Sea-change: negotiating the United Nations Convention on the Rights of Persons with Disabilities – a New Zealand perspective.

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Full fathom five thy father lies;
Of his bones are coral made;
Those are pearls that were his eyes;
Nothing of him that doth fade,
But doth suffer a sea-change
Into something rich and strange.
Sea-nymphs hourly ring his knell:
Ding-dong.
Hark! now I hear them — Ding-dong, bell.

William Shakespeare*, The Tempest*

Abstract

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was the first human rights convention of the 21st century. It was notable because of the high levels of involvement stakeholders – disabled people – had in the negotiations process. This project looks at the role played by the disabled New Zealanders in the New Zealand delegation to the Ad Hoc Committee considering the text for the CRPD. It examined to what extent the disability rights movement slogan 'nothing about us, without us' was reflected in this process. Through interviews with disabled people who had represented NGOs, national human rights institutions and disabled people's organisations at the UN, it finds that disabled people were instrumental in drafting a convention that addressed real-life human rights issues for disabled people.

Using Stienstra's (2003) framework for assessing the effectiveness and value of consultation process, it also finds that CRPD negotiations show how the involvement of stakeholders in consultation processes can greatly enhance both the process itself and the results. The process represents a sea-change in terms of how consultations with disabled people should be conducted. With genuine interest and willingness to listen to the lived experience of disability, governments have much to gain from genuine engagement with disabled people and their representative organisations. The implications for social policy are shown to demonstrate how 'nothing about us, without us' can move beyond being a mere slogan. When correctly applied during consultations, it can become a transformative and powerful guiding principle for policymakers and legislators alike.

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List of abbreviations

ACC	Accident Compensation Corporation
ADA	Americans with Disabilities Act
ADL	Anti-discrimination Legislation
CCS	CCS Disability Action, formerly known as the Crippled Children's Association
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organisation
DPO	Disabled Persons Organisation
DPA	Disabled Persons Assembly
DRM	Disability Rights Movement
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
IDC	International Disability Caucus
MFAT	Ministry of Foreign Affairs and Trade
NZDS	New Zealand Disability Strategy
NHRI	National Human Rights Institutions
ODI	Office of Disability Issues
UN	United Nations
UPIAS	Union for the Physically Impaired Against Segregation
WHO	World Health Organisation
WNUSP	World Network of Users and Survivors of Psychiatry
WPA	World Programme of Action
UDHR	Universal Declaration of Human Rights

Opening statement

> *All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.*
>
> Article 1, Universal Declaration of Human Rights,
> (United Nations, 1948)

Human rights are rights for all people, yet not all people need the same thing from human rights. Certain minority groups face unique sets of circumstances requiring extra or additional protection on top of the human rights they should enjoy solely by virtue of being human beings. For example, it is accepted that children can be uniquely vulnerable to human rights abuses because they have little agency over their lives and can easily be exploited by adults. Disabled people have the same rights as non-disabled people to access basic things – education, employment, housing, legal representation, but at times these rights cannot be exercised. Human rights abuses affecting disabled people have been well documented (Lawson, 2007) and disabled people are often doubly disadvantaged in that they are more likely to be among the poorest members of any society, making them more vulnerable to having their rights denied (Elwan,1999).

In times of civil and political unrest, disabled people can find themselves more disadvantaged than others. In some states they are unable to vote or participate in public life (Lawson, 2007). In response to the need to safeguard the human rights of disabled people, the United Nations passed the Convention on the Rights of Persons with Disability (CRPD) in 2006. The Convention recognised that disabled peoples' human rights needed additional protection to that offered by existing international human rights instruments. The CRPD was ground-breaking both in having the shortest negotiation time for any human rights convention at the UN and in having the highest number of signatories at its opening (Stein, 2007a). Another unique aspect of the CRPD, and the main focus for this research, is the level of

stakeholder involvement in the process of writing the text. Although the CRPD does not create new rights for disabled people, it does clarify how the Universal Declaration of 1948 relates to disabled people, especially given the unique human rights abuses they can face.

This research will look at the process of negotiating the CRPD from the points of view of the participants. It assumes there is value in examining what the role of disabled people and disabled people's organisations (DPOs) was in drafting the text of the CRPD. For decades the phrase 'nothing about us without us' had been adopted by national and international disability rights movements (DRMs) as a demand for stakeholders – disabled people – to be actively involved in shaping policies and processes that directly affected them (Charlton, 1998). This demand was based on an historical lack of consultation, let alone partnership, between disabled people and non-disabled people who were responsible for making decisions that affected disabled peoples' lives – most importantly by health professionals and service providers, but also by many others who felt non-disabled people simply knew or should know better than disabled people themselves what choices they should have in terms of major life issues such as education, employment, medical treatment and living arrangements.

This project examines the negotiations leading up to the signing of the CRPD from a New Zealand perspective. It has been said New Zealand played a significant part in the negotiations around the text of the Convention (Office of Disability Issues, 2007). It was deemed timely to assess what this contribution was, and to look in some detail at the experiences of some of the New Zealand delegates in terms of the part they played in this historic process.

Chapter outlines

In **Chapter One,** the research topic and questions are introduced. They are supported by some discussion of the background to the research and differing ways of conceptualising disability are examined. Differing 'models' of disability are examined, namely the individual/medical model and the social model as it was originally expressed in the UK and differing approaches from the United States. The chapter concludes with an examination of how the Disability Rights Movement developed in New Zealand and some major issues in New Zealand disability policy.

Chapter Two introduces disability as a human rights issue. It outlines the evolution of the disability rights movement and traces the history of disability human rights at the United Nations. The background to the decision to draft a separate human rights instrument specifically addressing disability human rights is described. This chapter also contains a brief discussion of the final text of the CRPD and some of the more controversial articles.

Chapter Three presents the methodology and philosophical underpinnings of the research. It examines some salient issues on disability research and looks at the role of the researcher in disability research. It goes on to describe the mechanics of the research – how the participants were selected, how the interviews were carried out and what research procedures were used. Ethics and limitations of the study are also discussed.

The data collected during the participant interviews is presented in **Chapter Four**.

Chapter Five provides a discussion of the outcome of all the data collected and attempts to analyse the data in terms of Stienstra's (2003) framework for assessing the effectiveness and value of consultation processes.

Chapter Six offers a summary of the research and its outcomes, as well as some recommendations.

Chapter One – Disability, the social model and social policy

Introduction

The focus of this thesis is disability rights and the involvement of New Zealanders in drafting the United Nations Convention on the Rights of Persons with Disabilities (CRPD). In 2007 New Zealand was awarded the Franklin D Roosevelt International Disability Award in recognition of national efforts to promote inclusion and rights for disabled people. The New Zealand application for this award describes at some length the role New Zealand played in drafting the CRPD (Office of Disability Issues, 2007). The aim of the research was to uncover several aspects of the negotiations process which took place over a series of six committee meetings at the UN in New York between 2001 and 2006.

Of key interest was the experience of the New Zealand delegates who were not career diplomats but who attended as representatives of New Zealand Disabled Persons' Organisations (DPOs) and human rights organisations. The fact that many of the delegates both in the New Zealand delegation and in the delegations of other states represented at the negotiations themselves identified as disabled people was of particular interest. As disabled people, these New Zealanders had a personal and a political stake in the outcome of the proceedings. Such a high level of stakeholder involvement was unprecedented at the UN (Moriarity & Dew, 2011) and was significant to the research in light of the insistence of the disability rights movement that disabled people must have equal participation and decision-making powers in matters that affect them. It was also deemed timely to look at how the process unfolded and how the delegates reflected on their part in the negotiations several years after the events.

The principal research question was formulated as follows:

In the negotiations leading to the drafting of the UN Convention on the Rights of Persons with Disabilities, how did the contribution of the New Zealand delegates reflect the maxim of the disability rights movement: ‘Nothing About Us, Without Us’?

The research focused on the following areas:

- Examining the negotiations as part of the story of disabled people in New Zealand and their struggle to reclaim power and discourse from professionals and experts
- Considering the discussions of the Ad Hoc Committee and how disagreements on the draft Convention were resolved between delegations
- The differing contributions made by government, DPO and independent body representatives such as national human rights commissions

Theorising disability – an introduction

For many people, the word disability conjures up various images. What these images will inevitably have in common is that they are associated with the human body. We recognise that the body is central to our experience as humans, and that impairments or differences in function within the body are related to what we now call disability. This section will examine differing theories of disability and trace their evolution to the present day.

Individual/medical model – “They think that we can’t do many things…”

(Feliza, cited in World Health Organisation, 2011, p. 192)

Thinking about disability as a ‘body’ issue comes naturally to us – as small children, we learn from our worlds what is typical and what is not. If a child only knows people who can hear, she will have difficulty understanding why or how some people cannot hear. If that child continues to not know anyone

who cannot hear, she will grow into an adult who has little knowledge of the experience of ‘not hearing’ and is forced to formulate her own thoughts and beliefs about what it would be like to not hear. These thoughts, not being informed by lived experience, will not necessarily be related to the reality of ‘not hearing’, but the individual has no choice but to interpret from her own (in this case limited) experience.

For non-disabled people, the scenario presented above can be repeated again and again every time they come into contact with a disability or impairment they are not familiar with. Not being able to conceive of a life different than their own, people without impairments concentrate on what they perceive – that an impairment leaves a person with limitations that they themselves do not have. They can only focus on the body (on what is perceived as being different), because they find it difficult to do otherwise. What they cannot do is find a place for themselves in the picture of the effects of the impairment. So instead they focus on what they might see as the ‘misfortune’ of the person with the impairment, or wanting to cure them or help them (as they see it) by making them more typical, more ‘normal’, more like themselves and the people they know.

Impairments can provoke many different responses in those who do not have them - pity, disgust, anger, compassion. But these responses do not inspire many people to ask what *they* do to contribute to the effects of the impairment on the person who lives with it. Until the second half of the 20th century many people, including people with all sorts of impairments, agreed this was the correct way to think about disability, as a personal problem of an unfortunate individual who has a difference or lack of function somewhere in their body or mind. This way of thinking has become known as an individual or medical model of disability, as it locates the ‘problem’ of disability in the body, and places the onus for overcoming this problem on the individual, with help from the correct medical or therapeutic input. Oliver (2009) points out that this has led to disabled people being forced to undergo interventions that

make little sense, pointing out that ‘In the lives of disabled children…anything goes, so long as you call it therapeutic’ (2009, p.38). Indeed, by medicalising disability and concentrating on illness (ascribed or otherwise) disabled people could be excluded from social life wholesale. As Borsay points out, “application of the sick role to disabled people does devalue their input to political debate by conveying the mistaken impression that, being indisposed, they are either unable to speak for themselves or have nothing worthwhile to say” (Borsay, 1997, p.122).

The characterisation of disabled people as being helpless victims of a personal tragedy was prevalent up until the last decades of the 20th century (indeed it may be argued even in 2014 this view has not been fully consigned to the ideological rubbish heap). As a result, systems were put in place which obliged disabled people to rely on non-disabled people to assist them to become more ‘normal’, or at least to not present an uncomfortable truth about the diversity of human experience to the non-disabled in everyday life. Historically, many people with impairments had lived in small rural communities where their skills and abilities could be used in accordance with the needs of the community as a whole (Barnes & Oliver, 1998). Social historians suggest there is little evidence that people with impairments were ostracised or mistreated as a matter of course in tribal or primitive societies, though there are some exceptions (Barnes & Oliver, 1998).

Up until the 19th century, social change happened at a very slow pace, however with the start of the industrial revolution in the early to mid-19th century, things began to change very quickly. Industrialisation placed an emphasis on intensive production of goods in factory-type situations, facilitated by machinery and extremely long working hours from factory workers. With low-intensity production, traditional small rural communities had been far better able to find a place for people with impairments than large-scale intensive factory environments were. Physical fitness was needed to help people cope with the demands of factory work and an

impairment that slowed a person's productivity could not be tolerated. At the same time there was a growing emphasis, which had begun during the Enlightenment, on the value of medicine and science in finding cures for various illnesses.

Some of mankind's most terrible misdeeds have been committed under the spell of certain magic words or phrases.

James Bryant Conant (cited in Blatt & Kaplan, 1974, p.18)

By the 19th century there was an increasing respect for the medical profession and the 'expertise' being developed at the time in many areas was extended to the treatment and rehabilitation of impairments such as mental illness and sensory impairments as well as diseases. This emphasis on the value of professionalism, coupled with a general enthusiasm for large-scale institutions already being developed as factories (and schools) meant it was a somewhat natural consequence for the Victorians to assume that disabled people were better off living in institutions. People with mental illness lived in special hospitals where they could be treated and maybe cured. Children with physical or intellectual impairments were removed from their families and sent to live in special 'homes' together with children who had similar impairments where they could be cared for (Georgeson, 2000; Barnes & Oliver, 1998) .

Unfortunately, these facilities rarely achieved their mandates. Children who lived in residential facilities experienced very little of the care and attention most children receive at home with their families. Hospitals for people with mental illness were in fact little better than prisons, where people were not only incarcerated but also punished for the crime of being different. Sadly, this scenario remained the status quo for over 100 years in the developed countries of Europe, America and Australasia (see for example, Morris, 1991; Blatt & Kaplan, 1974; Confidential Forum for Former In-Patients of Psychiatric Hospitals, 2007). Although in many countries in the developed world this type of institutionalisation and loss of basic personal freedoms for

disabled people is now a memory, on a global scale many disabled people are still living this reality in the present day (Human Rights Watch, 2014a).

A different approach – thinking about disability, thinking about rights

With the passing of time, certain things began to shift in the social order. In the aftermath of the Second World War, there was a recognition that human beings had certain responsibilities toward one another irrespective of nationality. As the full truth of the crimes against humanity perpetrated by the Nazis emerged, people began to speak about equality and justice for all people. Others began to speak of rights – the right to welfare, the right to education and the right to autonomy. These rights were seen to apply to all people, yet in fact they did not. Article 1 of the Universal Declaration of Human Rights is quoted at the beginning of this chapter. When all human beings are declared to have been born free and equal in dignity and rights, no disclaimer excludes disabled people from this provision. Articles declaring all people have equal access to the right to life, liberty and security of person, to be recognised as persons before the law, to receive an education and to participate in the cultural life of the community (United Nations, 1948) certainly also applied to disabled people, yet disabled people were denied these rights and many others in developed and developing countries alike.

This apparent paradox continued without causing concern to those who were responsible for designing and implementing policies and processes that denied disabled people their human rights – legislators, policy-makers, politicians, health professionals, educators and others. This is partly because of what Gerard Quinn describes as the “subject/object” paradigm – disabled people were traditionally seen as objects, people who only had needs, who only required help or intervention of some kind (Quinn et al., 2002). They were not subjects or citizens in the way non-disabled people were, that is people who had rights and freedoms, the ability to make decisions and the

entitlement to participate in what Quinn calls the “life world” (Quinn et al., 2002).

Beginnings of the disability rights movement

The United States and the minority group model

In the latter half of the 20th century, throughout the developed world, disabled people began to demand improvements in their living situations. These demands took different shape in different countries. In the United States, they were political – following on from the precedents of the civil rights movement in the 1960s and the women’s movement in the 1970s, disabled people (especially disabled veterans) demanded changes to legislature that would prohibit discrimination on the basis of disability or impairment (Fleischer & Zames, 2001; Hahn 2002). When one considers that civil rights are “rights of inclusion for the individual whom society otherwise excludes” (Engel & Munger, 2003, p.3), the appeal of the civil rights movement for disabled people becomes clear.

Disabled people began to organise and to view themselves as another minority group who were being unjustly oppressed and shut out from the mainstream (Linton, 1998). As a result, an end to discrimination on the basis of disability or impairment became a civil rights issue in the same way that, for example, African-American civil rights had been in the 1960s (Williams, 2001). One analysis of this approach is that it is typical of the US tradition of championing the rights of the consumer over all (Bickenbach, 2001). Others maintain it can be partly attributed to the high numbers of disabled former combatants in the US. Since the Civil War of the 1860s, Americans had fought in several wars that left hundreds of thousands of disabled ex-servicemen in American communities (Zola, 1994). These individuals had acquired impairments in the service of their country, and though they were subject to the same discrimination as other disabled people, sympathy for their position gave legitimacy to their claims for compensation and equality. Zola (1994) also points out that the Second World War in particular had a

transformative effect on American society and medical treatment in particular, with scientific research concentrating heavily on the preservation of life and the improvement of quality of life through rehabilitation and therapeutic interventions.

As happened with racial discrimination, the solution to the problem of disability discrimination was seen to be legal – changes in the law would protect disabled people against civil rights abuses. In a parallel with legal changes that outlawed racial discrimination, it could be argued that anti-discrimination legislation (ADL) was introduced in the US before societal attitudes had shifted sufficiently to understand or support the change. In his analysis of this approach, Oliver (1990) maintains that it is senseless to expect the instrument of the disabling system to protect the rights of disabled people efficiently, never mind to bring about real change.

While Oliver may have a point, in the case of racial discrimination there was no justification for its continuance to be protected by the law. It may have taken time (it may be argued it is still taking time), but there comes a point when discrimination must be outlawed whether public opinion has had a chance to catch up or not. For disabled people in the US, the major success of this approach was the Americans with Disabilities Act which was passed in 1990, a world first in terms of protecting disabled people from discrimination on the basis of impairment. It constituted a significant victory for disability advocacy groups in the US and is estimated to have given rise (in some cases nearly identically) to similar pieces of ADL in over 40 countries worldwide (Stein, 2007a).

In a sense, Oliver's prediction was right, and the ADA has not turned out to be a panacea for disabled Americans (Russell, 2002). Indeed, there will always be problems with ADL simply because it focuses intensely on the individual's impairment - firstly by requiring the person to prove they have an impairment (which requires an assessment, diagnosis or similar opinion from a medical or health professional) and secondly by outlining the effect of the

impairment which in turn necessitates the ‘reasonable accommodation’ employers and others have usually resisted conceding (Bickenbach, 2001). Disabled people in developed countries are faced with something of a mixed blessing in ADL that protects them against discrimination and guarantees access, but only via the mechanism of focusing the attention of everyone – the courts, the media, those that hold decision-making powers – on the limitations that impairments can impose. It can be said that from this perspective all ADL can do is change the rules of the game, while the game – the disabling society – remains the same.

Disability and the social model – the UK

In the UK, developments took on a different focus. Initial demands for equality for disabled people in the 1970s were based on social welfare equality and focused on disabled people wanting to achieve some control over their own finances. This quickly led to an increased awareness that welfare was only the ‘tip of the iceberg’ – more and more disabled people became cognisant that existing systems were failing to ensure they enjoyed the same rights as others to things such as access to education, employment, housing and more (Campbell & Oliver, 1996). Indeed, it was the threat of institutionalisation that held the most weight for disabled British people in the 1970s (Morris, 1991). Being housed in an institution meant the loss of so many freedoms for disabled people, it was seen as a “last resort to be resisted for as long as possible” (Finkelstein, 1991, p.19).

This fear was coupled with a sense of frustration that the relative affluence being enjoyed by many in the UK at the time was not being shared by disabled people (Campbell & Oliver, 1996). The Disablement Income Group (DIG) which began lobbying in the UK on social welfare issues was effective in raising some of its central concerns. A much more important effect of the DIG, however, was to bring together like-minded disabled people who realised that civil and human rights rather than income was the fundamental

issue. Some of these individuals formed the Union for the Physically Impaired Against Segregation, which in 1976 published a Fundamental Principles document (UPIAS, cited in Oliver, 1996) outlining a social model of disability:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group within society.
>
> (UPIAS, 1976, cited in Shakespeare, 2006 p.12)

This social model distinguished disability from impairment, and made the crucial step of locating the experience of being disabled away from the body and into society. Disability, then, was not something intrinsic to a person, but rather something created by systems, policies and processes that discriminated against people with impairments and denied them the access to participation in the life-world that they would have otherwise had. For example, for a person who uses a wheelchair, the problem of negotiating steps lies not in the fact that the wheelchair cannot climb stairs, but rather in the fact that the steps (which are only useable by people who walk) were built in the first place, instead of another type of access that could be used by walkers and non-walkers alike.

The social model gained credence throughout the 1980s and 1990s not just in Britain, but across the developed world. It is not without critics however, especially in relation to its focus on the social and systemic character of disability vs. impairment. What the social model appeared to be saying was that impairment is not the issue – disability is merely a social construct, something which can be created or destroyed according to the way the life-world is organised, both practically and attitudinally. What is missing from this analysis is the body. The social model does not expressly recognise that some impairments have an effect on a person's body and that these effects can contribute to the experience of being a disabled person. The original disability activists and scholars who were behind the UPIAS Fundamental

Principles had certain things in common, namely they were predominantly white, middle class, educated men who used wheelchairs (or, 'blokes with beards in chairs' as one participant in this research project termed it). For a person with a stable physical impairment, disability could truly be said to be located outside the body – impairments that cause little physical discomfort and are not likely to change over time do not constitute in themselves a barrier to participating in the life-world (hence the 'problem' in the legs/wheelchair/stairs analogy really *is* only the steps).

Among those who challenged this view were disabled people who felt the body and other elements to an individual's identity have a place in disability discourse. Feminist writers in particular were quick to point out that the social model gives too little account of individual difference to be useful – it pits disability against impairment and draws an unbridgeable line between both (Corker & French, 1999; Crow, 1996; Morris, 1991; Thomas, 1999). Jenny Morris (1991) notes that the body has a place in disability discourse that neither has to be positive or negative. Just as racism cannot be adequately countered with a pretence that race is irrelevant or invisible, so too with impaired bodies. It is not the existence or not of difference that is the issue, it is our response to that difference. When we acknowledge difference and see it is a strength or at least as something other than a problem, we create space for the person to be heard and offer their own definition of who they are and how they want to be seen. Morris writes, "We reject the meanings the non-disabled world attaches to disability, but we do not reject the differences which are such an important part of our identities" (Morris, 1991, p.17).

In its most pure expression, the social model also fails to account for the fact that many people live several different identities and may face discrimination as a result of one or all of them. This is what Ayesha Vernon (1998) calls being a "multiple Other". Writing about multiple oppression and the Disabled People's Movement, she refers to a dual invisibility that some disabled

people can experience which the social model does not stretch to accommodate. She gives the example of a woman who is a disabled lesbian – among lesbians she is a disabled person, among disabled people she is a lesbian, and as such is able to belong to both groups and yet remain an outsider in both simultaneously (Vernon, 1998). Vernon concludes that issues of race, gender, sexuality must be challenged from within the disability rights movement, not as a side-issue but as a recognition that it is not sufficient to focus discourse on ending one form of oppression (the disabling society) while racism or sexism is not addressed or challenged even within the movement itself.

The social model clearly was not unproblematic in its expression of disability as a social construct. It would be unfair, however, to say that Oliver, Finkelstein and others who first thought and wrote about the social model remained static in their views. They very much viewed the Fundamental Principles as a starting point, and certainly Oliver spent much of his later career defending the original principles while insisting the model needed to be expanded upon and developed by disabled people to form a nuanced and balanced account of disability that could account for the experiences of people with as wide a range of impairments and identities as possible (Oliver, 2004; Oliver, Sheldon, Traustadóttir, Beresford, and Boxall, 2007). Although thinking on disability has differed between countries and policy contexts, one common thread has been to conceptualise disability as a social issue rather than a personal one, as an issue of rights as opposed an issue of welfare and needs.

Along with the ideological awakening the social model brought, another aspect of the traditional approach to disability was wholeheartedly rejected by disabled people. This was the disenfranchisement of disabled people, not just in political terms but in personal terms as well: many disabled people had never been consulted about the major decisions that affected their lives, decisions that were routinely made by family members, health professionals

and others (Campbell & Oliver 1996). The slogan ‘Nothing about us, without us’ sums up an important part of the story of disabled people taking back control over their own lives and demanding to have the same influence over what happened to them as others did (Charlton, 1998).

New Zealand – a brief history of social policy and disabled people

In the pre-1900 period, New Zealand followed the lead of most colonies, importing the values and systems from the Old World. New Zealand had an existing indigenous population with its own approach to living with disability. Though research is scarce on traditional Māori *kaupapa* when it comes to disability, some general cultural principles apply. These include *whakawhanaungatanga*, which is related to valuing the connectedness between people through *whakapapa* or genealogy; and *manaakitanga*, which is the idea that people must work towards enhancing each other’s *mana* (roughly translated in English as status, authority or prestige) through working together and respecting one another. Any chance for these concepts to be translated into respectful and empowering ways for disabled people to live in New Zealand was overshadowed by the importation of colonial responses to disability, which relied on British Victorian preferences for institutionalisation as described earlier in this chapter.

Early disability policy in New Zealand predictably followed the path of medicalising disability and using institutions to either rehabilitate or contain people with impairments (Georgeson, 2000). In the late 19th century and into the 20th century, government responses to disability began to differentiate between different types of impairments, promoting for example the idea that people with sensory impairments should be educated and trained together. This approach also singled out people with intellectual disabilities for institutionalisation and meant the beginning of a sad and shameful chapter in New Zealand history, with large numbers of people being essentially incarcerated in mega-institutions such as the Kimberley Centre without any

opportunity to be part of their families/whanau or communities and at times suffering abuse at the hands of those charged with their care (Martin, 2012, private communication; Confidential Forum for Former In-Patients of Psychiatric Hospitals, 2007; Stewart & Mirfin-Veitch, 2008). Numbers of people living in institutions continued to grow throughout the 20th century - at its largest, the Kimberley Centre was home to 900 disabled people, many of whom spent nearly their entire lives in institutional care (Stewart & Mirfin-Veitch, 2008).

In the 1970s, the concept of community care for disabled people came onto the policy agenda. Influences from overseas were adapted and the government began a long term plan to move people from institutions to community-based care (Munford & Sullivan, 2005). The idea at the time was based on three main strands; firstly, as a response to the fact that disabled people living in institutions were often suffering in extremely poor conditions (Blatt & Kaplan, 1974), which were not considered tolerable in the long term. Secondly, groups of parents in New Zealand began to question whether institutions were appropriate places for their children to live. The Intellectually Handicapped Children's Parents' Association (IHCPA, latterly IHC) was formed in 1949, and began providing community-based care services to children with intellectual disability from 1953. IHC was one of several disability-focused groups to emerge that were not dominated by professionals – others included the Crippled Children's Society (CCS) and the Association for the Blind and Partially Sighted (Georgeson, 2000).

Normalisation theory was the final strand in the push towards community-based care. Having originated in Scandinavia, the normalisation principle basically proposes that disabled people have the right to have the same living conditions and patterns of daily life as others do. In order to live a 'normal' life, disabled people would have to move out of institutions and into more typical living situations. Normalisation theory was widely supported by policy-makers and disability service providers in New Zealand (Stewart &

Mirfin-Veitch, 2008; Munford & Sullivan, 2005) and served as an impetus for deinstitutionalisation to gain pace into the 1980s.

There were some notable legislative developments in the 1970s that also changed the policy landscape for disabled people. The first was the Accident Compensation Act of 1972. This established a system of government-funded compensation for people who sustained an accidental injury under a 'no-fault' compensation system. This is significant because the ACC was established not as a way to prohibit people who had been injured from suing for compensation, but as a response to need identified by a 1967 Royal Commission for injured workers to have access to a reliable, easily-accessed and long-term method of supplementing their incomes if they were unable to work (Bismarck & Paterson, 2006). The Accident Compensation Act (1972) turned this need into a right of all New Zealanders and was a world first.

Another important piece of legislation was the Disabled Persons' Community Welfare Act, which gave all disabled people the right to certain supports such as financial assistance, respite care and home help. These supports had previously been given under ACC to people with injuries but not those with non-accidental impairments. It also brought about a change in the Building Code, so that new buildings and renovations were legally obliged to be made accessible to disabled people. This was a small but significant development, in that the onus was now on builders and developers to work towards creating an accessible world, rather than requiring disabled people to fit in (Stace, 2007).

The process of deinstitutionalisation took about 30 years to complete, and ended with the departure of the last residents of the Kimberley Centre in 2006. As in other parts of the world, certain social developments influenced the nascent disability rights movement in New Zealand. The civil rights movement in the US, feminism, trade unionism, gay rights and disability

rights were all elements of a mounting cognisance that the world could and should be a better place for everyone to live. Increased emphasis on consumer rights was also enhanced by the Cartwright Committee of Enquiry of 1987, which examined research on the treatment of cervical cancer at Auckland's National Women's Hospital in the 1960s and 70s. The scandal over the non-treatment of some of the women's cervical cancer for research purposes brought alive in a stark way the need for patient rights, and led to the establishment of the Office of the Health and Disability Commissioner in 1994 (Cheyne, O'Brien & Belgrave, 2008).

At the same time, the social model became increasingly widely known and adopted by disabled people. This was described by one of the research participants as a process of conscientisation – an awakening of critical consciousness among disabled people and a growing awareness of the possibilities of living without oppression. The phrase 'Nothing about us, without us' was used to explain the social model to good effect because it was easy to understand and highlighted the lack of fairness in the way disabled people were being treated (Wicks, 2011, private communication).

The 1990s were a period of enormous change both economically and politically. In 1993 disability rights received an important boost when disability was included in the amendments to the Human Rights Act (Human Rights Act, 1993). In spite of this, nearly 10 years of National government in the '90s saw some damage done to the supports available to disabled people, as Disability Support Services were moved from the Department of Welfare to the Department of Health. This change was seen as a step backwards by DPOs and a "remedicalisation" of disabled people's bodies (Sullivan & Munford, 1998, p.189). It was characteristic of a time where sweeping changes were being made to welfare without any meaningful consultation with stakeholders (Cheyne et al., 2008). Also telling, though less obvious, was the shift from calling social assistance 'social security' to 'income support'. Cheyne et al. (2008) point out the underlying etymological

message from the National government from the early 1990s was that according to the government, welfare was to be based on needs rather than rights.

1999 saw Labour return to government and the DPOs who had been lobbying the Opposition for years were able to cash in their chips. There was a serious expectation that the relationships established with Labour politicians would not be in vain, and this was borne out by some significant developments for disabled New Zealanders early in the new century. Ruth Dyson was appointed Minister for Disability Issues and work on the New Zealand Disability Strategy (NZDS) began in 2000 (Office of Disability Issues, n.d.). Taking the social model of disability as a philosophical starting point, the consultation process for the strategy was comprehensive and sought input from disabled people all over New Zealand. Significantly, the initial plan to have a non-disabled Chair for the Sector Reference Group was vehemently opposed by disabled people in the group and Robyn Hunt was appointed as co-Chair with Jan Scown.

The Reference Group received over 700 submissions representing the views of an estimated 2,500 New Zealanders who personally experienced disability. In their summary document, the Reference Group noted the chief barrier to participation in society identified by disabled people was the attitudes of others, followed by lack of access to services, physical access (including accessible public transport), access to employment and education (Ministry of Health, 2001a).

The NZDS was launched in 2001, and comprises a set of 15 objectives and actions for government departments to meet in terms of how they make their activities accessible to and inclusive of all New Zealanders. The NZDS defines disability as a social phenomenon, and uses the social model distinction between impairments which people have and disability which is a

socially constructed process. The Strategy is not legally binding and should not be confused with ADL. It does, however, take a human rights approach to looking at disability.

The Strategy, and in particular the consultation process, was mentioned by several of those interviewed in this project as a kind of pre-cursor to the negotiations for the CRPD. Disabled people had seen what a truly representative consultation process could look like, and they were keen that this should be replicated at the UN. Moreover, the NZDS is clear that disabled people have the right to live in a non-disabling society according to a disability human rights paradigm. It contains a commitment to ensuring national human rights legislation upholds the rights of disabled people. Among the Actions for achieving Objective 2 is a commitment to exploring the development of a United Nations human rights treaty safeguarding the rights of disabled people (Ministry of Health, 2001b). An Office for Disability Issues was established in 2002 to provide policy advice and assist with implementing and monitoring the NZDS.

Conclusion

This chapter has introduced the research question and outlined the theoretical background for the social model of disability. It has looked at significant aspects of disability theory in the UK and the US in the latter half of the 20th century, outlining the development of the social model and some if its criticisms. In describing some of the history of social policy in relation to disabled people in New Zealand, including the rise of DPOs and the effects of social policy directions on disabled people, I have argued that New Zealand has followed in the footsteps of other Western countries in terms of institutionalising and medicalising people with impairments.

Though the 1970s onwards saw a mobilisation of disabled people and a growing focus on rights and autonomy, disabled people remained at the mercy of government with respect to having access to basic services and

living in an accessible and inclusive society. Some gains were made, for example with the inclusion of disability in the 1993 Human Rights Act, the NZDS coming into force and New Zealand Sign Language (NZSL) being recognised an official language, but other positive moves such as the Disabled Persons' Welfare Act were dismantled in changing political climates.

Yet more policy initiatives, such as the move to community care and deinstitutionalisation in the 1970s and 1980s can be seen to have had good intentions, but a lack of real commitment to workable solutions left many disabled people out of the frying pan of institutions and into the fire of 'community care' that failed to deliver as it should have. A change in government at the turn of the century saw new efforts to establish a non-disabling society, this time with the social model firmly at the core of government policy in the NZDS. New Zealand was beginning to take rights for disabled people seriously, a commitment that was to coincide with developments at the UN during the same time and which led to New Zealand taking a central role in negotiating the CRPD.

Chapter Two – Momentum: Human rights, disability rights, the United Nations and the road to the CRPD

Introduction

The previous chapter examined the rise of the social model of disability in the UK and New Zealand and its effect on domestic social policy. The social model sees disabled people as an oppressed group and demands rights of inclusion that will end oppression. This chapter will look at rights from the point of view of disabled people, firstly giving a brief overview of human rights. There follows a treatment of the disability rights movement and the history of disability rights at the United Nations which led to the development of a human rights instrument specifically aimed at disabled people. The chapter concludes with an examination of the Convention on the Rights of Persons with Disabilities, including an analysis of some significant articles in the context of this research project.

Human rights

The United Nations defines human rights as those that are rights that are inherent to all human beings (United Nations, 2014). Certain characteristics are common to all human rights, namely that they are universal and inalienable - as well as applying to all people, no human right may be taken away or denied to any person. They are also indivisible, interrelated and interdependent – human rights depend on one another and the enjoyment of one type of human right should promote and facilitate the enjoyment of other rights.

The nature of human rights has been the subject of a huge amount of study and debate, especially in the 20th century, and a comprehensive treatment of the theory and history of human rights is beyond the scope of this study. However, as this project takes an international human rights instrument as its

starting point, it is appropriate to look briefly at the broader questions involved in human rights and especially at the role of the United Nations in international human rights law. One of the most important and widely discussed elements of human rights – universality – has been the subject of much debate when it comes to disability rights – more of which to follow.

Human rights are broadly divided into two categories, positive rights and negative rights. Most human rights instruments, especially at the United Nations, have focused on negative or 'first-generation' (civil and political) human rights. These rights include the right to vote, the right to life and the right to not be held in slavery. Positive or 'second-generation' rights (social, cultural and economic rights) have traditionally been seen as belonging to economic and social development issues such as the right to housing or education (Stein, 2007a). Though most people would struggle to provide a definition of human rights, it is fair to say that people are very aware of the value of human rights when they no longer possess them. This is because human rights, though universal, also depend on a functioning state to protect them – in times of war, anarchy or dictatorship, human rights are subject to wholesale abuse.

In countries like New Zealand, people have the luxury of not having to know or think much about human rights precisely because they enjoy them. People understand they have freedom of movement, freedom of association and freedom of speech, and attempts by the State to interfere with these and other rights can be publicised, criticised and investigated. All New Zealanders have legal protection from human rights abuses under the Human Rights Act, 1993 and the New Zealand Bill of Rights Act 1990. New Zealand also has an independent Human Rights Commission which is separate from government and has the dual function of promoting human rights in New Zealand and investigating alleged human rights abuses.

New Zealanders do not live in a kind human rights utopia however, as human rights abuses still occur. The latest report by Amnesty International

(2013) criticised the New Zealand government for failing to protect children from poverty and expressed concern over high and increasing levels of violence against women. Human rights are also still an issue for Māori, as their claims for sovereignty over land and resources remain an ongoing dispute with the Crown (Human Rights Commission, 2010). The New Zealand Human Rights Commission states in its latest national human rights report that disabled people remain "among the most marginalised in New Zealand" (Human Rights Commission, 2010). While acknowledging the progress made by New Zealand in some areas such as the status of New Zealand Sign Language as an official language, the report calls for increased support to disabled children to ensure access to education. It also finds there is a need for meaningful engagement with disabled Māori, who it identifies as being at risk of double disadvantage.

Disability rights

The 2012 documentary *Ukraine's Forgotten Children* (Blewett, 2012) tells the story of thousands of disabled Ukrainian children who are signed over to the care of the state in infancy. This practice continues because of a widely-held perception that has lingered since the days of Communist rule that children with impairments are best cared for outside of their own families in state institutions. These children are known as 'social orphans' because, although they have no contact with their families, the overwhelming majority of them have living parents. It is clear they are placed in state care solely because of their impairments and are raised in under-resourced and poorly equipped orphanages where many have access to only very basic medical and rehabilitative resources – for example, the orphanage which features most in the film is home to several chronically ill children, yet the only health professional available to care for them is a retired dentist.

A worse reality awaits these children on reaching adulthood. Many young people who have been raised in orphanages are declared legally

‘incapacitated’ on their eighteenth birthday, a status which essentially makes them a non-person before the law, losing all rights to self-determination (Blewett, 2012). The individual loses basic civil and political rights, such as the right to freedom of expression, freedom of movement and freedom from enforced servitude. They are confined to psychiatric and geriatric institutions (in many cases against their will) with the expectation that they will provide free labour to the institution. These people have described failure to comply with the demands of institution staff as being met with beatings and torture via administration of anti-psychotic drugs. The film also contains allegations that some disabled people have been murdered while housed in state-run institutions.

This story from the Ukraine is a valuable illustration of how the interplay between disability and poverty can create situations where disabled people become uniquely vulnerable to human rights abuses. The overwhelming majority of disabled people (80% worldwide) live in poverty (Department for International Development, 2005; Quinn, 2009b). In a longitudinal study of disability and development, the British Department for International Development found that disabled people in developing countries are most likely to be among the very poorest in their communities, and have fewer opportunities than others to improve their circumstances and escape poverty (Department for International Development, 2005). Poverty enhances the powerlessness of disabled people because of the practical effect a lack of resources and education has in preventing them from living their lives on the same basis as others. They are, according one former World Bank president, “at the bottom of the pile” (James D. Wolfensohn, quoted in Department for International Development, 2005, p.9).

Disability is a human rights issue! I repeat: disability is a human rights issue.

(Beng Lindqvist, UN Special Rapporteur on Disability, cited in Quinn et al., 2002, p.9)

For disability to be seen as a human rights issue, disabled people have had to come a long way from the traditional medical-based approaches to

supporting people with impairments prevalent in the 19th and 20th centuries. We have already seen that disability has been conceptualised as a social and a political issue. The background to the CRPD comes from an extensive history of thinking and arguing for disability not just to be taken seriously as a social issue, but as a rights issue. Arguments for an expansion of thinking on disability and human rights have come from the disability rights movement for decades. In their analysis of the disability rights movement in the UK, Campbell and Oliver (1996) wrote of the future of the movement lying in the recognition and protection of the human rights of all disabled people, not only those in developed countries.

Disability is a rights issue because many human rights are simply not available or accessible to disabled people as illustrated in the example above from the Ukraine. But this is only one example from too many available to choose from in both developing and developed countries (Bickenbach, 2001; Despuoy, 1993; Lawson, 2007). The right to freedom of expression, for example, is not available to Deaf people when they are not permitted or facilitated to use sign language to communicate. The World Federation of the Deaf Education believes access to education in sign language is central to the development of Deaf children. Moreover, fluency in sign language is considered to be a critical skill for all teachers who work with Deaf children (World Federation of the Deaf, 2014). The 2011 WHO World Report on Disability notes two examples from African countries where Deaf children are much less likely to be enrolled in either primary or secondary schools (World Health Organisation, 2011).

Even in developed countries where human rights are commonly protected, disabled people can be vulnerable to human rights abuses because of unreasonable expectations. In the United States, for example, a basic lack of understanding and empathy for difference has in recent years had deadly consequences for innocent and unarmed disabled people. Many disabled people have become the victims of police violence simply because of a

failure to comply with police officers' demands. The situation in the US is of such concern that a Senate Committee met in 2014 to discuss law enforcement responses to disabled Americans and measures to protect people from excessive harm (Perry & Carter-Long, 2014). This type of behaviour is an example of how non-disabled people's responses to the effects of impairments can result in harm, violence and death for disabled people, even at the hands of those who are charged with protecting the community.

Legal capacity is another area where disabled people's human rights are commonly violated. Lawson (2007) cites a report by the International Disability Rights Monitor from 2004 which found in the Americas disabled people were frequently declared to be legally incompetent, especially when their impairments were of a mental or intellectual nature. Such a declaration means in practice that that person is no longer recognised as a person before the law, so the right to basic things such as ownership of property or the right to legal representation is taken away. Many people who experience mental illness are ruled to be legally incapacitated, losing the right to travel, to sign an employment contract, or to decide on matters concerning their own welfare or medical treatment options. A recent Human Rights Watch report from Croatia gives the example of a 47-year-old woman with schizophrenia who is not even able to move house without written permission from the person who was appointed her guardian without her knowledge or consent (Human Rights Watch, 2014b).

Looking at other rights, Clements & Read (2008) have collected essays using the example of the denial of one of the most basic human rights – the right to life. According to international human rights law, all people have the right to life, yet globally many countries still see higher than expected death rates among disabled people. This will often be due to poor access to medical treatment and the exacerbation of life-threatening conditions when disabled people live in extreme poverty. However, the termination of

pregnancies where the foetus is likely to be disabled and the withholding of treatment and nutrition to disabled children are still part of life in many countries. In China, for example, women are actively encouraged to terminate pregnancies where the foetus has been identified as having (or even possibly having) a congenital impairment (Petersen, 2010). Similarly, Chinese medical authorities have been found to have endorsed euthanasia for disabled infants (Dikotter, 1998, cited in Petersen, 2010, p.106).

Any consideration of the arguments over euthanasia or the right to life aside, fundamentally devaluing a human life when a person has an impairment is a violation of that person's human right to life (Quinn et al., 2002). This concept is behind the current attempt to have the New Zealand government indicted at the International Criminal Court for its ante-natal Down Syndrome screening programme, which offers free early screening for Down Syndrome to every pregnant woman (Saving Downs, 2014). The indictment contends that this screening represents a form of discrimination against people with Down Syndrome as it may lead women to terminate their pregnancies if the foetus is confirmed to have a high chance of having Down Syndrome. The argument is that it is illegal to terminate a pregnancy because the foetus has a genetic condition which is not life-threatening when the pregnancy would not otherwise have been terminated. In other words, people with Down Syndrome have the same right to be born as anyone else. Most of the challenges people with Down Syndrome and their families face could be removed by meaningful and well-designed support structures which would exist in an educated society committed to reducing barriers and providing a life-world designed to be used and enjoyed by everyone, not just non-disabled people.

Human rights are civil and political rights (negative rights), but they are also economic, social and cultural rights (positive rights). Divisions between the two types of rights have been assessed as being artificial and unhelpful, in that positive social, economic and cultural rights are equally as important to

disabled people as negative rights (Megrét, 2008; Weller, 2009). Examples that relate to the denial of these rights to disabled people are far too common – the right to work and to be provided with housing may be available in principle, but too many employers still refuse an interview to a person who discloses, for example, a history of mental illness on an application form (Ministry of Health, 2006). In New Zealand, the state will provide accessible housing to people who need it, but there is no obligation to make any other housing accessible, so that a disabled person may visit the homes of friends and family.

Situations like this can lead to social isolation and reduced 'visibility' for disabled people, making it a fundamental part of re-educating others to consider disability as a social, not a personal, issue. Gerard Quinn (in Quinn et al., 2002) writes of visibility being a very real consideration for disabled people in protecting their rights as citizens. He describes a process whereby disabled people are not seen or heard, and so are discounted from having a voice, and from participating in social and political debates. Further isolation and invisibility leads in a downward spiral, as disabled people eventually run the risk of themselves not expecting to be visible and present in society as other people are. He writes, "[The] prime message [of the DRM] is to remind us of something we should not need reminding about, namely that persons with disabilities are human beings and therefore share the same rights as everybody else and the right to enjoy them to the same degree" (Quinn et al, 2002, p.17).

Disability Rights and the United Nations

It has been argued that international human rights law did not - or should not - need a separate instrument relating to the rights of disabled people (Kanter, 2007). International human rights were universally covered by the United Nations 1948 Universal Declaration of Human Rights (UDHR) and by two general legally enforceable conventions – the 1966 International Covenant

on Civil and Political Rights (ICCPR) and the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR). There are four additional conventions that have been drafted with the protection of particular minority groups in mind:

- the 1965 International Convention on the Elimination of All Forms of Racial Discrimination
- the 1979 Convention on the Elimination of all Forms of Discrimination against Women
- the 1989 Convention on the Rights of the Child
- the 1990 Convention on the Protection of the Rights of all Migrant Workers and Members of Their Families

In theory, all these conventions, in addition to ICCPR and ICESCR, offer comprehensive protection to disabled people's human rights. The Convention on the Rights of the Child is the only one to specifically mention disability, requiring in Article 23 that States Parties safeguard the rights of disabled children to participate in their community (United Nations, 1989). In addition to these, the UN also made various declarations relating specifically to disability related issues – especially relating to mental illness (Stein 2007a). In discussing whether a separate treaty was needed on disability human rights, it was argued that disabled people could access redress to human rights violations using the existing instruments (Stein, 2007a). However, the person would need to "fall under a universal provision or possess a separately protected characteristic in addition to his or her disability" (Stein, 2007a, p.80). In reality, the core seven UN human rights treaties were rarely invoked to protect the human rights of disabled people.

By the 1980s, the disability rights movement had begun to encourage the United Nations to take disability on board as a social issue. The World Programme of Action Concerning Disabled Persons (WPA) was adopted in

1982 and it had three main concepts which neatly sum up the change in thinking that was (slowly) emerging: prevention, rehabilitation and equal opportunities (Quinn et al., 2002). The first two of these aims are very firmly tied to the medical/individual model of treating disability as a care and treatment issue. However, the same cannot be said of the equalisation of opportunities, which was defined, broadly speaking, as the concept of making society and social activities accessible to all people (Kayess & French, 2008). The World Programme of Action explicitly states that disability is not a phenomenon exclusively located in the body of a person with an impairment: “Experience shows that it is largely the environment which determines the effect of an impairment or a disability on a person’s daily life.” (WPA, cited in Quinn et al., 2002, p.20).

Attempts to begin the process of drafting a standalone disability human rights treaty were unsuccessful during the 1980s. Instead, 1983-1993 was declared the International Decade of Disabled Persons. In 1993, the United Nations rejected a call for a new human rights treaty on disability to be elaborated (Lawson, 2007). A set of legally unenforceable principles, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities was adopted instead. To say the Standard Rules were not enforceable is not to say they had no influence. A Special Rapporteur, Beng Lindqvist, was appointed to monitor the implementation of the Rules, and his reports at the end of two successive terms charted both the situation of disabled people globally in terms of discrimination and human rights abuses. They also continued to urge for stronger and more robust international human rights law to prevent these abuses (Quinn et al., 2002; Stein, 2007a).

In 2000, the UN commissioned a report into disability human rights under the existing instruments. The authors found that knowledge of human rights and how to use the existing treaties was extremely low among DPOs and national human rights institutions (Quinn et al., 2002). They recommended that a new treaty be formulated that would encompass both first and second

generation human rights as they relate specifically to disabled people, arguing that “a convention would mark a huge step forward and should not undermine but underpin the protections provided in the existing six human rights treaties” (Quinn et al., 2002, p.297).

Towards a Convention

The social and political climate had changed sufficiently by the early 2000s to allow a resolution to be passed in late 2001 at the UN General Assembly that an Ad Hoc Committee be established to draft a human rights convention dealing specifically with disability human rights (Lawson, 2007). Although various member states had previously proposed resolutions to begin the drafting process for such a convention, these were unsuccessful as other states pointed to the existence of instruments such as the Standard Rules. They had successfully argued that the Standard Rules were designed to underpin existing legally-enforceable treaties where additional detail was needed in the area of human rights for disabled people. In the end, the push for a new and separate convention was led by Mexico and supported by the Latin American regional group, and is evidence of a rising tide of international support for disability rights at the time.

The process of drafting the Convention bears dramatic witness to the strength and determination on the international disability rights movement. Firstly, the text agreed on was one drafted with the highest level of input from civil society organisations (in this case, disabled people’s organisations) of any other UN human rights treaty, with over 800 DPO representatives attending the final Committee Session (Lawson, 2007). This fact brings to life in an extraordinary way the DRM catch cry ‘Nothing about us, without us’. Secondly, in spite of encountering some extremely difficult and potentially polarising questions within the negotiations, these were completed in the shortest time it had ever taken to draft a human rights convention at the UN.

Although this thesis focuses on New Zealand DPO representatives who became part of the official government delegation, NGOs representing stakeholders - disabled people - were involved in the negotiations at a level that was unprecedented at the UN (Reina, 2008). This is true not only in terms of sheer numbers, but also in relation to the input the NGOs had. Traditionally, NGOs have occupied a peripheral role in negotiating human rights instruments (MacKay, 2009). Early on the in CRPD negotiations, many international, regional and national DPOs banded together to form the International Disability Caucus (IDC). The IDC was made up exclusively of DPOs and included representatives of every disability group. It proved a powerful and extremely effective lobby group, providing feedback on textual proposals both during the formal Ad Hoc Committee meetings and during 'informal' meetings in between sessions. There is no doubt that the 'lived-experience' perspective offered by the IDC and other NGOs present helped to precipitate and shape the negotiations process in a positive way (MacKay, 2009; Reina, 2008).

Turning to the final text, it can be seen how easily the discussions could have been derailed by the complexity the issues under discussion. I have already mentioned the right to life, which is referred to in Article 10: "States Parties affirm that every human being has the inherent right to life and shall take all measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others" (United Nations, 2007a). The questions of euthanasia, assisted suicide and abortion provided for lengthy and heated debates over the wording of this article – in the end, the language was kept as simple as possible with delegates "agreeing to disagree" (Petersen, 2010, p.99). It should be noted that because of the absence of an expressed protection for unborn children, the Holy See has refused to sign the Convention (Petersen, 2010).

Another article which was the centre of vigorous debate was Article 1, which sets out the purpose of the Convention and contains a definition of who 'persons with disabilities' are (Lawson, 2007). Any attempt to define disability will always be problematic – the medical/individual model wishes to define disability in medical terms, focusing on difference and deficit of function. The social model, however, (at least in its purest sense) defines disability as being completely separate to impairment, and sees it is a purely social phenomenon. World Health Organisation definitions of disability were criticised for focusing exclusively on the medical aspects of impairment (Kayess & French, 2008). Similarly, the social model itself has been criticised for taking too little account of the lived reality of impairment in many disabled people's lives (Morris, 1991; Shakespeare, 2006; Thomas, 1999).

Article 1 treads the line between the medical and social definitions by stating that "persons with disabilities include those who have long term physical mental, intellectual or sensory impairments which *in interaction with various barriers* [my italics] may hinder their full and effective participation in society on an equal basis with others" (United Nations, 2007a). This definition is not without its own problems, but as Lawson (2007, p.595) points out, the preamble to the Convention contains a 'get-out' clause in recognising that 'disability is an evolving concept', hopefully opening the way for future debate in developments in the area of forming useful working definitions.

The question of legal capacity was so complex and vigorously contended that it threatened on several occasions to derail the negotiations process completely. Don MacKay describes this was because:

> It was key to achieving the "paradigm shift" in the treatment of persons with disabilities, from being objects of the law to subjects of the law with the same rights as everybody else. It involved many quite complex legal issues, and was made even more complicated by the differing approaches taken under the various legal systems represented in the negotiations. (MacKay, 2009, p.11)

In fact, the matter was only settled at the final Committee meeting where the draft text was agreed on with a footnote to limit the meaning of the translation of 'legal capacity' in Chinese, Russian and Arabic (MacKay, 2009). This footnote was eventually dropped, but the World Network of Users and Survivors of Psychiatry (WNUSP) was so dismayed at any qualification being applied to the legal capacity provisions that they refused to accept the Convention had been anything but a pyrrhic victory. In terms of the rights of people who experience mental illness, the question of legal capacity crucially concerns the capacity to refuse treatment or not to be hospitalised against one's wishes. These issues were considered to be so important that the WNUSP would rather have had no Convention at all than a text that did not give full protection to all people - especially people who experience mental illness - to be recognised as persons before the law.

The Convention and beyond

While the remainder of this thesis will look at the negotiations process itself, it may be useful to give a brief outline at this stage of the final text of the CRPD as it was agreed in 2006. Implications for New Zealand in terms of policy will be examined in Chapter Five.

Just five years after negotiations began in 2001, the Ad Hoc Committee presented the Draft Convention to the UN General Assembly on December 13th, 2006. It was signed by 81 states and by the European Union, historically providing another 'first' for this Convention – the highest number of signatories to any human rights convention on its formal adoption. The Convention opened for signature in March 2007 and entered into force in May 2008. To date there have been 159 signatories and 151 ratifications to the main body of the Convention and 92 signatories and 85 ratifications to an Optional Protocol which allows states to voluntarily be exposed to additional monitoring and allows individual and group complaints to be brought to the UN. It was met with tremendous expectation and was hailed as 'the dawn of

new era' (Kanter, 2007, p.293) and 'a paradigm shift' (Kayess & French, 2008, p.3). There were many aspects to the Convention to be celebrated. The final part of this chapter will look at some of the most progressive articles of the Convention and will attempt to make some assessment of the its future potential for disabled people both in New Zealand and further afield.

The Convention contains far more in terms of content than the scope of this paper will allow for. However, there are some articles that are of great significance and have the potential to have far-reaching effects for disabled people in the states that have ratified the Convention. To begin with, some scholars have argued that the CRPD brings together two different types of human rights in a way that no other treaty has done before (Kayess & French, 2008; Megrét, 2008; Stein, 2007a; Stein 2007b). UN human rights treaties had, up to the CRPD, guaranteed civil and political rights on the one hand, and economic, social and cultural rights on the other. Michael Stein (Stein, 2007; Stein & Lord, 2008) argues the Convention brings both types of rights together in a way that is uniquely appropriate for disabled people, as there is a need not only to have negative rights preserved, but also to have positive rights in order to experience the same opportunities as others. For example, to participate in the democratic process, disabled people need not only the nominal right to vote (which would make them equal with other citizens), but also reasonable accommodations such as voting information in accessible formats and access to either an accessible polling venue or an alternative method of casting their vote (e.g. electronically or by mail) of their choice.

To give another example, it could be argued that access to education is part of the right to vote, as disabled people have the right to be educated and informed of their rights and responsibilities as citizens. This is a given for many disabled people, but not for all, especially people with learning disabilities. UNESCO reported in 2006 that more than 90% of disabled children in Africa had never attended school at all. Colm O' Cinneide writes:

> The Convention therefore adopts a particular conceptual view of the state's role in securing individual human rights as involving more than simple abstinence from the abuse of individual civil and political rights. Instead, the state is expected to play an active role in creating the social conditions necessary for individuals to be treated with dignity. (O' Cinneide, 2009, p.164).

Megrét (2008) points out that though the Convention stops short of creating new rights, it expands in some detail on the ways particular rights are to be applied for disabled people. For example, the right to education is contained in both the Universal Declaration of Human Rights and the Convention on the Rights of the Child. The CRPD deals with education in Article 24, and expands significantly on the expression of this right in previous conventions. It addresses the issue by first detailing why education is important to allow individuals to achieve their full potential. It then goes on to elaborate on the ways education must be made accessible to disabled people, including though reasonable accommodations and inclusion in mainstream settings. The Article also mentions the right of certain minorities to access education in their chosen language and mode of communication and also states that teachers must be trained in these modes of communication. Lastly, it includes a section on access to tertiary and vocational training.

Megrét argues that in using this approach, the CRPD is "getting its hands dirty" (2008, p.506) with practicalities in a way that is a dramatic departure from other human rights instruments. In this way, the CRPD can be seen as being uniquely effective in spelling out to states exactly how the rights in the CRPD are to be guaranteed. He also suggests that while falling short of creating new rights, the Convention names and amplifies certain existing rights in a new way, creating a sort of "human rights plus" (Megrét, 2008 p.507). For example, Article 16 concerns the right to freedom from exploitation, violence and abuse. This right is not mentioned in any other human rights instrument, probably because it expresses in negative terms

the right to life, liberty and security of the person contained in Article 3 of the UDHR. Megrét points out that in doing so, the Convention presents protections against some of the "root causes" (2008. p.509) of the human rights violations disabled people face.

Another specific departure for this Convention is in its monitoring provisions. True to the notion of 'nothing about us, without us', DPO involvement in implementing and monitoring the Convention at a national level has been built into Articles 4 and 33 (Stein & Lord, 2010). Article 4 requires governments to consult with disabled people (including disabled children) and their representative organisations when drafting legislation to implement the Convention. Moreover, Article 33 lays out a three pronged approach to monitoring the Convention once ratified, including a provision that "Civil society, in particular persons with disabilities and their representative organisations, shall be involved and participate fully in the monitoring process." (United Nations, 2007a).

This is envisaged to be part of an independent monitoring process that involves independent bodies outside of government such as human rights commissions, as well as establishing 'focal' points within government with specific responsibility for coordinating action on disability where it is potentially spread wide across many government departments. In the New Zealand context, this involves the Office for Disability Issues becoming the 'focal point', with the possibility of the New Zealand Human Rights Commission doing the independent monitoring, and DPOs such as Disabled Persons Assembly, Association of Blind Citizens and People First being actively involved in the monitoring process (Office for Disability Issues, 2008).

Another part of the monitoring process is at the UN level. Article 34 provides for the establishment of a Committee on the Rights of Persons with

Disabilities, which will monitor the implementation of the Convention and receive reports from States Parties. When states also sign the Optional Protocol, the Committee is designated to receive complaints of human rights violations according to the Convention from either individuals or groups of individuals (such as DPOs) from that state. One disappointment here is that the Committee is required to be representative of disabled people – but members do not have to be disabled. Having said this, States Parties are required to consult with CSOs on who they nominate for election to the Committee.

The idea that change will come quickly or that the Convention can be used as a sort of blunt instrument to ensure better equality is not in line with the spirit of the document (Quinn, 2009b). Those who drafted it point instead to a sea change and an increasing paradigm shift, as a continuum of the process of emancipation for disabled people put into motion by the disability rights movement. The Convention exists not only to help change discriminatory laws and policies but to ultimately stop those laws from being written in the first place. It has been argued that disabling attitudes cannot be changed by anti-discrimination legislation (ADL) alone (Russell, 2002; Young & Quibell, 2000). On the other hand, Rioux (2001) has claimed that ADL can have a positive effect in preventing the worst types of human rights abuses. Zola (1989) contends that because issues to do with impairment are likely to affect a large percentage of the population at some stage in their lives, ADL and disability policy must be based on this premise. Given that in New Zealand almost one in four people were identified as disabled during the most recent New Zealand Disability Survey (Moodie, 2013), disability and impairment are everyone’s business.

The question remains whether ADL has the ability to not only prevent discrimination, but change the attitudes that lead to human rights abuses in the first place. The CRPD would seem to be attempting to achieve both these goals, as it preserves negative rights, but also places an obligation on

states to be proactive in creating accessible and inclusive societies where all people have the opportunity to participate on an equal basis. In this sense, the idea that people may be equal but different is important. Just as human rights for women are not based on the idea that women and men have to be the same to merit equal respect, so it follows for disabled people. Stein (2007a) has argued that the CRPD represents an innovative approach to human rights that can be extended to other groups. It focuses equally on positive and negative rights, so that States have a duty not only to prevent disabled people from being harmed through human rights abuses but also through creating positive mechanisms to reduce and eliminate barriers and discrimination.

Conclusion

In this chapter I have looked at human rights and disability rights, with a special emphasis on disability rights at the United Nations and the CRPD. The fundamental reason why disability is a human rights issue is because disabled people have faced and continue to face discrimination on the basis of the impairments they live with. This stems from a societal belief that people are valuable not because of who they are, but because of what they can do. Any limitation in function therefore renders a person less important. An opposing view is that all people have an inherent worth, with potential unique to themselves. This tenet is at the core of disability human rights paradigm, which maintains that every person is "entitled to the means necessary to develop and express his or her own individual talent" (Stein 2007a, p.77).

Where the state places barriers in disabled peoples' way, they are entitled to challenge these disabling processes and have access to mechanisms for redress. The CRPD is born of the need for a protection for disabled peoples' human rights both under national and international law. It contains some unique mechanisms to ensure States Parties both protect disabled people

from abuse and encourage or facilitate mechanisms that allow full access and participation for disabled people. How effective the CRPD will be prove to be in the long term still remains to be seen. However, it is a hugely significant document for disabled people worldwide, and one as we will see in the chapters to come with special significance to the disabled New Zealanders who were involved in writing it.

Chapter Three: Methodology

Introduction

This chapter will outline the methodology used in the design of the research project. Taking the social model of disability as an epistemological starting point, it will outline some major themes in social research in general and in disability research in particular. There follows an exploration of emancipatory research as a paradigm in disability research and a positioning of this project in terms of how it aligns with Mike Oliver's emancipatory research principles Oliver 1992; Oliver 1999). The chapter then turns to the question of positioning the researcher in the research, with some treatment of the questions around non-disabled researchers carrying out disability research. It also contains an account of the research process, including how the data were gathered and the ethical considerations given to the project. The significance and limitations of the study are also considered.

Methodological design

Initially, a mixed methods approach was intended for use in this study. My aim was to analyse documents from six meetings of the UN Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. This was the committee set up to draft the text of the CRPD in 2006. Once I began my research, I realised that a comprehensive analysis of the proceedings of the Ad Hoc Committee would be beyond the scope of what this thesis could achieve, primarily because of my own limitations as a researcher in making sense of the documents and secondly because of the richness of the data I was collecting from my interviews with the delegates. To explain my comment on making sense of the documents, what I found was that the UN has systems and procedures that are very difficult for an outsider to make sense of. There are strict protocols with regard to the use of

language and these come into play when interpreting the meanings of statements by government delegation submitted to the Ad hoc Committee. In short, I found that without guidance from a third party experienced in 'UN speak', I was likely to miss the significance of much of the content of these documents.

I had understood from the outset that the documents were not going to be as accessible as I had hoped, however it was only with further reading that I realised the gap between my lay-person's interpretation of the language and what was actually being said was much wider than I had thought – so wide as to find myself extremely ill-equipped for the reality of undertaking a thorough analysis of these data. At the same time, I found that with their contributions, the participants were providing the research with a direction I had not foreseen at the design phase. My feeling was that the material contributed by the participants was answering the research question by itself. It was also generating new questions and providing a course for me as a researcher that I had not anticipated at the beginning. These two factors led me to change the focus of my research away from mixed methods and I concentrated solely on conducting semi-structured qualitative interviews with former delegates, allowing their responses to shape the conversation and the research.

Conceptual framework

> We can… begin to say from experience what good disability research is not like… it should not be embedded in, or regulated by, medical model ideologies; it should not attempt to be neutral or to disregard the impact of oppression in disabled people's lives; it should not reproduce the familiar, and so leave disabling personal political or practical barriers unchallenged; it should not exclude non-disabled people from

> its process or productions; it should not be controlled entirely by non-disabled people… (Moore et al., 1998, p.14)

Keeping Moore's guidelines in mind, the intention of this study was to carry out the research using the social model of disability as an epistemological starting point, using key informant interviews for data collection. Social research is largely divided into two approaches, qualitative and quantitative. Quantitative research maintains that society is knowable, that social knowledge is quantifiable and that a truth of some sort can be established through objective study in a similar way to that of natural science (O' Leary, 2004). An example of quantitative social research is survey research, which uses broad scale methods, usually questionnaires, to identify patterns in social life (Pawson, 1999).

Qualitative research counters this view, suggesting that that any attempt to 'know' a world that is in a constant state of flux is futile, and in social research this is doubly true as 'it is not possible to stand back and take a neutral point of view of any aspect of society' (Walliman, 2005, p.199). Qualitative researchers reject the idea that it is possible for the researcher to be objective. They argue that the researcher is a person with values, a history and an identity of their own, all of which works together to have a unique effect on any research they may carry out (May, 2001). Moreover, the onus is on the researcher to be upfront about who they are and what they bring to the work from the outset, as this will likely have an influence on the design of the project, the research questions, methods and conclusions.

May (2001) maintains the researcher's values will naturally lead them to choose to research a certain group above another, depending on what the researcher feels is doable for them. As an illustration of this, May points to the lack of research on social elites, pointing out that groups who have the

power to avoid or resist being researched are often able to do so (May, 2001). Mike Oliver writes:

> …people who are poor, unemployed, mentally ill, women, black people, disabled people and children are all frequently studied. In comparison research has uncovered little about the lives and activities of psychiatrists, bank managers, policemen, politicians, policy makers, political terrorists, captains of industry or even researchers themselves. (Oliver, 1992, p.110)

Disabled people may be seen as traditionally not having had the power to say no to research, a question I will address later in this chapter when I consider the ethical considerations given to this project.

Broadly speaking, the aim was that the research would have strong elements of ethnography, but rather than studying a way of life from the point of view of a (cultural) group, it would be exploring the experience of a process from the point of view of those who took part in it. Ethnography is rooted in the qualitative family of social research methodologies, and it acknowledges that knowledge is constructed through narrative and that meaning is relative – in the eye of the beholder (Pawson, 1999).The study cannot be called true ethnography, however, as the participants and researcher were talking about a process and events that had already happened. It was hoped that an account of the negotiations surrounding the Convention could be built up from the descriptions of those who were present. Just as the presence of the researcher can affect and change behaviour in the moment, I expected that the narratives of the participants would be affected not only by my presence as the researcher, but also by the passing of time.

One frequent criticism of ethnography is that conducting really in-depth, small sample analyses can lead the researcher to lose the ‘big picture’ and to be led astray (O’Leary, 2010). In the instance of this project, I believed initially that both quality and quantity could be balanced with sources that complemented one another. In reality, I found myself discussing the

negotiations process with individuals who were themselves used to seeing a ‘big picture’ - that is, thinking about disability and human rights on a national and global scale. The participants had all been part of the New Zealand delegation specifically because of their knowledge and expertise in the issues involved. I found without exception they were more than capable of keeping their reflections organised and clear to me as the interviewer and I imagine to a wider audience as well. In addition, I had some excellent help from Don MacKay as someone who held an overview of the negotiations process. His reflections helped to put some of my findings in context in terms of their significance from a UN perspective.

The social model of disability has already been discussed in preceding chapters, and it represents a strong philosophical framework to build the research on. This is important to state from the outset because, although I do not identify as a disabled person, my own philosophical understanding of disability lies firmly within the social model. The historical background to disability research bears some discussion here. Disabled writers have identified traditional research about disability-related issues and involving disabled people as being oppressive, unrepresentative and at times exploitative (Moore, Beazley & Maelzer 1998; Oliver, 1992).

A further criticism of disability research using a medical/individual understanding of disability is that the research is often neither relevant nor useful to disabled people (Oliver, 1992). In any social research, where research is not based on principles of participation or partnership, the gap between researcher and participant becomes a power struggle, with the participant cast in the role of ‘object’ and being disempowered from the start (O’Leary, 2010). This is even more relevant when the research participants belong to a group who have been consistently disempowered by social processes, and disabled people clearly constitute such a group. It is little wonder that Paul Hunt (1981, cited in Sullivan, 2009, p.72) refers to disability researchers as ‘parasite people’.

Mike Oliver tells a story illustrating how out of touch ‘traditional’ disability researchers can become with disabled people:

> I remember entering the conference room on the first morning [of a conference of academic researchers] with the other researchers, none of whom were disabled, and finding the words ‘what do you think you are doing talking about us in this way?’ written on the board. No-one except me thought it referred to us; (Oliver, 1999, p.15)

Disabled people have been unsurprisingly frustrated and angry about disability research which has excluded them and changed very little about the social processes which caused them to be disabled in the first place, thus taking its place among the many disempowering experiences disabled people are faced with.

One response to the ‘problem’ of disability research has been to reclaim the research process by changing the social relations of research production. Mike Oliver (1992) has formulated a theory of disability research based on an emancipatory paradigm. Broadly speaking, emancipatory research seeks to look at a research process in terms of examining the wider social context and attempting to transform the systems and processes that create that system (O’Leary, 2010). For disability research, this would mean not solely researching a disability-related issue, but also inherently critiquing the disabling society as part of the research process. Barnes (1996) expands on this theory by suggesting that disability research cannot be considered to be positivist, scientific or objective – researchers should aim not to be neutral, but to be engaged, to cultivate ‘solidarity not independence’ (Barnes, 1996, p. 110).

Oliver (1992) argues that in order to be emancipatory, disability research must have certain characteristics. The research must be owned by disabled people - commissioned by disabled people, directed by disabled people and

most importantly exist for the benefit of disabled people and contribute towards changing and dismantling the disabling society. Sullivan explains this as a focus on “exposing oppressive, disabling structures and changing them to extend the control that disabled people had over their own lives” (Sullivan, 2009, p.73). Rather than changing the way researchers conduct their research, Oliver proposed that the very nature of the process must be transformed: “researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever way they choose” (Oliver, 1992, p.111). The onus is not on researchers to empower their subjects, but disabled people *once they are themselves empowered*, may choose to engage with research processes to challenge the conditions and structures that disable them.

This study falls somewhat short of being emancipatory when assessed alongside Oliver’s criteria as described above. However it may be considered to be emancipatory in that the social model forms the epistemological basis for the project. The project therefore takes the view that it can be “guided by the spirit of the emancipatory paradigm rather than being straitjacketed by its law” (Sullivan, 2009, p.77). Shakespeare (1996) expands on this view of emancipatory research, suggesting that research cannot be based on an entirely equal relationship between the researcher and the research participants. This is partly because social research informs sociological discourse, which by definition involves complex theory and language that it is not commonplace – there is a role for the researcher as a skilled and reflexive, if not ‘expert’, practitioner. Shakespeare believes this balance can be achieved without abusing disabled people or wasting the time of those who agree to participate in research and his argument is convincing.

‘Whose side are you on?’ The researcher in the research

My personal interest in disability rights is not because I sit on one side of a disabled/non-disabled divide or another. It is instead because I believe the

real divide is between those who believe in taking apart the disabling society and those who resist change or simply don't care. I also believe that the processes that create a disabling society are everyone's business. Just as it is a moral imperative for each person to uphold human rights because the human rights of others are also our own, so it is with disability-related issues: we all have a body and a mind, and these things are fragile and in a constant state of flux. Some people are born with an impairment and find themselves on one side of the fence from birth. The rest of us will likely acquire impairments over time and at different rates, but there is such an inevitability to the fallibility of our bodies and minds that living in a non-disabling world can truly be said to be in everyone's best interests. This way of explaining my own interest in disability is neatly summed up in a quip someone once made in my presence: "Disability, coming soon to a body near you".

Insider epistemology describes an approach to research which takes the view that only those who identify as members of a particular group are entitled to carry out research on the issues that affect that group. It suggests that the 'outsider' as researcher can only have an agenda which is self-serving and ultimately damaging to those who become part of the research. Some writers, however, have criticised this idea as being reductionist and not allowing for the possibility that solidarity and ideological agreement can come from 'outside' (Fay, 1996). It is my belief that it is entirely possible that non-disabled researchers can conduct studies that are based on solid social model principles, so that rather than speaking for others, they join their voices to those of the participants. This argument is perhaps best summarised by Mike Oliver: in answer to the question 'whose side are you on?', the answer must be "we are all on each other's side" (Oliver, 1992, p.113) .

I believe that this joining of voices is key to the future of our understanding of disability and to the dismantling of so many of the barriers that disabled people still face. One writer makes an interesting point about the notion that

only disabled people may undertake to write or research about issues to do with disabled people, saying that this is as useful as saying only black South Africans should speak about apartheid (Duckett, 1998). In fact, when something is wrong in a society, when people are discriminated against or oppressed, it is up to *everyone* to take an interest in investigating how those processes work and how they can be changed.

This study looks at a moment of great significance for disabled people both in New Zealand and around the world. Rather than undertaking an analysis of the process to make a judgement about its value, I have been led to allow the participants to tell the story of what happened and hope that some conclusions will emerge. Above all, I believe it was important to record the recollections of the participants because of the time and energy they invested into the negotiations and because their efforts led to an outcome – the production of legally enforceable human rights for disabled people – of tremendous importance for disabled New Zealanders.

Key informant interviews as a research method

I chose to use semi-structured interviews as my main data collection method. Interviews were the data collection method that immediately sprang to mind when I thought about conducting the research, possibly because one-to-one is the situation where I feel most comfortable. I also have some experience of collecting oral histories, which I found to be a fascinating process, and this no doubt influenced my choice of method.

Another reason for choosing this method was because I wanted to conduct the research in person as much as possible. This is in keeping with an important principle of consultation in Māori culture which I believe has come to be absorbed and valued by New Zealanders, *kanohi ki te kanohi* or face-to-face. My own understanding of this principle is that when people are

seeking to engage in open, productive discussions, they must meet one another in person to be able to form a connection. I also believed interviews would be the best way to construct a narrative that could be built on gradually. I had no fixed ideas about what I would discover during the research and only a few questions to guide me. My aim was to remain open to whatever course the conversations would take.

Though the premise of sitting down and having a conversation may seem fairly straightforward, interviews are not an uncomplicated data collection method. Structured interviews are suitable when data are to be collected with narrow responses, for example for phone surveys about how much television people watch or how many cars an average household has in a particular city or area. The disadvantage with this type of interview is that little allowance is made for individual responses to questions, and the interviewer is not permitted to express anything of themselves or their agenda – they essentially read off a script and provide minimal feedback to the interviewee. This can lead to accusations of pretensions towards neutrality and objectivity in the research, an element which has influenced much of the tension between qualitative and quantitative social research (Pawson, 1999).

In contrast, unstructured interviews can be seen to provide little guarantee that relevant data will be collected at all. The use of unstructured interviews is largely more suited to classic ethnographical research, where the objective is to establish a relationship between the participant and the researcher over many meetings. The maxim that there is ‘no such thing as a wasted conversation’ may not hold when researchers have to somehow shape and interpret the outcomes of their interviews in keeping with timeframes, research questions or even funding deadlines.

I decided to use semi-structured interviews as I believed these would give me the best chance to find a compromise between the formality of a

structured interview with set questions and an unstructured interview with no set questions. I intended to do one or possibly two face-to-face interviews depending on how the initial meeting went. My intention was also to build on the accounts I gained from participant to participant, so although I would start with similar questions in mind for each person, I would explore issues during interviews that had been previously raised by other participants to get a different perspective or to judge whether something that had struck one person as having been significant was seen in the same way by others.

There were other factors to take into account during the interviews, for example the effect of the presence of the tape recorder, or that most of the interviews took place at my first meeting with the participants. By and large, I believe the interviews were pleasant experiences for the participants. While significant, the events that were reflected on were not traumatic or upsetting. All the participants expressed similar views that they believed the negotiations for the CRPD had been important, that they had been glad to be a part of them and were equally glad to reflect on the process several years on.

Selecting the participants

My approach to identifying participants was largely based on recommendations made by my supervisor and personal friends. I hoped to use a ‘snowball sample’ method, starting with one or two key people who could identify more participants during the course of their interviews once they discovered what it was I was interested in learning about. I also used records from the United Nations website to look at the members of the New Zealand delegation. There were several names I recognised from connections I had made through work and these were the people I contacted first.

In my initial contact with each participant I let them know who I had already spoken to or approached and asked if they could make any further recommendations once I had told them about the scope of my project. All the participants were very helpful in this regard and most proposed the same names which led me to believe I had identified the right people. I made approaches to seven participants, five of whom were willing to be interviewed for the project. One declined due to work commitments and one had already written an article describing his part in the negotiations which we agreed I could quote from rather than doing a recorded interview.

Limitations

In looking at the parameters of this study, it may be argued that a small sample of five participants may not provide enough data through key informant interviews to be reliable. Even with a small sample size, it was hoped the study could produce some valuable insights into the process of negotiating the CRPD. The intention of the research was not to build a 'true' or 'accurate' account of the contribution of disabled people to the negotiations process, but rather to balance individual and collective accounts against one another to identify major themes – as well as major discrepancies should these emerge. Having said this, my participants were to be drawn from a very small number of people, and I believe I managed to speak to most of the disabled people who had attended the CRPD negotiations, with one or two exceptions.

In this study I only interviewed participants who actually participated in the negotiations, and not those who contributed to producing reports or proposals to the Ad Hoc Committee. It was expected that most of the participants would be disabled people, however if non-disabled people were part of the New Zealand delegation, they may have been recommended by others as potential participants. As the study has attempted to build an account of the contribution of civil society organisations and DPOs to the

negotiation process, anyone who participated in that process would have been able to participate in the study, so I did not exclude participants from the study on the basis of disability *per se*. In the end, all the participants were people who identify as disabled.

My original intention had been to conduct a parallel textual analysis of the documents recording the proceedings of the Ad Hoc Committees. This approach was abandoned early on due to the reasons I have outlined above. It must be noted that had I proceeded with this approach, the research findings I have gathered by means of my interviews may have been balanced and altered by the use of an alternative source.

Ethical issues

The research involved the use of interviews and therefore needed to comply with the Massey University Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants (Massey University, 2010) and be approved by the Massey University Human Ethics Committee. The major ethical principles are:

a) respect for persons;

b) minimisation of harm to participants, researchers, institutions and groups;

c) informed and voluntary consent;

d) respect for privacy and confidentiality;

e) the avoidance of unnecessary deception;

f) avoidance of conflict of interest;

g) social and cultural sensitivity to the age, gender, culture, religion, social class of the participants;

h) justice.

In light of the principles of the Code of Conduct, the remainder of this section will outline the provisions that were adhered to for the purposes of this study.

In accordance with the principles of the Treaty of Waitangi, the process of gathering information for this study was underpinned by a kaupapa of partnership, protection and participation. Each of these principles informed the following points, as the study sought to inform, consult and safeguard the interests of the participants.

Participants were informed of the nature of the study, its background and intention from the outset. It was essential that participants felt confident they understood the purpose of the research and its focus from the beginning so their consent to participation could be informed. Participants were also informed of their right to discontinue their involvement with the study at any time, and any information they may have shared that could identify them would then not be used in the research if they so chose. Written consent was obtained via a signature on two copies of a consent form at the start of the first interview, one copy was kept by me and the other by the participant.

Recordings of the interviews were only listened to by myself during transcription and were stored securely at my home. Two of the interviews were taped on a cassette recorder, two were recorded onto an iPod and the file transferred to my laptop and one was only recorded as a Word document also stored on my laptop. Interviews were transcribed and transcripts of each interview were sent to the participants involved for comment and editing. Only the final approved draft of each interview was used in writing up the data. Participants were therefore protected from misrepresentation or having their stories told in a way they were not comfortable with. Participants were assured of confidentiality as far as is legally possible, i.e. except where keeping information confidential was likely to result in harm to the participants or others. I explained to the participants that information would

be stored securely and that their interviews would be transcribed by myself. Participants were given the opportunity to be identified by name in the published research if they chose.

New Zealand has three official languages – English, te reo Māori, and New Zealand Sign Language (NZSL). Participants were advised they were free to conduct any or all of their participation in the study through the language of their choosing. All the participants chose to conduct their interviews in English, though one participant requested a written interview process as a face-to-face to interview could have posed problems to me as an interviewer because of potential difficulties in understanding his speech. None of the participants was personally known to me before the research started, though I had briefly met two of the participants in a professional capacity a couple of years previously.

All the participants interviewed identify as disabled people, which posed an interesting question in working through the Massey University Ethics approval process. The Screening Questionnaire contained a question about the vulnerability of the participants and included a question on whether the participants were disabled people. Answering yes to this question would have meant I could not have used a Low Risk Notification. Together with my supervisor, I decided not to answer 'Yes' to this question because although all the participants were disabled people, I believed this did not make them vulnerable research participants. My belief was that this question was (rightly) aimed at screening research on vulnerable people who may not be able give informed consent or who are in a dependent situation as outlined by the Screening Questionnaire. None of my participants were in such a position, nor were they being approached because they were consumers of health or disability services. All the participants were well-known and active in the New Zealand disability community. Their involvement in the research had come about because of their skills and experience in the area of disability rights and self-advocacy.

Conducting the interviews

Each participant was initially contacted via email with a formal invitation to participate in the research attached, as well as an Information Sheet on the project. In some instances I followed up my initial email with a phone call. All the participants were positive about helping me with my research, and a couple commented on the fact that they would welcome the opportunity to reflect on the negotiations before much more time had passed and memories began to fade. I made appointments with each participant according to their schedules and met with four of the five participants in Wellington at a variety of locations depending on what suited them, either at work or at home. Two of the interviews were conducted at the DPA National Office in central Wellington. My interview with Gary Williams was conducted via email. We agreed this would be best because writing is a more effective method of communication for Gary, especially given that I am not familiar with his speech patterns and might have had difficulty transcribing a recorded interview.

The interviews took place over an 18 month period as I had to interrupt work on the project for an extended period in 2011/2012 and again in 2012/2013 for the births of my two children. My last meeting for the project took place towards the end of 2014. This meeting was with Don MacKay, who agreed to help me with my research. Instead of a recorded interview, Don supplied me with an unpublished article he had previously written on the CRPD and his role in the process. We met to discuss some of the more complex points he had referred to in his article which I was able to use as a reference. Don's input was crucial in making sense of some of the questions about UN process that arose during the participants' interviews.

Each face-to-face interview lasted between 60 and 90 minutes. I sent each participant a list of sample interview questions via email before their interviews to help them prepare (see Appendix C). In each of the formal interviews, I began by going through the Information Sheet (Appendix A) and a consent form (Appendix B), so that each participant had a clear understanding of what the purpose of the research was and how their contribution was to be used. The consent form contained a consent to participate in the study under the conditions set out in the Information Sheet, as well as specific consents to the interviews being audio recorded and to being named when material from the interview was being quoted in the text.

The consent form also asked participants whether they wanted the recording of their interview returned to them. All the participants received a written copy of their recorded interview once it was completed, and only one chose to receive an audio copy of the interview, with another participant expressing a wish that the interview be held in an archive. They also had the choice of remaining anonymous, which none chose.

Having covered the preliminaries, we began each interview by reviewing the research topic and talking about what it was I hoped to discover during the course of the interview. I explained I would begin by asking some of the questions I had provided in my email and the rest would be dictated by our conversation. I also asked the participants to let me know if they wished to take a break or stop the recording at any time during the interview. I reassured them that the transcripts of their interviews would be given to them to review and that no material would be used in writing up my research project without their consent. Overall the mood of the interviews was relaxed and informal. I had a sense the participants were reflecting on a time when they had participated in a process that was invigorating and exciting, both on a personal and a professional level. This was no doubt influenced by the outcome of the negotiations and the creation of the CRPD, which all the participants said they were pleased with and proud to have been part of.

Once the interviews were completed, I personally transcribed all the material and returned the transcript to the participants for review. Because of the breaks in my study, this process took several months in each case, with the exception of Gary Williams, whose written reflections were sent back and forth between us reasonably quickly before we had a transcript Gary was happy with. I explained to each of the other participants when we met that as I was about to have a baby there could be some delay in getting their transcripts to them, so they were all prepared for this.

Significance

This paper has already outlined the amount of research that already exists on disability as a socially constructed phenomenon and more recently as a human rights issue. Similarly, much discussion has taken place on the issue of consultation and partnership with disabled people – 'nothing about us, without us'. As the process of negotiating the CRPD involved both extensive consultation with and input from disabled people, the significance of the research project lies in examining what happens when disabled people are involved at the highest possible levels in negotiating a human rights instrument that affects their lives. The resulting Convention has enshrined several human rights principles that apply specifically to disabled people which are not expressed in other internationally enforceable human rights instruments (Stein, 2007b). This study will therefore be of use when considering:

- The impact of the disability rights movement on an international move towards disability human rights.
- The contribution and impact of the New Zealand CSO and DPO delegates as part of the process of negotiating the CRPD. In particular, examining this contribution can help inform future directions for implementing and monitoring the Convention at a national level.

- Stakeholder engagement in drafting policy and law. How does involving stakeholders, not just in preliminary discussions but in actual negotiations and discussions, impact on the policy or legislation produced?
- The experience of negotiating the Convention itself and its significance for those who took part. The study will give those delegates who participate an opportunity to tell their story of involvement in drafting a document that has potential to positively impact the lives of more than 650 million people globally.

As a chapter in the history of the disability rights movement, these stories are worth recording in their own right. I believe strongly that they form part of the broader social history of disabled people in New Zealand.

Conclusion

In undertaking this research project, I had hoped to do a large amount of textual analysis backed up by a small number of interviews. The change in the design of the project was largely up to my acknowledgement the UN had got the better of me when it came to obscure language and processes. I believed the strength of the material the participants were able to share with me would provide enough material to produce a piece of research that was both interesting and relevant. Disabled people's history with social research has often been overshadowed by the same oppressive and paternalistic themes experienced in other areas of life. In a rejection of this theme, some theorists have demanded that research on issues to do with disability should only be undertaken by disabled researchers. I have argued that non-disabled researchers may be involved in producing 'good' research, provided they are clear that they are speaking with and not for others.

My aim in this project was to try to draw together stories from a small group of disabled New Zealanders who had participated in a process that was significant both at home and abroad for disabled people. The research was built on the social model of disability in that it differentiated between the personal experience of impairment and the societal imposition of disability onto the person. I wanted the participants to retain the power in telling their stories, I was clear the knowledge belonged to them and would only be shared with their consent and cooperation. In doing so, I attempted to avoid repeating the mistakes of past researchers who have been accused by disabled people of producing research that is neither *for* nor *by* those it concerns.

Chapter 4: Data

Introduction

This chapter will present some of the data collected during the interviews for this project and the major themes that emerged. In analysing the data, it became apparent there were subjects which came up consistently for each of the participants. The first was the participants' own background and how they came to be members of the New Zealand delegation, in response to a question asked of each participant. Next came an exploration of how the political climate of the time had influenced New Zealand's involvement in and support for the negotiations process of the CRPD. Another theme was the negotiations process itself from a practical point of view – how things worked at the UN, accessibility issues and procedural issues that the participants remembered as being significant. Most of the participants also spoke about notable issues that came up during the Ad Hoc Committee meetings, particularly on articles that had been important to them personally or those that had contained concepts seen as contentious by some States Parties. Other themes included the participants' assessment of the process from the point of view of 'nothing about us, without us', and a retrospective assessment of the significant of the CRPD and its potential future value for disabled New Zealanders.

This project looked at the reflections of representatives of DPOs who were present at the negotiations for the CRPD. The reflections were recorded and categorised based on the responses of the participants to the questions posed during the interviews described in Chapter 3. Transcripts were returned to each participant after their interview was completed and the final text and quotes used in this chapter were those reviewed by the participants and approved.

As a further introduction to this chapter, it is perhaps fitting to set the scene for the collection of the data and the time the participants were reflecting on. The interviews were conducted in New Zealand some six-10 years after the Ad Hoc Committee meetings. Most of the participants had not reflected formally on their participation in the negotiations prior to taking part in this project, although Gary Williams had spoken to Lana Moriarity (Moriarity & Dew, 2010) as part of a research project she was conducting on the subject of the CRPD and the participation of disabled people in the negotiations process. The meetings themselves deserve description as they were held in New York City, half a world away from home for the participants. The Committee meetings also took place at the UN headquarters, a place of global significance for anyone with an interest in human rights and social justice. Robyn Hunt called her blog entry for the final meeting of the Ad Hoc Committee *Hot August Night* (Robyn Hunt, 2006), and a sense of the oppressive heat of New York in late summer and the urgency surrounding the final hours of the last meeting where the text of the CRPD had to be agreed on came through in the interviews.

Delegates' personal background

All the delegates I spoke with had long histories of involvement with the disability rights movement in New Zealand. Their participation in the CRPD negotiations came about in different ways however. Wendi Wicks, Mike Gourley and Gary Williams all held roles in Disabled Persons Assembly (DPA) that led to them being able to attend the negotiations in New York. Gary Williams was CEO of DPA at the time, and in this capacity he attended six sessions of the Ad Hoc Committee meetings. Gary pointed out that he did not only attend in his capacity as CEO of DPA, but also as National Secretary for both Rehabilitation International and Disabled People International. Gary also mentioned that on a practical level, his invitation from the Office of Disability Issues (ODI) to be part of the New Zealand delegation also included funding for a support person, without whom international travel would have been impossible.

Wendi Wicks and Mike Gourley were also DPA members, with Mike being National President at the time and attending three meetings between 2004 and 2006. Wendi attended the Third Ad Hoc Committee meeting only.

The background to Robyn Hunt's involvement in the negotiations was also slightly different, in that Robyn attended both as a representative of the New Zealand Human Rights Commission and as a member of the New Zealand delegation. At the time, Robyn was working as a Human Rights Commissioner, with 'unofficial' responsibility for disability rights (a Disability Rights Commissioner proper was not appointed by the Human Rights Commission until 2011). Being able to attend in a dual capacity meant that Robyn was able to have influence across a number of settings, primarily being able to provide human rights advice to the New Zealand delegation but also participating in an Asia-Pacific forum of National Human Rights Institutions. She recalls the unique advantages this gave her:

> The other thing that happened alongside starting to go to the meetings was that we set up a working group in the Asia-Pacific Forum of National Human Rights Institutions which did some work and produced some papers as guidance and we managed to influence some of the outcomes of some of the regional meetings that were held to send recommendations to the negotiations. So we were quite influential in our way, in fact at one point I found some of the European Commissions meeting, and I said 'Oh, are you guys meeting… Oh, that's our paper you've got there, oh good, can I come and join you?' in my typical antipodean way! And I discovered that they were nicking our paper and not crediting us so I made sure that we got a credit for the work! Because we'd done all that work, you know…

Of all the participants, Robert Martin shared the most about his background as a disability rights activist, and especially his work on behalf of people with learning disability in New Zealand. A large part of Robert's childhood was

spent at the Kimberley Centre, a large-scale institution for children and adults with intellectual disability which at one time housed 900 people. Robert's description of his childhood was very interesting because in tracing his own history with the DRM, I felt there were similarities between his personal account and the experience of gradual conscientisation that must have been common to many disabled New Zealanders in the latter part of the 20th century. Robert spoke of the cultural and social isolation he experienced as a child, and into adulthood where he started out working in sheltered workshops. He described his early realisation that disabled people were getting a raw deal in the first sheltered workshop he worked in in Whanganui:

> One of the guys wasn't getting a fair go and he said 'What can we do?', and I says 'We can go on strike', and he says 'What's that?' and I says 'It's when you turn up for work and you don't do any work', so we turned up for work the next day and people were given their shovels and picks and everything else, I says 'Oh, there's no work today boys, we're on strike!', they said 'What?!' and I says 'Yeah!' and we were told by the farm manager to go to work and we said no, we've got issues that we want sorted out. So even from then I was told I was a ringleader…

Robert became involved with People First, initially as Chair of the local group in Whanganui, and he soon became involved with the Special Olympics and Inclusion International. In this capacity he went to every one of the Ad Hoc Committee meetings, not as part of the New Zealand delegation but as a representative of Inclusion International. Although Robert was not a New Zealand delegate, he is viewed as an important leader in the disability community and I approached him for an interview in view of his contribution to the negotiations in terms of representing the views of people with intellectual disabilities. Robert Martin was also significantly the first person with a learning disability to ever address the UN General Assembly.

Although his contribution will be explored in more detail later, it is interesting to note that prior to his involvement in the CRPD negotiations, Don MacKay

had no personal or professional experience of the issues surrounding disability rights. In common with the other diplomatic staff in New York, his learning took place during the process itself. The speed and dexterity with which this took place is striking, but perhaps may be attributed to the extremely varied nature of the issues dealt with at the UN – from fisheries to armed conflict to epidemics, diplomatic staff by necessity must be flexible and learn the complexities of issues of international significance very quickly.

New Zealand political climate & NZDS

All the respondents but one spoke of the political climate in New Zealand in the early 2000s and the effect that had had on the New Zealand government's attitude towards the question of developing a Convention. In Chapter One, the political background of developments around 1999 and 2000 was discussed. After a long time in opposition, Labour had come to power and were keen to do some work on developing their policy in relation to disabled people. This work started with the writing of the New Zealand Disability Strategy, which set a precedent for a model of partnership and consultation when it came to developing policy and legislation about disability issues. Robyn Hunt says:

> I think it was partly because the Labour government had been quite sort of committed on disability issues. It had set up the Strategy, which was pretty ground-breaking, not so much the Strategy itself but actually *doing* [my italics] the Strategy… was quite ground-breaking, and the process that it used to develop the Strategy was a very consultative process and so it had built up high expectations amongst disabled people that they would be involved and so disabled people simply said, you know, 'You've got to take us with you, nothing about us without us'.

The writing of the Strategy had also given DPA an expectation that as a major DPO, they would be involved in any discussions about whether or not New Zealand was going to support the development of a UN Convention.

Mike Gourley credits the then-Minister for Disability Issues, Ruth Dyson, for her commitment to making sure New Zealand supported the Convention. He observes:

> we had a Minister who had come to power with a manifesto that included having a disability strategy. So really, what we were talking about here [the possibility of a Disabilities Convention] was a disability strategy writ large, for the whole world. So I think there was a real commitment from her to anything that would advance the rights of disabled people, both in New Zealand and internationally.

New Zealand's support for a Convention initially had a rocky start and New Zealand did not attend the first Ad Hoc Committee meeting in 2002. The New Zealand position on the Convention at that stage was based on advice from the Ministry of Foreign Affairs and Trade (MFAT) that was, to quote Mike Gourley's view, "lukewarm" on the subject. It was the Minister for Disability Issues who eventually injected some urgency into New Zealand's involvement, which Gary Williams attributes to her regular meetings with DPA during that time:

> DPA was having 6-weekly meetings with Ruth Dyson, Disability Issues Minister. A perpetual item on the agenda was the implementation of the NZDS. I would talk about the Minister herself having an enduring legacy if the New Zealand government took a leading role to get the need for a Convention agreed to, negotiated and adopted. She was convinced!

Once the decision to support a Convention was made by the Minister and ODI, the issue was referred to MFAT and Ruth Dyson quickly realised that the advice on a Disabilities Convention was not coming from the Human Rights desk. Mike Gourley explains:

> The Human Rights desk was peopled with officials who had a better sense of what was needed than say, the Asian desk or the Fruit desk or whatever. Yes, so that made a big difference to the stance of MFAT at that

time apparently. So as I say, Ruth Dyson was the person who clicked that at the time we were going to the wrong part of MFAT, so in any case what happened was that the New Zealand government finally came out in complete support of a Convention, and argued that position at one of the sessions of the UN to debate the question.

UN Process

Once at the UN, the participants described the start of the CRPD negotiations as being quite shaky. Diplomatic issues aside, once more and more countries began to include disabled people in their delegations, some practical matters came to the fore. Wendi Wicks describes the UN as being a "dog's dinner" in terms of the process of running the early Ad Hoc Committee Meetings, with participation being extremely rigid in terms of who was allowed to speak and when. She felt the positioning of the DPO representatives to one side of the meeting room was also symbolic of an early reluctance to genuinely engage with the disabled people present.

In practical terms, the UN struggled to make their information accessible, with the documents crucial for delegates being able to participate in meetings being produced in Times New Roman size 10 font and in print only, so that blind or visually impaired delegates were unable to access them. Robert Martin described the UN building as a bit of a "rabbit warren", where many people found it difficult to get around. He also bemoaned the lack of text in Plain English, which he said made it difficult for delegates with a learning disability to access the documents being produced.

Don MacKay (2009) pointed out that the UN's lack of experience in accommodating disabled people had an unexpected and happy consequence for the Working Party. Normally, NGOs and government delegations sit separately at official UN meetings. However, there were not

enough spaces for wheelchair users available at the back of the meeting room the Working Group was using. It was therefore decided that the NGO representatives would sit among the government representatives. This had the effect of intermingling both groups so that discussions were able to take place in a more natural way. Because people had easier access to one another, conversations were held with governments and NGOs on an equal basis. The result was that the Working Group was able to achieve an enormous amount in a short period of time, and the views of disabled people were taken into account in a way that might not have been the case if they had been stuck in a separate section at the back of the room.

When it came to communicating with Deaf delegates, other problems emerged with the scale of the work involved, as Sign Language Interpreters would have to interpret first into Universal Sign Language and again into each of the national sign languages for Deaf people present. Gary Williams explains another side to the issue of interpreting:

> And then there was the issue of interpreting between the various official languages of the UN. I realised this issue early on when a disability-specific phrase like “reasonable accommodation” was often called “adequate housing”.

Language in fact emerged as a sensitive issue for many of the delegates. Not only did non-disabled delegates need to learn appropriate terms for speaking about disability, but these varied from country to country. Robert Martin recalled having to explain to people what language was considered acceptable when describing mental illness or learning disability, noting that in the US the term ‘mentally retarded’ was still being used although this term was considered outdated and pejorative in other English-speaking countries.

In terms of learning about the issues under discussion, there was much more for diplomats to become familiar with than using the correct language. Mike Gourley and Gary Williams both spoke of a process of mutual learning,

whereby the New Zealand diplomatic staff helped to guide disabled delegates through the nuances of the workings of the UN. In return, as DPO representatives, the disabled delegates gave advice and guidance on disability-related issues. Mike says this meant relations were a little strained in the beginning as the disabled delegates tended to ask, “Non-disabled people, what are they going to know?”, when equally the diplomatic staff were asking, “Non-UN people, what are they going to know?”. Mike illustrated this point rather well in terms of a language-related issue, as words began to take on a life of their own in the diplomatic world:

> Well, this is where my inexperience nearly undermined one of the more delicate articles… I at one point intervened in one of our side discussions about defining what you meant by sex, and of course it was either boy or girl, male or female, because there is no gender neutral word in many languages for [a person who identifies as neither male nor female]. I said I knew people who were intersex, and we wanted to include references to people who were intersex, and I was almost pulled out from that, because Andrew Begg [a member of the New Zealand diplomatic mission] was there and he thought “Oh, shit…” because of course that would have opened up the whole question of sexuality and homosexuality and that would have been a debate that would simply derail the whole process and we wouldn’t have got through that one at all. So there’s an example of how my inexperience meant speaking of what I thought was a principle but it was just not appropriate to do so. That’s the fascinating reality of negotiating with delegations from countries that are so different from ours.

The issue of reproductive rights was one of the most contentious articles according to several people, not least because rather than meaning the right of disabled people to decide whether they wanted to have children or not, the term ‘reproductive rights’ was understood in the context of the UN to be a euphemism for access to abortion. This led to some confusion and some unusual and perhaps unintended alliances, as Wendi Wicks explains:

> I remember the Australian delegation at that time it was Heidi Forrest who was the President of People with Disability Australia who raised it [right to life of disabled people], the trouble was, you kind of got into some camps you didn't want to be in, and thereafter she kept having to duck into the loo after she had made a statement about this, saying you know, 'We believe that disabled kids have the same right to life as any other child does', thereafter the representative from the Holy See was very interested in making contact with her and used to sort of chase around after her, yes, we thought it was very funny too and we teased her endlessly about it!

Global politics also threatened to derail the negotiations on numerous occasions, as countries voted for amendments to the draft text along the lines of political allegiance. Another difficulty was the continuing instability in the Middle East which raised its head at several Committee meetings. Gary Williams said of Session Four:

> Just before this meeting [August 2004] Israel invaded Palestine and so the convention process became a sideshow for the Arab world to chastise the Israelis, who themselves counter punched with the USA. Much time was lost by these kinds of things.

The final Committee meeting in August 2006, Session Eight, was threatened by similar issues, as Mike Gourley recalled the Israelis were embroiled in conflict with Hezbollah in Lebanon at the time. Fortunately a ceasefire was declared before the Session commenced, narrowly avoiding agreement on a final text being hijacked by tactical voting between both sides' supporters.

In terms of process, perhaps one of the more unexpected themes to emerge centred on the work of the Committee Chair. Sessions One to Five of the Committee had been chaired by Luis Gallegos of Ecuador. Although judged a competent and effective Chair, Gallegos' work was overshadowed by the momentum and energy his successor New Zealander Don MacKay brought to the Working Group and Sessions Six to Eight. All those I spoke to were

unanimous in their praise of Don MacKay's work as Chair. He was credited by Mike, Robyn and Wendi for the short timeframe of the negotiations because he had an unusual approach to facilitating the Committee meetings. Rather than following a set agenda which used a hierarchical approach, he chaired the meetings in such a way as to promote open discussion. Gary Williams credits him with managing countries "so that they didn't negotiate behind closed doors".

It may be that the participants felt an extra measure of regard for Don MacKay as he was a New Zealander. It can at least be said that they could relate to his apparently easy-going style of facilitating discussions. Robyn Hunt described Don's contribution as interesting in that he presented as a typical laid-back Kiwi:

> just quietly… keeping it going, but what he was actually doing was driving it really quite hard, but because of his laidback manner, and because he was such a consummately good chair… he managed to keep everybody onside… and keep the process moving while making sure we got what we wanted.

Robyn also mentioned some very practical concerns Don held for DPO representatives, in that travelling to New York was hugely expensive. The limited budgets DPOs were working with meant that the process needed to be as short as possible for the sake of safeguarding continued representation from disabled people. Several of the participants quoted Don MacKay as saying 'the perfect is the enemy of the good' when people were wasting time arguing over things. In fact, he at one stage asked that no-one propose an idea during the next Committee meeting unless there was chance it could be adopted. This is reflected several times in the Daily Summaries for the Sessions chaired by Don, for example his insistence that "Because this is an ongoing process, nothing is decided until everything is decided. Flexibility is key and no one is "locked in" to a position." (United Nations, 2005).

The Chair's efforts to reach consensus and push the negotiations towards a resolution were successful, with rapid progress being made in the final three Sessions. In the end, more mundane questions of timekeeping and administration took the process down to the wire as the final hours of Session Eight dwindled away and no agreement on a draft text was reached.

Mike Gourley noted that at all UN meetings, the rule is that interpreters must be present to facilitate dialogue between delegation. On the evening of the 25th of August 2006, Don MacKay had negotiated for the interpreters to remain working past their normal 6pm finish time. In order to prevent delegations wasting time, he did not share this information with the delegates, so that at 5.50pm all present thought they had only 10 minutes left to agree on a text. To compound this, everyone was very aware that another Committee meeting would mean a new Chair, and as diplomatic staff were on rotation, a fresh set of people to introduce to the issues at hand. For those I spoke to, this final meeting was an extremely tense time. Mike says of those final hours:

> In fact Gary [Williams] laughs because I couldn't take the tension, I had to go out and lie down for a while in my hotel room. I told Gary that and he always laughs at me, and reminds me of it, 'you couldn't take it' he says, and he's quite right! And I came back just in time to see everyone vote yes, and we were all weeping and cheering and laughing, it was wonderful.

Notable articles

Most of the participants spoke during their interviews about articles of the CRPD that had particularly interested them or that they remembered as being especially contentious in terms of disabled people's involvement. Robyn Hunt mentioned the difficulty over agreeing on a definition of disability. In some respects, a definition is quite fundamental to the

Convention, yet none was ever included because not all delegations could agree on what the word disability means. Instead, one was included in the Purpose of the Convention:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (United Nations, 2007a, p.4)

The reason for this was because States Parties can submit reservations indicating they do not consent to particular provisions in a human rights Convention. This translates into States Parties not being able to be legally held accountable for observing that particular part of the convention. Reservations cannot be held on the Purpose of a Convention however, so this represented the easiest way to have a definition included without naming it as such. It was also hoped that by avoiding a definition, the naming of specific impairments the CRPD covers could also be avoided.

Robyn Hunt remembers forced treatment and legal capacity as being an issue that provoked enormous debates, both between delegations and within them, as people grappled with questions of how to write protections into the text while at the same time some delegations argued quite forcefully that exceptional circumstances can arise where consent cannot be given. Ultimately the latter argument was rejected, with Article 17 stating unequivocally, “Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others” (United Nations, 2007a, p.13).

Disagreement arose when different groups attempted to advance views that, though significant to people with specific impairments, were mutually exclusive. One example of this was education, with representatives of blind and Deaf communities arguing strongly in favour of separate education which would work to preserve the cultural identity of people with sensory

impairments, giving children a chance to learn Sign Language or Braille. For people with intellectual disabilities, Robert Martin pointed out it was felt equally strongly that the text should include guarantees of access to mainstream education to prevent children being segregated. Ultimately, these questions were resolved in Article 24 which became one of the longer articles in the Convention. It states that as well as all disabled children having access to the general education system and being given adequate support to participate in it, all people, especially those who are blind, deaf or deafblind, must also have the ability to access their education through the "most appropriate languages and modes and means of communication" (United Nations, 2007, p.16) for the individual.

As mentioned earlier, questions of language aside, articles on disabled people's right to life and reproductive rights were also extremely contentious. This led to some unusual groups voting together according to their views on abortion, with the US and many Arab states trying to veto attempts to ensure disabled women would have the same rights to abortion as nondisabled women. Eventually this guarantee was included in Article 25, with section a) stipulating States Parties shall:

> Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the *area of sexual and reproductive health* [my italics] and population-based public health programmes; (United Nations, 2007a, p.16)

Robert Martin spoke about the right of disabled people to be born, with reference to the eugenic aspects of antenatal screening programmes. This question was dealt with in Article 10 which asserts disabled people enjoy the right to life on an equal basis with others.

Gary Williams mentioned Article 26 on habilitation and rehabilitation as having been particularly important to him. He felt this article should not be

included because it made it possible that in the future the lives of disabled people would continue to be “populated by therapists and other professionals”.

Nothing about us, without us

One of the central research questions about how ‘nothing about us, without us’ was reflected in the negotiations process was answered in several ways by the participants. The first was in relation to the politics of partnership that had been established with the Labour government of the early 2000s, which made it easier for disabled people to insist they should be involved in the negotiations at a high level. The consultations on the New Zealand Disability Strategy had seen disabled people take a very hard line on insisting that their voices were heard in a process that would directly affect the lives of disabled New Zealanders. Originally, the Chair of the Sector Reference Group for the consultation phase of the NZDS was a nondisabled person. After objections from the group, Robyn Hunt had been appointed as Co-Chair of the Sector Reference Group. This small victory was important in the view of Robyn Hunt as it saw disabled people gain a “huge amount of confidence” in terms of asserting how disabled people must be not only represented but given positions of power during consultation processes.

The writing of the NZDS was described as ‘milestone event’ by Wendi Wicks, and one which gave DPA a certain amount of entrée with the ODI and Minister Dyson in terms of working together again on the CRPD. Having already established that disabled people could genuinely engage with government in formulating a Disability Strategy, in some ways it became a logical next step that the same would be repeated in New York. ‘Nothing about us, without us’ was used as a reminder that disabled people should not and could not be left out of the CRPD negotiations if a constructive and significant document was to be produced.

As the Sessions went on, more and more disabled people began to attend as part of their national delegations. Mike Gourley attributed the rise in numbers of disabled people forming part of delegations in part to the success of the model of participation countries like New Zealand were presenting. He went on to say:

> I think it made a huge difference, because these sessions and the fact that you've got different member states participating means that there's all sorts of tensions and conflicts that are going to come to the surface. And people are going to play politics, but I think over time it became less and less possible for people to play politics because of the people there in the room who had all the lived experience, keeping it real.

Robyn Hunt also described the contribution of disabled delegates as enhancing debate and moving things forward. She pointed out that it was very difficult for delegations to pursue points that were contrary to the opinions of the disabled people who were present with them during Sessions and giving feedback based on their personal experience. Wendi Wicks picked up on the same point, observing:

> This was the first time that people about whom a Convention was written were actually there and sort of saying "Hey, hang on, why are you saying that? Hang on, we want this! Hang on, that's not good enough! Hang on, what about… Hang on, you haven't got it in large point… hang on…' And I think that the governments, a lot of African ones and quite a few Asian ones were really not used to this kind of thing, whereas our government had kind of been a little bit habituated to this kind of thing because we'd just been bolshy for a little bit longer!

Don MacKay was struck by the effect the presence of the disabled delegates had on the Working Group and the Ad Hoc Committee meetings:

> The Working Group was also noteworthy for an absence of the polemics and rancour that often characterise United Nations meetings, and this

> carried over into subsequent meetings of the Ad Hoc Committee. Again, I would attribute this to the active presence in the room of disability organisations and their representatives. When there are people present for whom the issues are obviously quite crucial, it is not easy for delegates to side-track the debate.

Wendi described a sort of circular journey for the disabled delegates, in describing how the model of the NZDS had worked so well that it was repeated on a grand scale for the CRPD. This raised expectations in terms of how, once the CRPD was in place, disabled people could continue to be involved in making policy and legislation that affected them. These expectations, however, were not realised back in New Zealand. She describes disabled people as being slightly taken aback when:

> …we came later on back here and were trying to get the Convention sort of ratified… they were going back to what used to happen, they weren't involving us and we were saying 'Hey, hang on just a second, we've got this model here, it really was 'Nothing about us without us', why are you going back to the same old, same old?

Gary Williams, who was present from the beginning of the negotiations, says that there was more to 'nothing about us, without us' than just having disabled people on the delegation. He points out that disabled people from developing countries form the overwhelming majority of disabled people in the world, and that he had some work to do to convince others that a disabled person from a country like New Zealand or Australia didn't have a more 'sophisticated' viewpoint to offer.

All the participants mentioned 'nothing about us, without us' without prompting as part of their recollections of their time at the UN. Robert Martin saw it as a process of educating diplomatic staff and other disabled people

that people with intellectual disabilities could also contribute to the negotiations in a meaningful way. He explains:

> To have people with a learning disability as part of it was just not thought possible. And people said that people [with a learning disability] had more of an input in this Convention than probably any other disability sector because they just didn't think we could be part of it.

Legacy of the CRPD

All the participants were asked about their feelings on the finished text of the CRPD and how they feel New Zealand has implemented it. Overall the participants expressed satisfaction with the text and felt it was as good a document as it could have been. Gary Williams commented on the importance of building a text that was future-proof, using sheltered workshops as an example:

> The Convention could have established rights for people who worked there. Implicitly, this would have legitimised the existence of sheltered workshops as an option for disabled people. The adage of "build it and they will come" springs to mind. My view is that if the Convention fulfilled its promise and was very strong on the right to work for disabled people then there wouldn't be a need for segregated settings. So in the future, generations of disabled people will not be saddled with out-dated thinking and practice.

In terms of how New Zealand has implemented the CRPD, there were mixed views among the participants. Just as the lead up to the negotiations was influenced by the Labour government of the day, it seems the National government since 2008 has been rather less convinced of the benefits of working in partnership with disabled people. Wendi Wicks expressed some disappointment with the progress made domestically since the ratification, based, as she saw it, on a lack of willingness to engage with disabled people. She pointed out that the same old problems remain of people not

really being interested in bringing about change to address issues they have no experience of themselves – “it’s not such an urgent priority for you if you don’t live it”. Robyn Hunt referred to a mix of politics and economics to explain the lack of momentum:

> I think with the election and the downturn, it’s been really hard yakka ever since. And some of it has stuck, as it always does, I mean you never go quite back as far as you were, but it’s a bit of two steps forward one step back, and I also think that in some of the work I’ve been doing just quite recently, that the way the policy is established it’s very difficult to achieve some of these rights because disabled peoples’ power, there’s no power, there’s a huge power imbalance, because of the way funding works, because of who controls the money, because of how policy and funding work, it’s very difficult for disabled people to have the real power. And often I think there’s endless advisory groups and reference groups but you know, I think that we’ve slipped back a bit, I do, since it was signed and ratified. But we’ve still got the document, and that’s the important thing.

Robyn Hunt and Mike Gourley both pointed out the work of the Convention Coalition which has risen directly from the CRPD’s monitoring provisions has contributed substantially to our knowledge of the state of disability rights in New Zealand. Both the CRPD itself and the reports prepared by the Coalition also help to hold the government to account and serve as a tool to “rap across their knuckles” as Mike says, reminding the government that New Zealand has a legally binding commitment to safeguard the rights of disabled people. Mike Gourley also points out the language of the CRPD as being crucial, in that it contains imperatives rather than suggestions or encouragements – States “must” “shall” and “will” protect and promote the rights of disabled people.

In spite of some misgivings over the progress made in terms of promoting disability rights since its adoption, the participants were unanimous in their assessment of the usefulness of the CRPD into the future. Mike Gourley spoke of the Convention as kind of Treaty of Waitangi for disabled people, “our Treaty”, as it represents a blueprint for the relationship between the State and disabled people, establishing rights and responsibilities. Mike pointed out that like any Treaty, it can be honoured or dishonoured but it cannot be erased. In that, it holds some psychological importance for disabled New Zealanders, perhaps best summarised by Robert Martin, when he says:

> Seeing what we’ve got now, and knowing that that’s going to be part of the world now forever, I think that’s the really important thing about this Convention. We’ve got it now, and it belongs to us.

Chapter 5: Discussion

Introduction

This study so far has looked at some of the theoretical background to current thinking about disability. It has also described some of the history of the DRM and disability rights at the UN. Taking the evidence presented in Chapter Four as a starting point, this chapter will combine the theoretical perspectives with the data from the interviews to answer the research questions presented in Chapter One. I will argue that the negotiations for the CRPD represent one of the finest examples of the quality of debate/output that can occur when policy and law-making includes disabled people's views – 'nothing about us, without us'. It has become clear to me that the excitement and relief the participants described at the completion of the negotiations was not just the natural end of an intense process. Something very important had been achieved, momentous questions for disabled people worldwide and issues that have real impact on people's lives – these were the things the Convention addressed. To have completed the negotiations in such a short time, and to have produced a text that squarely and irrefutably puts disabled people's rights on the legislative and policy agenda for states signatories was an enormous achievement.

This chapter will address the significance of the negotiations for the participants. It will also look in more detail at the negotiations in light of the goal for absolute participation and equity in decision-making as expressed by the DRM through 'nothing about us, without us'. By outlining several key questions for stakeholder participation in policy-making, I will argue that the CRPD negotiations and the role of disabled people in drafting the Convention holds some important lessons for shaping social policy in New Zealand.

Some questions of process

During the interviews, all the participants referred at least once to issues of access (physical access or access to information) at the UN. This is a common theme with disabled people in terms of public consultation and being able to participate. On a basic level, disabled people cannot participate at all in consultation exercises if they cannot physically be in the location where the consultation is taking place. Unfortunately, this is a real issue for many disabled people where public transport and buildings continue to be inaccessible. Even where access is possible, disabled people must also be able to attend a meetings on an equal basis with others, which means accessible spaces for wheelchair users to sit with their group - being consigned to the periphery is not sufficient. In New Zealand, the recent DPO report to the UN Committee on the Rights of Persons with Disabilities has criticised lack of access to public buildings. It pointed to weak consultation with DPOs during a review of the Building Code (Disabled Persons Assembly NZ Inc. et al., 2014).

Once disabled people are able to attend the consultation, they also need to be able to access the information under discussion. Here the UN ran into numerous problems as systems were not organised for information to be distributed in diverse ways. Spoken submissions interpreted via headsets and printed documents were still the norm. To address both these issues, the Ad Hoc Committee produced a document highlighting the need for full access for disabled delegates. It includes provisions for:

(a) The facilitation of entry into United Nations premises by individuals serving as guides, personal assistants or interpreters for persons with disabilities;

(b) The holding of meetings in those United Nations conference rooms that are better equipped to facilitate that participation of persons with mobility-related and other physical disabilities;

(c) The adoption of a practice whereby documents distributed in the course of one meeting or shortly in advance of a meeting will not be discussed before the next scheduled meeting, thereby affording persons with

visual disabilities sufficient time to convert those documents into a format readable by them;

(d) The adoption, to the extent necessary and possible, of measures to enable persons with hearing disabilities to participate in the deliberations of the Ad Hoc Committee.

(United Nations, 2002)

The fact that participation was seen in such a positive light by the participants suggests the UN was able to improve and resolve these early issues with access and make the negotiations an arena where all delegates could take part on an equal basis. Unfortunately, for many New Zealanders access to information is an ongoing issue. Government websites are frequently inaccessible, material in Plain English and New Zealand Sign Language is not available for people with learning disabilities and members of the Deaf community respectively. The DPO report mentioned previously also points out that disabled people are frequently unable to obtain even high-risk documents such as medical consent forms in accessible formats (Disabled Person's Assembly NZ Inc. et al., 2014).

The significance for those who took part

All the participants in this study agreed they were pleased to have been part of the CRPD negotiations. It was chance to be included in an historic process for disabled people's rights globally. What is more, the process itself was hugely successful in capturing the spirit of social model/rights-based approaches to disability in a way that is practical and clear for States to follow. The participants were of the opinion that this was due to the involvement of disabled people and as such, the CRPD not only represents a template for governments to follow in terms of what they must do but also how they must do it – with direct and meaningful participation in decision-making for DPOs at every step.

As experienced and highly knowledgeable disability rights activists and self-advocates, the participants held a detailed understanding of disability rights issues from personal and community perspectives. This did not mean they were 100% representative though – Gary Williams described butting heads with others over who should be on the Working Group representing Asia-Pacific. He was acutely aware of the fact that he could only speak from the perspective of a disabled person living in a developed country and not the 80% of disabled people who live in the developing world. Robert Martin was at pains to point out the limits to his contribution – he could only speak on behalf of himself and maybe other men like him, not women, indigenous people etc. The lack of Māori representation on the New Zealand delegation is an important issue and will be addressed later in this chapter.

Political context, both before during and after the negotiations, was seen as extremely important by the participants. The timing of the Convention was very fortunate for New Zealand's involvement. With their 2001 *Statement of government intentions for an improved community-government relationship*, the Labour government had committed itself to improving its relationships with the community and voluntary sector (Moriarity & Dew, 2011). The process of drafting the NZDS can be seen as having fallen out of this commitment as well as an awareness of disability rights issues that DPA had worked hard to highlight with Labour while they had been in opposition. After the success of the NZDS, which the participants described as being a victory in terms of involving disabled people and taking on board their feedback on what the document should contain, disabled people's involvement in the CRPD was a natural next step. It was seen by some as a continuation of the NZDS process – meaningful consultation resulting in provisions that make sense from a disability rights perspective.

A combined effort

It is worth noting that the views of disabled New Zealanders were not only represented by those present at the Committee meetings in New York. While the negotiations were taking place, DPOs in New Zealand were canvassing their members at home on issues and feeding ideas and priorities back to their representatives at the UN. Robert Martin described this process as being helpful to him in his role with Inclusion International:

> So when we came together for the Inclusion International meetings [in New Zealand] we talked about the Convention, the meetings ahead, what we were going to do, I said to some of the people would you like to find out about this and this, I gave them jobs to do. So I wasn't doing everything, and it gave them a sense of leadership and trust and all that kind of stuff.

Wendi Wicks also mentioned work on the ground in New Zealand:

> … we'd have the DPO caucuses, those kinds of meetings to agree a common position so it was a little bit like a second bite at the cherry. You could say things at the New Zealand delegation and get that taken seriously and you could push it a wee bit further in the International Disability Alliance stuff, and you could also push it in the side-events and the weapon of choice was kind of the cocktail glass and the sandwich, you know, you'd go along to the formal receptions and bail people up and talk to them nicely!

The Office of Disability Issues was also involved in consultation during the negotiations process, so that the official government position on various articles was influenced by domestic feedback. Moriarity & Dew (2011) spoke to one government official as part of their research who gave the example of CCS's desire to have protections to prevent young people being put into institutional care included in the Convention. This was taken up by the New Zealand delegation in New York and eventually realised in Article 23, which states children and young people must not be removed from their families and where this happens they must have the choice to live within the community in a family setting. The result of this activity on the home front

was a funnelling approach – the disabled delegates were involved in a two-way flow of information which served to strengthen their position and additional feedback from government consultation in New Zealand lent legitimacy to what the disabled delegates were saying.

Questions of speed

The average length of a negotiations process for an international human rights convention is 10 years (Moriarity & Dew, 2011). The negotiations for the CRPD were completed in four (for a full list of Ad Hoc Committee Session meetings, see United Nations, 2007b). A swift negotiations process had several benefits. Remarkably, it led to few compromises in terms of the finished Convention. Several participants in this project spoke about the way the negotiations had been expedited, however none expressed an opinion that the Convention had been compromised by a wish to complete the process within certain timeframes. It seems that when it comes to human rights treaties, a good game is a fast game. The short length of the process was highly influenced by stakeholder involvement for two different and practical reasons.

Firstly, the inclusion of DPO representatives in States' delegations meant that most disabled people were attending on limited government or DPO budgets. They simply did not have the resources to continue travelling to New York several times a year for the best part of decade. Furthermore, DPO representatives were also taking time out from their lives and responsibilities in their home countries to attend. There was a risk that the longer the negotiations ran on, the more likely it would be that disabled delegates would have to be replaced by others. Gary Williams shared the impact of this during his interview, remarking:

> It took me one and a half meetings to feel comfortable with the process in New York. There was a naïve view from some disabled New Zealanders

> that the delegate could be different for every session. Such a scenario would have rendered the delegate useless. Apart from just getting to grips with the system, there was the need to know who the key influencers were, the issues that had been agreed so that they wouldn't be raised again and what certain phrases meant at the UN. For example, "reproductive health" is a code for abortion.

Robyn Hunt cited the commitment to keeping the DPO representatives engaged as one of the major motivating factors behind Don MacKay's decision to chair the Working Group and the latter sessions of the Ad Hoc Committee in such a way as to make the process as swift as possible.

Another precipitating factor was the fact that diplomatic staff were also on rotation. High levels of stakeholder involvement meant that diplomatic staff assigned to the Ad Hoc Committee were able to develop a solid understanding of the issues in relation to disability rights. Everyone feared that a long negotiations process would mean a change of diplomatic staff and the loss of that institutional knowledge. Don MacKay's appointment as Chair of the Ad Hoc Committee was also for a set period of time. Given his investment in making sure the negotiations were a success, he was under pressure to ensure the process was completed before another Chair was appointed. He was convinced that had the text not been agreed on in August 2006, a change of Chair and diplomatic staff would have meant a catastrophic loss of institutional knowledge. This would have resulted in a significantly weaker Convention that possibly would not have been agreed upon for several more years (MacKay, 2009). This is no small matter when one considers an example from the UK of a change in government and minister completely altering the focus and outcomes of a consultation process with disabled people on the Disability Rights Task Force. Suddenly the atmosphere changed and "from that moment it was confrontational.... When we started we were really looking at a clean sheet of paper and a new [disability] Bill. By the end we were obviously looking at a much more piecemeal approach" (Hurst, cited in Drake, 2002, p.378).

Participation and consultation

It is fair to say that disabled people have an uneasy history when it comes to government consultation over the shaping of policy and legislation (Drake, 2002; Oliver 1996; Shakespeare, 2006). From the start of the disability rights movement, disabled people have had various hurdles to overcome when it came to interactions with government (Barnes, C., 2002). There was a long road to travel from disabled people being cast in the role of 'object' (a recipient or consumer of services) to becoming 'subjects' with agency and power over the course of their own lives (Quinn et al., 2002).

The first question for disabled people to address is the issue of activism versus consultation. Put simply, if you can't beat them, do you have to join them? Like all those who want to see change brought about, disabled people have had to choose between trying to engage with the system in order to change it from the inside or lobby for change from without. Placing oneself outside the debate gives the advantage of independence, however it is no coincidence that activists are not famous for having enormous resources and power – governments can, and do, choose to ignore even large-scale public resistance to their policies and decisions because they believe (rightly or wrongly) they have been given a mandate by the democratic process to do so.

Joining with government in a consultative role can have its own pitfalls, however. Drake (2002) points out that disabled people's organisations have faced significant difficulties in having their voices heard during policy consultations because they are often competing with organisations *for* disabled people that are often well-resourced and well known to the government. These large charities may or may not have the interests of disabled people as their primary concern – they are often not controlled by disabled people and have a lot to lose in terms of the value of the contracts they hold with government. In contrast, DPOs are independent and may not

be willing to tell the government what it wants to hear. They may also be in receipt of some government funding, perhaps not as service providers but as advocacy groups which they may also not want to risk losing if their relationship with government deteriorates significantly.

Participation is still very much defined by those seeking input (i.e. government departments), who make the decisions in terms of what will be discussed, who will be invited to contribute and what the outcome will be. Drake (2002) views this question in terms of two central ideas – *purpose* (what is the reason for involvement?) and *control* (how are the decisions made and what happens to the outcomes?). Although disabled people may be invited to participate, there is usually no commitment that their contribution will be translated into policy or that any changes in direction will occur as a result. This can lead to a degree of scepticism and 'consultation fatigue' among stakeholders who may feel their time is being wasted by pointless workshops, seminars and meetings (Stienstra, 2003). An additional factor is that disabled people who take part in consultation may only represent certain views and the perspectives of disabled people who are also members of cultural, ethnic and other minorities can be lost. Bewley and Glendinning (1994), for example, found that in the UK, black people and people with learning disabilities are particularly unlikely to play a part in decision-making processes in community care planning.

Marian Barnes (2002) has argued that participation by disabled people in decision making processes must be seen in terms of the rules of engagement – firstly, in determining who is to participate and also in what way the engagement takes place. She contends that according to the social model of disability:

> a fundamental aim is to challenge dominant orthodoxies which have defined how 'mental illness' and 'disablement' are understood within a medical paradigm, which in turn serves to structure policies and services to address the nature of the 'problems' experienced. These 'contested

> knowledges' (Seidman, 1998) imply a different source of authority (from the professional, bureaucratic or 'formal' political) from which to claim a right to take part in debate about public policy. And if the bearers of such knowledges are to be included within processes previously determined by rules governing dialogue on the basis of scientific evidence, bureaucratic procedures and/or party political debate, then this may require rethinking those rules in order to accommodate them. (Barnes, M., 2002, p.323)

Barnes cites research from both the UK and Canada that illustrates examples of the types of complex issues disabled people and people with experience of mental illness encounter when engaging in policy-making processes. In the UK example, the political climate was seen to have greatly influenced the scope and nature of engagement, as a forum established by a left-wing government was gradually stripped of power when a political shift to the right resulted in steps to limit the power of local government and restrict the influence of stakeholder engagement (Barnes, M., 2002).

Church's (cited in Barnes, M., 2002) research from Canada brings in a further dimension of how the personal is political, arguing that personal experience has to be seen as legitimate, warts and all, if disabled people are to be allowed to represent their perspectives during consultation. Church's writing concerns psychiatric survivor participation in a legislative sub-committee tasked with developing Canadian community mental health services in the early 1990s.

> There was a view from some of professional/bureaucratic members of the committee that survivor stories adopted a 'confrontational' tone; that such 'horror stories' were outside the remit of the committee; and there was an example of committee members not knowing how to respond when one young woman started to cry when telling her story. (Barnes, M., 2002, p.328)

This kind of contribution was treated with reactions ranging from discomfort to hostility, with one psychiatrist suggesting that a survivor's memories of abuse had arisen from a lack of understanding of psychiatry and the workings of the mental health system (Barnes, M., 2002)!

The CRPD negotiations showed how personal experience can not only be legitimate and useful, it can also be crucial to both grounding and progressing dialogue. All the participants in this research were agreed on this point, with Mike Gourley pointing out that people had much less room to 'play politics' on issues to do with disability rights when disabled people were able to shut down these arguments by bringing their lived experience to the debate. As Church's research shows, the value of lived experience is really contingent on the attitudes of those in power during an engagement process. It also begs the question of how power is distributed – in the case of the Canadian psychiatric survivors, because the committee process was stacked in favour of the 'experts' (professionals and bureaucrats) it became nothing more than a re-enactment of the medical model of impairment that had led to the abuse in the first place.

Stienstra (2003) proposes a framework for evaluating consultation mechanisms by focusing on the following five key questions:

- Who is consulted?
- How is consultation elicited?
- Do those consulted have access to decision makers?
- How do those consulted contribute to the results?
- Follow-up – what happens once the consultation is finished? Are those consulted given information about how their contribution has been used? (Stienstra, 2003)

The remainder of this chapter will focus on assessing the CRPD negotiations using this framework in terms of looking at the effectiveness of the process in

including and respecting the voices of disabled people – especially in light of the research question relating to ‘nothing about us, without us’.

Who is consulted?

The issue of choosing ‘representatives’ is complex. Bewley & Glendinning (1994) point out that finding disabled people who are willing to take part in consultation exercises can be a challenging process. Firstly, there is question of representation – who is being represented by the person/people involved? Bewley and Glendinning (1994) illustrate this using the example of a committee in the UK choosing a disabled staff member to represent the interests of ‘consumers’, even though the staff member was not a consumer of the services under discussion and later expressed the view that he had taken part in a professional capacity and not in any sense as a representative of disabled people’s views (Bewley & Glendinning, 1994, p.307).

Secondly there is the issue of accountability. Where does the person or people involved in the consultation draw their mandate from, and are they accountable to anyone for their contribution to the process? Questions of representativeness are often as important to the ‘consulters’ as the ‘consulted’. Barnes writes of government officials ‘agonising’ over whether the people they are working with on a consultation are truly representative of the constituency they are targeting (Barnes, M. 2002, p.325).

Those chosen to be part of the CRPD negotiations were invited by the government and elected by their organisations which were controlled by disabled people, except for Robyn Hunt who was nominated by the human rights institution she worked for. According to the participants, consultation was elicited simultaneously by both the DPA and the ODI agreeing together that New Zealand would support a Convention and would make disabled

people part of the formal delegation. Moriarity & Dew (2011) describe this decision as 'revolutionary in the history of the United Nations' (2011, p.690) because hitherto any consultation would have happened with NGO representatives firmly in an advisory role without any formal decision-making powers. During our interview, Mike Gourley mentioned a telling episode that illustrates just how committed New Zealand was to keeping disabled people central to the process:

> There was one point at which, I think during the 2004 session… where there was an attempt to move the discussion to what they call 'informals' which, despite its name, means actually that only delegations can stay and discuss so effectively you get rid of all the NGOs and all the other people like us, and New Zealand made a stand against it saying that if that were to happen we would withdraw from the process. And I remember the woman behind us, from the Australian delegation said 'God bless New Zealand!' Because it really did require a bit of staunch drawing a line in the sand to stop that happening, because it would have meant getting disabled people out of the session and we weren't going to let that happen if we could help it. So that was I think the really important thing about the contribution of New Zealand, the partnership commitment right through to the end.

It is worth mentioning at this point that the New Zealand government and DPA both failed to ensure disabled Māori were represented as part of the New Zealand delegation. Māori have a unique position in New Zealand society as *tangata whenua*, and Māori views are elicited as a matter of course in most government consultations according the terms of the Treaty of Waitangi. Huhana Hickey (2013) has pointed out that Māori and other indigenous people were not represented during the CRPD negotiations at any significant level, and as a result the CRPD cannot be said to reflect indigenous views of disability and disability rights. The fact that the New Zealand delegation did not include Māori representation may have more due to accident than design. Hickey (2005), however, points to a more deliberate

exclusion of indigenous voices by the UN, acknowledging attempts by both Gary Williams and Jan Scown to have specific representation for indigenous disabled people put in place during the Working Group and Ad Hoc Committee meetings.

Whatever the reason for the failure to include specific indigenous/Māori representation, it cannot be overlooked that in New Zealand at least, indigenous perspectives are usually included in dialogue between the Crown and the community as a matter of course. Indeed, the Treaty of Waitangi establishes a relationship between the Crown (or government) and Māori based on principles not unlike the demands of the DRM – a relationship based on mutual respect and the principles of partnership, protection and participation (Sullivan, 2001). Indigenous approaches to rights may be quite different to the individualised concept of the 'personal sovereignty' espoused by the UN and which forms the basis of human rights theory because of the importance of collective identity in indigenous societies. But this does not mean that rights for indigenous people are incompatible with the individual-based model. Without participation, Hickey argues, it is impossible to know how indigenous perspectives can be acknowledged within existing paradigms (Hickey, 2013).

Access to the decision-makers

With regards to the question of access to decision-makers, again the participants shared they had felt free to access not only New Zealand diplomatic staff (who the participants credit as being enormously helpful) but also other disabled delegates from official government delegations, as well as NGO representatives outside of the formal delegations. Robert Martin described extremely long days, seven days a week, between formal Committee meetings, informal meetings and his work with Inclusion International. Robyn Hunt was also one who took advantage of having a dual role by gaining access to meetings in various different settings. In all, the

participants gave me the sense that they had free rein and were not restricted in any sense by not having access to decision-makers while at the UN. In fact, because the negotiations were so effective in representing the views of disabled people, it would be fair to say they also *were* the decision-makers.

In considering the issue of access to decision-makers, there is the matter of how decisions were made during the final sessions of the Ad Hoc committee. Don MacKay introduced a highly unusual method of resolving disagreements over amendments to the text, putting the impetus on those who proposed amendments to achieve consensus for their amendments or face dropping them altogether (MacKay, 2009). Several respondents told me during their interviews that this meant nothing could be included in the Convention text unless every state agreed to vote in favour of it.

This need for absolute consensus meant that in suggesting amendments to the text, disabled people, whether as part of their delegation or as NGO representatives had the job of winning any arguments first with their own delegations and then other states. Either a particular point would be adopted or it would not, in Don MacKay's words, 'nothing is decided until everything is decided'. As a result, there was no ambiguity or vague promises along the lines of 'thanks, we'll take that on board'. This had the potential to make proceedings move at a very slow pace. Gary Williams recalled a session where one sentence was debated for three hours without any resolution! Fortunately there were other more pressing factors that worked to expedite the negotiations which have already been addressed in this chapter.

Contribution to the results

On the subject of how those consulted contributed to the results, again the people I spoke to for this project were confident the views of disabled people

had been reflected in the text of the CRPD. Each participant spoke about Articles they had felt particularly strongly about and how these had been interpreted in the final draft of the Convention. The Working Group established to write draft Articles for the Ad Hoc Committee to consider was made up of government and NGO (DPO) and national human rights institutions representatives at a ratio of around 2:1. Robert Martin was one of the DPO representatives who was part of the Working Group on behalf of Inclusion International. He describes his involvement as being effective in that his own contributions and the perspectives of the other DPO representatives were given credence and worked into the draft text. During his interview, Robert remarked:

> …people say that I became the voice for people who weren't there, the people who often are the most vulnerable people in our society the people who don't have a voice, who don't speak the way you and I can and I think that was the really important thing that I brought to this Convention.

One reason for the success of the negotiations from the point of view of 'nothing about us, without us' was that once it was agreed that a Convention was needed, the delegations were able to start with a blank slate. This is not always the case in consultations. Drake (2002) notes that a type of 'participation' (which is nothing more than ticking boxes), can occur when governments have already decided on a particular course of action over a policy but are bound to engage in consultation which will not alter anything. An example of this in New Zealand is the consultation with disabled people which occurred in the 1990s over the shift of Disability Support Services from the Department of Welfare to the Department of Health which was mentioned in Chapter 1. When consulted, the disability community expressed immediate concern over this course of action which was to define disability once again as an issue of dependence, needs and charity:

> They [disabled people] proposed a third option: that DSS be a standalone enterprise under the control of disabled people who would define, implement and monitor service delivery in partnership with nondisabled

> professionals and service workers. Needless to say, this proposal was seen as too threatening and was rejected by the powers that be who had already decided that DSS would go to health (Sullivan & Munford, 1998, p.185).

It is also worth noting there were few specific fiscal questions to be answered during the negotiations at the UN. The negotiations were not influenced by questions over how much enforcing and guaranteeing new laws was likely to cost governments in the same way that similar processes at a national level might have been. This role was left to individual delegations who were bound to advance their countries' priorities on many levels, including political, cultural and religious concerns. This is a salient point, given the potential of financial concerns to derail any consultation process. According to Drake, 'if the Treasury is absent from policy discussion, or objects to the outcomes of such discussions, budgets may not be available for any desired changes in policy direction' (Drake, 2002, p.378). Any fiscal concerns were therefore left to be dealt with at a national level as part of the ratification process. It is also important to stress that the provisions of the CRPD were seen as being for progressive realisation – it was taken as a given that developing countries would embark on a process to change the situations of disabled people in their countries as opposed needing to comply with the entire CRPD from the outset.

A striking aspect of the negotiations process that the participants shared was about how much the members of the New Zealand delegation genuinely needed one another's help to navigate both the form and the content of the negotiations. This led to a mutual recognition by both diplomatic staff and DPO representatives that nothing would be achieved without apposite cooperation. This was underpinned by the fact that DPO representatives were present not as advisors to the New Zealand delegation but as part of the delegation in their own right. This factor is important because it signals that the disabled delegates were there to work and contribute on an equal

basis with diplomatic staff. Moriarity and Dew (2011) cite Kathleen Gurnsey as saying:

> This was a group with equal rights of participation, completely unique, completely unprecedented and I think you will find that for those government representatives who participated in the Working Group, this was the first time they had ever embarked on a process where people with disabilities were at the table with an equal right to share their opinions. (Moriarity & Dew, 2011, p.689)

From this perspective, the negotiations can be said to have incorporated 'Nothing about us, without us' in a way that was respectful and mutually beneficial. Moreover, the result of the process was a human rights instrument that was robust and largely uncompromising when it came to spelling out protections for disabled people's rights. Perhaps the best endorsement was that the Convention was universally welcomed by disabled people who had rather a lot to lose had this opportunity been lost.

Even where battles had been lost, there was a sense that the fight had been fair and an acceptance that not everyone's views could be accurately reflected in a document with such a broad range and scope. Gary Williams, for example says:

> I think that given the complexities of the issues, the text is better than we could have hoped for. Yes it's silent on issues like bio-ethics, eugenics and euthanasia but it does provide a stake in the ground for future generations.

In spite of the fact that a 'perfect' document was not achieved, there was a sense of pride and satisfaction with the Convention among the people I spoke to for this research project. I believe this is due to the CRPD being a ground-breaking instrument in terms of furthering disability rights on a global scale. As such, the part played by New Zealanders in producing such a document is something we all should be proud of. But there are other

considerations when it comes to an instrument like this, as the work did not finish on that 'hot August night' in 2006. Instead, it was transferred to a national sphere and here there were some mixed views on what has and can be achieved through the CRPD.

Follow-up – what happened once the consultation was finished?

Several participants expressed misgivings about how the Convention has been implemented in New Zealand since ratification, mostly because of a perceived lack of political commitment to disability rights. Robyn Hunt, for example, told me she felt the present (National) government had lost some ground with the disability community in New Zealand. Wendi Wicks also expressed concern, attributing New Zealand's lack of action on disability since ratification to:

> The political climate as much as anything. And they're back in their own setting and if you like, nobody wakes up and says 'It's a fine sunny day, I think I'll give up some power'! You know, they do what they've always done, what gets them their money, what they're comfortable with. It's not such an urgent priority for you if you don't live it.

Here is where the ground-breaking aspects of the CRPD come into force, because the monitoring provisions are deliberately designed to circumvent obstacles to enforcement, or at least to lay these bare where they exist. As I have previously mentioned, the Convention provides for the establishment of national monitoring mechanisms where government works in partnerships with national human rights institutions and DPOs. In New Zealand this has led to the establishment of the Convention Coalition Monitoring Group, which produces reports at least every four years to the UN Committee on the Rights of Persons with Disabilities. New Zealand's first appearance before

this Committee was in September 2014, where the report of the New Zealand government to the Committee was accompanied by an independent shadow report produced by New Zealand DPOs on the state of disability rights in this country. This shadow report gives the government little opportunity to spin statistics and numbers to make it appear that disabled New Zealanders' rights are being protected. Because of this, it is fair to say that disabled people have retained ownership of the CRPD and the mandate it has given government to protect their rights.

Conclusion

This chapter has provided an analysis of some of the major themes of this research. Using the content of the participant interviews and Stienstra's framework for evaluating the effectiveness of consultations, it concludes that overall the involvement of disabled people in the CRPD negotiations was extremely successful, with the notable exception that disabled indigenous people were not given specific representation during the process. Elements of the process seen to be significant to the delegates interviewed were closely linked to questions of access and mutual cooperation.

The process itself was influenced in a positive way by the involvement of disabled people, primarily through the richness the voices of lived experience were able to bring to the debates. Far from complicating or reducing dialogue, the personal was able to enrich conversations and cut through misguided points with a perspective that was difficult to refute. This may be because the disabled delegates themselves were highly skilled and experienced disability activists in their own right. However it sets a useful precedent for how consultation processes can use nothing about us without us to produce exchanges of ideas that are coherent and powerful in terms of representing the views of disabled people and embracing 'nothing about us,

without us’ as a central guiding principle for all types of consultation in production of policy and legislation.

Chapter 6: Conclusions and recommendations

This project came about because of my interest in disability rights and how the UN Convention on the Rights of Persons with Disabilities could be used to promote disability rights in New Zealand. In looking at the background to the Convention, I came under the impression that New Zealand had had an important impact on the negotiations, especially because New Zealand had included several representatives from disabled people's organisations as part of its official delegation. My intention was to examine the negotiations process from the point of view of the disabled people who had been part of it. I wanted to assess it according to the disability rights movement's insistence on disabled people being directly involved in decision-making (including drafting policy and legislation) summed up in the saying often used by the disability rights movement – 'nothing about us, without us'. The research focused on how well this demand for inclusion had been applied, and what the consequences of 'nothing about us, without us' had been.

This thesis looks at alternatives to the individual/medical model of disability and the emergence of the social and minority group models of disability. In spite of some limitations, the social model was revolutionary in mobilising disabled people to lobby for their own rights as people with impairments in a disabling society. This approach to thinking about disability has led to significant changes for disabled people, as policy has moved away from focusing on treatment and 'management' of impairment towards inclusion, access and rights. This shift was also apparent in New Zealand, where disabled people and the social model of disability contributed significantly to the Fifth Labour government's New Zealand Disability Strategy of 2002. In spite of this, the recent history of disabled people in New Zealand, especially with regard to disability rights, has not been unlike that of disabled people in other developed countries, being characterised by some successes with ongoing setbacks and disappointments.

The scope of this project only allowed a brief history of human rights and disability rights to be considered. The issue of rights for disabled people was raised with increasing frequency at the United Nations from the 1970s onwards. After Mexico finally was able to garner enough support for a resolution to be passed in 2001 that a convention on the rights of disabled people be considered by an Ad Hoc Committee, the negotiations for the Convention on the Rights of Persons with Disabilities (CRPD) began.

The Convention was drafted in the early years of the 21st century and was heralded as a major breakthrough, a 'new dawn' for disabled people when it finally came into force. This breakthrough is because the CRPD articles on 'positive' social, economic and cultural rights require States Parties to actively promote disabled people's rights in a way not seen before in other UN human rights conventions. In addition, the monitoring mechanisms give disabled people and DPOs a central role in reporting back to the UN on progress made by their governments in implementing the CRPD.

The research was based on a qualitative approach and was informed on an epistemological basis by the social model of disability. Five people were interviewed for the project using semi-structured interviews. Themes that emerged in the data collected in the interviews were: how much 'nothing about us, without us' was reflected in the negotiations process; difficulties with access physical and information access for disabled people at the UN; the chairing of the Working Group and Ad Hoc Committee by Don MacKay; discussion of certain articles in the CRPD that the delegates remembered as having been important to them; and the participants' feelings on the legacy of the Convention.

The data were analysed using Stienstra's framework on assessing the effectiveness of consultation processes. According to the participants, the negotiations had been extremely successful in terms of giving disabled

people access to the decision-making process and turning this access into something that not only helped the process but the outcome as well. What was produced was a document that is exceptional among human rights instruments in the many creative ways it requires States Parties to protect *and* promote the rights of disabled people. In addition, because of the high level of stakeholder involvement, the disability community represented by DPOs both nationally and internationally had a genuine sense of ownership of the resulting document. The process of negotiating the CRPD contains a number of lessons for the formulation and implementation of disability policy at a local level and these are addressed in the recommendations which now follow.

Recommendations

"Here we go again, trotting out people with disabilities. It's not as if the government hasn't heard this before. Just do it!"

(Lloyd Terry, former Council of Canadians with Disabilities member, cited in Stienstra, 2003, p.46.)

1. Access to decision-makers

That disabled people be involved in decision-making, including the writing of policy and legislation on an equal basis with government representatives. It is the role of governments and DPOs to identify together what barriers stand in the way of disabled people influencing policy and legislation that directly affects them and to work together to remove or minimise these barriers.

2. Contribution to the results

Disabled people must have the ability to influence the results of any consultation. Consultation that ignores the input of disabled people only results in disabling policies that fail to bring about the social change disabled people have been demanding for the best part of forty years. It also has the

effect of alienating the disability community – a community that is already marginalised and discriminated against.

DPOs have shown they are effective negotiators at the highest possible levels when it comes to issues that affect disabled people. The success of both the NZDS and CRPD negotiations are proof that giving disabled people the power to engage in consultations and to make decisions about key questions – what, how, why – on the same basis as others can have groundbreaking results.

3. Follow-up

Disabled people have often complained that once their time and energy has been spent on a consultation process, there is no follow-up. This can be in the form of formal feedback on the results of the consultation, ongoing involvement in review processes or invitations to be part of any subsequent work done on the topic in question. This thesis has shown that effective engagement can lead to effective follow-up mechanisms, as the engagement process itself will naturally lead a consideration of what the next steps should be and what involvement the disabled people or DPOs involved should have in that. This kind of careful and deliberate continuation of the process in subsequent stages can significantly diminish the ‘consultation fatigue’ experienced by many individuals and groups in the DRM.

4. Including Māori

The voices of Māori disabled people are a notable absence form this project. None of the participants identified themselves to me as Māori (in the context of my research, the participants’ ethnicity was not discussed). There is a significant lack of research and writing on disabled Māori, especially in relation to disability rights. Tensions exist between the very individual focus of the disability rights paradigm and the collective identity of Māori. Further

research in this area is needed to look at how disabled Māori have responded to the CRPD and how disabled Māori can contribute to improved consultation processes using a kaupapa Māori approach.

Closing remarks

If you have built castles in the air, your work need not be lost; there is where they should be. Now, put foundations under them.

- Henry David Thoreau

The title of this project refers to a phrase coined by Shakespeare in the *Tempest* – a sea-change. A sea-change refers to a process of shaping and moulding that is transformative, whereby what is left at the end is utterly different to what was there at the beginning. The CRPD negotiations represented a sea-change in terms of the way disabled people were involved in a process of consultation that was unique in nature and an overwhelming victory for the DRM in its achievements. This success was realised because disabled people finally, and on a grand scale, were able to bring 'nothing about, without us' to life at the UN. This was true for all the disabled delegates, and for the New Zealanders especially, who from the beginning were committed to full inclusion for disabled people in every aspect of the process.

My conclusion is that the negotiations process was an enormous success because of:

- A unified, experienced and coherent response from the disability community, on a national, regional and international level
- Commitment on behalf of government representatives to create a document that would be a true reflection of the human rights protections disabled people need, based on the lived experience of disabled people rather than political agendas

- Cooperation both at the UN and domestically, which meant that information and ideas were able to flow effectively between those directly involved in the process and the communities and organisations the delegates represented

Genuine engagement with disabled people during this process had the effect of producing a document that while not perfect, was at least an accurate reflection of the opinions and requirements of disabled people. ‘Nothing about us, without us’ was continued after the process was completed, through deliberately inclusive monitoring provisions that expressly prioritised feedback from DPOs. Gerard Quinn has said the CRPD gives disabled people and governments a “moral compass for change as well as legal benchmarks to measure that change” (Quinn, 2009b, p.34). The future use of the CRPD lies just as much with DPOs as it does with national governments. Continued efforts by DPOs to keep governments accountable must be combined with efforts to keep DPOs themselves functioning as effective and influential representatives of disabled people.

References

Amnesty International (2013.) Regional report: New Zealand. Retrieved from http://amnesty.org/en/region/new-zealand/report-2013#section-105-3

Barnes, C. (1996). Disability and the Myth of the Independent Researcher, *Disability & Society*, 11(1), 107-112.

Barnes, C. & Oliver, M. (1998). *Disabled people and social policy: from exclusion to inclusion.* London: Addison Wesley Longman.

Barnes, M. (2002). Bringing difference into deliberation? Disabled people, survivors and local governance. *Policy & Politics,* 30(3), 319–331.

Bickenbach, J. (2001). Disability Human Rights, Law and Policy. In G. Albrecht, K. Seelman, & M. Bury, (Eds.), *Handbook of Disability Studies*. London: Sage.

Bismarck, M. & Patterson R. (2006). No-fault compensation in New Zealand: Harmonizing injury compensation, provider accountability, and patient safety. *Health Affairs*, 25(1), 278-283.

Blatt, B. & Kaplan, F. (1974). *Christmas in Purgatory: A photographic essay on mental retardation.* Syracuse NY: Human Policy Press. Retrieved from http://mn.gov/mnddc/parallels2/pdf/undated/Xmas-Purgatory.pdf

Blewett, K. (Director) (2012). *Ukraine's forgotten children* [Documentary]. United Kingdom: BBC Retrieved from https://www.youtube.com/watch?v=Cs42-5HnQRQ

Borsay, A. (1997). In L. Barton & M. Oliver, (Eds), *Disability Studies: Past Present and Future* (pp. 115 – 137). Leeds: The Disability Press.

Campbell, J. & Oliver, M. (1996). *Disability politics: Understanding our past, changing our future.* London: Routledge.

Charlton, J.I. (1998). *Nothing about us without us.* Berkeley: University of California Press.

Cheyne, C., O'Brien, M. & Belgrave, M. (2008). *Social policy in Aotearoa New Zealand*. South Melbourne, Vic.: Oxford University Press.

Clements, L. & Read, J. (Eds) 2008. *Disabled People and the Right to Life: The protection and violation of disabled people's most basic human rights*. London: Routledge.

Confidential Forum for Former In-Patients of Psychiatric Hospitals (2007). Report of the Confidential Forum for Former In-Patients of Psychiatric Hospitals. Retrieved from

http://ndhadeliver.natlib.govt.nz/ArcAggregator/arcView/IE12126512/http://www.dia.govt.nz/diawebsite.nsf/Files/CFPages070627/$file/CFPages070627.pdf

Corker, M. & French, S. (Eds.) (1999). *Disability discourse*. Buckingham: Open University Press.

Crow, L. (1996). Including all our lives: renewing the social model of disability. In C. Barnes, C. and G. Mercer, (Eds.), *Exploring the divide: Illness and disability.* Leeds: The Disability Press.

Despouy, L. (1993) *Human rights and disabled persons*. New York:

United Nations.

Department for International Development (2005). *Reducing poverty by tackling social exclusion: A DfID policy paper.* Retrieved from www.dfid.gov.uk/pubs/files/social-exclusion.pdf

Disabled Persons Assembly NZ Inc., Association of Blind Citizens of New Zealand, Balance New Zealand, Deaf Aotearoa NZ Inc., Deafblind NZ Inc., Ngāti Kāpo o Aotearoa Inc., … Ngā Tāngata Tuatahi (2014). *New Zealand Disabled Persons' Organisations Report to the United Nations Committee on the Rights of Persons with Disabilities on New Zealand's Implementation of the Convention on the Rights of Persons with Disabilities.* Retrieved from http://www.dpa.org.nz/resources/sector-resources/the-united-nations-convention-on-rights-of-persons-with-disabilities/dpo-shadow-report

Drake, R. (2002) Disabled people, voluntary organisations and participation in policy making. *Policy & Politics*, 30(3), 373–385.

Duckett, P.S. (1998). What Are You Doing Here? 'Non-disabled' people and the disability movement: A response to Fran Branfield. *Disability & Society*, 13(4), 625-628.

Elwan, A. (1999) Poverty and Disability: a survey of the literature. Retrieved 15/5/2010 from World Bank website: www.worldbank.org

Engel, D. & Munger, F. (2003). *Rights of inclusion: law and identity in the life stories of Americans with disabilities.* Chicago: University of Chicago Press.

Fay, B. (1996). *Contemporary philosophy of social science: A multicultural approach*. Oxford: Blackwell.

Finkelstein, V. (1980). *Attitudes and disabled people.* New York: World Rehabilitation Fund.

Finkelstein, V. (1991) Disability: an administrative challenge? In M. Oliver, (Ed.). *Social Work – Disabled People and Disabling Environments* (pp.19-39). London: Jessica Kingsley Publishers.

Fleischer, D.Z. & Zames, F. (2001). *The disability rights movement: From charity to confrontation.* Philadelphia: Temple University Press.

Georgeson, S. (2000) *The Disabled Persons Assembly 1983-1999: successes, challenges and lessons for the disability movement in New Zealand: a thesis presented in partial fulfilment of the requirements for the degree Master of Social Work (MSW), Massey University*. Palmerston North, New Zealand: Massey University.

Hahn, H. (2002). The US disability movement. In C. Barnes, M. Oliver, & L. Barton, (Eds.), *Disability Studies Today*. Cambridge: Polity Press.

Hickey, H. (2005). Indigenous people with disabilities: The argument for representation in human rights legislation (with specific reference to the development stage of the United Nations International Disability

Convention). *He Puna Korero: Journal of Māori & Pacific Development*, 6(2), 9-20.

Hickey, H. (2013). Indigenous People with Disabilities: The missing link. In M. Sabatello & S. Schultz, (Eds) *Human Rights & Disability Advocacy.* Philadelphia: University of Pennsylvania Press.

Human Rights Act (1993). Retrieved from http://www.legislation.govt.nz/act/public/1993/0082/latest/DLM304212.html

Human Rights Commission (2010). *Human Rights in New Zealand: Summary.* Retrieved from http://www.hrc.co.nz/human-rights-environment/human-rights-in-new-zealand-2010/

Human Rights Watch (2014a). *Abandoned by the State: Violence, Neglect, and Isolation for Children with Disabilities in Russian Orphanages*. Retrieved from http://www.hrw.org/reports/2014/09/15/abandoned-state-0

Human Rights Watch (2014b) *Witness: Yearning for freedom in Croatia, Tatjana's story.* Retrieved from http://www.hrw.org/node/129713

Hunt, R. (2006). Hot August night. Retrieved from http://publicaddress.net/speaker/hot-august-night/

Kanter, A.S. (2007). The promise and challenge of the United Nations Convention on the Rights of Persons with Disabilities. *Syracuse Journal of International Law and Commerce,* 34, 287-321.

Kayess, R. & French, P. (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review,* 8(1), 1-34.

Lawson, A. (2007). The United Nations Convention on the Rights of Persons with Disabilities: New era or false dawn? *Syracuse Journal of International Law and Commerce,* 34, 563-619.

Linton, S. (1998). *Claiming disability: Knowledge and identity.* New York: New York University Press.

MacKay, D. (2009). [Unpublished article] *The creation of the United Nations Convention on the Rights of Persons with Disabilities*.

Massey University, (2010). Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants. Retrieved from http://www.massey.ac.nz/massey/fms/Human%20Ethics/Documents/MUHEC%20Code%202014.pdf?C5190D92CCD5AEF466A054461653D604

May, T. (2001). *Social research: Issues, methods and process.* Buckingham, UK: Open University Press.

Megrét, F. (2008). The Disabilities Convention: Disability Rights or Human Rights of Persons with Disabilities? *Human Rights Quarterly,* 30, 494-516.

Ministry of Health (2001a). *A Brief Summary of the Analysis of Submissions to the New Zealand Disability Strategy Discussion Document Making a World of Difference: Whakanui Oranga.* Retrieved from http://www.odi.govt.nz/nzds/strategy-history.html#publications

Ministry of Health (2001b). *The New Zealand Disability Strategy: Making a World of Difference: Whakanui Oranga.* Retrieved from http://www.odi.govt.nz/resources/publications/new-zealand-disability-strategy.html

Ministry of Health (2006). Employer and manager knowledge of and attitudes to mental health and mental illness. Retrieved from http://www.likeminds.org.nz/assets/Uploads/Employer-and-managers-knoweldge.pdf

Moodie, S. (2013). *Almost one in four New Zealanders were identified as disabled in 2013.* Retrieved from http://www.hrc.co.nz/2014/06/17/almost-one-in-four-new-zealanders-were-identified-as-disabled-in-2013/

Moore, M., Beazley, S. & Maelzer, J. (1998). *Researching Disability Issues.* Buckingham, Philadelphia: Open University Press.

Moriarity, L., & Dew, K. (2011). The United Nations Convention on the Rights of Persons with Disabilities and participation in Aotearoa New Zealand. *Disability & Society*, 26(6), 683-697.

Morris, J. (1991). *Pride against prejudice: A personal politics of disability.* London: Women's Press.

Munford R. & Sullivan, M. (2005). 'Disability and support: The interface between disability theory and support – an individual challenge'. In O'Brien, P. & Sullivan, M. (Eds) *Allies in Emancipation: Shifting from Providing Service to Being of Support (*pp. 19-31*). Melbourne:* Thomson/Dunmore Press.

O' Cinneide, C. (2009). Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Established Limits and New Possibilities. In O.M. Arnardottir, & G. Quinn, (Eds.), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*. Leiden: Martinus Nijhoff.

O'Leary, Z. (2010). *Doing your research project.* London: Sage.

Office of Disability Issues (n.d.). History of the Strategy. Retrieved from http://www.odi.govt.nz/nzds/strategy-history.html

Office of Disability Issues (2007). New Zealand Application for the Franklin Delano Roosevelt International Disability Award. Retrieved from http://www.odi.govt.nz/resources/publications/disability-award/index.html

Oliver, M., (1990). *The Politics of Disablement.* Basingstoke, Hampshire: Macmillan.

Oliver, M. (1992). Changing the social relations of research production, *Disability, Handicap & Society,* 7(2), 101-114.

Oliver, M. (1996). *Understanding disability: From theory to practice.* London: Macmillan.

Oliver, M. (1999) Emancipatory Research: Realistic Goal or Impossible Dream?. In C. Barnes & G. Mercer, G. (Eds.), *Doing Disability Research* (pp.15-31). Leeds: The Disability Press.

Oliver, M., (2004). If I had a hammer. In C. Barnes & G. Mercer (Eds.), *Implementing the Social Model of Disability: Theory and Research* (pp. 18-31). Leeds: The Disability Press.

Oliver, M., Sheldon, A. Traustadóttir, R., Beresford, P.,& Boxall, K., (2007). Disability Rights and Wrongs*?, Disability & Society*, 22(2), 209-234.

Oliver, M. (2009). *Understanding disability – from theory to practice* (2nd ed.). Basingstoke, Hampshire: Macmillan.

Pawson, R. (1999). 'Methodology'. In S. Taylor, (Ed.) *Sociology: Issues and debates* (pp.19-49). Basingstoke: Macmillan.

Petersen, C. J. (2010). Population Policy and Eugenic Theory: Implications of China's Ratification of the United Nations Convention on the Rights of Persons with Disabilities. *China: An International Journal*, 8(1), 85-109.

Perry, D.M. & Carter-Long, L. (2014, May 14). How misunderstanding disability leads to Police violence. *The Atlantic.* Retrieved from http://timeli.info/item/1601815/The_Atlantic_Health/How_Misunderstanding_Disability_Leads_to_Police_Violence___David_M__Perry_and_Lawrence_Carter_Lon

Quinn, G., Degener, T., Bruce, A., Burke, C., Castellino, J., Kenna, P., … Quinlivan, S. (2002). *Human rights and disability: the current use and future potential of United Nations human rights instruments in the context of disability*. New York, Geneva: United Nations.

Quinn, G. (2009a). The United Nations Convention on the Rights of Persons with Disabilities: Toward a new international politics of disability. *Texas Journal on Civil Liberties & Civil Rights,* 15(1), 33-52.

Quinn, G. (2009b). The United Nations Convention on the Rights of Persons with Disabilities: Address to New Zealand Parliament, Wellington. Retrieved from www.odi.govt.nz/what-we-do/un-convention/index.html#Monitoringimplementation3

Reina, M. (2008). *How the International Disability Caucus worked during the negotiations for a UN Human Rights Convention on Disability.* Retrieved from http://www.globalaging.org/agingwatch/events/CSD/2008/maria.htm

Rioux, M. (2001). Bending towards justice. In L. Barton, (Ed.) *Disability, politics and the struggle for change.* London: David Fulton.

Russell, M. (2002). What Disability Civil Rights Cannot Do: Employment and Political Economy. *Disability & Society*, 17(2), 117-135.

Saving Downs (2014). Action so far. Retrieved from http://www.savingdowns.com/action-so-far/#ICC

Shakespeare, T.(1996). Rules of engagement: doing disability research, *Disability and Society*, 11 (1), 115-19

Shakespeare, T. (2006). *Disability Rights and Wrongs.* New York: Routledge.

Sharma, K. (2014). Break the shackles of stigma on mental health care in Indonesia. Retrieved from http://www.hrw.org/node/129207

Stace, H. (2007). The long unfinished journey towards human rights for disabled people in Aotearoa New Zealand. *Human Rights Research* (Centre for Public Law, Victoria University of Wellington), 5, 1-13.

Stein, M.A. (2007a). Disability human rights. *California Law Review,* 95, 75-121.

Stein, M.A. (2007b). A quick overview of the United Nations Convention on the Rights of Persons with Disabilities and its implications for Americans with disabilities. *Mental and Physical Disability Law Reporter,* 31(5), 679-683.

Stein, M.A. & Lord, J.E. (2008). Jacobus tenBroek, participatory justice and the UN Convention on the Rights of Persons with Disabilities. *Texas Journal on Civil Liberties and Civil Rights,* 13 (2), 167-185.

Stein, M.A. & Lord, J.E. (2010). Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, Lost Opportunities and Future Potential. *Human Rights Quarterly,* 32(3), 689-728.

Stienstra, D. (2003). “Listen, really listen, to us”: Consultation, disabled people and governments in Canada. In K. Blackford & H. Enns (Eds.), *Making equality: History of advocacy and persons with disabilities in Canada*. Ontario: Captus Press.

Stewart, C. & Mirfin-Veitch, B. (2008). *The impact of deinstitutionalisation on the families of the Kimberley Centre residents.* Retrieved from http://www.donaldbeasley.org.nz/publications/DBI_KimberleyReports_Family.pdf

Sullivan, M. & Munford, R. (1998). The Articulation of Theory and Practice: Critique and resistance in Aotearoa New Zealand. *Disability & Society*, 13(2), 83-198.

Sullivan, M. (2001). Disabled people and the politics of partnership in Aotoaroa New Zealand. In L. Barton (Ed.) *Disability, politics and the struggle for change.* (pp. 93 - 109). London, UK: David Fulton Publishers

Sullivan, M. (2009). Philosophy, ethics, and the disability community. In D. Mertens, & P. Ginsberg (Eds.) *The Handbook of Social Research Ethics.* (pp. 69 - 84). Thousand Oaks, CA: Sage Publications

Thomas, C. (1999). *Female forms: experiencing and understanding disability.* Milton Keynes: Open University Press.

UNESCO (2006). *Education for All Global Monitoring Report 179.* Retrieved from http://www.unesco.org/education/GMR2006/fiill/chapt7_eng.pdf

United Nations (1948). Universal Declaration of Human Rights. Retrieved from http://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf

United Nations (1989). Convention on the Rights of the Child. Retrieved from http://www.ohchr.org/en/professionalinterest/pages/crc.aspx

United Nations (2002). *Participation of persons with disabilities in the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities.* Retrieved from: http://www.un.org/esa/socdev/enable/rights/adhocngo83e.htm

United Nations (2005). Daily summary of discussion at the fifth session 24 January 2005. Retrieved from http://www.un.org/esa/socdev/enable/rights/ahc5sum24jan.htm

United Nations (2007a). Convention on the Rights of Persons with Disabilities. Retrieved from www.un.org/esa/socdev/enable/rights/convtexte.htm

United Nations (2007b). Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. Retrieved from http://www.un.org/esa/socdev/enable/rights/adhoccom.htm

United Nations (2014). *Global Issues: Human Rights.* Retrieved from http://www.un.org/en/globalissues/humanrights/

Vernon, A. (1998). Multiple Oppression and the Disabled Peoples' Movement. In T. Shakespeare (Ed.), *The Disability Reader, Social Science Perspectives*. London: Cassell.

Walliman, N. (2005). *Your research project.* London: Sage.

Weller, P. (2009) Human Rights and Social Justice: The Convention on the Rights of Persons with Disabilities And the Quiet Revolution in International Law. *Public Space: The Journal of Law and Social Justice,* 4, 74-91.

Williams, G. (2001) Theorizing disability. In G. Albrecht, K. Seelman, & M. Bury, (Eds.), *Handbook of Disability Studies* (pp. 123-145). Thousand Oaks, CA: Sage Publications.

World Federation of the Deaf (2014). *Deaf education.* Retrieved from http://wfdeaf.org/our-work/focus-areas/deaf-education

World Health Organisation (2011) *World report on disability.* Retrieved from http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf?ua=1

World Network of Users and Survivors of Psychiatry (2008). *Implementation Manual for the United Nations Convention on the Rights of Disabled Persons*. Retrieved from http://www.un.org%2Fdisabilities%2Fdocuments%2FCOP%2FWNUSP%2520CRPD%2520Manual.doc&ei=aXB6VMHnH6WomgWnvYKYCQ&usg=AFQjCNHU0G8Rc7beuIpQGVodeOOCWw0Ntg&sig2=fUPlIG1yiNpuAxJsqi9mCg

Young, D. & Qibell, R. (2000). Why rights are never enough: Rights, intellectual disability and understanding. *Disability & Society*, 15(5), 747-764.

Zola, I.K. (1989) Toward the necessary universalising of disability policy. *The Millbank Memorial Fund Quarterly,* 67 (2), 401-28.

Zola, I.K. (1994) Toward inclusion: The role of people with disabilities in policy and research in the United States. In M. Rioux, & M. Bach, (Eds.), *Disability is not measles: New research paradigms in disability.* Ontario: Roeher.

Appendix A - Information Sheet

MASSEY UNIVERSITY

COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

TE KURA PUKENGA TANGATA

Negotiating the United Nations Convention on the Rights of Persons with Disabilities: a New Zealand Perspective

INFORMATION SHEET

This is an invitation for you to participate in a research project examining the role of the New Zealand delegation to the United Nations Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. The focus of the research will be on the experience of the New Zealand delegates, their impressions of the negotiations and their assessment of the contribution New Zealand made to the process of drafting the Convention on the Rights of Persons with Disability.

My name is Sinéad Roe. I am a part-time distance learning student at Massey University in Palmerston North, where I am completing a Masters in Social Policy. I am currently employed part-time as a foster care placement consultant with the Open Home Foundation. My role is to facilitate assessment of training and support needs for foster families who foster a disabled child or young person.

The title of my project is: **Negotiating the Convention on the Rights of Persons with Disabilities: a New Zealand Perspective.** The aim of the research is to examine the contribution of the New Zealand delegates to the negotiations of the Ad Hoc Committee, with an emphasis on relating this

process to the history of disability human rights in New Zealand. The focus of the study will be to determine:

- How the negotiations form part of the story of disabled people and the disability rights movement in New Zealand
- The role and contribution of DPO representatives during the negotiations
- The major themes and issues of contention in the negotiations

If you agree to participate in this research project you will be involved in a semi-structured interview that will take approximately one hour to one and a half hours to complete.

I plan to interview five former delegates about their role in the Ad Hoc Committee meetings. I will then compare the responses in an attempt to determine the perceived similarities and differences that emerge in participants' accounts of the negotiations process. Participants from several sectors that were represented in the New Zealand delegation will be approached – that is, representatives from New Zealand DPOs, the New Zealand Human Rights Commission and the New Zealand Government.

The interview will be audio recorded and then transcribed by the researcher at a later date. Participants will have the opportunity to verify the accuracy of their transcript before any information is included in the research report. Consent forms, audio tapes and the interview transcript will be kept in a locked cabinet at all times and the researcher will be the only person who has access to this material.

In order to maintain your confidentiality, you may choose to remain anonymous. If you do so, no names or identifying information will be included in the final research report.

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

- Ask for the audio tape to be turned off at any time during the interview
- Withdraw from the study at any time
- Ask any questions about the study at any time during participation
- Provide information on the understanding that your name and the name of your school will not be used in the writing or presentation of the research
- Be given access to a summary of the project findings when it is complete

A copy of the research findings will be sent to each participant once the thesis has been assessed by Massey University. A copy of the full report can be obtained by contacting the researcher after February 2013.

If you have any questions regarding this project please feel free to contact me or my research supervisor using the details provided:

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This project has been assessed by the Massey University Human Ethics Committees as low risk. The researchers 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

Thank you for considering my request. If you choose to accept this invitation please complete the attached consent form and return it to me at the address provided.

Appendix B – Consent Form

Negotiating the Convention on the Rights of Persons with Disabilities: a New Zealand Perspective

PARTICIPANT CONSENT FORM - INDIVIDUAL

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.

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

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

I do/do not wish my confidentiality be maintained by using a pseudonym when quoted in text.

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

Signature: ..... **Date:** .....

Full Name - printed .....

Appendix C – Interview questions

- What do you think the circumstances were that contributed to DPO representatives forming part of the NZ delegation to the Ad Hoc Committee?
- What led to you personally joining the NZ delegation?
- How many committee meetings did you attend? How would you assess what happened at each - progress in terms of getting resolution on contentious articles etc.?
- What were your initial impressions of the process in New York - how things work at the UN etc.?
- Did other countries have DPO representatives as part of their delegations? Do you think this made any difference to their stance on the issues being debated?
- What is your assessment of the impact having DPO representatives had on the negotiations - both from an NZ point of view (i.e. how stakeholders may have influenced the NZ response to certain questions under debate) and in general?
- When the process was finished and the final text agreed on, how representative of the views expressed by disabled people during the negotiations do you think it was?