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**Disability Rights in Aotearoa New Zealand:**

**Participation & Poverty**

**Large print version**

**A report on what disabled people in New Zealand say about their human rights**

**Finding 2 of the Contract 2013-2016 with the Ministry of Social Development**

**Karanga karanga karanga ra,**

**Karangahia aa Matariki e tohungia ai te oranga hou,**

**Whakamaharatia tonu nei a raaatou ma kua riro ki te poo**

**moe mai i te rangimarie, noo reira, okioki atu**

**Ka rere tonu ngaa kupu whakamihi ki te hunga tautoko, kua tutukina teenei kaupapa i teenei wa, Ma panga ma whero ka oti ai te mahi,**

**Noo reira, teenaa kautou teenaa kautou teenaa taatou katoa.**

# Disability Rights in Aotearoa New Zealand: Participation & Poverty

**This project was supported by the New Zealand Government through the Ministry of Social Development. It was administered by the Article 33 New Zealand Convention Coalition Monitoring Group, a collaboration of NZ Disabled People’s Organisations.**

**Formats**

**This report is available in: audio, Braille, easy read, electronic text, large print, New Zealand Sign Language**

**Copies are available through the following organisations:**

* **Association of Blind Citizens of New Zealand Incorporated,**
* **Deaf Aotearoa New Zealand Incorporated,**
* **Disabled Persons Assembly (New Zealand) Inc,**
* **People First New Zealand Incorporated —Nga Tangata Tuatahi**

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## Introduction

## Who wrote this report?

**This report is published by the Article 33 New Zealand Convention Coalition Monitoring Group (also called the “Convention Coalition”).**

**The Convention Coalition is a group of 8 Disabled People’s Organisations. The members are:**

* **Association of Blind Citizens of New Zealand Incorporated**
* **Balance NZ**
* **Deaf Aotearoa New Zealand Incorporated**
* **Deafblind (NZ) Incorporated**
* **Disabled Persons Assembly (New Zealand) Inc**
* **Ngā Hau e Whā**
* **Ngāti Kāpo o Aotearoa Incorporated**
* **People First New Zealand Incorporated —Nga Tangata Tuatahi**

**All of these organisations are governed by disabled people. They work together to monitor how New Zealand is implementing the United Nations Convention on the Rights of Persons with Disabilities. As monitors of the Convention, they collect information to see how well the Convention is being implemented and if it is making a difference to the everyday lives of disabled people.**

### **What is the United Nations Convention on the Rights of Persons with Disabilities?**

**It is an international agreement that New Zealand signed in 2007. The Convention says that disabled people should be able to access their human rights, without any barriers.**

**The role of the Convention Coalition is to make sure that disabled people are fully involved in monitoring how the Convention is implemented in New Zealand. This is a requirement under Article 33 of the Convention.**

### **Why was this report written?**

**One way that the Convention Coalition monitors the United Nations Convention on the Rights of Persons with Disabilities is by interviewing disabled people around New Zealand. The Convention Coalition trains disabled people to be human rights monitors. The monitors interview disabled people about their lives and experiences, especially if their human rights are being respected.**

**In 2014 the Convention Coalition interviewed people in Auckland and Wellington. This report shares what we learnt, from what they shared with us in their interviews. It focuses on two areas – participation in society, and poverty.**

### **How will this report be used?**

**This report is released publicly, in multiple formats. Individuals and organisations can use the information in this report in many ways, including to support advocacy efforts to improve the human rights of disabled people in New Zealand.**

**In particular, Convention Coalition reports are used by a group called the Independent Monitoring Mechanism. The Independent Monitoring Mechanism consists of the Convention Coalition, the Human Rights Commission, and the Office of the Ombudsman. These three independent partners jointly publish reports on their monitoring work.**

**This report is written for the wide range of people and organisations who work to improve the lives of people with disabilities. Most importantly, it is for the one in four New Zealanders who experience a disability. As much as possible, the report is written in the words of disabled people themselves. We sincerely thank them for sharing their experiences with us.**

## Acknowledgements

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## The interviews

## Who was interviewed?

**Ninety seven people in Auckland and Wellington were interviewed for the project.**

**Further information on the sample group for this report is contained in the appendix.**

## What were people asked?

**The interview questions were developed by a Canadian organisation called Disability Rights Promotion International (DRPI). The same questions are used in several countries around the world. People were asked questions about their lives and experiences over the last five years.**

### **What is Disability Rights Promotion International?**

**They are an international collaboration that is working towards developing a global disability rights monitoring system. Their approach to monitoring is unique for a number of reasons including:**

* **All monitoring activity is led by disabled people**
* **Human rights principles are considered when monitoring specific human rights**
* **A holistic approach is used that monitors both individual experiences, systems, and societal attitudes. Information from all three of these areas is then combined, to recognise that the “discrimination and isolation of persons with disabilities is complicated, widespread and often ignored.”**

**The interviews that this report is based on are part of the individual experience monitoring strand of the Disability Rights Promotion International model.**

## How is the information from the interviews analysed?

**The experiences are classified using the Human Rights principles used in the United Nations Convention on the Rights of Persons with Disabilities. These principles are:**

* **Dignity**
* **Autonomy**
* **Participation**
* **Inclusion and Accessibility**
* **Non-discrimination and Equality**
* **Respect for Difference**

**Analytical software called NVIVO is also used, which identifies common themes and issues raised by multiple people. This report focuses on common themes and issues relating to the topic of participation and poverty.**

**Some completed interviews could not be included in the final analysis. Most commonly, this was because of an error or issue with the audio recording of the interview. More detail on this is included in the appendix to this report, which also includes an explanation of the strengths and limitations of this research.**

**The project received ethical approval from the National Health and Disability Ethics Committee before interviews began.**

**It is important to remember that the themes in this report still represent a wide range of individual experiences and feelings. This was explained by one person who said “it doesn’t have to be like every disabled person would be embarrassed in that situation. But I was embarrassed in that situation.”**

## Summary of findings

**This section summarises the full Participation and Poverty report. It also notes some of the links between the report and earlier reports produced by the Convention Coalition.**

**The first focus area for the report is participation in society. During the interviews, disabled people shared many examples of times when they hadn’t been able to fully participate in society.**

**Although many different examples were shared, there were some common themes and issues.**

**Physical access.**

**To be able to participate in New Zealand society, people with disabilities need to be able to fully access their communities. This means being able to physically access places and buildings, but it also means access to services, events and information.**

**When people with disabilities go to public places and participate in events, they often experience barriers. In particular, there were reports of lifts being inaccessible, doors being locked, and disability car parks having insufficient space for disabled people to get in and out of their cars.**

**Interviewees explained that when they cannot access a place or service, this often causes significant interruption and inconvenience for them. It was suggested that if environments and buildings could be made more accessible, this would have benefits for everyone, including disabled people.**

**Access to information and technology**

**Advances in technology were described as helping people to participate and communicate in all areas of life. This was consistent with a previous finding from the Convention Coalition’s Youth Report (2013) where technology was reported as positive and as improving social connections and access to education.**

**However some difficulties were encountered. Often new technology is unfunded or has restricted funding. Additionally, new technology is often developed without consultation with people with disabilities, meaning that people are limited in their choice of services.**

**Housing.**

**Access to safe, accessible housing was a major concern for interviewees, especially in Auckland. Some people reported being offered state housing that was far away from their work, family, and disability services. This made it difficult for them to participate in social and family networks. A lack of affordable, accessible housing in the private sector was also reported.**

**For some interviewees, this lack of suitable housing meant that they were continuing to live with their parent/s, despite wanting to live independently.**

**Social life, sports and recreation.**

**Access to public facilities such as sports grounds and theatres was regularly raised as an issue. Some interviewees felt it was very difficult to maintain their health and wellbeing because of physical access barriers.**

**Public events such as sporting fixtures or cultural events were often described as inaccessible due to a lack of appropriate seating, lack of interpreters, or a lack of support.**

**Supports, services and funding.**

**Some people with disabilities require supports/services to participate in society how they would like to. Interviewees reported a number of difficulties in accessing these. Issues with assessments, and inadequate levels of funding, were common.**

**These findings seem consistent with the Convention Coalition’s 2012 Disability Rights in Aotearoa New Zealand report. There it was reported that the funding available for supports/services was considered inadequate to ensure high and consistent standards of service.**

**Participation in society and dignity.**

**Dignity is one of the human rights principles used in the United Nations Convention on the Rights of Persons with Disabilities. Throughout these interviews, hundreds of experiences have been shared and recorded. In almost all of these, people reported a loss of dignity when their human rights were not fully respected.**

**Poverty.**

**The second focus area for this report is poverty. During the interviews, disabled people discussed the impact of poverty on their lives. They discussed community attitudes about poverty, and explained how poverty impacts their access to services and opportunities to participate in society.**

**Community attitudes.**

**Almost all interviewees who discussed poverty mentioned the impact of community attitudes. All reported negative community attitudes, including that poor people are lazy, stupid, and have little to contribute to society.**

**Inequality.**

**A number of interviewees discussed the wider issue of inequality between the “rich” and “poor” and the potential impact of this on the disabled community. Some felt poverty was a long-term issue. Their lack of resources over a prolonged period made it more difficult to access services, and made them feel marginalised and isolated.**

**Access to resources and services.**

**The relationship between poverty and disability became clearer when interviewees talked about their access to resources and services. Having a disability was often seen as creating extra costs that had to be met somehow and financially disadvantaged some people. Higher travel and transport costs were a very significant theme.**

**The social welfare system and ACC.**

**Most interviewees discussed the social welfare system. Criticisms of the system often related to the bureaucracy involved. Knowing where to apply for funding (both private and government funding) and how to apply for funding was a difficulty encountered by participants.**

**Many participants, especially those with mobility disabilities, discussed the different criteria for ACC and Work and Income and the higher levels of assistance available under ACC. This inequality was described by some as a human rights violation. This finding is consistent with earlier Convention Coalition reports, including the 2012 Disability Rights in Aotearoa New Zealand Report. This report suggested a comprehensive rehabilitation system was lacking in New Zealand, with fragmentation between the main providers: Ministry of Health, ACC and District Health Boards.**

**Dignity and poverty.**

**As with the participation topic, dignity was a common theme in many of the experiences that interviewees shared.**

## Topic 1: Participation

**The first focus area for this report is participation in society. During the interviews, disabled people shared many examples of times when they hadn’t been able to fully participate in society. They outlined barriers that made participating difficult or in some cases impossible. Many different types of barriers were explained – from physical and environmental barriers to the attitudes and actions of other people.**

**Although many different examples were shared, there were some common themes and issues.**

## Access

**1. To be able to participate in New Zealand society, people with disabilities need to be able to fully access their communities. This means being able to physically access places and buildings, but it also means access to services, events and information.**

**2. When people with disabilities go to public places and participate in events, they often experience barriers. This was a very clear theme raised by interviewees, especially those with a mobility or sensory disability. More than half of those with a mobility disability raised concerns about access. In particular, there were reports of lifts being inaccessible, doors being locked, and disability car parks having insufficient space for disabled people to get in and out of their cars.**

**3. When lifts are unavailable, many public places can only be accessed by stairs. This means that some wheelchair users have to be manually lifted up the stairs or not participate at all. Interviewees talked of the pain and embarrassment they sometimes experience when being manually lifted.**

**4. Embarrassment and discomfort were also mentioned when people reported difficulties accessing toilets. Many people spoke of toilets that were inaccessible because of their design, or problems with lift access. Some reported that disabled toilets were being used as storage spaces. This was raised as an issue both in public places and private buildings. One interviewee explained the impact on her: “it made me think, well, OK, what’s the point in going out anywhere if you can’t even do something basic like going to the loo.”**

**5. Interviewees explained that when they cannot access a place or service, this often causes significant interruption and inconvenience for them. It was suggested that if environments and buildings could be made more accessible, this would have benefits for everyone, including disabled people.**

**Case study:**

**6. Kiri (not her real name) is an early childhood teacher who uses a wheelchair. During her training, she was asked to leave her course.**

**“They thought that I was incapable of teaching but when I spoke to my lecturer at university, she said it was because they felt uncomfortable because the building was inaccessible and they didn’t want to bring it up to code.”**

**Kiri was required to do practical teaching experience in an early childhood centre as part of her training. Because the centre at her university was not accessible for her wheelchair, Kiri had to find another option for herself. Eventually she found another centre to do her practical teaching experience at, but “it meant travelling all over [the city] instead of going five minutes up the road.”**

**When Kiri described her experience during her interview, she explained her frustration. She also explained that accessibility is important for everyone. She said, “knowing that early childhood centres and other public places should be accessible anyway, I was extremely frustrated and annoyed … I felt like an outcast in something which should already be accessible for able bodied people anyway with prams and things like that.”**

**Footpaths, roads and crossings**

**7. Footpaths, roads and pedestrian crossings were often reported as inaccessible and a challenging barrier for people. Almost all of the interviewees who raised this issue suggested that if councils and other agencies consulted with disabled people when they were building or modifying roads, footpaths and pedestrian crossings, most of these problems could be solved.**

**Access to information and technology**

**8. Advances in technology were described as helping people to participate and communicate in all areas of life e.g. being able to make submissions and give feedback online, use a cell phone to give instructions to drivers, on line shopping, technological advances in wheelchairs, video relay services, etc. However some difficulties were encountered. Often new technology is unfunded or has restricted funding (e.g. car adaptations).**

**9. Additionally, new technology is often developed without consultation with people with disabilities, meaning that people are limited in their choice of services. Sometimes, they are unable to access a service. A particular example of this is captcha. Captcha is a security test that requires website users to enter a code from a distorted picture on the screen, to confirm they are a legitimate website user and not a robot. This makes many websites inaccessible to blind people. Captcha can lead to a large amount of time being wasted e.g. one person spoke of their frustration at spending hours writing a submission and then being unable to submit it because of a captcha test.**

**Housing**

**10. Access to safe, accessible housing was a major concern for interviewees, especially in Auckland. Some people reported being offered state housing that was far away from their work, family, and disability services. This made it difficult for them to participate in social and family networks. A lack of affordable, accessible housing in the private sector was also reported. For some interviewees, this lack of suitable housing meant that they were continuing to live with their parent/s, despite wanting to live independently.**

**People with a house that they believed wasn’t accessible/satisfactory often said that they felt unable to complain. One person explained that they felt “like we are beggars and need a hand out from them [the government]… I felt like it was my fault and I didn’t feel I was even able to ask anyone for help……I feel I was stuck into being very polite and diplomatic and not complaining because if I do complain they could turn around and say …we’re not going to give you a house.”**

**11. People with intellectual disability suggested some particular issues with access to housing. The cost of housing was seen as a major barrier for three interviewees with intellectual disability who currently live in group homes but would like to live independently. It seemed that some people with intellectual disability, especially those living in private housing and working in low paid employment, were in vulnerable housing situations. One person with an intellectual disability had rented his house for fourteen years. He reported he had a new landlord who had increased his rent three times within one year.**

**12. Most interviewees lived with family/whanau. Families often provided physical support (e.g. housekeeping), accommodation, advocacy, and financial support.**

**Family**

**13. A number of interviewees discussed the impact of their disability, and barriers to participation, on their families. One talked of the impact on their children. “Because of my impairment, the children’s participation is restricted. It’s, I suppose, a worse feeling, or worse .. loss of participation than when your own personal participation is limited…[The] impact is on the whole family…it’s not just an individual experience if kids miss out… disabled parents need support.”**

**14. Some noted that there can be considerable pressure on relationships if support is not provided and the family has to finance the needs of the disabled person: “there’s this big burden on my wife, where she’s working and she comes home and there’s this bloke in a wheelchair. So we’re limited in what we can afford to do… My disability becomes her disability.”**

**Social life – including sports and recreation**

**15. Sports and leisure were important to the people we interviewed. When asked to describe the most satisfying things in their lives, one third of interviewees reported participating in sport or leisure activities/hobbies. Given we did not specifically ask about these activities, we believe that the total number of interviewees who participate in these sport/leisure activities is likely to be even higher.**

**16. Access to public facilities such as sports grounds and theatres was regularly raised as an issue. Some interviewees felt it was very difficult to maintain their health and wellbeing because of these access barriers.**

**17. One interviewee described her experience of being injured while trying to access a public swimming pool and the impact on her health. “I feel that there are a lot of barriers set up here and I can’t participate. For example, I like swimming as a pastime but also for health and fitness and I find this Council’s swimming pools are really difficult to access. They are quite a high risk and I have injured myself and had to have some surgery after the injury at one of them before. By not accessing them I don’t get any exercise and that’s having a huge impact on my health…**

**The entry into the swimming pools most of them have like step ladders that are quite slippery and they are not suitable for people with disabilities and by using those I slipped and injured myself and had to have some surgery. I find it extremely difficult trying to access most of the swimming pools. They have some ramps into the one that the children use but then the children are playing there and they bump you and so those pools aren’t suitable.”**

**Support and funding**

**Assessments**

**18. Some people with disabilities require support/services to participate in society how they would like to. Interviewees reported a number of difficulties in accessing support. Issues with assessments, and inadequate levels of funding, were common.**

**19. A significant number of interviewees, particularly those with mobility issues, found the needs assessments (of ACC and/or Ministry of Social Development) were excessive, inflexible and didn’t adequately take into account the person’s disability and needs. It was felt that a small number of supports were approved for funding and that the person had to fit the support rather than the support meeting his/her needs. One interview reported he had 25 assessments for one wheelchair. All of these assessments were within work hours, and this made it difficult for him to work. He described the system as having an “output focus rather than outcome focus. If you actually added up all of the staff time that went into the assessment process, I could’ve got the chair that I actually needed several times over for that cost.”**

**20. All interviewees who discussed problems with assessments and gaining support noted that they felt as if they were seen as “difficult”, “milking the system” or trying to get something they weren’t entitled to. “It was as though firstly that I was begging for something. It made me feel like ..despite having paid enough in taxes … I was asking for something I wasn't ... really owed or eligible for. " The frustration, inconvenience , cost of assessments and changes, inflexibility and narrowness of focus made the process extremely stressful and difficult for many people, excluding them from participating in normal activities such as using the bathroom or having access to a wheelchair. One person explained what they would have preferred to happen. “I wanted a single assessment that understood my needs, gave me options to choose from in an informed way and then actually responded to those decisions. And I think that would have made a significant difference. It would have saved everyone a lot of time and bother, it would have been cheaper…overall and it would have increased my satisfaction significantly."**

**Adequate funding**

**21. The funding for disability related needs available through the Ministry of Social Development/Work and Income was considered inadequate by some. One interviewee noted that he was allocated a small sum of money to install a wheelchair lift. The amount was only about a quarter of the actual cost of installation. He also said that he had little or no choice as to the placement of the lift. Many interviewees noted that once allocated funding they were not able to modify the plans to meet their needs, even when the modifications would not cost any extra.**

**Health**

**22. Some interviewees suggested that the health system is designed for the needs of able-bodied people, and isn’t flexible enough to support the full participation of people with disabilities. Communication issues with health professionals were reported. Mostly, these involved situations where the health professional was not seen to fully respect the person, or didn’t believe that the disabled person could make decisions about what was best for them.**

**Participation in society and dignity**

**23. Dignity is one of the human rights principles used in the United Nations Convention on the Rights of Persons with Disabilities.**

**24. Throughout these interviews, hundreds of experiences have been shared and recorded. In almost all of these, people reported a loss of dignity when their human rights were not fully respected.**

**25. A potential loss of dignity is clear across many different types of experiences, including ones that disabled New Zealanders experience every day as they go about their lives.**

**When people go shopping.**

**26. “What comes to mind is the shock when I realised that in a shop people will either ask your caregiver ‘what does she want’ if you are in a wheelchair or they will ignore you if you are alone. They will speak only to adults at eye level. You might be …the second one in the queue but if there are two people who are adult behind you they will serve the one person at the front they were serving and then the two behind you and they will ignore you. I have found out since I learnt to stand up that if I stand up they will serve me, which is very interesting…..It may be inadvertent that they only serve people at eye level or they think you are mentally deficient because you are in a wheelchair. Your legs don’t work therefore your brain isn’t working. I actually told the newspaper about it and they were going to do an article but they feared that if they took a photograph of particular premises they would be blaming.”**

**When people catch a bus.**

**27. “There was a situation where I was discriminated against on the bus. I was with … my partner at the time. We wanted to get on the bus.**

**It was the new bus and we knew that the new buses had two spaces available (for wheelchairs)…We weren’t trying to cause trouble for anybody at all. The bus driver refused to let the ramp down because he couldn’t be bothered and he said to me that he doesn’t get paid enough to help people like us. He was referring to our wheelchairs.**

**…It has actually happened more than once but obviously I haven’t taken the bus company to the Human Rights Commission more than once. I’ve got other things to do with my time than repeatedly follow up …again and again.”**

**Making changes using the Convention**

**28. This report is part of monitoring New Zealand’s progress on implementing the United Nations Convention on the Rights of Persons with Disabilities. Monitoring is important, because any Convention is only valuable if it is used to make progress.**

**29. As well as sharing their experiences, interviewees talked about solutions. Some talked about using the Convention as a solution. One interviewee challenged us to ensure that the Convention results in real, practical changes for disabled people in New Zealand.**

**30. He said: “we have all these conversations and we write all these policies and we put together all these project plans for the betterment of disabled people. We get all excited about the opportunities and the money and…all the rest of it and I can’t get on the bus! It really puts things into perspective.**

**Yes, we can get excited about the higher level stuff, we can get excited about policy and we should be excited about the ramifications (of the Convention). Please don’t feel that I’m not, but [I’m] putting it into context.**

**The bus company said to me directly that until the convention ratification becomes part of local government law they won’t be reacting on their own good will……[the government] have ratified it, but they haven’t written it into local law and until such time the bus company won’t react.”**

## Topic 2: Poverty

###

**The second focus area for this report is poverty. During the interviews, disabled people discussed the impact of poverty on their lives. They discussed community attitudes about poverty, and explained how poverty impacts their access to services and opportunities to participate in society.**

**Although many different examples were shared, there were some common themes and issues.**

**Explaining poverty**

**31. Poverty is a complex idea. It is not just about a lack of money – someone can have little money but consider themselves culturally and spiritually rich. Poverty has many possible causes. One interviewee explained the many causes of poverty like this: “Poor people are that for a wide number of reasons: they could have lost their job, their house, yeah, they might have flittered all their money away on gambling. Poor people might have made a wrong decision and they’re regretting it. Yeah, I think we need to be a bit more understanding towards poor people and see what their lifestyle is before we judge, I reckon.”**

**32. Another discussed the relationship between poverty and barriers in society, for example barriers to accessing education:**

**33. “They were never asked for a choice….it is about education and how people are brought up. Some people are poor because they just did not get…support. They were disadvantaged throughout. If they had good lives they would have been in a different situation. Probably we come back to that point of barriers again. They went through that their entire life. They didn’t get enough education; they didn’t have enough support.”**

**Community attitudes**

**34. Almost all interviewees who discussed poverty mentioned the impact of community attitudes. All reported negative community attitudes, including that poor people are lazy, stupid, and have little to contribute to society.**

**35. “ ... poor people are treated as if they've done something wrong to be poor. Poor people are treated as if they could stop being poor if they decided to. They're treated as if they are stupid and lazy. They are treated as if they don't know how to budget as opposed to just not having enough money. ….You know like, I think the stress of having no money is incredibly brutal and it means that people need coping strategies and if those coping strategies aren't what the state or society think are acceptable then they're seen as terrible people.”**

**36. Multiple interviewees felt that currently New Zealand society judges and shuns poor people.**

**Disabled poor people**

**37. Some interviewees suggested that community attitudes about disabled poor people were more positive than non-disabled poor people. One explanation given for this was that disabled people were seen as more “deserving” – as having a “better” reason to be in poverty. However some people suggested this wasn’t true for poor people with a psychosocial disability. One interviewee in particular explained how “astounded” he was that people within service provider organisations spoke about homeless poor people with psychosocial disability. He reported that they were generally seen as not having anything to contribute to society. Others thought being poor and having a disability was a double barrier - “I definitely think poor people get treated really bad especially if you are disabled and you are poor.”**

**The impact on individuals**

**38. Community attitudes impact individuals. Some individuals who we interviewed spoke of how they felt about being poor, and other people’s attitudes towards them.**

**39. One spoke of the shame she felt: “I am very, very sensitive of other people knowing that I am a beneficiary, that’s a great shame and you know its….there’s a lot of anger out there.”**

**40. One explained that she felt judged and scrutinised, and under pressure:**

**41. “It's very exposing, I think, I think being poor is really exposing because.... you know like I think of articles in the paper and it all has to be oh like I never spend any money on this. And I never spend any money on myself. And I never have anything I just enjoy. It has to be like they have to be the most virtuous, poor people to potentially get any other kind of support. And you know, they have to be grateful and they have to be like (sigh) they have to not be angry about being poor which yeah I guess it's that sort of thing like I feel like, I don't know how acceptable it is. I think it's more acceptable for disabled people to be angry. Not about being disabled but about being ...well I guess about being disabled, yeah, not about having any difference but it's more like well you shouldn't be angry, you should just feel sad about it you know. And you should still be the right kind of disabled person. In some ways I feel like I try too hard to be that kind of disabled person.”**

**42. One person who received a benefit because of their disability, explained how she felt about being labelled as a beneficiary when seeking services from a lawyer:**

**43. “So that is what I would have liked to have [been] different… just really go through the details and really show her [the lawyer] who I am because on my form it says I’m a beneficiary and that is technically true… but there are so many other elements to me and when the lawyer sees the word beneficiary they don’t take very much interest. They are not looking after a banker; they are not looking after an investor so this one is not a very big priority especially when I’m receiving legal aid.”**

**Inequality**

**44. A number of interviewees discussed the wider issue of inequality between the “rich” and “poor” and the potential impact of this on the disabled community. Some felt poverty was a long-term issue. Their lack of resources over a prolonged period made it more and more difficult to access services, and made them feel marginalised and isolated. Some did not believe that the situation would improve.**

**45. “…. the cost of living….you know, that’s a huge issue in our community right now, ..the rich are getting richer and the poor are getting poorer, and it’s getting wider and I think that – I think that’s really starting to kick in for disabled people.”**

**46. One explained the different experiences he had as a consequence of being well educated and financially secure:**

**47. “[A poor person would] be treated worse because effectively because I had means… I had mechanisms to circumvent some of the way I was being treated. I had educational background that came from my parents financial means that meant I was in a better position to advocate strongly for myself. I was in a position with my employment to actually take the time off work for the assessments. So a person without means or without financial resource would have been a lot worse off than I. “**

**Access to resources and services**

**48. The relationship between poverty and disability became clearer when interviewees talked about their access to resources and services.**

**49. One interviewee suggested that people assumed she could use internet shopping if she couldn’t get to the supermarket. However to do this requires a computer, access to the internet, and money to pay delivery fees. This was not a possibility for the interviewee.**

**50. Poverty had a clear impact on one support group of disabled people, and their ability to participate in society.**

**“[The disability support group members are] mainly all poor. When we decide to have a get together, no one can afford to go. There isn't one person who ..goes yeah..I can afford it and I'll pay for a few others to attend …We had a gathering in [city] two years ago and six people made it, three funded by government, one funded by relatives, and two under their own steam. The idea that anyone else had enough money for a bus fare to [city] and $88 a night to stay there for three days is a joke. This is a poor community.”**

**51. Some discussed poverty as yet another barrier that many disabled people encountered.**

**52. “Poor people have far more barriers in life. They haven't got access to a computer or to a book in interpreter or access to the phone for their needs. Rich Deaf people are more lucky. They try to receive what they can and they know how to access the resources better for example. A Deaf rich person, if they have an iPad they can FaceTime. But a poorer one can't.”**

**53. The impact of having to face multiple barriers was raised.**

**54. “ Well it can be tough to get the resources you might need. Tough to get housing close enough to areas which have transport. Tough to get the equipment that you might need and also the potentially the education that you might need as well so it can be quite cumulative.”**

**55. Having a disability was seen as often creating extra costs that had to be met somehow and financially disadvantaged some people. Higher travel and transport costs were a very significant theme. Many described taxis, including wheelchair taxis, as a luxury. One described the significant differences they noted when flying:**

**56. ‘Well … in terms of the traveling public there is a clear class system. They call it priority travellers or valued customers or whatever but it's clear that if you can't afford to for example if you're not a [airline loyalty scheme member] you have to sit down the back of the aircraft. It's clear that the leg room is increased in the first five rows of the aircraft. So that's a particular issue for me so unless I'm in that class of traveller I can't get that service if I can't afford a wheelchair taxi which was something like $100 from the airport to the hotel then I don't know what I would do. Because the bus links are not commensurate to adequate travel with baggage without considerable extra support. Having travelled on the bus once from the airport, the bus driver made no attempt to assist with luggage or you know grumbled when he had to extend the ramp and kneel the bus and all of that. And other passengers had to move all their stuff out of the way that they'd put in the wheelchair slot. So I don't go there with public transport in the majority of cases.... I have to pay.”**

**57. Having choices about which services to access was seen as strongly linked to financial status. Having choices was described as an important part of improving independence for disabled people and diminishing negative attitudes.**

**The social welfare system and ACC**

**58. Most interviewees discussed the social welfare system. Many talked about New Zealand’s history of providing social welfare. Some suggested this history had resulted in inequalities, for instance in differences in eligibility between different disability groups.**

**59. Criticisms of the system often related to the bureaucracy involved. In particular, medical professionals and Work and Income were seen as gatekeepers whose decisions were difficult to challenge. Some suggested that people could be disadvantaged if they did not receive full information or could not understand it. One interviewee suggested that this entrenched poverty.**

**60. Knowing where to apply for funding (both private and government funding) and how to apply for funding was a difficulty encountered by participants. One participant noted the need for centralised funding either through one agency or website. Another felt it was the role of agencies to facilitate these applications rather than take on the role of gatekeeper.**

**61. For those who found information on funding, understanding the different criteria and policies of different agencies was sometimes difficult.**

**62. Some specific funding criteria were criticised. One example was the policy of Work and Income New Zealand to consider a partner’s income when determining the Supported Living Payment and disability related costs. Partner’s income is not taken into consideration if a person is supported by Accident Compensation (ACC). This was considered by some interviewees to be discrimination.**

**63. Many participants, especially those with mobility disabilities, discussed the different criteria for ACC and Work and Income and questioned the higher levels of assistance available if a person is supported under ACC. This inequality was described by some as a human rights violation. One stated: “There’s quite substantial inequality between injury-related disability and chronic disability of non-accident causes which I think is a human rights violation to be quite honest.” Another talked about the importance of treating people equally: “Cos I think, my thinking comes about, whether a disability comes about from accident or misfortune, or genetic, your needs are the same, so that whole thing about the village looking after itself, looking after its people.”**

**64. How funding criteria are used to make decisions was discussed. Particularly for ACC, it was suggested that decision-making processes can be bureaucratic and that no flexibility is allowed when applying the funding criteria. The participants who were declined ACC felt that they were declined on technicalities, despite being eligible. They found the review process was extremely difficult, particularly meeting ACC’s short time frames for review. “Oh I just felt frustrated and angry, and I just think they are being deliberately obstructive. I think they are deliberately trying to avoid accepting as many claims as they can just to save money.”**

**65. It was suggested that the overall situation for disabled people receiving social assistance of all kinds was not getting enough attention.**

**66. “You know, there’s a whole lot of emphasis placed on this current government around women who are solo parents, you know, DPBs(Domestic Purposes Benefit) we hear about all the time in the media….it’s about 23,000 people in New Zealand that are on the DPB. OK, in terms of people that – disabled people that are involved in the welfare system, we make up something like over half of all people on a benefit…. I think we view people on DPB as being undeserving, so therefore they get a lot of attention which I don’t think is necessary. But what annoys me about that is that while they’re putting a whole lot of attention on people on DPBs, actually the real issues, for example, the fact that there’s all these disabled people sitting on welfare and we’re not really shifting – you know, not able to get those people into jobs, is not being dealt with.”**

**Dignity and poverty**

**67. As with the participation topic, dignity was a common theme in many of the experiences that interviewees shared.**

**68. We heard of experiences where people felt they had lost dignity:**

**69. “… I've been on benefits a lot in my life. But like, that whole thing about you have to justify yourself. You have to justify what you spend your money on. You have to justify how you spend your time. You have justify who you're having sex with or who you're in a relationship with.”**

**70. But also of positive experiences, where people felt their dignity was respected:**

**71. “I think the most satisfying thing for me is being able to be a productive member of the community. When I say productive; being able to earn money and developing relationships and developing projects for certain people. Just living the sort of life I believe everybody should be able to have access to.”**

**Appendix**

**Research method and limitations**

**This report is part of a wider research project by the Article 33 New Zealand Convention Coalition Monitoring Group. The aim of the research is to monitor the implementation of the United Nations Convention on the Rights of Persons with Disabilities. This appendix includes brief information on the research method used for the project, and the strengths and limitations of this report. It should be read together with the section in this report titled “The Interviews”.**

**The project follows a method developed by Disability Rights Promotion International (DRPI). The research is undertaken by disabled people who are trained to interview other disabled people about their experiences. A semi-structured interview is used that is based on the human rights principles in the United Nations Convention on the Rights of Persons with Disabilities. More information on the research method is available online at** [**http://drpi.research.yorku.ca/**](http://drpi.research.yorku.ca/) **along with reports from similar projects in other countries.**

## The Research Project

**The project consists of multiple rounds of interviews in sites across New Zealand during the period 2014-2016.**

## The Interview Sites

**This report includes information from the first round of interviews in Auckland and Wellington. These interview sites were defined as follows:**

**The Auckland site was defined by electorates. The electorates included were East Coast Bays, North Shore, Northcote, Auckland Central, Te Atatu, Mt Albert, Waitakere, Epsom, Tamaki, Pakuranga, Botany, Mt Roskill, Maungakeieke, Mangere, Manukau East, Manurewa, New Lynn and Papakura.**

**The Wellington site included the electorates of Wellington Central, Rongotai, Ohariu and Hutt South.**

**Both of these sites are urban areas, and many of the themes raised by interviewees clearly related to urban living. Future interview sites will provide a rural perspective.**

## Selecting Interviewees

**The ‘snowballing technique’ was used to recruit interviewees. The 8 Disabled People’s Organisations that are part of the Article 33 New Zealand Convention Coalition Monitoring Group were asked to nominate the first people to be interviewed. Then each interviewee was asked to nominate another two people to participate.**

**Demographic information from New Zealand sources was used to set targets for different characteristics (for example, age, gender, disability type) to ensure the group of interviewees was as balanced as possible.**

## The Interviewees

**Ninety seven people in Auckland and Wellington were interviewed. All interviewees had to be over 18 years old and have a disability.**

**Some completed interviews could not be analysed, mostly due to issues/errors with the audio recording of the interview. Most of these interviews occurred at the start of the interview period. When the issue was identified changes were made to how the audio recording was completed and the issue was largely resolved. Other reasons for exclusion included that the examples discussed by the interviewee happened in another country, or later finding that an interviewee was not within the age range for the research. In total, 80 of the interviews were able to be analysed.**

**In the Auckland interviewee group, 25 were female and 20 male. Disability types reported included mobility (19), sensory (15), intellectual (8), psychosocial (2) and other disability (1). Most were in the 18-44 year old age range (23 interviewees). 12 were aged 45-64 years and 2 were 65 or older.**

**In the Wellington interviewee group 18 were female and 17 male. Disability types reported included mobility (15), sensory (9), intellectual (4) and psychosocial (7). Most were in the 18-44 year old age range (18 interviewees). 10 were aged 45-64 and 4 were 65 or older. Age information was not recorded for all interviewees.**

**The demographic characteristics of the interviewee group were compared to the targets that were set. On the Wellington site all targets for gender and disability type were met, except for the “other disability” type. In Auckland the number of people with psychosocial disability was significantly below the target set. Most other targets were met or close to being met. Across both sites, the number of interviewees in the 65 or older age group was low. Also across both sites the number of interviewees with intellectual disability was high - almost three times the target number. This was considered a significant strength.**

## Limitations

**One limitation of the first interview round was that Maori and Pacific people were not specifically engaged/considered as a target population. Ensuring that this monitoring method is culturally appropriate for disabled people in New Zealand is an ongoing focus for future interview rounds.**

**In some areas, interviews were limited because it was difficult to find sufficient interviewees. It was particularly difficult to find interviewees over 65 (across all disability types), and interviewees with psychosocial disability. In some cases this was because we couldn’t identify potential participants using the snowballing technique. In other cases, individuals or services denied us access to potential participants.**

## Language and definitions

**Monitor and Interviewee**

**In this project “monitor” means the person conducting the interview. The person being interviewed is the “interviewee”.**

**Disability type**

**The Disability Rights Promotion International tool describes different types of disabilities. Their categories are: Mobility, Sensory (Blind/Low vision, Deaf/Hard of Hearing), Intellectual, Psychosocial, Others. As this study is based on the research design by Disability Rights Promotion International (DRPI) and is part of a sequential study, DRPI language and definitions are used for continuity and comparability.**