Copyright is owned by the Author of this thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. This thesis may not be reproduced elsewhere without the permission of the Author.

Hand Rails into the Ocean:

Contrasting Human Rights Disability Policy and Real-Lived Experiences in the Cook Islands.

A thesis presented in partial fulfilment of the requirement for the degree of

Master of Philosophy in Development Studies

At

Massey University, Palmerston North, New Zealand

Robyn Mourie

2012

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 though 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.

Acknowledgements

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.

Thanks to my Dad, Les Galloway, for proof reading and ensuring I have kept my writing accessible, who along with Mum, Liz Galloway having a continued commitment to renovating Te Vaerua Rehabilitation Council Centre in Arorangi. Thanks and love also to my husband, Adrian Mourie and three children, Hamish, Edan and Emilie, for their support in the juggling act between family and work commitments.

My supervisors Dr Rochelle Stewart-Withers and Dr Gerard Prinsen have provided me with insightful guidance and supervision, both having strong backgrounds in health in developing countries. Thank you for sharing your knowledge with me, it has been invaluable. For first suggesting an International Development Studies Diploma to me four years ago, thanks must also go to Professor Regina Scheyvens, as this has ultimately led to this thesis and my work in the Cook Islands.

Table of Contents

Abstract ..... **i**
Acknowledgements ..... **ii**
Table of Contents ..... **iii**
List of Tables ..... **vii**
List of Figures ..... **viii**
List of Acronyms and Abbreviations ..... **ix**
Karakia ..... **xi**
Chapter 1: Introduction **1**
Research Rationale 2
Research Aim, Key Question and Objectives 3
An Introduction to the Cook Islands 4
Geographical Situation 4
Social Situation 6
Political Situation 7
Economic situation 7
Structure Outline of Study 10
Chapter 2: Understanding Human Rights **12**
Introduction 12
Human Rights History 12
Human Rights pre 1945 13
The Universal Declaration of Human Rights (UDHR) 13
Human Rights and Development 16
The Controversy over the Universalism of Human Rights 18
The Cultural Relativism Debate 19
Weaving Together Of Human Rights and Culture 21
Looking at Human Rights through a Pacific Lens 21
Pacific Sub-Regional Human Rights Arrangements 24
The Value of using Human Rights in Development 25
Normative Rights 25
Pragmatism and Human Rights 26

Ethics and Human Rights....27
Capabilities Approach....27
The Importance of the CRPD....28
The History of the CRPD....28
The CRPD Weaves Human Rights and Disability Discourses Together....30
Conclusion....34
Chapter 3: Framing the debate over disability....35
Introduction....35
Definitions in Disability....35
The Evolution of Disability....36
Models of Disability....37
i. The Charity Model....37
ii. The Medical Model....38
iii. The Social Model....38
iv. Citizenship Model/Rights model....42
v. Cultural Model....43
Disability Paradigms....44
Disability as a Development Issue....46
Community Based Rehabilitation....49
Criticisms of Disability in a Development Context....51
Culture and Disability....52
Defining Attitudes....56
The Importance of DPOs....57
Criticisms of DPOs....58
Conclusion....59
Chapter 4: Methodology....60
Introduction....60
Philosophical Position of Researcher....60
Ethical Considerations....62
Theoretical Framework of Research Methods....63
i. Participatory Research Approach (PRA)....64
ii. Emancipatory Methodology....64
iii. Varied Sources of Data Collection....67

iv. Reciprocity and Empowerment 72
v. Participant Observation 74
vi. The Importance of Politics in Disability 76
Data Analysis 76
Conclusion 77
Chapter 5: Policies, Frameworks and Real-lived Experiences 78
Introduction 78
Human Rights-Based Disability Policy, Frameworks and the CRPD in the Cook Islands 79
The Pacific Regional Strategy on Disability 80
The Cook Islands National Policy on Disability Plan 81
The Biwako Millennium Framework (BMF) 82
Community Based Rehabilitation (CBR) 85
Millennium Development Goals (MDGs) in the Cook Islands 85
Convention on the Rights of Persons with Disabilities (CRPD) in the Cook Islands 87
Cook Island National Disability Council (CINDC) 88
Pacific Disability Forum (PDF) 89
Pacific Sisters with Disabilities Report 90
Disability Act 90
National Sustainable Development Plan (NSDP) 92
Real-Lived Experiences of People with a Disability in the Cook Islands 94
i. Uncovering Attitudes: What are the attitudes surrounding disability from a Cook Island perspective? 95
ii. Barriers to Development for People with a Disability in the Cook Islands 102
iii. Prioritised Needs for People with a Disability in the Cook Islands 111
Conclusion 116
Chapter 6: What is the Relationship between Disability Rights Theory and Practice? 118
Attitudes – Policy and Practice Relationship 119
Introducing a Capabilities Approach Assessment 121
Barriers to Development – Policy and Practice Relationship 122
Prioritised Needs – Policy and Practice Relationship 126
Concluding Remarks and Recommendations 128
Recommendation 1: Awareness Raising 129
Recommendation 2: Promotion of DPO 129

Recommendation 3: Improved Access to Assistive Aids, Health Specialists and Transport, a Rehabilitation Centre, CBR and Respite Care.....129
Recommendation 4: Improved Infrastructure and Access to Public Areas 131
Recommendation 5: Improved disability sector co-ordination.....132
Recommendation 6: Improved Sustainable Data Collection 132
Recommendation 7: Champions 133
Suggestions for further research.....133
References 135
Appendices 157
Appendix 1: Participant Information Sheet in English and Cook Islands Māori. 157
Appendix 2: Participant Consent Form in English and Cook Island Māori. 161
Appendix 3: Guiding Questions for Participant Interviews.....163
Appendix 4: Photos of Refurbished Te Vaerua Rehabilitation Clinic.....165
Appendix 5: Disability Action Pamphlet.....166
Appendix 6: First Capability Assessment Action Plan.....167

List of Tables

Table 1: Human rights conventions 15

Table 2: Medical and social models 40

Table 3: Paradigms in disability theory 46

Table 4: Disability specific human rights 48

Table 5: Six key research methods in design approach 63

Table 6: Participant groupings 68

Table 7: Proportion of the resident population with a disability or health problem in the Cook Islands 84

Table 8: A Snapshot of MDGs in the Cook Islands 86

Table 9: Attitudes surrounding disability 96

Table 10: Barriers to development of people with a disability, their caregivers and disability stakeholders 103

Table 11: Prioritised needs for people with a disability, their caregivers and disability stakeholders 112

List of Figures

Figure 1: Map of the Cook Islands 5

Figure 2: Qualms about general budget support 9

Figure 3: Slow and uneven progress of disability human rights.....29

Figure 4: The MDGs and disability 32

Figure 5: Improved quality of life through CBR 50

Figure 6: Disability and human rights-based frameworks in the Cook Islands.:.....80

Figure 7: Creative centre outing 101

Figure 8: Disability parking by the Punanga Nui market 107

Figure 9: Punanga Nui market gravel 108

Figure 10: Main (and only) pedestrian crossing in Avarua 109

Figure 11: Standing frame made from low-cost, locally sourced materials and cardboard ..124

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 atianga ravarai. 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)