

# **My Experiences, My Rights**

## **A Monitoring Report on Disabled Person's Experience of Housing in Aotearoa New Zealand**

**Disabled Person-Led Monitoring of the United Nations Convention on the Rights of Persons with Disabilities**

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**E rua tau ruru, e rua tau wehe, e rua tau mutu, e rua tau kai  
Persevere, keep at it, and success will follow**

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## 2. Acronyms Used in this Monitoring Report

ACC	Accident Compensation Corporation
CHRANZ	Centre for Housing Research Aotearoa New Zealand
DBI	Donald Beasley Institute
DRPI	Disability Rights Promotion International research model
DPO	Disabled People's Organisation
DPA	Disabled Persons Assembly
DHB	District Health Board
HNZ	Housing New Zealand
IHRL	International Human Rights Law
LGBTQIA+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, Plus
NZSL	New Zealand Sign Language
ODI	Office for Disability Issues
PA	Personal Assistant
RFP	Request for Proposal
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UDHR	Universal Declaration of Human Rights
WINZ	Work and Income New Zealand

## 3. United Nations Convention on the Rights of Persons with Disabilities - Articles

Preamble

Article 1 – Purpose

Article 2 – Definitions

Article 3 – General principles

Article 4 – General obligations

Article 5 – Equality and non-discrimination

Article 6 – Women with disabilities

Article 7 – Children with disabilities

Article 8 – Awareness-raising

Article 9 – Accessibility

Article 10 – Right to life

Article 11 – Situations of risk and humanitarian emergencies

Article 12 – Equal recognition before the law

Article 13 – Access to justice

Article 14 – Liberty and security of person

Article 15 – Freedom of torture or cruel, inhuman or degrading treatment or punishment

Article 16 – Freedom from exploitation, violence and abuse

Article 17 – Protecting the integrity of the person

Article 18 – Liberty of movement and nationality

Article 19 – Living independently and being included in the community

Article 20 – Personal mobility

Article 21 – Freedom of expression and opinion, and access to information

Article 22 – Respect for privacy

Article 23 – Respect for home and the family

Article 24 – Education

Article 25 – Health

Article 26 – Habilitation and rehabilitation

Article 27 – Work and employment

Article 28 – Adequate standard of living and social protection

Article 29 – Participation in political and public life

Article 30 – Participation in cultural life, recreation, leisure and sport

Article 31 – Statistics and data collection

Article 32 – International cooperation

Article 33 – National implementation and monitoring

Article 34 – Committee on the Rights of Persons with Disabilities

Article 35 – Reports by States Parties

Article 36 – Consideration of reports

Article 37 – Cooperation between States Parties and the Committee

Article 38 – Relationship of the Committee with other bodies

Article 39 – Report of the Committee

Article 40 – Conference of States Parties

Article 41 – Depositary

Article 42 – Signature

Article 43 – Consent to be bound

Article 44 – Regional integration organizations

Article 45 – Entry into force

Article 46 – Reservations

Article 47 – Amendments

Article 48 – Denunciation

Article 49 – Accessible format

Article 50 – Authentic texts



## 4. Foreword

Aotearoa New Zealand's housing pressures are well known yet little is known about how disabled people are faring in realising their right to a home. This research report, commissioned by the Disabled People's Organisation (DPO) Coalition,<sup>1</sup> sheds light on housing issues for disabled New Zealanders.

The evidence reported here paints a very grim picture of disabled people experiencing numerous and insurmountable barriers to housing, demeaning discrimination and human rights abuses.

Disabled people report limited choices in accessible housing; difficulties in getting necessary housing modifications; a lack of control over their living situation; affordability barriers and discriminatory attitudes from people in power such as landlords, real estate agents and government housing support services.

These barriers result in disabled people living in inaccessible and unsafe homes, young disabled people living in retirement homes, and forcing some disabled people into homelessness. The lack of accessible housing impacts on disabled people's health and wellbeing; and a lack of consideration of accessibility can lead to poor decisions and more costly accommodations. This is highlighted by the example of one disabled person's requests for their Kiwibuild home to be built to their accessibility needs being repeatedly ignored during the build meaning that their new home was then required to be retrofitted with accessibility features.

The right to housing is a basic human right. It encompasses the right to live somewhere in security, peace and dignity. The right to adequate housing is recognised in the 1948 Universal Declaration of Human Rights and in multiple international human rights treaties that New Zealand has ratified, including the Convention on the Rights of Persons with Disabilities (UNCRPD). Home is where we spend most of our time and this report shows that disabled people are often living in places that are not accessible and not safe.

The DPO Coalition has been established to raise the collective impact of DPOs to achieve disability rights in Aotearoa New Zealand. The DPO Coalition commissioned this research as part of its monitoring role, as outlined in the UNCRPD, ensuring the research was disabled people-led and gathering the views and experiences of disabled people. We call this "Disabled people-led monitoring".

The Government of New Zealand has a responsibility to ensure everyone has access to adequate housing, regardless of personal, social or environmental issues. This means that the Government must guide and monitor the provision of housing in New Zealand to ensure all people are able to access suitable housing (Human Rights Commission, 2020). The DPO

<sup>1</sup> The DPO Coalition is comprised of the following DPOs: Blind Citizens NZ, Disabled Persons Assembly NZ, People First, Balance Aotearoa, Deaf Aotearoa, Muscular Dystrophy NZ, and Kāpo Māori Aotearoa.

Coalition intends for this report to shed light on a large marginalised group, their inadequate housing outcomes, and to support urgent action so that disabled people can realise their right to a home.

The DPO Coalition looks forward to working with the Government to make a difference, sooner rather than later.

A handwritten signature in black ink, appearing to read 'Leo McIntyre', with a long horizontal line extending to the right.

**Leo McIntyre**

Chair

Disabled People's Organisations Coalition

## 5. Executive Summary

### 5.1 Background

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an international agreement that sets out what Governments must do to ensure that disabled people have the same rights as everyone else. In 2008 the Government of New Zealand ratified the UNCRPD, indicating their intention to implement the rights and obligations contained within the agreement.

Twelve years on, it is important to understand if, and how well, this is happening. One of the most innovative aspects of the UNCRPD is Article 33, which outlines how the Convention should be monitored. Specifically, Article 33.3 articulates the Government of New Zealand's obligation to ensure that civil society (specifically disabled people and their representative organisations) are fully involved and participating in monitoring the progressive realisation of the articles contained within the UNCRPD (United Nations, 2006). In 2018, the New Zealand Disabled People's Organisations (DPO) Coalition initiated the most current cycle of UNCRPD monitoring. 'Housing' was selected as the first subject to be investigated, including disabled people's right to choose where and how they live, and the right to an adequate standard of living. The Donald Beasley Institute (DBI) was appointed by the DPO Coalition as the research partner to carry out the monitoring research.

### 5.2 Methodology

In Aotearoa New Zealand, disabled people are homeowners, renters, boarders, living with families, living in group homes, or are homeless. Academic and anecdotal evidence suggests that disabled people routinely experience barriers when accessing their right to an adequate standard of living and other related rights laid out in the UNCRPD. In order to document disabled people's experience of housing, a monitoring methodology known as Disability Rights Promotion International (DRPI) was employed and adapted for the specific context of Aotearoa New Zealand. Based on the principles of Te Tiriti o Waitangi, the UNCRPD, and the New Zealand Disability Strategy and Action Plan, the DRPI model seeks to provide a voice to marginalised populations; enhance public awareness by documenting abuses and violations; reinforce a collective identity amongst the disability community; and support efforts to achieve social justice (DRPI, n.d.a). While the DRPI research model usually uses a three-pronged approach to monitoring individual experiences, systems and the media, this monitoring cycle only investigated the individual housing experiences of disabled people in Aotearoa New Zealand.

To ensure that the research agenda was led by disabled people, 26 disabled Monitors were recruited and trained in research and monitoring skills. Over a period of 12 weeks the Monitors conducted interviews with 61 disabled people ('Interviewees') in Northland, Auckland, Christchurch, Otago and Southland. The purpose of the interviews was to understand what is, and is not, working for disabled people when accessing an adequate standard of living, what they think and feel about the houses they currently live in, and what

types of homes they would like to live in in the future. The audio recordings of the interviews were then transcribed and analysed, before key themes were documented and collated, forming the structure of this report.

The findings below represent a short summary of those included in the full report. While the full report includes extensive Interviewee quotes, most have been removed from the executive summary to ensure it remains succinct.

## **5.3 Findings**

### **5.3.1 Choice and Control**

The first key finding of the monitoring report related to choice and control, as it appeared to underpin most, if not all, of Interviewee experiences. Within the context of housing, choice and control primarily relates to Articles 4, 5, 9, 14, and 19 of the UNCRPD, and was demonstrated by the limited choices Interviewee's felt they had when accessing adequate housing, and the lack of control they had over their living situations. This was exemplified by standout case studies: an Interviewee living in a group home; a young Interviewee living in a retirement home; an Interviewee with a degenerative condition who had recently invested in a New Build; and an Interviewee who was homeless. Through their stories, each Interviewee outlined the significant challenges they had faced when attempting to access adequate housing, and the very real impact that having little to no choice or control over where they lived and who they lived with, had had on their well-being and quality of life.

### **5.3.2 Access**

The next finding explored access in relation to housing, and Articles 4, 5, 8, 9, 14, 17, 19, and 28 of the UNCRPD. Included in this theme was the discrimination Interviewees faced when accessing the housing market; when implementing accessibility measures within their homes; and when accessing information and justice. For example, Interviewees reported significant barriers when trying to access the housing market as tenants or as buyers, with many citing negative attitudes towards disability held by landlords, agents, and other people in positions of power, as the main cause: "M: What do you think the biggest barrier [to adequate housing] is? I: Definitely attitude" (Interview #47). For some, the ongoing nature of these challenges led to the deterioration of their physical and psychosocial health. For others, these challenges had forced them into inadequate living situations and even homelessness.

Affordability was also considered a major barrier to adequate housing, which many Interviewees associated with the lack of accessibility features within and around the home. For example, some Interviewees were not eligible for funding for the modifications they felt they needed, nor could they afford them themselves. Affordable rent and rising house prices were also identified as barriers to adequate housing and living situations that met their basic needs. Finally, a lack of access to information and justice systems were reported by Interviewee's who felt limited by complicated and inaccessible legal documents, the effort

required to engage with justice systems, and the fear of retribution from landlords if they did decide to take legal action. For example, one Interviewee feared they would lose their home if they raised a maintenance issue with their landlord: “So, I had a leak above a light for quite a period of time at which he [landlord] refused to fix. But I felt so vulnerable at the time that if I did make a complaint, I would lose my home” (Interview #18).

### **5.3.3 Belonging**

The next collection of findings were collated under the theme of ‘belonging’ and included homeliness, rhythms and routines, and community connection. As a finding, ‘belonging’ primarily related to the preamble of the UNCRPD, as well as articles 9, 15, 16, 19, 26, and 28. Homeliness began by looking at how a home is created, including where and how it is set up, and whether ‘home’ is an environment where Interviewees felt comfortable, relaxed, and enjoyed spending their time. Several Interviewees reported that they enjoyed being at home, noting that home was where they were forced to spend most of their time as a result of their disability. However, a number of Interviewees also mentioned the size of their home, damp, cold, mould and inaccessibility as factors that contributed to the sense that they did not belong. Moreover, a large number of Interviewees indicated that because their home was inaccessible, they could not safely participate in standard activities in and around the home, such as cooking, cleaning and gardening - again, contributing to the sense of not belonging.

The next aspect of belonging looked at the relationships Interviewees had with the people they lived with, their neighbours, the wider community and online communities. Within this finding there was a noticeable difference between Interviewees who had positive relationships with their community, and those who did not. Positive relationships were associated with adequate access in and around the home, as well as in the wider community - a space where relationships are traditionally forged. Those who reported a low sense of belonging also experienced financial barriers that meant they were unable to choose where they lived, who they lived next to, and who they lived with. This had a direct impact on Interviewees’ sense of belonging, leading to feelings of insecurity and isolation: “A lot of the Housing New Zealand apartments are people who would be turned down for housing anywhere else. M: So not your ideal neighbours? I: A lot of stealing, a lot of drugs, that sort of thing. Just to be surrounded by that, I don’t like being around it” (Interview #45). As highlighted in this quote, for many of the Interviewees living in Housing New Zealand communities, their lack of belonging often reflected the negative relationships they had with neighbouring Housing New Zealand tenants. Finally, several Interviewees noted the positive impact of online communities on their sense of belonging. However, this observation was often followed by comments about the cost of internet as being a barrier to participation.

### **5.3.4 Safety**

The third key finding was safety, which included both physical and psychological safety. This finding primarily related to Article 3 of the Universal Declaration of Human Rights (UDHR), as well as the preamble of the UNCRPD and Articles 11, 14, 17, 25 and 28. Unsurprisingly,

safety was strongly linked to adequate housing. For example, physical safety was associated with access, modifications, heating, and maintenance. Psychological safety correlated with physical safety, location, access, choice and control.

Of the 61 interviews, 13 Interviewees indicated their homes were cold, and over half of the Interviewees (33) reported hazards within and around their home. Interviewees were quick to link cold homes to the cost of power, which reflected income barriers, relating to Article 28 of the UNCRPD (ensuring an adequate standard of living). Compromised physical and mental health were reported as by-products of living in cold homes, relating to Articles 25 (Health) and 17 (Integrity). For example, several Interviewees resorted to turning their heaters off and going without basic necessities in order to afford their electricity bills: “So, I go without food every winter, I go without food to pay my electricity costs” (Interview #15).

In addition to the cold, damp, and mould, many Interviewees reported hazards in and around the home that they felt were a risk to their health and safety. Hazards included entrance and exits of buildings; indoor and outdoor steps and stairs; inaccessible kitchens and cupboards; slippery and problematic bathroom layouts; and overcrowding. When discussing the reasons behind why such hazards exist, many Interviewees put it down to the lack of responsiveness and responsibility taken by landlords and housing agents, particularly when Interviewees made requests for maintenance. While this is a challenge for many New Zealanders (Flaws, 2019), Interviewee experiences indicated that unfixed hazards are even more problematic for marginalised populations, such as disabled people.

Emergencies, situations of risk and evacuation were also of concern for some of the Interviewees, many of whom had no way to exit their homes in an emergency: “So, I’ve had a fire drill, two fire drills and a genuine fire alarm where each time I have sat in my apartment and not a single person has come here” (Interview #39). This finding was raised by several Interviewees, ranging from wheelchair users who were unable to evacuate in an emergency, to Deaf Interviewees who required visual fire alarms to alert them of smoke and fire.

The other aspect of safety was psychological safety, which was often linked to stress, anxiety and depression - both as a barrier to finding adequate housing, and as a consequence of living in inadequate housing. Again, this was often associated with the affordability, adequacy, and location of houses. A further reason for distress was caused by the lack of consistency around lease agreements, with many Interviewees being forced to accept short-term leases, knowing that the landlord could increase the price with each new agreement, or decide not to renew the lease at all: “Like, the fact that I can’t have a long-term tenancy agreement just constantly puts me on edge and I never know from one year to the next whether or not I’m still going to still have my home.” (Interview #18)

The lack of psychological safety Interviewees felt in relation to their housing situation, which has been mentioned in several contexts and findings, was indicative of a real and perceived power imbalance between themselves and people in positions of power, including landlords, housing agents, and WINZ and Housing New Zealand staff.

### 5.3.5 Awareness of Rights

The fifth and final group of findings related to Interviewees' awareness of their rights under the UNCRPD, and in particular Articles 2, 8, 9, 19 and 28. In order to investigate awareness, Monitors began by asking Interviewees if they had heard of the UNCRPD and Universal Design. Even though this research is dedicated to monitoring the progressive realisation of the UNCRPD, of the Interviewees who answered these questions 29 had not heard of the UNCRPD and 33 did not know what Universal Design was. Monitors then read aloud two relevant UNCRPD articles and asked the Interviewees to reflect on what the articles meant to them personally. The first article was Article 19, which states that all disabled people have an equal right to live in the community with choices equal to others. Interviewee reflections were focused on choice and control, safety, and not being discriminated against on the basis of disability. The second Article that Interviewees were asked to think about in relation to housing was Article 28, which holds that the Government of New Zealand must recognise the right of disabled people to an adequate standard of living. Interviewees reflected on subjects such as design, access, safety, warmth, and choice and control.

Even though many Interviewees had not heard of Universal Design or the UNCRPD, after reflecting on Articles 19 and 28 they demonstrated a clear understanding of the treatment they believed they were entitled to. Having established key housing-related rights, Interviewees were then asked if the Government of New Zealand is making sure disabled people are not discriminated against in the housing and rental markets. The consensus was a resounding no, the Government of New Zealand is not doing enough. Finally, Interviewees were asked what they think needs to change in order for the UNCRPD to have an impact on their housing situation. Recommendations provided by the Interviewees called for the Government of New Zealand to:

- Acknowledge the impact of the housing crisis on disabled people;
- Increase the awareness of disability through education, consultation, advocacy and face-to-face engagement;
- Improve domestic laws and ensure stronger enforcement;
- Update the Building Code, to include private property;
- Incentivise the implementation of Universal Design standards;
- Employ disabled people in relevant housing positions;
- Increase resources for disabled people when accessing adequate housing;
- Draw on, and promote, examples of best practice.



## 5.4 Discussion

The findings generated from this monitoring research paint a bleak picture, with disabled people's experiences of housing in Aotearoa New Zealand leaving much to be desired. The purpose of the discussion aspect of the report was to take a step back and look at emerging themes that were not directly related to questions asked during the interviews and acknowledge Interviewee narratives in a wider context.

Many Interviewees related their experience of housing to the wider housing crisis of Aotearoa New Zealand, emphasising that their experiences often reflected those of other New Zealanders who were also struggling with the power imbalance between tenants and landlords, inadequacy of homes, and the unaffordability of the housing market. However, the UNCRPD clearly articulates that disabled people face greater barriers when participating as equal members of society and ongoing violations of their human rights (UNCRPD, Preamble, point 11). As this research has revealed the playing field is not level, including within the climate of the current national housing crisis. This was summarised by one Interviewee when discussing Article 28: "This one means to me that at least be as poor as everybody else, and not poorer." Given that the wellbeing of society as a whole relies on the wellbeing of the disability community (UNCRPD, Preamble, point 13), specific measures that are necessary to accelerate or achieve de facto equality of disabled people should not be avoided or considered negatively discriminatory (UNCRPD, Article 5.4) - even amidst a housing crisis. In fact, specific measures within the context of housing are an important aspect of progressively realising the UNCRPD, as well as the United Nations Sustainable Development Goals (SDGs) of which the taglines are "reach first those who are furthest behind", and "leaving no one behind" (United Nations, 2016).

The next point raised in the discussion referred to the inequality between the ACC and Ministry of Health (MoH) funding models. As noted in the Choice and Control and Safety findings, housing experiences were often related to income, employment, welfare, and funding. This was noted by several Interviewees as being exemplified by the disparity between the ACC model of funding and MoH model of funding - the latter of which provides less funding than the former. This point was also identified as a human rights violation in previous rounds of monitoring research (Article 33 Convention Coalition Monitoring Group, 2015), and was highlighted during the UNCRPD Committee's Concluding Observations on the Government of New Zealand's report during their last examination. This monitoring research has again revealed that the inequality generated by the different funding models is an ongoing and serious issue, exemplified by the impact that this disparity had on Interviewee's access to safe and adequate housing.

The next theme woven throughout the monitoring interviews was the notion of compromise. For example, one Interviewee referred to the fear of having one housing issue addressed but knowing that it meant they were likely to have something else taken away from them: "I think everywhere else is pretty um hard to get a house these days. Um, I mean most of



it is just the cost. Cost is building houses for our needs and that eh. Really down to it, just like if you need something done, you gotta take something away. And that thing is what do you have to take away?" (Interview #1). Compromise was also a key aspect of choice and control, particularly in relation to accessibility versus location. For example, Interviewees felt they were forced to choose between community connection and accessibility, or safety and affordability.

The next point of the discussion looked at Interviewee responses to questions that were designed to investigate what adequate housing might look like in the future. Towards the end of the interview Monitors asked Interviewees what their dream living situation would look like five years' time, if the Government of New Zealand was successfully implementing the UNCRPD in Aotearoa New Zealand. While this kind of 'golden question' might be expected to elicit answers of affluence, luxury, or even extravagance, Interviewee responses were much humbler, with most Interviewees emphasising the point that they simply wanted what they are entitled to under the UNCRPD: equal standards of living, warm and safe homes, and equal and balanced relationship with landlords.

The difference between rights, laws and policies, and their practical implementation, was also addressed. As noted by several Interviewees, even though disabled people have legal entitlements, the implementation of these rights is often where the problem lies. In general, Interviewees were doubtful and distrusting of the Government of New Zealand when it came to the progressive realisation of their rights. As the earlier findings revealed, these feelings were not without cause. There was also the sense of fatigue - on top of living with disability, the need to fight for their rights was exhausting.

Other recurring themes were gratitude and dignity. As Interviewees shared stories about the discrimination they had faced when accessing adequate housing many were also quick to acknowledge that they were grateful for what they had, feeling it could be a lot worse. For others, they were advised by people in positions of power to be grateful, despite the inadequacy of their living circumstances. Given that adequate housing is a right, the conscious or subconscious need to express gratitude for substandard living conditions is concerning and reflects aspects of the charity model of disability. Gratitude was also linked to dignity, which refers to the inherent nature of being human and being worthy or deserving of respect. Point 8 of the UNCRPD Preamble states that "discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person" (United Nations, 2006, Preamble). The findings of this monitoring research have again provided many examples of where Interviewees felt their inherent dignity had been threatened.

The final aspect of the discussion was best practice. Although this report paints a bleak picture of how Interviewees experience housing in Aotearoa New Zealand, it is important to acknowledge that negative experiences were intentionally extrapolated from the data for the purpose of monitoring. Even though most Interviewees discussed experiences which were

challenging at best, and human rights violations at worst, some Interviewees also provided examples of best practice. For example, one Interviewee noted the elation they felt when they came across a landlord who did not discriminate against them when they obtained a support animal. Another Interviewee recalled how a landlord had taken the time to go through legal paperwork in a way they could easily understand: “My landlord, he explained to us and sat down and explained, we could understand and everything” (Interview #52).

As shown by the small selection of diverse, yet positive, experiences included in the full report, simple actions by people in positions of power, authority and privilege, went a long way in levelling the playing field for Interviewees when it came to housing matters.

## 5.5 Final Comments

This report presented the findings of the 2019 Disabled Person-Led Monitoring of the UNCRPD in Aotearoa New Zealand. The purpose of this monitoring research was to understand how a selection of disabled people experience housing in Aotearoa New Zealand, specifically in relation to their rights under the UNCRPD.

While some of the housing experiences shared in this report were positive, the majority were not. Most of the stories shared by Interviewees were overwhelmingly negative, emphasising the challenges and human rights violations they faced when accessing adequate housing. These experiences demonstrate how far Aotearoa New Zealand has to go in progressively realising the UNCRPD and ensuring that no one is left behind. In particular, the limited awareness Interviewees had of their rights under the UNCRPD, together with the attitudes held by people in positions of power within the housing market, are reasons for concern and speak to the Government of New Zealand’s failure to invest in generating awareness of the UNCRPD amongst both disabled and non-disabled populations. Even so, though the findings of this report are bleak, the solutions, strategies, and tools for moving forward are clear, and can be found woven throughout Interviewee narratives. Even though Interviewees had limited knowledge of the UNCRPD itself, they still demonstrated a strong ability to advocate for themselves amidst intersecting challenges, providing expertise and strategies for effectively realising their rights. As the disability rights slogan says, ‘nothing about us, without us.’ Disabled people know what they are entitled to and what needs to change for their rights to be made real. Not only does this report provide important evidence of housing challenges and rights violations, but it also offers a blueprint for moving towards greater equality within Aotearoa New Zealand and beyond.

## 6. Introduction

This report presents the findings of the first cycle of a three-year disabled person-led research project to monitor the progressive realisation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in Aotearoa New Zealand.

In November 2018 the Donald Beasley Institute (DBI) was appointed through a request for proposal (RFP) process by the New Zealand Disabled People's Organisations (DPO) Coalition as the research provider for the Disabled Person-Led Monitoring of the UNCRPD. This monitoring project was funded through the Office for Disability Issues, which has worked alongside the DPO Coalition to review the monitoring work and to identify the DBI as the research provider.

The DBI is a national, independent, non-profit organisation based in Dunedin, New Zealand, that aims to advance the health and wellbeing of disabled New Zealanders through applied research, evaluation and education. With a 35-year history, and a strong commitment to both the UNCRPD and building capacity in disability research and disabled researchers, the DBI was well equipped and experienced to undertake this important project.

The three-year project contributes to the Government of New Zealand's obligation to monitor the progressive realisation of the UNCRPD in Aotearoa New Zealand. As advised by the DPO Coalition, housing was selected as the key issue to be investigated in the first cycle of monitoring (the rationale of which will be explained in the following chapters).

Drawing on the Disability Rights Promotion International research model (DRPI), this study aims to fill the research and implementation gap through a disabled person-led investigation which embodies the disability rights slogan 'nothing about us, without us'. In the first cycle, data contributed by 61 disabled people formed the basis of this report, which investigated the issues impacting on their access to housing and other interlinking issues.

The first part of this report provides the context and background for the monitoring research. The report begins with an overview of Article 33 of the UNCRPD and outlines the importance of disabled people being directly involved with monitoring its progressive realisation. Disability is then discussed within the context of the New Zealand housing crisis, before the relevance of this research to Māori is presented. The second part of the report details the monitoring process by introducing and justifying the use of the Disability Rights Promotion International (DRPI) research methodology. Interview questions are then examined, and the recruitment process of research participants (Interviewees) and researchers (Monitors) is outlined, including how they contributed to the data collection. Ethical issues are considered, before Interviewee locations are noted.

The following section of the report outlines the findings of the monitoring research itself, beginning with a brief demographic overview of the Interviewees. Five key findings are then presented, drawing directly from Interviewee quotes and narratives. Key themes include choice and control, access, belonging, safety, and awareness of rights. Interviewee housing

experiences are then discussed in a wider context, where issues such as the housing crisis, funding models, compromise, expectations, implementation of rights, gratitude, dignity and best practice are all considered. Finally, the report concludes by acknowledging the strengths and limitations of this monitoring research.

## **7. Background**

### **7.1 Monitoring the United Nations Convention on the Rights of Persons with Disabilities in New Zealand**

In 2008, the Government of New Zealand ratified the UNCRPD (Office for Disability Issues, 2016a). The UNCRPD is an international human rights treaty that promotes, protects and ensures the rights of disabled people so that they have full equality under international law (United Nations, 2006). Building on several existing treaties and conventions, such as the Universal Declaration of Human Rights (UDHR), the UNCRPD is the first and only international agreement to explicitly stipulate the rights of disabled people under international law (Phillips, Estey, & Ennis, 2010). To become a party to the UNCRPD, a government must first sign the agreement to signify that it agrees in principle. Next, the particular government is required to ratify the UNCRPD, and in doing so indicates that it intends to undertake the legal rights and obligations contained within the agreement.

One of the most innovative aspects of the UNCRPD is Article 33, which outlines how it should be implemented and monitored (United Nations, 2006). Article 33 addresses what is known as the “implementation gap”; that is, the gap between international human rights standards whereby States promise to respect, protect and fulfil said rights on paper, and the real-life impact of those rights in the lives of disabled people (MDAC, 2011, p. 13). In particular, Article 33.3 articulates the obligation to ensure civil society (specifically disabled people and their representative organisations) are involved and participating fully in monitoring the progressive realisation of the UNCRPD (United Nations, 2006). Progressive realisation is a monitoring concept embedded within the UNCRPD in which “Each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realisation of these rights” (United Nations, 2006, Article 4).

### **7.2 Principles**

This monitoring research is based on the principles and values outlined in the following key documents:

1. Te Tiriti o Waitangi
2. United Nations Convention on the Rights of Persons with Disabilities
3. 2016-2026 New Zealand Disability Strategy and Disability Action Plan
4. Disability Rights Promotion International monitoring methodology.

### **7.2.1 Te Tiriti o Waitangi (The Treaty of Waitangi)**

Te Tiriti o Waitangi is the founding document of Aotearoa New Zealand. As outlined in the 2016-2026 New Zealand Disability Strategy, the principles of the Treaty are:

- Partnership: Māori and the Crown have a relationship of good faith, mutual respect and understanding, and shared decision-making.
- Participation: The Crown and Māori will work together to ensure Māori (including whānau, hapū, iwi and communities) participate at all levels of decision-making. This includes the right to seek opportunities for self-determination and self-management.
- Protection: The Crown actively contributes to improving the wellbeing of Māori, including support for independent living and the protection of Māori property and identity, in accordance with Māori values. Māori have the same rights and privileges as other citizens (Office for Disability Issues, 2016b, p. 18).

Within the context of this monitoring research these principles were implemented through consultation with DPOs representing disabled Māori, as well as Māori scholars with expertise in Disability Studies, throughout all stages of planning, design, data collection, analysis, as well as the presentation of the findings. Further information is outlined in '6.4 Relevance to Māori' section of this report.

### **7.2.2 Principles of the United Nations Convention on the Rights of Persons with Disabilities, the 2016-2026 New Zealand Disability Strategy, Disability Action Plan, and Disability Rights Promotion International**

In addition to Te Tiriti o Waitangi, the core principles of the UNCRPD, Disability Strategy, Disability Action Plan, and DRPI relating to the rights of disabled people were upheld at all stages of the monitoring. These included:

- Dignity
- Autonomy
- Non-discrimination
- Inclusion
- Respect for difference
- Equality

## **7.3 Housing in Aotearoa New Zealand**

Research shows many New Zealanders face increased challenges when accessing suitable, affordable and healthy homes - whether as tenants, owners, residents, or within the national social housing system (Johnson, 2017; Johnson, Howden-Chapman, & Eaqub, 2018). This has been referred to as the 'housing crisis' of New Zealand (Roy, 2018). For disabled people - who make up 24 percent of the population (Stats NZ, 2014) - anecdotal and academic evidence suggests that these challenges are compounded, especially when accessing homes that suit their specific needs (McIntosh & Leah, 2017; Spink, 2016).

The right to housing itself is recognised in a variety of international human rights instruments, often in relation to the right to an adequate standard of living - such as Article 25 of the Universal Declaration of Human Rights (UDHR) (United Nations, 1948) and Article 11.1 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) (United Nations, 1966). More specifically, Article 19 of the UNCRPD obligates signatories to “recognise the equal right of all persons with disabilities to live in the community with choices equal to others.” A key focus of Article 19 is an individual’s right to choose their place of residence as well as access to the community supports they need to prevent isolation or segregation, and mainstream community-based services and facilities that are responsive to their needs (United Nations, 2006). Article 28 also articulates the Government of New Zealand’s obligation to recognise the right of disabled people to an adequate standard of living, including housing and the continuous improvement of living conditions. It requires the Government to take steps towards safeguarding and promoting the realisation of this right without discrimination on the basis of disability (United Nations, 2006).

While there is currently no disabled person-led research specifically addressing disabled people’s experiences of housing in Aotearoa New Zealand, it is possible to look to a small collection of national and international studies on disability and housing for context (for international examples see Aitken, Baker, Badland, Mason, Bentley, Beer, & Kavanagh, 2018; Smith, Rayer, Smith, Wang, & Zeng, 2012). In 2017, a report based on the Disability Matters Conference (hosted in Dunedin, Aotearoa New Zealand) highlighted that “New Zealand has a big issue with housing and accessible housing. This undermines many other rights like the right to participation in the community, the right to choice and control, and the right to employment” (Disability Matters, 2018, p. iv). Past research conducted by the DBI has highlighted the benefits of independence, choice and control, including in the area of housing (Milner & Mirfin-Veitch, 2012; Mirfin-Veitch and Conder, 2016; Conder and Mirfin-Veitch, 2018), while research commissioned by the Centre for Housing Research Aotearoa New Zealand (CHRANZ) focused on the housing market’s lack of capacity to respond to the rising housing demand linked to an ageing population and growing disability community (Scotts, Saville-Smith, & James, 2007). As highlighted by former Disabled Persons Assembly (DPA) National Policy and Relationships Manager, Dr Esther Woodbury, “In New Zealand, we build houses that exclude people” (Woodbury, 2017, p. 29). In response to growing concerns, organisations have been vocal in their requests to Government to consider Universal Design in future planning and policy (for example CCS Disability Action, 2017; Access Alliance, 2019; and Auckland Council’s Disability Advisory Panel, 2019). Furthermore, anecdotal evidence has also highlighted the needs of disabled people living in cars and tents due to the shortage of accessible and affordable homes (see Makiha, 2019; Williams, 2019).

In the 2019 September quarter, Stats NZ estimated that there are 1,903,400 private dwellings in Aotearoa New Zealand (Stats NZ, 2019). According to Lifemark, a New Zealand-based organisation that promotes, and endorses safe and accessible homes, only a very small percentage of these private dwellings meet Universal Design standards despite it being no extra cost to implement 90 per cent of the Lifemark accessibility standards (Lifemark,



2017). These figures are particularly relevant within the context of KiwiBuild - part of the Government's multi-billion-dollar work programme that promised to build 100,000 new homes within ten years (a target that was deemed "overly ambitious" and subsequently revised and "reset" in 2019) (Woods, 2019, para. 4-5). As highlighted by accessibility advocates, KiwiBuild presents opportunities to ensure Universal Design standards are implemented from inception, rather than retrofitting for accessibility in the future. However, investigations into whether KiwiBuild homes will be Universally Designed have been met with little resolve. Authorities have repeatedly delayed committing to policy that supports the Lifetime Home Design Principles of usability, adaptability, accessibility, safety and lifetime value. Meanwhile the construction of KiwiBuild homes has already started (Kelly-Costello, 2018).

Adding further complexities to the housing crisis is the lack of access to social housing. According to the September 2019 Public Housing Quarterly Report, in Aotearoa New Zealand there are 69,609 public houses (Ministry of Housing and Urban Development, 2019). Even so, as at 30 September 2019 there were 13,966 applications on the national Housing Register, many of which are from disabled people. This number represents an increase of 46.5 percent compared to September 2018 (Ministry of Housing and Urban Development, 2019). It might also be noted that shortly before the conclusion of this first cycle of monitoring, a new Crown agency - Kāinga Ora Homes and Communities - was established (1st October 2019) to transform housing and urban development throughout New Zealand. Included in Kāinga Ora's Accessibility Policy is a commitment to increase the number of State homes that meet Universal Design standards; meet the individual needs of customers (including modifications and specialised solutions); and improve information about customers' needs and the accessibility of State properties:

With our new Accessibility Policy, we have committed to ensuring that at least 15% of the new homes we are building across the country meet universal design standards, and the rest meet as many of these universal design standards as possible. We will also see how these universal design standards can be included as part of our retrofit programme for our existing homes and as part of this policy, we'll also collect more information about the accessibility features of our homes and more information about our customer's needs so we can better support current and future customers. From 2021-2022, we will be formally reporting against this target in accountability documents like our Annual Report (Kāinga Ora, 2019).

While the establishment of Kāinga Ora and subsequent development of the Accessibility Plan indicates a significant shift towards progressive realisation of the UNCRPD in Aotearoa New Zealand, evidence of the Plan's success can only be found in the improved housing experiences of disabled people, as reported by disabled people themselves. At the time of writing this report, the disparity between the need for adequate housing and its availability is cause for concern and urgent action. It is for these reasons that the DPO Coalition chose to investigate housing during the first cycle of the Disabled Person-Led Monitoring of the UNCRPD scheduled to occur during the period 2018-2021.

## 7.4 Relevance to Māori

Self-identification of disability among Aotearoa New Zealand's Māori population is higher than it is amongst the general population, at 26 per cent, compared to 24 per cent (Stats NZ, 2014). When adjusted for age, Māori have an even higher disability rate of 32 per cent (Stats NZ, 2015). Research shows that Māori are over-represented in incarceration rates (Department of Corrections, 2019), negative health and mental health statistics (Ministry of Health, 2018; 2019), and material hardship (Duncanson, Oben, Wicken, Richardson, Adams, & Pierson, 2018). Investigations into housing conditions have also highlighted the prevalence of overcrowding in predominantly Māori homes (Habitat for Humanity, 2019), many of which lack adequate insulation, ventilation and heating (Human Rights Commission & University of Otago, 2016). Furthermore, Māori are over-represented in rentals and underrepresented in home ownership rates (Stats NZ, 2016), with research highlighting the presence of implicit institutional racism against Māori within Aotearoa New Zealand's home lending industry (Houkamau & Sibley, 2015).

While different terminology is used to describe the intersecting identities of being disabled and Māori (for example, see Hickey & Wilson, 2017), under the recommendation of the DBI Kairangahau Māori Research Associate and Māori members of the DPO Coalition, this monitoring research and report use the term 'whaikaha Māori'. According to the 2017 Te Reo Hāpai (Māori glossary) 'Disabled' can be translated as 'whaikaha', meaning to have strength, to have ability, otherly abled, or enabled (Te Pou, 2017). While tangata whaikaha describes one person, tāngata whaikaha with a macronised 'ā' describes two or more disabled people (Kaiwai & Allport, 2019). This research project is a medium through which tāngata whaikaha Māori can express their experiences of housing, so to critique and/or contribute to the base of knowledge on the current status of oranga tāngata (Māori wellbeing). Projecting their experiences through research designed to monitor and progressively realise the rights of disabled people can draw attention to the ways in which the government and services can be more culturally responsive to Māori and more aligned with te ao Māori notions of support for wellbeing. This investigation is orientated by the normative aim of being responsive within the research process in addition to aiming to contribute to enhancing future responsiveness to tāngata whaikaha Māori in housing related legislation, policy, and practice.

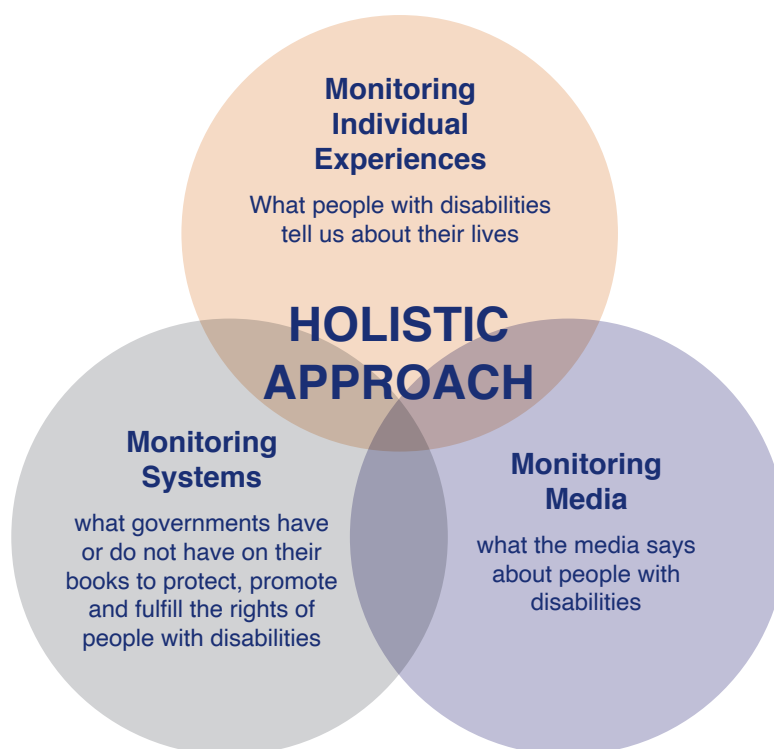


## 8. Our Approach (Methodology)

Mandated by the DPO Coalition, the chosen methodology for this investigation is the Disability Rights Promotion International (DRPI) research method, which seeks to:

- Provide a voice to marginalised populations;
- Enhance public awareness by documenting abuses and violations;
- Reinforce a collective identity amongst the disability community;
- Support efforts to achieve social justice (DRPI, n.d.a).

Originally developed in Canada, the DRPI model takes a holistic approach to monitoring disability rights so that data and evidence can be shared and compiled across regions and countries. The model has three broad areas for ensuring the progressive realisation of the UNCRPD:



DRPI's Holistic Approach (DRPI, n.d.b)

This research project is designed to monitor individual experiences only. According to the DRPI model this includes collating data and evidence with respect to alleged individual violations against the human rights of disabled people. Monitoring human rights violations against the disability community is an important aspect of increasing awareness of the nature and extent of violations. Comprehensive information on the experiences of disabled people is a powerful tool for promoting the social change needed to realise the UNCRPD. For example, credible and accurate data about human rights situations can persuade

governments that abuses are occurring, the prevalence of abuses and that action is needed to fulfil human rights obligations (DRPI, n.d.a).

## 8.1 Monitoring Questions

As outlined in the DRPI methodology, the purpose of this qualitative study is to understand disabled people's individual experiences of housing in Aotearoa New Zealand in relation to their rights under the UNCRPD. Principal research questions were informed by a wide and diverse range of sources such as housing surveys; human rights frameworks (specifically Articles 19 and 28 of the UNCRPD); consultation with disability rights researchers and disabled people; the 2016-2026 New Zealand Disability Strategy and Action Plan; and the 2017 United Nations General Assembly Report entitled "Adequate housing as a component of the right to an adequate standard of living, and the right to non-discrimination in this context" by Leilani Farha (United Nations Special Rapporteur on Adequate Housing). One Interview Framework was designed for interviews with people who identified as homeowners, boarders, disabled people living with family/whanau, public/private tenants, or disabled people living in group or retirement homes. Because not all questions were relevant to all participants, a second Interview Framework was designed for people who identified as having no fixed abode (homeless). Key themes covered by the questions included:

- Physiological and Physical Safety;
- Self Determination;
- Rhythms and Routines;
- Community Connection;
- Homeliness;
- Physical Needs;
- Affordability and Availability;
- Security of Tenure;
- Human and Disability Rights Awareness;
- Demographic details (including age, ethnicity, disability, location and income).

A full list of questions can be found in Appendix B. Drawing on the areas above, the research was framed to answer three key questions:

- What aspects of housing and accommodation are working well for the disability community of New Zealand?
- What challenges do disabled people experience when accessing adequate housing and accommodation in New Zealand?
- How do the housing experiences of disabled people align with their rights as outlined in the UNCRPD?

## 8.2 Who was Interviewed?

Over a period of 12 weeks, 61 disabled people were interviewed. In the first instance, potential Interviewees were invited to participate through DPOs and locality organisations in five key regions (Northland, Auckland, Christchurch, Otago and Southland). These locality organisations distributed letters of invitation, together with the Project Information Sheets and Participant Interest Forms in a range of accessible formats to people who are involved with their organisation or who are service users. In order to ensure that disabled people who were not connected with DPOs or disability service providers in the selected regions had the opportunity to participate, the research was also advertised via community groups, social media forums, in newsletters, and pānui (announcements, notices, notifications, and so on).

## 8.3 How we found the Interviewees (Sampling)

While snowballing is the standard technique used within the DRPI research methodology (Samson, 2015), DBI instead opted to use maximum variation sampling for this project. Maximum variation sampling enables a large group of “potential participants” to be recruited in a specified time period (Polit & Beck, 2017). This was an important feature of this project due to recognition of the need to achieve a diverse sample, and the time constraints the research team was working under. The purpose of using maximum variation was to ensure a diverse range of participants participated, including “subaltern identities”, which refers to minority identities within the dominant disability paradigm (Hickey, 2015, p. 221). Within the context of this monitoring research these identities included, but were not limited to, tāngata whaikaha, tertiary students, and disabled people with no fixed abode. To this end, interested potential participants were asked to supply key demographic information, which was then used to select a final sample that captured and reflected the diversity of disabled people and their housing experiences in Aotearoa New Zealand. As anticipated, this sampling strategy drew more potential participants than could be included. As such, the Project Information Sheet was clear that not everyone who expressed an interest in taking part in the research would ultimately be selected as an Interviewee. However, all people who returned a Participant Interest Form were asked if they would like to remain updated on the monitoring project as it progresses.

The people and organisations assisting with recruitment were familiar with the research protocol and able to assist with helping participants understand the Project Information Sheet and Participant Interest Form when required. All information was delivered in accessible formats:

- Plain English Doc, Docx and PDF
- Large Print
- Te Reo Māori Docx and PDF
- Online survey

- Audio recordings
- Hard copy Braille documents
- Easy Read
- New Zealand Sign Language (NZSL)

Potential Interviewees expressed their interest by filling out the online survey, by returning their Participant Interest Form in person, or by emailing their form to the DBI Research Team. They were also able to talk to the Research Team directly, over the phone or using the email address provided in the Project Information Sheet. Potential Interviewees who were Hard of Hearing or Deaf were invited to register their interest in NZSL by using an online video service.

To be eligible to participate in this research, Interviewees needed to be over the age of eighteen and able to provide full and informed consent. Informed consent was documented at the first face-to-face encounter.

## **8.4 Monitor Recruitment**

Following ethics approval (NZ/1/7B02113), the DBI recruited and appointed 26 Monitors to conduct the research interviews. Monitors were all disabled people who were trained in the DRPI research model and were recruited based on their skills and experience relevant to the project. Monitors who were appointed for this project were a mix of people who had undertaken this role in previous monitoring cycles, and some who had not performed this role before.

All Monitors, regardless of previous monitoring or research experience, underwent specific training to ensure they had the level of skill required to undertake this monitoring research. In particular, the training developed the Monitor's research interviewing skills to ensure Interviewee and Monitor safety in the field. The training combined existing DRPI training modules with the DBI's expertise in disability research within the context of Aotearoa New Zealand. The DBI is committed to safe and ethical research, and Monitors were required to follow the DBI's Field Work Policy which is in alignment with the Health and Safety at Work Act 2015. All Monitors signed a confidentiality clause within their contract before commencing work on the project.

## **8.5 Interviews (Data Collection)**

Individual interviews were used as the primary method of data collection. Once direct contact was made between potential Interviewees and the DBI Research Team, two Monitors were assigned to each Interviewee. To help Interviewees feel safe and comfortable, Monitors then arranged to conduct the interview at a time and place of the Interviewee's choosing, as well as organise access supports to ensure full and equal participation (for example, booking NZSL interpreters and accessible venues). The Monitors went through both the Project Information Sheet and the Consent Form with the Interviewee, then made a final decision on whether consent was fully informed based on the person's ability to identify the purpose

of the research and what they needed to do. Interviewees began with a clear understanding that they could withdraw at any time.

In circumstances where Māori Interviewees felt more comfortable participating in the interview with Monitors who were familiar with tikanga Māori and Te Reo Māori, this was arranged. The training of all Monitors was guided by the research team's consultation with Māori researchers and tāngata whaikaha Māori. For example, Monitors asked Interviewees if they would like the hui to commence with a karakia followed by mihimihi and closed with a karakia, and whom the Interviewee wished to recite the karakia (the Interviewee themselves, a member of their whānau or the Monitor). For meetings at the Interviewee's home, regardless of background or ethnicity, the Monitors asked what protocols to follow. All Interviewees were able to have a support person or people in the interview with them.

All interviews were semi-structured and took approximately one to two hours. A \$50.00 voucher was given to each Interviewee as koha, as an acknowledgement of the time and expert knowledge they brought to the research.

## **8.6 What we did with the Interviewee Responses (Data Analysis)**

Each interview was audio or video recorded and transcribed into a verbatim transcript. These transcribed recordings were then analysed along with field notes and any other data the person had agreed to have included in the report. Due to the limited timeframe of this research, transcripts were not given to the Interviewees for review, but were available upon request. All Interviewees were assured that contributions in the form of verbatim quotes would be anonymised. In addition to this, the draft report was reviewed by eleven Monitors, who provided feedback on the content, ensuring that it was a true reflection of their Monitoring experience.

The 61 interview transcripts were then compared and contrasted using the research software HyperRESEARCH. The Research Team began by reading the transcripts multiple times in order to familiarise themselves with the data. Throughout this process they identified and extrapolated rights violations, while noting emergent trends and patterns that reflected the purpose of the study. New themes were also generated through the Research Team's interpretation of the data as they uncovered meaning and developed a deeper understanding of the housing experiences of Interviewees (Patton, 2002).

## **8.7 Ethical Considerations**

This monitoring research was approved by the Northern B Health and Disability Ethics Committee (HDEC) on 16 of April 2019 (NZ/1/7B02113). Outlined below are the ethical considerations that were considered by the DPO Coalition and HDEC when planning this research.

One of the key risks associated with this research was the potential for emotional distress and discomfort during interviews, triggered by the recollection of potentially painful or traumatic memories (Jorm, Kelly & Morgan, 2007). This may have included the disclosure of unsafe living conditions, abuse, rights violations or discrimination within the New Zealand

housing sector. It was also anticipated that Interviewees may also feel a sense of frustration towards the research. Although the purpose of this research is to contribute towards monitoring the progressive realisation of the rights of disabled people in Aotearoa New Zealand, the Research Team and Monitors did not have the capacity to immediately alleviate substandard living conditions through the research project itself.

From a methodological perspective, the DBI was also aware that time constraints together with limited resources did not allow this research project to reach its full potential. Under more favourable circumstances, the DBI would have conducted a larger number of interviews, over a longer period of time, and engaged participants on a deeper level (that is, beyond 2-hour interviews, with increased reflexivity). This was also a concern shared by the HDEC.

To moderate these risks, all research encounters aimed to conclude on a positive note by asking questions that investigated Interviewee's hopes for the future (see Appendix B). Upon request, Interviewees were also provided with the contact details of organisations working in collaboration with housing and/or citizens advice services in their region. Interviewee expectations were managed sensitively, with complete transparency around the nature of the research. All members of the Research Team, including the Monitors, were trained and/or experienced in conducting sensitive research.

Given the high prevalence of homelessness and/or inadequate housing conditions within the disability community, the Research Team and Monitors were made aware before going into the field that this research might require them to navigate sensitive and sometimes distressing responses. This was particularly relevant as Monitors themselves identified as disabled and may have related to Interviewee's potential recollection of painful or traumatic housing memories. Responding to, and supporting, Interviewees throughout the interview process was emotionally and intellectually demanding. Monitors were all trained in how to respond in these situations and also engaged in a debriefing activity following every encounter with their monitoring partner, using a peer support approach. External supervision was also available to Monitors through regular contact with the research/advisory team.

A final ethical concern related to the inclusion criteria and the necessity of free and informed consent. In its purest form, the DRPI research model holds that monitoring research must be conducted by disabled people, with disabled people (Samson, 2015). Ethical research standards, on the other hand, require that research is only conducted with participants who can provide free and informed consent on their own behalf (National Ethics Advisory Committee, 2012). As a result of these criteria, important groups of people from within the disability community were unable to participate in this monitoring research. This included people with high and complex needs who were unable to provide free and informed consent on their own behalf, and people who did not themselves identify as disabled (for example, close supporters and family members). The implications of these ethical concerns were discussed at great length, and will be addressed in future cycles of monitoring (for further details, please see Chapter 12 Strengths and Limitations).

## 9. Interview Locations

Interview locations were selected based on the location of the DBI Research Team, to ensure that the data collection processes were carried out efficiently and effectively within the timeframe. Consideration was given to ensuring research information was made available in urban and rural settings, as well as amongst diverse populations. In total, 15 interviews were conducted in Northland, 21 interviews in Auckland, 10 interviews in Christchurch, 10 interviews in Otago, and five in Southland.

## 10. Participants - A Demographic Overview

The purpose of a demographic overview is to understand the basic details of the Interviewees as a whole group without revealing any information that might identify them personally. Of the 61 Interviewees, 19 identified as male and 42 as female. This included members from the LGBTQIA+ community. The youngest Interviewee was 19 years old and the oldest was 76 years of age, with the average age of Interviewees being 43 years. The scope of the participants was ethnically diverse, with many Interviewees self-identifying as multi-ethnic. This included 14 Māori, 43 New Zealand European and/or Pākehā, five Pacifica, and a small number of 'other's including Australian, South African, Dutch, Greek, French, and Danish. Interviewees self-identified as having a range of disabilities, including multiple conditions. Forty-six Interviewees indicated they had physical or medical-related conditions. Of these, seven were sensory impairments. Five people identified as living with disabilities related to neuro-diversity, 10 with psychosocial disabilities, and 12 people with learning disabilities. Of the 61 Interviewees, 11 indicated their impairment was a result of injury.

With regards to living situations, 13 Interviewees were homeowners, while three lived in family owned homes, five lived or boarded with family members, and one boarded with a family that was not their own. Sixteen Interviewees were tenants in private rentals, and a further 11 were Housing New Zealand tenants. Four Interviewees lived in boarding houses, three in university halls of residence, one in residential care, one in a group home, and three Interviewees had no fixed abode (car, shed and tent). It should be noted that Interviewees were asked to share experiences from the past five years, which meant that some experiences did not relate directly to their current living circumstances as listed above.



# 11. Findings

The next section of this report details Interviewee experiences of housing in Aotearoa New Zealand. The findings have been arranged according to Interview responses and interlinked issues, rather than the order of the interview themes and questions. The first key theme is choice and control, as it appeared to underpin most, if not all, of Interviewee experiences. This is followed by findings relating to access, belonging, safety, and awareness of rights, with relevant UNCRPD articles woven throughout. Following each finding is a brief summary of key issues, before relevant UNCRPD articles are listed, as well as suggestions of who might be interested in or concerned with these findings.

Throughout these findings, priority has been given to the voice of the Interviewees, by including as many relevant quotes as possible. Quotes are structured to reflect the verbatim response of the Interviewee, and when content has been removed by the Research Team, this has been indicated by square brackets and three periods (for example, [...]). When two voices are included in a quote, such as the Monitor and the Interviewee, this is represented by M: and I: to indicate the change in narrator. When direct quotes have been edited for grammar purposes or clarifying details added then square brackets have been used. To ensure that Interviewee responses remain anonymous, quotes have been coded as (Interviewee #1), (Interviewee #2) and so on, with identifying details removed from quotes.

## 11.1 Choice and Control

As highlighted by Sir Robert Martin during his keynote address at the Disability Matters Conference in 2017, Article 12 Choice and Control is the “heart and soul” of the UNCRPD (Disability Matters, 2018, p. 4). In much the same way that choice and control underpins both the UNCRPD and New Zealand Disability Strategy (Outcome 7), it was the lack of choice and control that were key themes underpinning Interviewee’s housing experiences. It is for this reason that we have positioned choice and control at the forefront of the research findings.

The denial of choice and control based on disability is a form of structural violence (Galtung, 1969; Francis, 2019). It can be difficult to identify as it often takes the form of injustice and discrimination built into systems with no single identifiable or concrete perpetrator. Even though ‘choice and control’ as a concept was not necessarily referred to in the interviews, analysis of responses revealed that many Interviewees felt frustrated with the limited choices they had when attempting to access adequate housing, and the lack of control over their living situations. This included where Interviewees lived, who they lived with, and decisions within and around the home - themes that will be discussed in greater depth in the following chapters on accessibility, belonging and safety. For example, one Interviewee who self-identified as having a learning disability and living in a group home, articulated that she had no choice or control over her finances, place of residence, or the people she lived with. When asked if she was happy where she lived, she said no, and that she would be much happier living in a flat on her own where “I probably don’t need the staff to boss me around” (Interview #56). When considered alongside the UNCRPD this experience, and



the experiences of other Interviewees, are hindering the progressive realisation of a range of Articles, most notably Articles 9 (Accessibility) and 19 (Living independently and being included in the community).

To further demonstrate some of the more notable experiences of Interviewees, three examples of where the absence of choice and control directly resulted in inadequate and unsafe living situations are presented.

The first example (Interview #45) was shared by an Interviewee who, following the amputation of her leg, was left unable to work and had been homeless for 17 months living in a tent: “I could no longer afford to live in a house. ACC took my income on the year of my accident as minimum wage so I only get 80 per cent of minimum wage and the rent prices went through the roof in [place name removed], as they have everywhere and we just couldn’t afford to live in a house anymore. So, I started this lifestyle. [...] I was living in a house but I was paying rent and power and couldn’t afford anything else. I was having to rely on friends to donate food to me.” When Monitors asked whether she had experienced abuse or insecurity while being homeless and moving between campsites, the Interviewee answered, “Yes, my first night out. [...] The first night, someone discharged a shotgun right beside my tent, during the night. And did it repeatedly throughout the night and because I only had one leg, there was no way I could get up and escape, I just had to lay in the tent. Hoping he wasn’t going to turn it on the tent. And you hear of people, a lot of socio-economic do this, go to campsites to live, and WINZ are using them a lot more. You get a lot of dysfunction and a lot of people arguing. And that’s not nice to be around. Very violent arguments.” Furthermore, the Interviewee indicated that the lifestyle had resulted in a deterioration of her condition, especially during the colder months: “There’s a couple of nights where I’ve wondered as I’ve been going to sleep that maybe I just won’t wake up because of hypothermia and there’s been a couple of nights where I’ve walked all night rather than go to sleep because of the risk of hypothermia. And not waking up. And my heart plays up a bit more now. I just think it’s a matter of time.” However, probably the most significant impact that the lack of choice and control had had on the interviewee was psychologically: “So I’m treated like an absolute nothing. I’m treated like everything is in my mind. That I’m not forward moving, all the blame is basically put on me. And I’m left to it.”

The next example (Interview #28) concerns an Interviewee who has a spinal cord injury. After a prolonged period in rehabilitation, efforts to find accessible accommodation near her support networks failed: “I mean, there are no options out there for younger people with a physical disability and we were kind of quite bewildered with that. Because you know, it’s [place name removed]. You would think there would be somewhere, and I was kind of too high functioning for mental health to put in accommodation and that wouldn’t have met my physical needs anyway. There wouldn’t have been any availability anyway cause the system is too stretched. But yeah, and then eventually had the NASC [Needs Assessment and Service Coordination] assessment and they decided because of the combination of the mental health, my family was reluctant for me to live on my own initially because of the risk

aspect. So yeah there was NASC decided that residential care was going to be the solution and [organisation name removed] had to discharge me at some point. I basically stayed a bit longer than someone with my level of injury would normally stay there 'cause they were trying to find somewhere for me to go which was good in terms of my rehab. So NASC presented me with basically three rest homes that took younger people [...].”

While the Interviewee tried to remain positive about her current living environment, and hopeful that she would soon be able to move to a newly purchased family home being renovated to meet her access needs, it was clear that, as a young woman, living in a retirement home was not a suitable solution. For example, the Interviewee was required to eat at the same time as the other residents, retreat to her room at an allocated bed time, and follow the general protocol of residential care: “The next youngest person without an intellectual disability would probably be sixty. So, there’s quite a big age group and they’re hard to socialise with cause a lot of them have dementia and various things. [...] I spend a lot of time on my phone, on the internet. So, when I first got here they didn’t have any Wi-Fi. [...] Yeah. I mean friends do come and visit me here but it’s not the nicest place for them to come and visit.”

When asked what would improve her living situation, the Interviewee alluded to having more choice and control: “I’d quite like some peace and quiet and not have to listen to not so nice entertainers. I don’t join in the activities an awful lot 'cause I have physio or something on most days and I don’t really wanna play bingo and I don’t want to sit with 90-year-olds who can’t talk when I’m having my meal. So, I eat in my room. [...] It’s just... yeah, it’s just not what a 30-something-year-old woman should have to do. The activities are not suitable for me. The food’s not suitable for me and I’m kind of in a very, very cramped room. Yeah and I would like to be a lot more independent but there’s constraints you have to fall within when you’re living in this kind of situation. You know, what times you have a shower, times you eat, times when staff are available to help you with things or yeah. M: So, would you say your freedom of life is pretty controlled? I: At least I have, like I get [taxi service] so that does allow me to go out kind of basically when I want.”

The third example (Interview #2) also relates to choice and control, but in the context of New Build initiatives for first-home buyers. The Interviewee who shared her housing experience lives with adult onset of a degenerative genetic disorder affecting muscle function: “Now, although it’s sort of devastating, you’ve got to get to grips with it and okay, this is me and how am I going to keep on going to the best of my ability. For me I want independence, absolutely. So, I thought, “How can I be? What type of home will I need to be completely independent?” [...] I needed a home where I wasn’t going to be paying a mortgage because how do you when you can’t work, and I know it’s only going to get worse? I needed a place that was on the ground, no stairs and new so I don’t have to be getting it fixed or anything like that.”

After inquiring into a home ownership scheme, the Interviewee was delighted to learn that even though she was not a first home buyer she was eligible: “So anyway I bought it and I knew the price and I’d done really, really well. I thought, “Oh my God, I can finally be independent and look after myself, financially look after myself.” But then when it came to, he [the developer] said, “Oh we’ll see as you go”. I said I’ll need a wet area bathroom, but I know that just needs to go in. They just need to make sure for the level of the concrete. So anyway, he said, “Yeah, yeah.”

Even though the Interviewee repeatedly requested minor changes be made to the building plans to ensure she could easily access the home she had already paid for, she faced resistance: “There was a shower box, the toilet. You couldn’t have got a wheelchair in between the shower and the toilet so I couldn’t have used the toilet.” The Interviewee even asked the builders to refrain from finishing the original bathroom to avoid wasting materials before she retrofitted for accessibility: “The bathroom scenario meant that it took another three months before I could move in because then it was fully kitted out. They said, “No you’ve got to have it.” I said, “But don’t bother putting the shower in.” “But we have to.” They had to put the shower in. They had to put the vanity unit in that I couldn’t use.”

The Interviewee went on to list all the features of the home that needed to be removed and replaced with accessible features including an entirely new bathroom, ramps, railings and the parking area: “It had to be ripped out. But they wouldn’t let me do it until move in date. It had to be finished and final consent for the whole building because they would only pay for one person to come out and do the consent. So here was me and yes, the house had taken two years to build and yes, it’s affordable and all that. I was thrilled to bits, lucky, lucky, lucky. But for somebody, if I wasn’t lucky enough to have that extra money there, what the heck do they do?”

When asked how the whole process of purchasing a new build had made her feel, she answered: “How did I feel? I couldn’t believe that I’m in this position of this is how you actually aren’t part of society. When I said to them, “Look, please if you do it now, it’s not going to cost me much more for putting a bathroom in. If you just lower the concrete now.” No, no, no. I mean there have been different times where all of a sudden you feel like I am a disabled person. But it was also they said, “Look, we will give you the money back that you pay for it and on sell it and you can get out of it right now.” I’m like, “You’ve just torn the rug out of my life. Do you realise what it means to actually own my own home and not have to be reliant on benefits or God knows what?” I said, “No, no, no. No, I don’t want to sell it.” But it’s like you have got this condition and you can’t live there, you can’t live here. Those aren’t your choices of houses. Yes, everybody else in New Zealand can have an affordable home if you meet the criteria. But if you have any special needs we’re not going to help you. [...] Yes. It’s just stupid. A waste of money. And for people who are already in a vulnerable situation then why for me to be just as comfortable as the person next door; why do I have to pay all that extra money there?”

As outlined in the three examples above, each Interviewee experienced varying degrees of being deprived of their liberty and security (Article 14); a lack of choice and control over where and how they lived (Article 19); and/or an inadequate standard of living (Article 9) as a direct result of their disability. These experiences were, for the most part, fuelled by discriminatory attitudes towards disability (Article 5). These issues were summarised eloquently by one Interviewee:

“Well to be clear it’s really hard full stop to find an accessible house. I guess my point is that because the choice is so limited, you know anybody else who owns their own home who wants to move into a different home, well they’ve got a lot to choose from. They’ve got suburbs to choose from. They’ve got different styles of housing to choose from. They’ve got a terrace or apartment or single level or whatever whereas I have to wait for that one house that comes on the market that’s got a ramp or a modified shower. That’s where we move to. It doesn’t matter how big the house is. It doesn’t matter – we don’t get any choice over the size of the section. We don’t get any choice over the neighbourhood or the amenities or the proximity to public transport. We just have to move to the accessible house. I mean this house that we’re sitting in right now – we were living in [place name removed]. It’s seven years ago. I would have been 24 or something. I didn’t want to move to this particular part of [place named removed] at 24. We were quite comfortable where we were, but we needed somewhere that was accessible. So, we went where the accessible house was and we found ourselves on this main road. A busy road. It’s like well it’s not ideal but it’s acceptable because we had to move here. I just feel like it’s not right that I just have to go wherever the accessible house is, even if it means living in a part of [place name removed] that I don’t want to live in that’s far away from other things, that’s not close to nearby schools. I mean we have such limited choice. I find that incredibly – it’s not even frustrating, it’s demoralising and unjust. I actually think it’s unjust because disabled people have no less right to choice than any other person about where they live. But it just so happens that for me as a wheelchair user, my choice is incredibly limited. I don’t want to drag my family to some far-flung corner of [place name removed] just because we found a house with a ramp in it.” (Interview #41)

### **11.1.1 Choice and Control - What are the key issues?**

Choice and control is the heart and soul of both the UNCRPD and the findings of this monitoring research. This chapter has drawn on a small selection of diverse Interviewee responses to demonstrate how important choice and control was to Interviewees, and the impact this had on both their physical and psychosocial wellbeing. Many Interviewees felt frustrated with the limited choices they had when accessing adequate housing, and the lack of control over their living situations - including where they lived, who they lived with, and decisions within and around the home.

### **11.1.2 What articles do they relate to?**

Article 4 – General obligations

Article 5 – Equality and non-discrimination

Article 9 – Accessibility

Article 14 – Liberty and security of person

Article 19 – Living independently and being included in the community

### **11.1.3 Who should be concerned?**

- Housing New Zealand
- ACC
- Work and Income New Zealand
- Ministry of Housing and Urban Development
- Central Government
- Local Governments
- Disability service providers
- Contracted builders
- Developers
- Architects

## **11.2 Access**

Outcome Five of the 2016-2026 New Zealand Disability Strategy (Accessibility) states that disabled Kiwis aspire to access all places, services and information with ease and dignity (Office for Disability Issues, 2016b). However, when it came to interview questions about housing and accessibility, Interviewees reported experiencing a wide range of discriminatory attitudes and practices. According to Article 2 of the UNCRPD:

“Discrimination on the basis of disability” means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation (UNCRPD, 2006).

While Interviewees were not asked to articulate their own understanding of discrimination, when considered alongside the definition above Interviewee’ experiences clearly indicated that they had been discriminated against when accessing the housing market; discrimination when implementing accessibility measures within the home; and when considered within

the context of tenure (conditions under which land or buildings are held or occupied), discrimination when accessing information and justice.

### **11.2.1 Access to the Housing Market**

Under Article 5 of the UNCRPD (Equality and Non-Discrimination), the Government of New Zealand and its institutions are required to recognise disabled people equally before the law and prohibit discrimination on the basis of disability. Furthermore, specific measures that are necessary to accelerate or achieve de facto equality of disabled people are not to be considered discriminatory. Within the context of the housing market, not only does this mean actively dismantling discriminatory attitudes within the housing sector, but also providing measures to ensure equal access to adequate housing for disabled people.

Even so, most Interviewees said they had faced significant challenges when trying to access the housing market as tenants or as buyers. For some, the ongoing nature of these challenges led to the deterioration of their physical and psychosocial health. For others, these challenges had forced them into inadequate living situations and even homelessness. For example, one of the first barriers Interviewees experienced appeared to be directly related to the attitudes of people in positions of power to exclude (Thomas, 2004) such as landlords, property managers, real estate agents, Work and Income New Zealand (WINZ) and/or Housing New Zealand (HNZ) staff. This meant that Interviewees were navigating real and perceived attitudinal barriers before even physically entering a property, potentially violating a myriad of UNCRPD articles including Articles 4.d, 4.i, 5, 8.1.b, 9, 17, 19, and 28:

“Yeah, I think too it’s the perception of most landlords is that if you’re not working, you’re not a viable tenant. If you have a disability and you express that you have a disability, you’re not a viable tenant.” (Interview #18)

“I think the biggest problem is probably the closed mindedness of landlords and the... they think something will be way more difficult than it actually would be. [...]” (Interview #12)

“I think there is the assumption made by landlords and vendors that you know, you are in some way going to be more difficult to deal with than an able-bodied tenant or an able-bodied buyer. [...] I’d often send an able-bodied envoy on my behalf to scope out rentals and flatting situations so that we weren’t unfairly disadvantaged by turning up at an open home and presenting as having a disability. I’d send, either my wife would go in on our behalf and so they wouldn’t know because you know. Landlords are out to make a quick buck and they don’t want to have to have any sort of added complications. We all know how that affects other marginalised communities and I think it affects people with disabilities as well.” (Interview #41)

“I spoke to her (Housing New Zealand staff) and said that I was in full time work, but you know, I wonder if they can help me look for a house. I need one on the flat and the comment I got was, “Um, well, just go look for one on the



flat then.” [...] And I couldn’t afford... I... most of my income was going to my medication because it wasn’t subsidised [...] so that comment hurt a little bit.” (Interview #9)

“I think landlords are often discriminatory if you are disability people.” (Interview #19)

“I think there are a lot of barriers... I’ll look at mental disability for a start. There’s a lot of barriers for people with mental illness. Because people still feel that those with mental illness are somehow mad. And so, they might catch what they’ve got if they lived somewhere near you or... I think people with mental illness are really discriminated against.” (Interview #22)

“She [the agent] kept putting me on six-month tenancies because they were not quite sure when they signed me up because they were with two different companies – how I can look after a property and what not with cleaning and what not and probably because of my age as well. [...] They were always the question, “You’re not going to need a guide dog, are you?” They weren’t quite happy with that one.” (Interview #16)

“M: So, would you say that having a disability has impacted on you being able to obtain a house? I: I’d say it creates concern for the tenancy agencies because they don’t know what your ability is.” (Interview #16)

“If I was renting the house, I’d need a fire alarm and I’d have to get permission from the landlord and sometimes they don’t want deaf equipment, they prefer to have hearing equipment so those kind of things can be frustrations in other houses. And that’s a problem and you have to explain to them that I need this, because I’m Deaf. It’s for safety, it’s free, it won’t cost you any money. And if you’ve got it set up then that’s really good. And if you’re following the law you would understand that I do have to have this, that kind of drama every time. One rental house, I was so grumpy about it, we set that all up, but they wanted me to take it away with me when I left. M: Was it easy to access Deaf Aotearoa about that? [...] I: Yes, Deaf Aotearoa was fine. No problems, it was the landlord, because it was their house, who was a bit moany about it and didn’t want it set up. But that fire alarm system that they had didn’t suit me.” (Interview #47)

“M: What do you think the biggest barrier [to adequate housing] is? I: Definitely attitude.” (Interview #47)

Only one Interviewee reported a positive change in how they had been treated by agents and landlords:

“I mean it was quite amazing actually from when I first purchased the place in [street name removed] to when we started looking out now - a lot more awareness to the agents these days with health and safety. They see the cane rolling up and the first thing they want to do is wrap me up in cotton wool and like I say to them, “It’s not me, it’s, tell your sighted people!” I’m a blind person who’s more aware of their surroundings, so they’re telling me where all the hazards and everything were and putting out cones even. But, yeah, no, it was, it has actually changed over the last 12 years.” (Interview #35)

However, despite the occasional positive experience being reported, Interviewees consistently emphasised the negative attitudes they felt subjected to. This left some people feeling conflicted over whether to disclose their disability to those in positions of power for fear of being turned down for a potential house or eventually evicted when the truth was exposed. This was particularly evident amongst Interviewees who identified as living with psychosocial disabilities, or who relied on service animals and/or assistive devices. Even though New Zealand domestic law prohibits discrimination on the basis of disability and/or certified service animals (for example, see the New Zealand Human Rights Act 1993), Interviewees who identified as being part of these sub-groups felt like they were perceived as being higher risk tenants or at risk of causing damage to a dwelling. Given the nationwide rental shortage this was particularly problematic for Interviewees who were tenants (as opposed to homeowners). High numbers of applicants per advertised rental property meant that Interviewees who were perceived as high risk were passed over for those who were perceived as low risk tenants (that is, non-disabled tenants). As outlined in Article 8.1.b of the UNCRPD, these are harmful stereotypes, prejudices and practices, perpetuated by people in positions of power to exclude (Thomas, 2004).

“So, I was just searching... I just searched on Trade Me and all the like, property sites. I just put studio or one bedroom like self-contained. And then I started off doing like pets allowed, but there would only be like one result available. And then because a support dog in New Zealand is not considered... he doesn’t have any rights unless like emotional wise, in New Zealand they’re not quite there yet unless my depression was worse, and I needed him to actually do tasks for me. And then he would have more rights. Like, my doctors gave him rights but a landlord at any point is just allowed to say no. [...] Yeah, um, he does have support from my medical people, but not a badge. Yeah so, I’d get no reply, or I’d get an email that just says no, no pets, no dogs. They wouldn’t even wanna meet him. And I’d send them a big long screeds of explaining, and I’d send them all my supporting documents and I’d just get no. Yeah, so that was real hard. [...] it was horrible, and I was in a state!” (Interview #12)

“I think if people had known in the private market what my diagnosis was they wouldn’t have given me the rental. So, we kept that hidden. Cause I had to get a rental place to qualify to get a state house. I had to get a private rental



to qualify to get a state house rental, but I never told those private landlords what the situation was. So, I just realised I couldn't otherwise they just tell you to go away. I have, people's expectation and understanding of schizophrenia is not very positive. M: So, is that why you didn't disclose it? I: Well, in that I disclosed it in other areas of my life to help people understand and make people realize that we're just regular people trying to live regular lives. So, I would do that regularly but not in that situation 'cause I knew there was a high chance I wouldn't have got the tenancy." (Interview #27)

Other challenges when accessing the rental and property markets were affordability and physical accessibility. Notably, this was almost always linked to employment, income, benefits, ACC versus Ministry of Health (MoH) support, and rising house prices (see Article 27 of the UNCRPD for further context). This also relates directly to Article 28.d. of the UNCRPD which ensures disabled people's access to public housing programmes. For example, when asked what the biggest barriers to adequate housing were, Interviewees responded:

"I think there's all sorts of things like I mean it's not just me, right? I mean affordability is a huge barrier for housing, right? Modifications for disabled people, that's a huge barrier. You can't just modify, and who pays for the modifications is a huge barrier too." (Interview #15)

"Apart from affordability, I think the big thing is it's difficult to find suitable housing that's wheelchair accessible and ticks all the boxes in that regard. [...] Cost is a big one and feeling like there's a premium. If I wanted to move into a warm dry home, that's modified for me, there's usually a premium compared to the next house down the road which might have all the same things except the modifications." (Interview #25)

"I: Accessibility. Doesn't need an elaboration on that. Houses are not accessible. M: What other things impact on your ability to have adequate housing? I: Price. Houses are really expensive and especially when you have health conditions that mean if you live in a cold or a damp house is usually what you can only afford has a negative impact on your health and then you're kind of caught in a vicious cycle of bad health but not gonna afford anything that's gonna allow you to have good health." (Interview #31)

"When I was looking for places like through Housing New Zealand you have to search as well, and I went online. And you know they always have pictures of the rooms. They have pictures of the bedrooms, they have pictures of the bathrooms and stuff. All of them that I went on to I didn't find any that I could have lived in. Maybe I could have gone in for a little while, a year or so, and then have to find another one. Like the bathrooms were too small and the shower was over the bath. There would be steps so I couldn't do the steps.

So, you... they weren't something that I could be in comfortably." (Interview #9)

"It was quite difficult because I had owned a house which was an ordinary brick house in [place name removed], which was totally wheelchair friendly and I had lived there for 26 years. Then the earthquake happened, and it was [condemned]. So, I found it quite hard to find this." (Interview #24).

"I think the biggest barriers to adequate housing we have is that not enough people are educated on what different disabilities need and how to just be compassionate to each other and so housing has become a commodity and a business as opposed to a general right." (Interview #40)

"I think to a certain extent more from home owner attitudes or agent attitudes, I can see that places that I thought that I would get, I would see that financially out of the people there at the viewings I was by far in away the better choice. But it doesn't mean that I got them you see. So, I'd say that's just because I was disabled. [...] just that I was a wheelchair and it was obvious I was visibly disabled and people just really and you know that was it three years ago the law changed here where damage from our equipment is considered wear and tear not damage? M: Do you wanna elaborate a little bit on that? I: Well it's made it that I can take the place that I was renting I still haven't got the bond back. It's made it so that I can take him to court and know that I'll get the money back. [...] M: Do you think that people are afraid because of the wear and tear coming under damages now that they're more resistant to having wheelchair users? Or do you think it's had an impact on that for you? I: Yeah I think it can definitely cost more because most places are not built with Universal Design in mind and so trying to get through doorways or I had a fall and fractured the pubic bone in my pelvis before I moved out of the other place and I needed to get some hand rails put in the toilet and this guy wouldn't do it. And so that meant the only way that I could do was to again reverse with the gutter frame to the toilet and it was like not a bathroom toilet in a bathroom. It was its own room. So it was like reverse. But that meant it scratched up the door massively and well not my choice and if he'd just put the hand rails there I could have managed without taking it in. But he thinks that he can take that out of the bond. But of course he can't. So, I think it will and that may not be helpful for us when people really understand." (Interview #39)

"Yeah, and landlords are getting very choosy. Even people with children, they're sending them away, they don't want children in the house. They don't want unemployed in the house. They don't want disabled in the house. They want these high professionals in the house and that's about it. They can afford to be really choosy and they are. So, a lot of extremely good tenants who would really look after the place are just being turned away. They go for what society values the most and that's certainly not disabled." (Interview #45)

“They [home owners] don’t worry about people. It’s mainly the stigma. They’re not worried about people who have disabilities. They just want to rent their house. If people have disabilities, it’s not – they’re not going to work around people who have disabilities. They see it more as a problem if you ask me.”  
(Interview #11)

In addition to affordability and accessibility, several Interviewees also noted that taking time off work to view potential rental properties was not financially viable, while also emphasising the logistical challenges of navigating public transport and travelling to and from house viewings:

“[J]ust the physical aspect of trying to get about to see the relevant people. When you can just hop in a car, bang! Go and be on somebody’s doorstep, it’s easy. Do you know what I mean? You can put yourself in front of people. But with a vision impairment it ain’t that easy. You’re restricted. You’re stuck with taxis, buses or walking everywhere and it’s not always convenient. You know, you’ve got a car, hop in it, turn a key, gone. You just do it, you take it for granted. I mean it’s those taking it for granted things that, once you’re visually impaired, you haven’t got an option. You gonna make a journey and you have to plan it all. Do you know what I mean? And it can take sometimes you make a journey and it can take days to make a journey that people [noise of exasperation].” (Interview #32)

“M: What other things impact on your ability to have adequate housing? I: Um, having the time and the space to actually go and find a house, the need for, need of being at work to actually earn an income to pay for the house. Um, getting time off to go and look at a house doesn’t always work.” (Interview #42)

“Yeah, it [my disability] probably has [impacted on my ability to find house] but maybe in the sense that I haven’t been well enough to be able to undertake the task of looking, finding a house. It’s also had an impact in terms of when I do look for homes. I’m very limited in terms of where and what types of home that I can take, and those options are, you know, that excludes a whole lot of places that I can potentially live in.” (Interview #18)

The intersecting experience of negative attitudes, affordability and inaccessibility led to many of the Interviewees feeling forced into accepting rental properties or purchasing homes that were beyond their budget and that were also inadequate, simply out of desperation:

“No, I just think coming into this place and first of all I was desperate for a place and I couldn’t find anything. So, I kind of just grabbed this. I was in hospital as well when I had to grab a place because I didn’t have a place to go after hospital. So, I grabbed this place and I wish that I hadn’t you know?”  
(Interview #11)

“I’m not happy with where I live but I need there because it’s the best that I’ve got at the moment.” (Interview #6)

One Interviewee felt they had made a rushed decision to purchase a house after a natural disaster had left their home un-liveable. The Interviewee emphasised that just because they could afford to purchase a home did not mean they had the financial resources to ensure it was accessible or safe:

“And it was easy because I was tired. The earthquakes had exhausted us. And the fact that [agency name removed] gave us a week to move out, which we then pushed to make it a month, I think we were under pressure, so I was sick. I had been in hospital for about a week and decided my house was sick which pushed [agency name removed] to hurry up, which pushed us so this is complicated because we [group name], we didn’t do open homes like normal people, a friend was selling a house, a friend was in real-estate, he has a house that would suit you, do you want to do it? We didn’t really look around because we were pretty tired, and it was a really poor winter for my health. [...] If I’m really honest and on my worst day, it’s a huge impact on my ability to function. And if somebody from somewhere... and we worked it out financially, it’s probably not much and we got that house properly accessible and able to be done and we had the right supports in, so I could have natural friendships instead of natural supports, I would probably be flying in my business and be as congruent and happy in myself as the world sometimes sees me. It wouldn’t be a battle.” (Interview #29)

Furthermore, for at least five Interviewees these challenges had led to homelessness at some point, and as was outlined earlier in the findings, the placement of young people in retirement homes.

### **11.2.2 Access in the Home**

Having established some of the challenges of accessing the housing market, Interviewees then articulated the issues they faced when making their homes accessible. These challenges are predominantly related to Articles 4, 5.4, 8, 9, 14, 17, and 19 of the UNCRPD. During the interview, Interviewees were asked both about the modifications or services they currently had, and modifications or services they do not have but felt they needed, to live a safe and secure life. One positive finding was that many Interviewees reported having access to devices such as shower chairs, but also noted that such devices had little to no impact on their dwellings. When it came to necessary alterations, such as ramps, handrails, widening of doors and emergency systems, however, landlords and agents were reluctant to allow these modifications even if at the expense of the Interviewee (tenant), thus potentially violating Articles 4, 8, 9, 14, 17, and 19, as well as other articles relating to safety and security (addressed further in Chapter 10.4 Safety).

“They managed to put a chair in there for me because I get quite dizzy in the bathroom. M: Is the chair adequate for your needs or were you wanting something additional? I: Yeah, I wanted like a railing to be put in there. But the landlord would not.” (Interview #11)

“M: Do you have any other modified things? I: No. I just really want a ramp, it would be safer for me and my partner to walk on. M: And what else would you think, that would make your life easier? I: It’s easier for me to get in and out the front door because my wheelchair’s big, it won’t fit the front door, because of my wheels.” (Interview #21)

“If I was living with my partner, it has to be a flat house, be easier for me to move around. Where I am now, I can’t move around at all, because our house is very small. I can go places, but I need to have my walking frame or my wheelchair with me, to help me support so I don’t fall down.” (Interview #21)

“M: And was there anything else that you could think of that might make a difference? I: Um, brighter lighting inside. But that’s not really gonna happen.” (Interview #4)

“It is an old home and my landlord is lovely as he is, and he’s not out for money, so I don’t pay an exorbitant rent. But he is useless at doing some of the maintenance in the house. There is an issue that I would have in that I’ve always had with home in that the layout of the house does not fit with how my brain works as a result of my impairments. The yard is incredibly difficult to maintain, and I am not provided assistance. I have to rely on family and I have very few family members who are able in [place name removed] now to help me with that. M: Have you sought assistance from elsewhere, for example? I: ACC and if I owned my own home, I would be – I would be able to access supports with the garden, with the lawns but, because I don’t own my own home, I am not eligible for access. M: That’s quite interesting so if you rent, you’re not eligible for ACC support? I: Yes, in terms of internally within the house, I don’t fit under any scheme for any supports to make the adjustments to my home that would assist me. I do not have mobility issues; therefore, I do not qualify for adaptations, physical adaptations, within the home.” (Interview #18)

“The only thing that’s accessible about the house that Housing New Zealand did was just a walk-in bathroom with handrails from the one handrail where the toilet is and the other handrail on the shower, so that’s about it. M: They did about the minimum of what they could get away with? I: Yep.” (Interview #6)

“A lot of the housing when they stick you in to it and claim it’s a home it’s for people with disabilities and disabled, you get in there and some of them they have to come back and remodify it because your wheelchair won’t go through the door. Or you got no turning space for your wheelchair even though some

of the new ones can turn on a dime. There's no room to manoeuvre your chairs around. You got handles in the wrong places that are no use for getting you in or out the bathtub, or out the shower, or even off the goddamn toilet in some cases. There are places that they need to put handles that they don't put handles. Like, one of the things is if you actually have the ability to stand and do stuff, they don't put one in the kitchen. You need one in your kitchen if you still able to stand and get up and down even when you've got a perching stool. I've got a perching stool for my bathroom as well. I've had all sorts of different equipment over the years. Some of it's really good, some of it is total [profanity removed]. Some of the alterations that they're supposed to do for your house again are total [profanity removed]." (Interview #10)

"I don't really have any modifications as such. I just have more assistance devices. Like I have that activity chair is new, and then just adaptive equipment for like the kitchen and then the in the bedroom I have step to get into the bed and just kind of small things like that. Nothing major. We have put in a couple of handrails on the deck. Like we did that ourselves. Haven't put one in at the back door. [...] M: Yeah, and ACC are they being as cooperative and as helpful as they can? I: [Laughs] No! M: I see your laughing. Are they not being so? I: When are they ever? When it comes to spending money, it's a different game altogether isn't it? They are making contributions, just not with what I see their role being." (Interview #31)

"We would quite like some hand rails but we haven't asked for those yet so we don't know if they would be provided and it has been suggested to us by therapists that we get a support cat but we're not allowed, well a support animal. But we're not allowed to have an animal in this flat." (Interview #40)

"I don't have a shower every day. I'll have one like on Sunday, my PA [personal assistant] will give me a shower. Tuesday, I go to aqua aerobics, Thursday because I go to [group name removed] then [name removed] will just give me a wash and then Friday I'm back at aqua aerobics and then I don't need it Saturday. So, you're back to Sunday. I have one major shower here in a week and two down at [pool name removed]. M: Because of the access? I: Yeah." (Interview #39)

"I have virtually no walking ability and a lot of the surfaces are very hard to walk on and quite often they'll send me, miles away from a bathroom block or something and if I have to get up during the night to go to the toilet, I have to muck around with the prosthetic which quite often does not go on because it's very unreliable and then walk all the way to the bathroom and back to the tent." (Interview #45)



“Yeah some days it is very painful. There’s been a couple of days where I’ve not been able to walk at all. To even step inside [the tent], like not go to the toilet or anything because of the socket right on the arthritis.” (Interview #45)

Further issues were also caused by landlords and agents either taking a long time to respond to maintenance requests or not responding at all. While this is a challenge for tenants throughout Aotearoa New Zealand (Flaws, 2019), for disabled tenants this experience was at best challenging, and at worst, dangerous (addressed further in Chapter 10.4 Safety). As summarised by one Interviewee, “It just makes it harder, that’s all. I just have to... It’s just more taxing. I pretty much have got the resign that it’s not going to happen and that I’ll do the best I can. Yeah.” (Interview #17)

“I, um, go to the bathroom and I’ve got a bathroom that’s got a bath and a shower. And I have to climb over the bath to get into the bath and there’s a shower there. I have a lift that’s on the side that doesn’t work. I have a, there is a toilet that’s separate from the bath and shower and I have a rail thing that’s in there that helps to sit down on the toilet. And that’s broken, and it moves around [...]. M: Do you remember who provided that? I: Housing New Zealand. And ah, it’s not the greatest, but it’s just something that I have to take into consideration whenever I’m going in there. [...] M: Have they said that they were gonna have a look at it? I: They would try to yes. M: Ok. How long has it been broken for? I: About a year and a half. [...] like I said I just make do with what I can do.” (Interview #23)

“I’ve been unable to get the managers to adapt it for a blind person. And they refuse to do that, unless I get a doctor or all sorts of people to ok it. And even when I’ve done that, there’s much more red tape than I can deal with.” (Interview #17)

“I have ramped access which wasn’t required for me initially but now is because I can’t use the steps now. So, my landlord’s ensured that I continue to need that by injuring me. I’ve got a disabled modified shower. Right? And they’ve refused to help me with the bath. It’s such an irony because the modifications made at my home were made under the HFA funding, not under my name, for my deceased aunts. So, the ramp was made for Aunty [name removed] and the shower was made for Aunty [name removed]. Housing New Zealand injuring me so that I’ve required a knee replacement and a knee revision means that I need to get into the bath to soak my knee for relief from pain and the bath is too low and they will not lift it for me. They’ve refused outright saying I’ve got a modified shower, so I don’t need that. So, it’s hard for me to get in and out of the bath to rehabilitate the injury Housing [New Zealand] caused me.” (Interview #15)

### 11.2.3 Access to Information and Justice

While many Interviewees felt like they could understand the legal information provided to them by landlords, banks, lawyers, and so on, a small number felt that they were at a disadvantage when it came to the accessibility of legal documents and the delivery of the key information. Under the UNCRPD, Article 21 (Freedom of Expression and Opinion, and Access to Information) states that disabled people have the right to access information intended for the general public in accessible formats (including New Zealand Sign Language and other formats). This, however, was not the experience of Interviewees who identified as having neuro- or sensory disabilities:

“M: And just sort of thinking about that too - do you think that information, rental information [...] could be far more easily accessible for you as a person with dyslexia? I: Yep. M: What sort of format would be suitable for you? I: Like dummy-downed writing I guess. Like I don't know, maybe like a format, maybe even if it was like online and you could like listen to it rather than have to read it? That would be like quite helpful 'cause they just send it over in like a document and you can't really copy and paste and listen to it for yourself like if it's in that kind of format.” (Interview #46)

“I do not believe it [my disability] has had an impact on my ability to find a house up until this point but I do believe it would definitely have an impact on my ability to buy a house or something that would have a lot more legal process because of my problems with comprehension. It takes me a long time to do any of that sort of stuff and I think buying a house or getting a loan or anything like that would be very much affected by my dyslexia.” (Interview #40)

“M: If people had a bit more Deaf awareness, some education, some access to sign language that it would help the general public? I: Most of the time I can just text the landlord, we can communicate with each other, that's not necessarily the problem that I find. They can text me, say they're coming for an inspection or whatever, but the problem is when you first move in and when you're applying, there's a lot more communication at the start, whether or not they'll accept you and the things you need to know, telling them what you need set up, like the alarms, that communication at the start is the issue. Those first couple of weeks and then after that, it's pretty smooth sailing I find. So, the problem is just at that initial consultation. So, if we could set up something to smooth the way there. I don't know why it has to be so difficult, to say, this is going to be my place, I'm going to be living here so I need my alarm, I don't know why they're so controlling about that. M: [...] Is there anything else that affects your ability to have adequate housing? I: So, some landlords don't have numbers that you can text. They'll only have a landline,



so they won't give you an option to text them, you have to ring them and that's a pain having to ring them, or if you send them an email, they don't answer but communication is really key to making things work. So that's a problem for access definitely." (Interview #47)

Considering the difficulties Interviewees had when trying to find accessible, affordable and adequate housing, many Interviewees also indicated a sense of fear that their housing situation would change, and a feeling of lack of control:

"M: Are you worried that your current housing situation may change? I: Yes, there will. Maybe. I now most of the houses are already empty, at the moment. Because most of the people who lived in our street moved out ages ago, because the houses here are getting demolished and rebuilt, it's just our house is just the [word unclear] part, it may be changing, maybe not. It just depends. M: And that's something that's worrying you? I: Yeah. It's always worrying me and my partner mainly." (Interview #21)

"M: Are you at all concerned that the landlord could just come and say, "I need you to be shifting now." Is that a stress for you? I: Oh my gosh, the biggest stress. If he says he needs the house for his family." (Interview #11)

When asked whether they had considered seeking legal help regarding housing issues, several Interviewees indicated they had, but with mixed results. Other Interviewees reported wanting to take legal action but deciding not to - either out of fear of losing their home, or because they felt that the time and effort needed to act was beyond their capacity. While this does not preclude the fact that within New Zealand all people have access to the legal system as equal citizens (regardless of disability), it does speak to the compounding nature of discrimination, consequential exhaustion, and the lack of specific measures to accelerate or achieve de facto equality before the law (UNCPRD Article 5.4):

"My previous flat – my previous home that I rented – I thought about taking some issues to the Tenancy Tribunal. The flat became so bad it, like I had rats and I'm talking massive water rats in my home. I found four of them dead in my lounge one day that my cat had killed overnight. My landlord refused, and this was the last straw of a multiple refusings to fix the house. So, I had a leak above a light for quite a period of time at which he refused to fix. But I felt so vulnerable at the time that if I did make a complaint, I would lose my home." (Interview #18)

"I used [organisation name removed] support last year to try and get out of my lease because I was not enjoying my flatmate's company and I couldn't. And then I tried to begin the [Tenancy] Tribunal process where they consider it. But then I got advised about two months in that they don't even it'll take them six months to even read it and by then I'll be out. That's probably the only time I've ever tried to do something serious. M: Right. That must have been quite stressful was it? I: Yeah it was horrible. Yeah. It was not fun." (Interview #12)

“M: And you’ve never been evicted? [...] I: Close to being evicted, like’s close a lot. [...] Yeah, ‘cause the only reason for that is ‘cause previously I think two years ago I think, I went through a lot of up and downs with Housing New Zealand because my stepdad had just lost his job and two weeks later my older brother lost his job. So that left only me working 15 hours a week. Plus receiving a benefit, so that wasn’t enough to house a family, it was enough to put food on the table, but it wasn’t enough to pay the rent and all that stuff. So, we kinda had to all help to get a lot of money to get back on track now, yeah. [...] it just takes one missed payment just to get on their bad side. And one thing I hate about them is – I don’t know if they’re allowed to do this, but you know how I rely on taxis to pick me up here and there? And I have taxi drivers waiting outside my house and we know the Housing [New Zealand] lady, she, they always come as Pasifika, but you know who they are, they are waiting out there. A few times the taxi drivers asked me, “Did you know the lady – the Housing lady – just asked, you know, how many people live in that house?” So, they’re kind of checking up on? And they have no empathy, no manners, they like just come straight knock on the door and expect you to... M: Oh wow! And they without making an appointment or anything? I: No. You see, that’s the thing, when you’re one week behind your rent, and you ring them up and you tell them you’ve missed a payment, they still show up the very next day with the letter, knocking on your door. M: Yes. How does that make you feel - to feel like that? I: Pissed off because if they’re so quick to come and collect the rent, why aren’t they so quick to come and fix our living arrangement about the house we live in? If something’s broken, they should fix it for sure. M: And are you afraid that your living situation will change? I: Yep. And with Housing, like, you don’t know how because when they come to the - it’s kind of threatening when they come to the door and they kind of say you’re - because the way they say it is you either pay or you get out! So, you either pay or you’re out! So that is quite threatening, it’s quite scary, ‘cos you don’t wanna be chucked out on the street. M: And especially with your access needs? I: Yeah.” (Interview #6)

“Yes, I was evicted on ANZAC Day last year because they thought I was unsafe because I forgot about something on the stove twice. For whatever reason, they wanted me to go. Since their word was law, that was it, really. [...] M: How did that make you feel? I: Well it made me feel hopeless, I had nowhere to go. And actually, I think, because I started standing up for myself, they took off their gloves and they started to think that... the second time, they seemed to have the idea that I was a trouble-maker and that I was doing it just to get my own back. They had no inkling of what they said. I said, “But I’m

disabled.” And they said, “Oh don’t you come up with that sort of malarkey. Excuses.” I could’ve gone to the human rights and all that, but they’ll just write letters, I won’t get a better place for it, and again they’ll just say I’m a trouble-maker. [...] M: Are you afraid that your current housing situation might change in the future? I: I’m not afraid, I’m sort of resigned to it, because of the Government’s new initiative to have more comfortable housing, I’m convinced that our place will be demolished, and we’ll be moved on somewhere else, and eventually a better place will be there.” (Interview #17)

“M: Have you ever wanted to take legal action related to housing or accommodation (for example Tenancy Tribunal, complaints process etc.)? If yes, did you? I: I’ve considered it but didn’t go through. [...] I just wanted to be done with the person. I didn’t want it to be dragged out and that’s the thing with the Tenancy Tribunal. It’s not a fast process and I really didn’t wanna have to deal with that landlord anymore.” (Interview #31)

“Well we do [worry] in a sense that if I was suddenly not able to do my job then we might have to sell this and try and get something smaller. Like if I suddenly, like I’ve had a seizure that wasn’t a seizure in the strictest sense, but I’d taken too much medication [...] we wouldn’t be able to sustain it financially. And health wise if I wasn’t able to work our standard of living would decrease dramatically. So, I mean I’m 67 now so I’m expecting to work be able to work ‘til maybe 75. M: So, have you ever wanted to take legal action to the tenancy tribunal? I: I’ve felt like it but I never have. In my [former] tenancy in Housing New Zealand, I thought about it, but I just thought, trying to deal with Housing New Zealand was just like trying to deal with a brick wall. They just wouldn’t move.” (Interview #27)

“M: Did you ever feel like you could complain or advocate for yourself to the owner [of the campground] about the distance [to the toilet from the tent] or did you just kind of just deal with it? I: Pretty much just have to deal with it. There’s not that many people who really care to make it disability friendly.” (Interview #45)

“M: Have the owners decided not to repeat the contract? I: Yeah. There has been one thing where it was... I was meant to... my time was up but they said they were gonna fill it out. So I went away, and then came back and found out that I had twelve days to leave. M: Oh wow! And how did that impact you? How did you deal with that? I: Homeless! [...] M: Are you afraid that your current housing situation will change? Why? I: Yeah, I’m worried that it’s gonna change. I’m worrying that the rent is gonna go up more. That’s my big worry. M: Have you ever thought what you would do if it did? I: Well I know I’m not entitled to Housing Corp unless I get five six no’s from real estates. So s’pose if I can’t find a place it’s back to Mum’s. But Mum’s house is full now, so

I don't know. M: Have you ever wanted to take legal action related to housing or accommodation (for example Tenancy Tribunal, complaints process etc.)? If yes, did you? I: Yeah done it a couple of times. No railing on the, up the stairs, to go upstairs, and I had to take the last tenants last landlords to Tenancy Tribunal 'cause I was getting electric shocked through the plug sockets. M: Oh wow! Ok. Did you get a result from that? I: They got fixed and then I had to move. Twelve days (Laughs)!" (Interview #20)

"M: Are you afraid that your current housing situation will change? I: Yeah. M: Why? I: Price." (Interview #14)

"M: So, your current housing situation, are you afraid that this place that you have now, that that situation will change? I: When it comes to January I'm a little bit sure that because I've been so assertive about things that I've been right. I think that they might end the tenancy." (Interview #11)

A further question inquired as to whether the Interviewees had insurance. Approximately one third of the Interviewees had no insurance, or car insurance only. Interestingly, as highlighted by one participant, by living in a higher risk area their insurance premiums had increased, making it unaffordable even though they needed it most. And for those who were homeless, having no fixed abode meant they could not access insurance at all:

"That's another thing, no one will insure me because I don't have a residential address. So, my motorbike is uninsured. They won't even give me third party so that I can protect other people on the road and other property owners. So, they encourage you to lie. WINZ encourage you to lie too. There's a lot you can't get from WINZ if you do not provide a residential address and I see that as a way of just pretending we don't have a homeless problem in New Zealand." (Interview #45)

On the other hand, when Interviewees were able to improve their standard of living through adequate housing, there was a noticeable difference in the tone of the interview:

"I've just got into an accessible house. So, it is absolutely amazing because it's what I wanted after a number of years. Yeah, it's great. It's everything I've wanted so I'm really happy." (Interview #9)

"I'm a lot more happy in this one than I have been in my previous flat. It's a lot warmer than my last one and the landlord's a lot more open to fixing our problems than previous landlords." (Interview #40)

For those Interviewees who were living in adequate housing, they commonly put this down to 'luck'. While luck refers to success brought by chance rather than through the Interviewees own actions, a more considered interpretation of this finding is that the Interviewees who did have support networks seemed to be more likely to find adequate housing than those who did not.

“M: How easy was it to find this place? I: Through sheer luck at the time. Very easy in that I knew the owner.” (Interview #18)

“M: Do you think housing options are limited for disabled people? [...] I: Completely limited. Financially, there is a massive barrier, in particular, to home ownership. Home ownership for somebody with a disability - a severe disability - unless they have family who are loaded with dosh, so to speak, is impossible, almost impossible.” (Interview #18)

“M: How easy did you find it to find a suitable place? I: I had to start looking about last year this time last year because I have such issues with my support dog. But, and I couldn't find anything for ages. And I started freaking out and then I just found it by luck basically. Yeah. One of the um real-estate agents saw me and asked me if I'd sorted a place for last year or for next year, and then she just said hey I've got this place, they might not take dogs, but we'll see what happens. And they did, so...” (Interview #12)

“And the only way I found the place was through word-of-mouth with friends. Because when I contacted Housing New Zealand they said to forget about it [...]” (Interview #15)

“M: What are the advantages where you stay [in a family owned home]?”

I: That unlike most rental accommodations, I have security of tenure. It would be, and I have income-related rent. I couldn't even possibly without income live in the private rental market and I couldn't even possibly, all those questions you asked before about being safe? I'd be so unsafe as a woman with a disability trying to live in private rental circumstances and perpetually, potentially having to move because of, you know, moving is not exactly great for the back.” (Interview #15)

“M: And how easy was it to find this place? I: Easy. M: Easy yeah? I: Because it was my parent's.” (Interview #19)

“The bonus of the situation we're in now where my grandparents own the house is if there's an issue or I need something in a better way, we're actually in a position that we can fix or modify it ourselves. My grandfather will help with that. [Name removed] will help with it but it's mostly funded by myself. The house is in my grandparent's name, but we just take care of it and do all the maintenance ourselves.” (Interview #16)

“So, the property managers um, or the property owners, are a friend of my cousin, and I had been looking for a property for six months, um, and this became available. So, I grabbed the chance, cause before that I was living in my mother's two bedroom attached unit with her with two kids.” (Interview #42)

“My, thanks to a friend of mine, he knows a guy and I met the guy and he took us through the house. M: Oh, I see, you’ve got good networks. I: Yep.” (Interview #52)

“I’ve got stability, I know I can be here as long as I like. I will be given the opportunity to, for the very first time, be able to paint the walls and stuff. I’ve never been able to, ever, do any, thing, like that.” (Interview #43)

“M: So how easy was it to find this place? I: It was pretty easy online. My brother lives around the corner on [street name removed] and he just googled in [place name removed] and places to live and the [place name removed] came up and we looked into it and we found it on the weekend and got me in on the next Monday.” (Interview #57)

As highlighted by one Interviewee, their ability to find adequate housing relied on knowledge and power - those who did not have personal support networks or who were not experienced in self-advocacy were at a bigger disadvantage:

“There’s a lot of prejudice out there anyway and they’re just suitable for other people. You know? They only select who gonna go in to these homes. But that just like anything else. You know? It’s all down to who gonna go, who’s got a big mouth. And the only way they shut them up is get them what they want. But if they’re little mice, well you end up going out the back door. M: So, the louder you are the more you get? I: Yeah. And you have to! You have to be spoken these days! [...] Knowledge, person with more knowledge can go further. Cause you know knowledge is power. And people without that power or without that knowledge, well those ones will get abused and left behind. [...]” (Interview #1)

#### **11.2.4 Access - What are the key issues?**

Within this theme, access was linked to access to rental properties and the housing market, access in and around the home, and access to information and justice. Interviewees noted that their lack of access was often caused by discriminatory attitudes and insufficient funding. The time taken for landlords to respond to maintenance requests, together with refusals to allow home modifications, were problematic, and some Interviewees felt restricted in their ability to make a complaint - either out of fear of retribution, or simply because they did not have the energy or capacity to pursue their legal rights.

#### **11.2.5 What articles do they relate to?**

Article 4 – General obligations

Article 5 – Equality and non-discrimination

Article 8 – Awareness-raising

Article 9 – Accessibility



Article 14 – Liberty and security of person

Article 17 – Protecting the integrity of the person

Article 19 – Living independently and being included in the community

Article 28 – Adequate standard of living and social protection

### **11.2.6 Who should be concerned?**

- Housing New Zealand
- Work and Income New Zealand
- ACC
- Landlords
- Real Estate Agents
- Tenancy Tribunal
- Insurance companies
- Ministry of Business, Innovation and Employment

## **11.3 Belonging**

The next collection of findings has been collated under the theme of ‘belonging’ and includes homeliness, rhythms and routines, and community connection. Within the context of housing, these subthemes all impacted on Interviewees’ sense of belonging both within the home and their surrounding community. The UNCRPD is clear on the position of disabled people in society: we belong. For example, point 13 of the UNCRPD Preamble recognises “the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty” (United Nations, 2006).

Not only do disabled people belong, but our belonging is directly linked to the wellbeing of society at large.

### **11.3.1 Homeliness**

The first key theme that was investigated was homeliness, which looked at how a home is created, including where and how it is set up, and whether home is an environment where Interviewees felt comfortable, relaxed, and enjoyed spending their time. It is interesting to note that even though most Interviewees felt their living situation was inadequate, home was where they spent most of their time due to the nature of their impairment, and/or the inaccessibility of their community:

“Well I keep myself occupied with some arts and crafts. Yeah and lots of things that I like. Most of the time because I’m 90 percent housebound so I do a lot of things from my bed, you know?” (Interview #2)



“I have no choice but to spend time at home because of the situation I am in.”  
(Interview #18)

“Yeah I spend a lot of time at home because of my anxiety. I find it very difficult to leave the house.” (Interview #40)

“I love spending time at home because that’s about the only thing I can do.”  
(Interview #2)

“I Love it. Because I’ve adapted. That’s what we do when society gives us a disability. And so I’ve managed to live and work in my home.” (Interview #29)

“I’m comfortable because I initially stay, mainly stay at home. Because if I go out, I end up having really bad spasms in my legs. So, I mainly stay at home. [...] If I go to the mall, I might fall down, and it’s really difficult for me to go anywhere. So, I stay behind and... just comfortable at home.” (Interview #21)

A key aspect of homeliness is being able to invite people onto a property, as well as keeping unwelcome visitors out. The latter point was not reported as an issue, and many Interviewees felt they could invite their friends and family over to visit. However, for a small selection of Interviewees their living circumstances meant they felt uncomfortable inviting friends and family around:

“I do have people over to mine occasionally but it’s not always like the first place I’d suggest just because it’s like not that friendly to have lots of people over. It’s not like a place like where we can like hang out and chill. I mean it’s also like out of the way from where everyone else is.” (Interview #46)

“M: So, do you have family or friends come and see you when you’re in these camps [sites]? I: No, I always have to go to them.” (Interview #45)

“M: Do you invite friends and/or family to your home? I: No. No. I did have a meeting here two weeks ago, very first time, in any of my houses, and I cleared this table off, and hid it all in the bedroom, and had a meeting, and then got the shakes, for no other reason than I was overawed at the emotion of actually having people.” (Interview #43)

“So I guess in some ways, like, I feel embarrassed, I don’t know how else to say that. I feel embarrassed about my circumstances. Yeah. I do. M: So, do you invite your friends and/or family to your home? I: No. No.” (Interview #15)

“[A]ll my friends they’re getting married, they’re having babies [...] But they’re living on their own and have great careers and here I am in a rest home at 30. So, I’m a bit embarrassed to be in this situation.” (Interview #15)

A further point raised by several Interviewees was that the inaccessibility of their home meant they could not invite their peers from the disability community around to their house, even though Outcome Three of the New Zealand Disability Strategy highlights that “[a]ccess to

high quality peer support enables us to recover from periods of being unwell, and flourish with the confidence that we are not alone” (Office for Disability Issues, 2016b, p. 28):

“I: And they [friends] can’t get into my house. This is another reason why people don’t come anymore because they can’t get up the steps. Well it is ‘cause they have a disability as well. Right? M: What’s the impact on you then? You wanna see those people and you have to meet elsewhere? I: I do. I have to meet them elsewhere. Yes. And that isn’t always conducive for them because they’re stuck at home and they can’t get out which is quite depressing for some people. I miss having the company in my house. I don’t like living alone. I don’t! I can live alone. I’m quite comfortable. But I would like to be in the situation where I could have a shared tenancy. We’re not allowed to do that. Housing New Zealand won’t allow it.” (Interview #44)

“I’d like to have... more people over, um but I don’t really have a very accessible house for some of my friends to actually get into. So, I don’t have any handrails throughout the property at all. Um... Certainly don’t have wheelchair access into my home, um and physically there’s not enough room for having family over for meals and things like that. So, I’d like to do that more.” (Interview #42)

And for some Interviewees, the size of their home was a barrier to hosting people:

“Yep, Yep, I have my friends over sometimes. But um, not often because it is small compared to their houses. So, it’s just better going to their house ‘cause there’s more space to, like, breathe and stuff.” (Interview #12)

“M: Do you often have friends or family to your house? I: Not really no. If family is coming over, the communication is always a problem. And then it’s an issue of space. If I have to have them over, it’s more of a grin and bear it type of thing. They just can’t speak my language [NZSL]. So, I do sometimes withdraw a bit. I don’t really want people visiting me all the time in my space, only very close friends I would want there.” (Interview #48)

“M: And are there some things that you can’t do at your home, but you would like to? I: Entertain. M: Entertain? And so, is that again an issue of not having enough space? I: Yeah.” (Interview #19)

When asked about what their home said about them, most Interviewees answered honestly - busy, messy, lazy, and so on. The idea behind this question was to understand how disabled people create spaces that feel like their own, especially when renting. Although many landlords do not allow tenants to hang items on the walls, alter the house, or have animals or children residing on the property, surprisingly, this was not raised as a major issue during the interviews. Even though many Interviewees reported living in inadequate situations, they did what they could to make the environment as comfortable as possible, and home was generally where they felt most comfortable and safe:

“M: So, from the garage to here, you mentioned it’s an upgrade. So perhaps, can you go back to being in the garage and just give us a little bit on that as well? I: Sure, it was like we had a garage and Mum kind of made it as much as home as possible, so it had like a little lounge area with the TV and no running water. We had to go inside and use the taps or fill up water bottles. We had power so that was good. We had the TV going and managed to get the wi-fi out there. But yeah it was just a garage with power pretty much and some cooking equipment to cook with. It was all good. M: So was it lined? I: Yeah, it was lined. Mum kind of made this wall in front of the doors, where the roller doors were and she made kind of just a makeshift wall so make it feel more like a room and block the draft so she got some pieces of ply and put them up so yeah, it was kind of like a home, it had a really homely feel.” (Interview #57)

“M: Are you able to put up things of your choice like family photos or artwork or? I: I do, yeah, I do. We’re not, they say that they don’t want us... there is something somewhere that says about putting things on the walls. But no. I’ve got pictures.” (Interview #44)

“M: What makes your home, homely? I: The people in it. And the memories that we make in it. And the animals being there, though we’ve always been bought up, and it’s my Nan’s Māori influence: a house is just mortar and bricks until you’re in it. And sometimes I curse her because it’s cold and I don’t want to make her cold but that’s our philosophy. But we have what’s called a hui table and we bring people for dinner and we get people to share stories and laughter. So that’s what makes it a home. And that’s what makes it hard to leave. Because even though our outside community is not strong, our inside community is strong. People know they can come through our back door and have a cup of tea and that’s what makes a home.” (Interview #29)

### **11.3.2 Rhythms and Routines**

Crafts, cooking, cleaning, video games, internet, gardening, listening to the radio, reading, and studying were all activities Interviewees enjoyed doing at home. However, many Interviewees noted that even though they liked participating in these activities, the inadequacy of their living circumstances impacted on how often they could do them. The most common activities that Interviewees liked to do, but could not do to a satisfactory level, was cooking independently and safely and/or tending to a garden. These basic tasks relate directly to living independently, as outlined in Articles 19 and 26 of the UNCRPD:

“The kitchen is not accessible at all, shelves are all too high for me to reach or too low to reach. Sink is not accessible, so I can’t really contribute when it comes to washing dishes which I used to love doing. I love cooking, but I can’t cook at home because the stove is not accessible to the wall. I can’t use the kitchen bench to cut, so if I was to cook, I do it in a dangerous way where I

have a large extension cord leading from the kitchen to the kitchen table and an electric pan just on the table and I use it that way to cook.” (Interview #6)

“But yeah I would love to be able to cook what I wanna cook and have friends over and to fit in my room. Yeah.” (Interview #28)

“And also, because we’ve never been able to modify our kitchen. So, the kitchen is really not set up for somebody in a wheelchair at all. In fact, I normally have a standing wheelchair and haven’t had it since November but because I had the standing wheelchair, it means that most of my kitchen is only accessible when standing. So, it’s very difficult when you are not in a standing wheelchair.” (Interview #58)

“Gardening, I just don’t have the strength and ability with my impairment so really reliant on others to help me with my pot plants. I don’t have a garden, but I’d love to have a vege garden. I’d love to be able to turn the dirt and do that.” (Interview #61)

“Yeah. I’d like to be able to do more gardening. And I would love a wheelchair friendly kitchen, but it’s not.” (Interview #24).

And for one Interviewee, the inaccessibility of the home had disrupted family rhythms and routines to such a degree that he could not physically access the bedrooms of his young sons:

“I’d like to be able to use the bathroom upstairs. Obviously, I’d like to be able to see the boys in their bedroom. I think that’s the big one really is like you’ve got kids. You want to tuck them into bed at night. You want to read them a story in their bed and all those things. Those are the big ones there. I want to be able to see my kids in their bedroom and I want to be able to use the toilet upstairs. I’d like to do a whole bunch of things. I’d like to be able to reach and reach the sink. I’d like to be able to access the stove. There’s things that after a while you sort of just write it off as not possible.” (Interview #41)

In this case it could be argued that the inaccessibility of the housing market, and thus the Interviewee’s home, directly impacted on his right under Article 23 of the UNCRPD Respect for Home and Family, which holds that “States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities” (United Nations, 2006).

### **11.3.3 Community Connection**

Outcome Three of the New Zealand Disability Strategy highlights the importance of community connection for disabled Kiwis:

The importance of belonging to and participating in our community to reduce social isolation, and increase our overall wellbeing, is recognised and supported. We get involved in sport, recreation and arts activities, and are

recognised and valued for this. Those of us who identify as members of other communities do not face barriers participating in and contributing to cultural activities because of our impairments. We are supported to be healthy and well, and can participate in community activities on an equal basis with others (Office for Disability Issues, 2016b, p. 28).

When Monitors asked Interviewees about the advantages of living where they did, the most common responses were location and ease of access to the community. This included health centres, food stores, public transport, schools and workplaces, and reflects Article 19 of the UNCRPD, which states that access to services and supports prevents isolation or segregation from the community. As summarised by one Interviewee, “Advantages... oh well community connectedness. And I really like the area as well. It’s a lovely area. I really like it here. I feel like I sort of suit the community that I live amongst. That’s important for me. Belonging” (Interview #48). However, when Interviewee’s were not able to easily access their local community independently, they were conscious of needing to rely on the availability of others:

“M: Okay so how connected do you feel to your neighbourhood? I: What neighbourhood [laughs]? The cows and the sheep and the pigs? [...] I guess just like in [place name removed] I had a carer and we would go out on a Thursday. We’d have coffee. We’d go to the mall and we’d have coffee. We would do all our shopping and then we’d go and do my grocery shopping and then we’d go home. That was an all-day thing. I really miss that. M: So again, that’s something that is really important. You have to live here because this is the opportunity that’s offered to you? I: Yeah. M: To live with a [family member] who loves and cares for you, but you’re quite a long way out of town and do some shopping and have coffee is very difficult. I: It’s got to be organised, yeah. [...] The thing as well as that is the fact that I have a van but I can’t drive that van which means that I’ve still got to rely on somebody to drive the van for me whereas it would be nice if I could have a van of my own to drive.”  
(Interview #51)

Relationships with neighbours was also an important aspect of community connection. Of the Interviewees who identified as living in social housing, the close proximity of neighbours who were also living in social housing was a point of contention. For some Interviewees this provided a sense of security and community, while others felt this imposed on their sense of security and wellbeing (relating to UNCRPD Articles 14, 16, and 17):

“In the unit, I’m on my own, but there are six units there that belong to Housing New Zealand Corporation and one of them holds a meth-addicted person who is violent, who presents a number of behavioural issues and his next-door neighbour is a psych-affected. Now they’re not a problem to me but there’s no support from that and I feel very unsafe from this Housing New Zealand tenant and the people he brings there because I’m not able bodied to defend myself if there’s an incident. And in the early stages, the psych-affected tenant wasn’t

well looked after so he actually threatened me with a gun and he, yeah, I had a fence built to keep my aunty safe when I was getting her in and out. And the one next door attacked another boarder with a machete. So that's what I live with!" (Interview #15)<sup>2</sup>

"We have trespassing neighbours which on the Housing New Zealand side they trespass to get fruit and to cut through our property to get to the back property quicker. We had to install cameras because Housing New Zealand didn't believe us. We tend to send them quite a lot of video evidence and footage of these people coming onto the back of our property. They've stopped trespassing from the front, but they still come onto the back to steal fruit and what not. M: So, does that make you feel like a little bit unsafe? I: A little bit. If we complain to Housing New Zealand we get verbally abused. We have had our cat stolen which had the Police involved. We have had gravel which the Police didn't know where it would have come from thrown at our ranch slider door which kind of nearly smashed it the amount they threw. They had to be quite close and on the property to reach that ranch slider at that height." (Interview #16)

"A lot of the Housing New Zealand apartments are people who would be turned down for housing anywhere else. M: So not your ideal neighbours? I: A lot of stealing, a lot of drugs, that sort of thing. Just to be surrounded by that, I don't like being around it. Quite a few campsites that I go to, they smoke marijuana and I don't even like being around that. To be permanently living in that sort of situation, you go downhill psychologically, and they seem to think that it's more important that you have a roof over your head than what you are psychologically. They don't care about the psychological support or detriment of where they put a roof over your head." (Interview #45)

"Oh yeah, just for example, not last weekend but the weekend before that, two weeks ago on a Saturday night, me and my little brother around 1:00 were in my room playing games and all of a sudden we started hearing gunshots just from down the road so and that's something you've never heard before like obviously we had a dead body murder down my street five years ago but that didn't really scare us. Yeah! So, safety wise, it's still pretty secure because we've got the dogs but if you're going out late in the community for a walk or going to the shops or something, not that we do it, it's just you don't know what's going to happen, like anything can happen like when you go to the dairy now." (Interview #6)

Community connection also extended to online communities, with several Interviewees noting this as important to their sense of belonging. As previously mentioned, many Interviewees spent a significant time at home so utilising the internet to connect to the outside world was important for preventing isolation and loneliness (UNCRPD Article 19).

<sup>2</sup> "Pysch-affected" is not a term supported by the authors or sponsors of this monitoring research.



“I do realise my social world is extremely small. And if it wasn’t for social media, it would be even smaller.” (Interview #17)

“Well I’d have to say, I found Facebook really fantastic. It allows you to learn who your neighbours are and chat with them so that’s been really good. Having Facebook groups, because we didn’t know each other so we set that up and that’s been really fantastic support. You know you walk past each other, and you don’t know who they are, then you can have a look on Facebook and connect with them, so that’s been really great to have that. It’s really kept us all in touch. But you can’t have an interpreter for everything so it’s really lovely to have that. But I will say, but if you fall out with someone, that can be quite awkward. Then if you meet someone outside of the Facebook group and they don’t realise you’re Deaf, then communication can be a bit difficult. [...] M: What do you think would improve your connectedness with [place name removed]? I: That’s hard, I guess I feel like the main barrier is Deaf Club is a bit far for me to go, it’s a bit of a haul so technology as it changes is always helping, I mean technology is amazing isn’t it? So yeah, I think technology is what is improving it mostly. To have high speed internet to make sure we have those connections, all of those things have just been a huge boon to us.” (Interview #48)

“Because I’ve managed to get the internet on and... because I wouldn’t survive without my computer. As many of us don’t, today, how did we survive before we had them?” (Interview #22)

“I’ve chosen to pay for my own internet because I have a smart TV which means I can go onto the internet. I’m a night owl.” (Interview #51)

However, online communication was also hindered by the financial cost of Wi-Fi, relating to Article 28 of the UNCRPD which recognises “the right of persons with disabilities to an adequate standard of living for themselves and their families” (United Nations, 2006):

“M: Are there other things that we haven’t talked about that impact on your ability to have adequate housing? I: So, from Work and Income I get \$480 [...] then take away my rent. I get left with \$90 and I tell you what. It’s crazy. That’s all I can say. [...] I don’t do anything with my life. I just sit at home, that’s all. M: Because that’s kind of barely enough to pay for, like, food? I: And my internet so I can have a life. That’s about it.” (Interview #11)

“M: ‘Cause just to reiterate in this section that you mentioned before that you don’t tend to use the heater because it’s too expensive eh? I: Yeah. M: And how about um internet and electricity? I: Well internet, I need that for my talking to my son. Cause he can’t talk, and he uses an app on his computer that he talks through the computer. So, I need that but I use things as little as I can. M: Because of the cost? I: Yeah.” (Interview #23)



### **11.3.4 Belonging - What are the key issues?**

The findings of this chapter include subthemes such as homeliness, rhythms and routines, and community connection. Home was where many Interviewees spent the majority of their time. Even though Interviewees suggested that home was where they felt most comfortable and safe, when Interviewees provided further details about home life it became clear that they were often living in places that they would prefer not to be. Interviewees enjoyed participating in standard activities at home, but were limited by accessibility, space and independence when it came to basic routines such as cooking, gardening and childcare. Community connection - both physical and digital - were important to Interviewees. However, accessibility and income were restrictive. A final aspect of belonging was neighbours. Many Interviewees had very little choice over where they lived and were often placed in close proximity to people in challenging circumstances. For some, this provided a sense of community connection and belonging. For others, this contributed to feelings of insecurity and isolation.

### **11.3.5 What articles do they relate to?**

UNCRPD Preamble

Article 9 – Accessibility

Article 15 – Freedom from torture or cruel, inhuman or degrading treatment or punishment

Article 16 – Freedom from exploitation, violence and abuse

Article 19 – Living independently and being included in the community

Article 26 – Habilitation and rehabilitation

Article 28 – Adequate standard of living and social protection

### **11.3.6 Who should be concerned?**

- Social housing providers
- Housing New Zealand
- Work and Income New Zealand
- ACC
- Landlords

## 11.4 Safety

The next key theme of the findings is safety and includes both physical and psychological safety. Under Article 3 of the Universal Declaration of Human Rights (UDHR), all people have the right to life, liberty and security of person. The UNCRPD builds upon the UDHR in Article 14 by reiterating that disabled people are also entitled to liberty and security of person. Throughout the monitoring interviews, it was revealed that security and safety are inherently linked to adequate housing. For example, physical safety was linked to access, modifications, temperature and maintenance. Psychological safety correlated with physical safety, location, access, choice and control. While many of these issues have been identified in previous findings, outlined below are a collection of experiences that stood out when examining the physical and psychological security of Interviewees.

### 11.4.1 Physical Safety

Of the 61 interviews, 13 Interviewees said their homes were cold, and over half of the Interviewees (33) reported hazards within and around their home. Interviewees were quick to link the cold to the cost of power, which reflected their income. Compromised physical and mental health were reported as by-products of living in cold homes, relating to Articles 25 (Health) and 17 (Integrity).

“No, I’m really not happy. This house is like an icebox. Yeah it is so cold. I’ve actually had to move my bed to the lounge and this is where I’m going to be sleeping for the rest of winter and probably spring as well. That side of the house when you walk there you can just feel instantly it’s just so cold. [...] It’s really actually depressing living here. It’s affected my mood because it’s really dark as well. When we came to see the place, I knew it would be a little bit dark, so they cut some trees down. They said it would be really light. They cut the trees down but it’s still I’ve got to turn on lights throughout the house so it’s affecting my power bill. I have to turn on the bathroom light, turn on the passage light all the time. It’s just really dark down that way.” (Interview #11)

“But because of the payments for, because of the power payments are so high, I just don’t turn it [the heater] on at all.” (Interview #23)

“M: Is your home warm? I: Largely there are – I, and partly through choice, my main source of heating is a wood burner and so it’s very dependent on whether or not I can afford wood.” (Interview #18)

“It was over a hundred years old, the house, and there was no insulation, and we couldn’t afford to use the heat pump. ‘Cause one month we did use it as we liked, and we couldn’t afford the power bill. So, we stopped using it. And then last year it was because of my flat mates they didn’t agree with increasing the power bill over winter even though I though you know, quality of life is a bit more important.” (Interview #12)

“I pay more than my income-related rent because the house is cold and damp and not properly insulated. M: Isn’t there new legislation about that? I: Yep. So, Housing New Zealand were one year late putting insulation. They were meant to have insulation in the properties by June of 2016. They didn’t put it in my mine until June of 2017 and then they used the old insulation which is not up to code and, actually, it’s made the problem worse. And then in December of 2017 I had a rat infestation thanks to my neighbours and now that insulation is contaminated and a year-and-a-half of trying, I haven’t managed to get them to remove it and re-insulate it. So, in looking at my costs and speaking with the electrician the other day, in the time I have lived there, I have paid \$21,000 more than a normal bill. So, \$1000 each year, more than a \$1000 each year of my energy costs because I’m an asthmatic with pulmonary disease.” (Interview #15)

“We only heat this area in the winter and the front part of the house we don’t heat. It’s just too expensive.” (Interview #33)

“So, I go without food every winter, I go without food to pay my electricity costs.” (Interview #15)

As a result of cold and damp dwellings, some interviewees also reported having issues with mould:

“There seems to be some mould issue as well in the back part in my bedroom. I didn’t realise it until two weeks ago. There was all this mould on the ceiling. I contacted the landlord and they sent the house the guy that does just the odds and ends in this house. The agent sent him just to clean the ceiling, so I wasn’t too sure if they should have sent somebody else to do a more professional job. But they just sent him just to wipe the mould down. With having chronic fatigue mould is one of the worst things to be around. It actually exacerbates the situation. So that’s why I’ve moved my bed [into the lounge] as well.” (Interview #11)

“The damp is definitely a hazard. The damp and mould is a hazard. I sugar soap every year. It was not free of the hazard of the maintained wheelchair ramp which is where I fell. [...] I feel like the house will kill me because of my pulmonary issues. I actually feel the water in my lungs through winter. I just, I know that sounds extreme, but I feel Housing New Zealand have killed tenants before through that mould and damp issue. Mould and damp is, it’s extremely dangerous, it’s toxic. I’ve got toxic red mould in the hall cupboard at the moment. If I didn’t sugar soap my property every year, you would see mould and you can see mould in the bathroom. I do believe because my lungs are weak that ultimately that will be what takes me out and it’s because Housing New Zealand don’t meet their obligations to insulate or yeah.” (Interview #15)

“I: I call the mould a hazard to me. [...] The ceiling on the conservatory, that conservatory is actually not done with the Council approval. So that conservatory had mould on the ceiling so badly. I approached the agent to ask the landlord to do it. He refused. M: Okay so I can see black mould out there now. It hasn’t been removed properly. I: Yeah. He told me I must go ahead and do it. I had to pay, and I had to save up to pay to have it done. Which was wrong you know? And because I thought I’m going to get sick if I don’t have it done. And he politely sent the agent a request to say I’m welcome: “I am more than happy for her to go ahead and do it.” M: If you pay for it. I: Yeah. And I had to pay someone to come and do it. And it’s not cheap you know?” (Interview #11)

In addition to the cold, damp, and mould, as evidenced by the extensive quotes below, many Interviewees reported hazards around the home that they felt were a risk to their health and safety. Hazards included entrance and exits of buildings; indoor and outdoor steps and stairs; inaccessible kitchens and cupboards; slippery and problematic bathroom layouts; and also, infestations of bugs and rats:

“I: Steps, every entrance has got steps and for me that’s a hazard. M: Have you fallen down the steps? I: All the steps have collapsed underneath me, and I’ve got injured shoulders from it. More than once. They went, the front steps went through when my mum was coming up. So, it’s a few years ago. The floors are not safe. They’re vinyl and they’re custom wood. They’ve got no finish on the custom wood so the way the house was built the nails are coming up through the floor. So, there’s holes where the custom wood is disintegrating. We can’t really wash the floors because it’s eating away at the you know? There’s the front door water comes in under the front door. Water comes in under the laundry door. When you close the ranch slider you can actually see that it doesn’t fit. M: So, I probably should have asked this before - who is the house owner? I: Housing New Zealand. [...] It’s just that when we moved in I was more mobile than I am now, but I’ve challenged Housing New Zealand about it. It took eight years to get it, took them twelve years to get the steps redone. It took eight years to get the bathroom floor redone because it collapsed and the rot you could see it in the bedroom next door. So, we’ve actually not been able to use the third bedroom. The floor was just absolutely rotten, and it was pink! Cause it goes pink and then on the inside it was black mould!” (Interview #44)

“Free of hazards... I think the only one that I have got at the moment with my house is I’ve got a shub bath and I’ve got to climb into it and climb out when I have a shower. I’ve had some nasty falls.” (Interview #20)

“I mean we would like to have no steps in our house, and we’ve got one step just here by you know going down into the conservatory. But I know it’s there,

so I have to make sure I hold on to the side of the door before I go down the step. So probably the steps are the major issue. So, I've got rails on my other steps and I just have to hold on to the door on that step. And we did look around some years ago to find a house that might not have steps. And you can find them, but they're newer houses and they're so expensive and we can't afford it." (Interview #13)

"I have some steps out the front and then some steps by the deck. I have to be careful because I have fallen down steps before and crutches are not an easy thing to use when you have no depth perception." (Interview #16)

"My bathroom's a hazard. I have to reverse and go in backwards to the toilet. So but it's the only way that I can get in and out of that bathroom because it's a lovely bathroom but it's not, not designed for a wheelchair user and nor is the general bathroom which doesn't have a bath it has a big shower." (Interview #39)

"I have a, um... they've put carpet on the floor and I am very thankful. You know, lots of Housing New Zealand houses don't have carpet on the floor. But I have a, my house is full with bugs. The kitchen full with cockroaches. I've put in bug bait and things, but you know. I... I fight to get in to my microwave with the cockroaches cause they're everywhere!" (Interview #23)

"Yep, the garage, it had a rat. We couldn't get rid of this one rat. We tried all these different ways to get rid of it. It was a big one too and some nights we'd see it and then it would scatter off again, but we couldn't catch it." (Interview #57)

"M: Can I ask, have you ever fallen down the stairs or tripped? I: Yes, yes. Many times. [...] M: Have you ever fallen in the bathroom? Because the rails and things aren't secure? I: Yes, I have. I have. My hips, I need new hips. I need new knees. And me falling in the bath is not gonna be good for my health to do that too often." (Interview #23)

"At the moment, it's not really good because the house is really small. And it's hard to get in and out of the front door." (Interview #21)

"There are areas, aspects of the property – I'm talking about the outside that aren't in a good shape. The stairs for example, my outside stairs are a hazard." (Interview #18)

"[...] I'm just struggling with the in and out of the house." (Interview #21)

"The bathroom floor, I do fall sometimes in the bathroom, they could actually have something, when the floor is wet, they could actually sort of have some kind of thing. [...] It's just the bathroom is lino and lino sort of... it's not exactly, they don't make houses for people with disabilities." (Interview #49)

“Yeah, but the, for cooking is hard because I’m not stable enough at the moment. Because I can easily burn myself as well.” (Interview #21)

“I: It’s probably like, the bench heights, yeah, and like the access to the sink and all that. M: So that would be unsafe because? I: Can’t make you really reach into it because you kinda gotta like lean forward out of my chair. I: So, you could fall? I: Yeah!” (Interview #60)

“No there’s no steps inside the house but I can’t get in the bathroom. [...] The OT [occupational therapist] was out here this morning bringing a piece of equipment to help me have a shower. That’s not going to happen because it’s not going to work. She told me that if that piece of equipment was to work, it could be temporary. I said to her, “How long is temporary?” She said, “five to 10 years.” I don’t class that as temporary. After all these months which would be at least three or four months when we first got hold of them, she hasn’t even put an application in for funding. The OT. [...] I haven’t had a shower for at least two months and no I’m not smelly.” (Interview #51)

And while most Interviewees indicated their homes were big enough for the number of people that lived there, a few were affected by overcrowding:

“Yes, imagine like a double space garage and we made that into a room with a kitchen and lounge area. And it was enough room. We just made it to be enough room. Just two beds set up and we had a place for all the clothes and we had the TV set up for the lounge and there was enough room. Just! Three people would be too many people. My little brother stayed out there with us as well, but he stayed in the shed. He didn’t stay in the garage with me and mum. He had his own room in a shed and that was his own little set up.” (Interview #57)

“M: Is your home big enough for the number of people that live here? If you don’t feel it is big enough, please explain. I: Um, no, ‘cause I have to share my room with my six year old son, but that’s a choice that I make, so I have a boarder as a form of income, yep.” (Interview #42)

“M: How many people live in your house? I: So, you’ve got Mum, Dad, - that’s two - little brother - three - plus my other little brother - that’s four - plus my other brother - five - his wife’s, six, plus the new born baby. And I’m eight plus the two dogs.” (Interview #6)

For an Interviewee who had purchased her home under a new build house scheme, she had only been able to retrofit the bathroom, and entrance/exits of her house for accessibility: “I’m only hazard free because I paid for it” (Interview #2). The Interviewee highlighted that even though the house was new, parts of it were still inaccessible and unsafe, including the plug sockets which were low to the ground and out of reach, and the parking area at the back of her property:

“Because what they did have for me out there to get in was little squares of concrete with stones all in between. And of course, I stand on that I’m just gone, you know. And there’s another thing. When I did shift that, and I had to pay for all that, which like I say, I understood that I was going to have to pay for it. But it’s just not fair. I just think, “Come on.” And out the back here still the concrete where how I’ve had to change so I can actually come into the house safely, but the concrete they have laid is all like this and very unsteady. It’s all you know. And I said were they able to fix that? No.” (Interview #2)

One of the primary reasons that hazards were problematic for Interviewees, particularly within rental properties, seemed to be the lack of responsiveness by landlords when it came to maintaining the properties and ensuring they were safe and secure for tenants. Even though this is an issue throughout Aotearoa New Zealand, it appeared to be particularly problematic for disabled Interviewees:

“It depended what it was, and it did vary. Some [landlords] were quite good. Others made it seem like it was an inconvenience and made it seem like they were doing you a favour even though it was a basic thing that you were paying for and they really did make it seem like they were doing you a favour in getting it fixed.” (Interview #31)

“There are some areas of the house that need attended to pretty urgently but as I said my landlord’s pretty hopeless at getting things done. Like it took me a year of badgering him before he put insulation in the roof for an example.” (Interview #18)

“Our landlords have greatly disabled me. My primary disability when I moved in, I was able-bodied, and I had to be to look after a high-needs disabled, elderly aunt. I had some back issues which we just called in lay terms a ‘nurse’s back.’ But I’ve had multiple injuries at the property due to my landlord’s lack of maintenance and I have required ten orthopaedic surgeries as a consequence and I am now permanently and significantly disabled because of them. So, I have to say I carry a level of resentment towards them.” (Interview #15)

“I would ring up [name removed] on my housing coordinator and I would tell them that this is on the blink and it’s nearly falling to bits. And I knew that he had lots of things on his plate. He had, um, and I would patiently wait. But nine times out of ten you either have to make do or improvise. You know?” (Interview #23)

“Well, there’s a lot of things broken inside the house. A lot of things. But they already tell the owner. But the owner never reply back. Like the company, they never reply back.” (Interview #7)



I: So, yep, I've had a lot of things break down in the house. No, I did not try to fix it myself because if I did try to do that, Housing [New Zealand] would then send the bill to me and say, "You take it, you pay for the whole thing yourself." So obviously I know it's a simple thing, easier to fix, I would do it, but then Housing would end up kind of screwing me over like they usually do. M: And potentially you could risk getting booted? I: Yeah, I could potentially get kicked out of the house. I don't wanna do that. So, I've, of course, we ring them up, we tell them what's the problem, we do the whole - we do it on over the phone and all that stuff and then they say no, someone will be there – they'll say we'll take care of you. Ah, no, about a month later they get back in touch with you. You say these are the dates, two months later when the next technician can get out to you to fix that stuff, unless it's a real emergency and all, you know that, they're sending someone within the next week or two weeks. That's only a proper emergency call. So, it's annoying like they are so fast to hit you up when - in why didn't you pay your rent? Like one day, they're straight on you. And then they come straight away and say, "Oh, we'll fix this in two months." I still have stuff in my house that is five years still not been fixed. Like they come, they have their housing assessments and all this stuff saying we're going to replace that, we're going to fix this and we're going to do that, they say all that but then the only thing that gets done is the carpet. M: So basically, the power relationship is a bit out of whack? I: Yes, a bit out of whack. And they're so quick to claim money off you. But they don't fix the housing, like, the house that we're staying in is like it's not exactly five star, it's not even properly insulated. I can put my hands through the wall and there's no, none of that purple insulating Pink Batts." (Interview #6)

"But the issues that I have with my landlords about maintenance, I don't feel comfortable, I don't feel safe, but it is about their lack of responsibility as landlords too, you know what I mean? And the lengthy battles I have to have to get anything done." (Interview #15)

"I'm still waiting for stuff to be done in this house. Well, my cooker for a fact. I mean one of the rings on my cooker, you put a plate on it. You turn it on, put a plate on it and the ring falls off. You know, like it goes in to a bracket, the ring. It goes into a socket. It falls out that socket and the ring stops working. So, I can only use three of the rings that are on my cooker. And I've been here there mm, three and a half years and it's not been fixed yet." (Interview #32)

"You've certainly got to push Housing New Zealand to get things done. They're not great landlords really." (Interview #49)

Emergencies, situations of risk, and evacuation were also concerns for Interviewees. These safety concerns are referred to in Article 11 of the UNCRPD, which articulates the responsibility of the Government of New Zealand to ensure the protection and safety of

disabled people in situations of risk, including situations of armed conflict, humanitarian emergencies and natural disasters. However, multiple Interviewees were fearful that their housing situation increased their vulnerability during emergencies, situations of risk, and during evacuations:

“I: So, I’m not, I don’t worry around safety except maybe when they do their fire drills and this I don’t actually understand how it works, but this building has some sort of exemption where they do not have to consider how they get us out of the building in a fire drill. It’s not their responsibility it’s supposed to be for me to work out. [...] So it means I get left here and we’ve had like fire alarm. It wasn’t a big deal ‘cause it was somebody like burned some fat or something and opened the front door and didn’t know that you don’t do that. So, I’ve had a fire drill, two fire drills and a genuine fire alarm where each time I have sat in my apartment and not a single person has come here.” (Interview #39)

“M: Do you feel at home, relaxed and comfortable? I: Ah, yeah, mostly. We’ve had the house next door to us across our driveway fall, which made me very aware that I’ve only got one form of exit. So, and just aware, one of my friends who is with ACC has two ways to get out of her house in case of an emergency. So, when the kids recently had the fire department come and visit their school and said everybody in the house has to have two ways to get out in case of an emergency, I became very aware that I have one way to get out. So that does play on my mind. M: So, playing on your mind means that you’ll do something about it, or you don’t know what to do about it? I: We can’t really afford to do anything about it. It would mean having to build another ramp out the front. Which is just a cost that we can’t afford. [...] I feel like everyone should have two ways to getting out of their house. [Incident details removed]. So, everybody was evacuated apart from me because I had no way to get out. So, I had me and one fireman, stay. And also, I was acutely aware that I’m really vulnerable and that everybody should have two ways to get out of the house.” (Interview #58)

Several Interviewees with hearing impairments also referred to the extra vigilance they needed to take when planning for emergencies while at home:

“The other thing I was thinking of is, with the reverse parking, there is a risk, if there is a fire, because of how you have to get out, it’s 10kms away to get to town. 10kms. And there is a lot of bush there so there is a possibility of fire. [...] So yeah, we try to be really vigilant and we have a plan for what to do if there was a fire, if it was to happen but so far, we haven’t been affected by that. But we’re all very vigilant about it. [...] And of course we get a lot of tsunami warnings and flash flooding where we are and being Deaf, that can be a bit negative because... you know we’re lucky, it’s low risk but we had to

pay \$220 to civil defence because there wasn't enough free. So, we had to buy something, when there was a tsunami warning there would be a generator to provide us with power. Because that can be a real problem because if you don't have power, it's really tricky. If you have to pack things up to move off, so we bought that kind of thing so that's cost us money. You know sleeping bags, pillows. So, we have, like, a disaster kit ready for us, that's cost us money. So, I guess that's a bit of a negative. We haven't had to use them, we haven't had our alarm system go off for that, but you know, it's just a risk because of the area and it's a worry when you're Deaf to not be able to hear those kinds of things." (Interview #47)

"Think of the fights you have to have to get a [flashing] fire alarm installed. To have the security that you need. Those things are number one. [...] People think oh you're Deaf, and they don't realise that I know what I need." (Interview #47)

"Yeah, so I called them [hall of residence] up beforehand and they installed a fire alarm thing next to my bed. So, it has a buzzer that goes in my mattress, so it shakes my bed and then it also has, like, the sound is right next to me. It also flashes as well. And luckily the sound that this building's fire alarm plays is the best tone is the one tone that I hear so well. 'Cause at home it was like this super high pitched one that I couldn't hear, my hearing aids wouldn't register it. Without my hearing aids I still couldn't hear it. I would just see a flashing light and everyone getting up. But here, it's the perfect sound. And then I have the whole buzzer and flashing light in my room." (Interview #30)

### **11.4.2 Psychological Safety**

Relationships with neighbours was a key finding outlined in the last section on belonging. However, it is worth reiterating the issues some Interviewees had with challenging neighbours and both the effect it had on their sense of belonging, as well as their physical and psychological safety. For example, one Interviewee with a vision impairment noted the behaviour of her neighbours had impacted on her sense of security, ability to sleep, and had even become a barrier to applying for a service dog:

"On our bedroom is that side of the fence so our curtains don't get – our top curtain gets opened but our curtains directly facing the other property don't get opened because the adults harass us when they're drinking, and the children just harass us in general. And throw rubbish over the fence and stuff. M: So, you basically don't feel very safe? I: No, not very. Not outside. Inside, yes. Outside, not so much. M: Okay. And you don't feel like they are listening? The actual organisations [Housing New Zealand/Police] are listening? I: No. We told them [the neighbours] that our dog had a problem and they needed to stop feeding our dog and because they encouraged our dog to keep digging

under the fence by putting scraps under there because we told them off for throwing over the property – it increased the problem that was with our dog had. So, our dog actually ended up having to be put down because he was very very sick and we told them not to feed him. That’s another reason why even though I’ve been told I can possibly have a guide dog I wouldn’t on my property because of the neighbours. [...] M: Is your home a private space to go inside when you feel threatened? I: Yes, I just hang inside if I’m having too much trouble from the neighbours and I don’t want to hear them. I kind of have to go into the lounge because it’s the furthest point from there because there’s three properties along our fence line. One is at the front, one is at the back because it’s on this side. It’s the back ones that are closest to end bedrooms and the backyard which we have the most problem with.” (Interview #16)

A recurring theme throughout the interviews was also the anxiety and depression Interviewees said they experienced either as a result of their living situation, or because negative housing experiences amplified pre-existing anxiety and depression.

“M: Is your home a place where you feel comfortable and relaxed? I: No, I don’t. It’s really caused my anxiety in a lot of really quite I must be honest. I really am quite, it’s caused me a lot of anxiety. It really has. I’m trying not to. I’m not a person who likes to show my anxiety. I kind of suppress it you know. But this has really caused me a lot of anxiety.” (Interview #11)

“I just think in terms of a university experience mainly, there should be, like... um a more holistic approach when you wanna get out of a lease because you don’t like your flatmates. I know so many people that have gone to [mental health facility name removed] because they can’t get out of their lease and they’re forced to live with people that hate them. And I just think that’s cruel. And if you can’t afford to pay two lots of rent you’re not going to get out of your lease and move.” (Interview #12)

“Do I need to be happy? Um, mentally not. Would appreciate living in an insulated room that has walls thick enough that I don’t have to be so anxious about who’s living next door whether I will be able to sleep. Yeah. So, peace of mind not good.” (Interview #14)

“M: Do you just feel that sometimes it’s a bit too much? I: I’ve just got nothing to look forward to. There’s nothing ahead. I can’t cope with the injustice of what’s happening to me, right now at times. Let alone in the future when I’m going to be forced to face it.” (Interview #45)

“Looking at housing, um... we, we, looked at safety, but I’m wondering, um, my, my, my unsafe stuff is... um, yeah worry, worry about when I’m on my own.” (Interview #43)

A further cause of anxiety was the lack of security and consistency around lease agreements. Many Interviewees indicated that they were fearful their living situation would change, whether by eviction or by not having their tenancy renewed:

“M: Are you afraid that your current housing situation will change? I: Yeah, I am. It’s and that is a sheer fear of not being in control like with, I know that my landlord could decide that he wants to have somebody else in there, so he can charge them a hell of a lot more rent. There’s constant fear. And, for some reason, he’s decided that you can’t have a long-term tenancy agreement that you have to do it year-by-year. Like the fact that I can’t have a long-term tenancy agreement just constantly puts me on edge and I never know from one year to the next whether or not I’m still going to still have my home.”  
(Interview #18)

“But Housing New Zealand do sell and remove houses so although there’s a greater security of tenure with them than a private landlord would, it’s not like I own it, it’s not like I can definitely say it’s my home for life, you know. So, it’s a low-level anxiety that that might change at some stage in the future.”  
(Interview #15)

“M: What makes this home less than ideal for you? I: I don’t own it. So anytime, Housing New Zealand could tell me that I have to move. [...] Well it’s about children in my care, it’s about my income, and it’s about government decisions whether Housing New Zealand will own their homes or whether they’ll look at service providers and hapu and iwi to be responsible for social housing.” (Interview #61)

“Yeah I’m worried that it’s gonna change. I’m worrying that the rent’s gonna go up more. That’s my big worry.” (Interview #20)

“Yes, I am concerned about the fact that I could be asked to move. It will be a huge burden for me to move because I have a lot of stuff.” (Interview #44)

Other issues with landlords were cause for concern, suggesting a power imbalance between landlords/agents and their disabled tenants:

“But my landlord used to just show up at my house and I was like, excuse me, you can’t just arrive at my house. [...] Yes but I found that quite strange. What was he doing there? And it can make you feel quite anxious as well when someone just shows up at your house. And I said, in New Zealand we have rules around this. You know you can’t just come here. But it’s quite awkward to tell off your landlord. It makes you feel a bit on the back foot. So, I don’t like when landlords do that kind of thing. So, if they do that, I’ll tell them once, don’t do it again, otherwise I’ll make a complaint and consider moving away. Because I read in the newspaper, that landlords aren’t allowed to just show up at your home. And sometimes they’ll come, and they’ll set up cameras and

you don't know about it which is creepy. They have keys to your house and they can just get in. And I don't feel like that's fair enough. I certainly don't want that happening to me. I certainly don't want them setting up a camera in my shower. I don't want them arriving when I'm in the shower. I think for Deaf people, that's very uncomfortable and landlords aren't allowed to do that, and I hope that they all know that, and they don't forget about that. And that they know, how long it is, and which hours are ok for them to come and visit.” (Interview #47)

“Well last year we were never asked if we wanted to renew our tenancy in our old place, they just told us they were showing new people through without asking us if we wanted to stay in the flat or not. This year the landlord we had already had a conversation previously that we wanted to do some work in the garden and he said we could do that if we stayed on. So, he knew we wanted to stay on so there wasn't any issue getting it renewed. M: How did it make you feel in the previous place when they just did that without consulting with you first? I: Quite shocked. Just to have the landlord show up with people to come through our house was quite off putting and quite shocking and we were very uncomfortable with it.” (Interview #40)

For one interviewee, the intense and unlawful behaviour of a former landlord had led to significant distress:

“There was a lot of abuse and the landlady she took over. She basically just took over. It was as if she was living in the house with me. That's why I was desperate to move and just grabbed this house you know? She knew I was unwell, and she took full advantage of it. She would come and ask who is visiting and their names. She didn't want my family to visit. She basically took over my life when I'm unwell. At certain points I crash, and I get really burnt out and spend, like, weeks in bed. She was constantly, “What can I do for you?” You know, it just became too much. She was in my house breaking rules. You know, just coming in any time and just moving things around in my house. Eventually my son had to tell her she's doing things wrong. When he told her she just got mad and started doing some really horrible things. [...] Absolute year of hell. I ended up in respite because of her. [...] I was so unwell from her behaviour that I unfortunately made an attempt on my life. She really pushed me to such a bad place that I couldn't cope. I couldn't find another place to move to. Everywhere was just shut in my face, every door. Work and Income couldn't put me in a place. You know, there was no prioritising because I wasn't, like, I wasn't homeless. So, they wouldn't take into account that I had these illnesses and I needed to be helped, you know? So, I just felt like there was no end in sight. So sadly, I just thought that was it. So, I ended up in hospital and then I went into respite care afterwards. I just grabbed whatever you know.” (Interview #11)



Once out of hospital, the Interviewee continued to face ongoing issues with subsequent landlords:

“M: So, in terms of like being turned away from places, were you talking about what you needed in terms of your disability? Did you feel like there was discrimination on that front? I: Oh yeah, yeah, I did. They didn’t put anything, any effort into saying, “Okay you’ve got this that’s going on for you.” I had one situation where a woman actually said, “Oh, I can see what you’re going through. I’ll get you this house.” I went through everything, even the paperwork with WINZ. The day I’m supposed to be moved, this is in [area name removed]. The day I’m supposed to be moving my family came and put all the furniture in the truck and everything and I’m phoning this lady and phoning her. She’s not answering the phone. It turned out she never bought the house. M: So, somebody like pretending to be a landlord? I: Yeah. She took advantage of my situation and the fact that I was unwell. So, it turned out she never bought the house. I found out from a family friend of hers and so I had to put everything into storage and go live with the family member who really didn’t have enough space to keep me in their home.” (Interview #11)

Interviewee #11 also revealed to the Monitors that she had stayed in an abusive relationship simply because she could not find an accessible house to safely move to:

“M: So, are you kind of happy being in a small townish type of area? I: Yeah, I’m happy because I came out of quite an abusive marriage and just on the last end of getting divorced so I also don’t want my husband to know where I was living. [...] When I first left my husband two years ago and I really struggled to find a place because each time places that I found would have steps or would be difficult to manoeuvre around. At some point I had to share with the landlord, “Look I’m not well. Would it be okay for if maybe we did this or did that?” Very flexible things you know. The landlord would look at me as if I’d just fallen out of the sky. It was definitely just like this huge stigma. I was in a situation which was quite a dangerous situation to be in with my husband. I was living in one room, locking doors at night and things like that. I needed to get out and finding a place was becoming so difficult, really difficult. [...] M: Do you feel like because you knew it would be hard to find a place that you ended up living with your husband for longer? I: Oh yes. Yes, that’s so true, very very true. And you know what? He knew it that I couldn’t find a place. Then he started to take advantage of it. That I couldn’t find a place. He would even say it and mock me about it you know?” (Interview #11)



### **11.4.3 Safety - What are the key issues?**

Interviewees shared a vast array of housing experiences that had left them feeling physically and psychologically unsafe. Cold and mould were reported as being significant concerns, with Interviewees associating this to the affordability of warm and dry homes. Hazards in and around the home were also a concern for Interviewees, and many had experienced injuries and a deterioration of their physical and mental health as a result. In some circumstances this was the result of a lack of funding for safety modifications, and at other times it appeared to be a result of landlords avoiding their legal responsibilities to their tenants. Other recurring safety concerns included the ability to safely and/or independently evacuate or leave a property during an emergency, feeling unsafe due to the neighbourhoods Interviewees lived in, and the psychological impact of real and perceived power imbalances between tenants and landlords.

### **11.4.4 What articles do they relate to?**

UNCRPD Preamble

Article 11 – Situations of risk and humanitarian emergencies

Article 14 – Liberty and security of person

Article 17 – Protecting the integrity of the person

Article 25 – Health

Article 28 – Adequate standard of living and social protection

### **11.4.5 Who should be concerned?**

- ACC
- Housing New Zealand
- Landlords/Agents
- Ministry of Housing and Urban Development
- Emergency Services
- Disability Service Providers
- Mental Health Services
- District Health Board

## 11.5 Awareness of Rights

The fifth and final group of findings relates to Interviewees' awareness of their rights under the UNCRPD, particularly in relation to housing. In order to investigate awareness, Monitors began by asking Interviewees if they had heard of the UNCRPD and Universal Design. Even though this research project is dedicated to monitoring the progressive realisation of the UNCRPD, of the Interviewees who answered these questions 29 Interviewees had not heard of the UNCRPD and 33 did not know what Universal Design was. Furthermore, only eight Interviewees were members of a registered DPO. These numbers suggest that many Interviewees had very little, or no, awareness of their rights within the context of international human rights law (IHRL). This finding calls into question the progressive realisation of Article 8 of the UNCRPD and the Government of New Zealand's obligation to generate awareness about disability rights and the UNCRPD itself. Monitors then read aloud two relevant UNCRPD articles and asked the Interviewees to reflect on what the articles meant to them personally. Following this, Interviewees were asked whether they believed the Government of New Zealand is ensuring disabled people are not discriminated against when accessing adequate housing, and what needs to change for the Government of New Zealand to progressively realise the UNCRPD in Aotearoa New Zealand.

### 11.5.1 Article 19 – Living independently and being included in the community

Interviewees were first asked to reflect on Article 19, which states that all disabled people have an equal right to live in the community with choices equal to others. Interviewee reflections were strongly focused on choice and control, safety, and not being discriminated against on the basis of disability:

“That everyone [laughs], that everyone should be able to like be able to stay close to where they want. Yeah. No one should be discriminated due to, like, a disability, physically, mentally, socially.” (Interview #46)

“First thing that pops into my head is that is not the case.” (Interview #12)

“Ah it means that... um... our disability should um, never prevent us from... ah should never create any boundaries for us in where we choose to live.” (Interview #4)

“It's like before when I said that we should be able to live in different areas. An area that we actually want to live in and that when I go down to the local shop I have the same right as you. I'd be able to get in to the shop ok.” (Interview #9)

“I think it means that everyone should be treated equally in terms of housing. They should be able to feel safe and secure in their housing as well as have adequate housing and basically be able to have a home and pick where they might be able to live.” (Interview #5)

“Well to me personally it means that every disabled person has a right to choose where they want to live not where their parents want them to live. And we know people that are living in places they haven’t chosen themselves to live. They’ve been chosen by other people to live there. And they have the capability to choose for themselves.” (Interview #13)

“That if you manage to get a place, that it should be warm and secure and leak-proof and... that’s about it really. Yeah.” (Interview #17)

“It means that people with disabilities can choose where they live and with whom they want to live.” (Interview #25)

“It means that disabled people should have housing. All disabled people should have housing and that they have housing of their choice. They shouldn’t have eighty percent of the housing market knocked out of their options because the house isn’t accessible.” (Interview #31)

“That we should be treated the same as our sighted peers or other people with disabilities.” (Interview #35)

“It would mean Māori, Pākehā, Hearing, Deaf, Disabled, whatever sexual identity, we can all mix. Adults, children and everyone could have choices that suited them. And have the lifestyle that they want. It would be fair, it would be open, if you wanted to live in a Marae, a home, social housing, whatever. You have choices and people cannot discriminate against you based on your sexual identity. Whether or not you’re a lesbian or gay, they can’t do that because of who you are. Whether you’re Deaf, disabled, blind or you use a wheelchair, it doesn’t matter. Whatever is your lifestyle, that’s fine and you can live it. But the UN doesn’t mean that a landlord has to at this stage. Housing is just open market.” (Interview #47)

“It means Deaf people have voices. We have choices.” (Interview #48)

“That New Zealand is failing. [...] Yes disabled people, elderly people, mainly across the board but because I live mainly in a disabled community, that’s where I get my robust conversations from. The honest ones. That’s what I would say. I’ve never sat down with a whole lot of able-bodied people and asked them how they’re feeling about their choices, might be the same.” (Interview #29)

“I really hold on to Article 19 because if I didn’t know that, I think I would have been intimidated by Housing New Zealand. I think people would have intimidated me. I wouldn’t have known what law or what pieces of mandated stuff I could use to give me some mana and strength to ask for what I needed. Because when it comes to Housing New Zealand you’ve got to be armed with the knowledge. Otherwise they just push you over.” (Interview #61)

### 11.5.2 Article 28 – Adequate standard of living and social protection

The second Article that Interviewees were asked to think about in relation to housing was Article 28, which holds that the Government of New Zealand must recognise the right of disabled people to an adequate standard of living. Interviewees reflected on subjects such as Universal Design, access, safety, warmth, and choice and control:

“We should get the proper housing and proper living, you know that would be suited and accommodate us in the proper way, the right way.” (Interview #11)

“That it’s the same standard as an able-bodied. You know you have the same facilities, the same conditions, yeah.” (Interview #9)

“An adequate standard: safety, basic things like heat and affordability, also bringing into things like power, the basic utilities - the cost is incredibly prohibitive.” (Interview #18)

“People with disabilities should be able to have access to any required assistance that they would need and again be able to have a house that feels like a home instead of just a place that you can survive.” (Interview #5)

“To me, that just sounds like being like everyone else, wanting to have your own home and to live as you please. Yeah, like in a comfortable house and surrounded in a comfortable kind of community as well and not kind of isolate you off in a Housing [New Zealand] home, I don’t want to say it, but I don’t want to be in a Housing [New Zealand] home filled with other people with disability.” (Interview #6)

“Say like to me, like they’re building all these new houses but why only two percent of them has to be accessible? Like, are they saying that someone who is able has more to contribute than someone who is disabled? I do as much or more than someone who is abled and out there in the community.” (Interview #6)

“Adequate means that it’s warm, dry and that people can get in to that there is enough stock in the housing market that people can with a reasonable search, find what they’re looking for.” (Interview #25)

“To be happy and healthy where you are and not to feel the need to move on in order to have your basic needs met.” (Interview #25)

“Safe, secure, warm, affordable [...] And choice too actually.” (Interview #24)

“I don’t know what that means but it should mean that all people have warm houses. They should be able to get into that house safely and what not. If you’ve got a problem with either where you are or anything in the vicinity around you that is causing a problem, you should have the right to speak up about it and have someone actually listen and help try to sort it out.” (Interview #16)

“Okay so if that was law, then the New Zealand government would go to jail.”  
(Interview #51)

Even though many Interviewees had not heard of Universal Design or the UNCRPD, after reflecting on Articles 19 and 28 they demonstrated a clear understanding of the treatment they believe they are entitled to. Having established key housing-related rights, Interviewees were then asked if the Government of New Zealand is making sure disabled people are not discriminated against in the housing market. The consensus was a resounding: “No. Quite firmly no” (Interview #31):

“I’d say it means they’ve got a fair bit of work to do. Yeah to make me feel like I used to feel, like just an ordinary Joe Blogs, I don’t want to feel anything special. But just to feel normal, they’ve got a long way to go.” (Interview #2)

“I would say that they are taking steps towards it but the fact that Universal Design is not carried out across all housing and that a lot of properties are still would require changes to be made for them to be accessible. Mm. Saying that it’s still not quite adequate enough.” (Interview #4)

“I think they could work harder. I think they could actually talk to disabled people and spend more time listening to them to find out exactly what we want and what we need.” (Interview #9)

“I don’t think they’re doing enough. I’m unsure as to what is happening behind the scenes currently, but there has been no talk of making, of specifically targeting or addressing the needs of those with disabilities within the policy makers and yeah.” (Interview #18)

“I think the Government’s doing a terrible job of inclusion. [...] With regards to housing, I mean it’s one thing I haven’t mentioned is the Government’s pet project of KiwiBuild and how they’re wanting to build all these hundred thousand houses. But yet, are twenty percent of them going to be accessible? Oh, no they’re not! I think in this development just round the corner, of the two hundred houses that they’ve built, I think five. Hooh! Five! Have ramps or wide doorways or wet area showers. You know, that’s disgusting! That’s discrimination 101! If you know that you’ve, I mean it’s not just currently disabled people, it’s the elderly as well. We’re going in to a where baby boomers are now retiring, wanting to down size, having hip replacements etc., etc. Becoming less mobile and we’ve got a hundred thousand houses and none of them are planned to be accessible! I mean stupid! Stupid! Stupid! Government! Terrible policy.” (Interview #26)

“I: Not as yet. Because we just get pushed on the side. [...] From a disabled point of view, getting pushed on the side and not actually getting what we need to get when we have to try our best and get all upset to go and find someone to take us to do the job that we can’t do.” (Interview #20)

“I: No, they’re not! M: Ok, in the housing/accommodation market? I: No, in anything! I don’t care which government, ‘cause the National Party was as bad before the Labour party came in. [...] I mean I’ve been trying to see what policies they’ve helped to bring forward for disabled people, and they haven’t even brought policies forward for ordinary people. All they seem to have done so far is start committees and they’re all looking at stuff and there’s hundreds and hundreds of committees they’ve started. And they only things they’ve tried to start they’ve flopped. Extra housing, KiwiBuild. What a load of rubbish that is! I mean supposed to be affordable housing for people to... and the ones I was seeing, well I looked on the internet a while ago. The ones I was seeing, they were like five and six and seven hundred thousand dollars! You can’t offer that to a disabled person. There’s no way on earth they could afford that.” (Interview #32)

“Yeah, it’s a bit tricky because they’re one thing they say yes! Vote for me and I will save you save all you people. Oh, we’ll give you all these houses and design you everything. And we give you all this money for all you people. Yes vote. They forget I will remember each one of yous. Come to the day, “Oh who are you? What are you doing here?”” (Interview #1)

“Yeah... nah. They like to pretend they are but there are some cases where it’s not.” (Interview #16)

“I think we are fortunate at the moment to have a government at the moment that has good intentions. I think that they just don’t know the things that they need to do. Because until you’re disabled you really don’t get it.” (Interview #39)

“Um, I feel that... yeah I feel that when it comes to actual physical disability, that there has been a step back, not a step forward. Unfortunately. And I don’t think they actually realise.” (Interview #43)

“I think they [Government of New Zealand] have actually given housing, especially Housing New Zealand, all the power so they just do what they want.” (Interview #51)

“I would say Universal Design has been forgotten from physical to warmth to function to community. So, on the spectrum of any individual on the planet should expect to receive, I think that disabled people, particularly in this country and in the city are the last people that are thought of. And so, heating, what the Government is saying to do for rentals, I think is a start but every person should have that healthy home, happy home, a place that they can call home. So that’s why we say, a difference from a house. There’s plenty of housing out there but when they talk about social housing or this and that housing, they don’t think about an individual that wants a home. It should be a human right.” (Interview #29)

“No, I don’t think they’re doing enough.” (Interview #58)

Finally, Interviewees were asked what they think needs to change in order for the UNCRPD to have an impact on their housing situation. A selection of Interviewee suggestions are outlined below:

- Acknowledge the impact of the housing crisis on disabled people:

“It would take many people looking at... looking at problems and not just shuffle them around, actually doing something to help with the problems. You may not fix the problem, but at least if you’re acknowledging it, acknowledging that there is something there.” (Interview #23)

- Increase the awareness of disability through education, consultation, advocacy and face-to-face engagement:

“I believe that the Government should get in there with some disabled people and live the life of them, as you know. Understand what they go through. Wants and needs and what we’re doing here is half the job, is half the job.” (Interview #23)

“A stronger awareness of different types of disability and how they affect different people and how they can be assisted.” (Interview #4)

“The people behind the systems need to be more informed about what it is that the people kind of need. Then they need to do something to kind of make their systems work better because sometimes I just felt like I was getting kind of ignored or swept under the rug with certain things.” (Interview #16)

“I really believe that there has to be a better connection between people who have health issues, physical issues, their landlord, Housing New Zealand whoever it happens to be, to make sure that those properties and that there is a connection that people are listening and actually looking at the situation with an open mind because too often they’re like this.” (Interview #44)

“Capacity and capability definitely needs to be amongst, not just for disabled people to find their voices and government to come on board, we need to roll out Enabling Good Lives in other regions but we also need society to be ready. We talk in terms, about being visitor ready or guest ready. We need to be disability ready. Builders to be ready to come in and do the Universal Design and to be on their radar so five years is a big ask but I think that within my life time, if we could all get together and go look forward and be future thinking it could happen, but I don’t believe that we have... all political we have some good young politicians who have this on their radar if we support them to find our voices and take them to parliament and let the workforce, I said builders, but mean workforce of painters and roaders and councils and all these workers that they need to get the city to be accessible again.” (Interview #29)



- Improve domestic laws and ensure stronger enforcement:

“And I think they definitely need to follow through with everything [policies] and make sure people are listening and taking on board. You know, sometimes I think they say they put something forward, but people underneath don’t follow those rules and regulations to the T. [...] I think they need to get on to Work and Income and change their rules and regulations towards people with disabilities.” (Interview #9)

“Yeah I think definitely having new laws passed making people’s living conditions a lot better. I know that there’s a renting law coming out soon about having insulation. I think that could really change the game in renting. I think just more housing availability and more good housing availability as well. They need to be putting money into that sort of thing. [...] There needs to be almost more person to person contact as well. I think a lot of it goes through companies and that’s fine if you’re going from company to company. But really if you’re working with people and their lives, you really need to be having more personal touch to it.” (Interview #5)

“So, I think, one of the main things that the Government can do is again putting in the things like they’ve done with the insulation. Making sure that rentals are healthy. It’s not just for disabled people, that’s for everyone and also that they can the biggest impact they can make is with social housing. So yeah, the biggest impact is on social housing and the statistics around housing is disabled people are one of the highest groups that access social housing. So, it should be one of their focuses to make them accessible and future proof as well. Again, it’s not just good for disabled people it’s actually good for everyone.” (Interview #31)

“So, I think it would be very important that a lot of laws around stuff becomes available in a lot of different ways as opposed to just pen and paper and that there are more laws put in place with landlords to ensure that people with extreme anxiety conditions and things like that are able to come to approach them with things that they need and get help.” (Interview #40)

- Update the Building Code, to include private property:

“I just think there is a real need for the building act to be amended and updated.” (Interview #61)

“I think we need to have accessibility in the building code for private houses. [...] Every new build to be made accessible. So, to raise the housing stock. Particularly in Housing New Zealand. [...] As well as intentional social housing less restrictions on Enable Funding because I’m not eligible for Enable Funding to get accessibility.” (Interview #19)

- Incentivise the implementation of Universal Design standards:
 

“There needs to be incentive for developers to develop homes that are wheelchair that are accessible in a variety of ways.” (Interview #25)

“Incentive for landlords to maybe, say if I was looking for somewhere long term, and you were a landlord. You had a nice house and it suited me, might have even been a cottage. There’s no help as I understand it for you to make that place vaguely, well not vaguely, accessible for me.” (Interview #24)
- Employ disabled people in relevant housing positions:
 

“But we need to have people you know with those expertise in deciding jobs. Like in government jobs. I don’t know, I suppose in Housing New Zealand. They should have some disabled people in decision making jobs, you know in senior management that have got architectural building qualifications behind them and so that they understand the needs of disabled people. Cause to my way of thinking a house that is suitable for a disabled person is suitable for anybody.” (Interview #13)
- Increase resources for disabled people when accessing adequate housing:
 

“Improving access to interpreters, more funding for them, more technology, putting more subsidies access to interpreters, those kinds of things would be really nice. There are some models in Europe that are really great that would help with access to housing.” (Interview #48)
- Draw on, and promote, examples of best practice:
 

“Well in the capacity building we need to have enough kaitiaki or guardians to support people to find their voice. I think it will be really easy. There’s a whole lot of talk about it, mines a physical so I can find my own voice but it’s still hard for me. What if there are people out there who don’t even know what housing looks like for them? How will they find their voice and that’s often when the Government end up looking at that 10 – 20 percent struggling or for Māori, the 13% that needs the most help. No one ever says there’s 87% doing really well. It would be nice sometimes to pick the ones doing well to start modelling good housing and what good housing could look like to support those who are really struggling.” (Interview #29)

### **11.5.3 Awareness - What are the key issues?**

This final key finding investigated Interviewee awareness when it came to their rights under the UNCRPD, specifically in relation to housing. Although not all Interviewees knew about the UNCRPD or Universal Design, they demonstrated a good understanding of the kinds of rights they are entitled to as disabled people living in Aotearoa New Zealand. However, there was also a sense of distrust in the Government, and disbelief that they would ever fulfil these rights, with many Interviewees laughing and implying that the implementation

of Universal Design (Article 2), and Articles 19 and 28 of the UNCRPD in Aotearoa New Zealand is a “joke”. The chapter then touched on a small selection of suggestions for helping the Government of New Zealand progressively realise UNCRPD rights within the housing market.

#### **11.5.4 What articles do they relate to?**

Article 2 – Definitions

Article 8 – Awareness-raising

Article 9 – Accessibility

Article 19 – Living independently and being included in the community

Article 28 – Adequate standard of living and social protection

#### **11.5.5 Who should be concerned?**

- Ministry of Housing and Urban Development
- Ministry of Social Development
- Work and Income New Zealand
- Local Governments
- Central Government

## 12. Discussion

The findings generated from this monitoring research paint a bleak picture, with disabled people's experiences of housing in Aotearoa New Zealand leaving much to be desired. In previous chapters, Interviewee experiences regarding choice and control, access, belonging, safety, and awareness were presented - their responses spoke for themselves and needed little interpretation or analysis. The purpose of this chapter, however, is to take a step back and look at emerging themes that were not directly related to questions asked during the interviews and acknowledge Interviewee narratives in a wider context. The discussion begins by looking at the broader housing crisis in Aotearoa New Zealand and how this has affected the disability community. Inequality between funding models is linked to Interviewee housing experiences, before issues such as compromise, implementation, gratitude and dignity are considered. Finally, this chapter acknowledges that Interviewee housing experiences were not all negative or in breach of the UNCRPD, by presenting examples of positive experiences and best practice.

### 12.1 A National Housing Crisis

It is important to contextualise Interviewee experiences within the broader housing crisis of Aotearoa New Zealand. As highlighted by the Interviewees, their experiences often reflected those of the wider New Zealand population and other marginalised communities also struggling with the power imbalance between tenants and landlords, inadequacy of homes, and the unaffordability of the housing market:

“I think housing options are limited for everybody. To be fair, there isn't the housing stock in this country to make life easy for anybody, disabled or non-disabled, it makes no difference.” (Interview #32)

“But then the whole housing issue for this country is an issue. The whole thing, for everybody. So, the whole housing issue is an issue.” (Interview #24)

However, the UNCRPD clearly articulates that disabled people face greater barriers when participating as equal members of society and ongoing violations of their human rights (point 11, Preamble). As this research has revealed the playing field is not level, including within the climate of the current national housing crisis. This was summarised by one Interviewee when discussing Article 28: “This one means to me that at least be as poor as everybody else, and not poorer.” Given that the wellbeing of society as a whole relies on the wellbeing of the disability community (point 13, Preamble), specific measures that are necessary to accelerate or achieve de facto equality of disabled people should not be avoided or considered negatively discriminatory (Article 5.4) - even amidst a housing crisis. In fact, specific measures within the context of housing are an important aspect of progressively realising the UNCRPD, as well as the United Nations Sustainable Development Goals (SDGs) of which the taglines are “reach first those who are furthest behind”, and “leaving no one behind” (United Nations, 2016).

## 12.2 Funding Model Disparity

The next emerging theme was the disparity between funding models and the impact this had on Interviewee housing experiences. As noted in the '10.1 Choice and Control' and '10.4 Safety' findings chapters, housing experiences were associated with income, employment, welfare, and funding systems. This was noted by several Interviewees as being exemplified by the disparity between the ACC model of funding and MoH model of funding.

“Obviously there’s the discrepancy between those under Ministry of Health and those under ACC. People with you know spinal injuries where there was an accident or medical thing or whatever, then they’re just under totally different support packages I suppose. And it doesn’t really seem fair.”

(Interview #28)

“M: What other things impact on your ability to have adequate housing? I: So, probably there’s the income/funding thing which was you know, in the early days under Ministry of Health it was a big worry for me and my family.”

(Interview #28)

“I: I think different DHBs [District Health Boards] have different rules. I’ve heard of other people in other areas having better, not better luck, better support. M: And better access to modifications that they needed? I: Yes. [...] if I was an ACC client I would have no trouble. But I was born pre-ACC.”

(Interview #33)

“Modifications for disabled people, that’s a huge barrier. You can’t just modify and who pays for the modifications is a huge barrier too. Unless you get modifications through ACC funding, I mean who’s paying for it?” (Interview #15)

“I fractured my ankle about four years ago and last year I was starting to get the surgery through ACC and it was, the contrast between, like there was an infrastructure there for support for me to step into, whereas at the same time I was trying to get my health stuff sorted and WINZ stuff sorted because I had to do it all myself. And ACC, once you had it approved, they basically took care of things. [...] I had an ACC appointment at the hospital and then I had a non-ACC appointment and one of them was super easy. I just show up, get taxi, go straight there, it’s all sorted, no stress, and then the other one was such a hassle, and I had to worry and every little bit of it had to be managed. And there was no way to get there.” (Interview #50)

“[...] the advantages to living here is that it’s been fully modified to the standards of ACC which Ministry of Health people wouldn’t normally get. I mean if I moved into a house there’s no way that Ministry of Health would pay for a lift to be put in for instance, right? So, I’m still piggy backing off an alternative system, which provides [a] much better outcome.” (Interview #41)

“In five years’ time, yeah, I would definitely want my own house out in [place name removed], big back yard where I can do barbeques every weekend with the kids and all that and have my own garden. It would probably have like a four year or five-year-old son with a newborn, or wife who is currently expecting again with another one. I will get married there. [...] M: How do you think you would feel if that happens [...]? I: I’d feel like I’m on ACC. I’d be living the good life!” (Interview #6)

“I went to less than half of my normal income overnight when I turned 65, ACC to Super.” (Interview #39)

“I don’t know much about it, but I do know that the funding for modifications to houses to make them accessible isn’t great through the public health system. Mine’s been under ACC but working with the clients I work with at the [organisation name removed], getting bits changed to their houses, especially if it’s just for a short time is actually quite difficult. And it’s not as much funded as it could be and sometimes they have to choose between one thing or another.” (Interview #31)

“No, it isn’t fair in New Zealand. There’s a thing called ACC which is there for hundreds of thousands of you can have a new car. We’ll build an accessible mobility van, set it up for thousands of dollars. But for me who needs an electric seat to be able to get myself in a driving position da da da da, I have to pay for it. So, a huge discrepancy and not that I would ever not want somebody getting ACC if they deserve it – but there’s millions going there and it isn’t fair. It certainly isn’t a fair society.” (Interview #2)

“M: This time because this project is just housing, we might say next time do employment or that or healthcare. I: Here’s one for you, oh wait, I know you would perfect. The first one would be the whole gap between ACC and the Ministry of Health is changed I guess. Like that is totally unfair.” (Interview #6)

It is also important to note that the inequality caused by different funding bodies was also identified as a human rights violation in previous rounds of monitoring research (Article 33 Convention Coalition Monitoring Group, 2015), and was also highlighted during the UNCRPD Committee’s Concluding Observations on the Government of New Zealand’s report during their last examination:

59. The Committee is concerned that persons with disabilities have a lower socioeconomic status when compared with other New Zealanders. In particular, children with disabilities are overrepresented in statistics regarding child poverty and are more likely to be living in one-parent households. The support and income/pension provided to persons with disabilities is different based on the cause of disability, which results in an unjustified and unreasonable difference in their standard of living and social protection. 60. The Committee recommends that a review be undertaken of disability-related

costs to ensure sufficient allocation of compensation, in particular for children with disabilities, and their families (Committee on the Rights of Persons with Disabilities, 2014, p. 7).

This monitoring research has again revealed that the inequality generated by the different funding models is an ongoing and serious issue, exemplified by the impact that funding had on Interviewee's access to safe and adequate housing.

### 12.3 Forced compromise

The next theme woven throughout the monitoring interviews was the notion of compromise. For example, one participant reported that under the MoH funding model, they only had access to one housing modification in their lifetime. As a tenant they moved around, meaning they had to choose where to use this entitlement, and when to compromise their safety within the home by choosing not to have a rail installed. Other Interviewees referred to a fear of having one issue addressed but knowing that it meant they would probably have something else taken away from them: "I think everywhere else is pretty um hard to get a house these days. Um, I mean most of it is just the cost. Cost is building houses for our needs and that, eh. Really down to it, just like if you need something done, you gotta take something away. And that thing is what do you have to take away?" (Interview #1).

For example, one Interviewee suggested that help with the garden would be useful and meaningful. However, this meant that their inhouse care hours would be inevitably be reduced:

"I'm not sure how the NASC would feel about that but it would be lovely if the NASC would do that but I kind of, with the way the government budgets are at the moment, and deficit everywhere I think they'd tell me that I'd have to sacrifice some of the support I get in the house to have that." (Interview #61)

Compromise was also a key aspect of choice and control, particularly in relation to accessibility versus location. For example, Interviewees felt they were forced to choose between community connection and accessibility, or safety and affordability:

"I love the suburb but the house itself is not meeting my health needs."  
(Interview #29)

"So that's not ideal and I'd really like to live in a house where I can visit my children in their bedroom. But currently it's nigh on impossible to find somewhere else to move to and it's not just about finding an accessible house because if you have an accessible... I mean my wife and I both work. We've got day care arrangements. If we find an accessible house that's in [place name removed] for instance, that's no help to us because our work places aren't in [place name removed] and we don't live in [place name removed]. So, it's almost like it's a needle in a haystack. But then when you find the needle it might be so far away, it's not worth even thinking about." (Interview #41)



## 12.4 Moving forward

Compromise segues into the next theme, which was derived from Interviewee' responses about their expectations when it came to housing. Towards the end of the interview Monitors asked Interviewees what their dream living situation would look like five years into the future, if the Government of New Zealand was successfully implementing the UNCRPD in Aotearoa New Zealand. While this kind of 'golden question' might be expected to elicit answers relating to affluence, luxury, or even extravagance, Interviewee responses were much more humble:

"Possibly a home that's got access to the outside a little bit but not a huge garden or anything, yes." (Interview #17)

"I hope I'm still living in the same home that I'm in. I would like to by that stage have the opportunity to purchase my home, to be a homeowner and to look at making the alterations to my home to make it better function for me." (Interview #18)

"I think, um, my only thing I want and know I'll have in five years is a garden for my dog. I'm quite passionate about that! But um, other than that I'd accept that I'm not gonna own a house in my lifetime." (Interview #12)

"I think in five years if people with disabilities were able to have equal standards of living as everyone else I would be able to have a home where it's warm and again safe to live. I'd be flating with people who I don't feel unsafe around and I would be able to talk to my landlord if I didn't feel safe around them and they would legally have to do, or they would at least have to acknowledge not feeling safe." (Interview #5)

"We want a good landlord, not nasty that a person. Someone who treats us and respect us, and we can do it back to them as well and they need to do their jobs properly." (Interview #52)

"In five years' time, I would be working, and I would be feeling like I was part of helping others rather than needing help." (Interview #22)

"My dream – single woman can buy houses by themselves would be my dream. And with a big garden, that we are not discriminated against for not being in a couple. You don't need couples, that's discrimination. Single women are being discriminated against and that's not ok. Needs to have a fair system where individuals are considered for loans as well. It's the same, Māori struggle to have that access as well. They have those same difficulties. White people have a lot more privilege. So, come on everybody. They don't seek the advice they should to make sure that everybody is on an equal playing field. Māori people need to be brought up to the same standard as the rest of us. Treated the same way. I think I should be able to have my own house, my own way, doesn't matter that I'm Deaf or single, doesn't matter if you're hearing or in a couple." (Interview #47)

“It’s not really a specific location I would want to live in. I just know the type of house that I’d want to live in, which would pretty much just be an accessible home, open plan, as that’s more accessible with everything like at the same level as me and so I can easily just do things in my own home.” (Interview #60)

“I would really like to live in a house that had two ways to get out in case of emergency, because I do really think about it. Because I’ve been trapped in this house with a gas leak, it definitely plays on my mind. I feel really vulnerable. I’d like to live in a house that was modified more for somebody that was in a wheelchair. Where I didn’t have to battle with the bathroom door several times a day and do a four-point turn to get out of my bathroom.” (Interview #58)

Based on these responses - that is, the dream of having equitable access to the housing market, and homes that are safe, warm, dry, mould-free and accessible - questions remain: Are disabled people asking for too much? Should disabled people compromise on these dreams? Or are these dreams, in fact, basic entitlements and rights, that disabled people are missing out on because of the lack of progressive realisation of the UNCRPD in Aotearoa New Zealand?

## 12.5 Implementation of Rights

The next theme emphasised the difference between rights, laws and policies, and their practical implementation. As noted in Chapter 7 Methodology, the DRPI research methodology has three important components: monitoring the media, monitoring systems and monitoring personal experiences. While this particular research project only monitored personal experiences, a brief review of New Zealand’s housing laws and policies reveals that legally, all New Zealanders should have access to safe and adequate housing (see The Residential Tenancies Act 1986, Residential Tenancies (Healthy Homes Standards) Regulations 2019, Housing Improvement Regulations 1947, and so on.). As noted by several interviewees, however, even though disabled people have legal entitlements, the implementation of these laws is often where the problem lies:

“In my opinion, you can tell them [organisations/public service] what your rights are ‘til you’re blue in the face but getting them to actually respect and respond is another story.” (Interview #15)

“Again, it means a good intention [UNCRPD], but whether it’s enabled is another story. Not a lot. I mean yeah. In practice, not a lot, no.” (Interview #17)

“Basically I’m... it’s a great goal but that depends where you live and how it’s achieved. I think the people who make policies and funding type always looking for an easy route. They try and put a band aid on something until there’s a disaster.” (Interview #33)

“It might be a government requirement but out on the streets in the real world of out on the paddock on the grass roots, you’ve still got to fight for your right. It’s not known. It’s there but people don’t practice it. People don’t live by it so therefore we’re always constantly trying to push it. Unless you’re in the sector and you know it, it’s not common knowledge for people outside of the disability sector.” (Interview #61)

“What it [Article 19 UNCRPD] means and what actually has done are two totally different things. What it means is that I’m supposed to be treated like a fair person and treated equally and my needs are supposed to be met. But the actual truth of the matter is New Zealand ignores it.” (Interview #10)

“Well I think it’s a good thing to aspire to, but I don’t think we’re there yet. Because at the moment, for one it is incredibly expensive to try and live in a modified house and really hard to try and access in the community that other people can access.” (Interview #58)

“It’s a joke. There is no way I can get what other citizens get.” (Interview #45)

“It means it’s a great idea, but I wonder if it’ll ever happen.” (Interview #43)

“I still feel it’s just lip service.” (Interview #15)

As highlighted in the quotes above, Interviewees were doubtful and distrusting of the Government of New Zealand when it came to the progressive realisation of their rights. As the earlier chapters revealed, these feelings were not without cause. There was also the sense of fatigue - on top of living with disability, the constant need to fight for their rights was exhausting:

“Once again it goes back to your dignity. [...] And with abuse, because that’s, my PTSD’s from abuse, you get to the point where you’re fighting for everything. You fight for who you are as a person, you fight for who you are, and you get to that point that you don’t have any more fight in you. And so, you allow people just to... you know, that’s the way it is.” (Interview #22)

“You haven’t seen the three hours it takes to get ready. For me I’m someone that’s late a lot and I people just think that I’m late but that’s because there’s no ramp to get out of my house or I had to get the car differently when reversing. You’ve got to watch this, you’ve gotta step over that. You park in a park and you wait. Then all of sudden a disabled person has 50 things before they leave the house and another 50 things that an able bodied wouldn’t even have before they’ve even got to wherever they are to shine.” (Interview #29)

## 12.6 Gratitude

Another recurring theme was gratitude. As Interviewees shared stories about the discrimination they had faced when accessing adequate housing many were also quick to acknowledge that they were grateful for what they had, knowing it could be worse. For others, they were advised to be grateful by people in positions of power:

“Am I happy where I live? Um... I’m thankful for every opportunity that I can get. I know that there are a lot more people worse off than me that are staying in worse houses and living on the streets. And I’ve done it before and yeah.”  
(Interview #23)

“I have a, um... they’ve put carpet on the floor and I am very thankful.”  
(Interview #23)

“Yeah. And again, they said, why am I complaining, I should be thankful that I should be thankful that I’ve got something.” (Interview #17)

“M: Does it [income] cover heating? I: No and thankfully Work and Income give an extra \$20 for heating.” (Interview #11)

“I can choose to feel bitter and angry and feel sorry for myself, negative, or I can just choose to make do with what I’ve got. And I feel I’ve been left with pretty much nothing, the absolute dregs at the bottom of the barrel is what I feel I have to work with but still it’s not a choice to be negative and bitter and feel sorry for myself. You’ve got to make the most of what you’ve got.”  
(Interview #45)

Given that adequate housing is a right, the conscious or subconscious need to express gratitude for substandard living conditions is concerning and reflects aspects of the charity model of disability. Largely driven by the desire to help disabled people through emotive appeals of charity (Bhanushali, 2007), the charity model considers the experience of disability as a tragedy or misfortune that must be alleviated or erased by the generosity of non-disabled people (Clare, 2001). Although the charity model is primarily concerned with attitudes held by non-governmental organisations, these same attitudes can also be present within government welfare systems. As has been demonstrated throughout this monitoring research, such attitudes may be the underlying reason behind the belief that disabled people must be grateful for any support they receive, and that they should also refrain from complaining or rocking the boat (Hunt, 1988). Although welfare is indeed a crucial aspect of the progressive realisation of the UNCRPD, it is also important to acknowledge that welfare laws and policies can also play a significant role in developing, furthering, and reinforcing the power hierarchies to which disabled people are subjected (Mor, 2006).

## 12.7 Dignity

Issues relating to gratitude were also linked to dignity, which refers to the inherent nature of being human and being worthy or deserving of respect. Point 8 of the UNCRPD Preamble states that “discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person” (United Nations, 2006). The findings of this monitoring research have again provided many examples of where Interviewees felt their inherent dignity had been threatened:

“[...] they started treating me like [profanity removed] because I’m an individual and I don’t have children. Which is why I started getting angrier and angrier with the way things are. Because people are treating me as a lesser person than I already am. Whereas I’m not disabled enough, I’m not homeless enough. And now because I don’t have kids you don’t have the respect they’re treating me with at least some sort of dignity.” (Interview #10)

“You know, for me to even have to go to WINZ and ask for help is like... And it’s not the asking for help, it’s the going in there and being made to feel, I think its shame, it goes back to that whole shame thing.” (Interview #22)

“Also, there’s like this attitude, like, “Oh you’re Deaf and you’re buying a house?”, they treated me like I was a bit thick and that was quite shocking for me. And for my partner as well. There was that attitude out there, there was a lack of awareness. I felt quite uncomfortable. They treated me like I was a sick person.” (Interview #48)

“A lesser human being because I’ve got this mucked up 19th chromosome. You know, that person next door can walk in with nothing, no problem. You know, it’s yeah. Why are you made to feel so inadequate?” (Interview #2)

## 12.8 Best Practice

The final aspect of this chapter is best practice. Although this report has painted a bleak picture of how Interviewees experience housing in Aotearoa New Zealand, it is important to acknowledge that negative experiences were intentionally extrapolated from the data for the purpose of monitoring. Even though most Interviewees discussed experiences which were challenging at best, and human rights violations at worst, some Interviewees also provided examples of best practice. Outlined below are a small selection of positive Interviewee experiences:

“But I’ve found out that you can apply to the council [to put out the rubbish bins] and they will come and do it. So, I’m in the process of applying to the council.” (Interview #9)

“I just feel more comfortable. I know things will get done. You know they have a handy person that they can contact for different things. So, if I ring and,

say um, they've got a 24/7 helpline. So, if I say my toilet is blocked they'll get somebody out there." (Interview #9)

"But yeah the only things I do is give her board money every Wednesday so to learn how to flat with my friend [Name removed] one day. So, to learn that idea." (Interview #8)

"[I] got here, and the bed was literally like you couldn't sleep on it. Like the springs were poking out and stuff. And it was so old, and it stunk and it was awful. And I actually wrote in one of my inspection things like I invite anyone to spend a night on this bed and tell me otherwise. And they [landlords] bought me a new bed. Like they've honestly been amazing. They bought me a new bed straight away." (Interview #12)

"When I first got my dog, I got him like halfway through the year. And I sent a text to my landlord saying hey my doctors have recommended I get a dog, a support animal, blah blah blah. And she literally replied, "Sweet as, pick up the poo." Like, yeah, she was great! Yeah. So, there are good people out there." (Interview #12)

"The power bill is sort of manageable now that we, who was it, [name removed], gave me an extra \$30 a week." (Interview #24)

"M: What makes this a good home to live in? I: It's warm, it's dry, it hasn't got mould, it's cool in summer and warm in winter, which is what you'd want for everyone to have. That opportunity to have a home that's comfortable where you can grow and develop." (Interview #27)

"M: And do you like this location? I: Yeah, I can see the trees in the park, the lights in the night time over the motorway, that pohutukawa sculpture. I get all of that. It's like if I have bad days and I'm stuck in bed, I don't mind." (Interview #39)

"M: And you know when you went to live there, was it easy for you to understand information or legal documents in relation to, for example, leases and? I: Yeah. My landlord, he explained to us and sat down and explained, we could understand and everything." (Interview #52)

As shown by this small selection of diverse, yet positive, experiences, simple actions by people in positions of power, authority and privilege, went a long way in levelling the playing field for interviewees when it came to housing matters.

## 13. Strengths and Limitations

Reflecting on the strengths and limitations of monitoring research is important for evaluating and strengthening methodologies in subsequent cycles of monitoring. Outlined below is a selection of key strengths and limitations of this housing research.

### 13.1 Strengths

One of the greatest strengths of this monitoring research was that it prioritised the voices of disabled people as Interviewees, Monitors, and within the Research Team. Throughout this research 61 disabled people were interviewed, 26 disabled Monitors trained, and five disabled people contracted within the Research Team to plan, execute, and deliver a rigorous monitoring report. In reflection of the ethos of the disability rights slogan ‘nothing about us, without us’, at every stage of the monitoring disabled people led the research agenda.

A second key strength was the defined research focus of housing, as selected by the DPO Coalition. Traditionally, the DRPI model has taken a broader approach to documenting human rights violations, with the original interview framework designed to consecutively investigate violations as isolated events. However, for this cycle of monitoring research the interview framework strategically crafted interview questions in a way that helped build a holistic overview of Interviewee experiences in relation to the specific subject of housing. This represents a genuine effort to give expression to Article 33 of the UNCRPD, by moving beyond earlier monitoring efforts and shifting towards the documentation of disabled people’s experiences of an issue affecting all New Zealanders.

The third key strength was the accessibility of the research. Under the guidance of the DPO Coalition all aspects of this research were designed with accessibility in mind, including all audio, video and written documents. For example, two monitoring interviews were conducted entirely in New Zealand Sign Language. These interviews were video recorded and then interpreted at a later date, before the verbal interpretations were transcribed into written English for coding and analysis. This provided an important pathway forward for monitoring Deaf Interviewee’s experiences of housing, and one that will be strengthened and expanded in future monitoring research. This also relates to the final key strength, which was the capacity building of disabled researchers. As well as documenting human rights violations, one of the primary tenets of the DRPI research model is to increase the training and research experience of disabled people. More specifically, this monitoring research included people who had trained in previous monitoring research and other disability research projects, as well as disabled people who were completely new to the research experience. By pairing less experienced Monitors with those who had interviewed before, Monitors were able to share their own expertise with each other and build stronger research relationships.



## 13.2 Limitations

One of the biggest limitations of this monitoring research was the lack of time and resources. The tight time frame, as recognised by the HDEC, meant that the planning, recruitment, data collection, analysis, and report writing was rushed at times. This cycle of monitoring research would have benefitted from an increased timeframe, a larger scope of Interviewees who were engaged over a longer period of time, and a more experienced research team (particularly with regards to research with subaltern populations).

Related to this was the time and resources allocated to Monitor training. Due to time and resource constraints, Monitors were only able to participate in two days of training before entering the field to conduct monitoring interviews. This limitation was reflected in the feedback, with Monitors suggesting that a more in-depth training in future cycles of monitoring research would be beneficial.

The quality of audio and video recordings during the interviews were also noted as limitations by both the Monitors and the transcribers, which in some cases impacted the quality of the transcriptions and quotes. For example, in three instances malfunctioning audio recorders meant that interview audio was not recorded, resulting in the analysis being derived from written notes taken during the interviews. A further challenge related to the quality of video filmed during NZSL interviews conducted remotely by Zoom. These limitations will be addressed and strengthened in future cycles of monitoring research.

As noted in the Ethical Considerations and Methodology chapters, a final major limitation was the inclusion criteria of this research, which was aimed at “securing [the] voice” of disabled people as “integral sources of monitoring information” at all stages of the DRPI process (Samson, 2015, p. 239). The purpose of this is to ensure that disabled people are provided with an opportunity to speak on their own behalf, and report directly on their experiences in relation to the UNCRPD. However, as a result of this inclusion criteria, together with the consideration of the ethics around free and informed consent, important groups of people from within the disability community were unable to participate in this monitoring research. This included people with high and complex needs who were unable to provide free and informed consent on their own behalf. Furthermore, because the methodology maintains the primacy of disabled people’s individual voices, close support people and family members were not able to contribute their perspectives on the issue of housing and how it impacts on their family member or person they support. This meant that people with high and complex needs were not captured within this monitoring research. Members of the deaf-blind community, and people who identified as deaf or with hearing loss, but who do not use NZSL were similarly omitted. Other communities who were not well represented in this monitoring research included disabled people living rurally, people outside of the key geographical areas, disabled people under compulsory care or who are in prison, and disabled children. As such, while expansive, the findings of this report do not represent the experiences or interests of the whole disability community, nor collective cultural identities.

In response to this limitation, further monitoring research is now under way to ensure the housing experiences of people with high and complex needs and other aforementioned groups are captured in this cycle of monitoring, through close family members and support people. This additional report is expected to be completed in 2020. Efforts to create a greater level of responsiveness to a wider range of disabled people and collective voices will be implemented in upcoming monitoring cycles, including alterations to the methodological approach.

## 14. Final Comments (Conclusion)

This report has presented the findings of the 2019 Disabled Person-Led Monitoring of the UNCRPD in Aotearoa New Zealand. The purpose of this monitoring research was to understand how a selection of disabled people experience housing in Aotearoa New Zealand, specifically in relation to their rights under the UNCRPD.

While some of the housing experiences shared in this report were positive, the majority were not. Most of the stories shared by Interviewees were overwhelmingly negative, emphasising the challenges and human rights violations they faced when accessing adequate housing. These experiences demonstrate how far Aotearoa New Zealand has to go in progressively realising the UNCRPD and ensuring that no one is left behind. In particular, the limited awareness Interviewees had of their rights under the UNCRPD, together with the attitudes held by people in positions of power within the housing market, are reasons for concern and speak to the Government of New Zealand's failure to invest in generating awareness of the UNCRPD amongst both disabled and non-disabled populations. Even so, though the findings of this report are bleak, the solutions, strategies, and tools for moving forward are clear, and can be found woven throughout Interviewee narratives. Even though Interviewees had limited knowledge of the UNCRPD itself, they still demonstrated a strong ability to advocate for themselves amidst intersecting challenges, providing expertise and strategies for effectively realising their rights. As the disability rights slogan says, 'nothing about us, without us.' Disabled people know what they are entitled to and what needs to change for their rights to be made real. Not only does this report provide important evidence of housing challenges and rights violations, but it also offers a blueprint for moving towards greater equality within Aotearoa New Zealand and beyond.

## Appendix A: Monitoring Team

### Monitors

Áine Kelly-Costello

Andrea Courtney

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Crystal Mackenzie

David King

David McCloughen

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Elinor Niha

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Limoni Aumalesulu

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# Appendix B: Interview Questions

## Interview Framework #1

On the Participant Interest Form you indicated that you are a homeowner, renter, living with family, boarding, or living in a group or retirement home. Tell us about where you live now:

- Where do you live?
- What sort of a house do you live in (house/flat/group home/etc.)?
- When did you move here?
- How easy was it to find this place?
- Are you happy where you live? If not, where would you most like to live?

Tell us about your disability...

### SAFETY (PSYCHOLOGICAL AND PHYSICAL)

- How do you feel about the people you live with?
- Is your home a place where you feel comfortable and relaxed?
- Do you like spending time at home?
- Is your home free of abuse and intimidation?
- Do you feel like you can freely and openly embrace your cultural/religious/sexual/other identity where you currently live? Why? Why not?
- Does your home have water, hot water and electricity all the time? If not, why not?
- Is your home warm?
- Is your home free of hazards?
- If your home big enough for the number of people that live here? If you don't feel it is big enough, please explain.
- Do you have a safe and private space to go to if you need to?

### SELF DETERMINATION

- Why did you decide to live here?
- Who made the decision to live here?
- Who do you live with?
- Who decided who you live with?
- What are the advantages of living here?

- What makes this a good home to live in?
- What makes this home less than ideal for you?
- Were you able to easily understand the information or legal documents you were given about your house/mortgage? (for example, lease, banking information etc.)

#### RHYTHMS AND ROUTINES

- What kind of things do you like to do at home?
- What kind of things can't you do at home, but would like to do?
- Who controls what happens in your home?

#### COMMUNITY CONNECTION

- How connected do you feel to your neighbourhood?
- How safe do you feel in your neighbourhood?
- How easy is it to get to, and use, facilities where you live? For example, shops, healthcare, school, community centre, cultural spaces etc.

#### HOMELINESS

- What do you think your home says about you?
- Do you invite friends and/or family to your home? Why? Why not?
- Aside from the people who live here, can you stop others from entering the house and/or property? If not, why not?

#### PHYSICAL NEEDS

- What modifications and/or assistance do you have at home? Please explain what you currently have, and what else you need.
- What difference do these things make in your life? (thinking about things like your ability to go to work, reducing the need for support or your overall well-being)
- Thinking now about the home modifications and/or assistance you need but don't have. How does this impact your everyday life?

#### AFFORDABILITY AND AVAILABILITY

- How much of your income goes on rent or a mortgage?
- Does anyone else contribute to your personal rent or mortgage? (for example, family or Government Agencies)

- Do you think housing options are limited for disabled people? If yes, what are the biggest barriers to adequate housing?
- What other things impact on your ability to have adequate housing?
- Thinking of a time when you needed something fixed. Were you A) able to fix it yourself? B) could you afford to get someone to fix it C) were you able to ask the homeowner to fix it? How did they respond? What happened?

## SECURITY OF TENURE

- Has your tenancy ever not been renewed when you were expecting it to be? If yes, why was it not renewed? How did it make you feel?
- Do you think your disability has ever impacted on your ability to find a house (now or in the past)? If yes, why?
- Have you ever been evicted from your home? If yes, what happened? How did it make you feel?
- Are you afraid that your current housing situation will change? Why? Why not?
- Have you ever wanted to take legal action related to housing or accommodation (for example Tenancy Tribunal, complaints process etc.)? If yes, did you? Why? why not? What happened?
- Do you have insurance? What kind?

## AWARENESS

- Have you heard of the Convention on the Rights of Persons with Disabilities?
- What does Universal Design mean to you?

Article 19 of the UNCRPD tells us that all disabled people have an equal right to live in the community with choices equal to others.

- What does this mean to you personally?

Article 28 of the UNCRPD tells us that the Government of New Zealand must recognise the right of disabled people to an adequate standard of living.

- What does this mean to you personally?
- Do you think the Government of New Zealand is making sure disabled people are not discriminated against in the housing/accommodation market? Please explain.

Thinking ahead five years' time... the Government of New Zealand is doing a good job at making sure disabled people have an adequate standard of living.



- What does this mean for you? Where will you be living? Who with? What kind of home? How would it feel?
- What needs to change for this to happen?
- Thinking of disability and housing, are there any issues we haven't covered today?
- This research has been about your experience of housing. This is the first year of a three year research project. What two other issues would you like to see investigated in the next two years?

## **Interview Framework #2 - Homeless Participants**

Tell us about where you live now:

- Where do you live?
- How long have you lived here?
- Why are you homeless?
- While homeless, have you been forced to move? How often?
- Do you think your disability impacted on your ability to find fixed and secure accommodation (now or in the past)? If yes, why?
- How did you find this place?
- Do you have access to water, hot water, and a bathroom?
- How connected do you feel to your neighbourhood?
- How safe do you feel living here?
- How easy is it to get to, and use, facilities where you live? For example, shops, healthcare, school, community centre, cultural spaces etc.
- Are you happy here? If not, where would you most like to live?

Tell us about your disability...

- Have you heard of the Convention on the Rights of Persons with Disabilities?
- What does Universal Design mean to you?

Article 19 of the UNCRPD tells us that all disabled people have an equal right to live in the community with choices equal to others.

- What does this mean to you personally?

Article 28 of the UNCRPD tells us that the Government of New Zealand must recognise the right of disabled people to an adequate standard of living.

- What does this mean to you personally?

- Do you think the Government of New Zealand is making sure disabled people are not discriminated against in housing/accommodation situations? Please explain.

Thinking ahead five years' time... the Government of New Zealand is doing a good job at making sure disabled people have an adequate standard of living.

- What does this mean for you? Where will you be living? Who with? How would it feel?
- What needs to change for this to happen?
- Thinking of disability and housing, are there any issues we haven't covered today?
- This research has been about your experience of housing. This is the first year of a three-year research project. What two other issues would you like to see investigated in years two and three?

## References

- Access Alliance (2019). *Working together to put accessibility at the heart of a more inclusive Aotearoa New Zealand*. <https://www.accessalliance.org.nz/>
- Aitken, Z., Baker, E., Badland, H., Mason, K., Bentley, R., Beer, A., & Kavanagh, A. M. (2018). Precariously placed: housing affordability, quality and satisfaction of Australians with disabilities. *Disability & Society*, 121-142.
- Article 33 Convention Coalition Monitoring Group (2015). *Disability Rights in Aotearoa New Zealand: Participation & Poverty*. <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/nzs-monitoring-framework/monitoring-reports-and-responses/reports-from-convention-coalition/#P>
- Auckland Council's Disability Advisory Panel (2019). *Lack of accessible housing a key issue for Disability Advisory Panel*. <https://ourauckland.aucklandcouncil.govt.nz/articles/news/2019/05/lack-of-accessible-housing-a-key-issue-for-disability-advisory-panel/>
- Bhanushali, K. (2007, February 20-21). *Changing face of disability movement: From charity to empowerment*. [Paper presentation]. National Seminar On Revisiting Social Work in the field of Health - A Journey from Welfare to Empowerment, The Maharaja Sayajirao University of Baroda, Vadodara. [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=965999](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=965999)
- CCS Disability Action. (2017, November 13). *Joint briefing to Hon Phil Twyford Minister of Housing*. [Briefing]. <https://www.ccsdisabilityaction.org.nz/assets/resource-files/Joint-briefing-to-the-Minister-of-Housing.pdf>
- Clare, E. (2001). Stolen bodies, reclaimed bodies: Disability and queerness. *Public Culture* 13(3), 359-365.
- Committee on the Rights of Persons with Disabilities. (2014). *Concluding observations on the initial report of New Zealand (CRPD/C/NZL/CO/1)*. United Nations.
- Conder, J., & Mirfin-Veitch, B. (2018). *From presence to belonging: Experiences and outcomes of living independently for adults with intellectual disability*. The Donald Beasley Institute.
- Department of Corrections. (2019, June). *Prison facts and statistics – June 2019*. [https://www.corrections.govt.nz/resources/research\\_and\\_statistics/quarterly\\_prison\\_statistics/prison\\_stats\\_june\\_2019.html](https://www.corrections.govt.nz/resources/research_and_statistics/quarterly_prison_statistics/prison_stats_june_2019.html)
- Disability Matters. (2018). *Executive summary high profile areas*. [Conference Report]. Kia whai tikanga te Kawenata Making the Convention Real Disability Matters Conference 26 – 29 November 2017, Dunedin, New Zealand.
- Donald Beasley Institute. (2019). *About DBI*. <http://www.donaldbeasley.org.nz/about/about-dbi/>

- DRPI. (n.d.a). *About: What is disability monitoring?* Disability Rights Promotion International. <https://drpi.research.yorku.ca/welcome-drpi/>
- DRPI (n.d.b). *Disability rights monitoring.* Disability Rights Promotion International. <http://drpi.research.yorku.ca/disability-rights-monitoring/>
- Duncanson, M., Oben, G., Wicken, A., Richardson, G., Adams, J., & Pierson, M. (2018). *Child Poverty Monitor 2018 Technical Report.* NZ Child and Youth Epidemiology Service, University of Otago.
- Farha, L. (2017, July 12). *Adequate housing as a component of the right to an adequate standard of living, and the right to non-discrimination in this context (A/HRC/31/L.11).* [Report]. <https://digitallibrary.un.org/record/1302425>
- Flaws, B. (2019, August 26). Landlord held onto rent overpayments, failed to fix water problems. Stuff. <https://www.stuff.co.nz/business/115243728/landlord-held-onto-rent-overpayments-failed-to-fix-water-problems>
- Francis, R. L. (2019). Searching for the Voice of People with Disabilities in Peace and Conflict Research and Practice. *Peace & Change* 44(3), 295-320.
- Galtung, J. (1969). Violence, peace, and peace research. *Journal of Peace Research* 6(3), 167-191.
- Habitat for Humanity. (2019). *The need in New Zealand.* <https://habitat.org.nz/about/the-need-in-new-zealand/>
- Hickey, H., & Wilson, D. (2017). Whānau hauā: Reframing disability from an Indigenous perspective. *MAI Journal: A New Zealand Journal of Indigenous Scholarship*, 6(1), 82-94.
- Hickey, H. (2015). Marginalizing the subaltern within: How to effectively engage with and monitor diverse cultural identities with disabilities when individual identity dominates the collective identity framework. In M. H. Rioux, P. C. Pinto, & G. Parekh (Eds.), *Disability, Rights Monitoring, and Social Change: Building Power out of Evidence* (pp. 221-236). Canadian Scholars' Press.
- Houkamau, C. A., & Sibley, C. G. (2015). Looking Māori predicts decreased rates of home ownership: Institutional racism in housing based on perceived appearance. *PloS one* 10(3), e0118540.
- Human Rights Commission. (2020). *Economic and social rights.* <https://www.hrc.co.nz/our-work/economic-and-social-rights/>
- Human Rights Commission and University of Otago. (2016, August). *Inadequate housing in New Zealand and its impact on children: Thematic snapshot report to the United Nations Committee on the Rights of the Child.* [Report]. Human Rights Commission.
- Hunt, R. (1988) *People with disabilities.* [Report]. Royal Commission on Social Policy IV: 767-804.

- Johnson, A., Howden-Chapman, P., & Eaquad, S. (2018). *A stocktake of New Zealand's housing*. Government of New Zealand.
- Johnson, A. (2017). *Taking stock: The demand for social housing in New Zealand*. [Report]. Salvation Army.
- Jorm, A. F., Kelly, C. M., & Morgan, A. J. (2007). Participant distress in psychiatric research: A systematic review. *Psychological medicine* 37(7), 917-926.
- Kāinga Ora. (2019, December 16). *New Kāinga Ora Accessibility Policy*. [https://kaingaora.govt.nz/news/new-kainga-ora-accessibility-policy/?fbclid=IwAR1QokrMys5n18eIDPTEvc m2N51zYHF\\_IeBA9FhHG5ri1PIboltjA4j4ThU](https://kaingaora.govt.nz/news/new-kainga-ora-accessibility-policy/?fbclid=IwAR1QokrMys5n18eIDPTEvc m2N51zYHF_IeBA9FhHG5ri1PIboltjA4j4ThU)
- Kaiwai, H., & Allport, T. (2019). *Māori with disabilities (Part Two): Report commissioned by the Waitangi Tribunal for the Health Services and Outcomes Inquiry (Wai 2575)*. Wai 2575.
- Kelly-Costello, Ā. (2018). *Opinion: New KiwiBuild apartments are affordable, but are they accessible?* Newshub. <https://www.newshub.co.nz/home/new-zealand/2018/09/opinion-new-kiwibuild-apartments-are-affordable-but-are-they-accessible.html>
- Lifemark. (2017). *Accessible housing by the numbers*. <https://www.lifemark.co.nz/news/accessible-housing-by-the-numbers/>
- Makiha, K. (2019, June 9). *Family of seven living in a tent with two severely disabled children pleads for help*. NZ Herald. <https://www.nzherald.co.nz/rotorua-daily-post/news/family-of-seven-living-in-a-tent-with-two-severely-disabled-children-pleads-for-help/MGVGCM27EVJG2SZGUFABFA7DCM/#>
- McIntosh, J., & Leah, A. (2017). Mapping housing for the disabled in New Zealand. *New Zealand Medical Journal* 130(1457), 69-78.
- MDAC. (2011). *Building the architecture for change: Guidelines on Article 33 of the UN Convention on the Rights of Persons with Disabilities (1st ed., Rep.)*. MDAC.
- Milner, P., & Mirfin-Veitch, B. (2012). *"I am here" The Article 19 Project*. [Report]. Donald Beasley Institute.
- Ministry of Health. (2018). *Mental health*. <https://www.health.govt.nz/our-work/populations/maori-health/tatau-kahukura-maori-health-statistics/nga-mana-hauora-tutohu-health-status-indicators/mental-health>
- Ministry of Health. (2019). *Annual Update of Key Results 2017/18: New Zealand Health Survey*. <https://www.health.govt.nz/publication/annual-update-key-results-2017-18-new-zealand-health-survey>
- Ministry of Housing and Urban Development. (2019). *September 2019 Public Housing Quarterly Report*. <https://www.hud.govt.nz/assets/Community-and-Public-Housing/Follow-our-progress/September-2019/Housing-Quarterly-Report-September-2019/1d4d8c1877/Housing-Quarterly-Report-September-2019.pdf>

- Mirfin-Veitch, B., & Conder, J. (2016). *What it is like for young disabled people who have had to live away from home under Section 141 and 142 of the 'Children, Young Persons, and Their Families Act 1989'*. [Report]. Donald Beasley Institute.
- Mor, S. (2006). Between charity, welfare, and warfare: A disability legal studies analysis of privilege and neglect in Israeli disability policy. *Yale Journal of Law & the Humanities* 18(1), 63-76.
- National Ethics Advisory Committee. (2012). *Ethical guidelines for observational Studies: Observational research, audits and related activities (Revised ed.)*. Ministry of Health.
- Office for Disability Issues (2016a, December 8). *About the Convention*. Retrieved 10 January 2019 from <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/about-the-convention/>
- Office for Disability Issues. (2016b). *New Zealand Disability Strategy 2016–2026*. Ministry of Social Development.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods (3rd ed.)*. Thousand Oaks.
- Phillips, C., Estey, S., & Ennis, M. (2010). The Convention: On paper and in practice. *Forced Immigration Review, Disability and Displacement* (35), 23-24.
- Polit, D. F., & Beck, C. T. (2017). *Nursing Research Generating and Assessing Evidence for Nursing Practice* (10th ed.). Wolters Kluwer Health.
- Roy, E. A. (2018, August 17). *'Stress is huge': New Zealand's foreign buyers ban brings home scale of crisis*. The Guardian. <https://www.theguardian.com/world/2018/aug/17/stress-is-just-huge-new-zealands-foreign-buyers-ban-brings-home-scale-of-crisis>
- Samson, R. M. (2015). Securing the full participation of persons with disabilities and their representative organizations in disability rights monitoring. In M. H. Rioux, P. C. Pinto, & G. Parekh (Eds.), *Disability, rights monitoring, and social change: Building power out of evidence* (pp. 237-248). Canadian Scholars' Press.
- Scotts, M., Saville-Smith, K., & James, B. (2007). *International trends in accessible housing for people with disabilities*. [Working Paper]. [https://repository.digitalnz.org/system/uploads/record/attachment/361/housing\\_and\\_disability\\_\\_future\\_proofing\\_new\\_zealand\\_s\\_housing\\_stock\\_for\\_an\\_inclusive\\_society\\_-\\_working\\_paper\\_2\\_.pdf](https://repository.digitalnz.org/system/uploads/record/attachment/361/housing_and_disability__future_proofing_new_zealand_s_housing_stock_for_an_inclusive_society_-_working_paper_2_.pdf)
- Smith, S. K., Rayer, S., Smith, E., Wang, Z., & Zeng, Y. (2012). Population aging, disability and housing accessibility: Implications for sub-national areas in the United States. *Housing Studies* 27(2), 252-266.
- Spink, E. (2016, August 7). *No houses available for disabled New Zealanders*. Stuff. <https://www.stuff.co.nz/national/health/82528058/no-houses-available-for-disabled-new-zealanders>
- Stats NZ. (2014, June 17). *Disability Survey: 2013*. [http://archive.stats.govt.nz/browse\\_for\\_stats/health/disabilities/DisabilitySurvey\\_HOTP2013.aspx](http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx)



- Stats NZ. (2016, June 9). *Māori and Pacific peoples' home-ownership falls over 25 percent in cities*. [http://m.stats.govt.nz/browse\\_for\\_stats/people\\_and\\_communities/housing/maori-and-pacific-mr](http://m.stats.govt.nz/browse_for_stats/people_and_communities/housing/maori-and-pacific-mr)
- Stats NZ. (2019, October 7). *Dwelling and household estimates: September 2019 quarter*. <https://www.stats.govt.nz/information-releases/dwelling-and-household-estimates-september-2019-quarter>
- Stats NZ (2015, June 23). *He hauā Māori: Findings from the 2013 Disability Survey*. [http://archive.stats.govt.nz/browse\\_for\\_stats/health/disabilities/He-haua-maori-findings-from-2013-disability-survey/disability-amongst-maori.aspx](http://archive.stats.govt.nz/browse_for_stats/health/disabilities/He-haua-maori-findings-from-2013-disability-survey/disability-amongst-maori.aspx)
- Te Pou. (2017, June 27). *New Māori glossary helps bridge the gap in understanding mental health addiction and disability issues*. <https://www.tepou.co.nz/news/new-maori-glossary-helps-bridge-the-gap-in-understanding-mental-health-addiction-and-disability-issues-/1003>
- Thomas, C. (2004). Rescuing a social relational understanding of disability. *Scandinavian Journal of Disability Research* 6(1), 22-36.
- United Nations. (1948). *Universal Declaration of Human Rights*. <https://www.un.org/en/universal-declaration-human-rights/>
- United Nations. (1966). *Covenant on Economic, Social and Cultural Rights*. <https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx>
- United Nations. (2006). *Convention on the Rights of Persons with Disabilities – Articles*. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>
- United Nations (2016). *The Sustainable Development Goals Report 2016*. <https://unstats.un.org/sdgs/report/2016/leaving-no-one-behind>
- Williams, L. (2019). *Whangārei people with disabilities join city's homeless*. Radio New Zealand. <https://www.rnz.co.nz/news/national/388549/whangarei-people-with-disabilities-join-city-s-homeless>
- Woodbury, E. (2017). Luck and love: Housing and disability. In S. Austen-Smith & S. Martin (Editors), *Progressive Thinking Ten Perspectives on Housing* (pp. 29-31). New Zealand Public Service Association
- Woods, M. (2019). *Government resets KiwiBuild to help more New Zealanders into home ownership*. Government of New Zealand. <https://www.beehive.govt.nz/release/government-resets-kiwibuild-help-more-new-zealanders-home-ownership>





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