users of health care ratified this view, calling for a review of policies to accommodate Māori cultural systems.

But the systems we design, the procedures we follow, the policies we write are all geared to mainstream kiwis and like I said before, the kiwi world view well if you’re with us, you’re a good Māori, if you’re not well then you’re obviously one of those other Māoris, you’re a protester or you’re a drunk, that’s how they see us.

SB.NZ.IM4

Participants perceived that social deprivation has been imposed by colonial hegemony. Its relationship to social deprivation is now examined

III. Social deprivation

Senior bureaucrats, UN delegates and Māori users of health services stated that Māori people are a socially oppressed group in New Zealand, particularly those with
disability. They perceived that despite recent improvements, the health outcomes for Māori are significantly poorer than for non-Māori. Māori tend to have poorer access to health services and their average life expectancy remains lower than that of non-Māori. All participants believed that being born Māori increased their chances of being poor, illiterate, unemployed and sick. Māori with disabilities were perceived to be at a greater risk of living in severe poverty. All four groups of participants concurred that the negative social trends experienced by Māori had created a vicious cycle of poverty and advocated for interventions in health care.

If you take any individual age group, Māori are more over-represented than non-Māori in terms of disability statistics. Every single age group but in total numbers, if you’re just going on a numbers basis, Māori is slightly under-represented and that’s because Māori die on average about 10 years younger at a guess.

The data revealed that there was a strong perception linking being Māori with the experience of severe social deprivation due to poverty. Such disadvantages were also perceived as being embedded within social structures and systems of governance and progress is hindered by the lack of robust data leading to tailored interventions, as explained below.

**IV. Lack of reliable statistics about Māori with disabilities**

Senior bureaucrats and UN delegates remarked that not enough information and statistics have been collected on Māori with disability. Lack of data was seen as making their health needs invisible at the policy intervention level, regardless of the rhetoric of human rights instruments, such as the CRPD. Invisibility also hindered the potential benefits from international and domestic laws, policies and services.
You actually need to understand your client population in a way that tells you, okay why are we getting Māori over-represented in this area ... We don’t have that level of information, to have that sort of thorough analysis of the problems.

The lack of reliable data has great impact not only on planning for health services, but on the access to a broader range of social determinants, as exemplified by education, which is discussed below.

V. Lack of access to education among Māori

Senior bureaucrats, UN delegates and users of health care perceived all levels of the education system to be highly restrictive for Māori with disabilities. These restrictions were perceived to prevent people from gaining the skills and training required to get a well-paid job, as well as from gaining information about social and medical benefits. They also perceived that the school system has not been responsive to the principles of the Treaty of Waitangi.

Users of health services were divided between two groups: one comprised those who were highly educated with great expertise in human rights, and the second people with a significantly lower level of education and literacy, but who were very active within advocacy groups and in their own communities. Regardless of their qualifications all users of health care reported negative experiences with respect to accessing the school system, particularly caused by bullying and discrimination. In many cases these negative experiences were referred to as character-building; however, for some it caused them to leave the education system, hence denying them the health checks often available within the school system.

Māori senior bureaucrats and UN delegates also perceived that the school system
was unresponsive to Māori values and the Treaty of Waitangi. They stated that *kura kaupapa Māori* schools are limited as is educational support for Māori students.

What do the numbers tell us, education poor success rates for Māori kids it’s shocking. We would outstrip the *pakeha* heaps by under-achievement. So people are starting to, ooh maybe we should sort that out, do some special things for the Māori kids and just in reflection they shut down over half the Māori schools in New Zealand over the last five years and mainstreamed everybody and it’s just getting worse.

Non-Māori senior bureaucrats challenged this viewpoint and said that the education system was up to CRPD standards and had been welcoming of Māori. Nevertheless, it was recognised that there was a low representation of Māori at all levels of the education system.

Going forward then where we’ve got (need for) real on-going realisation to occur around all those things like services, health, education, social, economic, cultural ...changes are needed still.

Lack of education was perceived to be a barrier to other services and to employment opportunities. These relationships will be analysed further in the following section.

**VI. Poverty traps and job opportunities for Māori with disabilities**

The combination of poverty and living with a disability was perceived by users and senior bureaucrats to be a major cause of social isolation. Being Māori and living with a disability was often associated with being at greater risk of poverty. They elaborated on the poverty traps that have perpetuated negative health outcomes, such as
constraints in finding a job in their communities where they could also access health care. Users of health care stated that access was limited due to the availability of services and where it is available moving location could jeopardize ongoing specialist treatment. They were trapped in a cycle where access to specialized health care was interrelated with low paid employment opportunities.

I think of (working in) other areas, but the thing is sometimes like the waiting list is so long (waiting list for a medical specialist) to get in, it’s really hard. Sometimes you can’t get in when you need to get in straight away I can’t take the risk of being in services that can’t deal with emergency needs or high medical care.

U.NZ.IF1

Users of health care stated that obtaining a regular income apart from disability welfare could break poverty cycles. They also put forward that finding flexible work opportunities, which are adequately paid, was very difficult for disabled Māori people. All the participants agreed on the complexities underpinning the status of poverty, as well as the lack of effective responses from the government.

Employment was a divisive issue amongst participants; almost half were employed and the other half unemployed, but they all agreed that New Zealand has a very restrictive labour market for Māori people with disabilities. They said that jobs for people with disabilities were hard to come by.

Interviewer: ‘And you will stay in Auckland or you will go back to…’

Respondent: ‘I will most probably stay in Auckland ‘cause there’s not much jobs up North. I don’t think up there, you either go fishing, hopping on a
boat, do fishery, or what’s the other one oh forestry workers. But that’s way up North. There’s not that many jobs.

Some qualified users of health services stated that the lack of disability awareness in specific professional fields forced people to dismiss their qualifications and look for new careers in ‘welcoming areas’. New training often led to obtaining a qualification within a ‘disability friendly’ labour market irrespective of their personal interests or previous experience. For those who had acquired a disability as an adult, skill transferability was described as deficient, regardless of their level of education. Most people were unable to continue with their previous occupation after they acquired an impairment and this issue affected the majority of the users.

Yeah but it took me like, when I first got hurt I couldn’t move for five years but I just kept pushing it, I went back to MIT, it’s like a university to do a management diploma on call centres, because I was an engineer before I got hurt then I had to change to a different way of life so I had to go back to school again. Learn something new and get a job.

The lack of accessible jobs and restricted health care was seen as perpetuating poverty and ill health for Māori with disability. The link to housing is outlined in the next section.

VII. Inadequate housing

Users reported that there is a relationship between ill health and inadequate housing. Inadequate housing was linked with poverty and the limited choice of housing. The
majority of Māori service users with physical impairments stated that income restrictions did not allow them to access suitable housing and/or housing that was located in a community of their own choice. Where housing was available for Māori it was in socially disadvantaged areas. Also Māori participants indicated that they ideally prefer to live in the same area as their extended family (whanau), part of their cultural tradition.

You can’t afford to have a house that’s air conditioned or a house that’s been given insulation, a healthy house so the people up there are very unwell. Here there’s a lot of our Māori Pacific Island peoples. It’s actually a well-known area for prostitutes this area.

Although gaining access to their own choice of housing emerged as a difficulty, some participants, particularly those with intellectual impairment, who lived within service settings were satisfied with their living conditions, as illustrated below

Interviewee: In our whare, like our house, the house that I live in.
Interviewer: Yeah how is it?
Interviewee: It’s good, it’s awesome because you get up and do things. We work, I work. I’m also the foreman of the boys.

Having an adequate standard of living and housing is highly valued by users of health care, as is accessing community services, which is explored in the following section.

VIII. Challenges due to distance and transportation

Distance and accessible methods of transportation emerged as challenges for the
sample of users of health care. Lacking a means of transportation often stopped them from being involved in community activities and interfered with them accessing health care. All participants with mobility restrictions stated that an appropriate means of transport in either the rural or urban setting was often unavailable, unaffordable or unreliable, with only about one in ten buses accessible. Taxis were perceived as providing the most adequate door-to-door service, but the price was too high with a reliance on a third person for keeping appointments more common. A significantly low proportion of users were vehicle owners, most claiming that the cost of buying and running a car, inclusive of insurance, was an obstacle to community engagement.

I’m having a bit of trouble with the insurance company they call like ACC but they’re always putting hurdles, I’m entitled to it but they won’t sort of help you get there.

U.NZ.IM5

The cost and limited availability of accessible public transport has a negative influence on the health outcomes of Māori with disability. Issues with transportation and barriers arising from it were also triggered by negative attitudes towards Māori. The effects of racism and discrimination will be analysed further in the following section.

IX. Discrimination and racism

Racism was particularly relevant to health as most Māori users of health care reported having felt discriminated against. This was in the form of one-on-one verbal or physical abuse and unfair treatment, which had a negative effect on their relationship with health settings. Users of health care often saw that non-Māori had benefits, connections and support that they themselves did not and although
legislation existed it was not effective in providing equal opportunities. This mismatch was a barrier to Māori with disability engaging positively with health services.

I should have the right to health regardless of economic status, gender, age, disability or ethnicity. I’m guaranteed that right under the Human Rights Act in New Zealand and the UN CRPD and the Declaration and the Treaty and the Universal Declaration on Human Rights. All of those documents say to me that I’m supposed to have access to primary health care. The reality is different.

Users of health care described experiencing long-term discrimination, leading to negative self-perception, but nevertheless showing pride in their Māori identity.

A lot of people talk about it’s the worst of black people, there’s a lot of racists out there, in our society. They should accept people for who they are. Yeah move on with life and help other people out like myself… I’m proud to be Māori, I’m proud of my culture. Yeah it’s good.

Institutionalised racism was reported to exist by health workers and policy-makers. They reported feeling vulnerable when dealing with Māori issues with the state. Different institutional barriers were described, including: hostile governance systems lacking support for Māori with disability; poor access to health benefits; barriers within governance to experiencing cultural elements that contribute to their wellbeing. The Māori with disabilities interviewed had often found support from unofficial avenues and networks outside of the state infrastructure.
They’ve told me there isn’t any help for me to get to a small thing like getting to a cemetery where I can’t get there, I miss out on my funerals and things like that, tangis. Then my mate, pakeha, he got sort of like a four wheel drive vehicle, a small sort of six wheel thing that was offered to him. There’s little things that I find outside the system through my mates.

U.NZ.IM5

Users of health care reported that being a Māori with disability was negatively perceived by society and they elaborated on the barriers faced every day, such as, negative attitudes, lack of accessible public buildings, and limited work placements.

With public services anyway; it’s hard to put my finger on what they need to change a bit for the disabled. Especially like me going to an office and I can’t get up there.

U.NZ.IM5.

Most Māori from the four groups of participants reported feeling discriminated against, either for being Māori, or on the basis of living with a disability. Some Māori had internalised this and spoke very negatively about themselves or other Māori people.

Interviewee: ‘Well it’s just like saying to another Māori boy how would you like to be a doctor, he’ll say the same thing, he’ll say no. The only reason why I say it is because you’ve got to have the right skills.’

Interviewer: ‘You don’t think Māori would be that skilled?’

Interviewee: ‘You barely see any Māoris being a doctor ( ) these white doctors are pretty good, they’re pretty smart.'
Racism and discrimination are part of the social determinants of health that are perceived to be shaping the health of Māori with disabilities. In general, participants from all groups stated that Māori are at a greater risk of living in poverty and experiencing ill health as a result. Such social and economic barriers was evidence of a social divide, which influences the effective delivery of health care. Māori expectations of health will be discussed in the following section.

5.4.4 Health needs of Māori with disabilities

I. Overview of the theme

In this theme, participants’ concepts of disability are explored along with what health and health services mean for users of health care. In it the relationship between Māori philosophy and disability is analysed, as well as participants’ concepts of heth and their ontological approach to disability.

II. Health and health services for Māori with disability

UN delegates, senior bureaucrats and health workers stated that the history of inadequate policies associated with Māori health remains an obstacle to the design and delivery of health interventions that are culturally sensitive. A mistrust of medical practitioners among users of health services has been generated. Some participants reported preconceived fears of medical practitioners and the health system. Trusting their doctors was described as a slow and delicate process. Users of health care reported severe negative perceptions of hospitals and described them as places for punishment. For some users these fears were associated with past stories outside the health system.

It’s pride, it’s also fear. Doctors are seen as people that kill you. In the old days when the hospitals got established, Māori went to hospital to die. So there’s
still that thinking, so to go into hospital and then come out alive, it's hard to see.

U.NZ IF1

This historical mistrust of western medical institutions by the Māori community still interferes with people's acceptability and trust of health services. Although areas such as primary health care seem to be gaining in acceptance by its users, they are not used to their full extent as will be explained next.

III. Primary health care

Most users of health services declared that they had fair access to primary health care. However, they felt that general practitioners (GPs) were not well prepared for dealing with Māori patients with disability and described their communications with GPs as deficient. They felt that GPs had very little or no understanding of their condition. However, access to primary health care was described as sufficient. Users emphasised the need for the development of positive relationships with health practitioners, which would require medical professionals investing time in Māori patients and developing a deep connection with their communities.

It's taken me a long time to get a doctor that understood my condition and understood what I needed and understood me as a Māori woman and as a whānau member, accepted my relationship and was totally able to turn that round.

U. NZ. IF1

Although GPs were fairly accessible, this was not often the case in rehabilitation, preventive care and specialised health care. Primary health care was positively perceived, affordable and accessible for users of health care. However, other areas
of specialised care, such as reproductive health, were not as successful in engaging with Māori with disabilities.

**IV. Inadequate sexual health services**

All users of health care concurred on their lack of efficient sexual health services available to them. Sexual health services when available were described as poor and inadequate. Furthermore information and awareness about sexual and reproductive health was generally received outside the health system, and generally linked to the school system. Access to reproductive health was often linked with issues of personal capacity. Senior bureaucrats and United Nations delegates showed particular concern regarding informed consent on reproductive health. As major violations have occurred in the past, United Nations delegates and senior bureaucrats stated that New Zealand’s history had witnessed sterilisation of women with disabilities without their consent. They stated this practice had been restricted as there is now law and policy in practice to protect women today. They elaborated that it has left behind a legacy of fear and mistrust in users of health care. Today the focus was on guaranteeing informed consent regarding reproductive health, and protecting the right to refuse procedures and treatments. Women with impairments were perceived as being at particular disadvantage regarding accessing sexual and reproductive health services as they often faced gender-based violence and discrimination. Furthermore moral debates around issues, such as sexual freedom and abortion added complexities to this field. United Nation delegates stated that this was a universal issue. It was a contentious issue during the negotiations of CRPD due to different traditional beliefs and views regarding abortion and personal capacity across member states of the United Nations.

Yeah, but as for sex education, I never talk that much with the doctors. I
don’t know. It just never came up at the doctors. So I never quite got to it.

U.NZ.IM3

The provision of sexual health services was perceived as limited and inadequate by Māori with disability. Other areas, such as, preventive care reaching Māori with disabilities will be now explored.

V. Preventive medicine

Most users of health care within this research tended to not prioritise preventive care; this disengagement was corroborated by health workers and senior bureaucrats. Lack of access to preventive care led to the development of further disabilities or aggravation of their current health conditions. This attitude was often related to financial constraints or family difficulties that stopped users from accessing health care or living healthy lifestyles. Living in extreme poverty often prevented people from finding time to plan preventive health care, attending only to emergencies and/or reduction in pain. Users of health care reported finding themselves constantly in crisis due to their economic and/or social context. There was a link between preventive care, risk behaviour and the social context. As a result users of health care found healthy food more expensive and that unhealthy over-eating brought pleasure into their economically disadvantage lives.

I need to lose weight, I need to watch because I’m getting older ... there are things that happen when you’re at risk of diabetes, blood pressure, all come in a lot more. But I don’t drink or smoke I enjoy food!

U.NZ.IF1

All groups of participants believed that historically preventive care strategies have failed to find acceptance with Māori as they did not acknowledge the need for
prevention, but are engrossed in coping with the constraints and difficulties of everyday life.

They say that there are always other more important things to do, if nothing is wrong why you would go to the doctor.

HW.NZ.FG1

Lack of preventive care was linked to the high rates of chronic illnesses such as non-communicable illness, including heart and renal failure, diabetes type one and two. All users were either diagnosed of having, or at risk of acquiring, chronic illnesses. Those already diagnosed said that prevention was never important enough. They elaborated on the major consequences that obesity is having on Māori today and its relationship to disability.

Well I would say I’m big, I’m wide, I’m proud to be huge … I just don’t like to see my own people obese, we’ve got problems there. I’ve got a sister and she’s obese. She has a disability too. She can’t barely walk.

U. NZ.IM3

This negative health trend was corroborated by senior bureaucrats.

Māori are still dying earlier, they are still having higher rates of diabetes and obesity and so on and some of that may be related to more than just treatment. I mean disability brings additional barriers that make it harder to access the services anyway.

SB.NZ.IM13

Senior bureaucrats acknowledged that there is a high prevalence of non-communicable diseases among Māori, and the strong relationship between their
prevalence and acquired disabilities. The over-representation of disability within the Māori population does not appear to have influenced the dissemination of knowledge about the cultural needs of Māori with disability across the health sector. The competency of health personnel to deliver services in a culturally-sensitive manner will now be discussed.

VI. Culturally appropriate service delivery

Cultural appropriateness is one of the biggest factors, to date, experienced by Māori with disabilities, blocking their access to health care. Senior bureaucrats, UN delegates and health workers claimed that this could be overcome by increasing the Māori-driven approaches to health service delivery. They believed that often the health system in New Zealand was not responsive to, and was even hostile to, Māori. They said that Māori would like to have Māori values and Māori medicine embedded within the health system. The gaps described included: availability of Māori traditional healing, communication, empathy and understanding of their needs. Users of health care sought a definitive Māori approach to health care.

Cross-cultural understanding needs to occur and that’s when you talk about holistic health in Māori, that’s really about recognising Māori concepts of health.

Cultural competency and effective communication between Māori and non-Māori emerged as an issue. The vast majority of users of health care stated feeling misunderstood.
5.4.5 Convention on the Rights of Persons with Disability (CRPD) for promoting improvements in health outcomes

I. Overview of the theme

This theme addresses theme participants’ discourse regarding the CRPD. It begins by portraying participants’ views on how the implementation of the CRPD in New Zealand, specifically Article 25, could improve the health outcomes and wellbeing of Māori with disabilities. Māori participants tended to relate the CRPD to the Treaty of Waitangi, as a means of protecting and promoting the rights of Māori with disabilities.

Policy-makers acknowledged that the lack of awareness of the CRPD represents a challenge. All Māori with disabilities reported awareness of the Treaty of Waitangi and stressed that the legitimate dissemination and implementation of any law or policy in New Zealand, including the CRPD, must honour the principles of the Treaty of Waitangi.

The following sub-themes will now elaborate on the role of Māori and Māori values in the design, implementation and monitoring of the CRPD.

II. CRPD negotiations and the lack of representation of Māori

UN delegates, senior bureaucrats and some users of health services believed that the current social isolation and overrepresentation of disability among Māori needed recognition in the implementation of the CRPD in New Zealand. They claimed that at the meetings of the UN’s *ad hoc* CRPD committee different indigenous groups lobbied for the development of a separate Article to protect the rights of indigenous persons with disabilities. They compared the role of indigenous lobby groups with other sub-groups such as women and children who obtained support from the *Ad Hoc* committee to accomplish a specific article within the binding text of CRPD. UN
delegates and senior bureaucrats believed that women and children were recognised due to the strong lobbying and advocacy, which indigenous peoples lacked. The movement to advocate a separate Article was positively supported across all four groups of participants.

UN delegates elaborated on the possibility of a separate CRPD Article on indigenous health, stating that international political land rights issues hindered the representation of indigenous peoples. They also said that various member states did not recognise the sovereignty or even the existence of indigenous people within their territories.

There were various countries and various groups that wanted a separate mention of lots of different groups…but that’s partly because they had a really strong women’s rights person leading their delegation. Really pushing for a separate article for women, indigenous peoples were lacking on that at the UN meetings.

The UN delegates perceived that the monitoring mechanism embedded within the CRPD gave those protected by a separate article a much stronger voice at the UN and domestic levels accordingly. However, they felt that having the term indigenous in the Preamble to the CRPD and inclusion of Article 30, ‘Participation in cultural life, recreation, leisure and sport’, indigenous Māori people have some recourse to advocate for health services in a culturally appropriate manner.

The UN CRPD preamble does recognise the vulnerable population such as indigenous peoples but it doesn’t explain it and by not having an article on indigenous peoples outlining what it means for indigenous peoples to have
rights and spelling those out, basically we’re in the same position we were before the UN CRPD except it says that we’re recognised.

The senior bureaucrats, UN delegates and some health care users believed that having a separate article within the CRPD would influence policy-making and human rights awareness among Māori with disabilities.

**III. New Zealand and the CRPD**

Participants who were involved with the negotiation stages of the CRPD recapped on the role that New Zealand played at the *ad-hoc* Committee, which was chaired by Don McKay, a New Zealand delegate. The UN delegates highlighted that both Mexico and New Zealand were instrumental in the development of the CRPD. The UN delegates interviewed stated that these two countries were key to establishing an ethos involving full inclusion of people with disabilities, as well as incorporating non-discrimination and accountability. They believed however that for the CRPD to have an effect for Māori, Māori must play a significant role on domestic and international committees.

We ended up being able to broker a midway point partly because New Zealand and Mexico got on pretty well and have always since then been friends of the convention as such, tried to take quite a leadership role between them.

Some participants stated that although Māori people formed part of the delegation in New York, Māori values associated with disability and rights did not represent a strong discourse on their mandate. They highlighted the value of lobbying for a specialised article within a UN Treaty, such as the CRPD, as a means of legal
protection. The lack of support for indigenous peoples at the negotiations of the CRPD needs to be rectified through the setting up of an ongoing dialogue within its monitoring committee and other review bodies.

IV. The Treaty of Waitangi and CRPD

All Māori and non-Māori participants felt that the implementation of the CRPD must honour the principles of the Treaty of Waitangi, with Māori culture and its implications for health services embedded in consultations with Māori about Māori health services for Māori. Senior bureaucrats defended the idea that this approach would be the most effective, but that it would require both time and total commitment on the part of the New Zealand government. Participants believed that social equity will be achieved once Māori are fully represented, as dictated by the Treaty of Waitangi, at every level of governance including international law mandates.

We have the Treaty of Waitangi. The treaty is our Magna Carta in New Zealand. It’s the thing that distinguishes us from Australia and the United States and everybody else that’s been colonised or are colonisers.

SB.NZIM1

The Treaty of Waitangi was viewed as being more instrumental in the protection of the rights of Māori with disabilities than any other human rights treaty including the CRPD as it represents fully the claims of Māori people and it engages with their history and their reality. This was corroborated by all Māori and non-Māori interviewees. Of note was that all Māori users of health care with disability were aware of the existence of the Treaty of Waitangi, while just a minority knew about the CRPD or other human rights treaties.

We have the Treaty and we have the United Nations Article 3 and we talk
about the principles of the Treaty, principles of the Convention and say hey look these are really similar so this is what Māori said 150 years ago and this is what we’re saying now, so I talk about the first human rights document in New Zealand which was the Treaty and then I talk about the latest human rights document which is the Convention (CRPD).

U. NZ.IF4

All participants acknowledged that the CRPD must honour the Treaty if effective engagement with the Māori community is to be pursued, but the first challenge is the lack of effective dissemination of the CRPD. Senior bureaucrats and UN delegates stated that having information will make people more likely to denunciate human rights violations, and fully utilise the key features of the CRPD. So, improving dissemination is fundamental to the full implementation of the CRPD. It was also found that human rights awareness and advocacy would be more efficient if it were related to fostering knowledge about the Treaty of Waitangi. For the Māori interviewed within all the groups the concept of human rights was associated with Māori sovereignty and self-determination.

5.4.6 General Summary

The findings of this case study indicate that Māori with disability face severe social disadvantage, including inadequate access to health services. Elements such as education, employment, social violence and the ongoing effects of colonisation were recognised as playing a role in the degree of ill health experienced by Māori with disabilities, who are at a greater risk of being affected by severe poverty. Discrimination and a sense of oppression were reported to be embedded within various aspects of the lives of Māori people with disability.
Senior bureaucrats, UN delegates and users of health services believed that New Zealand governance has not been adequately responsive to Māori, stating that inadequate policies and a lack of respect for the Treaty of Waitangi had generated the current inequity. Moreover, the current limited provision of specialised health care negatively affected employment and housing. As users of health care they reported not being able to move to cities where jobs were available, fearing that specialised services may not be available for them there due to waiting lists or lack of provision. They also preferred to secure access to such services, and take whatever residential accommodation was available close by, rather than obtaining more adequate settings. This is all exacerbated by the fact that most Māori with disabilities have very low levels of education, but even those who are educated struggled to find recognition and employment opportunities.

Participants stated that the renaissance in Māori values and the recognition of the Māori culture is positively influencing governmental policy-making on health. Participants highly valued their Māori identity and perceived that te reo, whakapapa, iwi and their connection with the land were fundamental to their health and wellbeing.

Historically, the health field has failed to respect the Māori cosmogony of health and wellbeing, including disability. Some users of health care believed that impairments have historically been more welcomed and accepted within the Māori worldview than by western approaches to life and medicine.

There is very little awareness among the users of health services about human rights and particularly about the CRPD. The Treaty of Waitangi was often referred to as the most important human rights framework for Māori. However, participants generally believed that the principles of the treaty have not yet been fulfilled and that the CRPD should embrace the Treaty of Waitangi if Māori rights to health are to be fulfilled.
Policy-makers believed that the CRPD could have a bigger impact on Māori if there was a separate Article for indigenous issues within the CRPD. Senior bureaucrats supported the view that pairing the CRPD with the Treaty of Waitangi would be the most effective method of ensuring an understanding of the role that the CRPD could play in recognising the right of Māori people with disabilities to live healthy, long lives with their needs, culture and spirituality fully recognised.
Chapter Six: Cross-case Analysis

6.1 Introduction

In this chapter, a cross-case analysis of the findings from the three case studies is illustrated, presenting parallel and contrasting themes. In keeping with Yin (2008), each case study was selected to show ‘replication logic’ of how indigenous peoples expressed their health needs, and how meeting these resonated with the policies and practices outlined in Article 25 of the CRPD within each of the three governments.

Yin (2008) suggested that multiple cases could be compared with multiple experiments, including the use of ‘previously developed theory as a template to compare the empirical results of the case study’ (2009, p. 38). The three case studies vary according to type of colonisation experienced by their countries, the recognition of native rights, and its geographical location: rural-remote (Australia), semi-rural (Mexico) and urban (New Zealand). Firstly, each case study was analysed individually and the findings have been presented in Chapter Five. Conducting cross-case analysis comprised the following steps:

1. Pattern matching, where patterns across the three countries were discovered; for example the pattern of social deprivation amongst indigenous peoples with disabilities, which has arisen from colonisation. Yin (2002) described this process as ‘discovering empirically-based patterns with predicted ones’ (p. 116).

2. Explanation building, where patterns were tested against a series of hypotheses; one of which could be that social deprivation is less apparent in countries where there is a history of recognising the sovereign rights of indigenous peoples.
3. **Time series-analysis**, where commonalities were looked at to see if they had moved with the times. An example of this could be whether the nature of social deprivation since colonisation has evolved from the perception of indigenous peoples as ‘other’; or for some ‘savages’, through to them having rights to citizenship.

4. **Logic model**, where connections between patterns of cause-and-effect were seen: for example, in relation to social deprivation the cause-and-effect of poor housing infrastructures and rates of otitis media.

5. **Cross-case synthesis** where a framework was developed that allowed an interpretation of how health needs expressed by indigenous people reference against the principles and Articles of the CRPD.

### 6.2 Cross-case findings

#### 6.2.1 Introduction

Three core themes have arisen from the cross-case analysis. Each theme is multi-layered and all three are interrelated. The three themes were related to the question of how the expressed health needs of indigenous peoples resonate with Article 25 of the CRPD. The first theme is ongoing colonial oppression, which refers to the disenfranchisement and social deprivation experienced by indigenous peoples with disabilities when they attempt to claim their right to health services and medical interventions.

The second theme addresses resilience, which was an underlying concept throughout the narratives of indigenous users of health services. Indigenous peoples possessed a stoic capacity to cope with the social oppression and stigma attached to being an indigenous person, and remained proud, strong and positive about their
identity, including impairments.

The third theme was emancipation, which emerged as a vision for the future. It was seen as a strategy to be built upon in order to improve the health of indigenous people with disabilities. Self-determination was defined as the driving force for overcoming oppression. Emancipation was linked to political mechanisms advocating culturally adequate responses to disabilities and appropriate health services for indigenous peoples with disabilities (See Figure 6.1).

Figure 6.1 Core themes arising from the cross-case analysis

6.3 Ongoing colonial oppression

6.3.1 Introduction

In this theme the discourse of indigenous users of health care is presented, which indicates that there is a political and cultural divide associated with them gaining access to health services compared to non-indigenous users. The relationship
between this divide and ongoing colonial oppression is elaborated upon, and the role played by underlying social determinants of health identified.

6.3.2 Them and us

The theme of ‘them and us’ was evident across all three case studies. There was a clear social divide between indigenous and non-indigenous peoples. The ‘other’, the ‘poor’, the ‘less civilised’ or the ‘stubborn’ tended to be the indigenous peoples. But indigenous peoples also distanced themselves from non-indigenous peoples. This action was generally antagonistic in manner and often linked to feeling oppressed. This is typified in the following comment by a senior bureaucrat:

The systems we design, the procedures we follow, the policies we write are all geared to mainstream kiwis and like I said before, the kiwi world view well if you’re with us, you’re a good Māori, if you’re not well then you’re obviously one of those other Māoris, you’re a protester or you’re a drunk, that’s how they see us.

SB.NZ.I.M4

The discourse of senior bureaucrats and UN delegates across all three countries claimed that ‘othering’ (Freire, 1970), or grouping those seen as least valuable or alien to the norm, leads to a failure to honour indigenous self-determination. ‘Them and us’, summed up the experiences of indigenous people, reflecting their exclusion from the social, political and cultural life of mainstream communities, with ill health seen as the outcome of deeper systemic issues within each country.

The ‘them and us’ theme was evident in all aspects of social life. The discourse of each of the three countries indicated that education was not culturally adequate, there were poor employment opportunities, and discrimination laws and policies were not
being used effectively as safeguards in order to ensure the health and wellbeing of indigenous peoples. Risk factors, hence, triggered negative effects on indigenous people’s health.

6.3.3 Lack of political representation

There were serious concerns about the inadequate political representation of indigenous peoples across the three jurisdictions, with senior bureaucrats and UN delegates agreeing that current democratic systems are driven by the opinions of the majority. Under these circumstances even if indigenous peoples were represented they would be a minority of the population: 2.1% in Australia, 14% in New Zealand and 12% in Mexico. Therefore, being represented alone would not avoid assimilation by the majority.

Sovereignty, however, was seen to guarantee the protection of native rights whatever the size of the indigenous population or political trends. Self-determination and sovereignty were perceived as legitimate and sustainable ways of representing indigenous peoples and resolve the issue of ill health. As a Māori participant expressed it:

We need to refocus and make sure that we can rebuild our language, our relationships with each other through our whakapapa activities on the marae, and to become good citizens as Māori citizens and to be responsible for our wellbeing.

SB.NZ.I.M4

6.3.4 Poverty

Poverty impregnated the narratives of users of health care across the three countries. Poverty was seen to resonate with experiences of social and health deprivation
regardless of whether the country concerned had a high or low Gross National Income (GNI). Although Australia and New Zealand have a considerably higher GNI than Mexico, the quality of life experienced by indigenous peoples with disability in these two countries did not reflect this difference. The manifestations of poverty that were observed and narrated by Aboriginal and Torres Strait Islander people were significantly more severe than those reported by Purepecha Mexicans and Māori. Lack of economic resources determined the ways in which indigenous peoples live; for example the sharing of unsafe accommodation without a proper infrastructure, which increases the risk of communicable diseases. Health workers in Australia stated that, ‘four or five families were living in the one house…they have to understand that they want to live in that house with 15 people drinking every day’. (HW.A.FG1). In general, across the three countries indigenous peoples were not able to afford specialised health care or medication, which often resulted in the development of secondary disability or a rapid deterioration in health.

More indirectly, narratives indicated the impact that poverty had on health and related this to the effects of colonialism, lack of education, and the denial of human rights. In effect, being treated as less than human was exemplified most poignantly by the Australian situation, where the voice of indigenous peoples was only recognised as late as in 1967, impacting on well-being:

Aboriginal peoples, we only got our rights as Aboriginal peoples in 1967. And the policy has been, we’ll try and breed Aboriginal peoples out; that was forced… they work for wages, [Aboriginal] people work for rations, which was a scoop of tea, a scoop of sugar, white bread.

SB.A.I F1
6.3.5 Lack of underlying determinants of health resulting in ill health

The findings from the three case studies reflected the literature on social determinants of health, suggesting that ill health is produced socially by poverty and the lack of political representation (Boseley, 2008; Carson, Dunbar, Chenhall, and Bailie, 2007; Solar and Irwin, 2010; The Lancet, 2012; World Health Organization, 2011). However, the findings also challenge the social determinants of health framework (Marmot, 2005) that is based on the premise of good health arising from its interrelationship with a range of determinants covering education, employment, housing, discrimination and other factors. Instead, the UN delegates shared a strong viewpoint with senior bureaucrats; this was that political representation and cessation of poverty were not sufficient unless they are sustained by indigenous sovereignty. Sovereignty was seen as counteracting past practices such as those of assimilation.

The voices of indigenous users resonated strongly with the experiences of failed assimilation of the stolen generation across Aboriginal and Torres Strait Islander people in Australia. Participants in Mexico and New Zealand also provided examples of the denial of human rights due to assimilation practices. This issue was also apparent in all three countries; an example was seen in New Zealand with the closure of Māori schools. The Mexican sample also linked the assimilation issue to ‘health awareness’ campaigns that were not responsive to Purepecha values. The narratives from both case studies also argued that poverty and social deprivation will not be reversed unless indigenous self-determination is honoured and fully implemented as mandated by the Treaty of Waitangi and the Mexican Constitution.

The following quote synthesised the discourse of senior bureaucrats, UN delegates and health workers who all defended the view that health cannot be thought of distinctly from having a dignified well remunerated job. ‘There is also no future or
space for democracy if there is not promotion of the economic development of every member of the society’ (UN.MX.I M2).

a. Access to education

Education was reported to be critical for indigenous peoples to maintain healthy lifestyles. Access to good health care was not only perceived being about as the availability of health services, but was also concerned with being literate about health awareness and understanding the importance of early identification, as well as being included socially in community life. The educational level among indigenous peoples varied across the three countries, with Māori having better access to education and a significant proportion holding university degrees, but it was also pointed out that, ‘Māori tend to be poor and poorly educated and that’s reflected in poor health status and our Māori disabled community are even more marginalised’ (SB.NZ.IM4). In keeping with this trend, both Australian and Mexican indigenous health care users had only a basic education with low levels of literacy being common. As both the Australian and Mexican users of health care services came from rural and remote areas, historically lack of literacy could be connected to a lack of access to specialised educational services. However, when interviewed users saw that going to school formed a bridge to the health care system where indigenous groups, ‘found out what other services they also needed to attend’ (HW.MX.FG1). The school system was also seen to serve as a facilitator for social inclusion and a pathway to social mobility.

b. Employment

The employment of indigenous peoples with disability differed significantly across the three countries. Employment was related to health as it facilitates social engagement,
economic stability and social mobility, which can all increase the chances of good health. In Mexico employment was connected to being able to access health insurance, whilst in New Zealand it was more to do with social inclusion. In Australia, users of health care indicated that employment was something that, ‘they can no longer do’. The user discourse across the three case studies reflects that health and wellbeing are linked to social inclusion and equity. Across the sample, participants who reported having either a formal or an informal job were more likely to attend health services, as they were more engaged with the community and aware of health risks. Employment was also connected to a feeling of self-satisfaction, which was related to the contributions made to their families and communities.

The employment status of indigenous peoples varied across the sample. In the Australian case study none of the indigenous users of health care were employed. This contrasted with the significant proportion of Māori with disability who held postgraduate degrees, most of whom were employed and involved in either human rights activism or community advocacy. In Mexico most indigenous peoples were working informally within their family craft businesses or that of their local community. A range of issues connecting employment with health arose from the cross-case analysis. Lack of employment was interconnected with mental health issues such as depression, which in itself prevented success in finding work. The relationship between work and health was circular, as evident from the following comment: ‘I can’t, I can’t get up that’s all, can’t work’ (U.A.IM4). Being healthy was interconnected with sourcing jobs and being creative in building opportunities, which starts within the school system with, ‘small strategies that foster certain types of occupation ...some kids will learn to do some craft work, so they can work and earn a living’. (HW.MX.FG1) At another level, striving to become professionally qualified was seen
as a means of achieving a better quality of life, but this was not without the challenge faced by indigenous peoples of feeling like outsiders, which was expressed as follows, ‘why is it that I’m not seen as the lawyer with the standing I should have. If I stand in a courtroom I’m seen equally. If I sit in the courtroom I’m not, why is that?’ (U.NZ.IF1). Apart from the feeling of being discriminated against, a lack of employment was seen as being interconnected with financial insecurity, overcrowded accommodation, deficient sanitation and, in Australia, substance abuse.

c. Lack of adequate housing,

A lack of adequate housing was a further determinant that has impacted on the health of indigenous peoples with disability, which is also related to the impact of social and sanitary safety. Nevertheless, feeling at home, happy and close to their family was a top priority for users of health care, irrespective of the challenges associated with accommodation. Housing issues reported from across the three countries included severe overcrowding, socially disadvantaged habitats, unsafe structures and a lack of universal design. Overcrowding was connected with communicable diseases and improved infrastructures were considered to enhance health as well to address the issue of preventable disabilities. ‘It’s all about a healthy house. This is what they need to do, even though they live in a tent why you need to blow your nose, when kids grow up they don’t have to be hearing impaired.’ (SB.A.IF2)

The lack of universal design emerged as a major issue across the three countries, with architectural barriers interfering with people’s social or medical needs. They also caused social isolation and a dependency on third parties to get in and out of their accommodation to receive health services.
d. Lack of effective universal health insurance for indigenous people with disabilities

Indigenous users of health care indicated that limited health insurance imposed a significant barrier to them getting involved with health care. UN delegates and senior bureaucrats across the three countries stated that there was a need for universal health insurance. In Australia health workers claimed that insurance coverage was inadequate for covering specialised health services and resources for peoples with disabilities, ‘people are still out of pocket. So for example they get the patient assistance travel scheme, (which) has huge problems in our part of the country. People travel and (all) they get (is) $35 accommodation’. (SB.A IF2). Similarly, in New Zealand and Mexico limited health-related coverage was perpetuating financial hardship. For example, in Mexico indigenous peoples with disabilities were reported to spend more than 30% of their household income on health related issues. Even in Australia and New Zealand where full comprehensive insurance was available, such insurance for those with disabilities did not always cover specialised services. Participating users faced the challenge of the gap between what the insurance paid out and the costs they actually needed to cover, which often stopped them from enjoying services or treatments. Participants considered that overheads were, ‘too expensive. Nothing is free. This government wants to privatise health. They’re out there but you’ve got to be prepared to pay for it and I don’t have the money’. (U.NZ. IF1).

e. Discrimination and health of indigenous people with disabilities

Race-based attitudes were perceived to be a barrier to health as they affect quality of life, social mobility and social inclusion. Discrimination affected the mental health of user participants and their feelings of self-worth. Feeling discriminated against was
often linked to anxiety and uncertainty about their health entitlements. This feeling was reinforced with race-based attitudes that hindered them from gaining access to health services, as well as leading to a lack of acceptance within their local and wider communities. The race-based attitudes described across the three countries involved indigenous peoples being seen as different, being reluctant to both learn and/or change their practices, as well as being stubborn and over demanding of services. In Mexico users of health care expressed concerns about negative social attitudes towards Purepecha people, reporting a sense of ‘othering’, which often judged their cultural protocols as ‘ignorant’. This was corroborated by the narratives of other participating groups across the Mexican case study. Some manifestations of race-based attitudes also emerged in Brewarrina, Australia: here they were a very strong sense of worthlessness, and a loss of hope on behalf of indigenous peoples with disability. UN delegates stated that race-based attitudes could be traced back to the effects of colonisation, which had led to, ‘a white Australia policy... that added to the difficulties of indigenous Australians’ (UN.A.I.M1).

All participating groups across all three countries claimed that discrimination was a barrier to improving the quality of life and health of indigenous people with disabilities. Even where success had occurred, as in the case of Māori indigenous participants gaining employment, their sense of wellbeing was disturbed by their having to take jobs that undermined their qualifications. Māori argued that they were hindered from finding a well-paid job by discrimination; additionally, they stated that claiming social benefits was more complex for Māori than for non-Māori.

The analysis arising from this theme has been re-shaped and contextualised in contemporary scenarios as the concept of ‘othering’ coined by Freire (1970). It provides an understanding of how current social and political structures seem to be
devaluing indigenous peoples as well enforcing social deprivation (Grech, 2009; Groce, Kett, Lang & Trani, 2011; Hall & Patrinos, 2012; Maru, Fletcher and Chewings, 2012a). Such a connection between poverty and ill health has been addressed previously in the literature on social determinants of health (Carson et al., 2007; Marmot, 2005; Marmot, Kogevinas and Elston, 1987; Solar & Irwin, 2010; The Lancet, 2012; World Health Organization, 2011). However, the intersection between indigeneity, disability and health remained relatively unexplored.

The findings presented in this thesis go deeper into the analysis of access to health services and how the mandate of CRPD is being observed, illustrating the systematic, historic and political barriers that have kept rights to health care from indigenous peoples. They emphasise the intellectual, social and economic oppression imposed upon indigenous peoples with disability, suggesting that the current oppression faced by indigenous peoples in Australia, Mexico and New Zealand could be linked back to the social class formation arising from colonial regimes (Good, 1976; Horvath, 1972; Marx, 1853; Moyn, 2010).

This study adds to the work of Hunt and Backman (2008a) by elaborating on the need to review our understanding of the right to health and its progressive realisation. It shows that if member states have the political will to observe Article 25 of the CRPD, they must take into account honouring indigenous self-determination, building resilience and promoting social mobility led by emancipation; elements that will be explored now in the following themes.

6.4 Building resilience

6.4.1 Introduction

The second theme refers to the embracing of a dialogue that builds resilience by
creating a dialogue on indigenous cultural understanding of health and disabilities, acknowledging land bonds, the respect of indigenous leadership and the recognition of culturally responsive health. It also outlines areas where challenges to effective communication were identified. This theme incorporates what indigenous peoples across the three case studies called inner-strength, or the inherent capacity to overcome historical challenges and those faced today. This capacity to cope will be discussed as the driving force behind recovery from colonisation.

6.4.2 Need to open up to the discourse about health and disability from an indigenous perspective

The findings reported a significant mismatch between the perceptions of health and disability of indigenous peoples with disability and health personnel. The users of health care tended to relate their perceptions of health to their feelings and their environment, including being at home surrounded by their family and sharing food; this was a part of their culture, as opposed to consumption of fast, processed foods. They did acknowledge diagnoses, such as diabetes, gastritis and hearing diseases. However, health workers often struggled to engage effectively with users as did not speak the same language, particularly culturally. Opening up to discussing differences was seen as a way of overcoming harm and the social distance imposed by past inadequate health practices. Co-developing interventions utilizing indigenous terms, ancestral knowledge and making references to the immediate environment would help to overcome this communication barrier. It promotes respect and effective engagement. This was expressed very positively by a senior bureaucrat in Mexico when describing the reaction from indigenous communities to the re-interpretation of dietary guidelines to accommodate indigenous traditional food and languages. She stated, ‘when we arrived with the new guidelines and training material they often say
Oh, they know our things! … so they were open to communicate with us’. (SB.MX. I F3)

Disability was seen by users of health care as an alien concept and often referred to as western or doctor’s language, suggesting an urgent need to create a dialogue between all stakeholders of indigenous health care and service users. Across the three case studies the majority of indigenous peoples with disabilities did not identify with people with disabilities. There was a reluctance to be associated with the concept of disability even though they all acknowledged their impairments. It is pertinent to recall that Shakespeare (1996) claimed that being disabled represents a specific social identity, which could be separated from living with impairment. For indigenous peoples within the three case studies, disability in either the sociological or medical context was seen as an imposition and an oppressive unwanted label. ‘Disability, it’s like when people tell you that you cannot do a thing.’ (U.MX.IM5). This distancing was often made by drawing comparison with indigenous people’s views on disability, which were described as less implosive and more welcoming to diversity. ‘In my community I’m not disabled. They see me as [profession] that’s how I work with my clients the best. But they [non-indigenous peoples] have got to start acknowledging indigenous ideology and the framework around that with disability.’ (U.NZ. I F1).

Users of health care recall indigenous values as a way of coping and battling against what they perceive as the oppressive labels of ‘sick’ or ‘disabled’. Their discourses addressed the impact that western medical culture has had on indigenous peoples, but it also pointed out that indigenous peoples with disability have found in their pasts and values the strength to reject such labels and embrace their acceptance by their communities.
6.4.3 Bonds to ancestral lands

Data from the three countries suggested that a connection to ancestral land, self-identification and culture have a very positive effect on indigenous peoples’ health. In relation to land, users of health care related inhabiting their land and owning the land with positive political discourse but also with feelings of relief and protection. ‘This is my house; my family is here, I am better here!’ (U.MX. IF3). Being an indigenous person and self-identification were seen from different standpoints within each of the case studies; common understandings included self-determination, land ownership, culture, resilience and pride in heritage. For some, the link between indigenous identity and a positive attitude was very strong such as in this case for an indigenous man in Australia: ‘What does it mean to be Aboriginal?’ Response: ‘Oh black power.’ (U. A. I M6). However, some indigenous participants also associated ‘indigenous’ with negative adjectives such as poor, uneducated and stubborn, which had arisen from a long history of social segregation and stereotypes created by social positions within an oppressed cultural group. Within all three countries being proud of being indigenous as an identity has evolved with time and with the creation of social and political movements, such as the Zapatista movement in Mexico, Māori Renaissance in New Zealand and the 1967 Referendum in Australia. Such groups and events have given indigenous peoples voices and created opportunities for dialogue and emancipation. These political, ideological and social movements were seen as a response to the indigenous peoples’ status as an underclass due to colonial practices. Such movements saw people claiming their heritages and making statements indicating pride such as, ‘I am Purepecha, indigenous Purepecha, a race of indigenous people, with long-standing tradition’. (U.MX.IM5).
6.4.4. Indigenous peoples’ leadership

Leadership and involvement in advocacy were strongly linked with gaining an awareness of disability rights including rights to health. Indigenous peoples’ leadership was also linked with positive health policy responses. For example in Australia, indigenous leaders, such as Professor Mick Dodson, was perceived as giving indigenous people hope, bringing back empowerment and embracing the resilience needed to recover from colonisation. Professor Dodson was credited with ‘getting our constitution to recognise indigenous peoples’. (SB.A.IF2).

Leadership at a community level was also very important, as those users within the study who were involved in local advocacy groups were more likely to have a connection with health services, and were more aware of their health and disability entitlements. Those involved in advocacy groups tended to be more active in the community and generally were employed either formally or informally, regardless of their level of disability and despite their level of education or geographical location.

Indigenous senior bureaucrats believed that where there was a lack of advocacy and local engagement it arose from a history of having programmes and policies imposed. They believed that leadership in communities, such as Brewarrina, Australia, must emerge from within the community if it is to be sustainable and legitimate. They also believed that small communities may be affected by complex and delicate politics that would be difficult for outsiders to interpret.

Leadership was linked with being listened to, which was stressed as being important to indigenous users of health care. They were often deprived of the opportunity to give an opinion, as summed up in comments such as, ‘I am Purepecha, that must be recognised, and people should trust us (Purepecha). It should be the same everywhere in the doctors as well’ (U.MX.I M1). Indigenous users of health care often
made claims that they had never been asked about their beliefs or perceptions of their disability and health needs. They found being able to speak about such things as both liberating and empowering.

6.4.5. Culturally responsive health care

Participants from groups across the three countries including users agreed that the fulfilment of Article 25 and any other mandates from the CRPD had not yet occurred with respect to indigenous peoples with disabilities. Their right to the highest attainable standards of health without discrimination and the underlying determinants of good health have continued to be infringed upon, with current structures failing to alleviate the high rates of ill health across indigenous peoples with disabilities.

Senior bureaucrats and UN delegates stated that health systems in general are reluctant fully to incorporate indigenous approaches to health within their mainstream provision. New Zealand and Mexico have integrated some traditional medicine into its health systems, but the availability remains limited. Whilst New Zealand provides the Rongoā Māori (traditional medicine), its availability was perceived as being highly restricted. The Mexican government has produced a series of training publications for all clinical personnel for the dissemination of traditional medicine, which is respected across the medical profession, and historically their presence has been very important within indigenous communities across the world (Durie, 1985; Fanon, 1978; Wilson and Richmond, 2009). For some indigenous peoples in Mexico, traditional healing was the only option available. This was delivered within communities, accessible, at no cost and the traditional healer tended to be well known within the community.

Health workers in Mexico reflected on their training in traditional medicine and stated that having traditional healers trained in western medicine has been a great success.
They claimed that this practice had resulted in the creation of reliable communication networks with indigenous communities, which allowed them to build upon the knowledge that traditional practitioners have about their own communities. ‘We now have communication with midwives, the process started not long ago, so the traditional midwife will come and receive training with the doctor, they receive information ... and now they come regularly to the medical services’ (HW.MX.I M1). In contrast in the Australian case study, there was a weak discourse about traditional healing across users of health care, although it was more robust across senior bureaucrats. It is important to clarify that this discourse may differ significantly throughout the Australian territory, as the use of traditional medicine appears to be more prevalent in central and Northern Australia (O'Connell, Latz & Barnett, 1983; Saethre, 2007).

Although traditional views on health and traditional healing were generally very positively perceived, some participants had concerns about the risks of practices within traditional healing. Health workers stated that this fear has been overcome by showing the positive results derived from engaging with traditional practitioners. In general, health services did not appear to be communicating effectively with indigenous peoples with disabilities and hence health workers believed that they were often judged to be not doing their jobs properly. They urged their health system to develop a better understanding of the issues within indigenous communities, by creating more culturally responsive protocols and providing health care workers with adequate cultural training. Such support is summed up in the following quotation, ‘you shouldn’t force white medicine on them or whatever without understanding that, you know their culture’. (HW.A.FG1).

The cross-case findings indicated that a much stronger partnership between health
services and indigenous peoples was needed, if the CRPD mandate to the right to health was to be fulfilled.

A need to build resilience through dialogue, partnership and equity for indigenous people with disability was recognised. The dialogue of indigenous peoples throughout the three countries was characterised by stories of inner strength. They had developed resilience in the face of oppression. Such inner strength will need to be sustained if the underclass status that has oppressed indigenous peoples since colonisation is to be rectified. The findings of this research add to those of previous studies that elaborated on the importance that indigenous resilience has on recovering and overcoming social challenges (Kirmayer, Dandeneau, Marshall, Phillips & Williamson, 2011; Maru, Fletcher & Chewings, 2012b; McLennan, 2009). The narratives of the three countries go on to suggest ways in which the existence of such underclasses can be overcome through emancipatory strategies. How emancipation was viewed and could be implemented further is covered in the next section.

6.5 Emancipation

6.5.1 Introduction

Being recognised, listened to and served in a culturally appropriate manner emerged as the goal of indigenous users of health care. Senior bureaucrats, UN delegates and some users believed that this could be achieved by indigenous peoples gaining social and political visibility

6.5.2 Article 25 of the CRPD

The CRPD was perceived as an emancipatory instrument that could facilitate advocacy for indigenous health and combat social and political invisibility. The CRPD
through its reporting mechanism was perceived to have a political and legitimate mandate to address the alarming rates of ill health and exclusion among indigenous peoples with disability. Although the three countries have submitted their reports to the CRPD committee, Australia, as yet, is the only one which has received recommendations back (Australian Government, 2012 report CRPD/C/AUS/1). These recommendations urged Australia to present data on Aboriginal and Torres Strait Islander people with disabilities, including their health. These recommendations were perceived to arising from the CRPD, indicating its potential as a strong legal mandate and tool for advocacy. However, participants, particularly UN delegates and senior bureaucrats, claimed that changes will only occur if partnership between domestic governments and indigenous peoples’ groups are strengthened. They clarified further that such partnerships must be based on legitimate grounds and honour indigenous peoples’ self-determination. The CRPD is laying the ground for moving towards equity on health and social justice. UN delegates in Australia believed that ‘[indigenous peoples with disability] have got greater potential now to get results from the CRPD than say five years ago’. (UN.A.IF1).

6.5.3 Input on disability studies

UN delegates and senior bureaucrats and, to a lesser extent, indigenous users of health care across the three case studies, claimed that disability scholarship and international governance had failed to portray the experience of living with an impairment from the perspective of indigenous peoples. Similarly, such scholarship has also failed to explore the oppression of indigenous people with disability due to colonisation. It was perceived that government consultations were often unidirectional and did not enhance the voice of indigenous peoples. Instead, such consultations aimed regularly to translate and apply a model that complies with the
interests of the member states, but does not often benefit from indigenous peoples’ knowledge. Indigenous users of health care believed that member states need to acknowledge their cultural beliefs and their attachment to the land. They claimed that governments and international organisations must reconsider their use of language in order to foster a deeper understanding of indigenous perceptions of disability. This was explained by a senior bureaucrat. ‘We know culture is culture and indigenous people’s culture differs from mainstream Mexican thinking.’ (SB.MX.IF4).

6.5.4 Visibility in human rights mechanism

UN delegates and senior bureaucrats from New Zealand and Mexico claimed that although their countries recognised indigenous peoples’ sovereignty, they were sorely aware that indigenous rights remained a highly controversial issue within the UN. Reasons for this include overburdening within the UN reporting systems and unresolved conflicts within occupied territories such as Palestine (Office of the United Nations High Commissioner for Human Rights, 2013). The UN delegates reported that although significant changes have been brought about with international treaties, such as the Declaration of the Rights of Indigenous Peoples, the implementation and effects of such documents remain unexplored. However, UN delegates and senior bureaucrats did not place all the responsibility on the UN system. They referred to the responsibilities that domestic governments have, not only as signatories of international treaties but under their own domestic laws. They, hence, urged for the full implementation of such laws as a priority as stated by a Mexican participant, ‘we have changed our constitution that must be the primary force to end with inequities’. (UN.MX.IM2).

UN delegates reported that governments and domestic advocacy groups must be strengthened to maximise the opportunities provided by instruments including the
CRPD, which is particularly relevant to addressing the right to health, culture, non-discrimination and social and economic development faced by people with disabilities.

**6.5.5 Voice of the global south**

The global south, that is those nations historically conquered by the global north (Connell, 2007), share the experience of having been subjugated by a colonial power and disenfranchised, with the indigenous peoples becoming socially and politically oppressed. The discourse of indigenous users of health care across the three case studies shared many of the characteristics of the global south. The concepts emerging from this study build upon the work of Meekosha, (2011) and Hollinsworth (2012) and their calls to decolonise indigenous disability.

Possessing the willpower for emancipation may alleviate feelings of oppression. These views were stronger across Māori people interviewed than the indigenous peoples from Mexico and Australia. Across the three case studies concepts related to emancipation were fuelled by political messages, idealism, future expectations and the motivation to be in control of their life. For example here is the view of a Māori participant: ‘Māori world view is about enablement about connectedness …Māori are in control of their destiny and of their resources… no matter what they are!’ (SB.NZ.IM4).

The voice of the global south, the once oppressed and colonised, must be listened to if UN member states are to comply with the mandate of the CRPD. Promotion of the leadership, advocacy and participation of indigenous peoples with disabilities in governance across state and international boundaries is called for. The outcomes of this research suggest the need to enhance the voices of indigenous peoples with disability if they are to overcome the ill health that can prevent them having a good
quality of life.

These three themes; on-going colonial oppression, embracing resilience and emancipation (see Figure 6.1 Core Themes arising from the cross case analysis) provide a portrait of the health needs of indigenous peoples in relation to their social and legal context. It portrays the high rate of ill health across indigenous peoples with disabilities as a social outcome. It suggests a theoretical and practical explanation of the bridges required for Article 25 of the CRPD to engage with indigenous peoples with disabilities.

6.6 Conclusion

The cross-case findings indicate the commonalities, differences and challenges across the three sample countries with respect to the health experiences of indigenous people with disabilities. The expressed health needs of indigenous people with disability were very distinct from the expectations embedded in Article 25 of the CRPD. The disassociation and limited engagement between indigenous peoples and the CRPD occurred with respect to the ethos, philosophy and operationalization of the overall document. Making law and policy arising from the CRPD requires a commitment on behalf of the member states to respond fully to the needs of indigenous peoples with disabilities. However, the lack of political representation and a failure to acknowledge grassroots problems reinforced ongoing colonisation. Together with a limited recognition of native rights this created a significant barrier between indigenous peoples with disabilities and the potential for them to gain from Article 25 of CRPD.

Understanding the health needs of indigenous peoples implies addressing the social and political oppression that has determined their historical underclass status, ill
health and high rates of preventable disabilities. Resilience and emancipation were seen as mitigating factors in advocating better health. Chapter 7 will now discuss the implications of the cross-case themes for indigenous people with disability in claiming their rights to health and a better quality of life as outlined in Article 25 of the CRPD.
Chapter Seven: Discussion and Conclusion

7.1 Introduction

The overall purpose of this research was to describe the health experiences of indigenous peoples with disability, drawing comparisons with and implications for the mandate of Article 25 of the UN CRPD.

The perceptions of indigenous peoples with disabilities of how their health needs are being met have been collected and analysed. These perceptions were then triangulated against those of UN delegates and senior bureaucrats (some of whom had been involved in implementing the CRPD within their respective member states of Australia, New Zealand and Mexico), as well as health workers based in selected indigenous communities. As a result, the findings from the three individual case studies of member states allowed me to compare and contrast them within a cross-case analysis, which is presented in Chapter Six. From such an analysis a pathway emerged that portrays the interrelationship between the oppression, resilience and emancipation of indigenous people with disability in relation to obtaining their rights, (see Figure 7.1, ‘Indigenous health trajectory’, which presents the pillars of the pathway). It illustrates a uni-directional trajectory with lateral interrelationships starting with the experience of oppression, being responded to by resilience, which acts as a catalyst for emancipation.
Figure 7.1 Indigenous health trajectory

The uni-directional movement of the trajectory does not deny that the relationship between the pillars may not always be forward looking. The pillar of resilience is needed to balance any disappointments arising from the struggle to be emancipated from poor health, whilst safeguarding against swinging back to feelings of oppression and hopelessness (see Figure 7.2 Resilience as a balancing element).

Figure 7.2 Resilience as a balancing element
Resilience represents a balancing process operating between oppression and emancipation. As a process it is strengthened by the honouring of indigenous people’s bonds to their ancestral land, self-identification as indigenous peoples and participation in creating culturally responsible health. However, such a process can also be hindered by oppressive social attitudes and systems of governance. Resilience, as a balancing element, was seen as instrumental to supporting indigenous peoples in coping with colonisation and the post-colonial oppressive practices as well as in their pursuit of self-determination and emancipation.

In exploring how indigenous peoples perceived how their health needs were being met, the research was also aimed at looking at how research outcomes aligned with Article 25 of the CRPD. A discussion now follows that maps the relevance and implications of the three key themes of oppression, resilience and emancipation onto the overall aims of Article 25. A discussion then follows on what needs to happen for indigenous peoples to enjoy the rights to the highest attainable standards of health, as outlined in Article 25, CRPD.

7.2 Health experiences of indigenous peoples with disability: from oppression to emancipation

Article 25 Health specifically advocates for people with disabilities to have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability to include specific and affordable health services that cover: sexual and reproductive health and population-based public health programmes; early identification and intervention for children and elderly people; health services as close as possible to people’s own communities, including in rural areas; free and informed consent through training of ethical standards for public and private health
care; life insurance and prevention of discriminatory denial of health care services, food or fluids on the basis of disability (United Nations, 2006 p.18).

In examining how Article 25 has been fulfilled with respect to indigenous people with disabilities findings have shown, as illustrated in Figure 7.1, a relationship between oppression, resilience and emancipation. The status of the specific elements of Article 25 as defined above, have been discussed previously and supported with evidence from findings derived from the three member state case studies (Chapter 5) and from the cross-case analysis (Chapter 6). The discussion will, therefore, be centred on what is required to move from oppression to emancipation if indigenous people with disability are to access what Article 25 has mandated. The trajectory, as outlined in Figures 7.1, is now explored further by responding to the following three questions

- What needs to happen for indigenous people with disabilities to overcome oppression and to take up the right to lead a healthy life, as outlined in Article 25, Health, CRPD?

- How can resilience be sustained?

- How will emancipation work as a way forward?

7.2.1 What needs to happen to overcome oppression?

It is pertinent to open with an overview of what oppression looked like for indigenous peoples with disabilities across the member states. Oppression emerged in the form of political disenfranchisement, evident from the lack of full execution of native rights (Andersen, 2010; Anderson, 2007; Moyn, 2010; Xanthaki, 2007). In the historical subjugation observed, negative labels were attached to indigenous peoples’
identities, and there was an absence of their representation in the decision-making processes associated with health issues (Boulton, Simonsen, Walker, Cumming & Cunningham, 2004; Cooke, Mitrou, Lawrence, Guimond & Beavon, 2007; Lawrence, 1994). Oppression was also related to the social deprivation arising from poverty, with systems of governance and social structures imposing systematic oppression leading to the ill health of indigenous people with disability (Anderson, Crengle, Leialoha Kamaka, Chen, Palafox & Jackson-Pulver, 2006; Hall & Patrinos, 2006).

Article 25, firstly, mandates the principles of non-discrimination regarding access to health on the basis of disability. However, the everyday lives of the indigenous peoples interviewed reflected discrimination and inequity across all public health institutions. Feeling oppressed or discriminated against was a common experience across all users of health care. Some areas were much more restrictive; for example the right to access sexual and reproductive health was denied to indigenous women with disabilities. These same women were also found to experience domestic violence.

Discrimination also arose from a lack of access to an equitable range, quality and standard of free or affordable health care; this was not helped by the lack of access to health insurance by indigenous peoples with disabilities. Denial also spread to the specialised services for indigenous peoples with disabilities, particularly within their local communities. The lack of available specialised care placed a burden on health personnel requiring them to go beyond their usual roles and expertise.

Similarly, early intervention was greatly hindered by social isolation, poverty and lack of education, which all contributed to a lack of agency on the part of indigenous people. Discrimination, however, was challenged by health professionals as reflecting
an indifference on the part of indigenous people with disability. Indigenous peoples argued that they were unable to avail themselves of such services due to financial constraints and challenging domestic circumstances, such as inadequate housing, and a lack of education preventing them from prioritising their health situation. Furthermore, indigenous peoples were greatly affected by both communicable and non-communicable diseases and their associated co-morbidities.

The outcomes of this research have indicated that, for indigenous peoples with disabilities, oppression is more than a denial of access; the findings reflect that oppression ‘is about being powerless and viewed as essentially worthless in an alien society’ (Fulcher, 1996 p. 12), leading to ill health, which metaphorically was the operationalization of social and political oppression. Feeling worthless and without control over their own lives, was argued by Quinn (2010) to have affected all people with disabilities. Quinn elaborated on the legal infringements that people with intellectual disabilities faced regarding control over their own lives, including legal control, in the form of legal capacity. He defended the idea that such legal infringements are based upon our limited legal and social notions of personhood, which historically has placed no value on those with disabilities. Quinn advocated for change through Article 12, ‘Equal recognition before the law’, which restabilises the right to take control of one’s life, in all its social and legal aspects. The research in this thesis has contributed to Quinn’s work from an indigenous perspective, including an analysis of the extent to which indigenous peoples have been devalued by society and by domestic and international law. Such devaluation (Wolfensberger, 2004) was also reflected by the lack of respect for cultural differences and notions of native rights and ultimately the lack of recognition of self-determination. On-going colonisation and oppression remains an unspoken issue for indigenous peoples.
worldwide. In keeping with Moyn (2010), it is necessary to challenge the concept of rights itself, and face the fact that their legal protection has not been universal. The findings presented in this thesis link with those of Moyn (2010) and Pasqualucci (2006) who defended the idea that historically indigenous peoples have been left behind with respect to the protection of human rights, and they are ‘painfully aware that western humanism had not been kind to them’ (Moyn, 2010, p.87). The non-discriminatory principles of the CRPD (respect for differences, equity and self-determination) cannot be achieved if the CRPD fails to address the current colonisation practices, as exemplified in the case studies of all three countries. The findings here add to the work of Meekosha (2011) in proposing a pathway for indigenous peoples with disabilities to overcome colonialism, taking the CRPD and its principles as a framework for addressing the grassroots problems of the global south.

To overcome oppression there is a need to develop positive relationships with indigenous peoples, based upon mutual responsibility and respect. Legitimate and effective policy responses need to be based on legitimate governance, which enhances and empowers previously oppressed minorities, such as indigenous communities and their advocates. Exclusion of indigenous people with disabilities from their right to health, as described in Article 25, has been fuelled by a lack of respect of rights and the negative attitudes towards them and will continue unless member states become sensitive and knowledgeable about indigenous peoples’ health and social issues (Harris, Cormack, Tobias, Yeh, Talamaivao, Minster & Timutimu, 2012; Harris, Tobias, Jeffreys, Waldegrave, Karlsen & Nazroo, 2006; Yoshioka & Hirotoshi, 2010). Ways must be found to include indigenous peoples with disabilities fully in communities, building upon their capacity and literacy about human rights, particularly about the CRPD. Such a notion recalls the ideas of Moyn (2012)
who claimed that human rights literacy is core to the self-emancipatory avenues
provided by human rights frameworks. This study supports Moyn’s claim that human
rights norms have to serve as popular tools that need to be reinterpreted to represent
fully the social groups protected by them. In order to do this correctly, literacy across
vulnerable groups, such as indigenous peoples with disabilities, needs to be
strengthened.

Discrimination as a form of ongoing colonialism had led to profound systematic issues
in all three countries with a great need for the redistribution of resources and
services. The link between governance and the social distribution of wealth has long
been discussed within the literature on the social determinants of health (Anderson et
al., 2006; Marmot, 2005; Marmot, Allen, Bell & Goldblatt, 2012; Thomas, Briggs,
Anderson & Cunningham, 2008). The findings of the present research support the
work of Marmot (2005, 2012) who pointed out that reorganization of resources will not
overcome health inequity unless such a rectification promotes a shift in power and
decision-making at governance level. Systematic discrimination could only be
overcome by an attitudinal shift in emancipating indigenous peoples so that they play
a role in designing, implementing and monitoring public health policies. Member
states must argue strongly that the right to health, as outlined in Article 25, will not be
met without addressing the historical and ongoing social isolation of indigenous
peoples, as the current power and material structures have enforced segregation of
indigenous peoples. It is necessary for indigenous peoples with disabilities to take a
central role in aligning policy priorities with local governments. Listening to indigenous
people with disabilities was seen as the key to overcoming decision-making practices
that had impacted negatively on their health experiences, as well as their personal
expectations and understanding about what it means to be a disabled person with
health issues.

Equity of access to health services requires health service infrastructure to be transformed, but as important is the transformation in the ways in which indigenous peoples are accepted, considered and perceived as needing to be in control of all decision-making that affects their lives. The case studies also suggested that indigenous peoples with disabilities have the capacity to cope with severe discrimination, adversities and remarkable degrees of ill health (Kirmayer et al., 2011; McLennan, 2009). Such resilience has helped indigenous peoples with disabilities overcome their current and historical disadvantages. Such resilience must be explored further, understood by health professionals and strengthened as a means of facilitating better health and wellbeing.

7.2.2 How can resilience be sustained?

Resilience emerged as the capacity that indigenous peoples showed to cope with social oppression. It also emerged as a capacity to overcome challenges. Building resilience appeared to be linked with the promotion of indigenous leadership and cultural responsibility for health.

Attachment to ancestral land and the exercising of native rights over such land arose as being driving forces behind indigenous peoples’ emotional strength. The findings of this research support the previous literature on land rights, which highlighted the crucial role that such legislation has had on improving the quality of life and ultimately the health of indigenous people with disabilities (Alcorn, 2011; Altman, 2012; Australian Department of Health and Ageing, 2012; Bramley, Hebert, Tuzzio & Chassin, 2005; Burgess, Johnston, Bowman & Whitehead, 2005; Calma, 2004; Rowley, O’Dea, Anderson, McDermott, Saraswati, Tilmouth, Roberts, Fitz, Wang,
Jenkins, Best, Wang & Brown, 2008; Stevenson, 2008; Watson, 2007). Given the positive influence that land rights have on improving the health of indigenous communities, it is important that not only Article 25 of the CRPD be considered, but all Articles, particularly those that have a direct influence on the wellbeing of the person, for example: Article 5 - Equality and non-discrimination; Article 8 - Awareness-raising; Article 12 - Equal recognition before the law and Article 16 - Freedom from exploitation, violence and abuse, among others. There is a need for the CRPD, arising from specific consideration of Article 25, to reinforce its mandate with domestic and international laws, as well as policies and jurisprudence that protect indigenous land rights, such as the Mexican Constitution (Honorable Congreso de la Union, 1917), the Treaty of Waitangi (The United Kingdom of Great Britain and Ireland Crown and the Native Chiefs and Tribes of New Zealand, 1840) and the Mabo Case (High Court of Australia, 1992). The connection between the right to land ownership and health emerged strongly throughout this study.

Indigenous identity was also associated with resilience. Strong self-identify was seen as core to overcoming the on-going effects of colonisation. For indigenous people with disability claiming their indigenous identity was a way of standing up to negative perceptions. Feeling proud of their ancestors was also reported to give strength to those members who partnered, as a political group, with cultural configurations from which they drew social and political strength.

Resilience sustained by self-identification, leadership and self-determination was seen to break cycles of invisibility and to promote improvements in indigenous health. Domestic governance systems of accountability need to honour the right to self-identify, in order to achieve the emancipation of indigenous communities (Anderson, 2007; Durie, 1985). The findings showed that where indigenous peoples were
recognised by the Law (Mexico & New Zealand), they tended to show a greater sense of entitlement than where such recognition and self-identification has yet to be achieved (Australia) and was often personally hindered by the fears of the past.

Self-advocacy and indigenous driven movements, for example the service agency run by Te Roopu Taurima in New Zealand, were also strongly linked with resilience, promoting both indigenous values and the dissemination of indigenous knowledge. However, self-advocacy was not well supported either within medical settings or community-based services for indigenous people with disability. Where self-advocacy was supported and promoted indigenous peoples with disabilities tended to have a more positive relationship with health services and were more literate with respect to their rights and entitlements. Fostering leadership amongst indigenous peoples emerged as being a pathway to emancipation, with local advocacy organisations such as those in ‘la Mesata del Lago’ emerging as legitimate and powerful promoters of good relationships with health services. Resilience could be built and/or further strengthened by promoting a continuous dialogue between health services and users of health care, leading to a culturally competent health system.

Fostering resilience amongst indigenous peoples requires the development of cultural competency at every level of governance and is based on two major points. The first of these refers to an active process requiring commitment from both parties (Balcazar, Suarez-Balcazar, Willis & Alvarado, 2010) and the second to it being evaluated (Balcazar, Suárez-Balcazar, Taylor-Ritzler & Keys, 2010) and, therefore, formally incorporated by human rights monitoring mechanisms.

Cultural competency has major relevance to this thesis given that it was found to be lacking from policy-making and from everyday practices within health services and settings. It is also necessary to understand that indigenous peoples’ cultural
competency has profound legal and social implications relating to issues of colonisation and the honouring of native land rights.

The five step model of how to achieve cultural competency proposed by Balcazar, Suarez-Balcazar, Willis and Alvarado (2010) required: 1) willingness to be engaged; 2) gaining critical awareness; 3) familiarisation with cultural knowledge; 4) skills development and 5) practical implications. This model of cultural competency could be adopted as a means of building resilience across indigenous groups of peoples with disabilities. It could also be used as a framework incorporating policy-makers, bureaucrats and health workers to build and or strengthen insight and competency into the culture, history and belief systems of indigenous peoples with disabilities across the three respective member states of this study. In keeping with Balcazar’s model (2010) if member states are to promote culturally competent health systems they would need to show a willingness to engage with indigenous peoples’ world view of their history of colonisation, as well as developing a critical awareness of negative and oppressive effects of their past practices. Capacity building in legal and health governance issues is also needed by health personnel and policy-makers if full awareness of the social and political barriers encountered by indigenous peoples with disabilities are to be advocated against. Increased awareness coupled with advocacy skills that identify and work to combat discrimination are at the core of building resilient, culturally competent member states. The building of resilience needs to be linked to concrete practices that lead to improvements in access to health care and better health outcomes for indigenous peoples with disabilities. This will help to overcome oppression, opening up a pathway to emancipation.

7.2.2 How will emancipation work as a way forward?

Emancipation emerged both as being a reality for some indigenous participants from
member states, but for the majority it was discussed as an ideal, of having a voice and taking control of one’s life, where indigenous peoples with disabilities could freely and openly decide about their own environments and health. Emancipation emerged as a stage in which indigenous peoples’ values and expectations of health will be core to decision-making on the design and provision of health services. Systematic change and political sustainability of such change requires a re-distribution of power, honouring indigenous sovereignty. It requires abolishing unilateral decision-making, limited participation and inefficient communication. The CRPD needs to be reconstructed with a language and discourse that makes sense of the needs and struggles of indigenous peoples with disabilities. As Quinn (2009) advocated, ‘we need a new vocabulary to reframe the debate that has just begun’ (p.5), because language is more than a channel of communication, it is a form of social action (Holtgraves, 2013). It is, therefore, necessary to have a re-interpretation of the CRPD for indigenous issues, posing new questions and raising new issues, whilst creating a new vocabulary that could successfully engage with every aspect of the lives of indigenous peoples with disability. If human rights are to live up to the expectations of indigenous peoples it will be necessary to challenge the language of the CRPD and ask what the CRPD means to the lives and health of indigenous peoples. The findings of this research suggest that it does not mean much, due to a lack of development and ongoing engagement with indigenous people with disabilities and the limited or lack of representation of the social and legal constraints faced by indigenous peoples with disabilities, such as ongoing colonisation.

The CRPD, with its related optional protocol, is a relatively new UN Convention, adopted in 2006, and coming into force in May 2008. Its monitoring mechanism has faced numerous delays due to the overburdening of the UN systems (Committee
Convention on the Rights of Persons with Disabilities, 2013), although delays and its current limited dissemination could be seen as part of its natural evolving developmental pathway. Nevertheless, the CRPD represents a major philosophical and legal paradigm shift (Lord & Stein, 2009; Quinn, 2010; Stein, 2007). However, its mandate relies on a state’s available economic resources and its political will to implement it. Fyson and Cromby (2013) added to this argument claiming that, ‘while international conceptions of rights such as the CRPD are undoubtedly important in setting a moral tone, the legal rights enforceable for individual citizens depend entirely upon the laws of the country in which they reside’ (2013, p. 1166). Whilst time could be a constraint, it is important to hold governments accountable and not to allow the time factor to be a justification for avoiding compliance with their human rights obligations, which require immediate intervention. It is imperative that indigenous people with disabilities gain equal access to health care.

The CRPD has created a forum for the discussion of disability and specifically health in relation to Article 25. However, from this study it appears that if indigenous people with disability are to be emancipated from their loss of rights, there is a need for a cultural framework to be embedded within the CRPD to protect culturally adequate health delivery and the native rights of indigenous peoples (Balcazar, Suarez-Balcazar, Willis & Alvarado, 2010; Hickey, 2008; Meekosha, 2011). The implementation of Article 25, Health of CRPD must be linked with other human rights instruments that protect indigenous rights, such as, the United Nations Declaration on the Rights of Indigenous Peoples (2006), where Article 24 ‘Traditional Medicine and health practice’ defends the right to the conservation of traditional medicine and the maintenance of cultural health practices. Similarly, The Indigenous and Tribal Peoples Convention 169, (ILO, 1989) Article 25 ‘Health’ mandates that,
'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' (p.8). To come into line with these mandates, which are focused on indigenous peoples as opposed to indigenous people with disability, the CRPD needs to address the gap associated with the health of indigenous people with disability by building into its Articles an indigenous pathway making rights infringements experienced by indigenous people with disabilities across the international boundaries visible and safeguarding them.

7.3 Conclusion

7.3.1 From oppression to emancipation

The findings of this study suggest that being born an indigenous person in any of the three countries increases the chances of living in poverty, experiencing ill health and developing preventable disabilities. The literature on the social determinants of health support the findings of this study, claiming that ill health is induced by an individual’s social context (Carson et al., 2007; The Lancet, 2012; Thomas et al., 2008; World Health Organization, 2011). The three case studies carried out in UN member states showed ill health and preventable disabilities to be related to social deprivation, which arose from colonisation and social oppression. The findings suggest that this vicious cycle of oppression could be significantly changed by addressing oppressive colonial practices (Anderson, 2007; Sherwood, 2013; Smylie, Anderson, Ratima, Crengle & Anderson, 2006). In this context the health outcomes of the New Zealand sample were significantly better than those of Australia and Mexico.

Disability is known to be a cause and consequence of poverty (WHO, 2011). It took almost 30 years, from 1976 when the UN adopted the Declaration on the Rights of
Disabled Persons to 2007 and the enforcement of the Convention on the Rights of Persons with Disabilities. For over 30 years people with disabilities have been advocating to achieving this binding international convention. In 2006 Mexico, a middle income country, empowered by a new wave of political will, took the lead in representing the biggest global minority and advocating the CRPD. This measure, led by Vicente Fox, legitimised a political movement coming from the underground or the oppressed minorities, which was supported by the global north.

The CRPD reflects a shift in global politics, advocacy and disability scholarship; however, its domestic systems of accountability need to honour indigenous sovereignty, self-determination and indigenous peoples’ right to self-identify, if the invisibility of members of indigenous communities with disability is to be overcome. The self-identification, leadership and self-determination of indigenous people with disability need to be promoted within the discourse that surrounds the bi-annual reporting of member states that have signed and ratified the CRPD. Cycles of invisibility and rights infringements can be counteracted by the mandatory reporting mechanisms of the CRPD and its optional protocols, as observed in the 10th session, where an Australian NGO urged a response from the Australian government and the CRPD Committee about the major disadvantages faced by Aboriginal and Torres Strait Islander people with disabilities (Australian Disabled Peoples Organisations, 2013). Australia is the only country out of the three sampled that has been reviewed and is in receipt of an outcome report from the CRPD Committee on the Rights of Persons with Disability. The committee has requested that Australia present data on its indigenous peoples, particularly with respect to their health (Committee on the Rights of Persons with Disabilities, 2013). This request is enhancing visibility domestically and internationally. It is creating a legal precedent to advocate such a
demand in other member states, such as Mexico and New Zealand. It is urging member states to refine their systems of accountability for monitoring the outcomes of the CRPD for indigenous peoples with disabilities. In the context of this research, it could be said that, it is the beginning of a discussion on the root causes of the ill health experienced by indigenous peoples with disabilities. In the spirit of ‘nothing about us without us’ (Charlton, 1998) indigenous peoples with disability must lead this discussion.

The findings here indicate that progression in the realisation of the right to health for indigenous peoples does not rely purely on the allocation of resources; it requires the recognition of indigenous sovereignty at its core (Bickenbach, 2009). The intersection between indigeneity, disability and health inequities is a significant challenge for the implementation of the CRPD and its optional protocol. UN delegates and senior bureaucrats across the three countries highlighted the need to disseminate knowledge about the CRPD in association with indigenous rights. The overwhelming discourse of the lack of awareness of the CRPD across indigenous peoples with disabilities reinforced the notion that its potential has not yet been reached. This is unlikely to occur unless relationships are built with indigenous peoples which could begin with the UN ensuring that the language of the CRPD does not alienate indigenous people with disabilities.

7.3.2 Need for further research

The findings of this research raise several questions for further exploration. No research project is without limitations (Marshall & Rossman, 2010, p. 23). The rationale for the design of this research was to portray, in the best possible way, how the health needs of indigenous people with disabilities were being meet within the theoretical and practical contexts of the CRPD. The need for additional research, to
understand diversity across indigenous peoples with disability and their experiences of health, has arisen from this study. Indigenous populations, even within the same country, may provide significantly different views on the matter. It is necessary to gather more data in regards to Indigenous persons with disabilities, with particular attention to prevalence and type of disabilities, as well as, the context in which Indigenous peoples with disability are living. It is important to know more about how contextual factors such violence, armed conflicts, traffic and human exploitation can impact the lives of Indigenous persons with disabilities, particularly Indigenous women with disability.

This study was focused on adults with disabilities of a wide age range, from 18 years upwards. A focus of further research could be to capture the views of young adolescents with a view to comparing and contrasting them with those of the elders across indigenous communities to see if the landscape of health, disability and rights is changing. There is also an urgent need to engage further with indigenous people with disabilities in remote rural settings, with a view to developing evidence-based practices associated with such isolated settings.

This study has used disability studies, social determinants of health and a human rights approach to health to investigate the implementation of Article 25 of the CRPD with respect to indigenous peoples with disability. Legal and anthropological frameworks should also be considered when carrying out further research on the lives of indigenous people with disabilities.

This study has raised the issue of the poverty experienced by indigenous people with disability and, in exploring this, further research is required to look at the legitimacy of the allocation of economic resources. This research showed that there is a severe mismatch between the provision of health services and the expressed needs of
indigenous peoples with disabilities. It demonstrated that such services are either abundant and badly distributed or non-existent. Therefore, it is relevant to compare the allocation of resources to indigenous people with disability to that of the general population from both a social justice and a health economics perspective. Economics and health are interrelated, so studies looking into the link between the denial of access to health services and the high rates of obesity and cardiovascular disease would be timely. A comparison of access to health across these two groups will point further to the actions needed to tailor areas of development in order to bridge the social divide reported by indigenous peoples within this study. Additionally, it is crucial to determine the effective dissemination strategies within indigenous communities to ensure that information about the CRPD is relayed in a culturally sensitive manner. Such material needs to be accessible bearing in mind educational levels and adapting it to the technical needs of people with different types of disability.

Lastly, my views and background as an indigenous Purepecha from Michoacán Mexico are reflected throughout the study. Positivist authors may call this a bias, however, qualitative researchers and particularly indigenous researchers (Bishop, Berryman, Cavanagh & Teddy, 2009; Denzin & Lincoln, 2008b; Smith, 2006, 2007) argue that our lived experiences allow us to provide a deeper understanding of indigenous issues. They also urge that our work must contribute to decolonising indigenous knowledge and responding to years of colonisation and intellectual oppression. In response, built into the design of the study was a set of safeguards associated with my own reflexive practice, as outlined in Chapter Four. I am a native Spanish speaker and having to conduct this research mostly in English could be seen as a challenge. My fluency in writing academic English has developed since living and working in English-speaking countries during the last seven years. Additionally,
my work in social research in various multi-lingual and multicultural environments helped me to utilise techniques, such as rephrasing and paraphrasing questions for participants, to engage fully by using their local expressions and colloquialisms.

7.3.3 Implications for the future

Ensuring equal access to health care should be aimed at eliminating the discrimination and marginalization experienced by indigenous peoples. We need a new language regarding human rights; an indigenous language that contributes to addressing and overcoming the marginalization experienced due to colonization. Because participation and social inclusion are about valuing diversity (Ballard, 1994), indigenous concepts must have both a legal and practical influence and involve indigenous peoples with disabilities in all initiatives that address their health and social status. The CRPD could be seen as a starting point for a debate about creating the environmental conditions conducive to good health and equity for indigenous peoples. The principles and mandates of the CRPD need to embrace indigenous worldviews and the lived experience of disability to alleviate the social and structural inequity experienced by this population. The findings have shown that any efforts to improve the health of indigenous peoples require:


- An analysis of the notion of equity and equal opportunities as equity cannot occur on unequal grounds (Casey, 2008; Diderichsen, 1998; Fulcher, 1989, 1996; Marmot, 2005; Marmot et al., 2012; Marmot et al., 1987; Marx, 1853; Moyn, 2010, 2012; Quinn, 2009; Quinn, 2010; Quinn, Degener & Bruce, 2002; Stein, 2007a).
• A redistribution of resources, as well as decision-making regarding health, responding to the overrepresentation of disabilities across indigenous peoples and the complexities that such an overrepresentation generates for health and social systems (Grech, 2009; Groce et al., 2011; Hall & Patrinos, 2006; Hall & Patrinos, 2012; World Health Organization, 2008; Yoshioka & Hirotsushi, 2010).

• Meeting an urgent need for reliable data on indigenous peoples, including disaggregated data that describes their health and disabilities (Bhopal, 2008; Hunt & Backman, 2008b; Rowley et al., 2008; Wiley, 2009).

• The cultural competency of health workers and policy-makers must be strengthened by gaining awareness of indigenous issues via capacity-building and fostering partnerships with indigenous communities (Balcazar et al., 2010a; Balcazar et al., 2010b; Suarez-Balcazar, Taylor-Ritzler, E, Keys, Kinney, Riush-Ross, Restrepo-Toro & Curtin, 2010).

• The honouring of indigenous sovereignty at all levels of governance (Anderson, 2007; Anderson et al., 2006; Awatere, 1984; Calma, 2004; Moreton-Robinson, Stratton & Fensham, 2007; Reyes & Kaufman, 2011).

Further efforts have to be put into developing culturally appropriate assessments, policy development and assurances to overcome what have historically made indigenous peoples with disabilities an invisible population regarding the provision of public health. The CRPD and other UN mandates and health policy initiatives need concrete responses if member states are to operationalise the intention of such treaties.

Human rights treaties need to strengthen their links with, and representation of, indigenous peoples with disabilities. Although the constituency of international human
rights treaties, such as the CRPD, the Indigenous and Tribal Peoples Convention No. 169 (1989), and the Declaration on the Rights of Indigenous Peoples (DRIP) (2006) include the defence of the rights of indigenous peoples with disabilities, none has concentrated on issues that affect them or achieved full representation of such a group. In response to this historical marginalisation, the CRPD committee recognised that ‘the rights of indigenous persons with disabilities have not been addressed centrally by either movement’ (referring to DRIP and CRPD), however, there is a growing effort to change this (CRPD Committee news, 2014 p. 1). This thesis and its findings contribute to these efforts, enhancing the voice of indigenous peoples with disabilities, pointing out gaps in the health systems; and calling for effective engagement of the CRPD with indigenous peoples’ issues in Australia, Mexico and New Zealand. It also provides a pathway that will contribute to meeting the health needs of these social groups, indicating that health outcomes for indigenous peoples with disability will not improve unless member states recognise that oppression needs to be overcome through emancipation, honouring native rights and building resilience among indigenous peoples with disabilities.
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Appendices


Appendix B - Example of a memo and its diagrammatic interpretation

Appendix C - Interview and focus groups schedules

Appendix D - Information Sheet and Consent Forms

Appendix E - Approval Letter from The Human Research Ethics Committee of The University of Sydney

Appendix F - Ethical approval from the Aboriginal Health and Medical Research Council

Appendix G - Invitation Letter
Appendix A: The Convention

Convention on the Rights of Persons with Disabilities and Optional Protocol

UNITED NATIONS
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

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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,
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,

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,

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.

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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;

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(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 the present 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.

2. 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:

(a) To 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) To 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) To provide training for stakeholders on accessibility issues facing persons with disabilities;

(d) To provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;

(e) To 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) To promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;

(g) To promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;

(h) To 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 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 the present 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 the present 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 lifelong 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.

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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.

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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:

   (a) To 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) To 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, paragraph 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 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 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 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 of the United Nations, 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, paragraph 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 States Parties shall be convened by the Secretary-General of the United Nations. The subsequent meetings shall be convened by the Secretary-General 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 the present Convention. Such organizations shall declare, in their instruments of formal confirmation or accession, the extent of their competence with respect to matters governed by the present 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, of the present Convention, 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 the present 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 present 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

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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 of the United Nations 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.
OPTIONAL PROTOCOL TO THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The States Parties to the present Protocol have agreed as follows:

Article 1

1. A State Party to the present Protocol (‘State Party’) recognizes the competence of the Committee on the Rights of Persons with Disabilities (‘the Committee’) to receive and consider communications from or on behalf of individuals or groups of individuals subject to its jurisdiction who claim to be victims of a violation by that State Party of the provisions of the Convention.

2. No communication shall be received by the Committee if it concerns a State Party to the Convention that is not a party to the present Protocol.

Article 2

The Committee shall consider a communication inadmissible when: (a) The communication is anonymous; (b) The communication constitutes an abuse of the right of submission of such communications or is incompatible with the provisions of the Convention; (c) The same matter has already been examined by the Committee or has been or is being examined under another procedure of international investigation or settlement; (d) All available domestic remedies have not been exhausted. This shall not be the rule where the application of the remedies is unreasonably prolonged or unlikely to bring effective relief; (e) It is manifestly ill-founded or not sufficiently substantiated; or when (f) The facts that are the subject of the communication occurred prior to the entry into force of the present Protocol for the State Party concerned unless those facts continued after that date.

Article 3

Subject to the provisions of article 2 of the present Protocol, the Committee shall bring any communications submitted to it confidentially to the attention of the State Party. Within six months, the receiving State shall submit to the Committee written explanations or statements clarifying the matter and the remedy, if any, that may have been taken by that State.

Article 4

1. At any time after the receipt of a communication and before a determination on the merits has been reached, the Committee may transmit to the State Party concerned for its urgent consideration a request that the State Party take such interim measures as may be necessary to avoid possible irreparable damage to the victim or victims of the alleged violation.

2. Where the Committee exercises its discretion under paragraph 1 of this article, this does not imply a determination on admissibility or on the merits of the communication.

Article 5

The Committee shall hold closed meetings when examining communications under the present Protocol. After examining a communication, the Committee shall forward its suggestions and recommendations, if any, to the State Party concerned and to the petitioner.
Article 6

1. If the Committee receives reliable information indicating grave or systematic violations by a State Party of rights set forth in the Convention, the Committee shall invite that State Party to cooperate in the examination of the information and to this end submit observations with regard to the information concerned.

2. Taking into account any observations that may have been submitted by the State Party concerned as well as any other reliable information available to it, the Committee may designate one or more of its members to conduct an inquiry and to report urgently to the Committee. Where warranted and with the consent of the State Party, the inquiry may include a visit to its territory.

3. After examining the findings of such an inquiry, the Committee shall transmit these findings to the State Party concerned together with any comments and recommendations.

4. The State Party concerned shall, within six months of receiving the findings, comments and recommendations transmitted by the Committee, submit its observations to the Committee.

5. Such an inquiry shall be conducted confidentially and the cooperation of the State Party shall be sought at all stages of the proceedings.

Article 7

1. The Committee may invite the State Party concerned to include in its report under article 35 of the Convention details of any measures taken in response to an inquiry conducted under article 6 of the present Protocol.

2. The Committee may, if necessary, after the end of the period of six months referred to in article 6, paragraph 4, invite the State Party concerned to inform it of the measures taken in response to such an inquiry.

Article 8

Each State Party may, at the time of signature or ratification of the present Protocol or accession thereto, declare that it does not recognize the competence of the Committee provided for in articles 6 and 7.

Article 9

The Secretary-General of the United Nations shall be the depositary of the present Protocol.

Article 10

The present Protocol shall be open for signature by signatory States and regional integration organizations of the Convention at United Nations Headquarters in New York as of 30 March 2007.

Article 11

The present Protocol shall be subject to ratification by signatory States of the present Protocol which have ratified or acceded to the Convention. It shall be subject to formal confirmation by signatory regional integration organizations of the present Protocol which have formally confirmed or acceded to the Convention. It shall be open for accession by any State or regional integration organization which has ratified, formally confirmed or acceded to the Convention and which has not signed the Protocol.
Article 12

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 the Convention and the present Protocol. Such organizations shall declare, in their instruments of formal confirmation or accession, the extent of their competence with respect to matters governed by the Convention and the present Protocol.

2. References to ‘States Parties’ in the present Protocol shall apply to such organizations within the limits of their competence.

3. For the purposes of article 13, paragraph 1, and article 15, paragraph 2, of the present Protocol, 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 meeting of States Parties, with a number of votes equal to the number of their member States that are Parties to the present Protocol. Such an organization shall not exercise its right to vote if any of its member States exercises its right, and vice versa.

Article 13

1. Subject to the entry into force of the Convention, the present Protocol shall enter into force on the thirtieth day after the deposit of the tenth instrument of ratification or accession.

2. For each State or regional integration organization ratifying, formally confirming or acceding to the present Protocol after the deposit of the tenth such instrument, the Protocol shall enter into force on the thirtieth day after the deposit of its own such instrument.

Article 14

1. Reservations incompatible with the object and purpose of the present Protocol shall not be permitted.

2. Reservations may be withdrawn at any time.

Article 15

1. Any State Party may propose an amendment to the present Protocol 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 meeting 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 meeting, the Secretary-General shall convene the meeting 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 of the United Nations 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.

**Article 16**

A State Party may denounce the present Protocol 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 17**

The text of the present Protocol shall be made available in accessible formats.

**Article 18**

The Arabic, Chinese, English, French, Russian and Spanish texts of the present Protocol shall be equally authentic.

IN WITNESS THEREOF the undersigned plenipotentiaries, being duly authorized thereto by their respective Governments, have signed the present Protocol.
Appendix B: Example of a memo and its diagrammatic interpretation

Extracted from Nvivo

Name: living for the now

Created On: 14/09/2013 6:49:51 AM

Created By: MRV

Size: 2 KB

Living for the now seems to be a common attitude among Aboriginal peoples. Health Workers explained that 'living for the now' comes from living in challenging environments, facing abuse, violence, prejudice, poverty and so on. Living for the now is a mechanism to keep going and focus on surviving the day one day at the time has become an approach to life.

As I remember people’s reaction to my question, the environments, it's easy to relate to this statement. However it’s more than, as it seems like, the loss of hope is superficial, it’s more like losing hope in the system rather than in themselves.
It is surviving or just ignoring health care?

Living for today

Health workers related this idea that people do not look after their health, health care does not have any cost for them, they received a disability/unemployment pension in most cases, health workers related this idea at the fact that people do not look after their health, maybe it is just their perception and indigenous people are not interested in dealing with them, is the attitude the same with other social services rather than health?

Indigenous peoples

Health care does not have any cost for them

A disability/unemployment pension in received in most cases

Poverty

Impressions

The environment was not very well look after. But people seemed to me to care a lot about it.

Family was always around
Appendix C: Interview and focus group schedules

Users of health care


Schedule of semi-structured interviews

The interview will have a semi-structured design. As the participant’s expertise in their field and their live experiences will be incorporated, scope will be allowed to enable new and unexpected issues to emerge. The order and trajectory of the list of questions outlined is flexible, lines indented refer to question-prompts.

The principal themes will be:

Health Services

When was the last time you went for a health check?

-What health services do you go on a regular basis?

Are they in your Community?

Where are your regular health services located?

Are there any specific services for Māori with a disability?

Do your services have any Māori staff?
What services do you need?

Are those services available to you?

Do you get any rehabilitation services?

	Could you describe them?

Did you get any early intervention regarding your disability/es?

	Could you describe them?

Are you attending any prevention programmes at the moment?

Do you get any sexual health services?

	Could you describe them?

Are health services different for men and women?

If so what are those differences?

Do you know about any special programme for women/ men with disabilities?

How do you perceive health services for Māori in comparison with other services?

Access

How do you get to health services?

Is travelling affordable/ accessible?

Does they have any Māori staff?

Do you have any health insurance?
If public do you have Community Card?

Do they cover all your medical expenses?

How do pay for finance those medical interventions/medications which are not covered?

Are they affordable to you?

**Cultural scope of services**

How would you describe your ‘disability/es’ [the world disability may be substituted by impairment which is prefer among certain indigenous groups]

-Were you born with this ‘disability/es’

How do you describe your disability/es within your community?

What impact does your disability have on the way you interact with your community?

How do you perceive services are for indigenous peoples with disability?

-Culturally responsive?

   How do you describe this?

-Ethically delivered (respectful

   What do you call ethically delivered service?

Are Māori/Aboriginal and Torres Strait islander/ Purepecha values met at you health services?

Do you feel understood when you use health services?

How do health services acknowledge your Māori identity?
Do you have access of any traditional healer/Traditional medicine?

Do you attend any alternative health services?

Do you visit traditional healers?

**Perception of human Rights**

Do you know about the United Nation convention on the Rights of People with Disability?

If yes

-Do what do you think about the implementation of the convention on the area of health for indigenous with disability?

-Do you think this documents reflects indigenous values?

-Do you feel identified with the convention?

If no

How do you understand human rights?

Do you think the health services you are getting are responsive to your needs?

How do you think health services should be for indigenous peoples with disabilities?

How do you consider your health is been respected as a indigenous person with a disability?

-Spiritual believes -Physical Health -Mental health

Do you think you have the same health services than the mainstream population?

Do you think you have equal opportunities that anyone else in relation to health access?
Have you ever feel or have being discriminated?

Health workers


Schedule of /focus Groups

The focus group schedule has a semi-structured design. As the participant’s expertise in their field and their live experiences will be incorporated, scope will be allowed to enable new and unexpected issues to emerge. The order and trajectory of the list of questions outlined is flexible, lines indented refer to question-prompts.

The principal themes will be:

Role and implications

Where do you work?

What services do you provide?

-Any specific indigenous protocols and/ or interventions?

Who has your health services?

-Are they indigenous peoples?

-From this community?

Are there any indigenous workers at the services?
Does your service have any indigenous staff?

**Community Engagement**

How do you connect with the indigenous community?

- Do you rely on other health workers or allied health?

Have you got any training about indigenous and disability awareness?

- Could you please describe it?

**Services Equality**

- Are your health protocols the same for indigenous and non-indigenous peoples?

- Are there any specific protocols for men and/or women?

Does the service have any specific programmes for Indigenous?

- Preventive care?

- Community care?

**Cultural identity**

Do you think that Māori/Aboriginal and Torres Strait Islander/ Purepecha values are being met at your health services?

How does your service recognize indigenous identity?

How do you acknowledge your indigenous identity?
Do you have available any alternative health services such as spiritual healing/ traditional medicine?

**Dialogue with indigenous people with disability**

How do you understand the needs of your indigenous clients?

Do you work with programmes such as educational, drug and alcohol among others?

How do you perceive health services for indigenous people with disabilities in comparison with other services?

**Human rights framework**

Do you know about the CRPD?

How do you think human rights for Māori with disabilities are meet at your service?

- Recognition of indigenous decision making process and protocols?

- Recognition of indigenous beliefs?

- Recognition of indigenous traditions?

Is the United Nation Convention on the rights of people with disability discussed at your services?

**Is yes**

- Do you think about the implementation of the convention in the area of health for indigenous with disability?

- Do you think this documents reflects indigenous values?
- Do you identify with the CRPD?

If no

How do you understand human rights?

Do you think the health services you are getting are responsive to your needs?

How do you think health services should be for indigenous people with disabilities?
Senior bureaucrats


The interview will have a semi-structured design. As the participant’s expertise in their field and their live experiences will be incorporated, scope will be allowed to enable new and unexpected issues to emerge. The order and trajectory of the list of questions outlined is flexible, lines indented refer to question-prompts.

The principal themes will be:

Role and implications

Describe your role and responsibilities?

Current Scene Implementation of the CRPD

Have there been any changes since the signing of the CRPD?

Do you think that the needs of indigenous peoples are being met have in the current health services structure?

How do you perceive The Right to Health services have being delivered for indigenous peoples with disability?

How do you perceive health services for indigenous peoples with disabilities in comparison with non-Indigenous peoples other services?
How do you describe the delivery of human rights for indigenous peoples with disabilities today?

**Areas of improvement**

How could the CRPD be used to improve the delivery of the Right to Health to indigenous peoples with disability today?

- Has any progress been achieved?
- Are there any perceived gaps?
- Areas for improvement

Could you share any examples of good practices in the good implementation of human rights frameworks in the delivery of health services for people with disabilities?

- Is there any evidence

Do you have any suggestion for first steps in the field?

What is the role of traditional healing?

**Human rights framework**

How has human rights framework been incorporated into health practices for indigenous peoples with disabilities?

How has CRPD been incorporated in day to day practices and health polices for indigenous peoples with disability?

How has the Declaration on the Rights of Indigenous Peoples been incorporated in day to day practices and health polices for Aboriginal and indigenous peoples with disability?
How is the CRPD reflected on the health services of indigenous peoples today?

- Progress
- Perceived gaps
- Areas of improvement

**Indigenous Health policy driven by the CRPD Article 25 ‘Health’**

How do you perceive human rights for indigenous peoples with disabilities?

- Recognition of indigenous beliefs?
- Recognition of indigenous beliefs?
- Recognition of indigenous decision making process and protocols?

What role do whanan play?

- How does the CRPD could enhance improvements for indigenous with disability

What are the implications of the Declaration on the Rights of Indigenous Peoples for the delivery of the CRPD in Australia/Mexico/New Zealand?
United Nations Representatives


Schedule of Interview

The interview schedule has a semi-structured design. As the participant’s expertise in their field and their live experiences will be incorporated, scope will be allowed to enable new and unexpected issues to emerge. The order and trajectory of the list of questions outlined is flexible, lines indented refer to question-prompt.

The principal themes will be:

**Background/ Experience**

Could you please describe your experience working at UN and with the CRPD?

- Were you involve at the negotiation stage?

- Does the CRPD attempt to incorporate any minority’s perspectives?

Where they any attempts to rescue the early collaboration of indigenous representatives?

If it was a known that this groups were been leaving behind, this challenge the core idea of inclusion of the CRPD?

**Representation**

Does the negotiation of the UN convention on the Rights of People with Disability involved any indigenous representatives? Yes and they run out of funding and they were leave
behind how at the same time that the CRPD was happening the Declaration was happening

How does the convention incorporates indigenous perceptive about disabilities? Could allocated the views of indigenous peoples?? how the Declaration and international legal framework could be embedded on the CRPD??

**Legal Framework and implications**

How does the CRPD aim of ‘social inclusion’ combines with the right to be different of indigenous with disabilities?

If does combine with the right of self determination.

How does the CRPD interact with the Declaration on the rights of Indigenous People?

Does the CRPD marginalisation of indigenous rights?

What are the limits disabilities civil and political rights and indigenous rights?

This in terms

- Community decision making

- Traditional rehabilitation

- Traditional Medical Interventions

- Traditional Medicine

What were the expected outcomes of CRPD for indigenous people?
Were they are reason to do not include the world indigenous and/or ethnicity this in the context that gender was included?

**Indigenous Health policy driven by the CRPD Article 25 ‘Health’**

How do you perceive human rights for indigenous peoples with disabilities?

- Recognition of indigenous beliefs?

- Recognition of indigenous traditions?

- Recognition of indigenous decision making process and protocols?

- How does the CRPD could enhance improvements for indigenous with disability?

What are the implications of the Declaration on the Rights of Indigenous Peoples for the delivery of the CRPD in Australia/Mexico/New Zealand?

**The Right to Health for Indigenous for people with Disabilities**

Do you think that Māori/Aboriginal and Torres Strait islander/ Purepechas values been meet thought the current health services structure?

How does the CRPD could influences the right to health / health services delivery and access for people with disabilities?

Does the CRPD have any specific obligation for indigenous peoples with disability?

How do you perceive The Right to Health is been delivered for indigenous peoples with disability?

How do you perceive health services for indigenous people with disabilities in comparison with anyone else?
The Convention on the Rights of Persons with Disabilities and its implications for the health and wellbeing of Indigenous peoples with disabilities

Version 3[30/08/2011]

Centre for Disability Studies
Royal Rehabilitation Centre

ABN 15 211 513 464

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PARTICIPANT INFORMATION STATEMENT FOR
INTERVIEWS WITH INDIGENOUS PEOPLE WITH
DISABILITIES

(1) What is the study about?

This study is about the United Nations Convention on the Rights of Persons with Disabilities, Article 25 ‘Health’. The researcher will be looking at how Indigenous peoples with disabilities get health care, how early Indigenous people can get access to health care and how close are services for Indigenous peoples’ to where they live.

(2) What do I have to do?

Minerva Rivas is doing this research for her PhD, at The University of Sydney under the supervision of Professor Patricia O’Brien and Dr. Clive Aspin.

(3) What do I have to do?

You are being asked to participate in an interview. The researcher will ask you about: what you think about your health; if you go to a health service or not, what health services are like for you, how do you feel about going into a clinic or health service, and how you get on with the staff? The interview will last for an hour and will take place at a mutually convenient time, date and place within the next 3 to 6 months.

(4) How much time will it take?

The interview will take one hour.

(5) Do I have to do the study?

It is your choice to take part or not to take part in the study. If you do decide to take part, you can still choose to pull out if you wish.
The Convention on the Rights of Persons with Disabilities and its implications for the health and wellbeing of Indigenous peoples with disabilities

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You can stop the interview at any time and any information you have given the researchers will not be used in the study.

(6) Will anyone else know?

The researchers may write a report about this study but you will not be named in the report and only the researchers will know your answers.

(7) Do I get anything for being part of the study?

Participating in this study will not benefit you directly, however, the study will help you to be heard about what you think needs to improve in relation to health services for indigenous people and what could be done for the implementation of the United Nations Convention on the Rights of Persons with Disability among Indigenous Peoples.

(8) Can I tell people about the study?

Yes.

(9) What if I have any questions?

If you would like to know more at any stage, please feel free to contact me: Minerva Rivas Minerva.rivas@sydney.edu.au ph: +61-2-8878-0500

My supervisors would also be happy to speak to you

Prof. Patricia O’Brien patricia.obrien@sydney.edu.au ph: +61-2-8878-0500

Dr Clive Aspin clive.aspin@sydney.edu.au Phone: +61 2 9036 7003

(10) What if I am not happy with the study?

Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

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FOCUS GROUP PARTICIPANT INFORMATION STATEMENT FOR FOCUS GROUPS WITH HEALTH WORKERS

(1) What is the study about?
This research will explore how Article 25 ‘Health’ of the United Nations Convention on the Rights of Persons with Disabilities is meeting the needs of indigenous people with disabilities. It aims to identify the perception of indigenous peoples with disabilities regarding their access to affordable healthcare, early identification and early intervention and accessible services.

(2) Who is carrying out the study?
The study is being conducted by Minerva Rivas, PhD Candidate at Sydney Medical School. It will form the basis for the degree of PhD at The University of Sydney under the supervision of Prof. Patricia O’Brien and Dr. Clive Aspin.

(3) What does the study involve?
You are being asked to participate in a focus group discussion. The group will consist of approximately 7 health workers who work with Indigenous persons with disabilities. Discussions will be about the needs of Indigenous peoples, how services are delivered, any cultural or physical barriers to health services for Indigenous peoples and how these could be overcome. The focus groups will be held at a mutually convenient time, date and location. With consent the group discussion will be audio recorded. The focus groups will take place within the next 3 to 6 months.

(4) How much time will the study take?
The focus groups will last for approximately one hour

(5) Can I withdraw from the study?
The Convention on the Rights of Persons with Disabilities and its implications for the health and wellbeing of Indigenous peoples with disabilities

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Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with The researcher (s), the Centre for Disability Studies, Sydney Medical School or the University of Sydney,

*If you take part in a focus group and wish to withdraw, as this is a group discussion it will not be possible to exclude individual data once the session has commenced.*

(6) Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

(7) Will the study benefit me?

Participating in this study will not benefit you directly; however this study will enhance the voice of indigenous people with disabilities to be heard, promoting the full implementation of the United Nations Convention on the Rights of Persons with Disability among Indigenous Peoples. This research participant will be offered access to the study findings. This study will lead to knowledge on how to improve services and policymaking in area of Indigenous health services.

(8) Can I tell other people about the study?

Yes

(9) What if I require further information?

If you would like to know more at any stage, please feel free to contact.

Prof. Patricia O’Brien patricia.obrien@sydney.edu.au Ph: +61 2 8878 0500
Dr Clive Aspin clive.aspin@sydney.edu.au Phone: +61 2 9036 7003

(10) What if I have a complaint or concerns?

Minerva Rivas Minerva.rivas@sydney.edu.au Ph: +61 2 8878 0500

Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email). This information sheet is for you to keep
The Convention on the Rights of Persons with Disabilities and its implications for the health and wellbeing of Indigenous peoples with disabilities

PARTICIPANT INFORMATION STATEMENT FOR INTERVIEWS WITH STAKEHOLDERS

1) What is the study about?
This research will explore how Article 25 ‘Health’ of the United Nations Convention on the Rights of Persons with Disabilities is meeting the needs of indigenous people with disabilities. It aims to identify the perception of indigenous peoples with disabilities regarding their access to affordable healthcare, early identification and early intervention and accessible services.

2) Who is carrying out the study?
The study is being conducted by Minerva Rivas, PhD Candidate at Sydney Medical School. It will form the basis for the degree of PhD at The University of Sydney under the supervision of Prof. Patricia O’Brien and Dr. Clive Aspin.

3) What does the study involve?
You are being asked to participate in an interview. During the interview you will be asked about how the United Nations Convention on the Rights of Persons with Disabilities is being implemented among Indigenous peoples with disabilities in regards to Article 25 ‘Health’. If you agree this interview will held at a mutually convenient time, date and location. With consent the interview discussion will be audio recorded. This interview will take place within the next 3 to 6 months.

4) How much time will the study take?
The interview will last for approximately one hour

5) Can I withdraw from the study?
Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with the researcher(s), the Centre for Disability Studies, The University of Sydney or Sydney Medical School.
The Convention on the Rights of Persons with Disabilities and its implications for the health and wellbeing of Indigenous peoples with disabilities

Version 3[30/08/2011]
You may stop the interview at any time if you do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

(6) Will anyone else know the results?
All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

(7) Will the study benefit me?
Participating in this study will not benefit you directly; however this study will enhance the voice of indigenous people with disabilities to be heard, promoting the full implementation of the United Nations Convention on the Rights of Persons with Disability among Indigenous Peoples. This research participant will be offered access to the study findings. This study will lead to knowledge on how to improve services and policymaking in area of Indigenous health services.

(8) Can I tell other people about the study?
Yes

(9) What if I require further information?
If you would like to know more at any stage, please feel free to contact.

Prof. Patricia O’Brien patricia.obrien@sydney.edu.au Ph: +61 2 8878 0500
Dr Clive Aspin clive.aspin@sydney.edu.au
Ph: +61 2 9036 7003

(10) What if I have a complaint or concerns?
Minerva Rivas Minerva.rivas@sydney.edu.au Ph: +61 2 8878 0500

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The Convention on the Rights of Persons with Disabilities and its implications for the health and wellbeing of Indigenous peoples with disabilities

PARTICIPANT INFORMATION STATEMENT FOR INTERVIEWS WITH UN DELEGATES

(1) What is the study about?

This research will explore how Article 25 ‘Health’ of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) is meeting the needs of Indigenous people with disabilities. It aims to identify the perceptions of Indigenous peoples with disabilities regarding their access to affordable healthcare, early identification and early intervention and accessible services.

(2) Who is carrying out the study?

The study is being conducted by Minerva Rivas, PhD Candidate at Sydney Medical School. It will form the basis for the degree of Doctor of Philosophy at the University of Sydney under the supervision of Professor Patricia O’Brien and Dr Clive Aspin.

(3) What does the study involve?

You are being asked to participate in an interview. Through the interview you will be asked about how the United Nations Convention on the Rights of Persons with Disabilities has been developed and implemented in your country, your experience of working at the United Nations and with the CRPD, whether the CRPD attempts to incorporate the perspectives of minority groups, and how the CRPD incorporates Indigenous perspectives about disabilities. If you agree to be interviewed, the interview will be held at a mutually convenient time, date and location within the next 3 to 6 months. With your consent, the interview discussion will be audio recorded. The study combines individual interviews and group discussions. If you agree, the session will be audio recorded. The information will then be transcribed and analysed. Names, titles and references to specific places will be kept confidential.

(4) How much time will the study take?

The interview will last for approximately one hour.
The Convention on the Rights of Persons with Disabilities and its implications for the health and wellbeing of Indigenous peoples with disabilities

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(5) Can I withdraw from the study?

Being in this study is completely voluntary. You are not under any obligation to consent and, if you do consent, you can withdraw at any time without affecting your relationship with the researcher(s) the Centre for Disability Studies, the University of Sydney or Sydney Medical School.

You may stop the interview at any time if you do not wish to continue. In this case, the audio recording will be erased and the information provided will not be included in the study.

(6) Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information about participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in this or any other publications.

(7) Will the study benefit me?

As a UN delegate, participation in this study will not benefit you directly. However, this study will help to enhance the voice of Indigenous people with disabilities. Also, it will provide insights about both enablers and barriers to good health for Indigenous peoples with disabilities in Australia, New Zealand and Mexico.

Research participants will be offered access to the study findings. The study will contribute knowledge about how to improve services and policymaking in the area of Indigenous health services.

(8) Can I tell other people about the study?

Yes

(9) What if I require further information?

When you have read this information, Minerva Rivas will discuss it with you and answer any questions you may have. If you would like to know more at any stage, please feel free to contact any of the following people.

Prof. Patricia O’Brien
patricia.obrien@sydney.edu.au
Tel: +61 2 8878 0500

Dr Clive Aspin clive.aspin@sydney.edu.au  Tel +61 2 9114 0776

Minerva Rivas
minerva.rivas@sydney.edu.au
Tel: +61 2 8878 0500

(10) What if I have a complaint or concerns?

Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

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The Convention on the Rights of Persons with Disabilities and its implications for the health and wellbeing of Indigenous peoples with disabilities

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Centre for Disability Studies
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PARTICIPANT CONSENT FORM INTERVIEWS WITH INDIGENOUS PEOPLE WITH DISABILITIES


I, .................................................................[PRINT NAME], give my consent to participate in the research project.

In giving my consent I acknowledge that:

1. The procedure required for the project and time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

2. I have read the Participant Information Statement and have been given the opportunity to discuss what I have to do.

3. I understand that I can pull out if I wish

4. I understand that my involvement is confidential and no information about me will be used in any way that reveals my identity.

5. I understand that it is my choice to take part or not to take part in the study.

6. I understand that I can stop the interview at any time and the audio will be deleted.

7. I consent to: –

i) Audio-taping YES □ NO □
ii) Receiving Feedback YES □ NO □

If you answered YES to the ‘Receiving Feedback Question (ii)’, please provide your details i.e. mailing address, email address.

Feedback Option
Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).
PARTICIPANT CONSENT FORM FOCUS GROUPS WITH HEALTH WORKERS


I………………………………………………………………………………….[PRINT NAME], give consent to my participation in the research project.

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.

3. I understand that I can withdraw from the study at any time, without affecting my relationship with researcher(s), the Centre for Disability Studies, Sydney Medical School or the University of Sydney now or in the future.

4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.

5. I understand that being in this study is completely voluntary and I am not under any obligation to consent.

Centre for Disability Studies
Royal Rehabilitation Centre

Professor Patricia O'Brien
Professor of Disability Studies
Director of Centre for Disability Studies (CDS)

www.cds.org.au
6. I understand that I can stop my participation in the focus group at any time if I do not wish to continue; however as it is a group discussion it will not be possible to exclude individual data to that point.

7. I consent to: –

i) Audio-taping  YES □  NO □
ii) Receiving Feedback  YES □  NO □

If you answered YES to the ‘Receiving Feedback Question (ii)’, please provide your details i.e. mailing address, email address.

**Feedback Option**

**Address:**  
**Email:**  
**Signed:**  ..........................................................  
**Name:**  ..........................................................  
**Date:**  ..........................................................

Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

Version 3 Amended 30/08/2011

Centre for Disability Studies
Royal Rehabilitation Centre

ABN 15 211 513 464

Professor Patricia O’Brien
Professor of Disability Studies
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Email: patricia.obrien@sydney.edu.au
www.cds.org.au

PARTICIPANT CONSENT FORM INTERVIEWS WITH STAKEHOLDERS


I, ...........................................................................................................[PRINT NAME], give consent to my participation in the research project.

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher(s).

3. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s), the Centre for Disability Studies, Sydney Medical School or the University of Sydney now or in the future.

4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.

5. I understand that being in this study is completely voluntary and I am not under any obligation to consent.
6. I understand that I can stop the interview at any time if I do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

7. I consent to: –

i) Audio-taping YES ☐ NO ☐
ii) Receiving Feedback YES ☐ NO ☐

If you answered YES to the ‘Receiving Feedback Question (ii)’, please provide your details i.e. mailing address, email address.

Feedback Option

Address:

Email:

Signed: ..................................................................................................................................................

Name: ..................................................................................................................................................

Date: ..................................................................................................................................................

Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).
PARTICIPANT CONSENT FORM INTERVIEWS WITH UN DELEGATES


I, .............................................................................................................[PRINT NAME], give consent to my participation in the research project.

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.

3. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s), the centre for Disability Studies, Sydney Medical School or the University of Sydney now or in the future.

4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.

5. I understand that being in this study is completely voluntary and I am not under any obligation to consent.
6. I understand that I can stop the interview at any time if I do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

7. I consent to:

i) Audio-taping YES ☐ NO ☐

ii) Receiving Feedback YES ☐ NO ☐

If you answered YES to the ‘Receiving Feedback Question (ii)’, please provide your details i.e. mailing address, email address.

Feedback Option

Address:

Email:

Signed: ..............................................................................................................................

Name: ..............................................................................................................................

Date: .................................................................................................................................

Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or rhumanethics@sydney.edu.au (Email).
Appendix E: Ethics Committee approvals

Human Research Ethics Committee
Web: http://sydney.edu.au/ethics/ Email: ro.humanethics@sydney.edu.au

Manager Human Ethics
Dr Margaret Faedo
T: +61 2 8627 8176
E: margaret.faedo@sydney.edu.au

Human Ethics Secretariat:
Ms Patricia Engelmann  T: +61 2 8627 8172 E: patricia.engelmann@sydney.edu.au
Ms Karen Greer  T: +61 2 8627 8171 E: karen.greer@sydney.edu.au
Ms Kala Retnam  T: +61 2 8627 8173 E: kala.retnam@sydney.edu.au

ABN 15 211 513 464
CRICOS 00029A
Ref: [MF/KFG]

7 September 2011
Professor Patricia O’Brien
Director
Centre for Disability Studies
Royal Rehabilitation Centre Sydney
RYDE  NSW  2112
Email: patricia.obrien@sydney.edu.au

Dear Prof O’Brien
Thank you for your final correspondence received 6 September 2011 addressing comments made to you by the Human Research Ethics Committee (HREC).

I am pleased to inform you that with the matters now addressed your protocol entitled ‘The Convention on the Rights of Persons with Disabilities and its implications for the health and wellbeing of Indigenous peoples with disabilities.’ has been approved.

Details of the approval are as follows:

Protocol No.: 09-2011 / 13883

Approval Period: September 2011 – September 2012

Annual Report Due: 30 September 2012

Authorised Personnel: Professor Patricia O’Brien
Dr Clive Aspin
Ms Minerva Rivas-Velarde

Documents Approved: Letter of Invitation (version 1, submitted June 2011) Interview Schedules (version 1, submitted June 2011) Participant Information Statements:
• Guardian Information Statement (version 3, 30/08/2011)
• Focus Groups with Health Workers (version 3, 30/08/2011)
• Interviews with Stakeholders (version 3, 30/08/2011)
• Interviews with UN delegates (version 3, 30/08/2011)
• Indigenous people with disabilities (version 3, 30/08/2011)

Participant Consent Forms:
• Guardian Consent Form (version 3, 30/08/2011)
• Focus Groups with Health Workers (version 3, 30/08/2011)
• Interviews with Stakeholders (version 3, 30/08/2011)
• Interviews with UN delegates (version 3, 30/08/2011)
Indigenous people with disabilities (version 3, 30/08/2011)

The HREC is a fully constituted Ethics Committee in accordance with the National Statement on Ethical Conduct in Research Involving Humans-March 2007 under Section 5.1.29.
The approval of this project is conditional upon your continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans.

A report on this research must be submitted every 12 months to the Human Research Ethics Committee from the final approval period or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of ethics approval for the project. Please download the Annual Report/Completion Report Form from the Human Ethics website at: http://sydney.edu.au/research_support/ethics/human/forms.

The HREC approval is valid for four (4) years from the Approval Period stated in this letter and is conditional upon submission of Annual Reports. If your project is not completed by four (4) years from the approval period, you will have to submit a Modification Form requesting an extension. Please refer to the guideline on extension of ethics approval which is available on the website at: http://sydney.edu.au/research_support/ethics/human/extension.

Chief Investigator / Supervisor's responsibilities to ensure that:

1. All serious and unexpected adverse events should be reported to the HREC within 72 hours.

2. All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.

3. You must retain copies of all signed Consent Forms and provide these to the HREC on request.

4. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

5. All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The following statement must appear on the bottom of the Participant Information Statement: Any person with concerns or complaints about the conduct of a research study can contact the Manager, Human Ethics, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

6. Any changes to the protocol including changes to research personnel must be approved by the HREC by submitting a Modification Form before the research project can proceed. Please refer to the website at http://sydney.edu.au/research_support/ethics/human/forms to download a copy of the Modification Form.

7. A Completion Report should be provided to the Human Research Ethics Committee at the completion of the Project.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely

Dr Margaret Faedo
Manager, Human Ethics
On behalf of the HREC

cc: Minerva Rivas-Velarde minerva.rivas@sydney.edu.au
Appendix F: AH and MRC approval

Dear Professor O’Brien

851/12 – The convention on the rights of Persons with Disabilities and its implications for the health and wellbeing of Indigenous peoples with Disabilities

I am pleased to advise you that the reviewers have recommended the above application for approval by the AHandMRC Ethics Committee, subject to the following Standard Conditions and Special Condition/s of Approval being met:

‘Standard Conditions of Approval (where applicable to the project)

1. The approval is for a period from 7 May 2012 until 31 May 2013, with extension subject to providing a report on the research by 31 May 2013.
2. All research participants are to be provided with a relevant Participant Information Statement and Consent Form in the format provided with the application.
3. Copies of all signed participant consent forms must be retained and made available to the Ethics Committee on request. A request will only be made if there is a dispute or complaint in relation to a participant.
4. Any changes to the staffing, methodology, timeframe, or any other aspect of the research relevant to continued ethical acceptability of the project must have the prior written approval of the Ethics Committee.
5. The AHandMRC Ethics Committee must be notified immediately in writing of any serious or unexpected adverse effects on participants.
6. The research must comply at all times with:

   the AHandMRC Guidelines for Research in Aboriginal Health- Key Principles
   the National Statement on Ethical Conduct in Research Involving Humans (April 2007); and
   the NSW Aboriginal Health Information Guidelines.

7. The final draft of the report from the research, and any publication or presentation prior to that report where new data or findings are presented, must be provided to the AHandMRC Ethics Committee to be reviewed for compliance with ethical and cultural criteria prior to:

   any submission for publication; and/or
   any dissemination of the report.

8. A copy of the final published version of any publication is to be provided to the AHandMRC Ethics Committee.

Special Condition/s

9. NIL.

I have drafted a letter for the Chairperson’s signature but as she lives in the country there will be a few days in the turn-around.

On behalf of the AHandMRC Ethics Committee thank you for submitting your application for Ethics approval.

With kind regards
Robert
Robert Fritchley
Project Officer
Ethics Committee

Aboriginal Health and Medical Research Council
Postal Address: PO Box 1565 Strawberry Hills 2012
Web: www.ahmrc.org.au

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Appendix G: Invitation Letter

NAME

TITLE

The purpose of this letter is to introduce you to Minerva Rivas, an Indigenous Mexican student who has come to Sydney to do her PhD at the Centre for Disability Studies.

Minerva’s study is looking at how Article 25 “Health” of the United Nations Convention on the Rights of People with Disabilities is meeting the needs of Indigenous people with disabilities.

She is exploring the perceptions of Indigenous peoples with disabilities in order to understand how their health needs are being met as well as issues such as affordable care, early identification and early intervention, accessible services, quality, and insurance.

Her study will consider and compare the implications of the Convention on the Rights of Person with Disability (CRPD) in three different countries: Australia, Mexico and New Zealand (Maori, Aborigines and Torres Strait Islanders and Purepechas).

The study takes a qualitative approach. It will involve focus groups and Interviews with Indigenous people with disabilities (this includes all types of disabilities, sensory, physical and intellectual). A balance of gender and rural and urban settings will be pursued. Health workers, policy makers and United Nations Delegates to CRPD will also be interviewed in order to triangulate information on the issues.

The main expected outcomes of the project will be an International comparative exploration of how Article 25 “Health” of CRPD is meeting the needs of indigenous with disabilities with regard to health. The project will identify gaps in the policies and practices of health services related to people with disabilities.
Minerva will be visiting New Zealand in November 2011 and is keen to meet people working in the field of disabilities and Maori health. I would be grateful if you or one of your staff could meet with Minerva to discuss her research endeavours. If you are available she will make contact with your office next week to seek an appointment for next November.

I look forward to hearing from you

With good wishes

[Signature]

Patricia O’Brien

Professor of Disability Studies

Sydney Medical School