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**Hand Rails into the Ocean:
Contrasting Human Rights Disability Policy and
Real-Lived Experiences in the Cook Islands.**

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Abstract

Globally, the Convention of Rights for Persons with Disability (CRPD) is coming into force, with over 100 countries ratifying to date. Moreover, policy-makers and practitioners in the disability field are increasingly looking to evidence-based strategies to assess and maximise the sometimes limited resources that Governments, NGOs and people with disabilities have. Of vital importance is that this assessment is undertaken alongside people with disabilities and any priority needs are understood within the local, cultural context.

That said, the Cook Islands ratified the CRPD in May 2009, after strong lobbying from several local disability groups. However, the CRPD has not necessarily come into play in the real-life experiences for people with disabilities in the Cook Islands. There appears to be a lack of awareness surrounding not only the lived-experience of people with disability, but what the priority needs may be. This was recently highlighted also by disability groups in the Cook Islands being undecided on a priority project when a funding application was offered by the Pacific Disability Forum (PDF).

With this in mind the aim of this research was to explore alongside people with disabilities their attitudes around disability, barriers to development and prioritised needs through application of an emancipatory methodological approach. The main method of data collection was through story-telling which not only fits with Cook Island tradition and allowed for a rich dialogue, but sought to ensure that the voices of those living with a disability were heard and documented.

Findings reveal a weak human rights perception around disability, largely due to a lack of self-belief by the people with disabilities. It was also found that even though good human-rights disability policy is in place, the two most prioritised needs; a lack of assistive aids and education on disability awareness hampered the personal development of people with disabilities. Hence, a new rights-based and capabilities approach assessment tool and action plan has been designed to further identify gaps and subsequently, future funding for this area is now in the application process with the PDF.

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Thanks to Pat, whose knowledge and love resonates through the people with disabilities and their families. Your supply of Noni juice kept me going on my wonderfully enriching weeks in field research. Thanks to Mataiti Mataiti for showing me around his family's Takitumu Conservation area where he has his motto engraved at the Pavilion. This motto epitomises his journey through his disability;

“Do not walk in front of me, I may not follow,
Do not walk behind me, I may not lead
Just walk beside me, and be my friend”.

Pare Tangata shared her invaluable cultural knowledge with me and undertook all the Cook Island Maori language translations. Thanks also to Te Vaerua Council whose love and support for people with disabilities is a beacon of light for continued development for people with disabilities in the Cook Islands.

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List of Acronyms and Abbreviations

ACE	Assistive Cardboard Equipment
ADB	Asian Development Bank
APIDS	Australia Pacific Islands Disability Support
AusAID	Australian Agency for International Development
BMF	Biwako Millennium Framework
CBR	Community Based Rehabilitation
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
CERD	Convention on the Elimination of All Forms of Racial Discrimination
CINCW	Cook Islands National Council for Women
CINDC	Cook Island National Disability Council
CRC	Convention on the Rights of the Child
CRPD	Convention for the Rights of Persons with Disability
CSOs	Civil Society Organisations
DPI	Disabled Persons Institute
DPOs	Disabled Person's Organisations
DSH	Disability Stakeholder
FCV	Family Caregiver
HDI	Human Development Index
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICF	International Classification of Functioning, Disability and Health
ILO	International Labour Organisation
IMF	International Monetary Fund
KIPA	Knowledge, Inclusion, Participation, and Access
MDGs	Millennium Development Goals
MOH	Ministry of Health
MOIP	Minister of Infrastructure and Planning

NGOs	Non-Government Organisations
NSDP	National Sustainable Development Plan
NZAID	New Zealand Agency for International Development
NZMFAT	New Zealand Ministry of Foreign Affairs and Trade
ORD	Organisation of Disabled Revolutionaries
PDF	Pacific Disability Forum
PICs	Pacific Island Countries
PIFS	Pacific Island Forum Secretariat
PRA	Participatory Research Approach
PWD	People With a Disability
SAPs	Structural Adjustment Programmes
Te Kainga	Te Kainga o Pa Taunga Family Services and Mental Health Association
Te Vaerua	Te Vaerua Rehabilitation Council
UDHR	Universal Declaration of Human Rights
UNDP	United Nations Development Programme
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNOHCHR	United Nations Office of the High Commissioner for Human Rights
UPIAS	Union of the Physically Impaired Against Segregation
WB	World Bank
WHO	World Health Organisation

Karakia

Prayer for the Disabled - Pure No te Iti -Tangata Pakipaki-tai.

Father I thank you for giving me much of your wisdom and knowledge to understand how significant everyone is in our society.

E te Atu, te akameitaki atu nei au ia Koe, no te kite e te pakari taau i oronga mai kia marama matou i te puapinga o te au tangata tatakitai, i roto i to matou ipukarea.

Though we may be different in so many ways you still love us no matter who we are.

Uatu to matou au tu tuketuke, kare rai toou aroa e tuke, uatu e koai matou.

This means whether we are disabled or not, you still love us unconditionally.

Noatu e kua akaparuparu tetai au mero o to matou kopapa, kare te reira e riro ei akakotinga i toou inangaro e toou aroa ia matou

So please help us to be more like you, to love and care for everybody, especially our disabled people.

E no reira, tauturu mai ia matou kia aite matou kia koe, i te aroa ia matou uaorai, e pera katoa to matou au taeake pakipakitai.

Help the disabled to know that in spite of their disabilities father, you can use them in a very special way.

Tauturu mai i to matou au taeake pakipakitai kia kite e, e angaanga takake taau i akanoonoo ia ratou kia rave, i roto i to ratou oraanga.

When we are troubled you will help us through any circumstance, so please help the more able ones like me, to provide as much support and care, so that the disabled may have their needs met so they live happy, successful lives.

I roto i to matou tumatetenga, naau e te Atu e tauturu mai ana ia matou i te au atiangaravari. E no reira, te pati atu nei matou kia koe, kia oronga mai koe i te ngakau aroa e te tauturu ki te aronga maroiroi, kia rauka ia ratou i te akono atu i te au taeake pakipakitai, kia puapingaia e kia mataora to ratou oraanga.

We pray all these things with humility and love.

Kua pure matou i teia au mea katoatoa i roto i te ngakau akaaka e te aroa.

Amen! Amene!

Karakia written for this research by Pastor Teina Taivairanga (2011)

Chapter 1: Introduction

Disability is defined by culture, and without an awareness of how disability is perceived in the target culture a disability programme does not stand much chance of being relevant or sustainable (Coleridge, 2000, p.1).

The Pacific region, compared with other regions of the world, has ratified the fewest number of core international human rights treaties (Pacific Island Forum Secretariat (PIFS), 2009a). However, in terms of what has been ratified, the Convention for the Rights of Persons with Disability (CRPD) came into force in the Cook Islands in 2009. As the CRPD is promoting an inclusive, barrier-free and rights-based society for people with a disability, it is now a good time to research how rights-based policies and conventions have been put into practice. Therefore, this study investigates if there is a gap between the rights-based policies and real-lived experiences of people with disabilities in the Cook Islands.

In December 2010, I was privileged to be asked to fill a volunteer Physiotherapist position in Rarotonga, Cook Islands for a 6 week period. This involved mornings working at Rarotonga Hospital for the Ministry of Health (MOH), and afternoons in the community for the Non-Government Organisation (NGO) Te Vaerua Rehabilitation Council (Te Vaerua). The work with Te Vaerua involved assessing people with disabilities and planning their rehabilitation. This opportunity gave me a brief insight into disability and how it is perceived and supported in the Cook Islands. The Cook Islands recently introduced a Disability Act (2008) to act alongside the CRPD. On my rounds visiting people with disabilities, their families and disability stakeholders, I started to see that disability policies and the CRPD had not yet translated into practice. While a global paradigm shift from a charity-based model of disability to a social model has occurred (Kett, Lang and Trani, 2009), promoting a shift from

the disability as a barrier to social and environmental factors as barriers was not apparent in the Cook Islands.

This introductory chapter will outline the research rationale and state the research aim, key question and objectives. It also introduces the Cook Islands and gives a brief outline of the geographical, political, social and economic environment. It concludes with the outline of the structure of this study.

Research Rationale

During the time volunteering, I was invited to observe in a disability stakeholder meeting which attempted to coordinate all the service providers with Government representatives and the Cook Island National Disability Council (CINDC). It was during this meeting that I made contact with a variety of disability stakeholders.

Working with, and talking to people with disabilities I mentioned I was planning to undertake research for Masters Study around the topic of disability in the Cook Islands. This was met with a lot of support. This amount of this support came as a surprise to me, due to the fact I was Papa'a (foreigner). Several people with disabilities mentioned the priority area/s they would like to see investigated. Predominantly, they wanted to voice their needs, which they all said they could not do independently. Family members of people with disabilities talked to me about barriers they were facing, including mostly social rights-based issues, such as poor access and lack of assistive aids. Disability stakeholders I talked to informally mentioned attempts, with limited funding, to raise rights-awareness.

Thus, while there is disability policy developed in the Cook Islands and support for people with disability, it appeared there was little translation of that policy and political goodwill into practice. As a student of International Development Studies, these gaps within rights-

based disability policies particularly interested me. I became interested in the idea of aiming my research to be applicable not only to those participants who were interviewed in the field research, but also the “invisible” people with disabilities. These include those who are still excluded from society, and those in the outer islands. Through studying inclusive development as a postgraduate student, I also realised the importance of conducting this study in partnership with people with disabilities, to make it an emancipatory journey for as many as possible, and to follow their disability officer’s motto “Nothing about us, without us”. For this reason, reciprocity is an important research method I have used to underpin this study, which will be further discussed in Chapter 4.

Research Aim, Key Question and Objectives

This study aims: **to explore critically, the human rights-based disability policies and frameworks, and the real-lived experiences of people with disabilities in the Cook Islands.**

The key question being: **‘What is the relationship between human rights-based disability policy and frameworks and the real-lived experiences of people with disabilities in the Cook Islands’?**

The three objectives following on from the research aim are:

- 1. To document human rights-based disability policy and frameworks in the Cook Islands.*
- 2. To explore real-lived experiences of people with disabilities, their families and disability stakeholders in the Cook Islands.*
- 3. To identify gaps, if any, between human rights-based disability policy and real-lived experiences of people with disabilities, their families and disability stakeholders.*

To help achieve objectives 2 and 3, the following four questions are asked. The first three questions were particularly asked for investigation by people with disabilities on contacting them prior to field work:

- i. What are the attitudes surrounding disability from a Cook Island perspective?
- ii. What are the barriers to development for people with disabilities?
- iii. What are the prioritised needs for development for people with disabilities?
- iv. How would a human rights-based capabilities approach assessment fit in with disability for development in a Cook Island context?

For the purpose of this study two theoretical lenses, are brought together to investigate the relationship between policy and practice of disability rights in the Cook Islands. These are:

- i. Human rights theory, with particular reference to the capability approach
- ii. Disability theory, including paradigm shifts from the medical models to social models.

These two frameworks will be discussed in Chapters 2 and 3 respectively.

An Introduction to the Cook Islands

To allow a broader understanding of the underlying factors of disability discourse in a country, a critical approach must be taken that incorporates social, political and economic factors of a country (Coleridge, 2000). The following background of the Cook Islands gives a brief outline of the current situation and sets the scene of what the emergence of disability rights and human rights is being woven into.

Geographical Situation

The 15 islands that make up the Cook Islands are dispersed over nearly 2 million square kilometres (Cook Island Government, 2011). Rarotonga, the main Island is 32 km around its

circumference and is where all the field research took place for this study (see **Figure 1**). Out of the resident 12,000 people of the Cook Islands estimated in 2010, two thirds live on the island of Rarotonga (New Zealand Ministry of Foreign Affairs and Trade (NZMFAT), 2011).

Figure 1: Map of the Cook Islands



Source: University of Texas (2011).

Jonassen (2009) explains that due to the wide dispersal of islands, Cook Island Māori people tend to regard themselves along tribal designations rather than a national one. A personal observation from volunteering in Rarotonga Hospital in 2010 was that when a new patient arrived, they were asked what Island they were from and which family. The tribal link is then

made and the background of that person is established with local knowledge surrounding that tribe or Island family. Addresses are not asked, not only because there are no postal services to houses, but once the family link is established, it is known that someone in that family will know where the individual is living. The family clan structure has very strong links but these links are weakening as further described below.

Social Situation

As mentioned every Cook Island Māori is part of a family clan, which is connected in some way to the ancient system of chiefs. Traditionally, families often live together in large groups, with grandparents living with children or grandchildren. Rarotonga has three vaka (literally meaning canoes): Takitumu, Te Au-o-Tonga (Avarua) and Puaikura (Arorangi). Each vaka's descendants have rights to tapere (segments of land) within that vaka. As noted by Sissons (1998) this traditional family structure is changing with post-colonial aid and tourist development widening class divisions causing less dependence on local kin as a result. Over ten years on, this continues to be true. The Cook Island Government (2006) identifies the average number of people per household with 10 people or more decreased from 14% in 1996 to 8%. Cook Islanders have a life expectancy of 74.3 years for women and 68 years for men. In 2002, with a Human Development Index (HDI) of 0.822, the Cook Island people had a good standard of living compared with other Pacific Island and developing countries (Catherwood, and Topa-Apera, 2003). Unfortunately more current data for the Cook Islands HDI is unavailable, due to having no reliable or missing data received by the United Nations (O'Keeffe, 2010).

The church plays a big part in the present day lives of Cook Islanders. Stubbs and Tawake (2009) describe how Christianity and other religions portray tolerance and respect, but can also be exclusionary. It has been a challenge for the church to change beliefs about the causes

and effects of disability with literal preaching from the Old Testament that asserts that disability is a curse from God and the only way forward is to be healed or reformed by the Messiah.

Political Situation

Since 1965, the Cook Islands have been a self-governing parliamentary democracy in free association with New Zealand with Cook Island citizens having automatic rights to New Zealand citizenship. There is a 15-member House of Ariki (chiefs) which was established in 1966, comprising of six ariki from Rarotonga and nine from the outer islands who advise Government on customary and land use issues (Jonassen, 2009).

Parliament consists of a single chamber of 24 elected members, 10 of whom are from the main island of Rarotonga and the rest are from the outer islands. Currently the Hon. Henry Puna is Prime Minister and leader of the Cook Islands Party. The current opposition is the Democratic Party led by Hon. Robert Wigmore. The Cook Island Government Internal Affairs Department is the disability national coordination mechanism, which has several disability and human rights frameworks and policies to work with that will be discussed in detail in Chapter 5.

Economic situation

In August 2009, as described by NZMFAT (2011), Standard and Poor's¹ downgraded its outlook for Cook Islands from stable to negative, due to uncertainty about projected tourism numbers and a deteriorating debt position. Problems with the Cook Islands economy stems

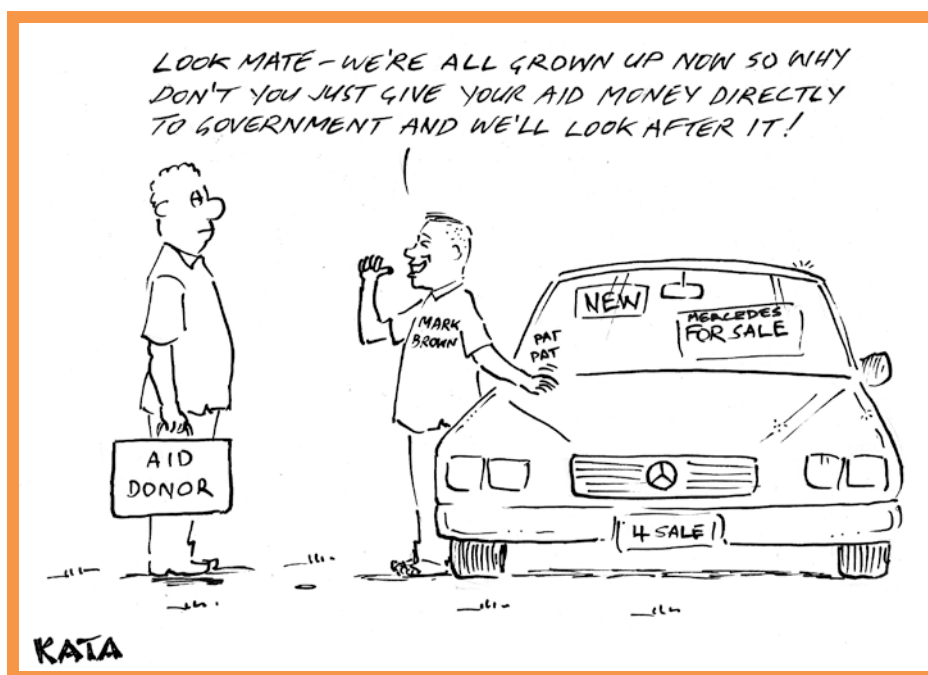
¹A credit rating is *Standard & Poor's* opinion on the general creditworthiness of an obligor, or the creditworthiness of an obligor with respect to a particular debt

from its narrow economic base being underpinned by tourism and marine resources making it vulnerable to external shocks and the global economic crisis. Jonassen (2009) tells of the massive Sheraton Resort construction that fell through in the 1990s putting the Government of the time approximately NZ\$100 million in debt. Further to this in the mid-1990s, a major scandal involving the countries offshore-banking industry led to a collapse in the economy. As a result of their deteriorating economic position the Cook Islands were forced to enter into an economic-stabilisation programme in 1996, and as a result approximately 2000 Government employees (one tenth of the population) lost their jobs. Many Cook Islanders left the country mostly to New Zealand or Australia seeking employment and a different lifestyle and today, 2.6 times as many Cook Islanders live in New Zealand as in the Cook Islands itself (Cook Island Government, 1996). As a result of this mass migration many households now receive their cash incomes from remittances, pensions and welfare (Catherwood and Topa-Apera, 2003).

Development Assistance

As documented in NZMFAT (2011), New Zealand and Australia run an integrated development cooperation programme in the Cook Islands, totalling more than \$17 million (NZ\$15 million plus Australia \$2 million) for 2010-2011. Health and education had been earmarked for \$4.8 million of this total amount however this year it was announced that NZAID would instead be providing aid directly into general budget support. This was met with some discontent by the general public due to the recent history of economic mismanagement, as portrayed in **Figure 2** seen in the Cook Island News (2011).

Figure 2: Discontent about general budget support



Source: Cook Island News, (2011)².

In summary, this section has articulated the shifting social, political and economic situations in the Cook Islands. As mentioned, disability research must look critically at all the factors within the country context to ensure a comprehensive understanding is reached. Volunteering there for 6 weeks in 2010 and immersing myself into the community has significantly helped towards reaching an understanding of the different contexts, which has had an impact on the way this research has evolved, particularly with more emphasis being placed on cultural factors.

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Structure Outline of Study

Chapter 1 has introduced the study aim, key question and objectives. A brief background to the Cook Islands has also been given regarding the geographical, social, political and economic environments. This context is what disability and human rights are woven into, which will be presented in Chapters 2 and 3.

Chapter 2 conceptualises an understanding of human rights. The history of the universal declaration of human rights is presented with particular reference to the CRPD. This is followed by discussion around how development and poverty alleviation weaves in with the human rights approach, being a helpful tool to improve basic freedoms. It will be explained how the capabilities approach can supplement the language of rights with particular reference to people living in the context of their own culture. The chapter is concluded with a disability meets human rights framework, the CRPD and its relevance to the Cook Islands.

Chapter 3 provides a theoretical framework for this study with particular reference to disability. A recent paradigm shift from a charity-based and medical model to a rights-based, social model will be critically discussed. Three other main areas debated are disability and development, attitudes surrounding disability, and the recent movement towards inclusive policy formation with the participation of Disabled Person's Organisations (DPOs).

Chapter 4 focuses on research methodology, particularly the use of an emancipatory methodology and participant observation. The data collection methods used and the importance of reciprocity and political links within the scope of this study are presented. This chapter also includes discussion on a rethinking of priorities for this study, shifting the focus on rights-awareness to a more needs-based study in keeping with in-depth interview answers and dialogue from people with a disability. This is not in keeping with the current paradigm

shift from a needs-based to rights-based development. This study does however, shift towards using a capabilities approach to enable data collection for Government officials and Disability Groups and will encourage people with disabilities to address their rights.

Chapter 5 focuses fully on the Cook Islands and the findings from the field research interviews, field journal entries, a small focus group and personal observations. These findings are divided into two main sections; the first section addresses the first objective of this study by including human rights-based disability policies and frameworks. The second section addresses the second objective of this study, reporting the findings from the lived experiences presented here using thematic analysis on the area of; attitudes, barriers to development and prioritised needs for people with a disability, their family caregivers and disability stakeholders.

Chapter 6 has discussion around the field research findings in Chapter 5, and weaves literature from Chapter 2 and 3 into this debate. The third objective of this study; to identify gaps between human rights-based disability policy and real-lived experiences of people with disabilities, will be presented. The chapter also discusses how a human rights-based capabilities approach of assessments fit in with a Cook Island context of developing disability rights. The study concludes with recommendations for Te Vaerua Rehabilitation Council to include in their annual report to Government.

Chapter 2: Understanding Human Rights

Introduction

This chapter outlines and debates the human rights framework, from its history to present day. The Universal Declaration of Human Rights (UDHR) is an important document which will be discussed along with its relevance in disability discourse. The particular link relevant to people with disabilities is the paradigm shift from a poverty alleviation approach to a social justice approach in development debate.

This chapter will also outline the debate between universalism and cultural relativism as well as the capabilities approach which links human rights, development and disability together. These on-going debates bring into play particular issues of human rights specific to the Pacific, which will be discussed. The value of using human rights in development will be explained briefly under three categories; normative, pragmatic and ethical. Here the link between human rights and development will be made by describing how human rights and development can be moderated to suit all states. The literature used in this chapter will be focussed further when it discusses how the CRPD and the four main ways it can potentially weave together human rights, disability and development.

Human Rights History

The UDHR formed in 1948 is seen as central to the human rights movement and is used for both state and non-state actors alike in realising rights of the marginalised. However, the concept of human rights has been around a lot longer than the 1948 UDHR. Many different cultures used human rights in their beliefs of which a brief history will be discussed below.

Human Rights pre 1945

Human rights ideas and practices arose not from any deep Western cultural roots but from the social, economic, and political transformations of modernity (Donnelly, 2007, p. 287).

As portrayed in the above quote, human rights practices have relevance irrespective of the pre-existing culture of the place. Donnelly (2007) notes that natural rights theory is evident as far back as John Locke's *Second Treatise of Government* published in 1689 in support of the (so-called) Glorious Revolution. The American and French Revolutions first used similar ideas to construct new political orders.

History in human rights discourse shows a pattern of rise and fall; each human rights movement has had setbacks after each rising. Ishay (2008) talks about the French Revolution setback by the nationalist reaction in France and the onset of World War I. The Bolshevik Revolution and liberal sister institutions, the League of Nations and International Labour Organisation (ILO) have also used a human rights framework. These too were set back by the rise of Stalinism and fascism during the interwar period. Human rights have been challenged in present day too, with nationalism in Russia, South Africa and Balkan states. This said, human rights have strengthened in the present day through the UDHR, particularly for those without a voice.

The Universal Declaration of Human Rights (UDHR)

The United Nations was formed in 1945, following World War II when over 100 million people were killed or disabled. The UDHR was subsequently formed in 1948, originally drafted, amongst others, by Chinese philosopher Pen-Chung Chang, Lebanese philosopher, Charles Malik and French legal scholar Rene Cassin. These scholars were members of the

Human Rights Commission, overseen by Eleanor Roosevelt during this time, who worked together to help form the UDHR. The United Nations Educational, Scientific and Cultural Organisation (UNESCO) were commissioned to circulate a global questionnaire on human rights which was added to the original draft (Ishay, 2008). This was an important gesture as it became a more inclusive document as will be discussed later in this chapter.

According to the United Nations Office of the High Commissioner for Human Rights (UN OHCHR, 2011) human rights are universal, and inalienable. Human rights are also independent and indivisible, equal and non-discriminatory. Technically, the UDHR has no signatories as it is not legally binding on its own. The UDHR is only one part of the United Nations Human Rights Charter, with the other two parts being the Optional Protocol and the International Covenant on Human Rights. Collectively they form the International Bill of Rights. There are currently 192 member States that each has one vote in the United Nation's parliament, the General Assembly (United Nations General Assembly (2011)). The following nine covenants shown in **Table 1** are legally-binding when ratified by an individual state.

Table 1: Human rights conventions

Treaty	Adopted	Monitoring Body
International Convention on the Elimination of All Forms of Racial Discrimination (CERD)	1965	Committee on the Elimination of Racial Discrimination
International Covenant on Civil and Political Rights (ICCPR)	1966	Committee on the Civil and Political Rights
International Covenant on Economic, Social and Cultural Rights (ICESCR)	1966	Committee on Economic, Social and Cultural Rights
Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)	1979	Committee on the Elimination of Discrimination Against Women
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment	1984	Committee against Torture
Convention on the Rights of the Child (CRC)	1989	Committee on the Rights of the Child
International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families	1990	Committee on the Rights of Migrant Workers
International Convention for the Protection of All Persons from Enforced Disappearance	2006	Committee on Enforced Disappearance
Convention on the Rights of Persons with Disabilities	2006	Committee on Rights for Persons with Disabilities

Source: Author.

Not all of the 192 states have signed and/or ratified the listed covenants noted above in **Table**

1. As Eagleton (2004) maintains, state actors are made accountable through using a rights-

based approach and rights imply duties, which lead to accountability. This relatively new legally-binding rights-based framework is a welcome respite for a range of actors as they can now have their rights realised and were able to come to the negotiating table. Even in countries where resources are low and infrastructure is non-existent, state actors must be seen to be providing human rights as best as they can. This is done by the state formally meeting three objectives based on Raworth, (2004):

- i. Respect. The state must not interfere directly with people realising their rights.
- ii. Protect. That state must stop others from interfering with people's rights
- iii. Fulfil. The state must build the legislation, institutions, norms to realise the right.

Human Rights and Development

For a long time, human rights were regarded as window-dressing on the development process or even irrelevant to it (Grugel and Piper, 2009, p.79)

However, development and poverty alleviation have been viewed through the human rights lens since the 1986 signing of the UN's Declaration of the Right to Development (Robinson, 2001). There has also been a paradigm shift from a charity or needs-based approach to a rights-based approach towards disability development as will be expanded on in more detail in the next chapter. The question is whether the two fields of human rights and development have converged in a practical sense as well as a theoretical sense, which is pertinent to the objectives of this study. Foster (2010) finds the major risk factors to non-successful development now is the lack of human rights and poverty of opportunity which concurs with Sen (1999), who views the human rights approach as being a helpful tool to an improvement in basic freedoms.

The paradigm shift towards using a human rights approach is due to several reasons. In the first instance, it has occurred due to the failure of past development agendas. An example of this is the macroeconomic based Structural Adjustment Programmes (SAPs), of the International Monetary Fund (IMF) and the World Bank. As Kanji and Manji (1991) maintain, these programmes often made the poor poorer by taking away health services and social services and subsidies used by vulnerable groups.

A second reason for the paradigm shift occurring within development is described by Cornwall and Nyamu-Musembi, (2004). They describe how at the end of the Cold War democratic discourse followed with a demand for legal frameworks to be put in place to encompass all rights. A third reason for the shift can be attributed to NGO's integrating rights as a normative framework for development, re-politicising development approaches, which will be discussed further below under normative rights. As Cornwall and Nyamu-Musembi (2004) and Barnes (1999) explain, rights-based approaches can encourage participation which has been partially lost through mainstreaming by powerful institutions like the World Bank.

By using the human rights approach and participatory development together, the practice of delivering development programmes may improve, using the hands on experience and theoretical concepts of both approaches. An important area of change from a needs-based to a rights-based approach towards development is the accountability of stakeholders, now bound by law and duties. Inequality, as argued by Pogge (2005), emphasises that poverty for the 44% of the world's population is solvable, and that the people in poverty only need one more percent of global product to lift them from the poverty line of earning over \$2 per day. Currently this 2,735 million people below the poverty line have only 1.3% of the world's global product and 955 million of people in the higher income countries have 81% of

the global product. These figures show a lack of human rights by people from higher income countries towards those who are poor.

It is hoped that by using the human rights approach within development, accountability of all stakeholders will rise and empower those previously without a voice. The introduction of human rights into development discourse is not without controversial issues. The next section will consider two of these issues; universalism of human rights and cultural relativism.

The Controversy over the Universalism of Human Rights

There is intense debate in the literature about the universalism of human rights versus that of cultural relativity. The critics and advocates arguing for and against the human rights approach and the UDHR framework will be discussed here. Universalism of the UDHR and its human rights model is based on the idea that there are certain covenants which are universal and invariable. The first main criticism of universalism in the human rights approach is that the focus is on the individual, not the community or a group. Ignatieff (2001) describes a positive proponent of this individuality is that women and children can have a chance to fight a patriarchal society for a better life. Article 29 of the UDHR (UDHR, 2011) states that “everyone has duties to the community in which alone the free and full development of his personality is possible”. This helps combat the individualistic emphasis a universal approach portrays. It is important to note that individual states have the option of ratifying a covenant with reservations, incorporating their state laws and values into their ratified agreement.

The second main criticism of the universalism of the human rights approach is that it is seen as solely Western-based. As mentioned earlier in this chapter, UNESCO sent out a questionnaire to all UN member states on their views of human rights drawn from their

country's religion, culture and philosophical backgrounds in order for these to be viewed by the Human Rights Commission to make up the UDHR. This participation of all member states in the UDHRs formation diminishes the argument that the UDHR is solely a Western-based document.

Donnelly (2007) discusses how movements of social justice and political opposition in developing countries are now using human rights language as it is increasingly being seen as a precursor to having political legitimacy in developing nations. Slim (2002) concurs with this by saying that rights-based talk stops people being perceived as victims. Instead, they are seen as people who present themselves as dignified and rightfully making just demands on their government.

As well as universalism being a main criticism of human rights in development, so is cultural relativism. Cultural relativism is an important underpinning concept with regard to his study in the Cook Islands, as will be discussed below.

The Cultural Relativism Debate

Cultural relativism is a recurrent product of a historical failure to promote human rights discourses in practice, rather than a legitimate alternative to the comprehensive vision offered by a universal stand on justice (Ishay, 2008, p.11).

Cultural relativism is an area that has critics as Ishay's quote shows above, and its proponents, both of which will be debated here. Farran (2009) and Ibhawoh (2000) criticise literature that uses cultural relativism as an excuse for not using a human rights approach. They stipulate that culture is not static, and people could belong to a number of different cultural identities in one country alone, making it difficult to form a national set of rights as relativists require. Ishay (2008) concurs and explains how cultural extremism led to

September 11, 2001, and the 'War on Terror', showing how fragile human rights can be. She goes on to recommend that security can be founded in human rights to overcome the 'War on Terror'. Mary Robinson, a former President of the UN High Commissioner for Human Rights, also says the importance of human rights was highlighted after the September 11 attack on innocent civilians, bringing a focus on combating xenophobia and intolerance (Robinson, 2001).

Ignatieff (2001) divides proponents for cultural relativism into three groups; Islamic, East Asian and postmodern Western groups. Challenges against the UDHR show a cross-cultural validity of these groups concerns. An example where Islamic culture is a proponent to cultural relativism is the challenge to Article 16 in CEDAW; the freedom of choice in marriage. Most Islam states did not ratify without reservations to CEDAW. This was due to marriage in Islam culture not giving women the right to choose their marriage partner by stating that the wisdom over the years have shown that this is not to be part of their traditional beliefs.

Katsumata (2009) explains the main challenge to human rights from an East Asian perspective. East Asian proponents state that not adopting a human rights approach is largely due to having economic success without it. They are only mimetically adopting human rights approaches, so they are seen as progressive, liberal countries.

The third proponent for cultural relativism is the postmodern West. According to Ignatieff (2001) previous imperialistic thoughts of human rights need to shift to become more culturally aware. National human rights should include culture and it is then up to the individual states to put these rights into practice as they see best fit. This will now be further discussed in the next section which weaves human rights and culture together.

Weaving Together Of Human Rights and Culture

Human rights should, and do, allow for the diversity of different values and cultures. Donnelly, (2007, p.281) states, “human rights, properly understood, leave considerable space for national, regional, cultural particularity and other forms of diversity and relativity”. The weaving of cultures and the legal framework of human rights aligns with the pragmatic approach, which is discussed in more detail below. New Zealand Law Commission (2006) produced a report on human rights in the Pacific which realises that human rights and culture can be woven together. Research in the report shows that this weaving, or harmonising, is done by looking at the underlying values of both human rights and culture. Respect for the individual dignity of all persons is one of the primary values underlying Pacific customs which harmonises with human rights values. The following section analyses an appreciation of human rights through a Pacific lens.

Looking at Human Rights through a Pacific Lens

There are many difficulties mentioned in the literature with Pacific Islands¹ adopting human rights approaches. Firstly, individualism is a problematic concept for Pacific Islanders to adopt within the human rights approach. Innes (2008) points out that the human rights approach is incompatible to the Pacific way due to its individualistic nature and that Pacific people do not have the tools required by an individual to lobby for changes. Wilkinson (2008a) and Jalal (2006) agree with this lack of tools, stating there is a lack in Pacific communities of awareness of rights services and policy guidance for the human rights approach to be effective. Innes (2008) voices the concern that there is a perception amongst Pacific Islanders that the human rights approach was not designed for their small nations, and

¹Pacific Islands are not a homogenous group and each country has its uniqueness, therefore using the term “Pacific” is a generalisation used in this study.

could interfere with indigenous power structures involved with inherited chiefly systems. However, in a Cook Island context the chiefs currently have little or no power at Governmental level (Jonassen, 2009).

Farran (2009) agrees that the emphasis on individual rights is a concern in the Pacific but also mentions the many references to communities in the human rights framework that should be highlighted to overcome this problem. Although saying that, there are some particular community groups in the Pacific that have difficulty accepting the human rights treaties. Jalal (2006) describes the Christian churches as one such community group as some churches view human rights as a threat to them. One example he gives is where established churches blame human rights for the loss of Samoans to new fringe churches. They argue the right to having religious freedom has resulted in this.

A second main difficulty of adopting a human rights approach in the Pacific is that for some nations, human rights could be seen as representing the thinking of the former colonial rule (Farran, 2009). Human rights could therefore be seen as a form of neo-colonialism. In defence of human rights, Brown (1999) argues that colonial rule in Pacific Islands did not alter the traditional customary laws much at all, in that the legal system remained patriarchal and women and children had no measure of capacity. However, Stewart-Withers (2008) states that in the Samoan context, women's status especially as a sister was often complementary within the cultural framework.

A third difficulty around human rights in the Pacific, as mentioned previously in Chapter 1, is the ratification rate by Pacific Islands is the lowest in the World (PIFS, 2009a). Jalal (2009) asserts that when ratification is performed, it consequently improves the international standing of Pacific Island Countries (PICs) and their Governments, which leads to improved economic performance. It is important to note that non-ratification does not exclude that

country being assessed in their human rights standards. The Cook Islands ratified the CRPD in May 2009, after lobbying from disability organisations. The importance of the CRPD will be discussed shortly in this chapter.

A fourth difficulty adopting human rights in the Pacific is that it is expensive. It takes many resources to adopt, comply, and report on treaty processes. Many developing Pacific countries struggle with this resource burden (Innes, 2008). Although Hunt (2010) and Jalal (2006) dispute that there are many free websites and resources for countries adopting and ratifying conventions, although access is not often readily available. As Farran (2009) suggests, a relatively inexpensive way to weave human rights awareness and development in the Pacific is through the role of the media. In the Cook Islands radio in particular has been important in raising rights awareness by both broadcasting messages about human rights breaches and general public education, particularly in the area of disability rights.

One suggestion to overcome difficulties of including human rights into the Pacific is presented by the New Zealand Law Commission (2006). They suggest developing an indigenous common law structure to run alongside the existing one. The report recommended that Pacific countries develop an indigenous common law, which included custom and human rights. This would ideally run alongside the legal frameworks currently in place. Currently, community justice bodies resolve many disputes in the Pacific countries, however they are frequently male-dominant and often need assistance with using human rights values specifically with groups who are marginalised. On the other hand, judges often need assistance with local customary laws. The development of an indigenous common law could help all parties. However, Brown (1999) claims that introducing an indigenous common law would be difficult due to the legal training required for community bodies and for the fact that most customary laws remain unwritten.

Pacific Sub-Regional Human Rights Arrangements

As Durbach, Renshaw and Byrnes (2009) explain, work on a Pacific sub-regional human rights arrangement is minimal. There have been a few unsuccessful attempts since 1982 to create a human rights mechanism for the Pacific. Recently in 2008 the idea was revived at a human rights symposium in Samoa with the result that a working group was mandated to draft a proposal for a regional mechanism to be considered. National offices of a regional mechanism may be a more affordable and accessible alternative to the establishment of national commissions, especially in the smaller Pacific nations.

Brown (1999) explains one difficulty of adopting a human rights framework in the Pacific is that in the West, human rights were gradually included into a normative approach however developing nations, like those in the Pacific, have to adopt with a much swifter compliance due to international pressure. This swift compliance brings the difficulty of human rights policy having to be met practically with enough institutional capacity to be exercised, which is not always an easy task.

Durbach et al. (2009), observe that out of the PICs in the Pacific Island Forum, only Fiji (1999), New Zealand (1993) and Australia (1986) have established Human Rights Commissions, with Papua New Guinea in the process of developing one. Innes (2008) writes that most Pacific countries constitutions already contain a bill of human rights referring to political and civil rights which were largely formed by the colonial powers without local participation in their formation. However, self-determination did prevail in some areas such as Western Samoa's Mau Movement, a non-violent rebellion against New Zealand rule in the 1920s and 1930s (Scheyvens, 2005).

Pacific Island Forum and Pacific Plan

The Pacific Island Forum is both a regional and international organisation who along with the Pacific Island Secretariat helps create regional consensus on human rights issues. The Pacific Plan, formed in 2005, represents the Forum agenda and consistently refers to human rights. As Jalal (2006) explains, the Pacific Plan encourages all member states to ratify international human rights treaties, although in many countries, Civil Society Organisations (CSOs), particularly NGOs, are the driving force behind conventions being ratified. An example of NGOs as driving forces behind ratifications comes from this study, where lobbying by NGO Te Vaerua and CSO Cook Island National Disability Council (CINDC) assured the ratification of the CRPD in the Cook Islands.

The Value of using Human Rights in Development

The value of using a rights-based approach in development can be classified into three categories: normative, pragmatic and ethical (Cornwall and Nyamu-Musembi, 2004). These values help minimise the cultural relativity criticisms mentioned above.

Normative Rights

A rights-based approach is defined by Robinson, (2001, Para.19, with emphasis added by the author) as “a conceptual framework for the process of human development that is *normatively* based on international human rights standards and operationally directed to promoting and protecting human rights”. The global human rights regime relies on national implementation of internationally recognized human rights making the approach a normative creation at an international level (Donnelly, 2007). Enforcement of authoritative international human rights norms are left almost entirely to the sovereign states. According to Rawls, cited in Bielefeldt (1995), the notion of an overlapping consensus of human rights by different

people from different cultures means a practical normative political and legal justice system has the potential to be formed.

A legal framework can be developed with all cultures, religions and philosophical backgrounds being able to adopt the same framework such as Islamic countries. The human rights approach does not claim to be opposed to, or superior to, cultural or religious traditions. In practice this has many challenges as Bielefeldt (1995) discusses from an Islam viewpoint with an example of traditional practices such as child marriage not fitting in with human rights conventions or rights for the child. Therefore from a conservative Islamists point of view, human rights are problematic. Cornwall and Nyamu-Musembi (2004); Slim (2002) and Ignatieff (2001) discuss how human rights are a dynamic, contested area and differing geopolitical regions will have some variance in its normative approaches towards development. This variance is explained in the value of using a pragmatic approach below.

Pragmatism and Human Rights

According to Rawls, cited in Bielefeldt (1995), priorities within human rights can be set to incorporate national sovereignty and cultural differences. Taking a pragmatic approach may have the potential for liberals and conservatives, as mentioned above in the Islamic example, to find a middle road. When human rights have flexibility, development could have the chance to progress with all persons following one framework and this could lead to forming a deeper understanding between cultures and religions. Pragmatism is operated to allow for some flexibility in the legal framework of the human rights approach as shown in an example in the CRPD where, according to the Office of the United Nations High Commissioner for Human Rights (OHCHR), (2011), Article 4 states that each State Party undertakes to take measures to the maximum of its available resources. This allows for flexibility being allowed to suit the country's economic situation.

Ethics and Human Rights

It is important that ethics within human rights are translated into practice, as Eyben (2010) observes, in some situations what is reported to officials is not necessarily what front-line development practitioner experiences. Findings from this study, as will be shown in Chapter 6, concur with this gap in official knowledge and real-lived experiences lived by people with a disability in the Cook Islands. In this situation when interviewing Ministry officials, it was a lack of knowledge that led to ethics not being translated into practice. The capabilities approach weaves in with a pragmatic and ethical approach, using participatory tools to prioritise needs in order to raise awareness rights which will now be theorised.

Capabilities Approach

Nussbaum (2011) describes Amartya Sen's capabilities approach to human development as providing further insight into the issues related to disability since it not only looks at what a person cannot do but at the range of possibilities that they can do - this is the capabilities set. Robeyns (2005, p. 94) definition follows:

The capability approach is a broad normative framework for the evaluation and assessment of individual well-being and social arrangements, the design of policies, and proposals about social change in society.

Biggeri, Bellanca, Bonfanti and Tanzj (2011), suggest the capabilities approach within the field of disability asks each individual to assess the level of difficulties faced, helping to assess the situation in a comprehensive manner. Since 1993, the Human Development Reports of the United Nations Development Programme (UNDP) assessed the quality of life in the nations of the world using the concept of people's capabilities. Influenced by economist/philosopher Amartya Sen, the UN have chosen that conceptual framework as basic

to inter-country comparisons and to the articulation of goals for public policy. This approach has been recommended to development practitioners to use, instead of having their focus solely on the GNP per capita approach.

Nussbaum (1997) advocates the capabilities approach needs to be combined with a focus on rights. Complementing human rights helps ensure the grounding of entitlements in the lives of ordinary people. Human rights can supplement the language of capabilities by making it clear that the idea of capabilities is not an optional entitlement but an urgent demand. This study has uncovered a capabilities approach tool that bridges the gap between a rights-based and needs-based approach to development in the disability field in the Cook Islands, which will be further discussed in Chapter 6. Using the CRPD to underpin inclusive policy is one way of ensuring a capabilities approach be used to collect data with people with disabilities.

The Importance of the CRPD

The CRPD shows a paradigm shift, moving away from the idea that disability is one individual's pathology, and moves towards the idea that the disability is the surrounding social and environmental barriers that a person with a disability faces. This is important for development practice as it puts responsibility on the Government and various stakeholders who must take up this challenge to ensure these barriers are negated. Its recent history and the weaving of human rights and disability into the CRPD are highlighted below.

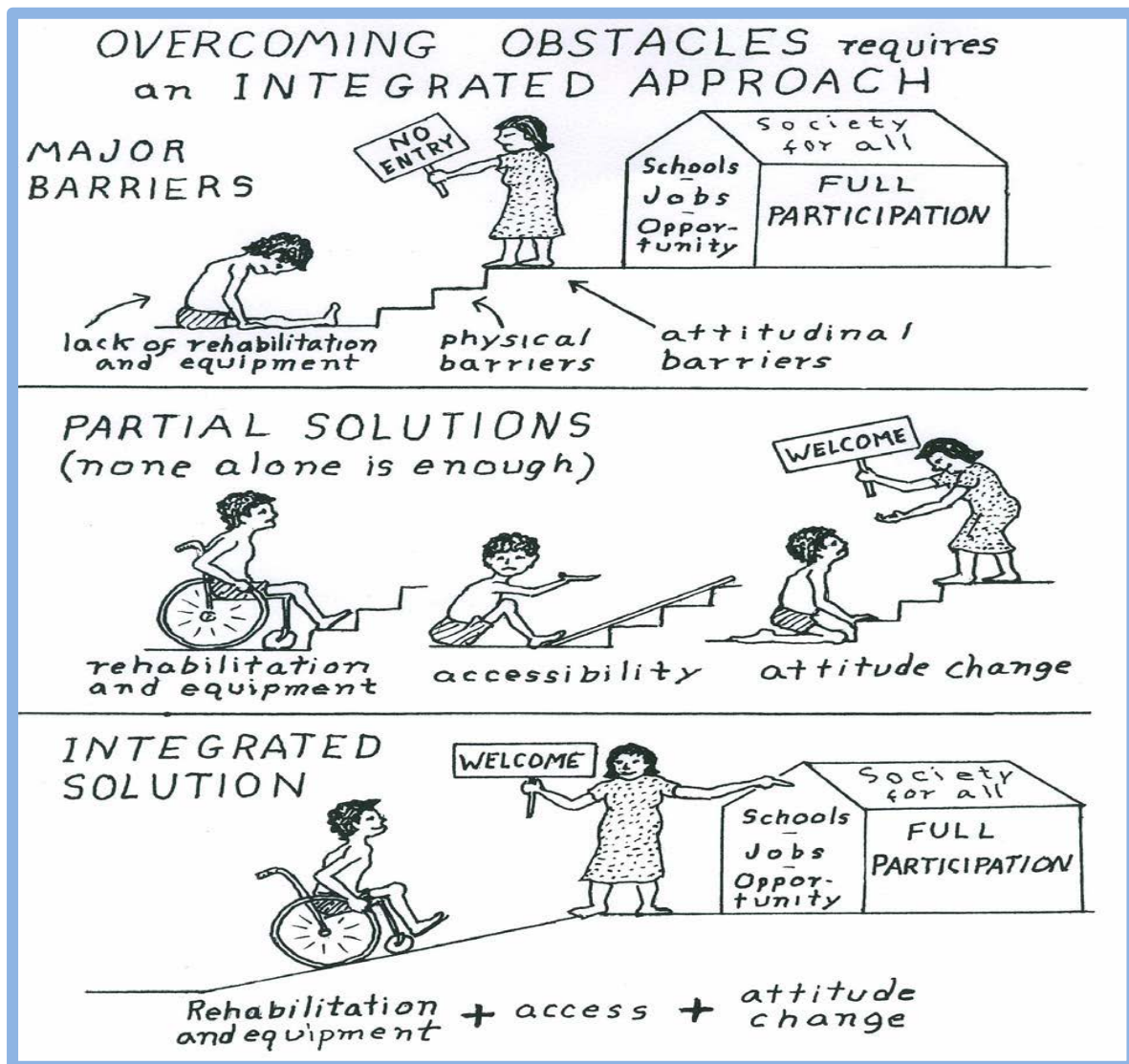
The History of the CRPD

Until recently disability has been the Brussels Sprouts of the human rights community, the bit everyone left until last and tried to hide so they would not have to eat it, and when they could avoid them no longer they tried to eat as little as possible. And yet when the time came to unavoidably confront human rights for disabled

people it seems States were at least ready to load up their plates. Time will tell how much they will really consume without having to be force fed. It is up to all of us to make sure they eat their greens. After all we know they are good for everyone (Hunt, 2010, p. 3).

The International Convention on the Rights of Persons with Disabilities was adopted by the United Nations on 13th December, 2006 and entered into force May 2008. The slow and uneven progress of disability human rights is epitomised in **Figure 3** below.

Figure 3: Slow and uneven progress of disability human rights



Source: Werner as cited in Katsui, (2005:18).

In 1993, the United Nations Standard Rules on the Equalization of Opportunities for People with Disabilities was adopted by the General Assembly. Quinn (2009), Akiyama (2007) and French and Kayess (2008) all agree that the potential of improving the lives of persons with disabilities under the treaty bodies previous to the CRPD was underused. Akiyama (2007) describes that the Declaration of Rights fell short of being realized in practice due to them not being legally binding with Kayess (2008) going further by actually called the CRPD the missing component in the human rights framework. Kayess (2008) also goes on to say the CRPD is unique in that civil society and DPOs have made significant contributions towards its development and on-going monitoring and evaluation as previously mentioned earlier in the UDHR section of this Chapter. The CRPD is made up of 50 different articles with the inclusion of the proactive feature that ensures development activities realise the rights of persons with disabilities. To date the CRPD has so far been ratified by 110 countries (United Nations Enable, 2011a).

The CRPD Weaves Human Rights and Disability Discourses Together

According to Katsui (2009) there are four main ways the human rights approach weaves in with disability discourse;

- i. Normative development
- ii. A paradigm shift
- iii. Stipulating state obligation
- iv. Transnational obligations.

i. Normative Development

The first way human rights and disability are woven together is by bringing people together into normative development, with which multilateral organisations are aiding. An example of

this is the UN which has developed a Department of Social Affairs called 'Enable' which leads the way on up to date information about the CRPD. The World Health Organisation (WHO) has Community Based Rehabilitation (CBR) activities for persons with a disability that are based on the CRPD. CBR will be unpacked further in more detail in Chapter 3. Ensuring that persons with a disability are included into normative development is essential in attaining successful Millennium Development Goals (MDGs).

The MDGs and CRPD are independent but mutually reinforcing frameworks (Disabled Persons Institute (DPI), 2010). CBR is an important bridge in the gap between the MDGs and the CRPD, particularly in the case of developing countries. MDGs have no specific mention to disability, yet persons with a disability are amongst the poorest in the world. Disability affects all eight of the MDGs with percentage statistics in **Figure 4**.

Figure 4: The MDGs and disability



Source: Goals summarised from DPI, (2010) with addition in Goal 3 from Mitra, Mouradian and Diamond, (2011). Photos: Author.

Having discussed the MDGs in general, now we turn to look at them in a Pacific context.

Feeny and Clarke (2008) say Pacific island countries have, in general, not performed well in

reducing poverty with the MDGs. Unreliable data, or missing data, from the Cook Islands, Kiribati, Micronesia and Tokelau hamper measuring their MDG progress. Fiji, Niue, Tonga and Vanuatu are classified as being on track to achieve the MDGs. Nauru and the Solomon Islands are at severe risk of not achieving the MDGs by 2015, with five other Pacific countries classified as being ‘at risk’ of not achieving the MDGs. These alarming statistics stress the importance of the CRPD, due to the lack of inclusion for persons with a disability in the MDGs.

The nature of poverty in the Pacific often relates to a lack of access to basic services and a lack of income-earning opportunities. Targeting specific needs in a Pacific context may be necessary to underpin success in meeting the MDGs, perhaps through a capabilities approach, discussed earlier in this Chapter.

ii. A paradigm shift

The second way, according to Katsui (2009), for weaving the human rights and disability is the paradigm shift from a charity-based approach to an empowerment and capacity building social justice approach. Persons with a disability must actively engage in building their capacity to address issues. DPOs will be discussed in Chapter 3, discussing how these organisations are potentially set to lead the way for persons with a disability. DPOs well quoted saying stipulates the importance of their participation in disability discourse and is mentioned in Pratt (2009, p.24) “Nothing about us, without us”.

iii. State obligation

Thirdly, the CRPD weaves disability and development for people with disability by stipulating state obligation to secure their rights. In some situations, as mentioned earlier in this chapter, pragmatism is needed with prioritizing goals implementing the CRPD in some

countries. It is important to note that persons with a disability are not a homogenous group and consultation over many factors should take place for these priorities to be set.

iv. Transnational obligations

Fourthly, the human rights approach towards disability creates transnational obligations. International agents are now officially duty bearers to fulfil the human rights of people in the South. This is very important as only 2% of people with an impairment in the South receive some kind of support at present (United Nations, 2000 as cited in Katsui, 2008).

Conclusion

A human rights approach has been woven into development and disability discourse, putting emphasis on a social justice and empowerment approach. The controversial universalism versus cultural relativism debate has been shown here to have potential for a middle road approach to be taken with regard to human rights and the CRPD. The CRPD encourages the paradigm shift from charity-based development to a social justice approach towards disability. The theory discussed must now be turned into practice with persons with a disability and DPOs leading the way in the decision making to ensure effective policy and practice occurs. This is particularly important within the scope of this thesis with a spotlight on human rights in the Pacific, particularly the Cook Islands. Using the human rights approach is not a panacea, it is currently an essential element in realising social justice and human dignity within both fields of disability and development.

Chapter 3: Framing the debate over disability

Introduction

This chapter focuses on the literature related to disability and presents four key areas of discussion. The first area covers definitions, models and paradigms of disability, portraying how concepts of and attitudes towards disability have developed over time. These are linked in with examples from developing country studies. The second area investigates the links between levels of development and disability. In the non-Western world development and disability are linked by poverty. Development programmes, such as CBR are in place, trying to combat this poverty cycle which will also be discussed in this chapter. The third area overviews literature and case studies focusing on culture and perceptions of disability, and shows these are in a continual state of change, in both country and global contexts, making it difficult for a one-size fits all development agenda. The last and fourth main area of discussion is of DPOs; advocacy groups, which are now the preferred avenue of helping to ensure the development and implementation of inclusive policy for those with a disability.

Definitions in Disability

Every person with a disability is a citizen with a universal human trait, that being in this case, a disability. Disability has many different levels and degrees of functionality, and as previously mentioned in Chapter 2, it is important to note that people with a disability are not a homogenous group. Given that the WHO and World Bank (WB), (2011) say approximately 15% of the world's population has a disability it cannot be regarded as a small minority group of society. Furthermore, this figure is likely to increase as our life expectancy continues to rise globally.

Finding a singular definition of disability has been difficult, with many groups using different definitions. This reflects the contested, complex issues surrounding disability and its discourse. I have chosen to use the term “person with disability” rather than “person with impairment”. This decision is due to the term ‘impairment’ not being commonly used or understood in the Cook Islands. Further to this, my definition of disability for this study has been sourced from the Disability Officer of the CINDC. His definition of disability is “differently abled” (DSH 1). A well-used definition comes from United Nations Enable (2011b, Para 10); “Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being”.

Finding a definition of impairment was also not straight forward due to the complex issues surrounding the different uses and meaning of the word in both medical and social models. The World Health Organisation (WHO) definition, as cited in United Nations Enable (2011b, Para 11), is “Any loss or abnormality of psychological, physiological, or anatomical structure or function”. However, because this definition is medically-based there is controversy over the social functions that should be included in the term impairment. It is for this reason I choose not to use the term impairment in this study, unless specifically referred to by literature.

The Evolution of Disability

Disability discourse stems from three main sources, Darwinism, early feminist works, and Marxism (Snyder and Mitchell, 2006; Oliver, 2006). As Gelb (2008) discusses, Darwin used intellectual disabilities to support the theory of evolution, by facilitating a reliance on heredity as definitive of persons with disabilities. Darwin’s theories moved towards advocating the use of eugenics and the elimination of persons with disabilities. The early feminist movement in the late 1800s challenged the justification for women not being able to

vote due to them being the “weaker sex”. As Snyder and Mitchell (2006) describe some feminists argued this point was obsolete due to the fact that men with disabilities could vote. Effectively, they used disability to alter policy.

Karl Marx, in the early 1900s, argued that capitalist greed had a crippling effect on human bodies. This class-based argument said “disability was a stripping of capacity from the body by excessive labour demands” (Snyder and Mitchell, 2006, p. 15). Marxist thinking is shown to be reflected in the social model of disability (Oliver, 2006), along with the capabilities approach, already mentioned in Chapter 2. Dominating models are woven through the evolution of disability following the different underpinning strands of theory surrounding disability.

Models of Disability

The three main models of disability, the charity, medical and social models overlap one another, as well as new models being developed since the 1990s. The newest models which will also be discussed here are the citizen model and cultural models, important in developing country contexts such as the Cook Islands. Each of these models, how they originated, their underpinning theories and paradigmatic changes throughout evolution will now be presented.

i. The Charity Model

Prior to World War II the principle disability model was the charity model. The charity model entrenched the ideas that people with disabilities were dependant, and needed help and care. This was accompanied by the fear that people with disabilities could also be dangerous and needed to be institutionalised to keep them from causing harm (Edmonds, 2005). Charitable organisations have not tended to promote either empowerment or awareness about disability as shown in this example by Gartrell (2010) of an NGO project in Cambodia. The charity

model was shown with the employment tasks set. These included; gardening, housework and cooking. These tasks were set in order not to challenge the social hierarchy of work where people with a disability could not have a complex job. These discriminatory attitudes of employers discouraged disabled people, helping to keep them in their place of low status, while believing they were “helping”.

ii. The Medical Model

The medical model emerged after World War II when health sciences, technology, and the pharmaceutical industry improved their ability to prevent causes of impairment. In the Western World institutionalisation and financing of medical and social welfare services grew significantly. “This came with a price – the medicalization of disability” (Edmonds, 2005, p.12). Under the medical model, rehabilitation and help is seen as being needed for people with a disability and as with the charity model, there was little room for empowerment. The medical model was developed with the same proponents as Modernisation Theory, which considered that less-developed countries should “progress” along a trajectory to ultimately become like Western societies (Kett et al., 2009). It was stipulated in the medical model that persons with disabilities wished to become “normal”. Therefore, both Modernisation Theory and the medical model of disability were underpinned by a similar deficit-theory of progress.

iii. The Social Model

Disability theorists, drawing increasingly from Marxist, feminist and postmodernist thought, and looking away from a medical model, began to advocate for the notion of disability as a social construct (Kett et al., 2009). The distinction between impairment and disability was first made explicit by a group of disabled socialists, The Union of the Physically Impaired Against Segregation (UPIAS), including anti-apartheid activist Vic Finkelstein, in 1976

(Slorach, 2011). This social model was used to promote better understandings of disabilities and was imperative in overcoming barriers faced by people with disabilities. This occurred by demarcating the difference between impairment and the social barriers that made people “disabled” and excluded them from mainstream activities. However, even within this model there were divergent views. Shakespeare (2006), a disabled sociologist who draws on a critical realist perspective, argued that the social model goes too far and “ignores” impairment, whereas Michael Oliver (1990), also a disabled sociologist argued that it did not. Oliver has the view that disability is formed by social barriers only. Oliver, in his introduction to his book *The Politics of Disablement* (1990), stresses the importance of defining disability and using the right language in the social model as discussed in this quote;

As far as disability is concerned, if it is seen as a tragedy, then disabled people will be created as if they are the victims of some tragic happening or circumstance. This treatment will ... be translated into social policies which will attempt to compensate these victims for the tragedies that have befallen them... If disability is defined as social oppression, then disabled people will be seen as the collective victims of an uncaring or unknowing society ... Such a view will be translated into social policies geared towards alleviating oppression rather than compensating individuals (Oliver, 1990, p. 2).

Below in **Table 2** is a simplified chart showing some fundamental differences between the medical and social models.

Table 2: Medical and social models

OLD MODEL : Medical model	NEW MODEL : Social model
<ul style="list-style-type: none"> • Object of intervention • Patient • Research subject • Need to “fix” the person • A “medical” problem 	<ul style="list-style-type: none"> • Community member • Participant • Researcher • Barriers need to be removed so that the person can go about daily activities to their capacity • A socio-environmental issue involving accessibility, flexibility and equality

Source: Author

Globally, there has been a continual move towards adopting the social model of disability. Moving away from a physical model of impairment (a medical model) to a social model, the WHO developed a framework called The International Classification of Functioning, Disability and Health (ICF). As WHO (2011) highlight, the ICF was endorsed in 2001, for use in 191 Member States as the international standard to describe and measure health and disability. The newest ICF, (ICIDH²), added social components into its assessment categories, whereas the original ICIDH¹ did not have these factors included. The overarching goal of the ICF is that it focuses on analysing the relationship between capacity of a person with a disability and performance of what people do in their usual environment (level of performance). If capacity is greater than performance, then that gap should be addressed through both removing barriers and identifying facilitators. WHO has not entirely dropped

the medical model, having found that the ICF works best when the medical and social models are used together (WHO, 2002). It was found that by using both models, biological, social and individual factors could all be included into classifying disability. This model is called the biopsychosocial model.

The ICF is not without critics, in fact Snyder and Mitchell (2006) go as far as saying that attempts to include social factors in function-based measures does little to decrease the emphasis being put on normalisation. These authors claim that the focus is still on the health concern model as opposed to the political model, and the political model does not attempt to “normalise” people with disabilities.

The social model, too, has its critics. Stone (1999) argues that the politicised social model is a Western model and should not be enforced on developing countries, referring to it as imperialistic, not empowering. Another criticism is that using the social model on its own, has not been an attainable concept. Shakespeare and Watson (2002, p. 5) agree, “Because it is such a powerful tool, and because it was so central to the disability movement, it became a sacred cow, an ideology which could not easily be challenged”. Gabel and Peters (2004) concur arguing that in this strong social model approach many activists still talk about their body impairments out of the public eye, in opposition to their rhetoric about only social barriers affecting their lives. Bailey and Hall (cited in Shakespeare and Watson, 2002, p. 23), note the effects of the shifting paradigms and models;

It is perfectly possible that what is politically progressive and opens up discursive opportunities in the 1970s and 1980s can become a form of closure – and have a repressive value - by the time it is installed as the dominant genre.... It will run out of steam; it will become a style; people will use it not because it opens up anything but because they are being spoken by it, and at that point you need another shift.

iv. Citizenship Model/Rights model

The 1990s further reconceptualised disability and elements of development according to Edmonds (2005), into the citizenship model. Accordingly, the citizenship model represents an international development paradigm in which people with a disability have the same opportunities as other citizens in their community. This model aims to conceptualise a development framework that focuses on building an inclusive civil and rights-based society drawn from a variety of disciplines that frames disability issues through the lens of human rights principles. As Isin and Wood (1999) contribute, the model is a multi-dimensional concept equated with community participation, group identity, public practice and responsibility. This model also assumes that various supports (for example; personal services, aids, and devices) will be needed by some people.

Research on CBR, to be discussed shortly in this chapter, and extensive literature reviews shaped the framework of the citizenship model, where empowerment is emphasised in ways not seen in medical or social models (Edmonds, 2005). As Nutt (2010) summarises, the citizenship model is all about people choosing their own definitions for their own lives. A priority of the model is to focus on the issues related to people with disabilities who are underrepresented. This includes women, youth, children, indigenous peoples, and those with “invisible” disabilities, such as intellectual disabilities, as these people are often the poorest of the poor in society. Yeo (2001) supports this saying that people with a disability are disproportionately amongst the poorest of the poor in all parts of the world, but in the poorest countries of the world that have no benefit system in place, have more severe implications of life or death than in richer countries.

The Knowledge, Inclusion, Participation, and Access (KIPA) framework, designed by the Asian Development Bank (ADB) promotes the citizenship model. This KIPA framework is used to find the gaps in an existing country system and to aid in mainstreaming the needs of people with disabilities. This framework helps to identify key poverty reduction strategies required by government, civil society, the private sector, and development agencies to address the needs of people with disabilities. For example, as investigated by Richan (2011), the KIPA framework was used in post-conflict Bosnia and Herzegovina. It emerged as intrinsic to the successful community integration of persons living with a physical disability, predominantly by unlocking attitudinal barriers and negative feelings toward people with a disability.

v. Cultural Model

In a cultural model, disability is defined as a combination of both biological and social factors (Snyder and Mitchell, 2006). The cultural model largely arises from critical disability studies (Roets and Goodley, 2008), mainly in the United States of America (Snyder and Mitchell, 2006). The cultural model recognises identity and body as constructed and is similar to CBR's underpinning theory, in that it is praxis-orientated. The cultural model of disability stresses the importance between therapeutic beliefs and the people with disabilities' actual experiences, which is significant to the key question in this study. There is emphasis that bodies are not to be subjected to normalisation schemes, such as gait analysis, which attempts to make the person with the disability walk "properly". Shifting the focus off both the medical and social models, the cultural model uses an "embodied revelation, designating disability as a site of resistance and a source of cultural agency" (Snyder and Mitchell, 2006, p.10).

The cultural model of disability, being a poststructuralist model, is based on Foucault's theory. Foucault suggested that "impairment is fully cultural and the body is an outcome of social processes" (as cited in Hughes and Paterson, 1997, p. 332). Foucault believes that post-structuralism underpinning the cultural model helps make the socialization of impairment possible, whereas the social model fails to do this. Ingstad and Whyte (1995) provide an example of personhood being viewed in a cultural manner. They describe research in which the Kel Tamasheq tribe in Mali see individual faults as including old age, illegitimate birth, ugliness, excessive freckles, having a protruding naval, absentmindedness, and flabby or small buttocks. Most of these impairments are not on the WHO list of disabilities. Individual faults are not homogenous and would be better assessed on an individual basis.

Assessing on an individual basis makes the knowledge of traditional beliefs and lived experiences surrounding disability vital to implementing development programmes for people with a disability (Coleridge, 2000). Policy-makers and practitioners in the disability field are increasingly looking to evidence-based strategies to assess and maximise limited resources. Such knowledge can also help establish what is universally true about disability and the uniqueness to specific cultures.

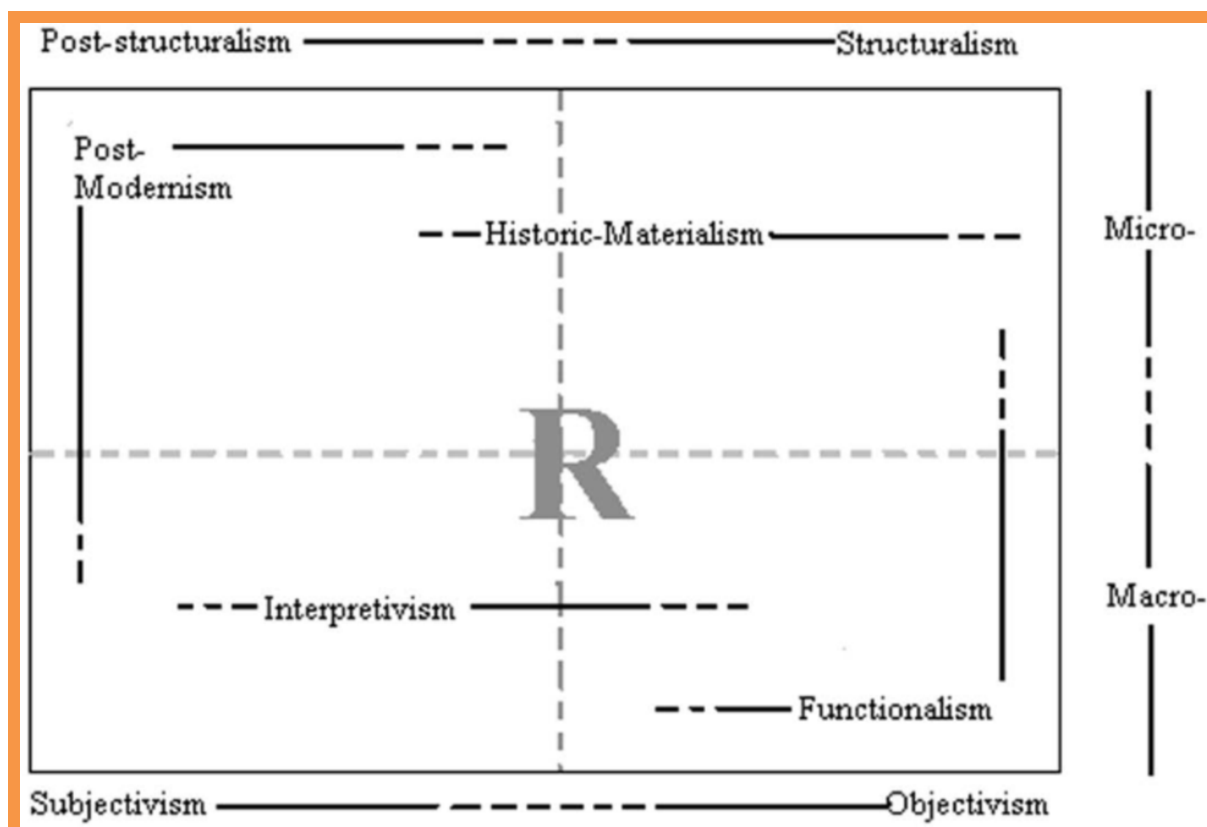
Disability Paradigms

Alongside and weaving through models of disability are disability paradigms. Gables and Peters (2004) put forth four disability paradigms, and I will discuss these now with their link into models of disability.

The first paradigm, the functionalist paradigm, fits with the medical model. From a functionalist world view, people with disabilities need to be fixed or rehabilitated due to their pathological condition. Secondly, interpretivism, another traditional paradigm in disability studies, emphasizes disability as an individual experience, albeit one situated within a social context. Like the functionalist paradigm, the interpretivism paradigm has a structuralist worldview explaining disability “as a product of oppositional structures within a socio-political system that produces disablement through inequities and social injustice” (Gable and Peters, 2004, p.587). Thirdly, the historical-materialistic paradigm is associated with the strong social model of disability and has a post-structuralist focus. An example of post-structuralism thread of thought is to label oppressors “non-disabled” (Hughes and Patterson, 1997). Shakespeare and Watson (2002, p.19) claim that;

... disability is the quintessential post-modern concept, because it is so complex, so variable, so contingent, so situated. It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality.

The fourth paradigm is post-modernism, which sees disability as a way to radically reverse stigmas attached to disability. The lines between the paradigmatic fields are overlapping as indicated by the broken lines in **Table 3** below.

Table 3: Paradigms in disability theory

Source: Gable and Peters (2004, p.590).

Disability as a Development Issue

Disability and development are linked by poverty and also by the barriers that hinder people progressing, such as a lack of education (Stone, 1999; Trani and Loeb, 2010). As mentioned in this chapter's introduction, this is the second main topic of discussion and important due to the fact approximately one in seven of the world's population having a disability and with 80% of these people living in developing countries (Disabled World, 2011). 100 million people have a disability due to malnutrition; for example 200,000 children have become blind due to a Vitamin A deficiency (Turmusani, 2003). The correlation between poverty and impairment is stronger in rural communities and is attributed to a lack of access to basic services which are more readily available in urban areas. The relationship between poverty

and impairment is not only prevalent in developing countries. In Western countries, such as the United Kingdom and the United States of America, two thirds of people with disabilities live below the poverty line (Turmusani, 2003). Thus, disability can lead to poverty, and vice versa (Yeo and Moore, 2003).

CBR has been involved in research that has found people with disabilities often have extra costs resulting from their disability. This leads to requiring more resources to achieve the same outcomes as non-disabled people. Amartya Sen calls this “conversion” handicap (Sen, 1999, p.70). The CBR research by Kuper, Polack, Eusebio, Mathenge, Wadud and Foster (2008) exemplifies this conversion handicap. They found that people with visual impairment due to cataracts, were already 20-28% poorer before their cataracts occurred. This fact, added to higher costs because of their disability, stresses the importance of the MDGs success in reducing poverty.

Women with disabilities are found to have a double-disadvantage as their access to services and employment is generally more restricted (Turmusani, 2003). However, Morris (1992) and Stuart (2006) do not agree with this double burden approach, describing the label of “double-disadvantage” as, itself, being disempowering. Morris (1992) argues that women with disabilities “do not want to hear how ‘awful’ their lives are because they suffer from two modes of oppression” (p. 163). Regardless, other research by Nosek, Howland, Hughes, (2001), has shown that women with disabilities suffer more abuse than those who are not disabled due to being less likely to be economically independent and making them more likely to be victimised. It is important to note that there is no homogeneity of women with disabilities and that women also experience other areas of oppression such as age, class, ethnicity and sexuality.

Disability, like gender, or the environment, is a cross-cutting issue, and most NGOs and UN agencies now promote a rights-based approach to aid and development to ensure all the issues are addressed. The UN have aided greatly in promoting disability as a human rights issue, as shown in the treaties below in **Table 4** that are specific to disability.

Table 4: Disability specific human rights

1948	The Universal Declaration of Human Rights
1966	International Covenant on Civil and Political Rights
1966	International Covenant on Economic, Social and Cultural Rights
1971	1971 Declaration on the Rights of Mentally Retarded Persons
1975	Declaration on the Rights of Disabled Persons
1979	Convention on the Elimination of All Forms of Discrimination against Women
1982	World Programme of Action Concerning Disabled People
1989	Convention on the Rights of the Child
1993	UN Standard Rules on Equalization of Opportunities for Persons with Disabilities
1993	Vienna Declaration and Programme for Action
1994	Salamanca Statement and Framework for Action on Social Needs Education
2000	The Commission on Human Rights
2006	The Convention of the Rights for Persons with Disabilities (CRPD)

Source: Katsui, (2005) with the 2006 addition by Author.

In 1983 the UN also developed the World Programme of Action Concerning Disabled Persons and 1983-1992 was the UN Decade for Disabled Persons. The above UN treaties have aided in policy formation for improved access to the labour market by persons with disabilities, making basic needs more accessible. One way of translating policies into practice is through Community Based Rehabilitation (CBR).

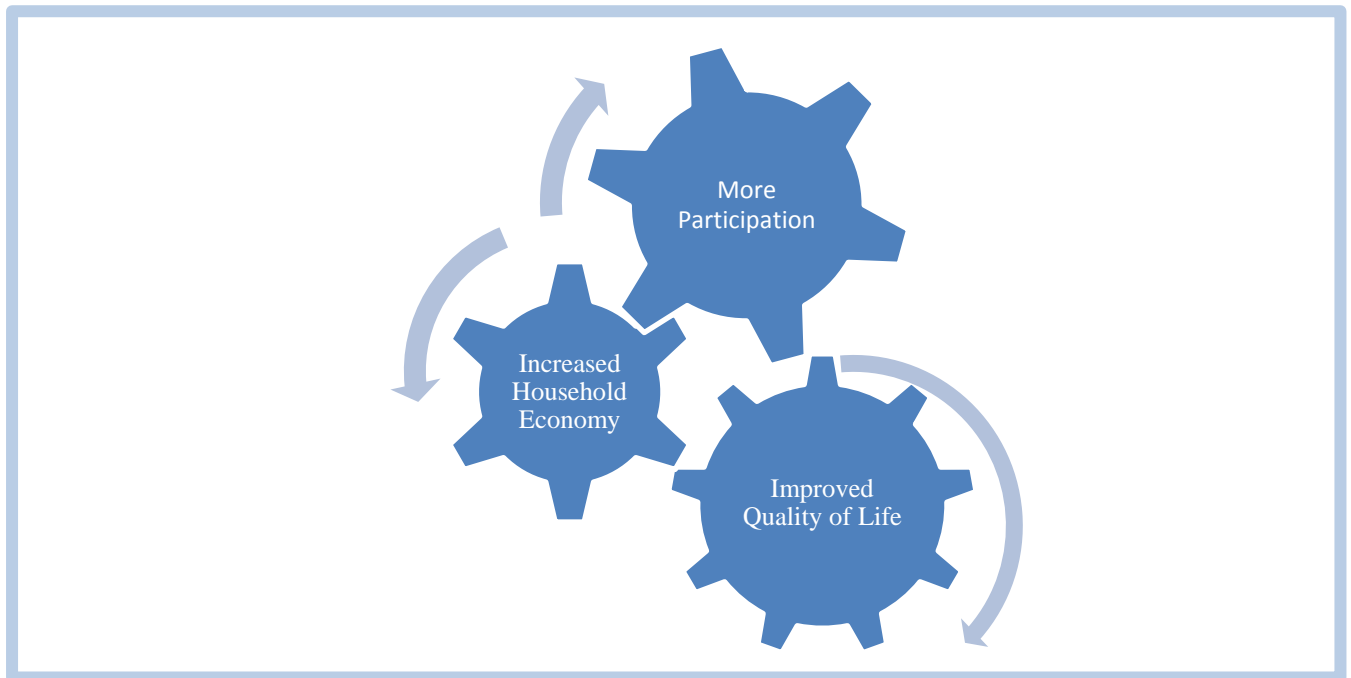
Community Based Rehabilitation

Since the late 1970s CBR has been an important strategy to respond to the needs of people with disabilities, CBR is used by the United Nations, particularly in developing countries, which is why CBR is hardly heard of in the West. CBR was initially developed by the WHO and promoted to deliver rehabilitation services in countries with limited resources. According to the WB (2011), in 1978, the WHO adopted the Alma Alta declaration, shifting support from city-based hospitals and institutions to the community. CBR evolved as a natural consequence of this initiative.

In the present day more than 90 countries around the world continue to develop and strengthen their CBR programmes. Most of the rehabilitation with CBR is performed in the person's own home, saving on expenses. Turmusani (2003) provides the following example from the Philippines involving a CBR social development programme for people with sight impairments. The CBR programme individual care costs \$155 per person, whereas institutionalised care costs \$444 per person.

CBR can also improve the chances of people with disabilities participating in the workforce (ILO, UNESCO and WB, 2004). As shown in **Figure 5** below, employment chances increased and care costs lowered through CBR, the economic situation of the whole family can improve.

Figure 5: Improved quality of life through CBR



Source: Foster (2010, p. 46).

Lang (1999) also stresses the importance of using CBR, citing the empowerment that people with a disability gain. This gaining in empowerment relates to educationalist Paulo Freire's work (see Freire, 2000). Freire explained how social change can only be realised when such groups come together and reflect on their situation and collectively plan to change (Lang, 1999). Praxis is this dynamic interaction between theory and practice and this reflection is vital for action.

Not everyone agrees with the use of CBR. Stone (1999, p. 8) emphatically states that it is;

An updated, less obviously imperialistic, version of what the missionaries were doing in the 1890s. Well meaning, but not always carefully considered, sensitively implemented, or appropriate to local practices and perceptions.

Further criticisms about disability in a general development context are discussed below, showing they do not always weave together harmoniously.

Criticisms of Disability in a Development Context

Having a globalised, developing economy does not ensure the prioritising of development in disabling social structures. For example, as explained by Kabzems and Chimedza (2002), the introduction of SAPs in Zimbabwe resulted in a restructuring of the workforce and left many people unemployed; as a result, disabled children were the first to be deprived of their education due to reduced finances in households. Mersland (2008) also reveals that people with disabilities have limited access to credit from mainstream micro-finance institutions.

Further criticisms of disability in a development context come from Kett et al. (2009) who view development programmes for people with disabilities as yet another “box to tick”. They conclude that inclusive development programmes have become “less about achieving rights and confronting prevailing negative attitudes than achieving targets” (p. 651).

Mainstreaming itself is not enough to develop disability as Coe and Wapling (2010) emphasise with deeply entrenched social attitudes and discriminations also needing addressing within development agencies themselves. Development agencies need to look at adopting a social model approach towards their programmes of disability. Research by Mwendwa, Murangira and Lang (2009) has found that not only many Government organisations, but also, many civil societies and even some DPOs are using the charity approach to development, not yet adopting a human rights approach.

The final issue mentioned in this section is the weaving of different cultures and attitudes into development programmes. Within each country, and even regions within a country, cultures

and attitudes can alter success rates of programmes (Coleridge, 2000). Debate on this complex issue will be unpacked now.

Culture and Disability

Culture and disability make up the third main area of discussion within this chapter. It is widely accepted that people's cultural beliefs affect the way they view illness and disability and also can determine what to expect from treatments and the health system. Most people have a weak relativist view of disability and universalism (Ingstad and Whyte, 1995), while understanding disability to include physical and environment variations. Radical relativists, on the other hand, reject using an international classification system for disability saying different cultures should construct disability uniquely or not at all. Üstün et al., (2001) conversely says that having a cultural view towards disability may not necessarily detract from using a universal system of disability classification. In Chapter 6, I discuss this in more detail why it was necessary to adopt a weak relativist approach in my research in the Cook Island situation.

According to Coleridge (2000) while working in community disability programmes, development programmers have a responsibility to research the local cultural factors affecting disabled people and as in this study, carry out an emancipatory approach. Development planners do not engage in acquiring an understanding of the local culture and, in fact, regard it as an impediment to development. It is argued that the local culture must be taken into consideration as "disability is defined by culture, and without awareness of how disability is perceived in the target culture a disability programme does not stand much chance of being relevant or sustainable" (Coleridge, 2000 p. 2).

According to Finkelstein (1980), predominant attitudes towards disability have been defined by members of the “helper” side of the disability paradox, and that those with disabilities can take on these “helper” views as their own. Katsui (2005) concurs, saying that self-awareness is essential because disabled people can often come to share a very similar negative image about themselves to that of the non-disabled people around them.

Bickenbach (2009, p. 1111) takes a middle view between culture and development in disability where he says;

The conflict between universalism of rights and cultural sensitivity exist only if these positions are expressed in extreme form: rights absolutism and cultural relativity.... in the form of progressive realisation of rights and situational sensitivity of difference – there is no conflict at all.

Summarising, Bickenbach (2009) sees the CRPD as being dynamic enough to accommodate cultures even though it is a universal concept. The capabilities approach, as discussed theoretically in Chapter 2 and in practice in Chapter 6, is an approach taken in this study to find a middle road between rights-based awareness and a cultural approach to promoting disability in a development context.

Poignantly, it is not always culture that stands in the way of developing with a disability, it can be attitudes. One example of this is provided by Ingstad and Whyte (1995) from Somalia. Two boys have similar disabilities with one boy coming from a prestigious family and treated very well. Unfortunately, the other boy, who was an orphan, was despised. Concurring with this is a similar study by Rasmussen (1989) who found that amongst the Turag in Mali, people with disabilities were also treated according to their socio-economic status. According to Turmusani (2003), countries in the Middle East have provided appropriate services for

persons with disabilities, where under Islamic faith this is partly due to meeting an obligation in the Qur'an where equal rights are promoted. Turmusani argues further that in reality, however, people with disabilities and other marginalised groups are generally viewed with negative connotations.

The situation is similar in China, with attitudes acting as barriers for developing disability programmes. In China the term for disability is *canfei*, meaning "handicap" and "useless". In many areas of China, disability is viewed as a punishment for doing something wrong in a previous life with Chinese people more accepting of someone with an acquired injury rather than a congenital one (Zhang-Liu, 2005).

A different perspective surrounding attitudes of disability is shown in literature from Marshall (1999) where Navajos believe it is the grandparents fault if a child is born with a disability. Maloni, Despres, Habbous, Primmer, Slatten, Gibson, and Landry (2010) show that in Bangladesh, most respondents seemed to hold a belief that their child's disability is temporary, hoping their child could be cured with treatment. It appears that in developed countries the focus is on the solution or treatment for a person with a disability, particularly within a charity or medical-based model, whereas in developing countries, such as mentioned above, the focus appears to be on the cause.

The term disability is not always easily translatable, making cultural comparisons difficult. Talle (1995) explains that the Maasai do not have a single term for being disabled. In Maasai "disabled" roughly translates to a lizard that walks in an awkward way. Among the Maasai, people with disabilities are a heterogeneous group, whereby individuals are simply seen as differing in their personal characteristics; that is, they may be tall, brown or short instead of having a disability. There is no direct referral to disabilities, as this is seen to incite the

sickness. Interestingly, this unexpectedly was highlighted in this study, as will be illustrated by an interview excerpt in Chapter 5's attitudes section.

As Coleridge (2002) explains, in poor countries the concept of disability is often less well defined and given less direct attention. "While dyslexia may be a considerable handicap in a society which relies on reading skills to be able to get a job and be a fully functional citizen, in a society where reading materials hardly exist, it is not a handicap at all" (p. 2). Coleridge goes on to make the point that, ironically, in traditional societies, the recognition and acceptance of disability may actually aid in leading a more humane social life, while in developed countries, the pressure of reaching equality can bring rejection. In an Afghanistan example it is common to see a disabled child being pushed along in a crude cart by other children, with no sense of embarrassment; "The main problem is not neglect but over-protection, under stimulation, and ignorance of how to help the child develop" (Coleridge, 2002, p. 12).

Living in poorer countries a person with a disability was nearly always looked after by family as Ingstad and Whyte (1995) found in a Tanzania study. Families are large and the responsibility of care is spread amongst family. However, they found labour migration and poverty has forced this situation to change. Ingstad (2004) had similar findings in Botswana villages where care of children with disabilities was left to grandmothers as the mothers were forced to work in town to earn money.

Groce (1999) provides a positive perspective of culture affecting human rights from Mexico and Botswana. It has been seen that the birth of a child with a disability is viewed as evidence of the parents having God's trust to care for that child. It has also been found through research by Maloni et al. (2010) that a mother's positive perception of disability can positively influence not only her family, but also her community and that this can carry over

to future generations. Human rights will be more readily upheld with these positive cultural perceptions.

Defining Attitudes

As shown above, the value of positive beliefs can be very influential in altering attitudes in a whole community. Many social psychology textbooks define attitudes in terms of its three components: beliefs (evaluation), affects (feelings), and behaviour tendency (Maio and Augoustinos, 2005). An attitude in this sense is a complex system of interrelations among these three components and if one component is changed, the overall attitude will change. Attitudes are also learned responses and are often based in socio-religious belief. Hereniko (1999, p. 138) explains how attitudes do evolve over time;

Our cultural identities are always in a state of becoming, a journey in which we never arrive; who we are, is not a rock that is passed on from generation to generation, fixed and unchanging. Cultural identity is a process.

Verweij (2004) identifies four ways of organising, justifying and perceiving social relations and attitudes: individualism, hierarchy, egalitarianism and fatalism. These four types of relations are in permanent contention and need to be interacting in order to prevent massive fatalism. Exclusion from a community can make a person apathetic and fatalist, which does not encourage development. Development is closely connected to the idea of empowerment, which means having a belief in our own self-worth. People with disabilities in the developing context tend to be the most disempowered and can develop negative social attitudes or apathy as described above. Coleridge (2000) insists that the only way out is for disabled people to start the process of change in themselves. When their culture is blocking their development of

rights and economic independence, it is especially important for people with disabilities to have a voice. This voice can result from becoming a member of a DPO.

The Importance of DPOs

The fourth and last main discussion in this chapter is about the importance of DPOs. DPOs are NGOs that are established, governed, and managed by people with disabilities. They represent the voice and interests of people with disabilities at the international and local community level with a commitment to the overall development of all. Shakespeare (1993) explains how many DPOs arose from disability movements which were inspired by civil rights movements and feminism in the 1960s, particularly in the USA. Returned servicemen from the Vietnam War also inspired the formation of disability movements due to the large number of young people with disabilities sustained from war injuries.

Edmonds (2005) stipulates that it is only through the participation of DPOs that it is possible to identify the needs of people with disabilities and effectively plan, implement, and evaluate poverty reduction strategies. Rioux and Bach (1994) concur with this saying that DPOs are the future for ensuring human rights frameworks and the CRPD are being met. Cornielje (2009) further explains that DPOs are usually seen as social, human rights movements, although a review of lots of community-based DPOs will indicate that many of them are in fact self-help groups. The more developed of such self-help groups become engaged in advocacy type of work and become a mouthpiece for those who are denied their rights. There is a lot of confusion as shown in this study's findings, in Chapter 5, about what actually does constitute a DPO and how it should be run as in the case of the local DPO, CINDC.

There are positive case studies of a DPO being successful, using a CBR programme, as described by Driedger, (1989). In Nicaragua, people with disabilities built wheelchairs on

contract by the Government. Their DPO was called the Organisation of Disabled Revolutionaries (ORD) and as well as starting the wheelchair contract, also initiated a sewing cooperative, providing employment for people with disabilities and non-disabled people. This provided employment for people with disabilities in an integrated environment.

The role of DPOs includes educating all people with disabilities about their rights, advocating for action to ensure these rights, and collaborating with partners to exercise rights to access services and opportunities. However, as Dube et al. (2008); Mwendwa et al., (2009) show in the following section, there are some further criticisms of DPOs in the literature and examples of many unsuccessful DPOs operating in countries, particularly in developing countries.

Criticisms of DPOs

DPOs often operate within CBR programmes and as Turmusani, Vreede and Wirz (2002) point out, at times it can be difficult for DPOs to participate fully in CBR programmes. Lack of transport, lack of accessible information and communication difficulties are significant barriers to the development of DPOs and to their participation in CBR. Findings in Chapter 5 from this study will also discuss similar barriers to the development of DPOs in the Cook Islands.

In the area of gender it has been found that women with disabilities' have issues that have not been effectively included and addressed by DPOs that have traditionally been led by disabled men (Coleridge, 2000; Hans and Patri, 2003). Coleridge (2000) found that most Afghanistan DPO members are predominantly men with amputations, who are ex-soldiers and have been disabled in war. These men are often forceful, and are not lacking in self-

esteem making it a problem trying to achieve representation of both gender and other disabilities in the DPO.

A further criticism is DPO effectiveness, again, particularly in developing countries. This can be problematic and will also be discussed in this study's findings in Chapter 5.

Conclusion

The literature shows that despite leaps in development, models, and paradigms in the past two to three decades, disability remains a contested area. Previously, usually regarded as having to be looked after, people with disabilities are now more likely to have a voice through the social and post structuralist models. DPOs, too, are ensuring in some cases that needs and rights of people with disabilities are addressed.

The literature reveals that culture plays a significant part in disability, in a development context. It is clear that two people with similar disabilities could experience very different opportunities to realising their dreams and aspirations, depending on what country they live in, and how much poverty their families have. CBR programmes works closely with DPOs to make rehabilitation more sustainable and more accessible to people with disabilities, however, not all succeed in doing this. This mixed or limited success indicates that continued political and social action is essential for people with disabilities.

The following chapter looks at how this political and social action can be included in disability research. The methodologies and data collection used will demonstrate six key research methods highlighting and validating the findings shown in Chapter 5.

Chapter 4: Methodology

A good head and good heart are always a formidable combination. But when you add to that a literate tongue or pen, then you have something very special — Nelson Mandela.

Introduction

This research is qualitative in design and applies an emancipatory methodology within a participatory approach to understand researching the needs of people with disabilities. These methodologies are in alignment with the social model for disability as discussed in Chapter 3. Using a participatory approach and forming partnerships with people with disabilities, their families and disability service providers was crucial to uncovering these needs, attitudes and the future goals that they have.

This chapter begins with my own philosophical position and ethical considerations. I then discuss the theoretical framework of the methodologies used and justification for using them. Following on from this, I list the data collection methods using extracts from my field journal entries to describe the reciprocity of the relationships and real-lived situations experienced. Finally, data analysis strategies are then explained.

Philosophical Position of Researcher

Ballard (1994) suggests that researchers cannot help avoid involving their own values, attitudes and perceptions into their research. Recognising this as fact became a tool to critically reflect on any biases and assumptions I made. Lather (1986), who writes about the tension between advocacy and scholarship, says as researchers we must be reflective and self-critical if we are to achieve trustworthy data. Previously, working as a physiotherapist and adopting an interpretivism paradigm in my work, I was often given questionnaire forms to

ask irrelevant and disempowering questions of my patients. I found with experience that if you asked an open ended question to patients, not only did you get most of the medical information you needed, but also you got the information required to best meet the needs of that particular patient. My interest in a more holistic view of health and not being comfortable working under a structured, medical model led me to undertaking this study. Being Papa'a, or foreign, to the Cook Islands, I regarded researching with the emancipatory method as potentially creating a mutual learning experience for myself, being the researcher, and the participants.

I acknowledge my position as a non-indigenous outsider and hoping to be an "allied other" as suggested by Kaomea (2004). Even though I was encouraged by people with disabilities, while volunteering, to undertake this study, I still struggled with how much insight I would actually have in order to write effectively and as close to real-lived experiences as possible. Vilsoni Hereniko, a Fiji Islander playwright, film director and Professor at Hawai'i's Centre for Pacific Islands Studies, questions the right of outsiders speaking for Pacific Islanders. However, he poignantly notes:

The least that outsiders can do, if they wish to speak as though they were some authority on Pacific societies, is to invite indigenous Pacific Islanders, whenever possible, to share the space with them, either as co presenters or as discussants or respondents. Not to do so is to perpetuate unequal power relations between colonizer and colonized (1999, p. 86).

Reading literature, including Hereniko, started me on a journey using emancipatory methods of enquiry, as I will further discuss below. Denzin and Lincoln (2005) describe bricoleur (quilt maker) researching, meaning the piecing together of narratives as they present themselves, which I have incorporated in my Chapter 5 findings. This is apt in Cook Island research as the tivaivai quilting is a cultural art that adorned many of the people's homes I

visited in field research. Weaving Rito hats is another art form, the word weaving I have used throughout my thesis, as a link to Cook Island culture.

Ethical Considerations

Prior to field work, I read the university code of ethical conduct and had an internal ethics review with my supervisors. I had taken steps to ask for any cultural sensitivity regarding this research by the disability officer from CINDC and a local Cook Island Physiotherapist who works with people with a disability. I had a letter of support from NGO Te Vaerua Rehabilitation Council, to undertake this research on the main Island of Rarotonga, with their hope of uncovering the needs for people with disabilities.

This research has adhered to all the ethical principles in the Massey University Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants (2010). This study was accepted by Massey University Ethics Committee as a low-risk notification. I applied to the Cook Island Prime Minister's Office to undertake study there, which was approved with a stamped card to present if required. Prior to interviewing, all participants were given an information sheet and required to sign a consent form, which were both translated into Cook Island Māori (see **Appendix 1 and 2** respectively). Throughout the consent process I emphasised that participation was voluntary and they could opt out at any stage. I used a tape recorder for taping the interviews, and acknowledged this to the participants. One female participant appeared hesitant so I did not use the tape recorder, taking notes instead. All transcribes were typed by the researcher.

Participants were given the option of using a translator and 3 out of the total of 25 participants requested one. A confidentiality agreement was signed by the translator prior to interviews. After talking with the disability officer of CINDC in Rarotonga, and other

contacts I had made in the disability sector, I was advised that it would not be appropriate to offer any koha or token to participants for partaking in the research. The translator was paid on a per interview basis.

Theoretical Framework of Research Methods

In designing an approach to conducting this research, the six research methods that I considered to be important are highlighted in **Table 5**.

Table 5: Six key research methods in design approach

i.	Participatory research methods/approach is generally adopted, as a prerequisite to the emancipatory design.
ii.	Emancipatory methods are to be adopted where possible.
iii.	Data collection methods are to be included from many sources; the people with disabilities, their families, government and local institutions.
iv.	The methods used should have the purpose of reciprocity and empowerment.
v.	Participant observation is to be included, to explore real-lived situations.
vi.	A political link is to be included, with the aim of promoting awareness of human rights with people with disabilities in the Cook Islands.

Source: Author.

I adopted these key research methods to uncover real-lived experiences to best help answer the key question of this thesis: ‘What is the relationship between human rights-based policy

and frameworks and the lived experiences of people with disabilities in the Cook Islands’? Each key research method mentioned in the above **Table 5**, will now be discussed further.

i. Participatory Research Approach (PRA)

The first key research method in this research design is PRA. As Kemmis and McTaggart (2005) point out, PRA has its roots in the neo-Marxist approaches to community development and human rights activism. As Chambers (1984) and French and Swain (1997) also point out, PRA is part of the qualitative research tradition which arises from phenomenological philosophy, which is a doctrine characterised by the belief that people create their own social world rather than others shaping their social processes. The three distinguishing factors from conventional positivist research are that there is shared ownership of the project, community-based analysis of the social problems, and an orientation towards community action (Kemmis and McTaggart, 2005).

ii. Emancipatory Methodology

Using an emancipatory approach is the second key of this study’s research method design. Emancipatory research has emerged within the disability movement as a result of inadequacies of traditional research combined with the increasing use of the social model of disability (French and Swain, 1997; Turmusani, 2003). This social structural model of disability uses the human rights approach as an underpinning framework, which is highlighted in my two main theory chapters of this thesis. The object of emancipatory research is to transform, - hence to emancipate and not engage in research for its own sake. As Barnes (1992, p. 122) states:

Emancipatory research is about the systematic demystification of the structures and processes which create disability and the establishment of a workable ‘dialogue’ between

the research community and disabled people in order to facilitate the latter's empowerment. To do this, researchers must learn how to put their knowledge and skills at the disposal of disabled people.

The problem with traditional data collection and statistical research is that in most cases the actual needs of people with disabilities are still not known (Oliver, 1992). This research moves away from using a positivist view of research as this can conceptualise disability as a problem that needs to be 'fixed'. Rioux (1997) argues that some positivist research based on the biopsychomedical model have even been shown to contribute to oppression for people with disabilities. Ballard (1994) concurs with this oppressive use of positivist research by arguing, for example that Māori, women, and people with disabilities, say much of what is written about them is wrong. He goes on to say that what is needed are approaches to research that accept culture, values and beliefs that make sense to those that are researched and can be used by them to improve their lives.

Using the emancipatory approach in research does have its critics. Emancipatory research is not outcome or statistically focused, it is process focused (Rioux, 1997; Hanley, 2005). Problems associated with this could apply to securing funding, where justification and quantifying project costs are required. Emancipatory research, being process focussed and social action-based research, does not lend itself to statistical gathering tools. In my interviewing I did include asking for a priority list of needs, barriers and a future wish list, which has given me some quantitative data. I realised more and more through field research that the gap between officials and people with disabilities was there due to the officials not knowing what the people with disabilities and their family's needs were. This is in keeping what people with disabilities identified as the area for my research. A Government official said in his interview:

If we had a list to work from of priority needs from the people with disabilities, we could then plan more effectively to achieve a better outcome for all parties (Interview, DSH 12, 19 May, 2011).

The importance of gathering some quantitative data became more of a focus throughout field research as officials commented they would like information from people with disabilities.

Accessibility to the research findings is important in the use of emancipatory methodology. The findings in this study could be potentially helpful to both people with disabilities, their families and disability stakeholders/Government officials, however, it has been noted in literature that problems may be encountered with using academic language in research that is being made accessible to the participants. Shakespeare (1996) argues that plain English should be used with writing research. However, Hanley (2005) argues that if researchers say things on a very basic level, there may not be very much to say. After talking with service providers and people with disabilities at the focus group held at the end of my field research, only one participant wanted a full version of the research, the others wanted a summary version, with the findings from field research and interviews. They enjoyed the graphs I presented at the focus group and want those to be included in the summary I send to them.

Further criticisms about the emancipatory approach, come from Oliver (1992, p.110). He regards emancipatory research as essentially “an activity carried out by those who have power over those who do not”. Research by Kabzems and Chimedza (2002); Katsui, and Koistinen (2008); Maloni et al. (2010) and Mmatli (2009) have a different outlook, viewing emancipatory research as offering tools for empowerment, in partnership with those who do currently not have the means to do it themselves. Oliver (1992) is not in favour of this having argued that disability research should not be carried out by able-bodied people at all.

Reading these strong views, including Hereniko (1999) as discussed in Chapter 3, did make me continually reflect on my position as a non-disabled, non-indigenous researcher. In a partnership with people with a disability, I wanted this study to bring reciprocity benefits and tools of empowerment that we could all generate while working together. This, for me, outweighed some of the awareness I knew I would lack as non-disabled and non-indigenous. Barnes (2003 p. 8) signals similar thoughts when he says:

... having a designated impairment does not automatically give someone affinity with people with similar conditions or disabled people generally... Emancipatory disability research is not about biology it is about commitment and researchers putting their knowledge and skills at the disposal of disabled people and their organisations; they do not necessarily have to have an impairment to do this.

Thus, it is with this in mind I undertook research as an able bodied person in the area of disability.

iii. Varied Sources of Data Collection

Gathering data from a variety of sources is the third key research method in this thesis design approach. Data collection included using semi-structured interviewing, field journal use, and using a focus group to help with unpacking field data, which will now be discussed.

Semi-structured Interviews

Before undertaking semi-structured interviewing I studied the underpinning literature, Government and other institution reports as secondary sources. The disability officer of CINDC worked with me in partnership to formulate interview questions and to ensure appropriateness and relevance to the Cook Island culture. This also enhanced the emancipatory research methodology used in this study. I also had feedback on the interview

questions and process from the translator prior to interviewing. The translator also helped unpack the information following and during the interviews she translated, as did the participants themselves in the focus group. See **Appendix 3** for the question sheet that I based interviews on.

Participants were chosen by purposive snowball sampling where participants with whom contact has already been made, use their social networks to refer other people who could potentially be interviewed or observed (Stake, 2005). Twenty five people were interviewed in total, 12 females and 13 males. These were broken up into three groups; People with a disability (PWD), a family caregiver of a person with a disability (FCV) and disability stakeholders (DSH). The transcribed interviews were given a number for identification codes on their order of being interviewed. See **Table 6** below for summary of participant groupings.

Table 6: Participant groupings

Participant Group	PWD	FCV	DSH	Total
Female	2	5	7	14 ¹ (2 females in two groups)
Male	9	2	6	17 ¹ (4 males in two groups)

Source: Author

¹Six of the participants fell into two groups and were given two codes, for example PWD 1 was also DSH 1 and therefore the total here is 31.

As the interview process progressed and people opened up to me, most of the interviewees started telling me their experiences and attitudes of disability in a story account. I found I did

not need to ask my questions listed as prompts, as most of the time everything was brought up in the stories they had to tell. Nowland-Foreman and Stubbs, (2005) explain that oral history accounts are part of Cook Island tradition. If I had used a structured interview method, the comfortable manner of storytelling may not have occurred. The story telling enriched the data collected as shown in this following example based on my field journal entry:

The interview today that I planned to take 45 minutes lasted 2.5 hours! As well as talking about his disability, I was told his story about being adopted as a young boy by Te Puea Hèrangī, a Māori Princess in New Zealand (Interview, PWD 7, 19 May, 2011).

This background information enriched his story on disability, giving me a glimpse of his beliefs and attitudes, leading into his current situation in Rarotonga.

My first interview and important lesson

Immediately after my first interview (PWD 1 and DSH 1), I thought the interview process had gone well. I felt as though I had reciprocated in an emancipatory manner, by presenting a copy of the Disability in Action pamphlet, which will be discussed further shortly. I felt that there was no feeling of oppression for the participant. At the conclusion of our interview, the participant pulled out his cell phone and played back a short segment of us speaking...he had been taping our interview. I had a moment of being taken aback when he said 'the interviewer is now the subject!' (Interview, PWD 1, 14 May, 2011). I realised he had cleverly turned the tables. How comfortable did I feel being taped and having our conversation kept by him? I realised I was not as connected with the feelings of being interviewed as I thought. It was an invaluable lesson and one I was humbled by. It made me realise no matter how

many emancipatory research methods I used in the interview process, there is still a 'feeling' of being interviewed and I had felt slightly oppressed by this feeling, even without actually being the interviewee.

Limitations in the Interview Process

As seen in **Table 6** above, one of the main limitations I encountered when utilising a purposive snowball method was that the men with disabilities referred me to other men with disabilities. The two females with a disability were recommended to me by local medical staff I had met. I contacted the local Cook Islands National Council for Women (CINCW) for possible referrals of women with a disability; however, I was referred back to Internal Affairs. They explained the National Disability Officer in Internal Affairs was their spokesperson on matters of women and disability. This National Disability Officer is the Government representative on disability and different from the disability officer of CINDC, although they have strong links to each other and work in the adjoining rooms. I had already been to interview her, so no further leads on possible female participants developed.

The second limitation with interviewing was trying to locate people. There are no street addresses, and some participants did not have contact phone numbers. This coincided with turning up at an agreed time, only to find the participant away or busy. Both these limitations made me very familiar with the two ring roads and tracks around Rarotonga.

Evolving the questions and approach

As more interviews were carried out, I found I had a dilemma. It became obvious that participants were not engaging in a social approach to disability and the rights-based CRPD had not generally been adopted or even heard of. This is further discussed in my Chapter 5 findings. I had expected a list of social barriers to be talked about. The big surprise was that

all but one participant with a disability out of 11 interviewed, said the barrier was themselves. I found that this part of the interview was consequently spent discussing disability rights and giving contacts to rights-based organisations. I was surprised to note that two of the PWD interview participants were also DSH participants involved in advocacy and awareness of the CRPD, yet they themselves still did not talk about any social barriers. This reflection on the interview process served as a self-emancipatory process. I discovered a weaker rights view than I initially intended and I had to adjust how I weaved rights-based talk into the interviews. One example from one participant on questioning him on barriers to access:

I cannot complain about the only pedestrian crossing not having a ramp up the curb, when I cannot actually get to town due to my disability (Interview, PWD 11, 20 May, 2011).

Fieldwork Journal

A further data collection tool within participatory research, is keeping a fieldwork journal of experiences and thoughts as the field research develops. As described by Clandinin and Connelly (2000, p. 80), “Field texts aid the inquirer to move back and forth between full involvement with participants and distance from them.” I spent every night writing in my field journal, finding it enhanced my reflection on the day’s events and gave me more insight for the next day’s interviews.

Focus Group

Paulo Freire, an educator in Brazil, has used “study circles” in his work with the cultivation of conscientisation (Kamberelis and Dimitriadis, 2005). These authors further say Freire followed a Marxist approach, where he viewed focus groups as engaging with people in their realities. The focus group I held was on the last day of my field research in Rarotonga with a lunch provided prepared by me and a friend who volunteers on the Island. It was held at her house that was located two minutes from the main town of Avarua. Almost all the

participants were invited to attend, however, only 8 attended. This was due to a variety of reasons, but mostly due to the people with disabilities not having access to transport to get to the focus group. The unpacking of information from this focus group was an essential part of using an emancipatory methodology. In Chapter 5 the focus group findings will be further elaborated on and difficulties discussed.

During the focus group it was mentioned by a participant to have a *karakia* written for my study. *Karakia* is an important part of any meeting and are performed when I was a participant observer at two meetings I attended. In keeping with the focus group and participants guiding me on my research process, I asked for advice on whom to ask for a *karakia*. One of the service providers at the focus group had a Papa who was a retired Pastor happy to write a *karakia* for me which preceded the introduction.

iv. Reciprocity and Empowerment

As stated in **Table 5** above, the fourth key research method adopted in this research design should reflect two emancipatory principles; reciprocity and empowerment.

Reciprocity

Assistive aids throughout all the Cook Islands are in very short supply, with not one spare pair of crutches or wheelchair available. A way I could reciprocate was to organise local rest homes around my home town in New Zealand to donate any second-hand equipment to the NGO Te Vaerua. As a result, 8-tonnes of equipment have been sent to the Cook Islands with free shipping arranged. Te Vaerua will prioritise these items amongst those most needing them, in collaboration with Rarotonga hospital Physiotherapist and Occupational Therapist.

I was asked by the NGO Te Vaerua when field research began if I could help to set up a physio clinic/meeting room for people with disabilities while I was there. The rooms had

been hired, but nothing had been set up. I saw this as a great opportunity not only to meet people in this mini project, but also to be another means of reciprocity and to give back to the community I was researching. (See **Appendix 4** for photos of refurbished clinic). I felt as a result of working with this mini project I was more connected with the participants and a richer dialogue of real-lived experiences was attained. Several hours was spent with providers and people with disabilities working on the mini project.

As Lather (1986) explains, reciprocity can enhance the richness of field research data by the researcher becoming a friend, and therefore potentially able to gather more relevant and personal data. When I volunteered as a Physiotherapist late last year, and talked about this study I was planning, people with disabilities identified two main areas they thought could benefit from research; having more information on disability service providers and a recognition of their needs for assistive aids. As a result of this I co-designed a service provider information pamphlet, in partnership with all the service providers included in the pamphlet (see **Appendix 5**). This pamphlet became a tool for empowerment.

Empowerment

I hoped that by partaking in reciprocity by instigating the pamphlets, it has also given an avenue for empowerment for people with disabilities in the Cook Islands. The pamphlet includes rights-based advocacy group CINDC's contact details. The pamphlet was given out to each participant and a bundle left at Internal Affairs, at their request. I published 100 copies of this pamphlet before I left for field research, and ensured that I left the word document file of the pamphlet with the disability officer for CINDC and the support worker for Te Vaerua Rehabilitation Services. They continue to print copies and alter the pamphlet as they require, keeping it a sustainable document. The pamphlet was translated in to Cook

Island Māori as recommended by the people with disabilities, especially as the elders in particular spoke and read Cook Island Māori as their first language.

As well as the disability pamphlet being a tool for empowerment, listing service providers and disability advocates, the interview process also became a tool for empowerment and advocacy. As one participant said:

It's been terrible, because after the accident I have not been given medicine or anything. I have been massaging with oil, that's all. If we can get another right underarm crutch that would be good, at the moment I am using one crutch and the wall and I nearly fell backwards. (It is) very hard with just one leg. Now I know where to go for help with these matters, thank you. (Interview, PWD 3, 23 May, 2011)

v. Participant Observation

The fifth key research method is to find out about attitudes towards, and actual experiences of, people with disabilities in the Cook Islands through participant observation. I wanted to study actual behaviour in actual social settings to get an accurate picture of attitudes surrounding disability. As Ingstad and Whyte (1995) explain, participatory observation identifies constraints and possibilities, beliefs and values, which help with coping with disability. As well as participating in the mini clinic refurbishment project already mentioned, I also went out in the community with people with disabilities, both individually and in a group basis with the Creative Centre. I wanted to see how people with disabilities move around their social spaces and how they are looked at and acted upon by others.

I was also fortunate enough to be invited on a walk through the Takitumu Conservation area with a participant in the study (PWD 1, DSH 1). A morning was spent with me being guided around some beautiful forest area, not usually visited and there was some off track tramping

and scrambling required. This wonderful outing gave me an insight into the culture and history of the Cook Islands as well as getting to know my guide and his wife who are now friends.

It has been shown that people's beliefs are sometimes not acted out in real life, giving a false impression of a situation (Ingstad and Whyte, 1995). This is why using participant observation was essential to the methods of this research study, as gaps can occur between what people believe, and what is really experienced. A relevant example from my field research is as follows:

There are only about 20 people with disabilities on the Island. I cannot spend all that money fixing up buildings for just 20 people. You only see two people out in their wheelchairs. If we make all the buildings have ramps, it will be for only two people. We can do it the old fashion way, get two strong boys to lift the wheelchair up the stairs. (Interview, DSH 13, 19 May, 2011).

The lived experience I saw through participant observation and visiting people with disabilities, mostly in wheelchairs, was that the terrain and transport were so inaccessible that they could not go out. The Disability Service Provider interviewed based his belief only on what he saw, not understanding the lived experiences of the people themselves who needed the changes with infrastructure to actually be able to get out in the community in the first instance. It has been interesting seeing how different actors can have different perspectives over similar issues. It also showed that some disability stakeholders, even as Government Ministers do not realise that 15% of the population do have a disability, making approximately 1200 people with a disability on Rarotonga alone.

vi. The Importance of Politics in Disability

For disability, emancipatory research begins by conceptualising disability in a social model term. Using a political link is the sixth and final key research method used in this study's design. As Hanley (2005) says, this involves socially imbedded discrimination and derived notions of power making it a political issue. French and Swain (1997); Morris (2001), and Ingstad and Whyte (1995) agree, saying that there should be a link between the disability research and disability politics. These links were present in my research, in the first instance, by interviewing two Government representatives. I also ensured the Government funded CINDC was included in the service provider pamphlet we designed and gave out to each participant. CINDC provide free awareness training and information on the CRPD human rights and act as an advocate for people with disabilities. This was discussed in each interview, giving a tool for empowerment if the person with a disability chooses to use it. This political link goes beyond just wanting data and moves into the realm of research in praxis, consciously aiding the participants to improve their lives as they wish. Using this praxis-orientated research within the emancipatory methodology has the aim of the research participants becoming more conscious of their rights and needs.

Data Analysis

Not everything that can be counted counts,
and not everything that counts can be counted.

– Albert Einstein

Reflexive analysis is a process that manages your raw data leading to interpreting meaning (O'Leary, 2010). I had to keep in mind my underpinning research aims and objectives while going through this process. It was hard to focus and not get side tracked as the pertinent

Einstein quote demonstrates above. My questions (see **Appendix 3**) were initially grouped into themes based on engagement with the literature and although these changed as the semi-structured interviewing took place, they were a good start point. Due to the interviews being story telling dialogue instead of purely questions and answer interviews I was told a lot of history and about Cook Island culture in general. On returning from field research while transcribing the interviews I had to focus on and sort the relevant information. I looked for interconnections in my findings, not only through the transcribed interviews but also through field journal entries and personal observation. Having some of the data unpacked by a small focus group on the last day of field research in Rarotonga also identified some common themes. Using the participation of the focus group maintained a holistic, unbiased view of analysis of the findings.

Conclusion

In conclusion, this chapter has presented the conceptual underpinning research methods used and considered philosophical and ethical issues that arose before and during fieldwork. This chapter has also described in detail the six key research methods adopted which were central to answering my thesis research question in an emancipatory manner. Being able to undertake research of this manner in a developing country context and working with the people with disabilities and their families has been a great privilege.

Research findings and other key information uncovered within the interview and observation process in the Cook Islands is now further discussed, and this data unpacked in the next two chapters, both by the author and the people with disabilities, by focus group dialogue and subsequent communications.

Chapter 5: Policies, Frameworks and Real-lived Experiences

Let us be like dolphins
 Sharing the same song
 As we brave rough seas
 Let us be like roots
 Of the coconut tree
 Nurturing the one body
 Let us be like wings
 Of the white tropic bird
 Co-ordinating our flight to Paradise
 Brothers and sisters of the Pacific
 Unite in spirit
 Unite in soul
 Kauraka (1999, p. 19)¹

Introduction

This Chapter is divided into two main sections with findings woven together from people with disabilities, their families, and disability stakeholders epitomised by the above poem that Cook Island poet Kauraka Kauraka wrote. The poem demonstrates the call for all people in the Pacific to unite. Firstly, and addressing the first objective of this study, human rights-based disability policies and frameworks are introduced including political links and interviews from field interviews. Secondly, and addressing the second objective of this study, is to produce findings from real-lived experiences sourced from semi-structured interviews,

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personal observations, field journal and a focus group.

These are presented here under the headings; attitudes, prioritised needs and barriers to development of people with a disability. These headings address three out of the four questions noted in the introduction outline of this study, and have been identified as main areas of findings by reading through my field journal and reflectively annotating the priority areas to be considered.

Human Rights-Based Disability Policy, Frameworks and the CRPD in the Cook Islands

As described in Chapter 1, there are three main objectives of this study. The first of these three objectives will now be considered;

- i. To document human rights-based disability policy and frameworks currently in the Cook Islands.

Specific to the Cook Islands are human rights-based disability policies and frameworks which will be expanded on now. Catherwood and Topa-Apera (2003), report that the Cook Islands have entered into many multilateral and bilateral treaties. This includes the signing of the CRPD in May, 2009. Other disability and human rights-based frameworks are described below in **Figure 6**. These frameworks are not an exhaustive list but are the principle working frameworks used for underpinning policy and practice for disability human rights in the Cook Islands.

Figure 6: Disability and human rights-based frameworks in the Cook Islands:



Source: Author: Based on Interview (DSH 10, 16 May, 2011).

Each framework or policy above will now be highlighted with its current applicability in a Cook Island context.

The Pacific Regional Strategy on Disability

This strategy was adopted by Pacific Ministries in October 2009 at the Disabilities Ministers' Forum. The strategy sets out practical mechanisms for the Pacific Islands Forum Secretariat

to support Governments, including the Cook Islands, to implement the CRPD. The Strategy will be implemented over a five year period (2010 to 2015) by governments in collaboration with civil society, regional stakeholders and development partners. At the 2009 meeting it was highlighted that the Cook Islands had adopted a National Policy on Disability Plan. Ministers also were to consider developing a “no gaps” approach to disability inclusive development through reviewing policy and legislation and strengthening coordination (PIFS, 2009b). The Cook Islands signed the CRPD on 8 May, 2009, however as this study’s findings show below there are gaps to bridge.

The Cook Islands National Policy on Disability Plan

The Cook Islands National Policy on Disability Plan is based on the Biwako Millennium Framework (BMF) model (Interview, DSH 10, 16 May, 2011). As Wilkinson (2008b) has found, there has been significant progress since 2003, with the formation of initiatives put in place through national disability policy in the Cook Islands. Fifty five percent of the tasks set in 2003 have been achieved in order to improve the lives of people with a disability in the Cook Islands. General progress for people with disabilities is apparent in this study’s findings. Interview participants specifically elucidated to noticeable general improvements in the disability field in the last 3-4 years (Interviews, PWD 7; DSH 9, 10, 13; FCV 4):

There’s a lack of public awareness of disability, it’s only come out in the last 3 years. A lot of people do not treat the disabled people as normal people. It’s really improved through us having to go out to the Doctor. If Mama was not in the disabled condition I would not have a clue. It’s not something the Cook Islanders like to talk about.
(Interview, FCV 4, 15 May, 2011)

The least improvement after introduction of the National Policy on Disability Plan, according to Wilkinson (2008b), has been in meeting the practical needs of people with a disability. These include rehabilitation services, assistive aids, access and awareness of human rights. These unmet practical needs are also found to be apparent in this study's findings and will be discussed in more detail in the *prioritised needs* section below

The Biwako Millennium Framework (BMF)

The BMF is based on the citizenship model (Edmonds, 2005). It promotes an inclusive, barrier-free and rights-based society for people with a disability in Asia and the Pacific, predominantly by strengthening the leadership of DPOs with a particular focus on women with a disability being included in DPOs.

The BMF contains four priority strategies to ensure inclusive practices (UNESCAP, 2002):

- i. A national plan of action (five years) on disability
- ii. Promotion of a rights-based approach to disability issues
- iii. Disability statistics/common definition of disabilities for planning
- iv. Strengthened community-based approaches to the prevention of causes of disability, rehabilitation and empowerment of persons with disabilities.

It is important to note that the BMF was written with the MDGs underpinning these above strategies. Adopting a national disability plan is the first priority strategy in order to meet the BMF framework inclusive practices, and has been discussed directly above this section.

The second BMF strategy promotes a rights-based approach to disability issues. The following quote is from one interview where the participant talks about this promotion on awareness and disability occurring in everyday life:

There's been a lot of public awareness programmes (on disability) from public health and health promotions section on Cook Islands Radio. It's always in Cook Islands Māori, as that's what we want to hear. (Interview, DSH 8; FCV 3, 14 May, 2011).

The third BMF strategy is to have updated disability statistics. The Cook Islands National Disability database has not been updated in over one year with the loss of funding for a physiotherapist position. The previous physiotherapist was employed 50% of the time by the Cook Islands Health Board and 50% by Te Vaerua Rehabilitation Council. Both areas have had a lack of funding to be able to maintain this position. The physiotherapist undertook home visits and updated the disability database:

There is an incomplete data base with some outer island information on it that is currently with Internal Affairs, but no one is adding to it currently. We were never very good at keeping data. We had Medtech in 2005 but for the first few years we never used it. We never knew the importance of the data base until the new hospital director came, and it makes sense now. If someone can keep the separate disability database going in the future that would be a priority. (Interview, DSH 4, 16 May, 2011).

Even though the disability database is currently not being updated, there has been the census enumeration in 2006 (Cook Island Government, 2006), where each person aged 15 and older was asked if they have any disability or health problem lasting six months or more. The results show that, 764 persons reported to have a disability or a health problem which was 7% of the resident population 15 years and older. This comprises of males (386) and females (378) with a disability/health problem. The majority of these disabilities were caused by

health and medical conditions (352 or 46%) followed by physical-intellectual handicaps with 177 or 23%. Exactly 50 people had a physical disability. These and other disability statistics are illustrated in **Table 7**.

Table 7: Proportion of the resident population with a disability or health problem in the Cook Islands

Disability, Health and Medical conditions	Total	Male	Female
Physical Disability	50	33	17
Physical-Intellectual Handicap:	177	82	95
-Intellectual	12	5	7
-Deaf/Hearing	81	39	42
-Blind/Vision	74	30	44
-Speech/Stuttering/Mute	10	8	2
Health and Medical conditions	352	170	182
Multiple Disability	83	50	33
Old Age (senility)	52	20	32
Other	46	28	18
Not Stated	4	3	1
Total	764	386	378

Source: Cook Island Government (2006).

The fourth priority strategy of the BMF framework is to strengthen community-based approaches to the prevention of causes of disability, rehabilitation and empowerment of persons with disabilities. Within the scope of this study it was found that rehabilitation services are severely lacking. Largely as a result of the lack of awareness about needs, empowerment for people with disabilities is also lacking, which will be further discussed under the *prioritised needs* section below.

Community Based Rehabilitation (CBR)

CBR is mentioned in Chapter 3 in detail and is seen as a way to bridge the MDGs and the CRPD (DPI, 2010). According to a WHO report (2009), “Community-based rehabilitation is coordinated by a multisectoral National Disability Council consisting of representatives from many relevant agencies and NGOs... CBR services are comprehensive and include home care and provision of food, water and sanitation”. In this study it was shown that the WHO report which showed the CBR services to be comprehensive are incorrect:

There is no concrete foundation been set for CBR, it is true that CINDC does coordinate CBR, but things are mixed up at the moment (Interview, DSH1; PWD 1, 14 May, 2011).

CBR? From my knowledge, there is none (Interview, DSH 10, 16 May, 2011).

The Te Vaerua Rehabilitation Council does provide a very limited community based service but here is no formal CBR framework followed. Due to funding limitations there is only one part-time occupational therapist, one part time maintenance officer and one support worker who is a volunteer. These three staff members have to cover all of Rarotonga’s population and be advisory to the outer islands. Their community rehabilitation centre in Arorangi has been in the process of being renovated over the past 3 years. The treatment room is ready to use, however there is no power and no plumbing in the building.

Millennium Development Goals (MDGs) in the Cook Islands

The MDGs underpin the BMF and are intrinsically linked to CBR in that CBR links the MDGs to the CRPD. As mentioned above, CBR is not currently active in meeting and developing rehabilitation in the Cook Islands. As already exemplified in Chapter 3, the

MDGs have no specific mention of disability, therefore the MDGs underpinning the BMF with respect to disability has limited value. United Nations (2008), report that the economy of the Cook Islands is among the better performing in the Pacific, with consistent economic growth, impressive social development and good progress in MDGs overall.

The MDG report produced in 2009 by the Cook Island Government comprises of 57 pages, however, there is not one reference to disability (Central Policy and Planning Office: Office of the Prime Minister, 2009). Below in **Table 8** is a snapshot of how the Cook Islands are performing in reaching the MDGs by 2015.

Table 8: A Snapshot of MDGs in the Cook Islands

Goal	By 2015:	Achieved	Probably	Potentially	Unlikely
1	Eradicate extreme poverty and hunger	◆			
2	Achieve universal primary education		◆		
3	Promote gender equality and empower women		◆		
4	Reduce child mortality	◆			
5	Improve maternal health	◆			
6	Combat HIV/AIDS, malaria and other diseases		◆		
7	Ensure environmental sustainability			◆	
8	Develop a global partnership for development		◆		

Source: Adapted from Central Policy and Planning Office: Office of the Prime Minister (2009).

Convention on the Rights of Persons with Disabilities (CRPD) in the Cook Islands

The CRPD history, its importance and relationship to human rights has been extensively discussed in Chapter 2. The CRPD from a Cook Islands perspective is detailed here. The Cook Islands Government ratified the CRPD and optional protocol on 8 May 2009. The first monitoring report is due with the United Nations in June, 2011. The report has not yet been released to the public due to the timing of the twice yearly sessions of the United Nations Human Rights CRPD Committee (UNHR, 2011).

The CRPDs Articles address a variety of specific human rights, and how they are applied in the disability context so that persons with disabilities can fully enjoy their human rights. As mentioned above in the Cook Islands National Policy on Disability Plan section above, the areas highlighted for improvement in the Cook Islands National Policy on Disability Plan according to Wilkinson (2008b) are rehabilitation services, assistive aids, access, awareness of human rights.

These were also listed as priority needs in this study's findings. The articles of the CRPD² particularly pertinent to the above four areas currently practically unmet in the Cook Islands are as follows;

- i. Article 26 of the CRPD requires habilitation and rehabilitation where states Parties must organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes.
- ii. Article 20 of the CRPD requires that personal mobility – obligates States Parties to take effective measures to ensure personal mobility for people with a disability, have access to quality mobility aids, devices and training in them.

²CRPD Articles information sourced from Disabled People's International (DPI), (2010).

- iii. Article 30 of the CRPD requires participation in cultural life, recreation, leisure and sport. States Parties must take all appropriate measures to ensure enjoyment of this right, including, amongst others, providing access to television and cultural materials in accessible formats; providing access to places for cultural performances or services. States Parties must also enable participation of persons with disabilities, on an equal basis with others in recreational, leisure and sporting activities. Such measures include, amongst others, providing access to sporting, recreational and tourism venues.
- iv. Article 8 of the CRPD requires awareness-raising where the States Parties take a variety of measures to raise awareness throughout society regarding persons with disabilities, combat stereotypes, prejudices and harmful practices, and promote awareness of the capabilities and contributions of persons with disabilities.

Cook Island National Disability Council (CINDC)

CINDC was formed in 2001, evolving out of a national disability workshop and is registered as a member of the PDF. There have been frequent office holder changes recently, with a new board elected in July, 2011. Through CINDC, self-help organisations have since been established on nine outer islands with disability awareness programmes and training undertaken on Mauke, Atiu and Mangaia. This has been funded by the Community Initiatives Scheme, a NZAID funded scheme (DSH 1, PWD 1).

Forming a DPO in the Cook Islands is difficult due to their small population and they struggle to get the numbers of people with a disability willing or able to form a DPO. There is office space set up for CINDC within the same building as the Internal Affairs and national Disability Officer. Recently however, this room has not been used due to office holder changes and a staff member leaving. There has been some confusion this year whether

CINDC is a DPO and information in a recent report by the PDF & Australia Pacific Islands Disability Support (APIDS), (2011), highlights this confusion over DPOs in the Cook Islands:

...the Cook Islands DPO context is different from other Pacific Island countries, in that while there are two member organisations of PDF which consider themselves to be DPOs, neither of these organisations appears to be consistent with the broader international definition of DPOs (PDF and APIDS, 2011).

The other member of PDF in the Cook Islands is Te Vaerua Rehabilitation Council who says they have never considered themselves to be a DPO (personal email, DSH 2, August 15, 2011).

Pacific Disability Forum (PDF)

The PDF was established in 2002 by combined national DPOs (Macanawai, 2007), to work towards inclusive, barrier-free, socially just, and gender equitable societies for people with disabilities in Pacific Countries and territories. The PDF has its resources funded by NZAID. As mentioned CINDC and Te Vaerua Rehabilitation Council are registered members and also Nooroa Numanga, who is the coordinating officer for government on disability issues in the Ministry of Internal Affairs. The PDF which is based in Fiji recently supported the Cook Islands CINDC by sending Mr Seta Macanawai, the CEO of PDF. He visited in July, 2011 and held a series of meetings with disability providers. He also clarified the DPO constitution that states that a majority of people in a DPO must be people with a disability. Previous to this it was thought 100% must have a disability (Interview, DSH 6; PWD 5, 14 May, 2011).

Pacific Sisters with Disabilities Report

In 2009, the Pacific Sisters with Disabilities Report was released. The report was funded by the United Nations Development Programme and was a desk-based study of data and research surrounding women and girls with disabilities in the Pacific. Authors Stubbs and Tawake (2009), state from the limited data they found the report has made 28 recommendations for Pacific Governments and 8 recommendations for DPOs. The Cook Islands have met some of these recommendations such as signing the CRPD and producing a Disability Act. Some recommendations are still to be fulfilled such as having a rehabilitation service available for people with disabilities. It emerged from the report that women with disabilities in the Cook Islands are not aware of the United Nations instruments such as CEDAW and CRC. The Cook Islands' review of their Disability Policy recognizes that women with disabilities should have a stronger role in the National Disability Council. This has recently been rectified with the new CINDC board elected in July. Three women are on the board of five, including Co-Vice President, Secretary and Treasurer. The President and Co-Vice President are male.

Disability Act

After consultation with CINDC, the Disability Act came into force in the Cook Islands in 2008. This Act provides a document for the Government to institute and maintain a Disability Strategy in respect of persons with a disability. It also provides "to make discrimination against a person with a disability unlawful, and to ensure that persons with a disability have access to certain buildings and to footpaths" (Cook Islands Office of the Ombudsman, 2011).

The Disability Act can now enforce new buildings and roads to be accessible for persons with a disability, through the building code. However, as the Minister of Internal Infrastructure and Planning (Interview, DSH 12, 19 May, 2011) says in the following excerpts:

Most of the buildings are for Non-profit organisations and then there is a burden on them to raise extra funds. In the past the family and friends have just lifted them up the stairs. It is a really difficult one at this time. It is very difficult to enforce, some do and some do not because of the financial constraint. It is also the toilets have to have disabled access. It is expensive providing toilets for the (people with) disabilities.

On interviewing the Minister and his team it became apparent that their communication was very limited with people with disabilities. I asked the Minister what changes were to take place in the immediate future with regards to public disability toilets and the Punanga Nui Market area. These were needs prioritised by people with disabilities and their families in recent interviews in this study. The Minister answered:

It really comes back to them. My question to them is where is difficult for them, if we could get some data from them how regular they use it, this is the information we need. We cannot think for them, and do things because of cost and if we can get some information from them, how regularly they use, just some simple data we can start some process of doing. This is the real concern, even though it's in the Act and has to be provided but the biggest question is how often would it be used?

I asked the Minister if a list of priorities by people with disabilities would help him and his team be able to prioritise.

If we can get the information, all this really is just a simple fix.

National Sustainable Development Plan (NSDP)

The Minister of Infrastructure and Planning explained that funding is limited for providing accessible public buildings for people with disabilities (Interview, DSH 12, 19 May, 2011). One of the reasons for this is explained due to NZAID and AusAID providing bilateral assistance based on sector plans, aid policy, budget priorities and the Cook Islands NSDP. The NSDP was initially set for the specific period 2007-2010 and included short to medium term strategic targets. The NSDP is part of an overarching vision that the Cook Islands Government prepared for future development through to 2020, named Te Kaveinga Nui – Living the Cook Islands Vision. From the NSDP there are six agreed priority areas of action to be developed with bilateral partners NZAID and AusAID (NZAID, 2011); Water and sanitation, pearl industry revitalisation, renewable energy, tourism sector support, public Financial Management and service delivery and education. Unfortunately, within these six prioritised areas of action, disability is not mentioned.

According to the Central Planning and Policy Office (Office of the Prime Minister) and the Economic Policy Division (Ministry of Finance and Economic Management) Government of the Cook Islands, (2007) there are four main areas within the NSDP in the area of disability to develop;

- i. To develop a multi-disciplinary community rehabilitation service. As shown in this study's findings and discussed further below in *prioritised needs* section below, this has not been developed yet.
- ii. Ensure all Government offices and at least 50% of public places are accessible to people with disability by 2010. There has been improvement with disabled parking areas around the main supermarket and one disabled park near the

Punanga Nui market. A new education building has been built with disability access.

- iii. Strengthen public-private and public-community partnerships with private sector and NGOs to facilitate greater social responsibility for the aged, young dependents and people with disability. There is a lack of coordination between NGOs and the Government and between the NGOs themselves as shown in these two following comments from a participant who is a disability stakeholder and family caregiver (24 May, 2011):

The Secretary of Health went to Mauke a few years ago and I took him around the people with disabilities on the Island. He said I had spoilt his holiday but said thank you for showing me, and was a great supporter for the people with disabilities after that visit. He had not realised how little they had to work with.

The disability providers (are the barriers to development). It's the so called people in charge not being aware of the needs. We should be spending more time with the families and people with disabilities asking what they need. Then go back to the Government and say look here are the needs. The Government will be supportive if you be specific and present the needs of the people to them. They may not have the money right then but will then be able to think about the needs and prioritise if the money does come. The big gap is the lack of each services direction.

- iv. Evaluate the performance of NZAID funded Community Initiative Scheme and consider localisation of funding by 2010.

NZAID still funds the Community Initiative Scheme, providing funding grants of between \$5000 and \$20,000 for projects carried out by non-government organisations, the community, schools, sports and church groups. A contribution from those running the project is expected, approximately 25% of the total costs. The scheme provides funding in other areas besides disability such as youth, elderly, domestic violence, mental health, reproductive health, and gender and development (Interview, DSH 1, PWD 1, 14 May, 2011).

Real-Lived Experiences of People with a Disability in the Cook Islands

The section above has identified areas of discussion to meet objective one of this study:

- i. To document human rights-based disability policies and frameworks in the Cook Islands.

The second and third objectives of this study are investigated in this section:

- ii. To explore real-lived experiences of people with disabilities, their families and disability stakeholders in the Cook Islands.
- iii. To identify gaps, if any, between human rights-based disability policy and real-lived experiences of people with disabilities, their families and disability stakeholders.

Further analysis on these gaps will be discussed in Chapter 6.

There is purposively a lot of dialogue used in these findings in keeping with the importance of hearing the voice of the people and their stories. Three main themes from the semi-structured interviews, field journal, observation, focus group will be the topic headings for discussion;

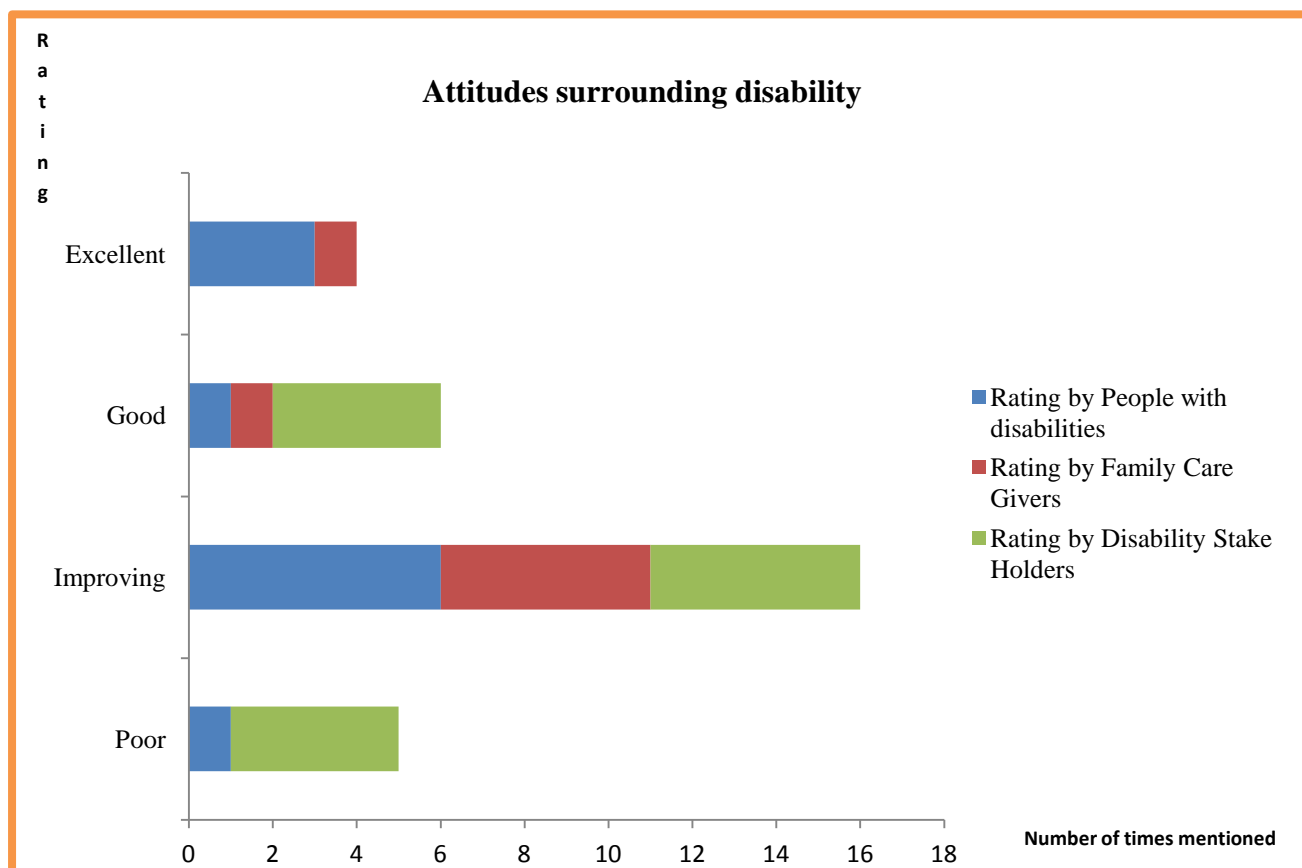
- i. Uncovering Attitudes - What are the attitudes surrounding disability from a Cook Island perspective?

- ii. Barriers to development for people with a disability - What are the barriers to development for people with disabilities in the Cook Islands?
- iii. Prioritised Needs - What are the prioritised needs for development for people with disabilities in the Cook Islands?

i. Uncovering Attitudes: What are the attitudes surrounding disability from a Cook Island perspective?

As suggested by Macanawai (2007) strong extended family systems in most Pacific Island countries encourages family members to look after their less fortunate relatives. The association of a disabling condition with ancestral curse, parental misdeeds, witchcraft, shame and fear still keeps persons with disabilities isolated, neglected, dependent and poor.

Generally, attitudes surrounding disability uncovered in the field interviews are seen as improving as seen in **Table 9** below. In the interviews I did not specifically ask for ratings as illustrated below. I found that most of the participants gave me their own specific rating during conversation. If they did not, I placed their attitude rating into what best fitted their comments on attitudes around how they thought people with a disability were viewed.

Table 9: Attitudes surrounding disability

Source: Author

Interestingly, the group that rated the attitudes surrounding disability the highest were the people with a disability. Only one participant with a disability rated attitudes as poor when he was speaking about the poor attitudes of his family towards him:

I am happy but the family is not and they are not talking about my disability with me.

Now I am not independent they are not used to it. I used to be independent (Interview, PWD 3, 23 May, 2011).

Four disability stakeholders rated the attitudes as poor in the Cook Islands. One example comes from a medical worker:

Priorities were set in our last health meeting, when it came to the disabled priority, no one lifted up their hand. No one wanted to volunteer and be responsible for that area. There's not enough people going out there and helping them understand, helping them to cope and telling them it is normal to take them out. (Interview, DSH 4, 16 May, 2011).

An example of an improving attitude surrounding disability from a disability stakeholder who has a disability:

There is a mind-set that has been established back from our missionary days and influences from that. If you have a person with disabilities in your family it is automatically attributed to sin and so obviously the family does not want that sin to be seen, and so they keep them in the background, they keep them at home to feed the pigs, feed the chickens, rake the lawns. I think the attitudes are changing. One thing that I have found is that the people are very supportive now. (Interview, DSH 6, PWD 5, 14 May, 2011).

One disability stakeholder who worked in the disability area in the 1990s shows how awareness surrounding disability, although still improving, has made progress in the past two decades:

When the Disabled Persons Institute was running in 1993... I found a young man who had never been out on the road. He had been brought up in a dog kennel outside. So I got him out, and he got working. Why were the people hid? A custom amongst Polynesians, you hide them away and you do not let them out. In Mauke, years ago, there were several kids with disabilities there that you never saw unless you crept up on the parents and found them. They were not talked to, never lived with the family,

lived in a shelter with enough food to live. The attitudes are pretty well dramatically changed now (Interview, DSH 9, 16 May, 2011).

A more positive observation on attitudes was written in my field journal entry (24 May, 2011):

Today I talked to a Cook Island Seventh Day Adventist Pastor. He reveals a compassionate approach towards people with disabilities and an understanding that disabilities are medical-based and not curse-based.

A positive development in the disability area is the screening of two TV “Attitudes” programmes played on Cook Island television in 2011. This was funded by Te Vaerua Rehabilitation Council who secured \$1000 funding from the Pacific Disability Forum. The aim of running the programmes is to gain exposure on disability issues and getting disability talked about. One participant said he felt people were supportive of him in public even though he looked different following his injury:

When I went to church everyone was amazed to see me alive when I first came back. As I walked in the airport everyone around the desks they all come over and say awesome. Is still had my helmet on and I was shy and I said talk to the hand. (Interview, PWD 4, 18 May, 2011).

Shyness is mentioned in five of the interviews, where it was described to me that you do not ask for anything because it was not in the culture to ask. This occurred even when it was to the detriment of the person with a disability:

A medical professional recalled a visit with a Papa. He had not been recalled for surgery as he was told he would, even though it was urgent. The medical professional called around there to check on the Papa about a disability matter (unrelated to the

surgical matter), and realised he had slipped through the cracks and not been called for his urgent surgery. On asking why they had not rung the Doctor or hospital about it, they answered that it was not their place to ring the Doctor, they just had to wait to be dealt with (Field Journal, 14 May, 2011).

Further examples of shyness in the Cook Island culture come from a disability stakeholder and person with a disability respectively:

We have to make the first move because the perception by the community is a shyness and unsure how to approach people with a disability and how to talk to them. (Interview, DSH 6, PWD 7, 24 May, 2011).

I used to have no idea what to do with myself, there is nothing I could do. I used to be shy when I could still walk. But now I come to the Creative Centre and hope for the future, a better life. (Interview, PWD 2, 24 May, 2011).

This shyness was also obvious when I personally observed a disability group out in the community, as illustrated in my field journal extract below in **Figure 7**. Overall, these findings illustrate there is not yet a normative view towards disability in the Cook Islands, a more pragmatic view is held. Using a pragmatic view, as described in Chapter 2, is relevant in a Cook Island context where resources are low and a middle road can be reached while the practical side of implementing policy catches up. This pragmatic approach also assists with including cultural differences into developing disability practice in the Cook Islands. An example of this pragmatic approach is portrayed below where the Creative Centre takes their members out into the community to educate their people on becoming more independent.

Creative centre outing

I was fortunate to be invited to meet up on a Creative Centre outing, the Creative Centre being a school for people with disabilities. The following observations, in **Figure 7**, were written in my field journal particularly regarding to attitudes surrounding us as a group including people with a disability.

Figure 7: Creative centre outing

We met at 1.30pm at Café Salsa with 2 staff and 5 members with a disability. This was an outing in order for the members of the Creative Centre School to become more independent by paying for their own drinks and socialising out in the community. The café waitress said she had the Creative Centre in there regularly and asked each member what they wanted which sometimes took a little bit of time. The waitress showed great understanding and empowered each member by letting them finish their orders independently and not turning to staff to order for them more quickly, which I have seen occur in New Zealand situations. One of the members had to be assisted up some stairs on the way out due to no ramp being available up to the rest rooms exit.

After having a snack and a drink at the café, we then as a group went to have a look around the large department store, CITV. One young woman who uses crutches previously had problems walking between the aisles at the CITV building as the aisles were very narrow. She had inadvertently broken an item while using her crutches due to the narrowness of the aisles and her family made to pay for reparation. Her family told her not to go in the shop again in case she broke something else. On this occasion however, there was no problem, as the aisles had been made wider due to the recent renovations in the shop which meant she could now go about the store without the fear of breaking anything.

Some people stared as we passed by as a group both by tourists and locals alike, but I would say no different to a similar situation in New Zealand that I have been involved with. The people with disabilities were very happy to be out and about, although appeared shy and did stick very closely together, not walking away on their own to explore. Every Wednesday the Creative Centre chooses a new place to go to out in the community to teach independence. I would say it works both ways; in that it is also educating the local people that people with disabilities can go out and about and mix in with the community activities as a normal everyday event.

Source: Field Journal Entry (26 May, 2011).

The impressions from both interviewing and personal observation are that attitudes surrounding disability in the Cook Islands are improving. This is especially significant in that disability has been an untalked about subject until recent years. The second main theme people with a disability identified for this study's priority research area is barriers to development which will now be reported on, showing unexpected results.

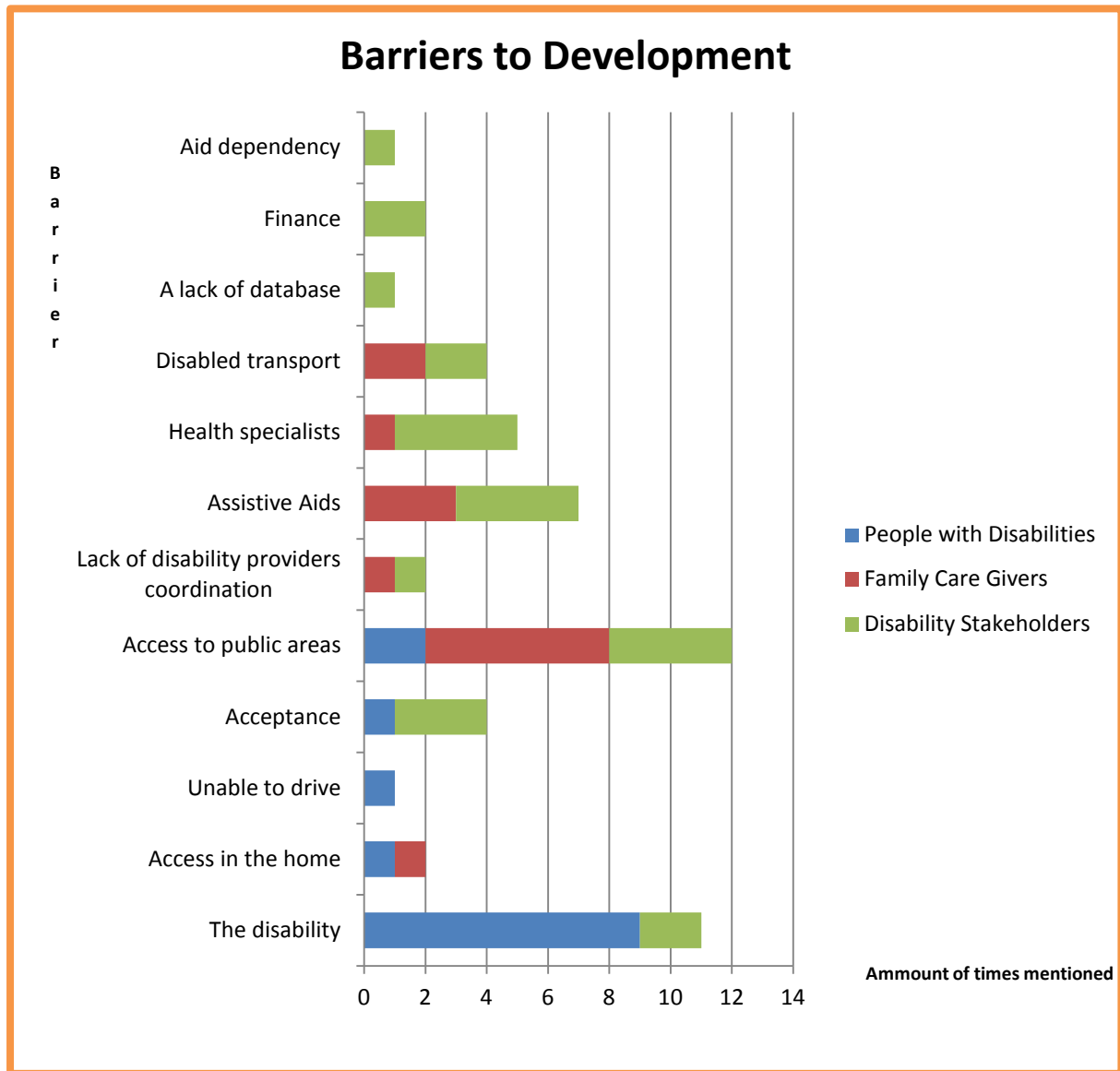
ii. Barriers to Development for People with a Disability in the Cook Islands

The following results shown in **Table 10** below, uncovered the biggest surprise in this study to me as a researcher, in that all but two of the people with a disability said the barrier to their development was solely their disability. I noted this in a field journal entry, 24 May, 2011:

There was little or no mention of social structures as barriers. I found nearly all of the people interviewed had little or no awareness of their rights. There was very little mention of social barriers as hindering their development.

It is important to note that what is seen as barriers to development by people with a disability is not the same as what a disability stakeholder or family member of a person with a disability views as being a barrier.

Table 10: Barriers to development of people with a disability, their caregivers and disability stakeholders



Source: Author.

Nine out of eleven people interviewed in this study who have a disability rated the barrier to development was solely their own disability. The remaining two people mentioned two social barriers each. One of the people with a disability who mentioned social barriers is also a disability stakeholder. In contrast to this however, two other participants who are disability stakeholders and also people with a disability, solely mentioned their disability as the barrier

to their development. In contrast to these findings by people with a disability in the Cook Islands is a U.S. traveller with a disability who is used to having no or limited social barriers and travelled to the Cook Islands in 2002. She never listed her disability as a barrier to getting around but instead had many social barriers she listed in her report:

My first sightseeing was the restroom. The terminal restroom had no stalls wide enough for a wheelchair, so as I crawled from my chair to the toilet, I chanted my mantra of keeping a good attitude. With the exception of the bank and a small grocery store, ramps were something I left behind in the U.S. There are no islanders in wheelchairs out and about. There are no provisions (for) any disabled person to mainstream into public life. I was looked upon with amazement, and often was complimented on my strength to wheel on my own power. At the Saturday market, I flagged down another tourist using a wheelchair (the only other wheelchair-user I saw) who was from Switzerland. He chose to stay in a larger resort where access was better, but he still needed help from the resort staff to access areas not ramped. Would I go back to the Cook Islands? Probably not. Not even paradise is a trade-off for independence (Arthur, 2002).

I asked one participant with a disability why they see their disability as being the only aspect that hinders their development and getting them out and about in the community. He answered:

I would not ask to have things changed, it is not me to ask for anything. It is my problem. It's easier not to go anywhere. I'm quite happy sitting at home (Interview, PWD 11, 20 May, 2011).

Another participant concurs with the above perspective:

We, the people with the disability are the barriers. We need to be strong and even though we have this disability there are things we can do and contribute to the community (Interview, DSH 6, PWD 7, 24 May, 2011).

I also asked this question at the focus group held 25 May, 2011. I provided a lunch at a central venue in Avarua. Maybe due to a lack of disability transport, there was only one person with a disability present (who is also a disability stakeholder) and 7 other disability stakeholders. When an APIDS group came to the Cook Islands just one month after my field research in June, 2011, they also reported the same difficulty. They planned a focus group for people with disabilities to talk about formation of a DPO: “As only eight stakeholders attended the research workshop which was organised for the end of the week’s visit, the planned schedule did not proceed” (PDF and APIDS, 2011, p.13). The following excerpt from my field journal (25 May, 2011) recounts asking the question about barriers to development to the focus group:

In the focus group it was said that people with a disability currently did see themselves as the barrier and had not yet come to terms yet with the idea that they have rights to ask for social barriers to also be barriers. The person with a disability at the focus group concurred, saying even though he is disability stakeholder he did not rate any social barriers as barriers to his development. He realises that you can ask for social barriers to be improved, such as access, but would not do anything on his own. He said it will take time to change the mind-set. He is also adamant that this mind-set has to change.

The only area that all three participant groups in **Table 10** stated as barriers, and the highest rated barrier to development, was access to public areas like the Punanga Nui market. Access

to public areas will be discussed in detail here due to the importance of its commonality amongst all participant groups. Barriers to accessing public area were highlighted by the U.S. traveller with a disability above, and with the Creative Centre outing, where some shop entries were difficult to walk around in or inaccessible.

Disabled car parking is one area that has had some progress with development of two new disabled parking areas, introduced in 2011. These parks were put in place to improve ease of access for people with a disability and their caregivers when going into town or the market:

The CINDC issued a disability car park ticket that you put in your car window, allowing you to park in the disability spaces available. Mama Tuki, past President of CINDC appeared on Cook Island News television explaining that you will receive a fine if you park in a disability park without a sticker in your car window. Field Journal, 16 May, 2011.

There are difficulties ensuring the disability parks are available for people with a disability to use, as shown below in **Figure 8** - the disability parking next to the Punanga Nui market:

The disabled parking at the market is blocked by scooters, and sometimes trucks, every Saturday. If you contact the organisers in advance, they will rope off the area to allow disabled access, but that does mean you have to pre-plan and cannot just go on a whim, and that you know it is possible to pre-arrange. Alternatively, if you get there by 8.30 (before the scooters) you can park there, but when you return to your car you will most likely find the doors blocked in as regards wheelchair space (DSH 2, 17 May, 2011).

Figure 8: Disability parking by the Punanga Nui market



Source: Pat Farr; 19 November, 2011.

As seen in **Figure 8** the disability car park on the day of the Saturday weekly market, had 15 scooters packed into the space. The other public area that has disability parking spaces are outside Food Town supermarket. One participant has had difficulties accessing this park too:

I want to park in the disability car park at Food Town when I take Mama who has a wheelchair but when I go there the park is always being used by someone who is not disabled (Interview, FCV 4, 18 May. 2011).

Part of the problem with the disability parking not being utilised comes from people with disabilities themselves. Due to shyness and embarrassment some will not use the parking as this participant describes:

You have car parks in town for disable people, nobody is using them because people do not want to go and be seen there (Interview, DSH 9, PWD 7, 16 May, 2011).

Specific mention about access inside the Punanga Nui market grounds are mentioned in three of the interviews, particularly with regards to barriers to public places. One family caregiver participant summarises with the following comment, illustrated by **Figure 9** below:

A main barrier for me and Mama is going to the Punanga Nui market. I can only push Mama around the tar sealed part of the market with the food stalls. I cannot push Mama around the crafts due to the ground surface being loose metal. I am a big strong man and cannot manage it. That is why we do not go there because we are unable to go to where she would like to look (Interview, FCV 4, 18 May, 2011).

Figure 9: Punanga Nui market gravel



Source: Pat Farr.

A further area that is highlighted in participant interviews as a barrier in a public area is the main (and only) pedestrian crossing in the main town of Avarua, Rarotonga (see **Figure 10**):

We do not go (to town) because we cannot move around. The main crossing, the only crossing on the road there is not good, there is a block of pavement so you cannot push up. I just look at it and just go oh no way! (Interview, DSH 8, FCG 3, 14 May, 2011).

Figure 10: Main (and only) pedestrian crossing in Avarua



Source: Author.

In the interview with the Minister of Infrastructure and Planning (MOIP), I raised some of the issues around access to public areas that people with a disability had talked to me about. The Minister responded with the following comments:

There must be access to people with disabilities into public buildings as it is in the Act and building code. Our job is to enforce it. As we receive all the plans coming in for the new buildings, it is now part of the building code. Sometimes we find out that the plans have no access and it has to go back to the architects. Some people tell you

disabled people do not go to movies but I say that's discrimination. It is hard for us to work with this issue of access. Some people say it costs a lot to have access. Who is going to pay? This is one of the difficulties (Interview, DSH 12, 19 May, 2011).

The coordinating officer for Government on disability issues in the Ministry of Internal Affairs and advocate for people with a disability, Nooroa Numanga, lists prioritised barriers most prevalent for people with a disability in the Cook Islands (Interview, DSH 10, 16 May, 2011);

- i. Inaccessible environment – infrastructure, facilities, public buildings, accommodations
- ii. Lack of appropriate assistive devices
- iii. Lack of specialists in various disability fields
- iv. Inaccessible public transports.

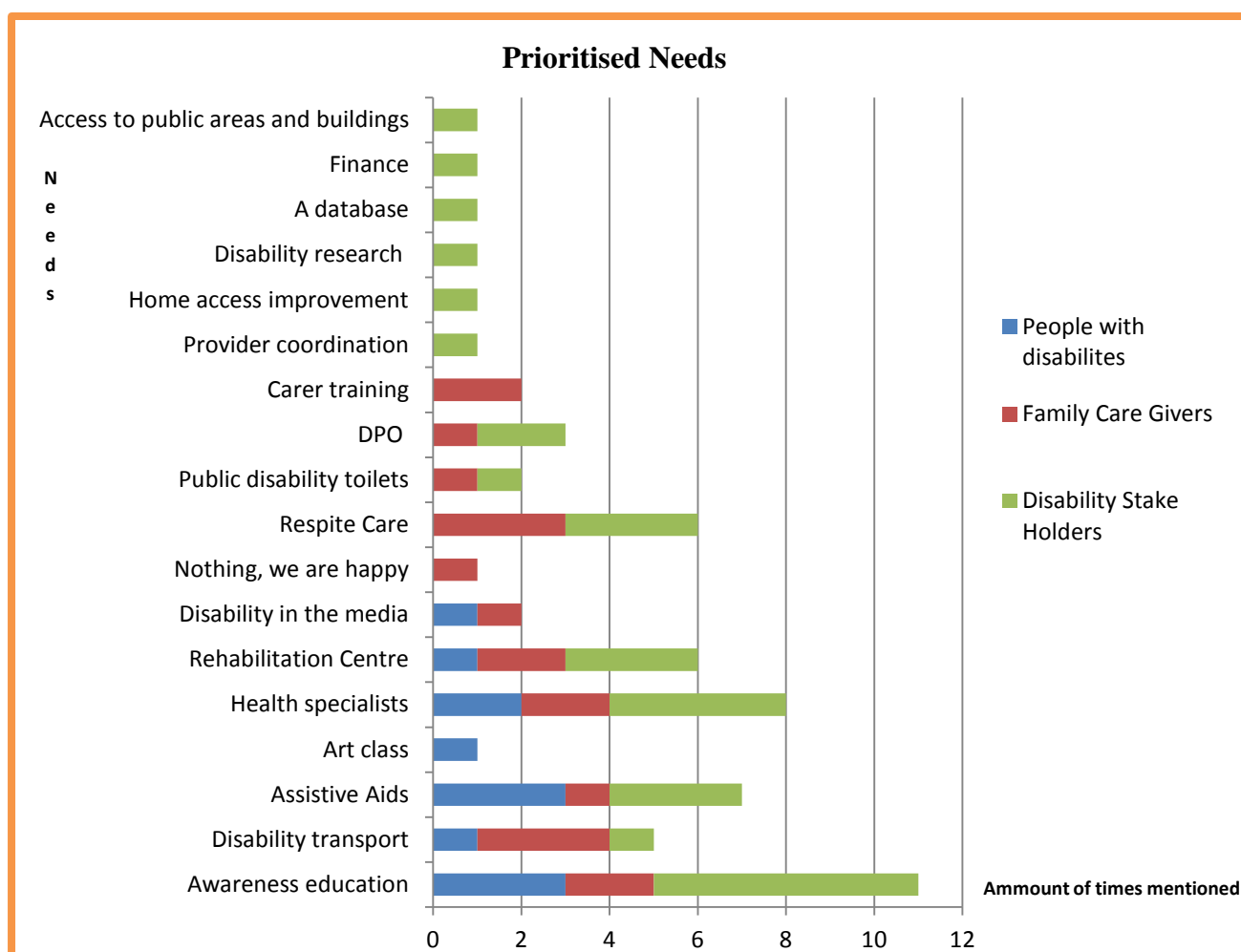
This list is similar to the findings from other disability stakeholders and families of people with a disability stating social barriers.

When interviewing participants, I expected the barriers and needs to show similar results which families caregivers of people with a disability and disability stakeholders did. However, for people with a disability this is not the case. Most of the needs listed by them were not seen as barriers to development. The prioritised needs for all three groups of participants in the study will be revealed in this next section.

iii. Prioritised Needs for People with a Disability in the Cook Islands

Assistive aids, awareness education surrounding disability and specialists are the highest prioritised needs for people with a disability found in this study, as illustrated in **Table 11**. This is interesting in the fact that these three areas listed as the top priorities for people with a disability, are not listed as barriers in the last section. The top need for disability stakeholders is more education on disability awareness, and for families of people with a disability the top equal needs are respite care and disability transport. These areas of importance will now be the focus of the results. The other needs on the graph not discussed here, are still important and should also be considered in any future disability policy.

Table 11: Prioritised needs for people with a disability, their caregivers and disability stakeholders



Source: Author

From personal observation I have noted that assistive aids are scarce in the Cook Islands. One Papa I interviewed had just had a leg amputated and needed walking crutches:

If we can get another right underarm crutch that would be good, as there is only one left at the hospital. At the moment I am using one crutch and the wall and I nearly fall backwards (Interview, PWD 3, 23 May, 2011).

A support worker spoke about her effort to get a splint for a Mama who had a stroke.

One Mama was having problems walking with her frame as her affected stroke ankle was dragging behind. No-one knew what to do. Her support worker took her to the Doctor who suggested getting a brace from CITC Department Store in Avarua. The brace was expensive for the family and another problem arose as described by the support worker - no one realised the brace had to be worn with shoes as it was made of hard plastic. As the Mama did not own a pair shoes, a pair of \$10 Crocs was also needed to be bought for her. Now Mama walks and stands better (Field journal entry, 16 May, 2011).

As well as assistive aids, education surrounding disability awareness was perceived as being a high prioritised need for people with a disability and disability stakeholders.

We are not up to it as far as we are looking after disabled people, unless you have been overseas and know how to look after the people with disabilities. But people here do not have a clue (Interview, FCV 4, 18 May, 2011).

From the perspective of people with a disability, comments emerged on how they view education on disability awareness. Although improvement is required and viewed as a need, education on disability awareness is talked about in a positive way. This corresponds with people with a disability perceiving the attitudes surrounding disability as generally good, as illustrated in **Table 9** above. These perspectives are summarised in the following two interviews. The first perspective is by a disability stakeholder with a disability who organises awareness talks. He knows the awareness is spreading but still has some way to go yet:

More education on all the islands (is needed), more awareness. There is still discrimination and ignorance. I will be doing some education on disability awareness in Mauke, speaking to the people. I have been to Atiu, Mangaia and Aitutaki. This is

to teach people the CRPD, you tell them what it is and then know they have rights
(Interview, DSH1, PWD 1, 16 May, 2011).

The next perspective is from a person with a disability who is on the board of a local NGO raising awareness and providing a limited rehabilitation service:

We are given a bit more media, we have the Attitudes programme on TV every Sunday morning. And every now and then we have a little slot in the paper. We are slowly getting the message across and at the same time we are strengthening ourselves and when we explode out there we have the foundation to take off (Interview, DSH 7, PWD 6, 24 May, 2011).

Mareana Taikoko, manager of Te Kainga o Pa Taunga Family Services and Mental Health Association (Te Kainga), said the pamphlets handed out in conjunction with this study and Te Vaerua Community Rehabilitation Council will help raise awareness (Interview, DSH 13, 23 May, 2011). These pamphlets, as mentioned in Chapter 4's emancipatory tools section, are helping to raise awareness and give all people involved in the disability area contact phone numbers for each other. As part of personal observation at the Punanga Nui market one day I saw a Te Kainga stall set up there. They were there to help raise awareness for mental health issues by having a stall in the Punanga Nui markets most Saturdays. The stall holder and staff member of Te Kainga said it was predominantly the tourists that stopped and asked about them, not many locals talked to them. He said the locals thought it was unusual that they were there with a stall, even though they sold goods that were made by the people who go to Te Kainga. He hoped that by being there, if someone needed mental health help that they would know there was a service on the Island.

Specialists are a high priority need, especially in the field of orthotics as talked about by one disability stakeholder working at the Rarotonga hospital. She would like the Cook Island

Government to fund for an orthotist specialist to come to the Cook Islands to see all the people with false limbs. She also found that a specialist has been on the Islands, but she was told too late and all her people with a disability that could have been seen, were not:

They do not do artificial limbs here and the old ones are worn out and they do not know who to help them. I want to get the person who looks at it to come over and I think that's important to get them all together as they cannot afford to go overseas so it will be cheaper to get someone over. Someone was asking for physio tape to repair their artificial limb. They are struggling (financially) as they have sick family members. Their boy works on a beach and the limb wears down on the beach and his mother is still paying off the debt from going over with him when he got his first limb.

A grandmother said the following about needing specialist care for her granddaughter:

If she had help earlier by a specialist in disability she would be ahead of where she is now, but she was left until a new physio came to see her and assessed her. Early intervention is so important (Interview, FCV 2, 23 May, 2011).

The areas highlighted as prioritised needs by family caregivers are improved disability transport and the need for respite care. Families of people with a disability are expected to care for them. As explained in Chapter 1 economic situation section, with the recent change in dynamics due to migration, this is now not always possible. This is shown in one case I personally observed where one family caregiver was asked by the family to return from overseas to look after their Mama who had a stroke. She was well qualified and on returning to the Island was offered a very good job which she took. This led to the problem of finding another family member overseas to now come and look after Mama. On interviewing her she said:

We could cope if we had respite care. Respite care would be awesome. I am working to get a place like this for the old people in my job, there is nothing like it on the Island, except Are Pa Matua (day care for the elderly). We are going to have more disabilities too as more people are getting to old age, so it is really needed. The Creative Centre is a life saver for us at the moment and Pat (From Te Vaerua) takes her to church, otherwise I do not know what we would do (Interview DSH 8, FCV 3, 14 May, 2011).

Disability transport also rates as a high priority and currently there is no disability transport available for the public. The Creative Centre has a disability van that was donated by New Zealand Rotary to pick up their students who cannot take the bus. Family caregivers do not take their family member with a disability out due to not being able to put them (or if they have a wheelchair) in the car. On this next occasion it is not that there is not a hoist van available but another problem:

Disability transport is a barrier stopping my Granddaughter from being fully included in any day to day activities. But it is due to me that she cannot be fully included in the community. She was given a van with a hoist, but I do not know how to drive a car (Interview, FCV 6, 20 May, 2011).

Conclusion

The findings in this chapter have covered the three main areas identified by people with disabilities. Attitudes surrounding disability, barriers to development and prioritised needs have been outlined using data from transcripts from interviews, field journal entries and personal observation which have validated these findings above.

Surprising results arose from these findings; people with disabilities see themselves as the main barrier to their own development and generally not recognising any social barriers. Barriers and needs identified for potential development of people with disabilities were varied between the families, disability stakeholders and the people themselves. This is an important finding showing the essential need for future development programmes and disability policy to consult all groups in their design.

The following chapter contrasts the human rights disability theory and practice and uses the previous chapters' literature to discuss the research question "*What is the relationship between human rights-based disability policy and frameworks and the real-lived experiences of people with disabilities in the Cook Islands*"? Concluding this thesis is a proposed list of recommendations for Te Vaerua Rehabilitation Council.

Chapter 6: What is the Relationship between Disability Rights Theory and Practice?

This thesis had one main aim; “to determine the relationship between human rights-based disability policy and frameworks and the real-lived experiences of people with disabilities in the Cook Islands”. Three objectives followed on from this aim:

- i. To document human rights-based disability policy and frameworks in the Cook Islands.*
- ii. To explore real-lived experiences of people with disabilities, their families and disability stakeholders in the Cook Islands.*
- iii. To identify gaps, if any, between human rights-based disability policy and real-lived experiences of people with disabilities, their families and disability stakeholders.*

To help investigate the research aim and objectives, Chapters 2 and 3 respectively reviewed the literature on human rights and discourse on disability arguing the following main points; A human rights approach has been woven into development and disability discourse, putting emphasis on a social justice and empowerment approach and while disability remains a contested area, people with disabilities are now more likely to have a voice through the social and post structuralist models. Chapter 4 explained the methodology used to uncover information through dialogue and personal observation to help determine findings. Chapter 5 addresses objectives 1 and 2 above by detailing relevant human rights-based disability policies and frameworks in the Cook Islands and the attitudes, barriers and prioritised needs of people with a disability, their family caregivers and disability stakeholders.

In this final chapter, the findings from Chapter 5 and the literature from Chapters 2 and 3 will be woven together to provide insights into accurately determining the relationship between

policy and practice in the disability area in the Cook Islands. The main areas of discussion are headed under attitudes, barriers to development and prioritised needs for people with a disability and their relationship between policy and practice. The capability approach is discussed here under the attitudes section. Recommendations to be included in NGO Te Vaerua Rehabilitation Council annual report to the Cook Island Government concludes this chapter, with the aim of highlighting areas of the policy and practice relationship that require bridging.

Attitudes – Policy and Practice Relationship

As I identified in the findings in Chapter 5, the Cook Islands currently do not hold a normative view of human rights with respect to disability. Instead, there is a weak relativist and pragmatic view of human rights. However, as explained in Chapter 1, a swift compliance to a normative view is expected of Pacific Islands (Brown, 1999), and although policy and frameworks have been put in place in the Cook Islands, there are gaps turning these policies into practice.

Attitudes surrounding disability however, take time to develop as argued by Miles (1996). On the basis of his study in Pakistan and other studies in 30 countries, noted that the progressive development in attitudes is from negative, stigmatizing and rejecting attitudes, through pity and compassion towards willingness to acceptance of persons with a disability on equal terms. Extrapolating from participant interviews and personal observations, the Cook Islands situation does seem to be shifting from one of negativity to a compassionate attitude.

Human rights-based disability policy and frameworks are in place and the Cook Islands are amongst the first Pacific Island countries to form a Disability Act, which was introduced in 2008. There are well meaning attitudes around the Disability Act as shown in the MOIP

interview in Chapter 5. The real-lived experiences in this study show that enforcement of the Disability Act with regard to infrastructure and public disability access remains difficult. Attitudes reverted to the old Island ways, where two strong boys were expected to get an immobile person up some stairs by lifting them rather than putting in an expensive ramp (Interview, DSH12, 19 May, 2011). The social model assists to illuminate the limitations of cultural relativism but also assumes there are finance and infrastructure to be able to fix the social barriers to development. As shown in this study, finance and infrastructure are limited in the Cook Islands.

A social/citizenship model of disability is not being fully realised to its potential by disability stakeholders and there is limited awareness of the approach amongst people with disabilities. Central to contemporary theories of disability and disability rights is the concept of citizenship and the citizenship model. As Edmonds (2005) points out though, basic survival overwhelms people with disabilities and their communities and the medical and charity models then prevail. With regard to poverty issues as identified in Chapter 1, adopting a socially inclusive view of disability is an enormous change for the Cook Islands to undertake. A priority of the citizenship model is to focus on the issues related to people with disabilities who are underrepresented. This includes women, youth and those with “invisible” disabilities who are often the poorest of the poor in society.

In the Cook Islands the BMF reinforces the citizenship model of disability and is used to underpin the Cook Island NSDP. Other citizenship-based frameworks such as CBR and KIPA are not utilised in the Cook Islands. It is essential for future development for people with disabilities to adopt these frameworks, as discussed in Chapter 3, as utilising them can lead to improved inclusion of the poorest of the poor and “invisible” people in the community.

Introducing a Capabilities Approach Assessment

The fourth question asked in the introduction outline of this study is “How would a human rights-based capabilities approach assessment fit in with disability for development in a Cook Island context?”

The capabilities approach has been identified as an approach that could be utilised in a Cook Island context. Through critique of literature and discussion with people with disabilities during and since field research, I have found that a capabilities-based assessment and action plan links in with the citizenship model. It also links human rights, development and disability together (Biggeri, Bellanca, Bonfanti and Tanzj, 2011), which would help promote human rights-based disability in a Cook Islands context while it is in its infancy. The capabilities approach is currently being piloted with Te Vaerua as a result of findings in this study which highlight the lack of data on people with disabilities’ needs.

The first matrix assessment performed in October 2011 is included as **Appendix 6**. The person with a disability who completed it said he found it useful to write down his goals and to be able to keep a copy to show other health professionals. Interestingly, his main goal he wanted prioritised was to be able to join a club, particularly to play cards with other men. Because of his disability he has not been invited nor put himself forward to join a group. This assessment and action plan assisted in changing his attitude from being too shy to ask to join a club, to being able to write it down and expect action on it from Te Vaerua. This assessment has already identified a need for a person with a disability that would have been missed by mainstream assessments. Two more assessments have been undertaken in November 2011 with similar results which can then be addressed using rights-based policy and frameworks that have been developed in the Cook Islands.

CINDC, with a newly elected board is the sole DPO in the Cook Islands. CINDC needs to be coordinated and lead the way in promoting awareness and a voice for people with a disability. Currently, as shown in Chapter 5 findings, there are concerns about the uncoordinated disability stakeholders in the Cook Islands. As Farran (2009) emphasises, human rights discourse does have many references to the community working together to uphold rights, making rights less individualistic. This is important as this study has shown that self-identity in people with disabilities is weak. NGOs, as grass-roots organisations, could lead the way in supporting people with disabilities.

Only 2 out of 11 of the people interviewed know about their national DPO, CINDC. One of the most deeply entrenched barriers militating against the sustained development and implementation of disability policy in the Cook Islands is the lack of an active, coordinated DPO. As mentioned above, it is essential to have an active DPO to overcome entrenched barriers identified by people with disabilities, which is a lack of awareness. CINDC, representing people with disabilities should be a strong voice and representative link to Government and policy makers. This is highly relevant as people with disabilities and disability stakeholders/policy makers, as found in this study, do not have the same perspective or world views. Consequently while good policy has been put in place in the Cook Islands, there remain gaps of what people with disabilities actually want or need.

The one DPO in the Cook Islands is not known about by most people with disabilities interviewed in this study. Improved coordination is needed to ensure everyone is moving forward together to improve people with disabilities potential development.

Barriers to Development – Policy and Practice Relationship

As shown in **Table 10**, in Chapter 5, surprising results showed that the majority of the people

with disabilities interviewed in this study listed themselves as the only barrier to their development. Due to their weak rights view and shyness, the people listed their barrier as themselves, with very few social barriers described. As one participant listed:

I cannot complain about the only pedestrian crossing not having a ramp up the curb, when I cannot actually get to town due to my disability (Interview, PWD 11, 20 May, 2011).

There is very little literature that identifies people with disabilities listing themselves as the only barrier to their own development. Richan (2011) however, has presented a shared story of one man with a disability he noted the only barrier to his development was himself. His journey found the best way for him to make a difference was working for and with other people with disabilities. This illustrated that barriers can be overcome by taking personal responsibility for inclusion in community activities and the need to rise above the stigma. Further evidence showing low self-esteem in people with disabilities in the Pacific comes from Nowland-Foreman and Stubbs (2005). Their research remarked on the high number of NGOs reporting back to them in their research that needs and aspirations are very low in people with disabilities throughout the Pacific and this was associated with a lack of services and support.

While social barriers are not identified by most people with disabilities, their families and disability stakeholders listed the following as the top three barriers to development;

- i. Access to public areas. As illustrated in Chapter 5, access to public facilities is poor for people who need assistive aids or a wheelchair to mobilise. It is stated in the NSDP and Disability Act of the Cook Islands that access will be improved by the Cook Islands Government. The NSDP initiated in 2007, had a goal of ensuring all Government offices and at least 50% of public places are accessible to people

with disability by 2010. This has not occurred. While the new education building has ramps included, there is little other progress in public area access.

- ii. Assistive aids. Article 20 of the CRPD requires that States Parties are to ensure that people with a disability have access to quality mobility aids, devices and training in them. Te Vaerua and very limited supplies at the Rarotonga Hospital are the only places you can access assistive aids. As illustrated in Chapter 5, one man with a recent amputation was given only one crutch for his mobilisation as there were no other crutches available. There is a need to look at training on using sustainable, local materials to make assistive aids where supply is poor, see **Figure 11**. Funding is required in this area to send someone for this training to ensure sustainable assistive aids are available.

Figure 11: Standing frame made from low-cost, locally sourced materials and cardboard



Source: People Potential (2011)

- iii. Health specialists. Maintaining adequate levels of specialist health advice to all Cook Islands people is highlighted in the Cook Island NSDP. It has been found in interviewing that specialist help in orthotics is not readily available and people's prosthesis' are wearing out. It is stipulated in the Article 26 of the CRPD that rehabilitation be started at the earliest possible stage, and is based on the multidisciplinary assessment of individual needs and strengths. This rehabilitation and advice is currently not readily available in the Cook Islands.

Evidence from other developing country research on barriers concurs with findings in this study. Central Asian research identified barriers where underdeveloped infrastructure and the lack of transportation means is one of the most frequently mentioned and main challenges for people with disabilities (Katsui, 2005). Lang and Murangira (2010) showed similar findings where research in India and South Africa found similar main barriers to development of people with disabilities, these being costs, access to services, and lack of transportation.

Another barrier for development in the disability area is the gender imbalance, where from personal observation women with disabilities are less visible in the community. As seen in the findings of this study, in Chapter 5, only 2 out of 12 participants with a disability were female due to their decreased participation in the community. The Cook Islands Government has also received criticism with their policies not promoting gender equality or having specific mention to women with disabilities in their national policy on gender (Wilkinson, 2008b). Women with disabilities must be more visible in order to fulfil their development to their full potential.

Prioritised Needs – Policy and Practice Relationship

Significant progress has been made since 2003 with the formation of initiatives put in place through national disability policy in the Cook Islands. According to Wilkinson (2008b), fifty five percent of the tasks set in 2003 have been achieved in order to improve the lives of people with a disability in the Cook Islands. The least improvement after introduction of the National Policy on Disability Plan has been in meeting the practical needs of people with a disability. Prioritised needs identified in the NSDP evaluation report are listed as rehabilitation services, assistive aids, access, and awareness of human rights. This concurs with the findings in Chapter 5, where the same practical needs were lacking as revealed in interviews with participants.

The practical areas where work is still needed are still present even though all disability policy and frameworks are in place. Evidence from research in Uganda (Yeo, 2001) has similar findings on people with disabilities' needs not currently met, even though comprehensive disability policy is in place. Uganda is seen as a world leader in political empowerment of people with a disability however, even with all their constitutional amendments, people with a disability remain the poorest of the poor. As in the Cook Islands much of the progress in policy changes has not translated into real-lives at the grass-root level.

Results from this study, illustrated in **Table 11**, show that people with disabilities list their priority needs as assistive aids, health specialists and disability accessible transport. It has been shown in a United Nations report (Lang and Murangira 2010), that having access to assistive aids is very important as they are a powerful tool to improve participation in the community and leads to more independence. Assistive aids have also been reported to reduce disability and may substitute or supplement support services, thereby reducing costs in care.

A reduction in disability would occur by people being able to mobilise with good equipment and lead healthier, more inclusive lives.

Disability stakeholders from NGOs' Te Vaerua, Te Kainga and Government funded Creative Centre, have all stated they are under-resourced and are inhibited by a lack of funding (DSH 2, DSH 6 and DSH 13). It has been shown in this study that people with disabilities have minimal contact with other people with disabilities. The changing ways of family structures in the Cook Islands are leading to isolation of individuals who do not now have the traditional support of family or tribe to care for them, as discussed in Chapters 1 and 3.

Currently addressing the minimal contact between people with disabilities and the community, is the Creative Centre, where their members get together daily in a school room situation. However, this is limited to people with a level of independence and does exclude people with many needs. As it is a school and running at reduced funding at this stage people with higher needs will remain excluded. Te Vaerua is near completion of its rehabilitation clinic, forecasting that power and plumbing will be in by the New Year 2012. People with all disabilities can then meet at the clinic with a planned meeting or gathering room to be utilised for people to sit and talk and have company. Te Kainga has three sessions per week for people with mental health disabilities to meet and is seeking funding for a similar clinic in Aitutaki. Bringing people out into the community is essential in the Cook Islands environment as it has been shown in the past that under the isolated environment, people have accepted their disability and given up on wanting or knowing how to develop themselves to their potential.

Concluding Remarks and Recommendations

To answer this study's key research question, the relationship and contrast between human rights disability policy and practice, is one that reveals gaps. Few countries in the Pacific have made such significant advances in addressing human rights-based disability policy as the Cook Islands. However, as found in Chapter 5 of this study, this policy is not always to positive effect in real-lived experiences for people with disabilities. The comprehensive policies and frameworks also discussed in Chapter 5 could be translated into practice by adopting a social, citizenship model towards disability and development that I talked about in Chapter 3. This should include disability rights awareness education for the people with disabilities themselves, most of whom have low self-esteem and a cultural shyness that present themselves as a barrier to further realising their development potential.

The following recommendations are an important consideration in the emancipatory and political linkage for promoting awareness of human rights of people with disabilities in the Cook Islands. Weaving these practical needs with the comprehensive policy already in place could make the Cook Islands a leading light for disability rights in the Pacific. There is hope and an excitement in the potential of this occurring and the attitudes are slowly turning towards rightfully expecting equality for people with disabilities.

My dream is that one day people would look at the Cook Islands and say; wow that's an island that has got their disability priorities... My dream would be that other Pacific Islands would say; "well for a little Island - gosh look how integrated everyone is, isn't it wonderful" (Interview, DSH 2, 17 May, 2011).

Recommendation 1: Awareness Raising

Raising awareness is the top priority that people with a disability want to see improvement. The majority of the people with disabilities interviewed in this study have low-esteem and do not realise their rights. Education on awareness and disability rights should be made a priority to change attitudes both with people with disabilities and the general community over the long-term. It is important to continue to work towards a normative view of human rights with respect to disability. There is a weak relativist and pragmatic view of human rights currently held in the Cook Islands. An attitudinal change from pity and compassion towards willingness to acceptance of people with a disability on equal terms should be promoted. Successes in this area are mentioned in this study and include screening of the television programme “Attitudes” and hearing information on disability on Cook Islands talk back radio.

Recommendation 2: Promotion of DPO

The promotion of the DPO, CINDC is needed. A DPO is a voice for those not yet able to voice their own concerns or needs therefore it is essential that people with disabilities know about and join CINDC. The promotion of involvement of people with disabilities in public activities is a key opportunity for CINDC to raise awareness for people with disabilities and within the community.

Recommendation 3: Improved Access to Assistive Aids, Health Specialists and Transport, a Rehabilitation Centre, CBR and Respite Care.

Improve access to priority needs. The top priority needs for people with a disability and where funding is required, other than awareness raising is;

- i. Assistive aids. There is training available in the area of making Assistive cardboard equipment (ACE) which is where low-cost, sustainable assistive aids are made out of cardboard and other locally accessible materials (People Potential, (2011)). See **Figure 11** for a Zambian example. This could be a job opportunity for a person with a disability and a potential source of funding if it was made into a small business.

Training should be funded for an equipment officer or similar to bridge the gaps where people of the Cook Islands should have access to good quality assistive aids but currently do not. The CRPD states that state parties are to ensure that people with disabilities have access to good quality assistive aids and training in them.

- ii. Improved health specialist help. There is limited access to health specialists in the field of disability; the area of orthotics being one area mentioned in this study. Coordination is needed when a visiting specialist does come to the Cook Islands as some health providers and people with disabilities find out about it after the specialist has left.
- iii. Public, accessible transport for people with disabilities. Currently there is none available for outings. Funding is needed for at least one disability van for public use. It is recommended that the van have a manual ramp to avoid ongoing, expensive motorized hoist parts when parts stop working.
- iv. A Rehabilitation centre should be a priority. Te Vaerua is currently near completion of providing a free centre for people with disabilities. Progress is being made as funding is available. Art classes and social group inclusion has been asked for by people with disabilities and it is hoped that support in this area can be given to Te Vaerua to address these needs. The Creative Centre is

an educational school for people with disabilities, however are getting their funding cut in 2012. Te Kainga is a centre also needing funding for people to meet there who have mental health disabilities. Funding is needed by Te Kainga to start a similar centre in Aitutaki.

- v. Following WHO's CBR guidelines is recommended. CBR underpins the CRPD and is a strong link between the CRPD and the MDGs. Disability is a crosscutting issue through all the 8 goals of the MDGs and improvement in highlighting disability is essential to their success.
- vi. A respite centre/respite care. Due to smaller family structures and many relatives living overseas, responsibility for dependant people with a disability is left to a few people. One of the top priorities for family caregivers and disability stakeholders is for some respite care or respite centre.

Recommendation 4: Improved Infrastructure and Access to Public Areas

Improved infrastructure and public access for people with a disability are paramount. As suggested from Minister of Internal Infrastructure and Planning in interviewing, a list of priority areas from this study's findings would help him improve areas important to the people as currently he does not know what the prioritised access needs are from the point of view of people with disabilities. Within the scope of this study the prioritised public areas predominantly by family caregivers for improvement are found to be;

- i. Pedestrian crossing ramps at both ends on the main crossing in Avarua.
- ii. Punanga Nui market gravel is currently very difficult for people who use assistive aids or a wheelchair. When resurfacing the Markets these needs should be addressed.

- iii. Improved access and enforcing of disability parking
- iv. Public disability access toilets are needed on the Island

Recommendation 5: Improved disability sector co-ordination

Improved co-ordination is needed in the disability sector. A new disability awareness pamphlet had been designed and is a sustainable document. The pamphlet includes all major disability stakeholders and their contact details and also includes CINDC contacts. Copies are available from the Physiotherapy Department at Rarotonga Hospital, Te Vaerua and the Department of Internal Affairs. This pamphlet will aid in decreasing the currently uncoordinated disability stakeholders operating in the Cook Islands.

Recommendation 6: Improved Sustainable Data Collection

Improved sustainable data collection is needed on the needs of people with disabilities. A recommendation of developing inclusive, sustainable data collection on people with disabilities and their needs will also ensure improved communications between people with disabilities and disability stakeholders. A capabilities assessment is currently being piloted by Te Vaerua's Disability support worker, Pat Farr. This new assessment completed with people with disabilities is a short questionnaire which turns into an action plan with priorities set by the people themselves. Data from these assessments can be used by disability stakeholders to ensure the people's needs are being met. As this study's findings show, disability stakeholders and family caregivers of people with disabilities have different prioritised needs to the

people with the disabilities themselves. It is therefore essential to include the people with disabilities in future policy formation.

Recommendation 7: Champions

Champions for people with disabilities need to be identified. Currently there are no obvious champions in the disability movement in the Cook Islands. Shyness and a lack of self-worth by people with disabilities are apparent in this study's findings and may be hindering this occurring. One such champion who is equipment officer for Te Vaerua is Mataiti Mataiti. He has received little recognition for his help with other people with disabilities. His work ranges from awareness talks on outer islands to being able to think about and reconstructing assistive aids. In one instance there was no assistive walking aid to help one young girl, but because of his own disability he had the insightful knowledge and could use resources available to modify what was there for her to use and begin walking much to her and her family's great delight.

Suggestions for further research

This thesis has drawn from two main lenses of theory; human rights and disability. The weaving of these discourses has shown that policy formation on the Cook Islands is progressive and a leading light for small Pacific nations, however there are gaps translating this policy into practice. Further research would be useful in this field, concentrating on one area in depth and having in depth interviews with all people involved in that one specific area. Suggested areas are; rehabilitation, disability and gender, mental health, disability NGO funding and DPO operating practice.

The capability approach assessment is one area of further research that could enhance disability rights in the Cook Islands. Self-belief and empowerment must first be part of a person with a disability in order for social barriers to development to be broken down. This will take time and due to the shy nature of Cook Islanders will take a special culturally sensitive approach to encourage the process. Further work on the capability approach, tied in with community rehabilitation assessments, may be one way of providing data on people's needs at the same time introducing human rights in a non-confrontational way, simply by starting to have people with a disability start thinking about their goals, attitudes, barriers, needs and dreams. In February, 2012, a funding application has been sent to PDF by CINDC for a capabilities-based assessment and action plan to be made for each person with a disability in the Cook Islands.

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Appendices

Appendix 1: Participant Information Sheet in English and Cook Islands Māori.

INFORMATION SHEET

My name is Robyn Mourie and I aim to write about the experiences of people with a disability and those who are involved with policy and setting priorities in the disability sector.

I am completing a Master's thesis in Philosophy at Massey University in New Zealand.

Ko Robyn Mourie toku ingoa, te tata nei au I te tu oraanga o te au aronga pakipakitaie e te aronga akateretere, akanooonoo I te tuanga tuku tika o teia putuputuanga pakipakitai. Te akaoti nei au I toku peapa teitei Masters no roto I te Apii Massey University I Nuti Reni.

Invitation: I would like to invite you to participate in this research topic: Cook Island Disability: How does national policy and procedures align with attitudes and priorities for people with a disability?

Patianga: Te Rauka nei iaku I te pati ia koe kia topiri mai ki roto I teia apii ranga oonu no te aronga pakipaki tai I roto I te Kuku Airani. Akapea te titoki anga I te au tika Basileia kit e orananga ete manakonako anga puapinga tidau o te aronga Pakipaki tai.

A Brief Summary: Actual experiences and attitudes by people with a disability gathered in this research will potentially uncover priorities and any barriers to development that they have. A comparison will be made on whether disability policy and plans are aligned with the priorities and needs of people with a disability.

Irava akamarama anga: Ko te tumu maata o teia apii ranga oonu ko to akaari mai anga I te ngata o te tu oraanga ta te iti Tangata pakipakitai e na roto nei e to ratau anoano maata. Ka

akaaite iatu kit e au ture Basileia tei akanoonooia no runga I te tikaanga o te aronga Pakipaki tai e me kua tano ainei te reira.

Participant identification and recruitment: Participants have been chosen by word of mouth by snowball sampling. All participants with a disability must have a physical impairment only, and be independent. I hope to interview 10 people with a disability and 10 people who work in the disability sector.

Te maiti mai anga: Kua iki ia mai e 10 aronga pakipaki tai me kare e mero kopapa to ratou tei akamate me kare akaparuparu. Ka iri katoa ia mai e 10 aonga e angaanga ana ki roto I te au putputuanga akateretere/turuturu I te iti Tangata Pakipaki tai.

Project Procedures: Please let me know if there is any question you do not wish to answer. Please let me know if you would like the tape recorder to be turned off at any time. This interview will take approximately one hour. If you would prefer to speak in Cook Island Maori, a translator will be present. The data from this research will be held by me and Massey University. If you would like a summary of the research it will be available after January, 2012 at www.massey.ac.nz. If you would like a summary sent to you, please put your email or address here:

Akanoonooanga o teia Apii: Me e uianga taau kare koe e inangaro kiap au ia e akakite mai. Me ka inangaro koe kia kore e rekoti ia e akakite mai. Ka pu rai mei te tai ora teia uiuianga, me ka inangaro Tangata uri-reo koe e akakite mai kia akapapa ia tetai. Te apii ka raunga mai mei roto I teia kimianga oonu ka vao iatu te reira ki roto I te Apii Massey University, ka

rauka atu te reira iakoe i te kiriti mai i muri ake i te marama Tianuare 2012, imere www.massey.ac.nz. Tata mai i toou imere me ka inangaro koe I tetai repoti naau.

Participant’s Rights: You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question
- withdraw from the study within one month
- ask any questions about the study at any time during participation
- provide information on the understanding that your name will not be used unless you give permission to the researcher.

Toou Tikaanga: E tikaanga toou I te patoi I teia patiangā. Me ariki koe e tikaanga toou i te:

- patoi i tetai uatu uianga
- i te akaatea mai mei roto i teia patainga. Me ariki koe e tikaanga toou i te
- uiui uianga no runga i teia apii kimi oonu i tetai uatu taime.
- Kua marama koe e kia kore toou ingoa e taiku ia me ka inangaro koe, naau e tuku atu i te tika kit e Tangata apii.

“This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University’s Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of

this research. If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Professor John O'Neill, Director, Research Ethics, telephone 06 350 5249, email humanethics@massey.ac.nz".

“Kua akarakara ia e kua akatika iatu teia apii ranga oonu e te Tipatimani o te Paraiminita o te Kaomani Kuki Airani. Kua akatika ia e kare e kino e tupu me raveia teia apii, me e manako taitaia toou me kore, kare koe e mareka ana I tei reveia no teia angaanga e aravei atu I te Professor John O'Neill, Director, Research Ethics, telephone 06 350 5249, emere humanethics@massey.ac.nz”

Researcher details: Robyn Mourie, 68 Harakeke Road, Otaki, New Zealand. TEL: +64063643032 or +64274907994 Email: mouriefamily@xnet.co.nz

Supervisor details: Dr. Rochelle Stewart-Withers, Massey University. TEL +6463569099 Ext 2464

Email: R.R.Stewart-Withers@massey.ac.nz

Appendix 2: Participant Consent Form in English and Cook Island Māori.

RESEARCH THESIS TITLE: COOK ISLAND DISABILITY:

Tumu tapura no teia Apii-Ranga-Oonu I roto I te Kuki Airani no te Aronga Pakipaki tai

How does national policy and procedures align with attitudes and priorities for people with a disability?

Akapeea te ture basileia i tataia i te tukatianga e te akatika anga I te anoano e te manako o te aronga e au mero kopapa to ratou i akamate me kare i aka paruparu.

Robyn Mourie – Researcher/tangata apii ranga-oonu

PARTICIPANT CONSENT FORM - INDIVIDUAL

PEAPA TUKUTIKA ANGA

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

Kua tatau au I teia peapa tukutika e kua akamarama ia mai kiaku te tumuanga o teia apii-ranga-oonu. Kua ariki au i te au pauanga ki taku au uianga e te marama nei au e ka tika rai iaku kia ui uatu i tetai uatu uianga me inangaro au.

I agree/do not agree to have my name included in the study.

Te akatika/patoi nei au I toku ingoa kia tata ia ki roto I teia apii-ranga-oonu.

I agree/do not agree to the interview being sound recorded.

Te akatika/patoi nei au I teia uriurianga kia recoti ia ki runga I te ratio.

I agree/do not agree to the interview being image recorded (photos).

Te akatika/patoi neia au kia nenei me kare kia taviri-tutu ia teia uiuianga tuatua e kia rekoti ia.

I wish/do not wish to have my recordings returned to me.

Te ariki/kare au e inangaro kia akaoki ia mai te au recoti anga katoatoa kiaku.

I wish/do not wish to have data placed in an official archive.

Te inangaro/kare au e inangaro kia tukuia atu teia au tataanga ki roto I te pia recoti taito a te Kavamani.

I agree to participate in this study under the conditions set out in the Information Sheet.

Te akatika e te ariki nei au e ka piri atu au ki roto I teia apii-ranga-oonu mei tei tata ia ki roto i teia peapa tukutika.

Signature:

Date:

.....

Full Name - printed

.....

Appendix 3: Guiding Questions for Participant Interviews

I'm going to ask questions around 3 specific areas in the field of disability:

- Attitudes surrounding disability
- What are the needs and priorities for people with a disability?
- Are there any barriers that affect everyday life for people with a disability?

Attitudes: What are the attitudes surrounding disability like in the Cook Islands?

Prompts:

Are there any cultural attitudes/perceptions surrounding disability in the Cook Islands?

Who would or have you gone to advocacy or communication regarding disability issues?

Who do you think the best person or group would be a good advocate for disability issues?

Is there any information you would like regarding disability on the Cook Islands?

Has anyone asked you what you would like to see as improvements for people with a disability on the Island?

What have you heard of the Cook Islands National Disability Council? BROCHURE

Barriers: Would you say there are any barriers stopping you being fully included in day to day activities?

Prompts:

Do you have any access issues into buildings or public areas? Your home? Do you know where to go to get this access improved?

What are the options to get involved in any sporting or leisure activities? Artistic activities?
Cultural activities?

What is the access to transport like on the Island?

Needs: Do you have any needs that aren't currently being met? List and rank priorities.

Prompts:

Do you know where to get any assistance devices you may need?

Is there any caregiver help you may use or know of?


What do you know and think of the rehabilitation services on the Islands? Do you use a rehabilitation service? If so, is there anything you would suggest to make the service more suitable to your needs?

Is there anything else you would like to talk about?

Appendix 4: Photos of Refurbished Te Vaerua Rehabilitation Clinic.



Appendix 5: Disability Action Pamphlet

<p>Useful Contact Organisations</p> <p>This brochure has been written to enhance the communication and networks of people with an injury or impairment. By working together in partnerships, barriers can be minimized <code>fresh_bro_cover</code> met.</p> <p>Kua tata ia teia karere ei akamatutu I te turanga kave kura e te taokotai anga o te aronga kua akaparuparu/akamate tetai au mero o to ratou kopapa.</p>	<p><i>Further enquiries to: Ms. Pat Farr Disability home support carer Contact: 682-50948</i></p>	 <p>Disability Action in the Cook Islands</p>
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<p>Cook Islands National Disability Council.</p> <p>A Disabled Person's Organisation (DPO)</p> <p>Contact Person: Ms. Tuki Wright (President)</p> <p>P.O. Box 1040, Rarotonga Tel: 682-20537 Fax: 682-24537 Email: mamatuki@oyster.net.ck</p> <p>An advocacy council for persons with disabilities and a coordinating body for all disability groups.</p> <p>E pupu akatanotano teia no te aronga pakipakitai e te akateretere I te pupu turuturu I te iti Tangata pakipakitai.</p>	<p>Te Vaeua Rehabilitation Services</p> <p>Contact Person: Mrs. Pat Farr (Coordinator) PO Box 280, Rarotonga Tel: 682-50948 Email: patfarr@oyster.net.ck</p> <p>For your home therapy and home carer support and provision of equipment and assistive devices.</p> <p>E putuputuanga aronga apinga tauturu e te tauturu rapakau e te tauturu katoa I te aronga tiaki I te ngutuare.</p> <p>Te Kainga Centre</p> <p>Contact Person: Mereana Taikoko (Director) Tel: 682-20162 Email: tekainga@oyster.net.ck</p> <p>This mental health centre organization provides outpatient and day rehabilitation services.</p> <p>Ko te ngutuare okotai ua teia e aronga ana I te tauturu rapakau no te aronga maki manako i te au ra tatakaitai.</p>	<p>Creative Centre</p> <p>Contact Person: Mr. Bob Kimiangatau (Manager) Tel: 682-20081 Email: creativecentre@oyster.net.ck</p> <p>The day centre engages in a range of activities including public awareness raising, advocacy, community access and rehabilitation programmes and offers daily healthy and nutritious lunch meals using local products.</p> <p>E ngutuare teia ta ratou au ravenga tuketuke no te akamaramarama I te iti Tangata, akatanotano, akatuera I te ara no te au porokaramu rapakau kit e aronga pakipakitai. E ngutuare kai I au manga natura o te enua.</p> <p>Rarotonga Hospital Physiotherapist</p> <p>Contact Person: Mrs. Pareina Tangata Physiotherapist, Rarotonga Hospital Tel: 682-22664 Email: p.tangata@health.gov.ck</p>
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Appendix 6: First Capability Assessment Action Plan

