



Disability Rights Promotion International

Disability Rights in Aotearoa New Zealand 2010


*A report on the Human Rights
of Disabled People in
Aotearoa New Zealand*

This report is an internal monitoring study of the Human Rights of disabled people in Aotearoa New Zealand since the ratification of the United Nations Convention on the Rights of Persons with Disabilities in 2008. It used a monitoring framework developed by Disability Rights Promotion International (DRPI). DRPI also provided training and technical expertise.

This study was funded by the New Zealand government through the Ministry of Social Development and administered by the Convention Coalition, a collaboration of NZ Disabled Peoples' Organisations (DPOs). One of the members, the Disabled Persons Assembly (DPA) acted as administrative fund holder on behalf of the other DPOs: Association of Blind Citizens of New Zealand Inc., Deaf Aotearoa NZ, Ngāti Kapo, Nga Hau E Wha, and People First New Zealand.

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Definitions, Abbreviations and Acronyms

Aotearoa New Zealand: The Maori name for New Zealand is Aotearoa, commonly translated as land of the long white cloud. It is common for the Maori and English names to be used together.

Convention Coalition: A collaboration of Disabled Peoples' Organisations comprising the Disabled Persons Assembly, Association of Blind Citizens of New Zealand Inc., Deaf Aotearoa NZ, People First New Zealand, Ngāti Kapo and Nga Hau E Wha.

Disabled People: According to the Convention disabled people are “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”. This definition is consistent with the New Zealand Disability Strategy. For a fuller explanation of why ‘disabled people’ rather than ‘people with disabilities’ was used in this report please see the preface below and section three, the Disability Movement in New Zealand.

DPOs: Disabled Peoples' Organisations. Organisations of disabled people.

DRPI: Disability Rights Promotion International (DRPI) is a collaborative project working to establish a comprehensive and sustainable international monitoring system to address disability discrimination globally. York University, 4700 Keele Street, TEL Building, Suite 5021 Toronto, Ontario M3J 1P3 Canada email: drpi@yorku.ca website: www.yorku.ca/drpi

Identity Politics: A politics or political movement based on a shared identity

Int: Interviewer/monitor

Maori: The tangata whenua, indigenous population

Monitors: The Monitors in this project conducted the interviews. In the body of this document the contributions made by the Monitors and the questions asked are referenced with “*Int:*”

Pakeha: Non-indigenous New Zealander

Par: Participant/interviewee

The Convention: The United Nations Convention on Rights of Persons with Disabilities

The Strategy: The New Zealand Disability Strategy

Te Tiriti o Waitangi: The Treaty of Waitangi,

Te Tiriti: The Treaty of Waitangi, Te Tiriti o Waitangi

Preface

This is a report on the rights of disabled people. We use disabled people rather than people with disabilities deliberately in this report. The name disabled people fits with the politics of the disabled peoples rights movement in New Zealand and with the philosophical underpinnings of the New Zealand Disability Strategy (the Strategy) (2001)

The Strategy provides a framework to guide government agencies making policy and services impacting on disabled people, The Strategy is a founding document for the development of disability legislation in New Zealand. A philosophical model of disability activism known as the Social Model of Disability (the Social Model) underpins the Strategy. According to Social Model theory a person has an impairment and the way that society is set up and organised *disables* the person with the impairment. From this perspective it does not make sense to use the label “person with a disability” as disability is something that happens to a person because of the social structures that surround them, not something that the person possesses.

Fifteen objectives are set out in the Strategy and broad cross-party support for the Strategy exists with a large number of crown entities and territorial authorities willingly taking part in its implementation. However, as the New Zealand National Interests Analysis on ratification of the Convention on the Rights of Persons with Disabilities (“the Convention”) states:

Despite the significant progress achieved through the New Zealand Disability Strategy, there remain many barriers experienced by disabled people in New Zealand that prevent their full participation in society. It remains a high priority for government to identify and remove these barriers. The Convention will

provide a new impetus and practical focus to removing these barriers. It will reinvigorate activity to implement the New Zealand Disability Strategy and the commitment to ensuring full rights of citizenship for disabled people.

It is not surprising that such support for the Convention exists in New Zealand. During negotiations around the Convention; from the beginning the NZ delegation was one of a few to consist of State officials and disabled people. New Zealand ratified the Convention on 26 September 2008.

Legislation is the beginning of a process towards the realising of human rights. Having ratified the Convention there is now recognition that effective monitoring requires transparency and accountability. The Convention recommends a framework to promote, protect and monitor the rights of disabled people, including at least one mechanism independent of government. Seeking to evaluate the implementation of the Convention to date, this report fulfils that recommendation. In line with the Conventions' recommendations, for the most part, the organization, interviews, analysis and presentation of this report have been undertaken by disabled New Zealanders.

Acknowledgements

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Convention Coalition representatives Wendi Wicks (Coalition chair) Rachel Noble Barbara Hart, Graeme Parish, Mary Schnackenberg and Nigel Ngahiwi. Wendi Wicks, Rachel Noble, and Rose Wilkinson (an original member of the Convention Coalition) formed a 'Rapid Response' Team to respond to urgent day to day issues. Collectively they put in many extra hours to 'get the show on the road'

Robert Cameron of DPA for the money management when things were not straightforward

Dr Martin Sullivan for his advisory role

Project Co-ordinator Gary Williams, Data Analyst Dr Michelle Mars, the Data Analysis Team and Transcribers. The Project Co-ordinator and the Data Analyst in particular ensured the project kept on course despite many obstacles

All of the Site Co-ordinators and Monitors who put in such commitment to find the 'real oil' from their fellow disabled New Zealanders

Project Summary

Summary of the project, the Disability Rights Promotion International framework, and key findings

The aim of the monitoring project is to provide robust information that Disabled People's Organisations (DPOs) and government can use to formulate better disability policy.

The project was undertaken using an international monitoring instrument developed by Disability Rights Promotion International (DRPI). DRPI is a collaborative project working to establish a comprehensive and sustainable international monitoring system to address disability discrimination globally.

Ninety eight interviews undertaken with disabled people by disabled people provide the information contained in this report. The monitoring project sample encompasses a cross section of impairments.

The interviews were analysed using NVIVO a qualitative data analysis package.

Extensive quotes are used in the report to better represent the voice of disabled people.

Social participation by disabled people in society emerged as by far the biggest single issue in the monitoring project. This was followed by negative experiences with regard to health. Lack of employment is also a major issue for the monitoring project participants, with high living costs and gender and ethnicity compounding the issues.

One phrase repeated in meetings over the course of the monitoring project is 'the resilience of disabled people'. This is reflected in the participants' analysis of the human rights implications of their everyday experience. Training and consciousness raising as a means of demystifying disability and changing negative attitudes to disabled people is the most pervasive theme in these results. Bureaucracy as disabling practice is another persistent theme in the monitoring project. In general, disabled people report human rights violations however, they are reluctant to cause a fuss in the workplace and are less likely to report transport issues with regard to public transport as it is perceived that nothing will be done. Most violations of human rights are reported.

Conclusions and Recommendations

Social participation includes tangible issues like work, transport and communication. However, it also includes drivers for true social participation, taken for granted in non-disabled peoples' lives, such as friendships and other social networks and access to the social and cultural world. Social participation is often limited by ignorance of the realities of disabled peoples' lives. The first recommendation is that New Zealand undertakes an awareness campaign.

Disabled people reported that the major barrier for them was bureaucratic structures that hinder rather than help, with many instances of institutionalised disablism reported in the study. The second recommendation is that key performance indicators be created and monitored for all public services and that disabled people are able to be part of a monitoring process.

With regard to work, there is a large resource of well-educated disabled people who are unable to access employment. It is recommended that reasonable accommodation is promoted and enforced for disabled people.

Leaving home for short or extended periods of time remains an issue for disabled people with discrimination unlikely to be reported in this area. The final recommendation is that an industry standard (similar to the tourism industry's

Qualmark) signalling a non-disabling environment and universal design features be developed.



Section 1

The Social, Economic, and Political Context in NZ

New Zealand is a Pacific Island nation comprising two main islands and many smaller islands. It is an isolated nation situated approximately 2,000 kilometres southeast of Australia, and about 1,700 kilometres southwest of Fiji.

Social: New Zealand has a population of approximately 4.4 million. Approximately 1.25 million in the greater Auckland area located towards the top of the North Island. The majority of New Zealand's population is of European descent. The indigenous Maori population, the tangata whenua, comprise around 14.5 percent of the population, with approximately 9 percent of people identifying as Asian and another 7 percent identifying as Pacific Peoples. One in five New Zealanders report having an impairment.

The Constitution Act 1986 is the principal formal statement of constitutional structure. The New Zealand constitution is unwritten. This means that it is written down in a number of places and is based on a system of convention. The role of the Prime Minister for example is a convention. In effect New Zealand is governed by a system of committees. Te Tiriti o Waitangi (The Treaty of Waitangi), a treaty between the British Crown and Maori signed in 1840, is a controversial document critiqued as being more honoured in the breach than in fact.

Te Tiriti o Waitangi is a challenging document for colonisers and also a document that highlights the many wrongs that majority cultures have imposed on the indigenous peoples of Aotearoa. Te Tiriti o Waitangi is the constitutional document that forms the foundation of partnership between the tangata whenua (people of the land) and the public sector. In accordance with the principles of Te Tiriti

departments of state, ministries, and agencies are obligated to demonstrate their commitment to Te Tiriti o Waitangi with the expectation that they will actively develop and implement protocols that uphold and are inclusive of indigenous people's rights rather than meretricious expressions of falsehoods.

Nonetheless it is an important constitutional document seeding a spirit of partnership and biculturalism in the public sector. In the spirit of biculturalism all departments of state, ministries, and agencies are required to include clauses in their mission statements expressing commitment to Te Tiriti and protocols in place for establishing a partnership relationship with local iwi (tribe).

English, Te Reo Māori, and New Zealand Sign Language are the official languages. Maori became an official language in 1987. In April 2006, New Zealand became the first country to declare a Sign Language as an official language with the strongest legislation in the world to support it.

In 1893 New Zealand became the first place in the world where women gained the vote. In 2001 New Zealand became the first place in the world where all of the highest official titles, Prime Minister, Governor General, Leader of the Opposition and Chief Justice, were held by women. In 2005 New Zealand elected the highest number of women ever to its parliament. In line with its reputation for innovation New Zealand has played a leading role in development of the Convention on the Rights of Persons with Disabilities with New Zealand Disability Sector Organisations and the New Zealand Government continuing to support the implementation of the Convention. In May 2010 the Government pledged NZ \$2.34 million to help promote, protect and monitor the rights of people in line with the Convention. The Government intends to 'resource disabled people's organisations to monitor disabled people's experiences and difficulties they encounter, such as with accessing government services'.

Political: New Zealand is a Constitutional Monarchy. Elections are held every three years under an MMP, or Mixed Member Proportional, system of representation. Since the introduction of MMP in 1996 New Zealand has been governed by a series of Coalition Governments. Post 2000, the political philosophy of the governing

parties allows the provision of social security whilst remaining focused on economic prosperity.

New Zealand follows a Westminster system of government. However, it is a Unicameral system, the upper house having been abolished in 1951. The House of Representative usually has 120 members. However, extra members can be added if required to achieve proportionality.

Three branches of the State exist, the Legislature, the Executive and the Judiciary. Division of power into three branches is designed to act as a mechanism to control power in the decision-making process. Because New Zealand is a parliamentary rather than presidential system there is also a 'fusion of power' with members of the Executive being drawn from the Legislature and the Governor General appointing Ministers, Judges and other officials on the advice of the Prime Minister or other Ministers. New Zealand ranks highly in international comparisons of a social economic and political nature, including lack of corruption.

The passing of legislation in New Zealand requires the assent of the Governor General acting on behalf of HM Queen Elizabeth II. The main function of the Governor General is to arrange for the leader of the main political party to form a Government. If a vote of no confidence in the Government is passed by the House of Representative then the Governor General has the power to dissolve the Government. The Governor General also chairs, but is not a member of the Executive Council which is comprised of Members of Parliament, who are usually also members of Cabinet. The Executive Council is the highest formal instrument of government. It is the part of the executive branch of government.

Executive political power is exercised by a committee of senior Ministers, led by the Prime Minister and known as the Cabinet. The Prime Minister is regarded by convention as 'first among equals' but is required to adhere to the decisions of Cabinet.

Legislative change in New Zealand is made by the Committee of the House of Representatives or, by Regulation, by a quorum of the House, in the Legislative

Council with the assent of the Governor General. There are no provinces, states or territories and regions are administered by local and regional councils.

Economic: From the start New Zealand has existed as a market economy reliant on exports. Mercantilism and Great Britain's need for agricultural goods drove both the colonisation of New Zealand and the developing economy from the 1840s through the early decades of the 20th century. During the post war period from the 1940's to 1984 New Zealand was widely regarded as a workers welfare State. Post 1984 a radical shift in political philosophy earned the country a reputation as one of the most right wing countries in the world, whilst the new millennium has seen a shift back towards human values. To this day New Zealand continues to be heavily dependent on free trade, particularly in agricultural products.

Real (inflation adjusted) GDP for the year ended March 2010 was NZ \$133.1 billion (or US\$ 97.5493 billion.) This equates to NZ \$30,470 (or US \$22,369) per capita. New Zealand is a low wage economy compared to many other developed nations. However, we consistently rank highly in measures of satisfaction or quality of life such as Social Capital. Our cities consistently rank among the worlds most liveable.

Section 2

Law, Policy, and Programs designed to Protect, Promote and Fulfill the Rights of Disabled People

New Zealand's human rights legislation, notably the Human Rights Act 1993, and other human rights legislation applicable to New Zealand, meant that the implementation of the Convention did not create new rights for disabled people. While the Convention does not create new rights for disabled people per se, it does build on conventional understandings of what is required to implement existing human rights as they relate to disabled people. The Convention elaborates on obligations already applicable to New Zealand internationally through other human rights instruments and domestically through human rights legislation.

The New Zealand Disability Strategy

The history of the New Zealand Disability Strategy can be traced to the rise of new social movements around the world in the 1960s and 70s; during this era indigenous rights, women's rights and gay and lesbian rights were making their way onto the political agenda for the first time. Since the 1970s political struggle for indigenous rights in New Zealand has moved towards biculturalism. The resulting bicultural policy framework, setting up an ethos of partnership between Maori and the Crown, has influenced and shaped the making of disability policy. The Treaty of Waitangi has been a major instrument in asserting indigenous rights in New Zealand and negotiations between Maori and the Crown have established important principles that are relevant to disability rights in New Zealand.

As a policy document Te Tiriti establishes a partnership relationship between the Crown and Maori. More specifically three guiding principles, partnership, participation and protection have emerged, each of which is linked to an article of Te Tiriti o Waitangi . The partnership principle requires that Crown and Maori act in

good faith with one another. Participation requires that each partner is able to participate in affairs of the nation. Protection means there is an obligation on the Crown to actively protect Maori interests. These principles are integral to the development of social policy in New Zealand.

According to Sullivan (1999): many within the Disability Rights Movement in New Zealand see themselves as occupying a similar position to Maori in mainstream society.

- Maori were colonised by the British; disabled people have been colonised by medical and associated professionals;
- Maori were made strangers in their own land; many disabled people were locked up in institutions and made strangers to their communities;
- Maori were forced to participate in a biased, mono-cultural system; disabled people were excluded from participating in their communities on their own terms;
- Maori are discriminated against by racism; disabled people by disablism/ableism;
- Maori have high rates of failure in an institutionally racist education system; disabled people are routinely excluded from an ableist, mainstream education system;
- Maori are subject to higher rates of unemployment and lower rates of income than non-Maori; disabled people have high rates of unemployment and many are condemned to survive on subsistence level income supports;
- Just as Maori have had tino rangatiratanga (ie self-determination) denied and made subject to British law, disabled people have had their humanity denied and made subject to pity, medicalisation and welfarism;
- Just as Maori have been granted a limited form of tino rangatiratanga over tribal resources, many disabled people have been granted limited control over their lives within the confines of services, individual life plans, group homes and so on.

In addition, a similar process can be seen in the suppression of Te Reo Maori (Maori Language) and New Zealand Sign Language within the education system. Like Te Reo, Sign Language was explicitly discouraged or forbidden, most deaf children in

New Zealand nevertheless picked up sign language as an unofficial 'playground' language in residential schools (Kennedy, 2002).

Given these parallels, it is not surprising that a number of disabled people in Aotearoa New Zealand came to the conclusion that they needed their own treaty; a treaty to establish a genuine partnership with government; a treaty to guarantee our equal participation in society; a treaty which affirmed the active protection of our citizenship rights by the state. With the election of a Labour-led coalition government in 1999, this seemed a distinct possibility because in opposition they had promised to have a Minister and Office for Disability Issues and the development of a New Zealand Disability Strategy¹.

After extensive consultation with disabled people, the Strategy was adopted in 2001. It is founded on the social model and aims to create a non-disabling society by progressively removing the barriers to participation which confront impaired people.

Underpinning the Strategy is a vision of a fully inclusive society. New Zealand will be inclusive when people with impairments can say they live in:

“A society that highly values our lives and continually enhances our full participation” (NZDS, 2001:1).

Fifteen objectives are set out for the Government to achieve on its way towards a non-disabling society. Ministries, departments and state agencies are required to report on the progress they have made in implementing the strategy in their annual reports to Parliament. In the 2004/05 Progress Report, it was noted that a growing number of crown entities and territorial authorities were willingly taking part in the Strategy's implementation even though they were not required to.

Given this, many disabled people in Aotearoa New Zealand saw the Strategy as their treaty with the Government building towards social participation on their own terms.

¹ This strategy was a requirement of s.8 of the Public Health and Disability Act 2000.

It also set the ground work for the development of a partnership between disabled people and the government and the active protection of disabled people by the government. Such a partnership was highly visible during negotiations around the Convention; from the beginning the New Zealand delegation was one of only a few to consist of State officials and disabled people.

The United Nations Convention on the Rights of Persons with Disabilities is an extension of an ethic and principle present in the New Zealand Disability Strategy and an acknowledgement that there is a need to proceed in the same direction towards the realisation of full human rights for disabled people.

United Nations Convention on the Rights of Persons with Disabilities

The impetus for a Convention gained momentum in 2001 when the General Assembly agreed to look at the need to address disabled peoples' rights. The Convention itself was drafted over the next five years and adopted on 13 December 2006 at the United Nations Headquarters in New York, and entered into force on 3 May 2008. The convention signifies a shift in attitudes away from the idea of disabled peoples as "objects" of charity, medical treatment and social protection towards viewing disabled people as "subjects" with the same human rights as other members of society.

No new legislation was required for New Zealand to implement the Convention domestically. However, a number of minor and technical changes were made to various Acts to ensure they were in line with the Convention. The Minister of Disability issues led the amendments to the legislation.

Implementation of the Convention meant that the Government and people of New Zealand must ensure to disabled people the full realisation of human rights and fundamental freedoms on an equal basis with others and without discrimination on the basis of impairment.

The Office for Disability Issues was established within the Ministry of Social Development in 2002. Within the structure of the New Zealand Government, while the role of the Office of Disability Issues is functionally different, its establishment parallels the Office of Treaty Settlements, whose role is to negotiate historical Treaty settlements in New Zealand. The Office for Disability Issues' core role is to promote and monitor implementation of the New Zealand Disability Strategy, and support the Minister for Disability Issues providing a focal point within government on disability issues and lead cross-sector policy development. The Office for Disability Issues has a role to monitor and implement the Convention.

The Convention requires States to take action to remove barriers to the participation of disabled people in society, whether this is done through legislation, practice, or other measures. Many articles interweave civil and political rights (such as non-discrimination or access to justice) which must be immediately realised at the time of ratification) and economic, social and cultural rights (such as the right to the highest attainable standard of health or accessible transport services, which may be realised progressively, to the maximum of available resources).

Where rights can be progressively implemented, it is up to the Government to decide how quickly and to what degree the implementation will happen, so long as there is a clear and concrete commitment that action will happen to the maximum of its available resources.

This process is similar to the current implementation of the New Zealand Disability Strategy, where any costs are met by government agencies' ordinary funding processes, whether by internal resource allocation or budget bids, and implementation is subject to obtaining the resources needed.

A right in the Convention that is not explicit in earlier human rights treaties is article 19 (living independently in the community). This article expands the need for States to recognise the right of disabled people to live in the community, with choices equal

to others, and to take effective and appropriate measures to facilitate this happening. Such measures include enabling disabled people to: choose their place of residence and choose who they live with; access a range of in-home and community support; and access community services and facilities available to the general population. While this is consistent with the New Zealand Disability Strategy, ratification of the Convention is likely to result in pressure for increased pace of change in its implementation.

Section 3

The Disability Movement in NZ

The story of an unfolding political consciousness from organisations *for* disabled people to organisations *of* disabled people is a far from easy one. However, what this story does demonstrate is that the current monitoring project on the Convention has brought disability organisations together and a spirit of partnership between disabled people and the New Zealand government. New Zealand is the first place in the world to receive government funding for the DRPI project.

Identity politics, the social model of disability, the relationship between Maori and the Crown are key influencers of the disability movement in New Zealand. The philosophical underpinnings and cultural context of the disability movement in New Zealand are discussed below. This is followed by a political history of New Zealand Disabled Peoples' Organisations.

Philosophy

The Disability Rights Movement in New Zealand followed on from other new social movements around the world from the mid 1960s onwards. These new social movements emphasized the need for social change asserting the rights of group members on the basis of a shared cultural identity. It is not surprising, therefore, that it was a group of disabled people, the Union of the Physically Impaired Against Segregation (UPIAS), who first articulated a radical new understanding of disability by separating impairment (body deficits people have) from disability (the social oppression impaired people experience):

....In our view, it is society which disables ... Disability is something imposed on top of our impairments.... (UPIAS 1976:3)

If society disables then material changes to the social world will enable a less disabling social world. Thus the social model provides a framework for material change. This politics of identity which finds its expression in the social model of disability provides the philosophical basis underpinning current disability policy in New Zealand.

Culture

Population and geography have played a vital role in shaping the politics of the disability movement and the way the struggle has unfolded. In the 1970s at the same time as UPIAS were launching their fight for disability rights Maori land rights marches were occurring in New Zealand. Biculturalism, a spirit of partnership between Maori and the Crown, was the outcome of the fight for equality for Maori in New Zealand culture. Biculturalism plays an important role in New Zealand social policy (see sections 1 & 2). For Maori the partnership principle is an expectation based on good faith, mutual respect and understanding, and shared decision-making in both policy making and resource allocation. This spirit of partnership pervades the public service and third sector organizations in New Zealand.

Sullivan (2001) writes for Maori, 'partnership' is an expectation of a relationship based on good faith, mutual respect and understanding, and shared decision-making in both policy making and resource allocation. However, when it came to powerful service provider organisations for disabled people, which traditionally, had a paternalistic relationship with their members, any talk of partnership was highly ideological; more often than not it was aimed more at defusing incipient demands from members for a greater say in running 'their' organisations than in seeking a true partnership.

The Convention has moved the position of disabled people beyond dependence on good intentions to a position of entitlement. For disabled people in Aotearoa New Zealand, true partnerships with the state and service providers are far preferable to the client relationship which previously held sway. However, legislative change does not guarantee human rights. It is now up to New Zealand to monitor and enforce the legislation.

The unfolding history of disability politics in New Zealand is told with reference to two organisations of disabled people the Disabled Person's Assembly (DPA) and the Association of Blind Citizens of New Zealand (ABC NZ) and the political struggles that were undertaken with older and more paternalistic organisations for disabled people. Despite a history of political disagreement and setback, the following description of the history of disabled peoples' organisations demonstrates a great deal of positive change for disabled people over the past thirty years in New Zealand and in particular a coming together of organisations of disabled people around the monitoring process.

DPA

In 1972 Coordinating Councils for the Disabled were set up in the four main centres, Auckland, Christchurch, Dunedin and Wellington. As the name suggests, the aim of these councils was to coordinate the responses of the various groups of and for disabled people on issues such as education and access. In 1978 they combined to become the New Zealand Coordinating Council for the Disabled (NZCD) and were soon at loggerheads with organisations *for* disabled people, who blocked their attempts to become the New Zealand representative on Rehabilitation International because they were "too much influenced by consumer interests" (Georgeson 2000:56). This should have served as an early warning of the entrenched and hostile attitudes of traditional organisations towards their 'children' when they start talking and organising for themselves. But, it did not.

At one of the many meetings set up to discuss issues facing disabled people during the International Year of Disabled Persons (IYDP) (1981), it was proposed that a cross-disability organisation be formed to continue the work of IYDP. In 1983, at an Extraordinary General Meeting of NZDC a resolution to change its name to the Disabled Persons Assembly (New Zealand) was passed.

From its inception, DPA aimed to be as inclusive as possible by creating categories of membership which would draw recruits from across the disability spectrum: individual, family, corporate and associate memberships. The vehicle chosen for

achieving inclusion was the partnership model. It was hoped that partnerships would develop between all these categories of members: together they would work to achieve DPA's vision for New Zealand society to be one "which provides both equity and maximum opportunity to participate for all people" (DPA cited in Georgeson 2000:65)

The DPA has won a significant number of political victories over the years. However, a number of service providers for disabled people adopt a traditional model. Such a model has been criticised by Munford & Sullivan (1997:18) as promoting an image of disabled people as "passive' dependent, powerless and requiring non-disabled people to do things for them". It is inevitable that such service providers will come into conflict with disabled people who wish to advocate for themselves (Sullivan, 2001).

ABCNZ

Eschewing the traditional model of service delivery the Association of Blind Citizens of New Zealand Inc. adopted a self advocacy model from the beginning. Founded in 1945 and called the Dominion Association of the Blind (DAB), ABCNZ is the oldest advocacy organisation in the disability sector. In 1996 the Association withdrew its corporate membership because it felt that DPA was not using the Association correctly as a consultative part of DPA's corporate membership, and withdrew from the organisation (Sullivan, 2001). The history of ABCNZ demonstrates the power of self-organisation and self advocacy:

Without the DABs [now ABCNZ] vigorous and sustained lobbying, some of the improvements which later occurred in blind welfare would have been much longer coming, and many would not have come at all. ...over the past 50 years, at all levels and in all areas in blind service provision, there has been hardly a single decision taken which has not been influenced by association input. (Newbold, 1995: 195-96)

Today ABCNZ have more members than DPA. However, in recognition of the role that DPA plays in the political arena, ABCNZ is once again an organisational member of the DPA.

Other DPOs in New Zealand include: Deaf Aotearoa NZ New Zealand (DANZ) is a not-for-profit organisation which promotes Deaf culture, New Zealand Sign Language and the interests of the Deaf community. Nga Hau E Wha Wha - a quarterly meeting for mental health consumers, funded by MOH, containing two members from each of the four regions of New Zealand – Southern, Central, Midland and Northern. Ngāti Kāpo O Aotearoa Inc was founded in 1983 upon the vision of self-determination (Mana Kāpo) and improving the quality of life of kāpo Māori and their whānau. The society in the 21st century is a national Māori health and disability service provider that is driven by and for Māori disabled consumers and their families - kāpo Māori and their whānau. People First New Zealand Incorporated Nga Tangata Tuatahi, is a national self advocacy organisation led by and for people with learning/intellectual impairments. People First was first brought into New Zealand by IHC NZ Inc in 1984 and was supported by IHC for almost twenty years. It was established as an incorporated society in 2003 following calls from its members to have their own independent organisation. People First groups assist people with learning impairments to learn to speak up in their own live, in communities and at a national level. All of these organisations play an important role in the history of disability advocacy in New Zealand.

What is clear today despite the complex interconnections and politics within DPOs in New Zealand is that advocacy by disabled people *for* disabled people in conjunction with the partnership principle works to achieve results. Amongst the DPOs involved in this project a previously untapped spirit of cooperation exists alongside the desire to push the movement along in a cohesive direction whilst respecting difference.

Section 4

The Study

The provision of evidence-based information for future policy making is the purpose of this project. Semi-structured interviews, undertaken by disabled Monitors with 100 disabled New Zealanders provide the information for the analysis undertaken below.

Key Objectives of the monitoring project

The project involved field interviews to collect accurate and reliable information regarding the human rights situation of disabled New Zealanders. At the same time the monitoring project developed a sustainable system to ensure that disability rights data collection continues beyond the duration of the formal project by creating networks of people to monitor disability rights and by building monitoring capacity within those networks. The project also developed the technical infrastructure needed to collect and store information of this type.

A key objective of the monitoring project is the generation of reports available to disabled peoples organisations, other groups working to improve the lives of disabled people, the media, government bureaucrats and politicians. The reports will inform people about violations of the rights of disabled people; address existing infringements of disability rights and provide information to prevent future rights violations. They will provide evidence to support advocacy for changes in laws, policies, and programs to improve the lives of disabled people. Finally they provide a benchmark to monitor the New Zealand government's progress in fulfilling the commitments it has made to disabled people through its ratification of international human rights treaties.

Interview questions:

The monitoring project attempted to find answers to two questions:

1) What barriers do disabled people face with respect to the exercise of their civil, political, social, economic and cultural rights?

2) How is the exercise of rights by disabled people affected by intersecting forms of disadvantage (e.g. race, gender, ethnicity, geographic location, age, education level and income level)?

Gathering information so that DPOs can submit empirically based information on the state of disabled people's rights in New Zealand to relevant national and international bodies.

The New Zealand Experience of the DRPI Disability Rights Monitoring Project:

There are four basic principles that underlie the DRPI monitoring of disability rights.

The first principle is involvement of disability organizations and disabled people individually, in all aspects of the project. In the case of New Zealand this process was managed and co-ordinated by Disabled People's Organisations. Ninety five percent of the people involved in the project were disabled. The Monitors were disabled, the majority of the transcription was done by disabled people, and three out of four of the analysis team were disabled people.

The second principle is capacity building of organizations of disabled people and disabled people individually in order to ensure the sustainability of monitoring activities beyond the life of the project. This begins with the initial training sessions and continues to be built in the feedback process built into the DPRI method. Capacity is built with respect to: understanding human rights and disability; how to

monitor disability rights (including associated privacy and security concerns); how to train others to monitor disability rights; how to store and protect the data collected; how to analyze monitoring results; and how to manage a monitoring project. A “train the trainer” model is employed with the expectation that those who have gained the skills will, in turn, train other people.

In New Zealand a five-day conference involving an explanation of the interview process, training in interview skills and background to the human rights legislation was held. At this conference interview skills were taught and practiced. The Monitors are a diverse group and this diversity came to the fore in interviewing techniques in the way that they engaged the interviewees. The skills learned during the training are transferable to other monitoring and interview situations. The analysis team now has skills in the use of NVIVO and analysis of interview data. In subsequent projects these skills will continue to be honed. The process of watching, learning and participating proved an excellent learning mechanism.

The third principle is involvement of people with different *types* of impairments, that is, a “cross-disability approach”. Consistent with the need to protect and in order to promote the human rights of *all* disabled people, it is necessary that those involved in project management and implementation and those who are interviewed, are representative of the broad range of impairments. By working together to gather information, people with one type of impairment gain a better understanding of the situation of those with other types of impairment. It is hoped that this will help build multi-group cohesion and strengthen the overall bargaining power of the disability movement.

The process of producing the report was organic with people from a variety of disability groups coming together and working in a cooperative manner. Amongst the DPOs a previously untapped spirit of cooperation is now in evidence.

The fourth principle is an emphasis on the personal stories and priorities of disabled people. The monitoring tool has been developed to ensure that disabled people have an opportunity to tell their own story and to identify those rights issues that are most important to them. The resulting information reflects the most important rights issues

raised by the participants. They identify those rights issues which are priorities to themselves. This is a process in which they are asked which stories they want to tell.

A connection between the Monitors and the interviewees is in evidence in the interview transcripts. It is clear that a bond is formed between interviewer and interviewee and that in many cases there is a shared or common experience underpinning the dialogue.

Collecting the information

The findings presented in this report come from the experiences of disabled New Zealanders. One hundred interviews were undertaken and ninety eight have been used in the analysis. The interviews were digitally recorded, transferred to CD, transcribed and analysed using NVIVO. Interview notes written by the interviewer providing additional contextual information such as an overall impression of the interview, location, and the number of people involved in the interview also inform this analysis. The Convention Coalition committee chose four regions in New Zealand as study sites: the South Island, Wellington, the Bay of Plenty and Auckland. The interviews were carried out over a two month period by interviewers working in teams of two.

A monitoring instrument supplied by DRPI that uses human rights standards defined by the United Nations was employed to collect data. The tool used a series of close-ended and semi-structured questions. Detailed records regarding interviewees' demographic characteristics and experiences were collected at each site. (See appendices for a copy of the monitoring instrument entitled Interview Questionnaire).

The Monitors (interviewers) were disabled people. Using a snowball sampling technique to identify and select interviewees there was an attempt to ensure the interviewees included a cross-section of different types of impairment, ethnicity, gender, class and education. Part way through the interviews the Project Coordinator audited the demographic characteristics of the interview participants subsequently recruiting participants in line with the missing demographic characteristics.

The Monitors worked in pairs each of whom had a different impairment. This enabled the interviewers to act as support for each other both in terms of capturing the data and in assisting each other. Whenever required, New Zealand Sign Language (NZSL) interpreters were employed. NZSL interpreters are at a premium in New Zealand. Difficulty in procuring them meant that some interview teams were obliged to conduct up to three interviews in one day. All the interviews were digitally audio recorded and notes were made immediately after the interviews and time was allocated for the Monitors to do that work.

Summary of the Analysis Process

The interview transcripts were coded into NVIVO, a qualitative data analysis package, using a coding scheme provided by DPRi. On completion of interviews the Monitors brainstormed ideas that had emerged from the interviews at a meeting in Wellington on August 6th. During the coding process the data analysis team met a number of times to discuss themes emerging from the interviews. On completion of the coding process they met and brainstormed emergent themes and important issues that arose in the course of the interviews. NVIVO was subsequently used as a tool to identify themes and issues from the interviews. The draft report was sent out to members of the Convention Coalition in order to gain feedback from the wider community. This process culminated in a meeting in Wellington on November 15th where themes arising from the interviews were discussed and recommendations formulated.

In order to facilitate cross cultural comparison the DRPI have formulated categories of analysis analogous to the Convention. Dignity, autonomy, inclusion, participation, respect are coded positively and negatively within the categories of: work, privacy and the family, social participation, income security, education, information, access to justice and health and habilitation. These classifications provide evidence-based results that have been used to back up the analysis of the participants. NVIVO classifies and categorises data allowing qualitative cross tabulation of information. This enables a comparison of the exercise of human rights in various domains of society and the evaluation of intersecting forms of disadvantage for example,

ethnicity and education level or gender and unemployment. If, for example, we discover that people in the Bay of Plenty have much lower employment rates than other interview sites, we can then query the data with regard to level of education and other labour related issues, to ascertain the significance of the information.

Findings from the Interviews

Self determination is a founding principle of disability politics. Participation strategies are a means that disabled people have employed in the journey to self determination (see appendix 1 for a discussion of the ethics and philosophy underpinning the data collection and analysis process of this project). In keeping with this principle the words of the participants and the Monitors have been used to summarise themes. Demographic information is presented below. Findings are organised according to the main themes emerging from the interviews. In the first section, analysing human rights, the main themes are organised around social participation, health, education and work. In the second section, 'resistance, recommendations and resilience' responses to abuse, reasons for not reporting abuse, the participants' recommendations for change, and systemic roots of disablement are analysed.

Demographic Characteristics of Participants

Key demographic characteristics and the participant selection process are described below.

Gender²

Male

Female

40
58
98 Participants

² No participants identified as transgender

Impairment

Mobility & Physical Impairments	37
Head Injuries/ Brain Disability	2
Vision	18
Hearing	11
Cognitive or Learning	15
Psychological	10
Other	5
98 Participants	

Ethnicity

European	57
Maori	21
Pacific Peoples	7
Other	13
98 Participants	

A sample size of 98 does not provide enough information for sophisticated data analysis. However, the combination of simple statistics and rich information from the semi-structured interview format provides rich data to inform future decision-makers. The participant checking exercise undertaken by the Project Co-ordinator part way through the interview process ensures a good range of impairments are included in the sample. Vision, hearing, cognitive or learning and psychological disorders are well represented, mobility and physical impairments is the largest category by a long way and head injuries/brain disability was chosen by two participants. The sample is skewed towards females [60 percent]. The majority of participants [89 percent] are aged between 22 and 64 years of age. The sample is well educated with all but one participant attending school and 54 participants having engaged in tertiary education 26 of whom have a university qualification.

The mandate for recruitment for the interviews was to move outside of known contacts. Initially, participants were to be recruited using a non-probability sampling method known as the snowball technique. This means that people who take part in interviews are asked to suggest new participants to be interviewed. Sampling error, or the degree to which a sample might differ from the population, cannot be calculated in a non-probability sample. We can however, build up a demographic profile of our participants thus providing a context for understanding the results.

The Project Co-ordinator and Site Co-ordinators started the process by selecting the first few participants in each site with the intention of implementing the snowball technique. However, this technique often resulted in deadends. Reasons for this include the reluctance to pass on details without seeking peoples' permission first, non-contactability of referrals and refusals to be involved.

With mounting pressure on Monitors to complete all their interviews in a very limited time-frame both the Site Co-ordinators and the Project Co-ordinator intervened to kick-start the snowballing again by resorting to convenience sampling methods. For example, Site Co-ordinators suggested people that they knew in the other sites and the Project Co-ordinator suggested other leads to follow for each site.

The Results

Human Rights

Evidence of a disabling society with regard to civil, political, social, economic and cultural rights all feature in this report. Of all of these categories, social participation emerged as the most pressing issue for disabled people.

Social Participation

With thirty nine of the participants directly mentioning experiences of segregation and isolation with regard to participation in social, cultural, and political life, in sports, recreation and leisure activities a total of sixty times, social participation emerged as by far the most significant single issue.

Experiences of segregation

	Participants	Number of References	% of participants
Education	8	13	8
Within the Family	5	7	5
Health Habilitation and Rehabilitation	7	7	7
Information & Communication	5	7	5
Access to Justice	2	2	2
Social, Cultural, and Political Life	41	62	42
Social Protection Schemes	10	13	10
Work	16	22	16

Being made to feel disabled

Social participation is a complex category. Tangible barriers to participation such as access to buildings and information are relatively simple and easy to identify. However, it is the intangible barriers to social participation, things that are taken for granted in non-disabled peoples' lives, such as friendships and other social networks, and access to the social and cultural world that are most pervasive in the results. This barrier to participation can be meaningfully expressed with reference to the participants' experiences' of 'being made to feel disabled'.

Par: ... more recently I've taken to judging restaurants, not by the quality of their food or the variety of their menu, but on how blind they make me feel, because I don't like being made to feel blind and some people are just brainless, and I think a huge amount more could and should be done in training of staff in how to deal with people with all forms of disability...

Non-disabled peoples negative attitudes and lack of understanding of impairment effects marginalises and excludes disabled people.

Par: When I say – I often – when I'm at a shop, I say that I am deaf and suddenly people change and they think I'm dumb and I think "Oh brother, oh brother!"..... I don't enjoy going out with somebody and people will say "Oh, Miranda's deaf." I'd rather they said, because I feel that's a label and people associate 'thick' and 'dumb' and 'couldn't care' and things like that, with the whole deaf person – deaf label.

I prefer people say "Miranda doesn't hear but she lip reads," or something or other, some sort of scenario, some sort of situation.

Int: You were saying having your knee trouble has made you feel disabled, do you think some of the fear you were talking about before is about people seeing you as disabled?

Par: they would treat me differently.

Int: How do you think they would treat you differently and how would that affect your life?

Par: I think sometimes the whole pity thing is condescending and offending and it kind of keeps you down like 'oh you poor thing, poor you I'm so great but poor you - I'm perfect and you're not'. In that circumstance I could say 'but you're not perfect, no one is and at least my disabilities might be physical but yours are inside of you, in your mind and your heart'.

Par: I saw a guy when I was at the shop – I went down there. I knew him very well but he totally ignored me and he wouldn't look at me – he saw me – he knew I was there but he wouldn't acknowledge that I was there.

Int: Do you think people look at you differently because of you're...?

Par: Yes.

Int: You do. Can you explain that? How do you think they see you as say yourself and as a family because you all have disabilities? Do they treat you differently?

Par: Yes, some of them. Yes some of them in [a small New Zealand town] and when you're walking down the road or somewhere and they would shout out in the car to you – at you.

Int: Really. What nasty names?

Par: Nasty names, yeah, because I look different and they would call me nasty names....my wife just says, "Just ignore them."... And you walk away. Sometimes I say – I say to her "I find it hard to do that".

Int: Yeah, you would. So she can walk away and just ignore them.

Par: Sometimes.

Int: Yeah, but it hurts, doesn't it?

Par: Yeah, it does.

Attitudes disable people. Being made to feel disabled is not contingent upon skills or aptitude and is present even when disabled people have the same or better skills than non-disabled people.

Par: The second thing was so that when I went across the road to the second quiz I was very nervous. But because I could answer the questions really well, I've got quite a good knowledge base, we won the quiz, quite handsomely actually, and I was kept on. I had essentially become valuable and the quiz team next to me was rather interested in getting me into their team, but they were a little bit put off by my appearance, so I told them basically to go to hell.

Physical environment

In order to participate in social life the social environment needs to accommodate peoples' needs. However, to get to social venues people need to be able to travel. Adequate transportation facilitates many aspects of disabled peoples' lives. The lack

of adequate transport in terms of availability, ease of use and cost featured in peoples stories. Airline travel can be hit and miss for disabled people and travelling away from mainstream centres can be tenuous.

Time and waiting for transportation is a frequently cited issue:

Par: I ordered a taxi and if I'm in another city I'll tend to say 'I've got a guide dog because it helps with identification, not because I have to get permission. But in Auckland I rarely do....because a well-known taxi company came [saw me and the dog] and left.

Par: there are mobility taxis around, but they are very very expensive and are not available at the times that I require them.

The poor quality of service of transportation services; particularly taxis and buses emerged as a systemic cause of stress for disabled people. Solutions to this ranged from education of providers to better subsidies for services:

Par: I think they should do some more disability awareness stuff [because the problem with the taxi drivers] wasn't just the odd person it was about twenty drivers.

Par: Better funding for, and support taxi companies, mobility taxi companies....

Overseas travel is an issue in terms of finding adequate accommodation, movement around foreign cities and travel to and from the destination:

Par: I would say because I'm a wheelchair user, find access um, the biggest barrier, um into participating. That prevents me from participating fully, especially around travelling. If I need to go overseas airlines make it very difficult. Also my wheelchair gets damaged almost all the time when travelling.

Access to venues is a major barrier to participation in social life:

Int: [Access issues question]

Par: Classic ones are some shop layouts and in particular pharmacies seem to be a complete nightmare.

Par: Oh that's the whole time.... there is so much I can't do because of accessibility. One was really bad was [name] our MP. I can't get into her office.

Int: What did she have to say?

Par: I said I hope you're embarrassed. She said oh we'll fix it up, nothing's been done.

Par: access into restaurants, into public places, um, you know. When my friends and I want to go out for dinner, we can't just go to a place that we want to go, we have to check for access, we have to check for accessibility, toilets, everything, and most places are inaccessible, especially clubs and bars and things like that. So, I just don't go to them, I guess, yeah.

Int: When you say you check into them, what, is there a place that you go to?

Par: Websites and phone numbers. But, good places, food places are those that put their information on the website for us to research, especially if they include pictures and pictures of their doorways and their restaurant layouts that really helps us, yeah.

Lack of suitable accommodation and accessible venues outside of main centres is an issue. Participants miss significant events in the lives of people in their social networks. The results suggest that there is an issue for people using larger wheelchairs and power chairs. Power chairs are particularly restricting because of the weight and lack of manoeuvrability over lips and curves. One participant could not go to the movies because the weight restrictions in the only local theatre:

Par: They don't have a lot of wheelchair ramps; and if they do, they're too small, the doors are too narrow.

Par: So access is, is a really big thing. I find that I can't go out. Some friends want to meet at a restaurant and you go there and you can't, you know, it's

just, you can't get in the door or the space is too tight. I've been to motels where they said that they have wheelchair access but then you get there, there's a big lip on the door, your chair can't get over it and they haven't realized you're in a power chair, and that your power chair alone weighs about a hundred and forty KGs, and with me on top of it, well. So it's like, you get into a lot of those situations, where is it, and just, the doors from a lot of venues, you go up to a place and you want to go in there but you can't open the door, and there's no-one around or, you know, it's just kind of, you don't want to ask people, could you open that door for me please? I mean I do now. But all of those kind of things, they would actually stop me from participating in stuff.

Par: In the last five years I have been left out of a great number of things. I'm unable to attend because of the hearing and the brain injury. It makes it difficult, a lot of friends that I had have dropped away from me and I've become more and more lonely and it is hard to join groups.

Communication and Social Isolation

Problems with communication lead to social isolation. This is an issue for people with a variety of impairments. The associated problems however, are illustrated very clearly in the deaf community:

Par: My experience of being left out is very common as a deaf person, not just at school but pretty much everywhere. That's the experience of being deaf, is not to be able to participate as part of what's going on around you.

Par: Yes, they probably think 'she can't hear the music and she won't have a good time'. But it would still be nice to be asked sometimes to go to a party or something. My brother who is eighteen, he goes to parties every weekend. He goes out with his mates and they go driving around in his car cruising - that's illegal now - but he has a good time. I bet if I was hearing I'd be more like him. I'd be out more.

In terms of exclusion, if you tell someone that you're deaf and you have to lip read, there's this instant... with some people you can tell they think oh, and then they just walk away; because of the difficulties in communication, they don't know how to communicate. Other people are just fine with it and they just keep talking. So if I go into a shop and someone comes up to me and I tell them I'm deaf and have to lip read, 75 percent of them will just walk away.

Being deaf means not only that you can't hear but also that if you are signing you are speaking a different language. Becoming deaf in later life means not only that access to the hearing community is limited but that within the deaf community you have a kind of second language status:

Int: Do you have some thoughts about why it's easier for a person, perhaps that's born deaf, to access communication and sign, but a person who experienced a later deaf disability doesn't have that same access?

Par: Definitely. The whole deaf language is really hard, the grammar's hard, the culture's different, I imagine it's exactly the same as if you come from another foreign speaking country like Arabia and get plonked in New Zealand, I imagine you have exactly the same problems as what I'm experiencing...

The example of deaf people illustrates the complexities of living with impairments. Beyond the issues associated with language and communication there are attitudinal difficulties associated with identity.

Par: Yes it's like I'm in the middle - even though people say I've got the best of both worlds it's not entirely true because I'm still stuck in the middle. Deaf people sometimes don't want to accept you because you have a cochlear implant and hearing people don't want to accept you because your disability, you're not all there - but I am all there, they just don't take the time to understand or have the time to learn about different kinds of being deaf.

Disability as Difference: Social isolation

This project is part of a process to demystify disablement. The participant above identifies people not taking time to understand or learn about different disabilities as a disabling practice. As H.P. Lovecraft wrote in 'Supernatural Horror in Literature' (1927) 'the oldest and strongest emotion of mankind is fear, and the oldest and strongest kind of fear is fear of the unknown. The following quotes illustrate the way in which fear of the unknown manifests with respect to impairment:

Par: I used to get on the bus, and I would sit in the seat, and the bus might have been crowded, but nobody sat next to me. Simply they would take one look and avoid sitting [next to me]. Which wasn't so bad for me but I was always wondering why nobody was [sitting next to me].

Par: Yeah, and anyway, again for like people in wheelchairs and people with disabilities they stereotype you and they sort of like stay away from you.

Par: Well, when I go to the shops, they think I look like I'm handicapped.

Int: How do people react when they hear that you have a hearing disability? Do they yell?

Par: No, they don't even bother to talk to me.

Par: But at the same time it's been a very difficult part of my life because I'm deaf, I'm often isolated. Some people think that I have some kind of sickness and they're too scared to come and talk to me and then on the Marae and stuff, it makes it worse, you know, and I feel like I'm further isolated. So a lot of the times I actually just give up.

These stories of social isolation occurring through people's negative reactions to difference are an integral part of the denial of human rights. A society that ignores disabled people is far from inclusive. However, sometimes non-disabled people's inability to deal with impairment becomes about power and control and as the following anecdote demonstrates disabled people are subjected to deliberately marginalising practices:

Par: One example would be where my daughter went on a North shore – to Wilson Centre... she was getting new splints, and one of the staff members there, and of course they had an interpreter, and the woman said to the interpreter, she said “Wait, don’t start signing at the same time, I’m going to explain it to you first and once I’ve told you the entire story, then you tell the deaf person.” And the interpreter tried to say to the hearing person “Well hang on, we actually sign at the same time as we’re hearing because then the deaf person has access straight away.” And she controlled that and she said “No you’re not, you’re going to stop signing and put your hands down, and you’re going to listen to me, and then you’re going to tell the deaf person the message.” That was a blatant disregard of my rights to get the information, the interpreter is simply there to bridge the communication gap. But to get it second or third hand, she made a decision about how I was actually going to get information. So in that sense, she controlled me but she also controlled the interpreter. And the whole point of the exercise was for my daughter’s health.

The irony of this particular incident is that it took place in a medicalised context. The social model of disability underpinning both the Strategy and the Convention had its inception in a critique of the medical model with its paternalism and tendency to categorise people according to impairment.

Health

References to negative experience with regard to health emerged as the second most significant theme. Instances of marginalisation with regard to health services are idiosyncratic and difficult to quantify. However the fact that health is an issue is not surprising given that disability politics grew out of a critique of the medical model. While the participants’ experiences do not lead us to particular issues, they do support the social model critique of the medical model of disability, demonstrating that in a medicalised environment, where impairment takes precedence over the person, marginalising practices such as the instruction to “*stop signing and put your*

hands down, and you're going to listen to me, and then you're going to tell the deaf person the message" reported in the precious excerpt, are likely to occur.

The quality of care received by people who need carers in daily life is intimately related to health outcomes. The problem of finding good carers is a consistent theme emerging from the interviews and an issue with substantial historical precedent. Since the move from bulk funding to contracting in New Zealand post 1984, quality and continuity of carers has been an issue for disabled people. Problems in this area are often attributed to the low wage and undervalued nature of caring work.

Par: It's difficult too because the hourly rate for attendant carers is not very good and it's hard to attract decent and reliable attendant carers at the low wage rate.

The results of the monitoring project clearly demonstrate that health continues to be an issue with experiences of negative dignity, disrespect for difference, lack of autonomy, discrimination and inequality and segregation and isolation featuring far more strongly than their positive counter points.

Health, Habilitation & Rehabilitation

	Participants	Number of References	% of participants
Discrimination and Inequality	10	14	10
Non-discrimination and Equality	4	4	4
Disrespect for Difference	19	26	19
Respect for Difference	2	3	2
Negative Dignity	23	43	23
Positive Dignity	12	14	12
Lack of Autonomy	12	15	12
Autonomy	8	9	8
Segregation & Isolation	7	7	7
Participation, Inclusion & Accessibility	0	0	0

Income Security and Support Services

The results with regard to income security and support services revealed a similar pattern of negative experience. There is an intimate link between health, income and support services, it is therefore not surprising that there are many references to overall health and the health consequences of inadequate care services in the income support and support services category:

Income Security and Support Services

	Participants	Number of References	% of participants
Discrimination and Inequality	9	9	9
Non-discrimination and Equality	0	0	0
Disrespect for Difference	17	24	17
Respect for Difference	3	3	3
Negative Dignity	23	41	23
Positive Dignity	6	6	6
Lack of Autonomy	11	17	11
Autonomy	5	5	5
Exclusion & Inaccessibility	10	13	10
Participation, Inclusion & Accessibility	1	1	1

Access to adequate care not only affects quality of life, it also often has an immediate impact upon health and in extreme cases the effects of inadequate care can be lethal.

Par: I've seen that happening to a lot of disabled. I've been like this for 36 years. I've been in Middlemore children's spinal unit six years and I've seen a lot of, a lot, of human rights and, and deprivation and friends just die because there is no support

When people complain about inadequate care or no shows, the care agencies don't seem to care.

Intersecting forms of disadvantage

How is the exercise of rights by disabled people affected by intersecting forms of disadvantage (e.g. race, gender, ethnicity, geographic location, age, education level and income level)? The interview guide directs the Monitors to ask questions about ethnicity, social class and gender. Despite this participants were not forthcoming with regard to comments in this area with one participant commenting on class and disability; four participants speaking about ethnicity and disability and four speaking about gender and disability. Nonetheless evidence of variation in the experiences of disablement exists in the participants' stories.

Education

While disabled people do face barriers in gaining tertiary education rates of participation in tertiary education are significant with close to half the sample having participated in tertiary education, including a number of Masters Degrees.

	University	Tertiary	Short Course or Diploma	Total	% of participants
Pakeha/European	16	4	14	34	59%
Pacific Peoples	1	0	2	3	42%
Maori	5	1	4	10	47%
Other	2	1	3	7	58%

Participation rates for Pacific Peoples and Maori are lower than the rest of the sample population. These figures demonstrate a degree of social participation with regard to the education system in New Zealand. Given that social participation emerged as the most pressing single issue in the study it may be that the education

system may provide some clues toward facilitative practices and systems in the wider community.

The education category in the monitoring instrument is specifically designed to gather information on life experiences that took place at school or through education. Within the categories measuring negative experience, disrespect for difference and problems with regard to participation, inclusion and accessibility occurred most frequently. On the other hand positive dignity also emerged as a significant category. Responses within the three categories cited above are approximately twice as frequent as any other education category with thirteen participants making twenty references with regard to disrespect for difference, eight participants making thirteen references with regard to participation, inclusion and accessibility. Within these negative categories most of the references relate to experiences within primary and secondary schools or to problems with accessing information such as lack of NZSL interpreters or Braille translations.

Education

	Participants	References	% of participants
Disrespect for difference	13	20	13
Problems with regard to participation, inclusion, accessibility	8	13	8
Positive Dignity	10	13	10

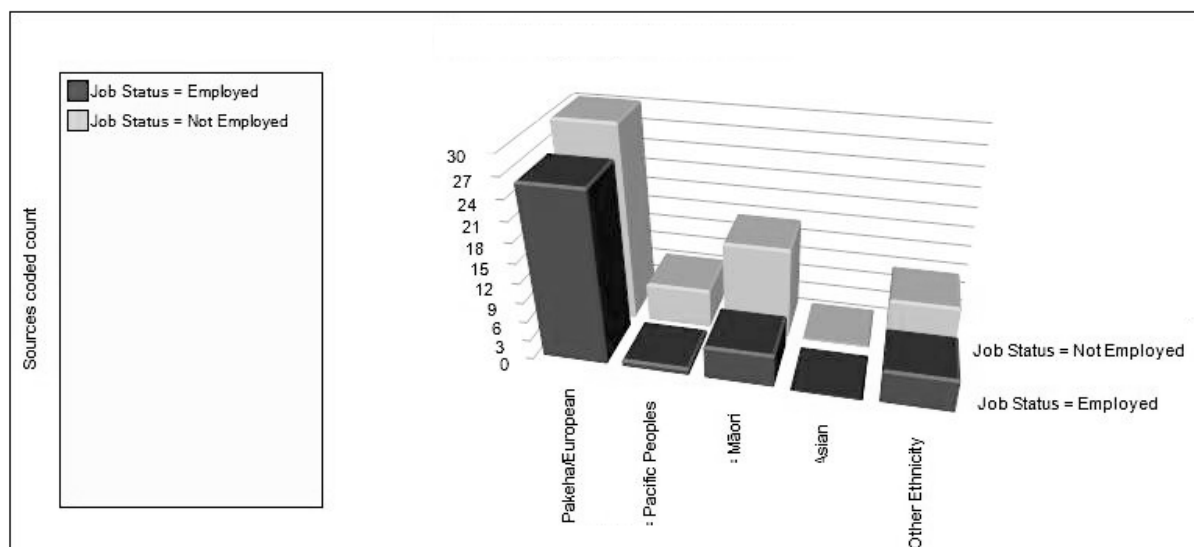
The positive dignity category shows thirteen references made by ten participants. Individual people's efforts to enable learning on a one to one basis are the main topic in this category. This finding adds weight to the idea, expressed time and again in this study that education and knowledge about disability enable participation, inclusion, and human rights.

Barriers to work force participation

The high rates of educational attainment demonstrate that those disabled people are capable and disciplined workers, yet this work ability is not reflected in their employment rates with a high percentage of unemployment evident in the sample. The unemployment rate for the sample is approximately 62 percent³. This is compared to seven percent in the general the population over the same time frame (Department of Labour, 2010).

Differences between employment rates of men (42 percent) and women (33 percent) are significant. Ethnicity is a very large factor in the employment statistics with Pakeha 46% percent identifying as unemployed as opposed to rates of 83 percent for Maori, 85 percent for Pacific People and 61 percent for all other ethnicities.

Employment and Unemployment by Ethnicity (Number of Participants)



The DPRI monitoring instrument did not require participants to disclose an income range however employment status is a good indicator of income level. Low income in

³ These statistics are significantly different from those gathered by Statistics New Zealand in 2006. It is likely that this is due to the non-probability nature of sampling frame selection and the fact that most of the interviews took place during work hours. The 2006 Disability Survey (Statistics New Zealand, 2008) revealed that less than half (45 percent) of disabled people were in the labour force, compared with over three-quarters (77 percent) of non-disabled people of working age.

combination with the higher living costs associated with disability compound to produce further barriers to participation in the work force. Well educated and work skilled participants report giving up jobs or not taking up work because the work environment or the pressure to work full time makes employment untenable:

Par: I've been on the benefit and I've worked part-time, self-employed and contract work, and I guess because I've had that experience working for a Government department and other places over the years, I've built up a few contacts so I've kind of been quite lucky with being offered work, and the, but the limitation has been more the energy that I've got to do that work so I've often said no to bits of contract work if it just, I guess my priority has to be, has been to be healthy rather than to get off the benefit or to earn heaps of money.

Int: So health and energy's been a bit of a struggle in the last five years...and sometimes it's hard to say no [to work]?

Par: Oh it's very seductive when you're offered work and you're, oh yes, that sounds exciting, and you think, oh I could do that, it might stretch me a bit, I could do it. Yeah, that's quite hard to say no to and to be honest, you know, to live on a low income is stressful too so you're kind of balancing the stresses that you choose

Lack of accommodation for the everyday reality of living with an impairment featured in many of the interviews. For many disabled people the energy that it takes to get up and dressed and make their way to a work place significantly cuts into their potential productivity.

While many disabled people have the capacity to work productively full time working five days a week, nine to five, within standardised work hours may not be a viable option:

Par: When I was appointed to the job I was expected to be regularly in the office. This was something I hadn't been expecting, I wasn't told that I'd be expected to do that. At home I could get my work done at any time of the day or night that I was awake. It didn't matter as long as I got it done, no-one

really worried. But because I find regular hours very difficult to keep to now, it was very difficult to be 'on song' for the same 8 hours every day, that became quite stressful.

Impairment effects can be both time consuming and physically demanding and as a result many disabled people develop strategies to get the most out of their days. Rigid work place policies may make it difficult to execute these strategies. Clearly there is a need for change in this area. The need for change in the area of employment, in the form of government supports to improve access to work for disabled people, emerged as the second most significant recommendation to improve the situation of disabled people. While the Strategy and the Convention enshrine non-disabling principles legislative change by itself is not enough to make significant change to a disabling society:

Par: I just was really tired. I talked to the managers about, could I come in later in the mornings, citing the disability strategy, citing the convention. Now this [was the Ministry of ...]. It was an organisation that was promoting both the Strategy and the Convention to schools, yet, I just said, could I come in at 10.30 in the morning instead of 9.30 and I could work later in the day? Because it was like I was so tired it was, I mean it wouldn't have been a final solution, because I just really needed a rest, but it was a way I could have continued, a way I could have worked in a short term. And they couldn't see past their own HR strategies as a government department, my manager said I needed to be there at 9.30 instead of 10.30.

Int: Did you ever, was there ever an opportunity to do any work from home?

Par: No, wasn't allowed either. So the Ministry of [...] is actually very, I mean the particular manager I was working under was probably a person who was unable to make any accommodations,

When disabled people are accommodated in the work place they are often perceived to be receiving special treatment. These attitudes are in themselves disabling:

Par: there's some people will look at me and think well she looks fine – like there's nothing (I won't say the word) – nothing effing wrong with her – like

why does she get the privilege of doing what she does or – because some of the time I go in I do different duties. It might just be like paper work and things like that and you know, - I suppose it might be looked upon as – she’s lucky, that’s all she’s doing but it’s not actually easy, it’s still physically demanding “you’re really lucky, or your – or those are good hours that you’ve got,” sort of thing.

The experience of disabled people in the work force offers a clear example of negative and disabling attitudes in New Zealand society. There is no logical reason why disabled people cannot participate more fully in the workforce:

Par: I don’t know why? I mean, I’ve got a Masters, I’ve got loads of experience, prepared to work incredibly hard, but obviously I’m just – and the longer I’m not employed, the harder it gets.

Small changes to attitudes and accommodation for the needs of disabled people in the work place have the potential to produce economic and productivity benefits that advantage the whole community, particularly if we are competing in an intellectual and productivity capacity in the global market place. In New Zealand for the Accessible Wellington Forum in 2006 IBM accessible technologies guru Mark Bagshaw pointed out that talented, motivated workers are going to waste in the disabled community, “They’re not just employable, but employable in productive, well-paid jobs,” Bagshaw said. Even four years later accessible technologies that were once expensive and cumbersome are now so available that many can be accessed on cell phones. With today’s connectivity it should be possible to create flexibility in the work force so that disabled people have the opportunity to participate.

Resistance, Recommendations & Resilience

The results in the preceding section come from the participants' analyses of the Human Rights implications of their everyday experience. In the next section responses to abuse, reasons for not reporting abuse, the participants' recommendations for change, and systemic roots of disablement are analysed.

Two hundred and seventy recommendations for change were voiced. It is clear that the DRPI interview process works as a vehicle for participation of disabled people.

Recommendations (for change)

	Participants	Number of References	% of participants
Raise Awareness	27	43	27.5
Other	53	130	54
Peer Support	5	7	5
Representation	5	6	5
Respect	17	27	17
Social Supports	8	14	8
Economic Supports ⁴	21	43	21
Total			270

As discussed in the opening of the analysis section, non-disabled peoples lack of understanding of impairment effects is a major factor in the social isolation of disabled people. While a large number and wide range of recommendations were made in the course of the monitoring project, the single largest category to emerge is the need to raise awareness. Calls for disability awareness training in all areas of life from the public sector to, service industries, to educational institutions, to society in

⁴ This category recorded 'government supports to improve access to work' for disabled people.

general pervade the results. Participants suggest a variety of strategies to raise awareness. In the following excerpt an argument is made for a media campaign:

Par: I think we – you know, we have come some way but for me it will be some really across the board – really-really visible campaign. A bit like the ‘like minds - like mine’ campaign. And I – and I know that, that has cost lots of money and I know that it’s not perfect....But, you know, I was watching those ads last night and thinking, that’s exactly what you need. So you just need ... there’s now a whole other set of ads they’ve just come out with now saying, “you know, what do you need to know to support someone through mental health,” and basically saying, just being there you know. So what do people with disabilities need? They need friends. They need employment. They need opportunities to experience the same things. So [we need] that kind of really systemic multi media campaign.

A clear message emerging from the project is that if you have an impairment, then people do not know how to relate to you. Education as a means of raising awareness is a simple and effective solution many participants suggest:

Par: luckily for me that we had these guys come in and talk to us [about] why people react in different ways and so that was fine. I went home and the next time I saw him, I went up and approached him and started talking to him. His whole manner changed. And that was just from saying that people don’t know how to behave around you.

Some people who you think, who you know very well, will be completely different and if I hadn’t been taught that I would probably never have spoken to him but because I understood that – they act differently well kei te pai and that’s good now. It’s just understanding that people don’t know how to approach you.

Another recurrent theme in the recommendations section and indeed throughout the results is frustrations experienced with regard to the inflexibility and time consuming nature of the bureaucracy. Bureaucratic processes and practices are not designed

with the everyday realities of disabled peoples' lives in mind. Systems are set up to cater to the requirements of the bureaucracy rather than the disabled person:

Par: Definitely more training for professionals, not just around the equipment but also around interpersonal relationships and disability awareness. We're too easily put into boxes and usually they are square boxes whereas most of us tend to have round lives.

Par:there's an assumption the needs of the client will be met by meeting the needs of the bureaucracy.

Par: With service providers I'd like to see them coming at it from the point of view of "how can we make this work" rather than from the point of "let's see if you crunch enough numbers or tick enough boxes for us to make it work".... I mean every year we have got to go through and drag out all of your receipts and substantiate anything to do with my disability. It's a bloody nightmare, it really is....

Par: People need to know that just because someone has a back injury and needs to stand at their desk, it's not going to pose a health and safety issue. Especially if you have a discussion with that person, and that person is a logical, intelligent, thinking person.

Par: Every time, or every year there's a needs assessment and they'll come and update the information and I – feels like I'm explaining the same information again and again and again.

Bureaucratic systems were clearly identified as mechanisms of power and control over disabled peoples' lives. A common example in the project is occupational therapists making inappropriate decisions about equipment and the design of house modifications:

Par: In this system you have to fight to have it recognised if the equipment doesn't work or isn't suitable. The OT held all the power and control and her

position held more weight with funders and service providers than my situation as a client did.

The story of the deaf secondary school teaching student forced to take music class is a classic example of deliberately disabling bureaucratic practice (see vignette from the interviews in appendix 3)

It may also be due to the fact that impairment effects manifest themselves in context specific ways so a participants' primary experience of disablement in daily life may not be different to that experienced in the interview context. For example, if a deaf person for whom sign is their first language lives alone in the country their Asthma may be their primary disabling experience whereas in an interview context second language status may be the primary issue.

The participants quoted in the preceding excerpts clearly feel they take second place to bureaucratic regulation. Occupational health and safety regulations, designed as social protection mechanisms are used to deny access to the work place. While the frustration of substantiating disability annually and retelling stories over and over to different agencies, departments and health professionals is a familiar trope. So familiar in fact that the Ministry of Health is already investigating the possibility of Local Area Co-ordination, where one person coordinates services across different agencies.

Reasons for Not Reporting

The results suggest that in general people will report human rights violations with relatively low instances of people failing to report. However, while nothing stands out as a particular barrier in this category there is mention of reluctance to report in the work place, resignation with regard to health and public transportation issues.

Par: Workbridge basically, for example, chose the taxi company for me to use, and I don't blame them, because there aren't many around, and are not available at the times that I require. So there isn't much choice really.

Int: So accepting it, how does that make you feel?

Par: Ah, not that great, but, and I feel powerless. However, if I want to participate in the society and if I want to do the things that I want to do um, I have to put up with it. Otherwise, I'll just end up staying at home.

Reasons for not reporting

	Participants	Number of	%	of
		References	participants	
Nothing Would Have Happened	7	10	7	
Other	12	15	12	
Self Blame	3	4	3	
Fear	5	5	5	

Seven participants reported that they had not reported human rights violations because nothing would have happened. Two of these relate to taxi companies and two relate to health. However, in the above example there is an element of acceptance, of things being 'not quite right' the participant does not go so far as to analyse this as a human rights violation. Examples of things being 'not quite right' are pervasive in the participants' transcripts. Fear of losing services is another reason people do not complain. Lack of financial means and lack of access and corruption were not significant.

Responses to Abuse

	Participants	Number of References	% of participants
Distancing	19	26	19
Other	20	29	20
Report Legal Action	24	35	24
Resisting	28	48	28.5

Querying the data with respect to ethnicity, education level and disability showed responses in proportion to the sample except in responses to abuse. Women are more likely to report abuse or take legal action with eighteen (thirty percent) of women compared with 6 (fifteen) of men reporting this action. The fact that significant numbers of participants articulate responses to abuse clearly demonstrates that disabled peoples' human rights are not guaranteed in New Zealand.

Systemic Roots of Discrimination

In terms of the systemic roots of disablement, acts of exclusion and discrimination against disabled people that are related to the ways in which economic activities are organised and delivered, was most significant.

	Participants	Number of References	% of participants
Economic	29	41	29.5
Legislative	23	39	23
Social	15	29	15

When participants raised issues with regard to economic factors, legislation and government support it echoed issues discussed elsewhere in the report such as bureaucratic inflexibility, lack of real understanding by government departments and

issues with communication demonstrating once again a lack of understanding of disability issues in New Zealand society:

Par: And there are also lots of instances where people will say to me, if it's a government service, well no, it's your responsibility to book the interpreter, you're Deaf, you should do it. And I'm like, "But hang on, you're a government service, I'm coming here, you need the interpreter so your hearing people can understand, I don't have a problem, I can understand Sign Language but you can't understand me. You book the interpreter, you have them here."

Section 5

Conclusions Recommendations

The conclusions and recommendations in this section come out of and are aligned to the monitoring projects' results. The project management committee took the draft report back to their organisations for feedback. Each organisation was asked to come up with three main recommendations that they considered realistically achievable. The following recommendations are the agreed outcomes of this analytical process.

The recommendations relate to social participation, the bureaucracy, work, getting out and about, and universal design.

Social Participation

The biggest drivers of discrimination toward disabled people are barriers to social participation. Disabled people want to participate in society realising the same citizenship rights and human rights as others. Participation is limited however, sometimes by lack of accommodations, but more often than not by attitudes borne from a lack of understanding of the everyday realities of disabled peoples' lives.

Currently we are aware that the New Zealand government are about to embark on an awareness campaign. This will probably focus on tangible issues like work, transport and communication. However, some thought should be given to the drivers for true social participation such as friendships and other networks that are taken for granted in non-disabled people's everyday lives.

Recommendation 1: That New Zealand undertakes an "awareness campaign" that targets all sectors of society and concerns the broader aspects of social participation, notably the attitudinal barriers that are a key driver of social exclusion.

DPOs should be full and active partners in decisions, design and delivery. There should be compulsory staff training in disability awareness, with the courses provided via DPOs.

The Bureaucracy

Disabled people reported that the major barrier for them was the bureaucracy that hinders rather than helps. As one participant said, *“there's an assumption the needs of the client will be met by meeting the needs of the bureaucracy”*.

From the project results we can conclude that bureaucratic expediency is often used as a rationale for disablement. People are acting in a rational manner and following the rules but the net effect of the rules is clearly discriminatory. The most obvious example of this is disabled people having to demonstrate year after year that they still have their lifelong impairments. The cumulative effect of this is that time and money is wasted proving the obvious.

Recommendation 2: A) That in partnership with DPOs, New Zealand undertakes a detailed assessment of the barriers that prevent disabled people from fully participating in society.

Recommendation 2: B) That key performance indicators are created and monitored for all public services and that DPOs and disabled people are part of a monitoring process.

Work

The project results suggest that there is a large resource of well educated disabled people who are unable to access employment. The biggest gains to be made in this area involve changing employers' misinformed attitudes about disabled people and to have more flexible working conditions.

Recommendation 3: That the requirement for reasonable accommodation for disabled people is enforced and those to whom it applies are made aware of their obligations.

Getting out and about

Leaving home for short or extended periods of time is an issue for disabled people. However, despite ongoing marginalisation people don't report discrimination with respect to transport because they perceive that nothing will happen. As one disabled person involved in the project reported, "the system bashes disabled people, the system wears you down until you are ready to accept anything".

Recommendation 4: That an industry standard (similar to the tourism industry's Qualmark) is developed. It should signal a non-disabling environment and universal design features.

Further Work

For the next two years government funding has been provided to enable DPOs to conduct disability rights monitoring on an annual basis to appraise the state of the human rights of disabled people. Annual reports of this assessment can be used to provide information for Human Rights monitoring mechanisms.

Conclusion: Addressing discrimination

Disability rights movements around the world recognise negative social attitudes as one of the major factors disabling people with impairments. The Convention recognises that negative social attitudes can prevent disabled people from participating in society as much as any physical barrier. The clear disability

awareness message coming out of this project supports the argument for the disabling nature of social attitudes. (See recommendation 1)

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Appendices

- Appendix 1 Ethical and Philosophical Underpinnings of the Project**
- Appendix 2 Details of the Monitoring Process and Learning from the Project**
- Appendix 3 Vignette from the Interviews**
- Appendix 4 Informed Consent**
- Appendix 5 Interview Guide**
- Appendix 6 Post Interview Brain Storm with Monitors**
- Appendix 7 Information Sheet**
- Appendix 8 People & Organisations Involved in the Project**
- Appendix 9 Plain Language Summary of the Project**

Appendix 1 Ethical and Philosophical Underpinnings of the Project

The New Zealand version of the DPRI project was the first to be funded by a Government and the first to be undertaken almost exclusively by disabled people. This is historically significant because non-disabled people have been the experts in the field of impairment and on disabled people. Differences in lived experience between disabled and non-disabled people meant that the knowledge produced by professionals in the field often failed to capture the lived reality of disabled peoples' lives. Deliberately participative methods, fostering collaboration between disabled and non-disabled people, have been utilised in the process of moving from the era of the non-disabled expert to self determination. Participative strategies take a variety of forms and have been applied as a method of enquiry and political strategies in many different settings (see for example, Lawrence-Lightfoot & Davis, 1997; Lunn, 2001; Noble & Robinson, 1999; Reason & Bradbury, 2001; Reinharz, 1992; Tierney, 2000).

By involving disabled people as much as possible the process of knowledge production, thus foregrounding the 'nothing about us without us' motto of disabled politics the DRPI framework utilises participative principles. Often the most challenging part of the process is to involve disabled people in the data analysis and reporting phase. In this project this challenge was met. Meetings of the Monitors toward the end of the interview process (see appendix 6 for a summary of the brain storming process) and then again to give feedback on the draft report meant that the entire project team participated in interim and final analysis of findings. DPOs involved in the project also gave feedback that was used in the construction of the recommendations section.

Allowing us to question the strategies by which knowledge is legitimated and how we come to know participative projects are part of a process toward more informed ways of knowing the world (see for example, du Bois, 1983; Lather, 1991; Lykes, 1989; Smith, 1987; Vaughter, 1976; Wallston, 1981). Operationalising an attitude of critical reflection, this project critically analyses the process of disablement in New Zealand

providing valuable information that can be used to develop methodologies that capture the New Zealand experience of disablement more accurately.

Appendix 2 Details of the Monitoring Process and learning from the Project

How the Organisational Framework for the Study Evolved

On 15 December 2008, Marcia Rioux addressed a workshop with invited disabled people's organisations and others to learn about the Disability Rights Promotion International project and discuss its possible benefit to New Zealand. The project investigates legal systems, individual experiences, and societal attitudes to monitor rights of disabled people. In summary, those disabled people's organisations present were in favour of the DRPI project being used in New Zealand.

Over the next year leaders from the disability sector continued the conversation with government about implementing the DRPI project. Subsequently, four or five DPOs met with the Office for Disability Issues to ascertain if funding was available to proceed with the project in New Zealand. One of the criteria for the funding was for a coalition to be formed. This consisted of DPA, People First New Zealand, Deaf Aotearoa NZ, ABCNZ, Ngāti Kapo and Nga Hau E Wha. The coalition met for several months and then were in a position to begin the project.

The study progressed in an ad hoc and organic way with key personnel coming on board at various times. The project commenced before the funding came through so a lot of goodwill toward the project was in evidence with people paying from their own pockets and significant time lags for reimbursement. As we know disabled people are often economically disadvantaged and under employed so this was a major issue for people who could not afford to self fund.

The Project Management Committee (PMC) consisted of representatives from the partner organisations. The role of the PMC was to organise the overall logistical management of the project including selecting the Monitors, Data Analysis team (see appendices for a list of the project personnel) and appointing a Project Co-ordinator;

Project Co-ordinator's Role

The Project Co-ordinator was offered their position two weeks before the training workshop was due to begin. He immediately recruited 3 of the 4 Site Co-ordinators from his networks. The last Site Co-ordinator was appointed a few days before the workshop.

The Monitors were recruited over the next 2 weeks using the Project Co-ordinator's, Site Co-ordinators' and Project Management Committees' networks. Many people approached would have committed to the monitoring had there been more time to arrange to be away from home for 6 days.

The Project Co-ordinator's role included:

- Overseeing the Monitoring work in the field and assisting with the development of field work modalities
- Assisting with identification of potential Site Co-ordinators, Monitors, and interviewees
- Plan and implement the dissemination of the report in appropriate formats.
- Oversee day-to-day coordination of the project, including administration of the budget
- Participate in the organisation of and attend training seminar
- Coordinate, supervise & support interviews in field (with Site Co-ordinators)
- Conduct site visits, as necessary
- Coordinate feedback meeting(s) with Monitors (with Site Co-ordinators)
- Participate in data analysis, report writing & publication

Data Analyst and Data Analysis team

The data analyst was recruited two weeks before the project began. She attended and participated in the training workshop. Two of the Monitors expressed interest in becoming involved in the data analysis. Another disabled data analyst later joined the team. The Data Analysis team:

- Were trained in the use of NVIVO and took part in a series of data analysis meetings over the course of the project.

- Attend training seminar, three of the four Data Analysis team members attended
- Liaised with Project Co-ordinator regularly (assisted with ensuring sample balance & interview quality control)
- Attended feedback meetings with Monitors and sought input on the draft report.
- Organized and supervised the transcription and translation (if necessary) of interview recordings.
- Established and maintained systems to safeguard the confidentiality of paper, and electronic interview records
- Coded monitoring data and generated reports using NVIVO software (overseeing others to assist with this work)
- Conducted qualitative and quantitative analysis of data
- Wrote draft report & finalized report for publication
- Participated in review(s) of the report by the Project Management Committee

Capacity Building

An intended outcome of the DPRI framework is to build the capacity of the people involved in the project. A team of disabled people with the ability to conduct research now exists. To further enhance New Zealand's reputation as a world leader in the field of participative studies with disabled people, disabled people should continue to be invested in. In the spirit of true capacity building it is recommended that a member of the Data Analysis team is employed as a research assistant so that they can observe, participate in and further develop skills in this area.

The Training Workshop

The initial activities of the project involved 6 days of intensive workshops setting the tone and substantial grounding for the project.

The workshop consisted of background information about Disability Rights Promotion International and introducing Monitors to the concept of Disability as a Human Rights Issue.

Marcia Rioux from Disability Rights Promotion International facilitated the training workshop. In advance DRPI had developed an interview questionnaire, a training manual for the Monitors, information and consent sheets, and a coding schedule. These items are internationally standardised. They provided technical advice and assistance regarding the organization and administration of interviews.

Most of the time was spent learning the practicalities of interviewing including training on interview techniques, role play and mock interviews to practice skills. Intensive training was provided on how to do an interview and to use the interview guide, techniques of interviewing, finding the interview subject using the snowball method, potential problems in the field, maintaining confidentiality, and the organization and administration of the monitoring project. The importance of gaining the consent of the participants both for the interview and of audio recording as well as the methods to ensure confidentiality were a central part of the training (consent and confidentiality procedures are outlined in the consent forms in Appendices).

The formation of monitoring teams was decided at the training and logistical details of the field work was also covered during the seminar.

The topics of the workshop included a wide range of issues including the following: a basic understanding of human rights and disability from a human rights perspective including the distinction between a charitable approach and a human rights approach to disability.

Guest speakers were:

- Hon. Tariana Turia, Minister for Disability Issues. The Minister attended the conference to announce three years of government funding for the project. New Zealand is the first country in the world to receive government funding for the DPRI project.
- Professor Ron McCallum, Chair of the UN Committee on the Rights of Persons with Disabilities. Professor McCallum outlined the role of the monitoring committee, how it works, and how the committee gives great weight to reports

from disabled people and their organisations. He emphasised that one 'shadow' report per country is best.

- Mr Don Mackay, Chair of the UN Ad hoc committee which drafted the Convention on the Rights of Persons with Disabilities. Don Mackay explained the Convention creation process.
- Dr Jan Scown, Director on the Office for Disability Issues. Dr Scown explained the ratification process and the ways in which the Convention fits with existing legislation.

The workshop was attended by the people and organisations listed in appendix 8 apart from one person who came on later as part of the Data Analysis team.

The Monitoring Sites

Four monitoring sites were chosen. They were Auckland, East Cape- Bay of Plenty, Wellington and Nelson –Marlborough (later expanded to include the rest of the South Island. There were a number of considerations behind the choice. First, the committee wanted to ensure there were opportunities for a good representation of disabled Maori and Pacific people in rural, provincial and urban settings. Second, the committee looked for sites where there might be groupings of Maori with impairments who might be particularly hard to reach, for example, Maori with learning impairments. Third, the committee wanted to tap into other hard-to-reach groups eg homeless. Finally, there was a desire to reach disabled people who did not often get interviewed - to extend beyond the 'usual suspects'.

New Zealand is a relatively affluent nation with a history of social protection schemes. It has a history of ad hoc provision with regard to social support services. It is likely that regional variations do exist in New Zealand. The choice of sites produced a degree of regional difference however exploration of the various sites within different categories of analysis did not provide conclusive results.

Monitoring Meeting

There were 3 meetings of the Monitors and, additionally, there was a meeting of the Site Co-ordinators on the last day of the training workshop.

Learning from the Research

Setting up the software and training analysts was more time consuming than anticipated, however we now know how to streamline the process. The project got off to a slow start, however, efficient interview collection and transfer processes evolved during the fieldwork process to accommodate changing circumstances. These processes will stand the DPOs in good stead when setting up a framework for future research.

The Disability Rights Promotion International is an international standard. Some of the categories are not relevant to a developed western democracy like New Zealand and do not need to be included in future research. For example, the distance to the police station in New Zealand is a function of rural or urban living, all houses in New Zealand have to conform to a building code so the question of what housing is constructed of is irrelevant and water is available in all New Zealand homes. Homelessness is an issue for some disabled people. However, New Zealand does not have statistics on this. In an effort to include homeless people the Wellington Site Co-ordinator approached a number of organizations in Wellington and the Hutt Valley, including Evolve, Desperate and drop-in centres for mental health consumers and street people. These approaches were unsuccessful. Measures of deprivation more relevant to New Zealand society should be developed. More relevant indicators might be access to public transport, opportunities for appropriate employment, the ability to procure fresh fruit and vegetables, use of food banks by disabled people and privacy issues. Participants were asked to choose one category of impairment. Choosing a single category proved difficult for participants and also means that the demographic information on type of impairment that can be extracted from NVIVO is limited as the analysis instrument did not reliably measure what it was intending to

measure. In future it is suggested that impairments are described by the participants and the sampling frame is systematically monitored to ensure a representative spread of impairment.

Appendix 3 Vignette from the Interviews

Par: So I've been studying up until last year and then I ended up getting into a bit of conflict actually, with one of the music teachers, saying that I had to study music. I mean I was like, I'm deaf so how does that work? So we had quite a confrontation about that with lecturers. I had a confrontation about that.

The instruments you have to learn like guitar and flute and recorder and that sort of thing are really difficult for me, especially being deaf. I can hear a tiny little bit but not enough. Depending on the type of music, maybe feel the vibration, sometimes the beat but the recorder wasn't as bad, but the lesson plans and things for me to do for music was a huge issue. And trying to teach music in Sign and like sing, sing a rainbow – that's what I plan to do was sing a rainbow in NZSL.

So I went to meet my lecturer and they said, "No sorry you're not going to get a pass for this." I was like, why? And they said, "Because you need to be – like you're actually pretending to teach a music class." And I was like, well I'm deaf and this is my language and this is how I would teach a music class. I would relate the language to the music. So as I say we to'd back and fourth between us about that ... so in the end I was told to copy from my class mates, just to hand that in. So I was really unhappy about that particular experience. And as a result I still have to do music, I can't pull out of that particular class, otherwise I won't get my BA. So that's the situation there.

So I know [another deaf person] also was fighting really hard for that as well and the same thing, yeah. So I feel really kind of a bit dumb really sitting in music and not being able to hear it and do anything, it's a bit crazy. So even after having massive discussions with it, the end answer is that we have to do it to be able to get the BA in music.

So this year I'm doing keyboard and learning the piano which is actually a lot more difficult. I have to use my hands and my eyes. I've got to look at my hands and look at the music the same time. And I really don't want to but it's part of the BA that I have to do. So I feel, yeah, not very happy about it. The university don't really realise that we're deaf and there's things that we can't do because we are deaf. I feel like, you know, we've really been pushed, that we have to do this study. It just doesn't really fit with us. So anyway I have to carry on with music for the BA that I'm studying.

My goal is to teach New Zealand Sign Language in either primary or Intermediate or High Schools and that's my ultimate goal, so I won't actually be teaching music or other subjects but I have to get this BA so I can do this.

Int: Yeah, you're not going to be teaching it but you have to do it to get the qualification. Bit crazy and a bit – a bit sort of bloody minded on the part of the university that they just don't realise that because you're deaf, music is sort of something that's really hard for you to do. So ...

Par: To my music lecturer. We had a meeting and I had a classmate that supported me last year. It was quite a heavy debate that we went through about it and we also had the community liaison officer from Deaf Aotearoa NZ come along to help try and solve it but it just wasn't successful. The end outcome was, no I had to do it.

Int: So did you try higher like to the dean or someone up in – in the administrative side of things?

Par: yes and he said, “No, I had to study it,” but my music lecturer was to try and match my needs. So last year we had to do recorder or guitar. Guitar was very difficult, so I did the recorder. It was still difficult but I did manage to pass, but I just had to copy a lesson plan from classmates. So I didn’t actually learn anything. My plan was to do, you know, New Zealand Sign Language sing a rainbow, teach a class that, in New Zealand Sign Language, but they refused. No you have to pretend like you’re a hearing person and teach a hearing music lesson. So they didn’t really understand about the fact that I was deaf and that things would be different.

The disability services person tried to explain to them about how – what it’s like being, you know, deaf and gave them information about being deaf and cultural things and working with an interpreter but ...

Int: Definite discrimination as far as I’m concerned. And so when the dean said no and all the people said no, you felt you had no other choice but to just do it?

Par: I think, you know, something needs to be done so that it can actually be, you know, suit the needs of deaf people in regards to teaching music. I’ve got another deaf friend who has also become a teacher. She’s done it at Otago University. She went into the music class but she wasn’t – she didn’t have to do anything. She just went into the class, observed, and took notes. I spoke to the University Of Canterbury about that but no movement from them.

Int: It makes a mockery of the education system if they just say copy your classmate’s lesson plan and that’s ridiculous.

Third Party: They’ve managed to sort something out at Otago but not here.

Int: Have you thought about complaining at a higher level again from the university, like to a member of parliament or to like the Human Rights Commission?

Par: they told me some options I think, and that I needed to do certain actions. The Human Rights said I needed to talk to the university more and if it became serious, I then think they would sort something out, but I just dropped it. I just – you know, because they said, “I had to do it.”

Fourth party: If you are unable to complete your BA because of the discriminatory nature of this university that is extremely serious.

Par: Yeah, I was hoping like, you know, my music lecturer, you know, could learn a bit more about me and deaf culture and how it works, but they just said, “No you need to try and be like a hearing person.”

Par: I worked at [a large commercial organisation]. I actually lost my job there because the company went under but my manager was really, really lovely and told my work mates that I – that I teach Sign Language. And so they paid for some of our work mates to go along and learn. So it was really, really lovely that they could learn what the culture was about and learn some Sign Language for me. And so [the

organisation] I think, paid for about seven or eight work mates to come along to learn, so they could communicate with me, like for example, like going toilet at break time, you know all those sorts of things.

Appendix 4 Post Interview Brain Storm with Monitors

As part of the participative monitoring process there was a mid-project meeting of the Monitors, Project Management Committee, Project Co-ordinator, and Data Analysis team at the Brentwood Hotel in Wellington⁵. At this point 94 interviews had been completed. The meeting included a brainstorm of issues and themes emerging from the interviews. The following is a summary of the issues noted by the Monitors during the interviews:

- OT's not listening to needs
- The right to appeal OT's decisions
- OT's as gate keepers.... Do they have too much power?
- Designers needed to design accessible and appropriate bathrooms
- Abuse of disability parking
- ACC cutting hours for home help and personal cares
- Carers- quality and quantity very inconsistent, not being able to say anything in case they lose support altogether
- Helplessness in the face of abuse
- WINZ benefit status
- Accessible and safe homes
- A lack of specific case managers
- Not being able to choose with whom they live (group housing? institutions)

⁵ Brain Storm with Monitors Brentwood, Hotel, Kilbirnie, Wellington, 6 August, 2010

- Accessibility to family/mail
- Lack of flexibility – home support ... Five days without a shower
- Lack of respect and fairness
- Lack of awareness by front line staff i.e. WINZ and ACC
- People who stick up for themselves labelled as trouble makers, a label that sticks with them (on file) for life
- Social isolation – lack of family and friends
- Lack of training for staff who deal with disabled people
- Rural isolation particularly a lack of transport options
- Transport in general a problem
- Harassment of females by taxi drivers
- Custody of children
- Community Education re disabilities needed
- Community support and understanding, not making a big deal of disability
- People's resilience
- Women's refuge cannot accommodate disabled women
- Fear of repercussions as a result of what they disclose
- Autonomy and the right to complain
- Lack of dignity came up in most interviews

Appendix 5 Informed Consent

FREE and INFORMED CONSENT FORM

I have read and understood the *Information Sheet*. The procedures have been explained to me and all of my questions have been answered to my satisfaction. I have been informed that I can withdraw from the study at any time without penalty and that, if I choose to do so, any data collected as a result of my participation will be destroyed. The potential discomforts that I might experience because I have participated in the study have been explained to me. I also understand the potential benefits of being a part of this study.

I know that I may ask now, or at any time in the future, any questions I have about the study. I have been assured that the audio and written records related to this study will be kept confidential to the limits of the law. I have also been assured that no information will be released or printed or made public that would disclose my personal identity unless I give permission for that to happen.

I hereby consent to participate

Printed Name of

Participant: _____

Date: _____

Signature of Participant: _____

I hereby consent to having my interview audio recorded

Signature of Participant: _____

Date: _____

Printed Name of Monitor: _____

Date: _____

Signature of Monitor: _____

Appendix 6 Interview Guide

INTERVIEW GUIDE

For Monitoring the Individual Human Rights Experiences of People with Disabilities

A. Beginning the Interview

Introductions:

- **[Introduce everyone present (e.g. monitors, aide(s) and anyone else attending the interview)]**

- **[Explain the equipment you have with you.]**

Request Written, Free and Informed Consent to Participate in Interview:

- **[Review the *Information Sheet* with the interviewee.]**

- **[Ask the interviewee if she/he will consent to participate by signing the *Free and Informed Consent Form*.]**

- **[If the interviewee does not want to sign the consent to participate line on the *Free and Informed Consent Form*, thank him/her for his/her time and END the interview. Do not proceed any further.]**

- **[If the interviewee signs the consent to participate on the *Free and Informed Consent Form*, proceed to the next step.]**

Request Written Permission to Audio Record the Interview:

- **[Ask the interviewee if she/he will consent to having her/his interview audio recorded by signing the *Free and Informed Consent Form*.]**

- [If the interviewee does not want to sign the consent to record line, thank him/her for her/his time and END the interview. Do not proceed any further.]
- [If the interviewee signs the consent to record line on the *Free and Informed Consent Form*, proceed to the next step.]

Write information on *Identification Sheet*:

- [Write the interviewee's name on the *Identification Sheet*.]

[BEGIN AUDIO RECORDING NOW BY PRESSING THE “RECORD” BUTTON]

**[MONITOR: Say into the audio recorder, “This is the beginning of Interview
(insert Interview Code here)”]**

B. Experiences faced by the Interviewee:

- (a) Please tell me a little about your life during the past five (5) years. What things do you do? Where do you go? Who do you meet?**
- (b) What are the things in your life that are most satisfying?**
- (c) What are the most difficult barriers or challenges that you face in your life?**

[1st EXPERIENCE]

1.1 Do you recall a particular time or event in the last five years when you were left out or treated badly or prevented from participating because of your disability?

1.2 WHAT happened? WHERE and HOW did it happen?

1.3 Is this still happening or did it just happen once?

Are there other details that you want to share with us about this experience?

[Dignity]

1.4 HOW did this experience make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/ unworthy?)

1.5 *WHAT made you feel that way?*

1.6 *What do you think made people treat you that way?*

[Autonomy]

1.7 Did you feel that you had a choice about what happened to you?

WHY? or WHY NOT?

1.8 If you had a choice, would it have made a difference to what happened? In what way?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (AUTONOMY) ASK:

(a) Did you want to make a different decision or did you want to do something else? WHAT was the different decision or what did you want to do?

(b) Did you have enough information to make that decision?

If not, what prevented you from having enough information?

(c) Did you feel pressured to act the way you did? WHO/WHAT was pressuring you? HOW did it make you feel?

[Participation, Inclusion & Accessibility]

1.9 Did people in your community who knew or saw what happened to you do anything about it?

If yes, WHO?

[MONITOR: interviewee does not need to give someone's name here – can give general description of the person e.g. “neighbour”, “sister”, etc.]

WHAT did they do?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO PARTICIPATION, INCLUSION or ACCESSIBILITY ASK:

(a) Were you kept apart or left out?

(b) Did you need a service or some assistance so that you could participate?

If YES, what service(s) or assistance did you need?

Did you receive it?

If you did not receive it, HOW did that affect you?

[Non-Discrimination & Equality]

1.11 How do you think your disability affected what happened to you?

1.12 Do you think that people without disabilities would be treated the same way you were?

WHY or WHY NOT?

HOW would they have been treated?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION or INEQUALITY ASK:

(a) Do you know anyone else who was treated in the way you were?

[Respect for Difference]

1.13 Were you treated the way you were because people thought you were different?

In what ways do people see you differently?

1.14 Do you think that a person without a disability would have been treated in a similar way?

If not, how do you think they would be treated?

1.15 Do you feel that people label you and then treat you differently because of the label?

If YES, what label do they use?

HOW does this label affect you?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE ASK:

(a) Would someone of a different ethnicity be treated that way?

WHY? or WHY NOT? How are people from a different ethnicity treated in your community?

(b) Would a woman be treated that way?

WHY? or WHY NOT? How are women in your community usually treated?

(c) Would a poor person be treated that way?

WHY? or WHY NOT? How are poor people treated in your community?

1.16 Did you report the experience to anyone?

yes no

- **If you REPORTED the experience, what kind of person / organization did you report it to?**

- government official / social worker
- police officer
- religious leader
- Human Rights Commission
- Mental Health Commission
- Health and Disability Commission
- disability organization (DPO)
- organisation /advocate
- service provider organisation
- other (explain) _____

- **how did that person react?**

- **what action was taken?**

- **If you did NOT REPORT the experience to anyone:
- WHY did you not report it?**

1.17 In your opinion, what action[s] should be taken to improve [or prevent] the experience in the future?

1.18 Is there anything else that you would like to tell us about that experience?

[MONITOR: HERE YOU WILL MOVE ON TO THE 2nd EXPERIENCE ...]

2.1 Do you recall another particular time or event in the last five (5) years when you were left out or treated badly or prevented from participating because of your disability?

2.2 WHAT happened? WHERE and HOW did it happen?

2.3 Is this still happening or did it just happen once?

2.4 Are there other details that you want to share with us about this experience?

[Dignity]

2.5 HOW did this experience make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/unworthy?)

2.6 WHAT made you feel that way?

2.7 WHY do you think people treated you that way?

[Autonomy]

2.8 Did you feel that you had a choice about what happened to you?

WHY? or WHY NOT?

2.9 If you had a choice, would it have made a difference to what happened?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (AUTONOMY) ASK:

(a) Did you want to make a different decision or did you want to do something else? WHAT was the different decision or did you want to do?

(b) Did you have enough information to make that decision?

If not, WHY NOT?

What prevented you from having enough information?

- (c) Did you feel pressured to act the way you did? WHO/WHAT was pressuring you? HOW did it make you feel?**

[Participation, Inclusion and Accessibility]

- 2.10 Did people in your community who knew or saw what happened to you do anything about it?**

If yes, WHO?

[MONITOR: interviewee doesn't need to give someone's name here - can give general description of person e.g. "neighbour", "sister", etc.]

WHAT did they do?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO PARTICIPATION, INCLUSION or ACCESSIBILITY ASK:

- (a) Were you kept apart or left out?**
- (b) Did you need a service or some assistance so that you could participate?**

If YES, what service(s) or assistance did you need?

Did you receive it?

If you did not receive it, how did that affect you?

[Non-Discrimination & Equality]

2.11 How do you think your disability affected what happened to you?

2.12 Do you think that people without disabilities would be treated the same way you were?

WHY or WHY NOT?

HOW would they have been treated?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION or INEQUALITY ASK:

(a) Do you know anyone else who was treated in the way you were?

[Respect for Difference]

2.13 Were you treated the way you were because people thought you were different?

If yes, WHY?

2.14 Do you think that a person without a disability would have been treated in a similar way?

WHY? or WHY NOT?

2.15 Do you feel that people label you and then treat you differently because of the label?

If YES, what label do they use?

HOW does this label affect you?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE ASK:

(a) Would someone of a different ethnicity be treated that way?

WHY? or WHY NOT?

(b) Would a woman be treated that way?

WHY? or WHY NOT?

(c) Would a poor person be treated that way?

WHY? or WHY NOT?

2.16 Did you report the experience to anyone?

yes **no**

• If you REPORTED the experience, what kind of person / organization did you report it to?

government official / social worker

police officer

religious leader

Human Rights Commission

Mental Health Commission

Health and Disability Commission

disability organization (DPO)

organisation /advocate

service provider organisation

other☹️explain)_____

• how did that person react?

• what action was taken?

- If you did NOT REPORT the experience to anyone:
 - WHY did you not report it?

2.17 In your opinion, what action[s] should be taken to improve [or prevent] the experience in the future?

2.18 Is there anything else that you would like to tell us about that experience?

MONITOR: HERE YOU WILL MOVE ON TO THE 3rd EXPERIENCE ...]

- 3.1 Do you recall *another* particular time or event in the last five (5) years when you were left out or treated badly or prevented from participating because of your disability?**
- 3.2 WHAT happened? WHERE and HOW did it happen?**
- 3.3 Is this still happening or did it just happen once?**
- 3.4 Are there other details that you want to share with us about this experience?**

[Dignity]

3.5 *HOW did this experience make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/unworthy?)*

- 3.6 WHAT made you feel that way?**
- 3.7 WHY do you think people treated you that way?**

[Autonomy]

3.8 *Did you feel that you had a choice about what happened to you?*

WHY? or WHY NOT?

3.9 If you had a choice, would it have made a difference to what happened?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (AUTONOMY) ASK:

(a) Did you want to make a different decision or did you want to do something else? WHAT was the different decision or did you want to do?

(b) Did you have enough information to make that decision?

If not, WHY NOT?

What prevented you from having enough information?

(b) Did you feel pressured to act the way you did? WHO/WHAT was pressuring you? HOW did it make you feel?

[Participation, Inclusion and Accessibility]

If yes, WHO?

[MONITOR: interviewee does not need to give someone's name here – can give general description of the person e.g. “neighbour”, “sister”, etc.]

WHAT did they do?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO PARTICIPATION, INCLUSION or ACCESSIBILITY ASK:

(a) Were you kept apart or left out?

(c) Did you need a service or some assistance so that you could participate?

If YES, what service(s) or assistance did you need?

Did you receive it?

If you did not receive it, how did that affect you?

[Non-Discrimination & Equality]

3.11 How do you think your disability affected what happened to you?

3.12 Do you think that people without disabilities would be treated the same way you were?

WHY or WHY NOT?

HOW would they have been treated?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION or INEQUALITY ASK:

(a) Do you know anyone else who was treated in the way you were?

[Respect for Difference]

3.13 Were you treated the way you were because people thought you were different?

If yes, WHY?

3.14 Do you think that a person without a disability would have been treated in a similar way?

WHY? or WHY NOT?

3.15 Do you feel that people label you and then treat you differently because of the label?

If YES, what label do they use?

HOW does this label affect you?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE ASK:

(a) Would someone of a different ethnicity be treated that way?

WHY? or WHY NOT?

(b) Would a woman be treated that way?

WHY? or WHY NOT?

(c) Would a poor person be treated that way?

WHY? or WHY NOT?

3.16 Did you report the experience to anyone?

yes **no**

• **If you REPORTED the experience, what kind of person / organization did you report it to?**

government official / social worker

police officer

religious leader

Human Rights Commission

Mental Health Commission

Health and Disability Commission

disability organization (DPO)

organisation /advocate

service provider organisation

other:

(explain)_____

- how did that person react?
- what action was taken?
- If you did NOT REPORT the experience to anyone:
 - WHY did you not report it?

3.17 In your opinion, what action[s] should be taken to improve [or prevent] the experience in the future?

3.18 Is there anything else that you would like to tell us about that experience?

[TURN AUDIO RECORDER OFF NOW BY PRESSING THE “RECORD” BUTTON]

C. Follow-up & Verification Information:

Is there anyone we could contact who saw what happened to you or who could provide us with more information about the experiences you talked about?

FOR 1st EXPERIENCE:

- What is their name? [write name on *Identification Sheet*]
- Can we contact this person? YES NO
 - If yes, what is the best way for us to contact him or her?
 -

[MONITOR: write details on *Identification Sheet*]

FOR 2nd EXPERIENCE:

- What is their name? [write name on *Identification Sheet*]
- Can we contact this person? YES NO

- If yes, what is the best way for us to contact him or her?
- [MONITOR: write details on *Identification Sheef*]

FOR 3rd EXPERIENCE:

- What is their name? [write name on *Identification Sheef*]
- Can we contact this person? YES NO
 - If yes, what is the best way for us to contact him or her?
 - [MONITOR: write details on *Identification Sheef*]

[TURN AUDIO RECORDER BACK ON NOW BY PRESSING THE “RECORD” BUTTON]

D. Background Information:

Now, if you don't mind, we would like to ask you a few questions about yourself.

- 4.1 What is your sex?
- 4.2 What is your ethnicity?
- 4.3 In what year were you born?
- 4.4 How would you describe your disability? [choose as many as apply]
- mobility
 - sensory – if so, blind low vision deaf hard of hearing
 - intellectual psychiatric other _____ (ask interviewee to describe)
- 4.5 How long have you had your disability?
- since birth
 - since _____ (ask interviewee to state the year)

4.6 Did you go to school?

- yes no

- If YES, what kind of school? [choose as many as apply]

- preschool primary intermediate
 secondary vocational short course diploma
 polytech or university
 specific needs schools
 mainstream or special unit

4.7 Is there a specific place where you live?

- yes no

If YES, do you

- own that place?
 lease that place?
 rent that place?
 live with someone who owns, leases rents the place?
 live in a group home place?

Is the place in a permanent building?

- yes no _____(explain)

If YES, what is the building made of?

- concrete wood brick fibrelite corrugated iron
 other: _____ (explain)

Does the place you live have:

- electricity?
 a water supply?
 a telephone?

4.8 How far do you live from the City Centre?

4.9 Who lives with you?

[MONITOR: interviewee should identify as many as apply]

- no one
- spouse
- children [if yes, how many children ?]
- parent(s) [if yes, how many parents ?]
- other family member(s) [if yes, how many family members ?]
- friend(s) [if yes, how many friends ?]
- caregiver(s) [if yes, how many individuals?]
- Whanau or extended family [if yes, how many extended family?]
- flatmate(s) [if yes, how many flatmates?]
- other _____ (explain) [if yes, how many?]

4.10 How far is the closest police station to where you live?

4.11 How far is the closest health centre from your house?

4.12 What type of care is offered by the health centre?

- primary care
- western medicine
- herbal medicine
- traditional indigenous e.g. rongoa
- other _____ (ask interviewee to describe)

4.13 Do you have a job?

- yes
- no

If yes, what is your job? _____ (explain)

Do you get paid?

- yes
- no

4.14 Would you say that the area where you live is accessible for people with disabilities?

- yes**
- no**

4.15 What makes the area where you live accessible or not accessible?

E. Ending the Interview & Identifying Other People to Interview

- **Do you have anything else that you would like to add?**
- **Do you have any final questions for us?**

[MONITOR: Answer these questions]

[MONITOR: Review briefly what will happen with the information the interviewee has provided the purpose of the project, and the relevant timeframes.]

[MONITOR: Say into the audio recorder: “This is the end of Interview (insert Interview Code here)”]

[STOP AUDIO RECORDING THE INTERVIEW NOW]

Identifying Another Person to Interview

Do you know someone with a disability who lives in your community who we could interview for this study?

What is his or her name?

What type of disability does he or she have?

How can we contact him or her?

[MONITOR: Write this information on the *Identification Sheet*.]

[MONITOR: Thank the interviewee very much for his/her time. Remember to leave the *Information Sheet* with the interviewee for his/her information.]

F. Completing Notes & Transferring Data

CHECKLIST:

- **Digital Audio Recorder**: Secure the recording by turning OFF recorder immediately after the interview.
- ***As soon as possible after the interview***, monitoring pairs should listen to the audio recording of the interview. If part of an audio recording is not clear, monitors should explain what is missing (if you remember) in the *Interview Notes*.
- The *Interview Notes* should also contain the following observations:
 - Provide your overall impression of the interview (e.g. interviewee seemed nervous or anxious over certain questions, the atmosphere was comfortable, etc.).
 - Provide details about the location of the interview (e.g. held indoors/outdoors, type of building, type of room, who else was around, etc.).
 - Provide information about who was present at the interview (number of monitors, interpreters ...)
 - Provide details about any challenges faced or interruptions that occurred during the interview (e.g. airplane flew overhead making it difficult to hear, lost electrical power so could not see, etc.), at what stage in the interview they occurred and what steps were taken to address them.
 - If you have any concerns about the truthfulness and/or accuracy of statements by the interviewee, identify the statements and explain why you feel this way (e.g. answers were very inconsistent, answers seemed rehearsed, etc.)
- Be certain that one of the monitors has signed and dated the *Free and Informed Consent Form*.
- Provide the Project Co-ordinator or Site Co-ordinator with the following documents:
 - audio recording of the interview labeled with the correct Interview Code
 - completed *Interview Notes*
 - completed *Identification Sheet*
 - signed *Free and Informed Consent Form*

[END]

Appendix 7 Information Sheet

for the study called:

Monitoring the Individual Human Rights Experiences of People with Disabilities

This information is provided so that you can make a decision about whether or not you want to participate in this study. We are giving you a lot of information because we want you to be able to make the decision that is best for you.

Sponsors:

The study is being sponsored by:

- Association of Blind Citizens of New Zealand Inc (website: www.abcnz.org.nz)
- Deaf Aotearoa New Zealand (website: www.deaf.org.nz)
- DPA (NZ) Inc (website: www.dpa.org.nz)
- Nga Hau E Wha
- Ngāti Kāpo O Aotearoa Inc (website: www.kapomaori.com)
- People First New Zealand Incorporated Nga Tangata Tuatahi (website: www.peoplefirst.org.nz)
- Disability Rights Promotion International (DRPI) which is a research project based at York University in Toronto, Canada (website: www.yorku.ca/drpi)

Why are we doing this study?

We are collecting information about the lives and experiences of people with disabilities by talking directly to people with disabilities. We want to see if their human rights are being respected. The information we collect will be studied and reports will be written. The names of participants will not be mentioned in the reports unless they have given us clear permission to do so. The reports will be available to organizations of people with disabilities, other groups working to improve the lives of people with disabilities, the media and governments.

The reports made will be used to:

- let people know about violations of the rights of people with disabilities

- help stop human rights violations
- provide facts to back up arguments for changes in laws, policies, and programs to improve the lives of people with disabilities
- keep track of the steps that the government has taken or has failed to take in order to fulfill the promises it has made to people with disabilities when it signed agreements at the United Nations saying that it would protect, promote and fulfill the rights of people with disabilities

What will happen in this study and what will you be asked to do?

Our project is going to various countries around the world to talk to people with disabilities about their lives and their experiences.

If you agree to participate, you will be asked a series of questions about your life and your experiences. We will particularly want to know if your human rights have been violated and how they have been violated. In other words, we will want to know if there are unfair things that have happened to you which have stopped you from participating in society in the way that people without disabilities participate in society.

If you agree to participate, you will be interviewed by two people with disabilities who are members of a local organization run by people with disabilities. We call these people the “Monitors”. We know that, in the past, people with disabilities have often been left out of research about people with disabilities. We think that it is only fair that people with disabilities play an active role in any research about them.

During the interview, the Monitors will take notes. They will also audio record the interview so that we can be sure to get all of the information you provide accurately.

Depending on the methods of communication that are used, the complete interview should take approximately 2 to 3 hours.

After the interview, the Monitors will give all of their written and audio recordings to the person in charge of the project who we call the Project Co-ordinator. The Monitors will not keep any copies and will not talk to anyone except for the Project Co-ordinator about what you said. The interview will be confidential.

The Project Co-ordinator will pass the written and audio recordings of your interview to the researchers who will study them. Your name will not be on any of the information given to the researchers, they will not know whose information they are studying.

After looking at your information and the information from interviews with at least 100 other people with disabilities in your country, the researchers will write reports that will be given to organizations of people with disabilities, other groups working to improve the lives of people with disabilities, the media and governments. Your name will not be mentioned in the reports without your clear permission.

Are there possible negative things that might happen if you participate in the study?

There are no negative things that will happen to you by participating in this study. However, you may feel uncomfortable when you start thinking about some of the questions that you are asked. For example, you may remember some things that have happened to you that are not pleasant to think about. If that happens, you can take a break from the interview or, if you want, you can stop the interview completely.

If you want to continue to talk about these things, that's fine, too. If you feel upset about these things, you can ask the Monitors for the name of someone you can talk to about your feelings after the interview is over.

Are there good things that might happen if you participate in this study?

You may or may not receive any direct benefit from participation. You might find that it makes you feel better to talk about some of your experiences. Also, we hope that organizations of people with disabilities, the media and governments learn from the studies and reports that are made and take steps to improve the lives of people with disabilities in your country.

Can you decide if you want to participate in the study?

You are free to choose to participate or not to participate in the study and you may choose to stop participating at any time. Your participation is completely voluntary.

Your decision not to participate in the study will not influence your ongoing relationship with any of the study sponsors, Monitors or any other person or group associated with the project.

Can you stop participating if you don't want to continue participating?

If, at any time during the study, you want to stop participating, for any reason, just let the Monitors know and they will stop asking you questions. If you want to answer some questions, but not others, you can do that, too. It is entirely your decision.

If you decide not to participate in the study, or if you decide to stop participating in the study, we will not use your information for our research. Any written or audio recordings made up to the point you decided to stop will be destroyed. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with any of the study sponsors, Monitors or any other person or group associated with the project. No one will treat you any differently if you decide that you do not want to participate in the study.

Will your information be kept confidential?

The information you provide will be kept confidential within the limits of the law. Unless you specifically provide your consent, your name will not appear in any report or publication of the research. The written and audio recordings of your interview will be safely stored in a place that is locked and will be destroyed at the end of the project.

Costs and Compensation

You will be reimbursed for the cost of your transportation to the interview location and the cost of any disability-related supports or assistance that you will need in order to participate in the interview. You will receive these things even if you decide to stop participating in the project at some point during the interview and/or decide not to answer certain questions.

If you have questions about the study

If you have questions about the study in general or about your own role in the study, please feel free to contact:

Project Co-ordinator: Gary Williams

Regular mail: 7 Blair Avenue, Papanui, Christchurch 8053

Telephone: 03-354-8308 or 021-499-422

Email: williamsgm@yahoo.co.nz

OR

Dr. Marcia Rioux

Principal Investigator for Project Co-Director, Disability Rights Promotion
International Professor, School of Health Policy and Management, York University

Regular mail: York University, 441 HNES Building, 4700 Keele Street, Toronto, ON,
M3J 1P3, Canada Telephone: +1-416-736-2100 extension 22112

Email: mrioux@yorku.ca

Appendix 8 People & Organisations Involved in the Project

Wendi Wicks	Chair Project Management Committee
Rachel Noble	Vice chair Project Management Committee
Rose Wilkinson	Rapid Response team
Barbara Hart	Project Management Committee/Monitor
Graeme Parish	Project Management Committee
Nigel Ngahiwi	Project Management Committee
Mary Schnackenberg	Project Management Committee
Dairne Kirton	Site Co-ordinator
Raymond Thoumine	Monitor
Latoa Halatau	Monitor
Tewai Halatau	Site Co-ordinator
Beverley Grammer	Site Co-ordinator
Poihaere Morris	Monitor
Elizabeth McGougan	Monitor
Kaeti Rigarlsford	Site Co-ordinator/Data Analyst
Chris Brown	Monitor
Nathan Bond	Monitor/ Data Analyst
Oliver Ferguson	Monitor
Talitha Borland	Site Co-ordinator
Peter Wilson	Monitor
Paul Blick	Monitor
Andrea Courtney	Monitor
Michelle Mars	Data Analysis Team Leader
Gary Williams	Project Co-ordinator
Bronwyn Hayward	Data Analyst

15 anonymous disabled volunteers for the mock interviews.

- **Association of Blind Citizens of New Zealand Inc**

ABCNZ is a national organisation of, and for, blind citizens of New Zealand. Founded in 1945, ABC NZ has branches throughout New Zealand and advocates on blindness-related issues as well as assists government and health agencies, utilities

and other organisations in improving services to blind people. One of the country's largest organisations of disabled consumers, the Association's aim is to heighten awareness of the rights of blind and vision impaired people and to remove the barriers that impact upon our ability to live in an accessible, equitable and inclusive society.

- **Deaf Aotearoa NZ New Zealand**

DANZ work with Deaf New Zealanders to make sure they can access the information and services they need to live independently, take part in our vibrant Deaf communities and to follow their dreams. Deaf Aotearoa NZ New Zealand (DANZ) is a not-for-profit organisation which promotes Deaf culture, New Zealand Sign Language and the interests of the Deaf community. We have Deaf and hearing staff who care deeply about Deaf culture, Deaf values and who always go the extra mile for our Deaf members.

- **Disabled Persons Assembly (New Zealand) Incorporated**

DPA is the collective voice of people with disability in New Zealand based on principles of human rights and equal value of life.

DPA is an umbrella organisation representing:

People with all types of impairments — physical, sensory, intellectual, psychiatric and neurological, acquired at any stage of life

People with all types of impairments — physical, sensory, intellectual, psychiatric and neurological, acquired at any stage of life

The families of disabled people

Disability advocacy organisations

Disability service providers

- **Nga Hau e Wha**

Influential Leadership –“ To Champion Many Voices” Nga Hau e Wha is a quarterly meeting for mental health consumers, funded by Ministry of Health. There are currently eight members, two members from each of the four regions of New

Zealand – Southern, Central, Midland and Northern. All members are mandated by their region and it allows regional issues to be tabled at a national level. Nga Hau e Wha meets with the Mental Health Commission and the Ministry of Health and any other organisation who wish to consult with them.

- **Ngāti Kāpō O Aotearoa Inc**

Ngāti Kāpō O Aotearoa Inc is a non-profit national consumer-governed provider of kaupapa Māori health, disability, education and social support services to Māori disabled and their whānau and Māori kāpō (blind, vision impaired and deaf blind persons) and their whānau in Aotearoa. Founded in 1983 by Māori kāpō and their whānau, the purpose of Ngāti Kāpō is “to advocate and provide services that enable Ngāti Kāpō members’ well-being and self sustainability.”

Ngāti Kāpō provides self-advocacy, information and advice, advocacy, peer support, policy advice, research and development, training and workforce development services. All Ngāti Kāpō initiatives reaffirm the importance of serving the needs and aspirations of not only Ngāti Kāpō members, but also disabled Māori and Māoridom.

- **People First New Zealand Incorporated Nga Tangata Tuatahi**

People First is part of an international self advocacy movement. It is led by and for people with a learning/ intellectual disability. People First members meet regularly in groups throughout New Zealand to learn to speak up for themselves and for their friends and:

- gives people the chance to talk about things that are important to them
- helps people learn about their rights and responsibilities
- helps people learn to make choices and get more confidence
- helps people to learn that making mistakes is OK and part of life

- tells people about laws and what they mean
- gives people the chance to have their ideas heard by government,
- is where people make new friends and have fun

People First also provides disability information and advice, provides translation of documents into Easyread undertakes a range of projects including creating resources, delivering Speaking up courses and also runs an employment advocacy service.

The Convention Coalition

While the Convention on the Rights of Persons with Disabilities (CRPD) was being written, there was a growing agreement among disabled people that their representative organizations, (which became known as Disabled Peoples' Organisations or DPOs) were the natural organizations to take leadership around disability rights. When the CRPD was finalized, article 33 explicitly recognised that disabled people and their representative organizations would participate fully in the monitoring process. They agreed that a DPO has 3 main features: they are national organizations, they are led and governed by disabled people, and they are there to promote and protect the interests and issues that their members decide.

In December 2008 Marcia Rioux of Disability Rights Promotion International led a NZ workshop about CRPD. Just under a year ago, DPOs in New Zealand began to discuss how they might work together on monitoring the CRPD. With initial assistance from the Office for Disability Issues, six DPOs worked intensively together to:

- appoint organizational representatives-agree one of the organizations (Disabled Persons Assembly NZ- DPA) to act as -administrative fundholder
- craft a memorandum of understanding (early February 2010);see below
- agree a plan and budget for a monitoring project -we agreed a project of 100 interviews and a report originally planned for completion in October (February-April)
- interview for then appoint a Project Co-ordinator (March-April)
- locate a data analyst (April)-begin arrangements for monitor training (March to May). In the monitor training coalition members were trained to act as interviewers should this be needed, with one representative doing so.
- urge funding arrangements (recurrently).

In the May 2010 Government budget, funding for 3 years for DPOs to monitor disability rights was announced by Minister of Disability Issues Tariana Turia. Since appointed contractors have taken over a lot of the day-to-day running of the monitoring project, the members of the Convention Coalition have been involved at various feedback and draft report sessions.

In October 2010, the Convention Coalition was officially named by the government as one of the three independent monitoring entities for the CRPD. Three members, the Chair, deputy chair and one other have acted as a "rapid response team" to deal with day-to-day operational and financial matters throughout the project.

The Convention Coalition monitoring project represents a significant new model of funding and contracting. Conventionally funds for such projects are managed directly from government departments, but here DPOs are, for the first time, collectively responsible for management and fundholding of such a project. This may well be a world first. While such an approach is likely to encounter, indeed has encountered problems of capacity and timing it has been a very good

tangible demonstration of a governmental commitment to walk the talk of disability rights.

DPOs MEMORANDUM OF UNDERSTANDING

1. **Background:** The United Nations formed an Ad Hoc Committee to oversee the development of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This significant treaty was signed by New Zealand at the United Nations on 30 March 2007 and ratified on 26 September 2008.

A significant part of the UNCRPD is the monitoring process. Thus New Zealand Disabled Peoples' Organisations (DPOs) have come together to form a governance level steering group called the Convention Coalition. Membership is principally for organisations that are governed by disabled people (as outlined in Article 33 of the UNCRPD). The Convention Coalition will lead disabled peoples' work on monitoring and implementing the rights of disabled people as spelled out in the UNCRPD, and other UN Conventions affecting disabled people.

2. **Vision:** DPOs unite to act at a high level to ensure there is leadership by disabled people to oversee the implementation of the UNCRPD (and other disability rights treaties) within New Zealand. The Convention Coalition recognises the importance of sharing its work with the regional and global disability communities.
3. **Values:** The Convention Coalition (members) will ensure the articles and principles of the Treaty of Waitangi (Te Tiriti o Waitangi) are upheld and reflected throughout everything we do. We will be guided by the following:
Unity: a commitment to developing shared outcomes while respecting the unique diversity of our communities and the autonomy of our organisations.
Leadership: the leadership of disabled people is paramount at all times.
Participation: members participate at a high level in good faith and will be well connected with their communities
Rights: members will work in ways that uphold the rights of disabled people.
4. **Objective:** The key objective is to coordinate an ethical mechanism for disabled peoples' input to monitoring of disability rights as spelled out in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and other Conventions. This will enable the production of a 'shadow' monitoring report and New Zealand government report from disabled peoples' organisations. This will be achieved through:
 - adaptation of the Disabled Rights Promotion International (DRPI) framework for implementation in New Zealand;
 - facilitation and implementation of the adapted framework;
 - ensuring the process is sustainable into the future.
5. **Participation:** Each organisation's Board will appoint a disabled representative to participate in meetings and planning on its behalf. It may

also arrange to appoint a replacement representative to attend when the appointed representative is unavailable.

The Convention Coalition will do whatever it takes to facilitate members' full participation.

Additional eligible DPOs may be invited to become a member of this Convention Coalition.

6. **Making Decisions**: Decisions will be made by consensus. Where there is not initial consensus, summaries of points of agreement and difference will be circulated and further discussed until agreement is reached, or until a member feels able to have a decision go forward even though they do not entirely support it.

The Convention Coalition accepts its members may need to discuss matters with their organisation in order to reach a consensus.

7. **Media**: Any statement released by the Convention Coalition reflects a consensus view in which all members have had an opportunity to have input into the process. Statements will be consistent with "Values" set out in this memorandum of understanding. All members of the Convention Coalition may be contacts for the media.

8. **Finance**: The Convention Coalition appoints DPA (NZ) Inc as the administrative fund-holder on its behalf. Expenditure of funds will be consistent with the agreed budget and the Management Committee's oversight. Provision of reports by the fund-holder will be as directed by the Convention Coalition.

9. **Project Management Committee**: Association of Blind Citizens of New Zealand Inc; Deaf Aotearoa NZ; Disabled Persons Assembly (NZ) Inc; Nga Hau E Wha; Ngāti Kāpo O Aotearoa Inc; People First New Zealand Incorporated Nga Tangata Tuatahi

10. **Dissolution/Winding Up**: The Convention Coalition can end at any time, provided all members of the Convention Coalition meet and reach a consensus decision to do so. In the event the Convention Coalition ceases to exist, all its assets will be disposed of in accordance with a consensus decision reached by members of the Convention Coalition at the same meeting.

Appendix 9 Plain Language Summary of the Project

What people said

You treat me like I have a disability - so that means I do

We want to go out and about

We want better health care

We want better carers

We want to work

What should be done

Tell non-disabled people about disabled peoples' lives

Make a design mark or a picture that tells disabled people that a bus, train, car or place to stay is good for disabled people

Make a set of guidelines so that non-disabled people know what disabled people need

Because people are more likely to disable you when they don't know about you