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

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 pakipakaitai 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 pakipakaitai, 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)