

Housing for Disabled People:

Family/Whānau and Close Supporter Perspectives

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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
DBI	Donald Beasley Institute
DHB	District Health Board
DPO	Disabled People's Organisation
DRPI	Disability Rights Promotion International
HDEC	Health and Disability Ethics Committee
ICESCR	International Covenant on Economic, Social and Cultural Rights
IF	Individualised Funding
MSD	Ministry of Social Development
ODI	Office for Disability Issues
OT	Occupational Therapist
PMLD	Profound and Multiple Learning Disabilities
SAMS	Standards and Monitoring Services
UDHR	Universal Declaration of Human Rights
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNCRC	United Nations Convention on the Rights of the Child
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

This report contains information about the housing of disabled people who have high and complex support needs, and who cannot easily speak for themselves. The information in this report was provided by their family, whānau and close supporters.

Research and data are critical to developing effective policy and services for disabled people, and progressively realising the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The Donald Beasley Institute was contracted as a research partner to the DPO Coalition to undertake research and report on housing issues for disabled New Zealanders. That research forms part of the Disabled Person-Led Monitoring required by Article 33.3 of the UNCRPD. The research is funded by the New Zealand government as part of its commitment to progressively realise the Articles of the UNCRPD in Aotearoa New Zealand.

This report should be regarded as a companion document to the related report entitled “My Experiences, My Rights: A Monitoring Report on Disabled Person’s Experience of Housing in Aotearoa New Zealand”. This report was produced separately because the disabled people it concerns were not able to give informed consent to participate in the research, yet their housing situations are of equal importance. The experiences of those interviewed in this report closely align with the experiences of disabled people represented in the related report.

This report speaks to the additional complexities experienced and reported by family, whānau and close supporters, and provides even stronger evidence of the gap between what disabled people experience, and what might be considered as reasonable, safe and adequate housing.

Both these reports remind us that housing is not a ‘stand-alone’ issue for disabled people. Access to safe, warm and affordable housing cannot be separated from choice and control, community participation, the right assistance, well-being and interdependence. It is more than accessing a roof and four walls. The following whakataukī speaks to this:

Ka mate te kāinga tahi, ka ora te kāinga rua.

When one house dies, a second lives.

Gone are the roof-and-four-walls solutions of the past (te kāinga tahi). The evidence in these housing reports reminds us that for many the second house (te kāinga rua) is not yet fully realised for many disabled people and their whānau.

The disability housing agenda is more than bricks and mortar. It is about connectedness, whānau, community, citizenship, belonging, choice and control.

Thank you to all who participated in this research. For the honesty, the wisdom, and what at times may have been the painful recollection of housing experiences. Thank you to the Donald Beasley Institute for your respectful and skilled approach to the gathering and reporting of evidence on an important topic such as this.

It is now the responsibility of officials and others involved in housing policy and services to read, consider, listen, take action and make progress.

Disabled people, their family, whānau and close supporters should not be left hoping for housing that most other New Zealanders expect and take for granted. Charity is not expected or wanted. What is expected is a fair go, the right for disabled people to have accessible, affordable, safe and warm housing, and the opportunity to exercise some choice and control.

A handwritten signature in black ink, consisting of a stylized, cursive 'L' followed by a horizontal line extending to the right.

Leo McIntyre

Chair

Disabled People's Organisations Coalition

5. Executive Summary

5.1 Introduction and 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 Convention (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 commissioned by the DPO Coalition as the research partner to carry out the monitoring research.

During the initial cycle of the monitoring, 61 disabled people were interviewed about their housing research. However, the report did not capture the experiences of people with multiple and complex disabilities who were unable to consent to participate in the research. This report details research that addresses this gap in the monitoring research.

5.2 Methodology

This project arose after concerns were raised about the inclusion criteria of the wider housing monitoring report, and the necessity of free and informed consent. People with multiple and complex disabilities are amongst the most disadvantaged groups in society, therefore it is crucial that their experiences are included in UNCRPD monitoring. This led to the Health and Disability Ethics Committee's (HDEC's) approval of amendments being made to the ethics application, enabling the inclusion of family members and close supporters of people with complex disabilities. To uphold the values of UNCRPD monitoring, such as those articulated by the DRPI research model, this research was conducted by disabled researchers (Monitors). While the Interviewees did not identify as disabled themselves, they were invited to participate in the research on the basis that they "know the profoundly disabled person well and can communicate with them effectively" (Moss, 2017, p. 2).

Methodologically, this monitoring research used a general inductive approach, which allowed for important themes to emerge from the experiences reported by the parents/whānau and close supporters of people with complex disabilities (Thomas, 2006). Over the

period of 12 weeks, 10 families and one close supporter of people with complex disabilities were interviewed. Due to the COVID-19 social distancing restrictions, all interviews were conducted via Zoom, WhatsApp or a phone call. The aim of the interviews was to find out what is, and is not, working well for people with complex disabilities who are supported by family/whānau and close supporters, particularly when accessing adequate housing and accommodation in Aotearoa New Zealand. The monitoring research also investigated how the experiences of people with complex disabilities align with their rights under the UNCRPD.

5.3 Findings

Outlined below are overviews of the five key themes that emerged throughout the interviews: choice and control, access, physical and psychosocial wellbeing, relationships, and advocacy and awareness. To maintain brevity, most quotes have been removed from this executive summary. However, extensive Interviewee quotes can be found in the full report.

5.3.1 Choice and Control

Choice and control was identified as an integral aspect of an adequate standard of living, as articulated under Article 19 of UNCRPD. Other Articles that provide relevant commentary on access include the Preamble of the Convention, together with Articles 4, 5, 7, 8, 9, 10, 12, 17, 20, 21, 22, 23, and 28. Interviews with family/whānau and close supporters of people with complex disabilities highlighted the limited choice and control they experienced when accessing housing and accommodation for the disabled person they supported.

One key example of limited choice and control was identified in relation to support services. Given that many people with multiple and complex disabilities require 24/7 care, access to home-based support services was identified as significantly impacted by a lack of choice and control. Individual Funding (IF), for instance is intended to provide disabled people with choice and control over the in-home care they receive. However, a lack of service providers, and appropriate, qualified support workers meant that some families felt they had little to no choice or control over who came in and out of their home to provide support for their disabled family member. At times, they felt that this had compromised both the safety of the disabled person, as well as the wider family. A lack of local respite care was also having an impact on families and disabled family members. As a result, the ability to access services when they were needed most, was very limited.

A further challenge relating to choice and control was timely access to relevant information. As stated by an Interviewee, “the Government only shows you the next card if you become really tired and run down and exhausted.” (Interview #7)

For one Interviewee whose young daughter recently acquired a disability, the family were experiencing great uncertainty over where she might move to when she came to the end of her allocated funding at the rehabilitation facility: “We [would] like her to be home with her family. At the moment, there’s not much choice, I think. Mostly it’s private hospitals for elderly people. I think they are still figuring out where to put her.” (Interview #9)

A lack of accessible rental properties also meant that families often felt caught out when selling and buying a new home. One interviewee summarised their situation as: “You effectively end up homeless because there’s nowhere that you will fit that has what you need for whatever period of time that you need it between selling and buying.” (Interview #11). Moreover, it was reported that current funding provisions for housing modifications only permit a single modification in a person’s lifetime. While systemic analysis was beyond the scope of this monitoring research, it appears that this arrangement fails to acknowledge the possibility that disabled people may need to move house and will continue to require modifications as their needs change over time. Another factor limiting choice and control was the lack of accessible accommodation within Kāinga Ora’s housing stock.

However, families who did have access to knowledge, support and resources appeared to have greater choice and control over their disabled family member’s housing and accommodation arrangements. This meant that not only were the disabled person’s basic needs more likely to be met, but also their best interests, will and preference.

The dependency on 24/7 care meant that disabled family members had to either remain in the familial home into adulthood, or transition into a residential facility - that is, a much more limited choice than is afforded to the dominant non-disabled population. For those who had moved, or who were looking to move from their home into a community residential care arrangement, the transition required a significant amount of advocacy and planning by families/whānau and support people. There was a general consensus amongst the families that they felt residential facilities lacked the capacity and resources to meet the will and preferences of their disabled family members. These situations left families feeling like they had to compromise their loved one’s will and preference, or maintain the responsibility of caring for their disabled family member well into adulthood.

In summary, Interviewees reported that supports, services and legislation were not responsive to the evolving needs of the people they care for, thus restricting the choice and control over their disabled family’s right to access an adequate standard of living and housing.

5.3.2 Access

People with complex disabilities and their families reported limited access to an adequate standard of living and housing whether as homeowners, when building, within the private rental market, or when accessing Kāinga Ora housing. The UNCRPD articles relating to access include the Preamble, and Articles 4, 5, 8, 9, 12, 14, 17, 19, 20, 21, 28 and 30. In particular, Article 9 states that “States Parties shall take appropriate measures to ensure persons with disabilities access, on an equal basis with others, to [...] housing”. However, most existing houses do not meet accessibility standards. For one family, living in an inaccessible house meant that their child with complex disabilities could not access the bathroom. As such, he could only be washed outside with a bucket when the weather was warm. For another family, a lack of accessible housing meant that the disabled family member could not be present in the living room, and was therefore excluded from spending

quality time with his family in a communal space. The size of housing was also identified as a challenge that restricted everyday household activities, due to the number and size of equipment needed for the disabled family member.

With regards to public housing, Article 28.d of the UNCRPD specifically articulates that disabled people must be able to access public (state) housing programmes. However, one Interviewee reported living in an inaccessible Kāinga Ora house for two years before an accessible house became available. However, this wait time was extended even further when a day before the move date it was discovered that the 'accessible' property did not actually meet accessibility standards.

Building a new home was identified as one way of ensuring access to a completely accessible space tailored to the specific needs of the disabled family member. However, building also came with great challenges, including tense interactions with authorities who were not accustomed to, or supportive of, accessibility. As one Interviewee summarised,

“You would think that if you paid an architect, would think of those things [access needs] but it didn't happen. I raised these things during construction time but they just ignored me.” (Interview #7)

Affordability was also a key factor impacting upon disabled people's access to an adequate standard of living and housing. Limited financial security meant that many families had no choice or control in terms of accessing adequate housing for their disabled family members. One Interviewee articulated that the current health and disability funding system was insufficient to meet the housing needs of the disabled family member, especially within the private rental market. The cost of building an accessible house was also prohibitive, particularly when considering variation fees attached to new build housing schemes,

“Because having a person with disability does make you poorer. For us, we've had to sink a lot of money into this and we've been fortunate that we could do that but we definitely shouldn't have to do that but if you haven't got much to start with then it's not fair.” (Interview #8)

While Interviewees acknowledged that funding for housing and living costs exists, it could not always be used for the specific or unique needs of the disabled person they were caring for. This was also impacted by inconsistencies between funding systems. For example, families whose children were funded by the Ministry of Health were often denied financial contributions for home modifications. On the other hand, one Interviewee whose child was funded by ACC felt that they had received generous support when modifying their home for accessibility. However, being accepted as qualifying for ACC funding often took time, effort and advocacy. For example, the young woman who recently acquired multiple and complex disabilities had not been approved for ACC funding, and her family are now trying to have the decision reviewed. For another family, a lengthy legal battle eventually led to their child transitioning from MoH to ACC, which significantly improved the child's standard of living within the home.

A final key theme was access to the community. The location of accommodation was important to Interviewees as it embodied the potential for both the disabled person and the wider family to be able to participate in and contribute to their community. As stipulated in Article 19.b, disabled people have a right to be included in their community, in order to prevent isolation or segregation. Even so, it was noted that for many Interviewees, location and community access were low on their priority list, when compared to things like affordability. Interviewees expressed that they had little choice or control over where they lived, and were living in locations dictated primarily by affordability and accessibility.

5.3.3 Physical and Psychosocial Wellbeing

The third emergent theme was Physical and Psychosocial Wellbeing which relates to the UNCRPD Preamble, and Articles 10, 11, 14,17, 19, 25 and 28. Family members of people with complex disabilities reported feeling extreme fatigue, ongoing anxiety and concerns for the wellbeing of the disabled person they are caring for. These experiences are often derived from what they felt was a never-ending struggle to obtain support, and the pressures of feeling like they were the only ones who could care for their disabled family members. This led to feelings of isolation and loneliness. Family members also experienced anxiety relating to the long term nature of the health and disability conditions of the person they were caring for. For example, some family members had felt pressured to sign a Do Not Resuscitate Order, while others had been informed that their child had a shortened life expectancy. Caring for a family member with complex disabilities was physically demanding, often resulting in pain and injury. The Interviewees also highlighted that siblings of children with complex disabilities often became the only reliable source of support, particularly in single parent households. Having access to accessible housing was identified as a key factor in alleviating some of the negative psychosocial and physical experiences of caring for a disabled family member.

5.3.4 Relationships

The fourth finding related to the importance of relationships, which reflects the Preamble, and Articles 8, 9, 15,16,19,26, and 28 of UNCRPD. Interviewee responses suggested that the adequacy of their housing and living arrangements were directly impacted by the relationships between the disabled family member, the family, and support workers or service providers. When families felt that support workers could not be trusted to meet the needs, will and preference of the disabled family member, this added to the pressure on both the families and the disabled family member. As a result, the wellbeing of the disabled person was often compromised and/or put at risk. When a positive relationship existed, and families felt they could trust the support workers or service provider, the standard of living increased. Several family members noted that even having one positive relationship could make all the difference on the family and disabled individual's wellbeing.

A high turnover rate of support workers was identified as a major challenge, as well as the significant amount of unpaid time and resources families had invested into training support

staff. All of the Interviewees who identified as primary caregivers, were mothers. This highlights the gendered nature of care and the risks experienced by mother's and children when housing and living standards are compromised. This monitoring research also showed how positive relationships with people in positions of power have the potential to improve, or fast-track the improvement of living conditions. This was particularly true when people in positions of power had had personal experience with disability (specifically, people with multiple and complex disabilities).

5.3.5 Advocacy and Awareness

The final collection of findings, "Advocacy and Awareness", related to the UNCRPD Preamble, and Articles 2,5, 8,9, 10, 17, 19, 23, and 28. Four out of eleven Interviewees had not heard of UNCRPD. However, all of the Interviewees displayed an intimate understanding and awareness of the standard of living the person they supported was entitled to. Articles 19 and 28 of the UNCRPD are particularly relevant to this monitoring research, referencing the right to "live independently and being included in the community" and access to an "adequate standard of living and social protection."

However, there was a perception amongst the Interviewees that UNCRPD did not apply to people with multiple and complex disabilities, as they were put in the 'too hard basket'. All of the Interviewees were committed to improving their disabled family member's living conditions. Knowledge and advocacy support was amassed through peer support groups and collective action, rather than other key stakeholders such as service providers, government agencies, or the wider disability community. However, families also articulated that despite their advocacy efforts, community living arrangements would never meet the best interests, will and preference of their disabled family member, in the way that could be met within the family home. This had generated some resistance towards transitioning family members into the community. For others, who had transitioned their family member into a community living arrangement, or for families who were thinking about it, there was a sense of feeling forced to compromise between the disabled family member's health and wellbeing, and the health and wellbeing of the wider family, particularly as the disabled person and their primary caregiver/s aged.

5.4 Discussion

Much like the findings generated by the wider housing report, this monitoring report also continues to paint a bleak picture, with disabled people's experiences of housing in leaving much to be desired. For people with multiple and complex disabilities, challenges in accessing adequate housing were magnified by an inability to directly communicate their housing needs. As a result, this created further barriers in ensuring their best housing interests were met, as well as their will and preference. Outlined below are more general points that were significant to the findings.

5.4.1 Gratitude and Compromise

A common theme found in both interviews with families of people with complex disabilities and disabled people, was the sense of gratitude. While gratitude is a positive quality and not to be dismissed, a more critical analysis reveals the pressure and expectation experienced by the disability community to be grateful for whatever they are afforded - even when it does not meet standards outlined in the UNCRPD. The absence of choice and control, underpinned by a lack of funding, inadequate services, low qualified and low paid support workers, together with the scarcity of services, appear to be linked to the theme of gratitude and compromise, although further research and analysis is needed to understand the correlation. This often led families expressing gratitude for a compromising situation they were in.

5.4.2 Similarities and Differences to the Wider Report

A primary challenge of monitoring disability rights concerns non-disabled people speaking on behalf of disabled people and articulating information and experiences that are not reflective of the experiences reported by disabled people themselves.

During this monitoring research, careful consideration was given to 'voice' within a disability rights-based framework. Through comparing and contrasting the results from this research and last research with disabled people, the disabled researchers who co-authored this report conclude that the housing experiences reported by family members of people with complex disabilities, reflected the experiences reported by disabled people. These include limited choice and control, access to the housing market, affordability, access within the home, community access and belonging, wellbeing, support services, and awareness. Although the key themes manifested in different ways, the commonality of rights violations were found throughout the entire community. In this way, the two housing reports serve to enrich and support each other in the shared aim of progressively realising the UNCRPD.

However, it might also be noted that there were unique and additional layers of complexities affecting people with multiple and complex disabilities and their families/whānau and close supporters. For example, the dependency of disabled people with significant health needs on family and service providers is often lifelong. Family members were likely to be unemployed, meaning there was a total reliance on government welfare as the only income for entire families. In many cases, the caregiver role was carried out by the mother, casting a further gendered lens on the rights violations experienced by the disabled family member. Additionally, the uncertainty around the health and life expectancy, and/or behavioural needs, of the family member with complex disabilities had a significant and direct impact on the social, psychological and economic situation of entire families. Although these experiences are not unique to people with complex disabilities, these challenges were reported with greater consistency and severity throughout the interviews in this report, than were shared in the wider housing report.

5.5 Best Practice and Recommendations

Just as family/whānau members and close supporters are in the best position to inform and guide the support and services provided to their family member, they are also in the best position to recommend how best to ensure the UNCRPD is being progressively realised in circumstances where a disabled person cannot express their own will and preference. Below are a selection of recommendations and examples of best practice which demonstrate the benefits of families/whānau and support people contributing to the progressive realisation of housing-related rights.

- Embrace a kaupapa Māori approach to ensuring people with multiple and complex disabilities can enjoy adequate living conditions and housing.
- Take a life-long approach to improving housing and living conditions that includes close family/whānau members and supporters as co-designers.
- Increase accessible state housing stock and incentivise accessible housing in the private rental market.
- Engage close family/whānau and supporters of people with multiple and complex disabilities as co-designers when discussing the amount of funding that is needed for adequate housing, what the funding is needed for, and when the funding is needed. Acknowledge that these needs change over time.
- Ensure access to more supported living options and respite services, with increased choice and control.
- Ensure families, whānau and close supporters can easily access information in a timely manner so that they have a complete understanding of what people with complex disabilities are entitled to, and why, without having to seek out the information themselves.
- Provide age-appropriate care for people with complex health needs to ensure families can remain together post-injury.
- Prioritise disabled people and their families/whānau in accessible state housing.
- Address the inequalities between funding models.
- Provide extra financial support for women caring for disabled children and single parents.
- 12.11 Update the Building Act (2004) and Building Code to align with the UNCRPD.

5.6 Strength and Limitations

The greatest strength of this monitoring research is that it was led by disabled people who were supported by a wider team of scholars with extensive experience in inclusive research methodologies, and research collaborations with families/whānau and people with complex disabilities. The researchers also had the benefit of recently completing the wider housing report, which had already provided insight into the rights violations affecting disabled people's access to adequate housing in Aotearoa New Zealand.

A second strength related to Covid-19 restrictions, which meant that all interviews were conducted remotely using phone and video conferencing technology to ensure Interviewee safety, rather than in select geographical locations. This allowed for the scope of recruitment to be broadened to include Interviewees located anywhere in Aotearoa New Zealand.

However, this also created some challenges such as the necessity of having access to a phone, laptop and wifi, and lack of face-to-face engagement between researchers and Interviewees. Covid-19 restrictions also meant that families who were isolated at home without their usual support workers and networks, were often unable to dedicate time to an interview. This had a negative impact on participant recruitment efforts. In particular, the recruitment of Māori and Pasifika Interviewees was hindered, with several interviews falling through at the last minute due to pressures associated with Covid-19 and social distancing.

Finally, as with most research endeavours, this research was limited by the capacity and resources afforded to this project. This research would have benefitted from a wider scope of Interviewees, increased participation of Māori and Pasifika family/whānau/aiga members and supporters of people with complex disabilities, and the engagement of Interviewees over a longer period of time. This would ensure that the experiences of a wider range of people with complex and multiple disabilities could be captured in greater depth.

5.7 Conclusion

Although the scope of this monitoring research was small, Interviewees provided a wide range of experiences, linked by a common theme: people with multiple and complex disabilities are amongst the most systematically marginalised groups in Aotearoa New Zealand, especially when it comes to housing. Indeed, while Aotearoa New Zealand may have made significant progress since the days of mass institutionalisation, as a nation we are still a far cry from ensuring that all disabled people have adequate housing and an adequate standard of living.

Throughout the interviews, family/whānau members and close supporters articulated the challenges and barriers they had experienced and continue to experience - all of which had restricted their disabled family members from fully enjoying their rights. From access to the housing market, affordability, in-home and community access, to physical injury and psychosocial distress, complex relationships with providers and people in positions of authority, and a lack of awareness about what supports a person with complex disabilities is entitled to under New Zealand law.

Not only has this report highlighted rights violations and problematic accommodation arrangements that fail to align with the ethos of the UNCRPD, Te Tiriti o Waitangi, the Disability Strategy, and the Action Plan, but the report has also served to amplify the voices of people with multiple and complex disabilities through those who know them best - their family/whānau members and close supporters. Throughout the Interviews a range of solutions and recommendations were provided as to how best progressively realise the housing rights of people with multiple and complex disabilities. Despite having only

scratched the surface, this report demonstrates the potential for disability and family/whānau-led progressive realisation of the UNCRPD in Aotearoa New Zealand and a future where all people, including those with multiple and complex disabilities, can enjoy their rights, freedoms, and dignity in a full and meaningful way.

6. Introduction

In December 2019, the Donald Beasley Institute (DBI) was appointed by the Office for Disability Issues (ODI) as the research provider to investigate the housing experiences of people with multiple and complex disabilities, from the perspectives of families/whānau/aiga or other close supporters of this group of disabled people. The DBI is a national, independent, non-profit organisation based in Dunedin, New Zealand, whose aim is to advance the health and wellbeing of disabled New Zealanders through applied research, evaluation and education. With a 36-year history, and a strong commitment to the UNCRPD and research pertaining to people with learning disabilities and their families/whānau/aiga, the DBI was well placed to undertake this monitoring research.

The aim of this research project is to document the housing experiences of people with multiple and complex disabilities. During an initial cycle of monitoring in 2019, data contributed by 61 disabled people formed the basis of a wider report, which investigated the issues impacting on their right to access housing, an adequate standard of living, and other interlinking issues (Donald Beasley Institute, 2020). However, the experiences of some members of the disability community were absent from the discussion. In response, this report seeks to extend the scope of monitoring to ensure a deeper and more holistic perspective is gained.

The first part of this report outlines the context and background for monitoring research. It begins with an overview of the UNCRPD reporting process, and in particular Article 33.3 of the Convention which articulates the specific monitoring role of civil society. Disability is then discussed within the context of the housing crisis of Aotearoa New Zealand, before the relevance of this research to people with multiple and complex disabilities and Māori is presented. The second part of the report details the research methodology before interview questions are examined, and the recruitment process of research participants is provided.

Following this, the findings of the monitoring research are introduced, beginning with a brief demographic overview of the Interviewees. Five key findings are then presented, drawing directly from Interviewee quotes and narratives. These include choice and control, access, physical and psychosocial wellbeing, relationships, awareness, as well as a discussion on broader emergent themes.

Finally, the report concludes by acknowledging the strengths and limitations of this qualitative monitoring research report.

7. Background

Established in 2006, the United Nations Convention on the Rights of Persons with Disabilities (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). To become a signatory to the Convention, a State Party (government) must first sign the terms of the Convention, indicating that it agrees in principle. A further commitment is then made through ratification - an act by which the State becomes legally bound by the terms of the Convention before taking further steps to fulfill its own national legislative requirements. Having signed and ratified the UNCRPD, the State must then undergo periodical reviews by a United Nations Committee in Geneva. This process affords both the State Party, as well as civil society, an opportunity to report on how the legal rights and obligations contained within the agreement are, or are not, being met. To conclude, the examining committee responds to the State Party with a set of recommendations on how to ensure the UNCRPD is being progressively realised in an effective and meaningful way. Having ratified the UNCRPD in 2008, the Government of New Zealand (State Party) is now approaching its second examination by the UNCRPD Committee.

As noted above, civil society, and in particular disabled people and their representative organisations, must be fully involved and participating in the monitoring and reporting process (Article 33.3). In 2019, the DBI was contracted to monitor the housing experiences of disabled people in Aotearoa New Zealand, for the purpose of contributing data and evidence to the reporting process. During the first cycle of monitoring 61 disabled people were interviewed about their housing experiences. During this next phase of research, however, the scope has been extended to ensure that a wider range of disabled people have the opportunity to share their housing experiences. Through this research report the DBI and civil society will be able to give the Government of New Zealand and the United Nations rigorous information on the housing experiences of people with multiple and complex disabilities, and suggestions on how to meet their accommodation needs in the future.

7.1 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

7.1.1 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, 2016, p. 18).

Within the context of this monitoring research these principles were implemented through co-design with DPOs representing disabled Māori, Māori members of the DPO Coalition, as well as independent Māori scholars with expertise in Disability Studies and human rights. Further information is outlined in section 7.4 of this report.

7.1.2 Principles of the United Nations Convention on the Rights of Persons with Disabilities, the 2016-2026 New Zealand Disability Strategy, Disability Action Plan

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

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

7.2 Housing in Aotearoa New Zealand

Housing is a complex issue that is impacted by income, health, transport, and a vast array of interlinking issues. 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. For example, Article 25 of the Universal Declaration of Human Rights (UDHR) states that:

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. (United Nations, 1948).

Article 11.1 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) also references the right to housing as a key aspect of an adequate standard of living:

The States Parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions. (United Nations, 1966).

Even though the UNCRPD does not create new rights for disabled people, it builds on the aforementioned concept of ‘adequacy’ throughout different articles. For example, Article 28 of the Convention states that signatory governments must recognise the right of disabled people to an adequate standard of living, including housing and the continuous improvement of living conditions. It requires Governments to take steps towards safeguarding and promoting the realisation of this right without discrimination on the basis of disability (United Nations, 2006).

Further to this, Signatories are also obligated to “recognise the equal right of all persons with disabilities to live in the community with choices equal to others” (Article 19). A key focus of Article 19 is an individual’s right to choose their place of residence, while being able to access community supports to prevent isolation or segregation, as well as mainstream community-based services and facilities that are responsive to their needs (United Nations, 2006).

In 2019, the disabled person-led monitoring report on housing confirmed that disabled people face increased challenges when accessing their right to an adequate standard of living. Most Interviewees (participants) who contributed to the research reported negative housing experiences - from evictions, homelessness, and hazards, to intimidation, discrimination, abuse, poverty, and more. For example, 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, were identified as key issues impacting not only upon their access to housing, but their general health and wellbeing as well. As summarised by the report, these issues, amongst others, speak to the Government of New Zealand’s failure to promote awareness of the UNCRPD and disability rights amongst both disabled and non-disabled populations (Donald Beasley Institute, 2020).

7.3 Housing: Relevance to People with Multiple and Complex Disabilities

The purpose of this research report is to monitor the housing experiences of a specific group of people within the disability community. People with multiple and complex disabilities are amongst the most marginalised and neglected groups of society, particularly when it comes to the progressive realisation of their rights (Moss, 2017).

According to the Complex Care Group of Aotearoa New Zealand, people with multiple and complex disabilities include any “disabled child/young adult, who also has either multiple disabilities, a serious, ongoing medical condition and/or behavior that requires a high level

of support” (Complex Care Group, 2020, para. 1). Other common terms associated with this group include people with cognitive impairments, people who are non-verbal, people who are profoundly disabled, severely disabled, or who have profound and multiple learning disabilities (PMLD), as well as disabled people with intensive support needs or high and complex needs (Moss, 2017). For the purpose of this report, these terms have been shortened to ‘complex needs’ and ‘complex disabilities’.

Internationally, the number of people with complex disabilities is conservatively estimated to be between one and three per cent of the total population, depending on the definition used (Dowse, Dew & Sewell, 2019). Though small in number, people with complex disabilities often require high levels of support delivered by family/whānau members, close supporters and disability services, as well as greater funding over longer periods of time (Milner & Mirfin-Veitch, 2012).

When it comes to the needs and experiences of people with complex needs there is currently little reliable data available. This is in part due to the diversity of people from this community, together with the lack of a universal definition, resulting in individuals falling through the cracks of systems and strategies (Dowse, Dew & Sewell, 2019). A further reason for their absence from research is that ethical guidelines often require research participants to provide free and informed consent to participate on their own behalf, while also ensuring that individuals do not speak on the behalf of others (Dee-Price, Hallahan, Nelson Bryen, & Watson, 2020). Effectively, this means that people with complex needs have been routinely excluded from participating in disability-related research, and so too have their family/whānau members and close supporters. Consequently, the needs and experiences of people with complex disabilities have been systemically omitted from data and evidence on issues that directly affect them, and by virtue, from the dominant disability narrative (Moss, 2017).

However, this does not diminish the importance of ensuring the needs and experiences of this particular group of disabled people are represented in UNCRPD monitoring and reporting. People with complex needs are more likely to spend a longer amount of time at home than the average person, with their living conditions forming the foundation of their well-being (Milner & Mirfin-Veitch, 2012). As highlighted by Moss, “[T]hose whose voice is not heard are more vulnerable” (2017, p. 15). This rings particularly true when considering the housing crisis of Aotearoa New Zealand and the current Covid-19 epidemic, with anecdotal evidence suggesting that people with complex needs and their families/whānau are amongst the most adversely affected by the lack of implementation of their right to adequate living conditions. For many families/whānau caring for a family member with complex disabilities, this has led to unsafe and inadequate living conditions and in extreme circumstances, homelessness (Checkpoint, 2019; Makiha, 2019; McRae, 2019; Nicol-Williams, 2020).

7.4 Housing: Relevance to Māori

To understand the housing experiences of people with complex disabilities, it is important to begin by engaging those who are closest to them and who know them best. In most circumstances this is a person's family, whānau, aiga, close supporters, or friends. It is also important to consider this approach within the wider framework of Te Ao Māori (Māori world view). As highlighted by Hickey and Wilson (2017), dominant northern hemisphere cultural perspectives have had a significant influence on how disability is perceived and responded to. Take, for example, the 'models of disability' which discuss the individual experiences of a disabled person in relation to the society they live in.

However, as useful as the models of disability can be, they often do not take into account Indigenous worldviews, which tend to be more holistic, relational and collective (Durie, 1998; Hickey, 2015). Referred to as the universalism versus cultural relativism debate, there are underlying tensions between Western-dominated individual human rights-based frameworks, and non-Western collective identity perspectives (Hickey, 2015). "For many, the problem lies in the individualistic nature of existing human rights discourse. The concern is that existing instruments emphasize individual needs and entitlements in a way that inadequately compares the collective nature of groups with non-Western world-views and priorities" (Holder & Cornassel, 2002, pp. 126-127). With this in mind, it was essential to consider Māori perspectives on disability throughout the monitoring, particularly in relation to whānau and cultural relativism, in a way that incorporates both individual and community rights.

7.4.1 Overview of disability and housing amongst Māori

According to the 2013 national census, Māori reported a higher rate of disability (26 per cent), than the general population of Aotearoa New Zealand (24 per cent). When adjusted for age,¹ this number increased to 32 percent - that is, almost one third of Māori (Stats NZ, 2014; 2015). While it is unknown what proportion of these statistics are people with complex disabilities, it is estimated that one in four Māori have very high support needs (Ministry of Health, 2012). A deductive approach might assume that Māori are disproportionately represented amongst people with multiple and complex disabilities, however further research is needed.

As summarised in the 2020 housing report (Donald Beasley Institute, 2020), research shows that Māori are also over represented in negative health statistics (Ministry of Health, 2019), mental health statistics (Ministry of Health, 2018), and material hardship (Duncanson, Oben, Wicken, Richardson, Adams, & Pierson, 2018). Housing research has also highlighted the prevalence of overcrowding in predominantly Māori homes (Habitat for Humanity, 2019), and the lack of adequate insulation, ventilation and heating (Human Rights Commission & University of Otago, 2016). Māori are also more likely to be renters rather than homeowners (Stats NZ, 2016), with evidence pointing to implicit institutional racism against Māori within the home lending industry (Houkamau & Sibley, 2015).

¹ That is, the disability rate an ethnic group would have if their population age profile was the same as that of the total population.

It is also important to note that there are different ways to describe Māori who also self-identify as disabled. For example, Hickey and Wilson (2017) outline how historically Māori did not have a word for ‘disability’, recalling how ‘whānau haua’ is a term and description that was gifted by Donny Rangiahau (Tuhoe) to Te Roopu Waiora, a Māori disability agency based in South Auckland. Others have drawn on the term ‘whaikaha’, meaning to have strength, ability, otherly abled, or enabled (Te Pou, 2017). Under the recommendation of the DBI Kairangahau Māori Research Associate and Māori DPO members, this research acknowledges and embraces the different terminologies, but primarily draws on ‘whaikaha Māori’.

In summary, monitoring human rights is an important process through which tāngata whaikaha Māori can express their experiences, so to critique and/or contribute to the base of knowledge on the current status of oranga tāngata (Māori wellbeing). In doing so, Māori can draw attention to the ways in which the government and services can be more culturally responsive to tāngata whaikaha Māori and more aligned with te ao Māori notions of wellbeing. By taking a multiplicitious approach, this report embraces a more holistic approach to monitoring, by considering both universalism and cultural relativism, particularly through the engagement of families and whānau.

8. Our Approach (Methodology)

The chosen methodology of this qualitative research is the general inductive approach (Thomas, 2006). A key aspect of the general inductive approach is flexibility, particularly in the search for, and presentation of, important themes as opposed to the generation of new theories (Liu, 2016). Qualitative interviews are the most common form of data collection. Once the data is collected, it is then transcribed, coded, and sorted into categories or themes. As common themes are identified, findings begin to emerge, allowing for understanding of the findings without interpretation or presumption (Thomas, 2006).

It might be noted that during the former cycle of monitoring, the Disability Rights Promotion International (DRPI) model was utilised - a methodology which holds that monitoring must be conducted by disabled people (Monitors), with disabled people (Interviewees) (Samson, 2015). However, it has been acknowledged that monitoring disability rights using the DRPI model has limitations: “For example, interviews are not conducted with persons with disabilities under the age of 18, nor with persons who do not have the capacity to consent to be interviewed, nor with persons who use certain forms of augmentative and alternative means of communication” (Samson, 2015, p. 244).

Given that this research includes participants who identify as family/whānau members and close supporters of people with multiple and complex disabilities (rather than disabled people only), it has been important to utilise alternative methodologies that are better suited to the task at hand. Where possible, the values of the DRPI model were upheld, for example, maintaining the deployment of disabled researchers (Monitors). By doing so, the DBI was able to fulfill the mandate of gaining a broader understanding of the housing experiences of disabled people in Aotearoa New Zealand, while also building the capacity of disabled researchers.

8.1 Monitoring Questions

The research questions used in this monitoring project were based on the original Interview Framework from the initial monitoring cycle. The Interview Framework was informed by a wide and diverse range of 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 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 (former United Nations Special Rapporteur on the Right to Housing).

However, for the specific purposes of this linked project, the Interview Framework was adapted for family/whānau members and close supporters of disabled people with high and complex needs. Key themes covered by the questions included:

- Accessibility (physical and financial);
- Physiological and Physical Safety;

- Physical needs;
- Type of support required by the person they support;
- Rhythms and Routines;
- Community Connection;
- Homeliness;
- Affordability and Availability;
- Security of Tenure;
- Human and Disability Rights Awareness;
- Demographic details (including age, ethnicity, disability, location and income).

The questions were used as a guide, but did not always follow the exact wording or order of the questions in the Interview Framework. 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 people with multiple and complex disabilities, as reported by their families/whānau and close supporters?
- What challenges do families/whānau and close supporters of people with complex disability experience when accessing adequate housing and accommodation in Aotearoa New Zealand?
- How do the housing experiences of people with multiple and complex disabilities align with their rights as outlined in the UNCRPD?

8.2 Who was Interviewed?

Over a period of twelve weeks, 11 families and close supporters of people with complex disabilities were interviewed. Initially, organisations in Auckland and Dunedin were contacted as the first step of the recruitment process. These localities were familiar with the research protocol and were able to assist with helping participants understand the Project Information Sheet and Participant Interest Form when required. However, due to the impact of Covid-19 in Aotearoa New Zealand, the limitation of geographical location was lifted and all interviews took place by phone, WhatsApp, or Zoom. This meant that participants located anywhere in Aotearoa New Zealand and who met the criteria could participate in the research.

8.3 How we Found the Interviewees (Sampling)

Maximum variation sampling was selected to ensure the participation of a diverse range of participants (Patton, 2002). As a sampling method, maximum variation helps researchers to understand how a phenomenon is understood among different people, in different settings and at different times. To ensure research information could be disseminated to specific, harder-to-reach populations, snowball sampling was also introduced towards the end of participant recruitment. Potential participants were invited to express their interest in participation by filling out an online survey or by returning their Participant Interest Form in person or by email 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 Information Sheet.

Further to this, potential participants were also asked to supply key demographic information, which was then used to select a final sample that attempted to capture and reflect the diversity of families and close supporters of disabled people, and the housing experiences of the people they support. The Research Information was clear that not everyone who expressed an interest in taking part in the research would ultimately be selected as a participant. 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.

To be eligible to participate in this research, participants needed to be over the age of eighteen, and able to provide full and informed consent. Informed consent was documented at the outset of each interview.

8.4 Interviews (Data Collection)

Individual interviews were the primary method of data collection, with one or two researchers from the DBI research team assigned to each interview. Due to the impact of Covid-19, and in order to ensure participant safety and adherence to the alert levels, all interviews were conducted via phone, WhatsApp or Zoom. Interviews began with the researchers going through both the Project Information Sheet and Consent Form with the Interviewee, before Interviewees were provided with the opportunity to ask questions and sign the consent form. Interviewees had a clear understanding that they could withdraw at any time, with all Interviewees opting to provide consent verbally using a video or audio recorder.

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.

8.5 What we did with Interviewee Responses (Data Analysis)

Each interview was audio or video recorded and transcribed into a verbatim transcript. 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 automatically 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 and any information that could identify the person has been deleted from the quote.

The 11 interview transcripts were then compared and contrasted. 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. These trends and patterns were then coded and grouped under key themes in order to capture significant meanings (Thomas, 2006). 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 the Interviewees (Patton, 2002).

Finally, once the report had been drafted it was then reviewed by two family members of individuals with multiple and complex disabilities, the DBI research team, the Office for Disability Issues, and the DPO Coalition, to ensure that the findings were an accurate representation of the issues at hand.

8.6 Ethical Considerations

This project arose after concerns were raised relating to the inclusion criteria of the wider housing monitoring report, and the necessity of free and informed consent. As a result of the participation criteria, important groups of people from the disability community were unable to participate in the initial cycle of monitoring research. This included people with multiple and complex needs who were unable to provide free and informed consent on their own behalf, and their family/whānau members and close supporters. As highlighted earlier, people with complex disabilities are amongst the most disadvantaged groups in society, therefore it is crucial that their experiences are included in UNCRPD monitoring. This led to the Health and Disability Ethics Committee (HDEC) approving amendments to the initial ethics application, enabling the inclusion of family/whānau members and close supporters of people with complex disabilities.

To uphold the values of UNCRPD monitoring, such as those articulated by the DRPI research model, this research was conducted by disabled researchers (Monitors). While the Interviewees did not identify as disabled themselves, they were invited to participate in the research on the basis that they “know the profoundly disabled person well and can communicate with them effectively” (Moss, 2017, p. 2). In order to maintain ethical standards of research, all Interviewees were required to agree to: “only speak on my own behalf, and not on the behalf of others”. This was achieved by encouraging Interviewees to provide their own unique perspectives, in relation to the person they care for.

This monitoring research was approved by the Northern B Health and Disability Ethics Committee (HDEC) on 22 of January 2020 (19/NTB/15/AM01).

9. Participants (Interviewees)

The aim of this section of the report is to provide an overview of the basic demographic details of the interview participants without revealing any information that could personally identify them. Of the 11 Interviewees, ten identified as female and one as male. The youngest Interviewee was 35-years-old and the eldest was 85-years-old, with the average age of Interviewees being 57 years. Four different ethnicities were self-identified amongst the Interviewees, with Pākehā being the most common. Among the Interviewees, ten identified as a mother of a person with complex disabilities, while one Interviewee identified as a social worker. Six interviewees lived in Tāmaki Makaurau (Auckland), two interviewees lived in Ōtepoti (Dunedin), two in Kirikiriroa (Hamilton), and one in Whanganui-a-Tara (Wellington).

Interviewees were also asked to provide basic non-identifying demographic information on the disabled person they were supporting - four females and seven males. The youngest being younger than 10, and the oldest being older than 60, with an average age of 26-years-old. Six different ethnicities were identified among the disabled people supported by the Interviewees. Eight had disabilities from birth, one acquired disabilities at a young age, and two had recently acquired disabilities from injury. In regards to their living situations, six lived with family at home. More specifically, one family lived in a private rental house, while five other families were homeowners, two of whom had built their own home. One family lived in a Kāinga Ora house, two people lived in a group home, one lived in emergency housing (motel), and one person was living in a rehabilitation centre.

It is worth noting that the interviews were designed to capture their current and past housing experiences. As such, some stories that have been shared do not necessarily reflect the current living situations listed above.

10. Findings

The findings of this report have been arranged according to key themes that emerged throughout the interviews. The first finding is choice and control, which underpins most, if not all, of Interviewee experiences. This is followed by findings relating to access, physical and psychosocial wellbeing, relationships, and awareness of rights. Following each finding is a brief summary of the key issues, before relevant UNCRPD articles are listed, as well as suggestions of who might be interested in or concerned about these findings.

Throughout these findings, priority has been given to the experiences of 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 (researcher) and the Interviewee (participant), 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 (Interview #1), (Interview #2) and so on, with identifying details removed from quotes.

10.1 Choice and control

For many families and supporters of people with complex disabilities, choice and control are the cornerstones of both the wellbeing of the disabled family member, as well as the wider family/whānau unit. When discussing choice and control within the interviews, it was primarily in reference to Article 19 of the UNCRPD, which states that as a States party to the Convention, the Government of New Zealand must “recognize the equal right of all persons with disabilities to live in the community, with choices equal to others” (United Nations, 2006). This includes a disabled person’s ability to choose where they live and with whom; access to in-home, residential and other community support services; as well as services and facilities that are available to the general population.

10.1.1 Will and Preference

In Outcome Seven of the New Zealand Disability Strategy, it is further clarified that in Aotearoa New Zealand, when an individual cannot exercise choice and control on their own or with support, decisions must be made based on their will and preference:

In the rare circumstances when decisions need to be made on our behalf, they are based on the best interpretation of our will and preferences, as opposed to just thinking about what is in our best interests. Needing support does not diminish our independence or our ability to have choice and control over our lives. We will make informed choices based on what is available, rather than settling for a less desirable option because that is all that is offered to us. (Office for Disability Issues, 2016, p. 36).

For the Interviewees who contributed to this monitoring research, choice and control were multifaceted phenomena. Given that the disabled person they cared for was restricted in their ability to directly exercise their own choice and control, most Interviewees indicated that their living circumstances were primarily determined by meeting the best interests and basic needs of the person they cared for. Will and preference, on the other hand, were perceived to be aspirational and desirable goals that were limited by the lack of choice and control.

10.1.2 In-Home Services and Supports

Individualised Funding (IF), for example, meant that on paper family/whānau members of people with complex needs had choice and control over the in-home services and supports their disabled family member received. However, the types of services that were available, location of services, as well as the qualifications and suitability of support workers, meant that families often felt like they had little to no choice or control over who came into their home and when.

“[T]his is not a very desirable job, looking after someone, especially personal care. And the changing nappies of an older child is not nice. And working in an environment where you cannot interact and talk is not nice, and perhaps some kids might be aggressive. So, that is why it is not a pleasant job and then it is minimum wage. I tried with the minimum wage, it’s very hard to find someone [...]. So, only those who are desperate and maybe just need something will respond, and those are usually have no qualification, people who are not employable in any place. [...] And then if you look at the groups according to their age and ability, there is not much people that I can hire. And I often ended up hiring people randomly, from street adverts or noticeboards or Facebook and it’s very hard. I’m a single person and we have no male person at home and our safety and security would be jeopardised if I just bring someone, even if I don’t like someone, I cannot talk to those people and tell them I don’t like you, you’re fired. Because they can do anything to us. They have full access to our home, they know how we live, who we are, where my son goes, where I work, they have all of our information because they have basically become part of our family in two or three months so it becomes very hard hiring people, especially for a person like me.” (Interview #7).

For one Interviewee who is a single parent, the complexity of the disabled family member’s needs meant that some support workers had refused to work with them. This meant the family felt compelled to accept whichever support workers were available and willing to provide care, which in turn impacted upon their choice and control. This Interviewee also reported that a lack of services in their area meant that her son could only attend school or respite care on certain days. Furthermore, because the Interviewee did not have a driver’s license and care hours were restricted, the whole family (including a sibling) were regularly confined to their rental accommodation for extended periods of time.

“I have problem to take him to respite myself. Because I sometimes can’t get a driver. My friend is busy or my Dad is not feeling well so they can’t take him to respite or pick him up. [...] I can’t have the respite and spend the time with my older son but because of that [...] I have to cancel the respite sometimes on the weekends or the holidays. Yes it is a very very big challenge for me. Like I said, I’m trying my best to get my licence but the depression comes in between and memory loss as well sometimes.” (Interview #6).

“We don’t have much respite around [place name]. Like say my son goes to [organisation name] for his respite, and other places say he is very complicated and we can’t look after him. [...] So, basically right now when he goes to respite, he goes on a Wednesday and then he comes to school on a Thursday, comes to school on a Friday then he comes home from there. So he misses one day of school while he is at the respite because it’s too far away. They can’t have transport picking and taking him back because it is too far away. And he cannot travel for that long, it is very hard for him to travel. And he doesn’t like travelling for long. I don’t get weekends off. It’s very hard for me to leave my son there [respite] on the weekend. It’s very hard. They don’t have the slots for the weekend. Basically parents need that weekend but they don’t have enough space for kids to be there at the same time. I would love a weekend because my [older] son comes on a Friday so that I can take him out to a movie or maybe just take him to the family’s place and have a little dinner with families and stuff like that.” (Interview #6).

10.1.3 Post-Rehabilitation Accommodation

Another Interviewee whose daughter had recently acquired a complex disability articulated a lack of choice and control when it came to housing options post-rehabilitation. Funding for the rehabilitation facility where the Interviewee’s daughter is currently living is based on the progress of her rehabilitation, meaning there was a time limit on how long she could stay at the facility.

“They won’t allow her to be there [rehabilitation facility] for a long time because the funder won’t allow her to be there for more than the thing is suitable for her. It is suitable for her, but the funder will want to measure her continuance, to measure the further progress she is making, if she is making further progress, they think it is worth putting for her to continue to be there. But if her progress is slowed down or plateaus to a certain level, they think she needs to move to a longer-term care facility. Or even home care if that is possible.” (Interview #9)

“We [would] like her to be home with her family. At the moment, there’s not much choice, I think. Mostly it’s private hospitals for elderly people. I think they are still figuring out where to put her. The funder I think also finds not

much choice for them. They would prefer actually that she can stay home, because based on her situation, she is so young, only [age]. And she has [list of family members] - a family that she really misses them I think. To be able to stay home would be the best. Staying home [would mean] being able to find suitable housing for her. For the moment, we really don't know whether New Zealand got this housing provision for people like her. But immediately I think if she needs to move out, I think they're trying to find out whether any residential facility, most of the residential facilities, they don't have [injury type] with that type of severity. Looks like they just couldn't find anything at the moment. Whether they're going to work out a package or how, I haven't heard from them. From the Ministry of Health I think. But they did try to identify one elderly care facility hospital I think, eventually they found it was not suitable. During the lockdown time, before when we were in Level Three, we did come together for interview, for discussion. But I think, so far I haven't heard from them. From what I know it's really very limited. Because she needs 24/7 nursing care. Most of the residential don't have 24, they have nursing care probably until 10:00, 11:00 at night, so they don't have overnight nursing care. Even the aged facility, that have nursing care I'm not sure, they probably don't have that intensity. Now she is in [facility name] she is being cared for 24/7." (Interview #9)

10.1.4 Access to Information

Choice and control were also limited by difficulties in accessing information on what funding a disabled family member was entitled to.

"[T]hings are not really transparent and clear, the government rules and policies, you have to go through and it's like you're in the middle of nowhere or in the middle of a maze house. You don't know where to go. You go somewhere and when you have a problem or issues, and when you resolve it, then you find out how you reach or resolve it. It took me two or three years that there was some sort of funding available and that I could use it more efficiently rather than an agency and the Government doesn't give you all the cards first, they give you what you think is best and you have to work that out first and when you really, the Government only shows you the next card if you become really tired and run down and exhausted. So, I have gone through five or six stages of that kind of period to reach the next level of help." (Interview #7)

Another Interviewee who is a parent to a child with complex disabilities had been told they could only access funding for a single bathroom modification in the child's lifetime. Because the family had used up their allocated funding on a former property, there was no support for modifications to be made in subsequent properties.

“From what I gather, they will only fund one bathroom modification in the lifetime. When we were needing to move for the other members of our family to have what they needed, every house we looked at we had to factor in plus the extra to renovate the bathroom.” (Interview #11)

10.1.5 Housing Market

The challenges identified above were further heightened, with two Interviewees recalling the difficult circumstances they faced when selling their home. Given the lack of accessible rental properties available, the families were caught between homes, with one being forced to live in an inaccessible property - inhibiting choice and control throughout the transition period.

“When we did find it, you need to find your house and secure the purchase of it before you can even start trying to sell the house that you’re in, because you can’t risk selling your house and not having the new house ready to move into. A lot of people will sell a house and rent for a little while, while they look for the exact right thing. They’ll know exactly how much their budget is, because they already have sold their house and have that money. That was another consideration. We bought this house and then the old house didn’t sell for as much as we thought it was going to. That added a bit of stress on it as well. But obviously not as much stress as it would if we had to rent. Because we’d never have found a rental that was suitable. You effectively end up homeless because there’s nowhere that you will fit that has what you need for whatever period of time that you need it between selling and buying. So you have to buy first, well I did, for my own security. So that’s something that, if you didn’t have a disabled person in your family, and have a bit more flexibility in how you do that. It does limit your options. What order you do things in.” (Interview #11)

“We moved in here as a temporary arrangement while we built the house that was accessible. We are in a compromised house, we have two bedrooms and we’ve got five people in our family. We’ve been here for two years now [...]” (Interview #8)

10.1.6 Knowledge, Support and Resources

For Interviewees who did have access to knowledge, support, and resources, there appeared to be a wider range of options and choices available. This meant there was greater capacity to ensure choice and control within the home which was driven by the disabled person’s will and preference (rather than only their best interests). For example, one Interviewee who is a home owner reported that their family circumstances meant they could purchase an adequate home in an area that was based on not only the best interests of the disabled family member, but also his will and preference.

“He has Autism and he needs a bit of space where we live, so going smaller wasn’t an option for us. But we just decided that we would just set the zone

of the school as being the perimeter of our search zone and that's what we decided to do so yeah." (Interview #3)

"He actually doesn't choose to go in his room very much during the day. In fact hardly ever, he prefers to be in the family areas and in a sunny bedroom but that's another reason why the house is good because there are a number of inside spaces he can choose. The master bedroom or the living room which is very sunny or we've got a big kitchen and dining area with a big seating area so he can also go there. The house is on three different levels and I think that just gives him a sense of movement around the house. If he needs to move he can do that." (Interview #3)

10.1.7 Community and Supported Living

A further challenge related to the evolving needs of the disabled person who Interviewees were caring for, most of whom needed 24/7 support. When considered alongside the wider housing report, where most disabled people who were interviewed followed a traditional life's trajectory and moved away from their familial home during early adulthood, the families interviewed in this report did not feel that their disabled family member had the same choice and control. In fact, many felt abandoned by social services once their child had left the education system.

"They get everything up until the time they leave school. The moment they leave school there is just nothing. Done." (Interview #2)

In circumstances where community living was an option, it tended to occur at a much older age than the general population. The transition required a significant amount of time, planning and preparation, and did not always go according to plan.

M: And was it hard for you to find a place for him?

I: Very very very difficult. We've been trying since he was 21 so several years.

M: Wow, so that was the first time he successfully moved out of your house?

I: Yes, he used to go for respite but other than that, it's the first time he has totally lived away from home.

M: I see, he must be, he was born in [year] meaning he must be [age] so you've been trying for 15 years.

I: Yes, we kept getting promised things and they kept getting squashed." (Interview #2)

"She found it difficult because my mother died a couple of years ago and I moved into her little unit and it wasn't well set up for [name] really, ultimately. So, yeah, she has had her own house through Housing New Zealand for the last four years. [...] When she got it [Housing New Zealand house], she was relatively mobile and it had eight steps up the front and within the year, and a

very tiny bathroom, I have to say. She was then only supported by one person at a time during the day and night and so it did meet her needs at the time that she moved four years ago but within about a year, her condition deteriorated quite a bit and so we had the house assessed to see if we could make any alterations to make it accessible for her but it wasn't possible. So, three years ago we put into Housing New Zealand for a modified house for her and it took until August last year, so she's been here, I guess it's close to nine months now, to finally get an accessible house." (Interview #1)

It was also noted that families felt the range of supported living arrangements were limited, and at times, inadequate. This led to questions over whether the individual's will and preference could be more effectively realised within the family home, or in the community.

"You know there's that phrase, 'home is where the heart is' and the heart of your life isn't it and we think about the choices that we had as young adults at university or heading out of university and the places that we choose to live in and who we choose to live with. And a lot of it is about choice and we make these choices for [name] and with his input as far as he is able to do that. But being part of a safe, welcoming, vibrant community is super important. So, when I see these residential providers purchasing group homes and they're just stuck in some big suburban area, it's you know, soulless. Yeah, it's just not the right thing to do." (Interview #3)

For family/whānau members of disabled adults in supported living arrangements, they continued to experience challenges when training support workers, especially when it came to will and preference.

"That's been interesting too because trying to explain to support workers that this isn't your place of work, this is [name]'s house and so I'm pedantic about people knocking on the door when they come. I always do it when I come to stay with her and I might just open it and call out and say, "Hi can I come in?" Sometimes she says no and I say, oh well that's fine and then she call's out no no no, come in so yeah. I think that's really important because I wonder whether support staff ultimately don't see more, that this is about a life for [name]." (Interview #1)

10.1.8 State Housing

One Interviewee who is a social worker also noted that the lack of accessible Kāinga Ora homes meant that someone he currently supports had no choice and control over their living situation. Having recently acquired a significant injury, the disabled person and his whole family had been moved to a motel because there were no accessible state houses available. At the time of the Interview, the family had been living in the motel for several months.

"[T]hey'd prefer to get state housing but they may have to go to private rental first. [...] I think it would be quite a stretch if they went to a private rental." (Interview #5)

10.1.9 Changing Needs

A final point relating to choice and control was the evolving needs of the person who families and supporters were caring for. This was linked to both the often fragile nature of the family member's health, as well as the impact of their changing needs throughout the course of their life. For the most part, Interviewees felt that supports, services, and legislation, were not responsive to the disabled person's changing needs.

"We can extend the bathroom now but in the future he will need a bigger room and we will have to go back to Housing [New Zealand] anyway. So, at the end of the day I'll have no choice but to go back to Housing [New Zealand] and going through the application again and telling them that I have been through agencies and get the proof that I have been there and provide it to them."
(Interview #6)

"Yes, as the time comes, our kids will grow up and we'll need a bigger and wider place to move around. With wheelchairs and things like that, to make life more easier for us parents because the stress that we go through." (Interview #6)

"I'm becoming older and fragile and not as strong. While my son is the opposite. He is growing bigger and heavier and stronger. His father was a big tall person and once he becomes bigger how will I lift him? And not only that, because I'm [age], I might not have long until I lose my job so how could I build a house? So, I knew that I had to rush and I knew that a couple of years ago and knew that I should build a house. I tried to alter my old house but it was a split level house and it was very difficult so that is why I decided [to build an accessible house]." (Interview #7)

"I haven't been able to put my child into the bath by myself independently for a wee while now, and my husband is just getting to the end of his ability to do it. Because really our house is too small, we cannot get a hoist into the bathroom or into my son's bedroom. Because it's got a really narrow hallway and you can fit the hoist, it is too big to make the corners. So, I either have to rely on the carer, so I can do two persons lift with my carer or my husband is putting him to the bathroom.

M: By himself?

I: He does. But he's just got to the point where it's a bit much for him.

M: I can imagine it's quite a toll on the physical side.

I: Yes it is.

M: And your son is growing.

I: Yes he is growing a lot. Bath is the worst one because you have to lean over as you are doing it. So it's the biggest strain on your back and things."
(Interview #8)

10.1.10 Choice and Control - What are the Key Issues?

The families and close supporters of people with complex disabilities reported a lack of choice and control when it came to adequate housing and living conditions for the person they care for. Limited funding, inaccessible funding information, together with a lack of support workers and access to service providers meant that the disabled person's basic needs were likely to be prioritised over will and preference (as described in the New Zealand Disability Strategy). Family/whānau members also indicated that current services and supports were not responsive to the changing needs of both the disabled person and the wider family/whānau, and that there is a lack of community living arrangements that can provide the same, or higher, level of care than can be provided within the family/whānau home environment.

10.1.11 What Articles do they Relate to?

UNCRPD Preamble

Article 4 – General obligations

Article 5 – Equality and non-discrimination

Article 7 – Children with disabilities

Article 8 – Awareness-raising

Article 9 – Accessibility

Article 10 – Right to life

Article 12 – Equal recognition before the law

Article 17 – Protecting integrity of the person

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 28 – Adequate standard of living and social protection

10.1.12 Who Should be Concerned?

- Kāinga Ora
- ACC
- Ministry of Health
- Work and Income New Zealand
- Ministry of Housing and Urban Development
- Central Government
- Local Governments
- Disability service providers
- Social service providers

10.2 Access

When considering access, four key themes emerged across the interviews: access to the housing market; financial accessibility (affordability); access within and around the home; and access to the community.

According to Article 9 of the UNCRPD, in order for disabled people to live independently and participate fully in all aspects of life, the Government of New Zealand must ensure they can access the physical environment, transportation, information and communications, and other public facilities and services, in both urban and rural areas. When it comes to housing and accommodation, the UNCRPD states that disabled people must have access to adequate housing and the continuous improvement of their living conditions, without discrimination on the basis of disability.

10.2.1 Access to the Housing Market

According to the Interviewees, it is difficult for families of people with complex disabilities to access appropriate and accessible housing in a timely manner. For example, as summarised by one Interviewee, the list of accessibility considerations is long and the housing market is not prepared to accommodate those considerations.

“A lot of houses that you go to look at, they’ve renovated the bathroom to put it on the market so it would appeal to buyers, the bathrooms only just been finished, and the first thing we’re going to have to do is rip it out. Which is a waste. Some houses we went to look at, they had an internal access garage, you think that’s great, it will be nice if we’re moving to not have to put the hoist down after the van and get it out of the van in the rain, but then they had steps between the garage, even though it was just a doorway between the garage in the house, there was three steps. It may as well not be there because we can’t use it. There is always something. Plus, I’ve got four children, we’re happy to have some of them share a bedroom but a lot of houses that had living rooms big enough had some bedrooms upstairs and some bedrooms downstairs. And I can see why your average family would like the parents to be separate from the children, so you’ve got your own space and stuff. But house size for predominantly two-storey, and the master bedroom was on a different level to the other bedrooms. I can’t sleep that far away, because if she calls out in the night, I need to be able to hear her. If the children’s bedrooms were upstairs, I’d be carrying her upstairs every night and downstairs every morning. And if the master bedroom was upstairs, firstly I’d be afraid I wouldn’t wake up and secondly if I do wake up, I’ve got to go all the way downstairs to figure out what the problem is and fix it and then try to get back to bed. Whereas here, all the bedrooms are on the same level, so you just roll out of bed and get the job done and they’re all back. So it doesn’t feel like you’ve interrupted your sleep as much as having to get conscious enough to go up and downstairs.”
(Interview #11)

Another example can be found in the state housing sector. Under Article 28.d of the UNCRPD, disabled people must have access to public (state) housing programmes. However, for Interviewees who were engaged with the state housing system, they reported waiting long periods of time until their family, or the person they were supporting, could move into a state home that suited their specific needs. According to one Interviewee, they had been on the waitlist for an accessible Kāinga Ora home for two years, before discovering that families without access requirements had been prioritised for state accommodation.

“Yes, it appears that accessible housing is very difficult to get through Housing New Zealand. I was a bit annoyed because we found out that the family that was here before, nobody was disabled yet it was set up for a disabled person.”
(Interview #1)

For the family who had been moved into emergency housing (motel), the newly acquired health and disability challenges they were experiencing were magnified by the inadequacy of their living arrangements.

“The [organisation name] has a contract and they have to find houses within a certain time but it’s unlikely that they’ll find a house within that certain time because there are no houses in [place name]. [...] They don’t have anywhere to go. They feel under pressure, because the motel is not permanent so they do feel the pressure of needing to find a place so there is always that unsettled feeling that they have.” (Interview #5)

In addition to this, the attitudes of people in positions of power within the state housing sector had caused distress, as well as further delays in finding adequate accommodation. For example, one Interviewee had been in ongoing discussions with Kāinga Ora for an extended period of time, only to find out that the accommodation that was eventually provided was unsuitable for the disabled person’s needs.

“Housing New Zealand is quite funny about allowing you to see it before your moving date so they told us that [name] was going to move there next week and the moving truck was arranged for Tuesday, this was about the Monday the week before so I said that’s great, can we go down and have a look at it and they said no. The people that were here before had clearly made a huge mess of it and I can understand they didn’t want us seeing that so much. Anyway, in the end I managed to convince them. I said I need to know that the fridge is going to fit, which wasn’t true at all. [...] So we got in and had a look around except [sibling’s name] said, “I don’t think [name]’s wheelchair will fit through the door.” So, between the laundry and the kitchen there so I said, “Well, I’ll measure up the wheelchair.” So, we measured up the door which was 68cm and we measured up the wheelchair and it was 74cm so I rang them straight away and said, “You just need to widen that doorway because otherwise the wheelchair won’t go through there and access to the house is through the laundry.” So that was the beginning of it. We had to

go through a ridiculous process. They asked us to go and get a community OT [Occupational Therapist] assessment and I said there and then, it takes at least six to eight weeks to get a community OT assessment through the DHB [District Health Board]. So, I went down to the office and got them to tell Housing New Zealand they couldn't do it and in the end they got an urgent OT around and they agreed and they needed to put a rail in the shower and put some more concrete out on the driveway so her wheelchair could be run up beside the car there. So, then had to go back through [organisation] and the Ministry and then, who was going to fund it? Was it going to be Housing New Zealand or was it going to be the Ministry of Health? So, this went on and it took us three months before we could actually get in the house. The whole process, and I had all sorts of people contacting the regional manager trying to hurry it up for us including [advocate name], so I contacted her and said this is crazy. And of course we were packed up. We were ready to move on the Tuesday so we lived in [name]'s other house with it half packed up for the three months until we finally moved her down here." (Interview #1)

The attitudes of people in positions of power - such as authorities within the construction industry and governmental agencies - had also caused distress and delays in securing adequate accommodation. As summarised by one homeowner with experience of building an accessible home, she felt it was her responsibility to always be one step ahead.

"Well one thing I have learnt is that you stay one step ahead, rather than wait for them to do things and then you sort of just mention them a lot before they happen. And I guess I've learnt that because I'm on some posts with other people, not specifically around housing but other people who have had experiences. It's just really heightened my awareness that I have needed to be really proactive about making sure they get the point before. And it's something I really said to them a lot was I need you to get these disability things right." (Interview #7)

10.2.3 Affordability

Another key factor of accessibility was affordability. Article 28.c of the UNCRPD ensures that disabled people are provided with disability-related expenses, including adequate training, counselling, financial assistance and respite care. However, Interviewees articulated that the financial support provided by health and disability funding systems was insufficient to meet the disabled family member's basic needs, especially within the private rental market.

"Well up until four years ago when [name] had her Housing New Zealand house, we had to privately rent houses for her, thank goodness it stopped four years ago, I thought I'd be working forever. Rent, I think the highest she paid was about \$485 and so she paid a small portion out of her benefit for that and she got a bit of temporary supplement [...] but I had to make up all the rest of it and rentals in [place name] are through the roof." (Interview #1)

“We still have a mortgage but the real financial issue is if we had to rent somewhere else for my husband and I to live [while the disabled family member lives in the family home], that suddenly starts getting really expensive. Particularly because we’d still want to be close by and it is an expensive area to rent in.” (Interview #3)

Inconsistencies between different funding systems were also reported as barriers to adequate housing. For example, one Interviewee whose child is funded by the Ministry of Health described her experience of trying to access funding for an accessible home.

“They [the Government] were saying things like in a new build we don’t fund this because it’s not more expensive than normal and they said that about all sorts of things and I actually thought, it’s not actually true. [...] It’s expensive because you’re paying for more concrete, more flooring, more everything for gaps, if you weren’t doing it for disability you would be paying less because your house wouldn’t need the big spaces and the bigger gaps.” (Interview #8)

“I looked at the cost contribution and it just provides a big excuse why they weren’t going to pay. So, all I went for was the ceiling hoist and they only wanted to pay for half of that.” (Interview #8)

On the other hand, an Interviewee whose child was funded by ACC felt the funding for home modifications were generous.

“We built a house and ACC [Accident Compensation Corporation] gave us money towards it. Like they gave us seventy thousand dollars towards all the modifications for the house which I thought was amazing! [...] I don’t know what other people get for building houses. It does seem to be quite a lot. No one ever tells you though. But I know two people that have built houses through ACC, children with ACC funding and they’ve both said, yes oh it’s very generous what they give you. But no one’s ever actually said numbers before. Like we were shocked. We thought we’d get ten thousand.” (Interview #10)

However, for the family of the person with a newly acquired disability, the ongoing legal battle over whether ACC or MoH would provide funding was impacting on their ability to find accessible and adequate housing.

“At the moment she is with the Ministry [of Health], because her claim to ACC they declined in the first place. [...] We are putting up an objection, a lawyer representing her to ask for a review. Her case will be reviewed, I think [...] Because obviously, the lawyer thinks there is grounds for the loss of opportunity for proper treatment in the hospital. So, he wants for an explanation, an investigation into that. So, I hope that will come out with something positive that will give her more options for her care, her level of care will be really high. The Ministry of Health, they have limitations. [...] Once we move her out of that facility, if she had ACC, they will have a continuation

there now. If she is not under ACC, under MoH, that continuity will depend on how long is the queue for that residential therapy to be coming in. We won't accept her going into any residential without the continuation of the therapy team to be with her. And having doctors available if she needs it."

(Interview #9)

Again, adding to the distress around who would fund the transition from the rehabilitation facility into the community, was a lack of access to health and disability information, and in particular, funding entitlements under the different systems.

"M: If you can transfer to ACC, do you think there is a potential for her to come back to live with you or stay by the family?"

I: We definitely want, because if she comes back home, if our home is suitable, that is fine. The thing is our home is a two-level home, so the access will be quite hard for her. The innovation that the Government [Ministry of Health], the funder will support is just one-off for her lifetime. You cannot change to any other premises. Eventually if you want to move, there won't be funding there. Eventually if she moves out, it would be better to be home. We are not sure if there is any housing, disability committee or body that has housing provision. I have no idea, at the moment. If there is, her [family], they can stay together. Her husband's desire is to stay together, that she can stay together with the family. That is our wish and also what [name] wants. Earlier when she still could talk a little bit, she tell us when she can go home? It's her heart, her desire to be back home I think. We are trying to figure out, is there a way that we can find accommodation that is suitable for her? I think it should be one level house, single-storey house. This would be easier for her access in and out. With the two levels, to climb the stairs with her wheelchair is hard, difficult.

M: Yes. I'm also in a wheelchair so I know how hard it is to climb stairs.

I: Housing, the funder told me housing provision or subsidy is not from them. So it should be somewhere else. I'm not sure how much that support will be. Besides income or any other support, I'm not too sure on that. [...] Now the main thing is where she is going. The best option we think is she stay home. She come back to live with her family and see her [child] growing. Can see her [child] every day, to see him growing. Now for the past few months, she can't visit him, she misses so much. Previously he used to visit for a few hours every day. Now it's not... She can see him on the screen sometimes but not really in person. So it would be better for her to see her [child] growing."

(Interview #9)

"It's quite challenging yeah. [...] Homecare, we need the financial support. The family can't financially support her in the long term. So we need the Government to come out to support her care." (Interview #9)

Another Interviewee, who is a homeowner, had sold the family home to invest in a new build scheme. In order to adapt the developer's building plans, she paid a \$30,000 variation fee for modifications that would allow her child to safely access the house. However, upon inspection of the construction site, she was devastated to learn these had not been fully implemented by the developers. The Interviewee - a single parent - was forced to pay additional fees to ensure her child could live in the new house, in addition to legal fees to seek reimbursement for the modifications that had not been completed.

"I would come at each main stage and would check and then there's variation costs started building. I said, "Look you charged \$30,000 to \$40,000 already." They said we didn't tell you these were included. They were separated. So, for example, I would want this many power points and they need to be at least one metre height for wheelchair user, so that goes up. On top of the variation costs they also charge their margins of 15% and I needed every job, I wanted to find my own contractor who could do things cheaper but they wouldn't allow me. They said, this is a land and house package, you have to choose to go through our contractor. So, when I go through their contractor, things are very expensive, but I had to accept. So, those things added another \$70,000 on top of the \$650,000.00. So at the end of this house, almost \$800,000.00."
(Interview #7)

When asked about the developer's attitudes towards the family and disability access during construction, the Interviewee noted:

"You would think that if you paid an architect, would think of those things but it didn't happen. I raised these things during construction time but they just ignored me. They bullied me and intimidated me because it is just me, like I am a single person, I would always visit on my own. So, they would take advantage of me. Then I hired two lawyers and I'll say it costed me \$8,000. So at least that should have given me \$60,00 - \$70,000 worth of compensation but I only ended up getting \$10,000." (Interview #7)

The impact of this experience on the family resulted in significant financial and psychological stress. Given that this interview was conducted during Covid-19 Alert Level Four, the Interviewee was also aware that she was at risk of being made redundant and was fearful for her family's situation.

"I work full time but it looks like I will not be able to work full time after this virus crisis, because I need to look after my son. Because finding carers is so difficult so I finally opted to look after my son. I had to change my hours, the day we had our meeting, I work for [workplace], and we had been told that there might be some redundancies and that I might be included in that redundancy as well." (Interview #7)

As summarised by one Interviewee, the financial barriers to accessible housing when a family member lives with complex disabilities are significant.

“Because having a person with disability does make you poorer. For us, we’ve had to sink a lot of money into this and we’ve been fortunate that we could do that but we definitely shouldn’t have to do that but if you haven’t got much to start with then it’s not fair.” (Interview #8)

For another Interviewee who had previously lived in an accessible state housing arrangement, an attempted break-in had left the family feeling unsafe and traumatised. Having had little communication from the housing provider, they requested to be transferred to accommodation in a different location. After two years of waiting for a response, and increasing anxiety around their safety, the family decided to leave the housing provider and move into a rental which was owned by an extended family member so that they could be closer to family.

“So, basically they couldn’t find me a proper house. So, first I said it was cold, and they said just to use the heater. And another thing, when the break in happened, there were not much support from [housing provider], they were not checking if we were safe or not, nobody rang me up to see if I was safe or not. But I was expecting someone from [housing provider] to see how we were doing after that. [...] They said I could reapply, so I reapplied for [housing provider] and I said that I would wait and I waited for a couple of... I think it was two years I waited for. [...] And the other option was, you can look for a house with private rent and they offered me private rent where someone can fix your bathroom and all that that was another option I had. I was told to go and look for another house but with my bank credit I can’t go through the agents to get a house. And I don’t even know if the tenant will allow me to make the house bigger, you know, do things like that. [...] My uncle said this house was empty and I could have it if I want, and even with my bad credit and rent me this house. [...] My parents are just next door so it is very easy for me to leave my older son with them and stuff like that.” (Interview #6)

However, as the family prepared to leave the public house, the child became extremely unwell and required a long period of hospitalisation. As a single mother, the Interviewee was required to spend most of her time at the hospital, and was therefore unable to clean the house before moving out. Following the property inspection, not only was she denied her bond, but she was also required to repay the housing provider a significant sum of money as reimbursement for cleaning the property on her behalf. This had left her in a significant amount of debt.

“It is very challenging and when I left the housing house I couldn’t make it to how they gave it to me. Because I was in and out of the hospital and I was trying to clean up the house to make sure it’s clean before I leave there and

what happened is they gave me \$1,300 or \$1,500 of bills to pay just because there were some things not right in there. But it was because I couldn't do it, I didn't have the money. And I was mostly in and out of the hospital and I tried explaining that, but they didn't understand the first time and so I just left it and then they called me about how I'm going to pay this and what's going to happen. So, basically I'm paying \$15 a week now towards that." (Interview #6)

As a single mother of two children, one of whom has significant medical needs and requires 24/7 care, the financial support they are now receiving is barely enough to cover the living costs of their three-person family.

"I actually pay my dad, if he takes me anywhere, I pay my dad \$30 per week and then \$50-\$60 goes to the van so all that and then I've got other payments, so in total right now, after the extra payment that I got, I'm getting \$447. [...] rent gets paid before my money comes in and then I've got power to pay for, internet to pay for, kid's clothes, food and stuff." (Interview #6)

As summarised by another Interviewee, funding for people with complex disabilities exists, but it is not always able to be utilised for what is needed to ensure adequate living conditions.

"It's weird, you can have a whole lot of funding in one pot but you can't spend it on what you need, and then the stuff that you need, they think no you don't need that - you just want it and you can't have it. Or if you want it, you have to pay for it yourself and it's ridiculously expensive so no one gets it. [...] Yeah, and there's a lot of that, there's a lot of things you hear of later that other people have managed to get. I don't know why it's like that. There's a lot of things that you can get that you don't want or don't need. They're quite happy to say you can have this money for this piece of equipment. We don't need that, it's not something that we would use. But we would use one of these, oh no, You can't have any money for that. [...] It's nuts, I give up. You never work out how the system works because it depends on who you get on any given day end it depends on who you are I suppose, and if they like you, probably? If there's a need and it can be met, meet it. They either really like you and change things to get you what you need or you're really annoying, so they get you what you need to get you to go away. And all the people in the middle just get nothing." (Interview #11)

A final aspect of affordability related to the ability of caregivers to maintain employment while caring for a child with complex needs. For example, most families indicated that they either had to reduce the hours they worked in order to care for their disabled family member, or not work at all.

"Since I had [name], me and my husband were trying to do part time, both of us, we can't both work full time, there's no way we can. Because [name] has about one appointment a week, and it can be any day of the week and he's

also sick and if he gets sick, we can be off for two weeks with him. So, we've always played it that we don't work the same day so what I was doing, the most I did was I worked three days and my husband worked three days, but we didn't work the same days because it just doesn't work out for us both. [...] I definitely think having a child like [name], means there is no way... I mean some amazing woman do it, but I really don't know how they do it. They must have really understanding bosses or maybe really supportive extended family, like grandparents, that can help them out. But my situation is that we can't both work on the same day because it doesn't work." (Interview #8)

"I'm not allowed to work, reason being my son gets sick any time and he ends up in the hospital and it's months or weeks that I have to be in the hospital and no employer will employ me because of that reason." (Interview #6)

10.2.3 Access in and Around the Home

Linked to affordability was the issue of access in and around the home. For the family who had moved out of public housing following a break in, the private rental home they moved into was not accessible and the disabled family member is unable to physically enter the bathroom. As a result, the child is washed outside with a bucket of water.

"So, he doesn't have a bathroom yet to have a shower in. He has a shower outside only when it's sunny. So outside, people walking on the street can see him. And it's not very nice but we don't have any other option. [...] We put water in a bucket, both hot and cold water, take him outside and wash him over. [...] The only time we give him a shower outside is when it is nice and hot is when we give him a shower outside because we don't want him to get sick. So, winter time is just sponge wipe, the whole winter." (Interview #6)

For the Interviewee who had invested in the new build scheme, the developer's lack of attention to access requirements had had a significant impact on where the disabled family member could spend his time within the home.

"So, for our son, our only area is near our table where there is a rug on the floor. So he spends time on that rug. It's a kitchen and family together, one huge open space. In the original plan there was an island so I removed that and we just have a dining table instead. But when my son is on the floor, the dining table blocks his views so he feels like he is isolated all the time. I cannot move my dining table so I have to check on him often. It is a concrete floor, there is vinyl over the concrete floor so it's very cold. So, sometimes he can do a little bit of commando crawling and then he comes over to the vinyl area but it's cold so I have to pull him back to the rug and then basically we are then blocked by the dining table because he is little. So, it doesn't really, I mean this house compared to most houses in New Zealand and our old home, it is ok and accessible, well better, but I wouldn't say it's the house I envisioned, designed and planned." (Interview #7)

This Interviewee also highlighted the challenges she had had with securing Government funding for modifications that would increase accessibility for her son within the home, such as a ceiling hoist. Given that the Interviewee's son needed a hoist to move around the house, an application was submitted to the Ministry of Health. The Interviewee was informed a ceiling hoist unit would cost approximately \$40,000 in total, with the Ministry of Health covering approximately \$12,000 of that. The Interviewee was required to pay the remaining \$28,000. In addition to this, the Interviewee had to agree to surrender the hoist into MoH ownership once her son no longer needed it - with no reimbursement of her initial investment (\$28,000). As previously mentioned, ceiling rails for the hoist were one of the modifications that were not fully implemented by the developer.

"I wanted the ceiling hoist to cover this lounge so that I can also bring my son in this room but unfortunately it was not included but I had still paid for those things." (Interview #7)

"I want to cuddle with my son and sit with him yet I cannot lift him and put him on the couch and sit together. So, I'd like to bring my son onto the couch and my family and friends could visit us and we could have some time together like that but we can't have that because he can only have access in a wheelchair. So, this [living room] is basically not usable for my son. Only able-bodied people." (Interview #7)

These same challenges were also noted by another Interviewee, who was also funded by the Ministry of Health, but under a different financial arrangement for their ceiling hoist - speaking to the inconsistencies, confusion and apparent contradictions experienced by different Interviewees.

I: And we've also joined the main bathroom with his bedroom and we're getting a ceiling hoist. And the government paid for half of that and we have to pay for half of it.

M: That's good that they can pay half of it at least. Did you have to sign any contract when you got that hoist?

I: We haven't got the hoist put in yet because we have to wait for the painting to be done. But basically, it's called a cost contribution that his occupational therapist did and we have to pay for it first and then they come in and check it over, and then they pay for their cost contribution. I think that's how it works.

M: I see and then the hoist will be permanently your son's?

I: Yes, interestingly it is, that hoist belongs to us but we have to pay for the repairs. Yes and we're getting a wheelchair that we might have to do a cost contribution to because we wanted some extra feature in it that they don't want to fund and they say, they own that so they're paying for the repairs but they own it, we don't own it so when he's finished with it, they get it, even

though we've contributed to it financially. We don't have any say in it. But it is interesting how different things are, there's the hoist in the van which they paid to put the hoist in, we paid for the van but we have to pay for all the repairs. So, there's different rules about who pays for what. And who owns what."

(Interview # 8)

In addition to physical access, the size of affordable rental homes (private and public) was also noted as a challenge. This was particularly relevant for people with complex disabilities who rely on hoists, wheelchairs, standing frames, personal hygiene items, and so on. For families in these circumstances, space was of the essence.

"Yeah, because the house is small. Not big enough. And when he grows up to be a teen it's not going to be big enough for him with his wheelchair and stuff like that so in future this house is not perfect for us." (Interview #6)

"I have a storage problem in this house where I am. He's got a sitting frame that I can put him in and do activities with him but there is not much storage so that stays outside all the time. And it is heavy so it's really hard to bring in and out. So, when it's a long holiday I actually put it in my room and I use that sometimes to do activities." (Interview #6)

The importance of having a large storage space for different equipment was highlighted by an interviewee who had dedicated space in her new accessible house.

"I know one of the features that's really important for me which I think is really significant for disability housing, we've got a massive storage cupboard and it's taken room out of our lounge. But I don't care because it's big enough to park up a wheelchair and then be able to charge it up as well. In the actual cupboard. And I can fit a standing frame and a walker in there. So yeah, we invested in a really deep cupboard that is really big." (Interview #8)

When interviewees were able to have choice and control over accessibility within the home as well as the size suited to the disabled family member's specific needs, there was a noticeable difference in the wellbeing of that family member, which had a positive impact on the whole family/whānau as a result.

"[T]he house is absolutely fabulous. It's really good, it's big, it's got three big bedrooms. So [name] has a room and she has two beds in there so myself or a staff member sleeps in there with her every night because of her seizures during the night and next door to that is another room which belongs to the cat. [Name] got a kitten for Christmas and she's gorgeous and so we were trying to make that into a snoezelen room. So [name] loves the hammock usually, so when she was in hospital I bought her a really big hammock much to the horror of the hospital staff, we had this big hammock in her bedroom up there since we were there for five months. So, the hammock is in there and she's got a little tent that she likes to crawl in there and have some space to

herself and we had some fairly lights but when we decided to get the kitten and it had to be inside for so long, [name] set that room up for the kitten and the third bedroom is where the 2nd staff member sleeps. [Name] requires 2 staff with her 24/7.” (Interview #1)

“[T]he choices are really important for him. Because he often wants to be with us but sometimes he wants to be on his own and he’d prefer to be in the sunshine so there’s a couple of options for him.” (Interview #3)

10.2.4 Access to the Community

A final key theme was access to the community. The location of accommodation was important to Interviewees as it embodied the potential for both the disabled person and the wider family/whānau to be able to participate in and contribute to their community. As stipulated in Article 19.b, disabled people have a right to be included in their community, in order to prevent isolation or segregation. Even so, it was noted that for many Interviewees, location and community access were low on their priority list, when compared to things like affordability. Interviewees expressed that they had little choice or control over where they lived, and were living in locations dictated primarily by affordability and accessibility.

“It’s not a long drive but [house location] is separated by a hill from main central [location] area. However, it’s still ok. A taxi comes and picks him up in the morning, so it’s about a half an hour drive [to school]. [...] You cannot have everything you know because the cost and finance decides everything. I knew this because it’s a trip, if someone really wants to make a trip, for example this is one of the reasons why I am now looking after my son, because it was difficult to find a carer and on top of that now I am a little bit further away from the central area because this area was the cheapest at that time.” (Interview #7)

“That was one of the deciding factors of buying here, we didn’t have to renovate another bathroom. [...] We did look at some on the other side of town but they weren’t suitable. That was the main deciding factor, going to look and the bathroom was upstairs or the master bedroom was upstairs and all the other bedrooms were downstairs, we can’t live like that. I guess we would have shifted out of zone if we had to, but it was nice to not have to.” (Interview #11)

For families who had more support, choice and control, there was greater access to their local community.

“When I come at 2.30pm on my days, she immediately leaps in the van and we go to a mall down the road. [...] she does love pottering around and she knows people there now and people smile and talk to her and things so that’s been really nice.” (Interview #1)

“He has all the various activities and roles outside the house and in the community, which happen during the week.” (Interview #3)

“We’ve got nice neighbours. We are a bit rural so we’ve got a little bit of land. It’s not a big bit of land, it’s only three quarters of an acre but we had nice neighbours and we liked where we lived, so we decided to stay on the same land.” (Interview #8)

“At our old house, we were out of zone for the special needs school that she goes to. So, I have to drive, drop her off and pick her up. But when we shifted, we actually shifted into that zone of that school. So now we have access to the Go Bus, they come and pick her up in the morning and drop her off. I’ve been doing it the last couple of weeks, after this whole lockdown business, but I’ve organised for them to start doing that again from Tuesday. Yeah, when I was doing it all the time, I didn’t mind it, and I was having to drop my other children off anyway. But once we shifted, my other children could walk to school, so it was like well I’ll give the bus a go. Now that I’ve been back dropping her off these last two weeks, I actually miss having the bus coming to pick her up and drop her off. It saves me a lot of time.” (Interview #11)

10.2.5 Access - What are the Key Issues?

Access to adequate housing included access to the housing market (public and private), affordability, access within and around the home, as well as access to the community. Interviews with families/whānau and close supporters of people with complex disabilities highlighted the barriers they continue to face when securing accessible and adequate accommodation in a timely manner - whether as private renters, state housing tenants, or as homeowners. People in positions of power reportedly lacked understanding of access requirements, or were impeded by systemic barriers, causing distress and untenable delays for families/whānau trying to improve their living conditions. The wellbeing of the disabled family member was impacted by the availability of funding, the location of available and accessible housing, which in turn determined connectedness to their local community. However, by necessity, location and community access were lower on the priority list than affordability and access within and around the home.

10.2.6 What Articles do they relate to?

UNCRPD Preamble

Article 4 – General obligations

Article 5 – Equality and non-discrimination

Article 8 – Awareness-raising

Article 9 – Accessibility

Article 12 – Equal recognition before the law

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 20 – Personal mobility

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

Article 28 – Adequate standard of living and social protection

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

10.2.7 Who should be concerned?

- Work and Income New Zealand
- Ministry of Social Development
- Ministry of Health
- Ministry of Business, Innovation and Employment
- ACC
- Kāinga Ora
- Disability service providers
- Landlords
- Real estate agents
- Tenancy Tribunal
- Insurance companies
- Developers
- Architects
- Lawyers

10.3 Physical and Psychosocial Wellbeing

While the physical and psychosocial wellbeing of disabled people featured prominently in the wider housing report, a key theme woven throughout this cycle of monitoring research was the physical and psychosocial impact that caring for a family member with multiple and complex disabilities has on caregivers.

10.3.1 Psychosocial Wellbeing

All of the Interviewees who were family/whānau members spoke about extreme fatigue, ongoing anxiety, and concern for the wellbeing of the disabled person they were caring for - particularly when considering the lack of support that was available - and the long-term nature of the health and disability conditions.

“Of course, I am not embarrassed to say that I am afraid. I am afraid. There was a question that you had asked about if I was worried and afraid, about if my current housing situation would change. Yes, there are a lot of things that I am afraid and worried about. I am the only breadwinner. This house is very expensive. How will I pay my mortgage? What will happen if my health gets worse? If I cannot look after my son? What will happen? That worries me as well.” (Interview #7)

“So [name] has a room and she has two beds in there so myself or a staff member sleeps in there with her every night because of her seizures during the night [...] spending time with [name] every five days limits my things as well, but also because I really want to know that when I’m not here, she will be [okay]. A very real fear we all share too is fear and anxiety about what will happen to our disabled loved one if we die. There is very little trust or faith in current providers so many of our families have adult children at home believing this is the only way they can enjoy the best life possible and be safe. Experiences and rumours abound along with media articles to confirm this anxiety and fear.” (Interview #1)

“When he was sick the first time, he wasn’t breathing and we were told if we were five minutes later he would have been dead and so that happened twice so that is what made me not go to sleep.” (Interview #6)

“Traumatising. And it’s also so horrible. We’ve been going through a really hard time. And now, ongoing is the least we expect is to have good care for her. Not something that we are asking for much, it’s a minimum that the authority, the insurer should be looking at.” (Interview #9)

For some Interviewees of young or adult children with complex needs, they had felt pressured to sign a Do Not Resuscitate Order (DNR), while others had been informed that their child had a shortened life expectancy. As a result, they had ongoing and underlying fears for their child’s life.

“She has an intellectual disability but she has quite good receptive ability and unfortunately people treat her like she doesn’t have that and talk about her in front of her and so that makes it really difficult too and she has quite a few strong autistic traits which are part of her condition which is a thing called [condition name]. I was told her life expectancy was five years, max. She turned [age in thirties] last November and so it’s been very difficult because adult neurologists have never looked after these kids [into adulthood] before.” (Interview #1)

I: I don’t think it’ll [housing situation] change because he’s finally got a place that somebody cares for him.

M: That’s good.

I: The only thing that is going to change is that our son passes away. We almost lost him this time last year so his health is very fragile.

M: That is very worrying.

I: It is very concerning. It is, because we’re still not getting appointments with doctors and things that we need but never mind. And we’re also very aware that he has outlived what anybody ever expected. So, it’s not in our hands anymore.” (Interview #2)

“The first time I had that conversation [DNR conversation] was in Starship and I cried. I was very upset because I had no support around me that day. And I rang up his father to check on him what he says, he had no answer. He blamed me for everything. And I had to make choices which now I feel good and bad also.” (Interview #6)

10.3.2 Physical Wellbeing

Caring for a family member with multiple and complex needs was also physically demanding, with familial caregivers often risking their own physical health for the wellbeing of the disabled person they cared for.

“I’ve got a bit of a bad back for obvious reasons, most of us have at this age, particularly from caring. But yeah, I’m really hoping that somehow, we can get a new provider and we can start improving [name]’s life for her.” (Interview #1)

“[H]e is almost 25 kg so now I have lots of pain in my chest and back, just lifting his bottom to change his nappy is a difficult task.” (Interview #7)

“I have managed to find a second-hand ceiling hoist that I want to put in so that we can put her from her bedroom into the bathroom through that doorway. And then she’ll be able to use the bath again too which she really enjoys, but it’s a bit hard on your back to get her into the bath and out of the bath. When she was little we just did it anyway, but a ceiling hoist would make that much

easier. Safer. Yeah, it's something we wanted for ages but couldn't get funding for." (Interview #11)

10.3.3 Persistence

Contrary to Article 28 of the UNCRPD, which ensures an adequate standard of living and social protections, interviewees reported needing to be persistent and at times relentless in their advocacy, in order to access support. They were also limited by the conditional nature of the support they did have access to.

"A lot of people think, people with carers and people with disability get lots of funding from the government but in fact it's not and it always comes with catches and conditions like this. [...] When we get the help from the government to hire carers for our son, my son is provided with some amount of funding so I can hire carers and as soon as they give that they also increase the rates so that the amount we receive basically becomes not enough. So, they say that I can hire someone at minimum wage but they put in the conditions, you cannot hire someone at minimum wage because carers need to be paid at this level. They increase the rates so what we receive basically becomes half of what we were allocated so there is always something like [this]." (Interview #7)

"What we've been fighting for is like an individualised service that is specifically tailored to whoever the person is." (Interview #1)

"We need to fight for our rights. Fight for her, because she can't talk, it's the family that need to be standing up for her, for her minimum care for her." (Interview #9)

"But one thing that really frustrated me, which I think is so unfair, we had this lift, at the old house and it got us up from the ground to the wrap around veranda and when we moved, it just so happened that the lift was the perfect height for us to come into this house. And we said to them, can we just get the lift moved to this house [temporary inaccessible property] and we'll never need it again. We're building a new house and then once we're done, you can take the lift back and we'll never again need that expensive lift because we're putting all this money into an accessible house and it's level access. And they made us pay to move the lift and get all the modifications done because it was a temporary home, and I found that really annoying because I thought, we're saving you so much money by building ourselves an accessible home and you can't even be bothered to pay for just two more years for us to have this lift in a different house and then you can have the whole lift back. But it was a bit frustrating because I thought that as really unfair when we're trying to help ourselves and build an accessible house and had to be in temporary

accommodation that they couldn't bend the rules and recognise that actually we were saving them heaps of money. [...] It wasn't just moving it, it was doing modifications at this end as well so it was actually quite a lot. Probably about \$1,500.00. [...] But they just tend to have very black and white rules." (Interview #8)

"They wouldn't do a ceiling hoist anyway, they would do the standing hoist, the ones on wheels that you have to push around, but you can't lower someone into a bath with one of those. They told me that having a bath is a luxury. If you can get in the shower and wash them that's all you need. I did push back on that a bit and say it's better for her muscles to relax in the bath and then have a massage afterwards so it wasn't just luxury. But no, that didn't fly. I did have a friend that got a ceiling hoist recently and I still can't believe it. She needed it and she got it but it was a big fight." (Interview #11)

10.3.4 Isolation

The lack of choice, control, and support experienced by caregivers had also led to loneliness and isolation, particularly for those who did not have wider family support.

"[T]he only person supporting me with that is [name] and she's not from a friend, she works for [organisation name]. She is my biggest supporter. When I get stressed out and get my depression, she's the only one who understands me. She's the only one who can calm me down." (Interview #6)

"I'm an immigrant here and I have no family here. [...] I wanted to bring my close families. My sisters. But they couldn't come and the reasoning is because they think they have no financial or social incentives to go back home. [...] And so bringing family from home is impossible but for us, going home is impossible." (Interview #7)

"So, it's very hard to cope honestly, I had lots of thoughts. I had to juggle my job and I have to leave my job during work hours to attend appointments, take my son sometimes, and sometimes I tell my boss and sometimes I don't tell my boss. So, that causes lots of anxiety and stress but my managers have been very understanding but that cannot continue forever." (Interview #7)

"Do you mean somebody who coordinates with all those bodies? Not at the moment no, nobody helping me in this way." (Interview #9)

The culmination of fatigue, the physical toll on caregivers' body and mind, worry for the health and safety of their family members, the lack of choice and control, isolation, and loneliness, had led to ongoing periods of anxiety and depression. Another interpretation of this is that the housing rights violations experienced by people with complex disabilities, had often manifested as psychosocial and physical disabilities experienced by caregivers themselves.

10.3.5 Siblings

Although siblings were not interviewed in this monitoring research, some Interviewees also alluded to the pressures felt by siblings of children with complex disabilities, particularly within single parent families. These experiences reflect research by Dodd (2004), which shows that parents of children with disabilities often become reliant on non-disabled siblings. As a result, siblings become more mature than their peers. Article 23 of the Convention on the Rights of the Child (UNCRC) states that disabled children and their families are entitled to receive the support they need. However, the reported experiences of the families interviewed in this monitoring project suggest that siblings are often considered the only other reliable person who can look after the disabled family member. Despite this reality, parents often expressed that they wanted to ensure that their non-disabled child/ren were able to pursue their own aspirations and not be unduly restricted by a sense of obligation to their siblings.

“Only my older son will know how to look after him. So, my older son has been trained on how to give him his milk. And his GJ [Gastro-Jejunal (GJ) Tubes] and how to flush it, little bits and pieces that he learned just by watching me. [...] So, from five years old he’s had that responsibility to look after his mum. So, he’s been doing this responsibility thing since he was a very young boy. He’s had to grow up just because he has a younger brother who has a complex case and because he doesn’t have his father in his life.” (Interview #6)

“[I]f something happens to me, my daughter knows where she could send her brother if she cannot look after him. I just don’t want to pass my responsibility onto my daughter because she will have her own life. I said to her that she can look after her brother from a distance. You don’t know what husband she will end up with. So, all of those things worry me. [...] She [daughter] had been helping me so much but I now have to let her go. She needs to pursue her own dreams and move. She was eight years old when I had my son and I need to let her go now.” (Interview #7)

However, as previously noted, when people with complex disabilities and their families were provided with sufficient individualised support, this had a positive impact on caregiver’s physical and psychosocial wellbeing, which in turn had a positive impact on the disabled family member’s living conditions. As was highlighted by one interviewee:

“I think it’s going to be really worth it [building an accessible house]. It’s been really expensive but I think it’s a good investment. It’s not just an investment in his lifestyle because obviously he gets all the freedom, but also for us. Because it’s going to be so much easier on our backs.” (Interview #8)

10.3.6 Physical and Psychosocial Wellbeing - What are the Key Issues?

The physical and psychosocial wellbeing of people with complex disabilities was inherently linked with the physical and psychosocial wellbeing of caregivers, which was significantly impacted by funding - the type, provider, amount, delivery and timeliness. However, the lack of support provided to families/whānau of people with multiple and complex disabilities had led to extreme and prolonged fatigue. This included the level of support, adequacy of support, and proximity of support.

In addition to this was the fear and anxiety of losing their family member at any time. Mothers, who were primary carers for the family members with multiple and complex disabilities, often felt that they were the only person who could provide the level of support their child needed. This feeling was embodied by the lack of competency and accountability found in the current service providers. This has led to many families/whānau believing the only way for their disabled family member to be safe and to have the best possible life is to stay at home. However, this was often at the expense of their own wellbeing, and the wellbeing of the wider family/whānau. Several Interviewees noted that the challenges they had experienced in accessing adequate housing had led to their own physical and psychosocial conditions.

10.3.7 What Articles do they Relate to?

UNCRPD Preamble

Article 10 - Right to life

Article 11 – Situations of risk and humanitarian emergencies

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 25 – Health

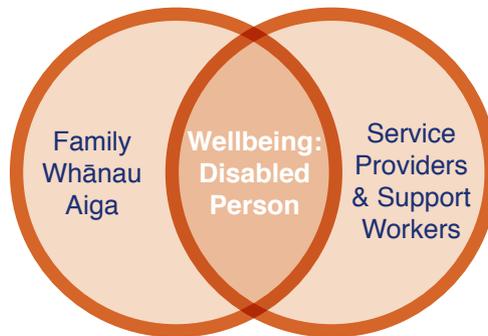
Article 28 – Adequate standard of living and social protection

10.3.8 Who Should be Concerned?

- ACC
- Kāinga Ora
- Landlords/Agents
- Ministry of Housing and Urban Development
- Emergency services
- Disability service providers
- Mental health services
- Ministry of Health
- Ministry of Social Development
- District Health Boards

10.4 Relationships

The next key theme to emerge from the interviews was relationships. According to Interviewees a defining factor of the housing experiences of people with complex disabilities was the tri-factor relationship between the disabled person, family members, and service providers.



Research shows that if families have had negative experiences in the past, it is not uncommon for them to distrust unfamiliar service providers and workers (Clift, 2014). Similarly, Interviewees reported experiencing negative and distrustful feelings towards service providers, which had impacted upon the adequacy of the disabled person's living conditions and wellbeing.

“I had incidents a couple of times, my carers had bought their boyfriends and they were in my bedroom. And I just did a random check, because you do have instincts sometimes, and I had some carers who said they don't smoke but they would be smoking and I had carers who didn't care. I would say we have cameras and if you have bad intention camera exists. I used to say that. They would leave my son for half an hour or 45 minutes playing on their phone. Or they would go out, I can't see where they are and my son would be sitting in his room on his own for one hour and I would ring her and say where are you but they would say I was in the bathroom. For one hour.” (Interview #7)

“I love that saying, if you walked in the shoes of the person you supported, would you be happy with your life? And I think often, and it's not their fault. If they're not supported and given the right set of values before they come or the organisation doesn't have the right set of values, it's just that we found it incredibly difficult to find an organisation that does have the right set of values. You know, their mission statements all sound wonderful and the moment you meet with them and you say what's really important, as we did with this one, about the team leader and about them valuing and supporting the staff because it's a difficult job and they all say, “Yeah, yeah, that's definitely what we do.” But then that's just never proven to be the case, it's always the thing that lets the whole service down.” (Interview #1)

“[W]ell the more I’ve found out about [name of institution] since it closed, the more distressed I feel that I put him out there.” (Interview #4)

“My son was all ok all the time and then suddenly coughing coughing and then vomit and then it became difficult for them and they said we can’t do it anymore, we can’t look after him because he is too complex.” (Interview #6)

“I couldn’t send her to one with carers that I didn’t have a relationship with previously. And I couldn’t send her to a rest-home or something like that. Some of them are great and you hear good things for those but there’s plenty of horror stories that I don’t want to be on the receiving end of.” (Interview #11)

10.4.1 Positive Relationships

When positive relationships were formed with service providers, and families felt a sense of trust and respect within the tri-factor relationship, this alleviated many of the aforementioned anxieties. It was also highlighted that even having a positive relationship with just one person in a team of support workers, made a significant difference.

“We have been very fortunate in that the main support worker, we actually had in our home for five years so she’s now worked with him for over seven years so she is a hugely valuable resource. [...] I provided all the information about his diet, his medicines and how they’re given. All that has been part of the training process. They have to write reports three times a day which go to the head office. So, I know that things are being done. If they haven’t been done, I also know about it. Because my main support worker who has also become a friend over the seven years will tell me and I can just get in there and rectify things.” (Interview #2)

“We have actually been through every provider in [place name] I think with no success and one of the biggest problems is, we always ask for a really robust team leader to manage and be responsible for [name]’s team and the other thing is we always ask for a provider who is actually prepared to value and support their staff and so we had one excellent provider, I don’t know if you’d know, [name] [...] So, he set up a service that we had for a year and it was absolutely perfect and exactly what we wanted but that’s what [name] taught us, that you had to have one key person that had the skills and capability to manage [name], as I would, as far as the care side of things went. And we had an excellent person. [Name] loved it so much, in fact she was only staying there three nights a week and home the rest of the time with me but she kept wanting to go back there which was unheard of.” (Interview #1)

“I’ve got no complaint with the staff at all. The ones I know are really lovely.” (Interview #4)

“I: Luckily there’s only two that come in at the moment. We’ve got such a lovely lady who’s adopted us, and then another lady. [...] Sometimes we go

overseas and then we get twenty-four-hour care for her and they all, the main lady comes and moves in, and the others all take shifts to look after her.

M: It must be a big relief for you to know that she'll be looked after, even if you go away.

I: Yes. It is. It's still a worry. I still worry every day when we're away, but yeah. They're really good carers so that's good." (Interview #10)

"Previous carer was with us for 13 or 14 years, which was fantastic. She's on leave at the moment, so that forced my hand to find someone else. Our new person we've had yeah, probably since last July. And she's really good. Our previous one I can get hold of if I need to, if I'm desperate or whatever." (Interview #11)

10.4.2 High Support Worker Turn-Over

However, families also noted that regardless of the type of relationship they had with service providers, high turn-over of support workers remained an ongoing issue. For example, even when trusting and respectful relationships were formed between the disabled person, support worker or service provider, and family/whānau, this was often overshadowed by the feeling that the support worker would leave the family/whānau sooner rather than later - causing disruption and distress to both the disabled person and the family.

"After a year, unfortunately [name] sort of moved sideways in his organisation and his partner both professional and personal, took over and she didn't want to have any clients in [place name] so she stopped the whole thing. And it's been really difficult since." (Interview #1)

"You have to train them for two or three months and then when after three months, you think, okay this person is really good and you want to carry on with them, that person would only work a few months and then would leave and I would have to start from the beginning." (Interview #7)

Reflecting on these issues, one Interviewee concluded:

"When a support worker leaves, do they leave a hole in the life of that person or do they leave a bridge to community? So, we've always said that family and family fostered relationships, social relationships are [name]'s personal life and that the support workers are there to enable these other parts of [name]'s life. And a number of our support workers have actually become very close friends, we are really careful that they are not the be all and end all personally in his life because it's too difficult when they move on, as they do and they have every right to do." (Interview #3)

Other Interviewees articulated that their relationships with support workers and service providers had been impacted by the incompetence of the support workers themselves, who at times had failed to provide adequate services and support for the disabled person. For example, some families felt they could not rest or leave their disabled family member alone with a support worker.

“The help that I get from [organisation name] is only for the helpers to come and look after my son and I’m here with them full time. So, I’m watching what they are doing, how they are giving him his meds. How are they giving him his bed bath? And they tell me every step, this is what I am doing. For me, I’m comfortable for them to come but I can’t sleep or rest because I want to know what they’re doing or see that they’re doing it right. So they come in with no training and they go with lots of training from me.” (Interview #6)

10.4.3 Support Worker Training

Many of the Interviewees also indicated that they felt solely responsible for the training of support workers on how to care for their disabled family member - which took a great deal of time and effort, especially with the high turnover of workers coming into their home.

“We provide a training manual which we wrote when we ran the service with a lot of information and assisting me with eating, assisting me with personal care, assisting me with hygiene, it had all these chapters in it and [name] the psychologist from [organisation name], she’s been brilliant but there’s been no training done actually what it is, lovely girls, we’ve got some really lovely girls, no accountability, no support and no training. And that’s where it has all fallen down, yet again. These kids are just determining what they’ll do themselves. Nobody is overseeing it.” (Interview #1)

“We’ve been with this organisation basically since he was born I supposed, almost when he became disabled after a few months, but this has been the most help we’ve had from them. And they just don’t want to put a foot wrong because it’s the first time they have taken on somebody with high complex needs and they were really scared at the beginning. But my husband and I have worked with them and encouraged them and told them not to be so scared. [...] I’ve done extensive training with them [support workers] and they know they can ring me at any time if they’re concerned about anything” (Interview #2)

“Yes, every time there is a new one coming in I have to train them.” (Interview #6)

“All the training and things, we have to do it. Because if I hire someone who has training and experience, that will cost us. Very expensive. But the funding we receive is only \$17.00 to \$19.00 an hour. Who will work for that? So, I usually end up paying a person with no experience and I usually train

them, and it takes a while to train them because no person can absorb all the information within one or two days. It's an overwhelming job so little by little, maybe feeding one day and then changing nappies later. And also because caring is not just for that person. It's a whole household thing. Because that person will most likely be solo, because I will be working. So, that person has to do everything for my son. Because my son cannot talk, he cannot express himself." (Interview #7)

10.4.4 Gendered Nature of Care

It was also noted that in ten of eleven interviews, the primary caregiving role was carried out by the mother - many of whom expressed feeling like they were the only one who could care for their disabled family member. This reflects research by Jennings (2019), which shows that the gendered nature of care can potentially lead to a compromised standard of living for both the child and mother. The gendered nature of care also reflects research on work arrangements, caring responsibilities and the gender pay gap, (Employment New Zealand, 2020; StatsNZ, 2019).

"One bedroom is very small and one room is big where me and my son is sleeping and I was told by the nurses that I should be trained to sleep, to leave him alone, like let him sleep alone at night time so that he gets used to that. Because when I sleep with him I don't get enough sleep myself. Anything I hear from him, I'll get up and look at him. So, that's another thing for me to train at. So, I'm in the process of buying a sofa bed so that I can sleep in the lounge." (Interview #6)

"Yes, it is very hard if you have someone with a complex disability and you are the only one to look after him. There is no one else able to look after him, because I cannot train anyone else. My family has already said they are very scared to look after him. It's not easy to look after him. They've seen it, they don't want him to get sick just because they've done something wrong. So, I'm the only here that can look after him and if I get sick there is no one else to replace me." (Interview #6)

"So, at the end of the day, it's only me that can look after my son. And you do get some 'help' from the Government but there are always conditions and things." (Interview #7)

"I knew that I would have trouble finding carers but I thought it's difficult anyway and once my daughter finishes school I will have no one to help me. I will have no option to change my job or become a full-time carer and maybe stay on the benefit or something so I need my shelter. That's how I decided my options." (Interview #7)

“As a mother, I want to look after my son by myself as long as I can if my health allows and want to keep my family together. As a responsible individual, I do not want to be a burden on the health system of New Zealand government.” (Quote from extra documentation provided by Interviewee #7)

10.4.5 People in Positions of Power

A final key relationship impacting upon disabled people’s access to adequate housing and living conditions, were the relationships that families had with people in positions of power.



For example, for families who were directly engaged with people in positions of power (that is, people with authority), the likelihood of their disabled family member’s rights being met appeared to be higher than those who did not have such relationships.

“[Name] then picked up, when [daughter’s name] was in hospital, picked up our plight, and with [name], a psychiatrist from [hospital], they managed to fight for us to get us the right service.” (Interview #1)

“[T]he main person who I go to for his MSD [Ministry of Social Development] funding, he’s a really good one I can go to, as is the other one and just say that I’m not happy with what is happening. Can we look into this? Or whatever.” (Interview #2)

Lived experience was also noted as a defining factor of relationships. For example, when families engaged with people in positions of power who had experience of disability themselves or within their wider family/whānau, there was a higher chance of families receiving the accommodation support they needed.

“We were incredibly lucky to be honest, you have to do an interview with somebody in Wellington and then I was told I had to go down and sign the forms at WINZ [Work and Income New Zealand] and when I went down, the woman that I spoke with had sadly lost a daughter when she was two, with a severe disability, and I have a feeling that she may have bumped us up the list a bit.” (Interview #1)

“Well it had to be a property that could be completely enclosed. Our son doesn’t have much understanding of personal safety so we needed the previous owner to put in a full fence before we moved in so that was pretty stressful but they supported us through that and as it turned out they had a niece with high and complex needs who lived in a [organisation name] group home so they were quite familiar in many ways with our situation so they let us put up the fence before settlement so actually before they moved out which was very kind of them.” (Interview #3)

Another Interviewee added further to the concept of ‘it is not what you know, it is who you know’. For this Interviewee, the support they had received was not based on an established relationship, but instead which authority they were dealing with on any given day:

“I’ve been told for years that I couldn’t have a little ramp at the front door because we can come in through the garage. And if you can get into your house through the garage, anything else is extra. “You can get in, you can get out, what’s the problem?” [...] If there’s a fire in the garage, what do you do? I said she’s got friends who won’t be able to fit through that door because their chairs are much wider. And surely, she’s allowed to have friends over, so we should get a little ramp.” [...] The occupational therapist from there arrived and saw the little ramp and said “oh do you want a proper sized one?” “Yeah”. “Oh, I’ll get you one”. “I’ll believe that when I see it”. And three weeks later she arrives with a new ramp. And that was after years of being told by the other OT that I couldn’t have one because we could come in and out of the garage.” (Interview #11)

For example, one Interviewee who is a parent of a child with complex disabilities was initially funded via the Ministry of Health. Even though the family endured a multi-year legal battle to recognise the cause of disability was medical misadventure, the legal battle ended abruptly when someone within ACC reviewed their case, and decided that it indeed was an accident:

I: It was six years of fighting to prove that it had been a birth accident. Ah yes! They did not wanna fund us. We were all set to go to the high court when suddenly they employed a - I don’t know who they employed. Somebody and that person looking through it for ACC said, “Good grief! These people need funding! This was a big birth accident for them!” So that was a relief.

M: That’s so good. So it was actually somebody that they hired also?

I: Yes. Yes. They’d been fighting us for six years and then they said we got a letter and they said um this person is doing a report and they’ll probably write a two page letter and then we were gonna head to court. And it was a kind of a, yeah it was kind of a nasty letter. It was kind of a fighting letter. And anyway this person did, like, a fifty page report all in our favour! And suddenly ACC were like, “Oh we’re really sorry, yes yes.” And they were so kind. They came rushing around with people.” (Interview #10)

Once the incidents that occurred during the child's birth were accepted as an accident, the family were then able to access the support and resources they needed to be able to provide adequate housing and living conditions for their child.

10.4.6 Relationships - What are the Key Issues?

The relationship between families, support workers, and service providers were crucial factors when considering people with complex disabilities' access to an adequate standard of living. When positive relationships were experienced, where families felt they could trust the support workers and service providers, families felt more at ease and that the disabled family member's best interests, will and preference were being met. However, based on experience, some family members felt ongoing distrust of support workers, leading to anxiety, frustration and fatigue. Regardless of the nature of the relationship, support worker training was most often carried out by family members, particularly mothers, who were in primary caregiving roles. It was also noted that when families had a good relationship with people in positions of power (that is, people in positions of higher authority than support workers or service providers), there were better housing outcomes.

10.4.7 What Articles do they Relate to?

UNCRPD Preamble

Article 8 – Awareness-raising

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

10.4.8 Who Should be Concerned?

- Community housing providers
- Kāinga Ora
- Disability service providers
- Ministry of Health
- Ministry of Social Development
- Work and Income New Zealand
- ACC
- Landlords
- Lawyers

10.5 Advocacy and Awareness

Towards the end of the interviews, Interviewees were asked about their awareness of the UNCRPD, and in particular articles relating to housing. All Interviewees had a heightened sense of awareness about the wellbeing of the person they were caring for, and respect for their best interests, will and preference. However, the UNCRPD was not always at the centre of this awareness, with four Interviewees stating that they had not heard of the Convention, Universal Design, or the right to adequate housing and standard of living.

“Hearing about this right now and talking to you guys, it makes us feel like we can be heard by other people. Other people care where we are coming from and there are other people who really understand us. And care about the disability of our kids and what we go through everyday. So, before that I didn’t know that people can hear us and put our thoughts through to the government and say this is what is happening with this kind of situation. And so they can look into and see where they can help me, where they can change things.”

(Interview #6)

“There was a question here about [...] ‘Do you think housing options are limited for disabled people?’ In my opinion it’s not limited. There is basically none. Because New Zealand houses are not accessible. That’s what I said in the beginning. Just because you build a wooden ramp, doesn’t make a house accessible. So, that’s what they think that accessible means a whole lot of things. You just have to make doors a little bit wider. They should change the standard. Instead of newly built houses in New Zealand having a standard of 760mm wide doors, change the standard that doorways should be 1m. Or in certain areas it should be 1200mm. That would make a lot of people’s lives easier.” (Interview #7)

“There are still gaps I think. My girl, her name is, [name], her care is quite exceptional care, we have difficulty finding a suitable home care for her. Not sufficient... I think there’s quite limited choice for her. We have a substandard way, not our ideal home care for her. New Zealand, maybe generally they are complying but in a very specific detailed level there are still gaps, like housing, 24 care, how detailed they are, whether they have access to rehab doctors, the therapy team, how long they have to wait for the waiting list. They can’t wait. People’s lives, they can’t wait, you have to have that provision. [...] Not much choice for housing for her cares, not much choice to accommodate her.”

(Interview #9)

“Our whole culture around that has changed dramatically over the last few decades. Maybe it changed because of that clause, section 28, and if it did then great. I’d like to think that it’s done its job. And then I can imagine that in some places that won’t have, you do still have some horror stories. And

that does scare me for the future, when I think of future housing. Or what I would do if my daughter couldn't live with us anymore, but I find that scary. So maybe it [UNCRPD] does still need to be in there." (Interview #11)

10.5.1 Articles 19 and 28

Some Interviewees did, however, have extensive knowledge of the UNCRPD, Universal Design, and specifically Articles 19 and 28.

"People in poverty end up in horrible situations with disability. They end up permanently in houses like what we're in now. And I don't think it's right and I don't think it's saving anyone money because these people end up breaking their backs and being on ACC. So, I think they have not succeeded in that [Article 19] at this stage." (Interview #8)

I: [Reflecting on Article 19] Um. Yeah, they don't really do they? Just for, yeah yeah things like just getting the equipment and just modifying houses like bathrooms and kitchens and getting into the house and parking and...

M: Yeah, so the basic things, even the basic things there aren't too many choices.

I: No. No.

M: And in the Article 28 of the Convention, it says that the New Zealand Government must recognise the rights of disabled people to an adequate standard of living. What does this one mean to you personally?

I: Mm... Yeah, I think no again, I think. It's hard because I guess they do, I mean what's adequate? They would say there's a ramp and there's a, you've got a mobile hoist and that's that. So I suppose adequate is not ideal. The difference between you know, what they mean, the difference between what would be very workable, to what just they just have to make do." (Interview #10)

However, as was noted there tended to be a sense of disappointment at the way in which the progressive realisation of the UNCRPD had occurred in Aotearoa New Zealand. That is, it had generated high hopes and grand aspirations, but had resulted in little change for people with multiple and complex disabilities.

"I did a seminar presentation at the end of last year on Article 19, and I spoke to some Mums of people in residential care and asked them things like, did their sons have any choice about who they lived with? No. Did they have a choice about where they lived? No. And I asked them how did they feel about Article 19 and one of the Mum's said that she wished it had never been enacted because it was impossible to achieve and made her feel like a failure as a parent and it was very honest but very heart breaking." (Interview #3)

“It is a human rights issue that really upsets me and I think that mantra of ‘nothing about us without us’ has to apply to all disabled people. Not just those who are cognitively able and who can communicate effectively.” (Interview #1)

“[W]e say a lot of what is in that Convention that’s been written down, applies to what we call the ‘walking wounded’. The ones with the lesser disability. But when it comes to those with the profound disability, we’re all in the too hard basket. And that’s what really concerns me.” (Interview #2)

10.5.2 Family or Community Living?

Regardless of whether Interviewee awareness was directly linked to the UNCRPD or not, it was still a key motivating factor behind the desire to provide a higher standard of living within the family/whānau home than could be provided by residential care. For example, one parent whose adult child had transitioned from institutional care to community-based care in the early 1990s highlighted that her son’s transition was only made possible by the awareness and commitment of parents and families.

“I was president of a parents association when they were in [name of the institution] and when they came out we continued as another group and we had a lot of input. [...] We laid down all the conditions under which we would allow our people to come into the community and it was to be 24-hour care and not sleep over care so they have awake staff at night, right through 24 hours.” (Interview #4)

For families of people with complex disabilities who had not experienced institutionalised care, they also felt there was no other living arrangement that could provide the same level of support than was provided within the family/whānau home environment. For other Interviewees whose disabled family member lived away from home, there was a sense that they had had to make compromises.

“I’m really aware that in the group home setting there are very few personal unpaid relationships in the life of a person being supported in a residential facility. [...] I just know the hours that we put into planning and supporting [name]’s life, there’s just no way that’s possible to happen in a residential facility” (Interview #3)

“It will never be the same as home and so we just accept that.” (Interview #2)

For others who had their disabled family member living with them, they were resistant to the idea of them living away from home.

“My husband wants to buy another house and have her live there with carers, and I want her to stay here. So, it’s a big... we’ve had a couple of fights over it. Cause I think if she goes into another house, the care isn’t gonna be as good as when we can kind of monitor it. I suppose I’m a real control freak. So, it is hard to yes, decide about the future. So, we still don’t know about that” (Interview #10)

“All I can say to that is that my daughter will be living with me, I can’t imagine a time when she won’t be. What I’ll do when I’m 80 and she’s 60 something I don’t know. I’ll leave that until it happens.” (Interview #11)

10.5.3 Advocacy

In order to provide an adequate standard of living, families felt they had to continue to fight and advocate for the rights of their disabled family member at every stage of their life.

“[Name] is probably the oldest in our particular circle in the [organisation name], there would be very few that would be older. The majority now, probably between 20 and 30, still living at home. Choice and community living which was supposed to be set up for high and complex needs, never turned out that way. It tended to be moving people out of residential care in groups of four or something to go flatting and all the stories for choice and community living were about people catching a bus and going to work. So that was again, very disappointing but again people finding it very difficult. I know a couple of people who managed to find their multi-handicapped young people which is probably to be honest, easier to find flatmates for than the likes of those who are a bit more on the Autistic Spectrum.” (Interview #1)

“They [people with complex disabilities] can’t advocate for themselves. Their parents are too tired or they’ve been given everything all the way along and then all of a sudden when their child is 18 or 21 and they haven’t got the school system anymore of their programs they were going to. They’re like, “Oh my gosh, what do we do now?” (Interview #2)

10.5.4 Relationships and Peer Support

When asked what other factors had impacted upon their journey towards an adequate standard of living for the disabled person they cared for, knowledge, advocacy and relationships were identified as key features, particularly in the effort to ensure their family members could fully enjoy their rights - both as members of the disability community and in society.

“Well, I’ve been involved in the medical system as a nurse till my senior life and then I’ve been on the health board. I don’t let anything pass me by. [...] We have fought for the rights of the disabled. And I have done that for many years. Even presented papers with the Government so I will not let anything go by.” (Interview #2)

“It was knowledge. So, it was family organisations, so in New Zealand it was SAMS (Standard and Monitoring Service) family courses I went to with them. Really powerful. An organisation called [organisation name] which [name] set up and ran, it’s now called [organisation name] and this other organisation called [organisation name] so they’re all family and disabled

person organisations. And so, the stories that I heard and the academics that they brought in to talk to families and ideas and the opportunity to network with other families and understand shared experiences, and some of my own academic work but those three organisations have been absolutely powerful in the creation of a vision and the support to keep pursuing that vision.”

(Interview #3)

Interviewees who were aware of disability rights under the UNCRPD, indicated that they had gained this knowledge (and thus, power) through peer support groups and collective action, rather than through governmental agencies or service providers. Families who were connected to peer support groups appeared to be more empowered to exercise their rights than those who were not.

“[M]y friends and I with that code of rights, we formed a very vocal support group for those, who especially over the age of 16, because we didn’t know what was going to happen with them.” (Interview #2)

“I went to a number of workshops or different family organisations, so [organisation name] in [location]. I’ve been going to their workshops for quite a long time now and met some amazing speakers and got some fantastic ideas to bring back from people like [name of a speaker] and [name of a speaker] and concepts like social role became very important and I developed a set of principles or a kaupapa for our family of what I considered to be essential for a good life.” (Interview #3)

“[M]ost of the people in my group, the parents association, we were a pretty close knit group the 12 of us [...]” (Interview #4)

10.5.5 Advocacy and Awareness - What are the Key Issues?

Thirty-six per cent of Interviewees (four out of eleven) had no previous knowledge or awareness of the UNCRPD. Even so, Interviewees demonstrated an intimate understanding of rights of people with multiple and complex disabilities. This awareness was a key motivator behind their persistence in advocating for the person they cared for. However, family members also articulated the disappointment they felt in the inequality experienced by their disabled family member, particularly in relation to housing and the wider disability sector. For Interviewees who were engaged with the UNCRPD, this disappointment was linked primarily to Articles 19 and 28 of the UNCRPD and the lack of progressive realisation for people with multiple and complex disabilities. Peer support groups were identified as the main source of disability rights knowledge and power.

10.5.6 What Articles do they Relate to?

UNCRPD Preamble

Article 2 – Definitions

Article 5 – Equality and non-discrimination

Article 8 – Awareness-raising

Article 9 – Accessibility

Article 10 – Right to life

Article 17 – Protecting the integrity of the person

Article 19 – Living independently and being included in the community

Article 23 – Respect for home and the family

Article 28 – Adequate standard of living and social protection

10.5.7 Who Should be Concerned?

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

11. Discussion

Much like the findings generated by the wider housing report, this monitoring report also paints a bleak picture, with disabled people's experiences of housing in Aotearoa New Zealand leaving much to be desired. For people with multiple and complex disabilities challenges in accessing adequate housing were magnified by an inability to directly communicate their housing needs. As a result, this created further barriers in ensuring their best housing interests were met, as well as their will and preference.

In previous chapters, Interviewee experiences regarding choice and control, access, physical and psychosocial wellbeing, relationships and awareness were presented - with the responses needing little interpretation or analysis. The purpose of this next chapter, however, is to take a step back and look at the emerging themes in a wider context.

11.1 Gratitude and Compromise

A recurring theme found in both interviews with families of people with complex disabilities and disabled people, was the sense of gratitude. While gratitude is a positive quality and not to be dismissed, a more critical analysis reveals the pressure and expectation experienced by the disability community to be grateful for whatever they are afforded - even when it does not meet standards outlined in the UNCRPD.

For example, a number of Interviewees whose family members lived in residential or supported living homes expressed their gratitude for the arrangement. In particular, they were grateful to know that their disabled family member would be cared for, especially for Interviewees who identified as an ageing parent. However, it was also acknowledged that the disabled family member was likely to have less choice and control than they would have had otherwise. Another interpretation of this might be that families felt like they had to compromise between the meeting of their family member's basic needs, and their full enjoyment of Article 19 of the UNCRPD.

“[Sister's name]'s been down here at about 4:00pm and found that [name] has had a bath and is in her PJ's [pyjamas] and had her dinner at half past three. And last time [sister's name] enquired what she had for dinner and it was french toast. So, that's kind of the stuff we're up against” (Interview #1)

“It's a hard life for him, the fact that he's not verbal and his hands don't work for him so he can't use a computer or anything but he knows he is loved and cared for so what more could you ask?” (Interview #2)

As summarised in the 2020 housing report:

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) [...] 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). (Donald Beasley Institute, 2020, p. 93)

The absence of choice and control, underpinned by a lack of funding, inadequate services, low qualified and low paid support workers, together with the scarcity of services, appear to be linked to the theme of gratitude and compromise, although further research and analysis is needed to understand the correlation.

11.2 Similarities and Differences to the Wider Housing Report

One of the biggest challenges of monitoring disability rights is capturing the experiences of a diverse representation of disabled people, including those within the disability community who are unable to provide informed consent to participate in research activities on their own behalf. While there is little doubt that all disabled people should be able to enjoy the same rights as all people, a history riddled with paternalistic representation of the disability community has left many feeling cautious - a primary concern being non-disabled people speaking on behalf of disabled people and articulating information and experiences that are not reflective of the experiences reported by disabled people themselves.

During this monitoring research, careful consideration was given to 'voice' within a disability rights-based framework. For example, during coding and analysis, the responses of those who contributed to this particular report, were considered alongside the responses of the 61 disabled people who contributed to the initial housing report. As a result of this process, the disabled researchers who co-authored this report conclude that the key themes identified throughout the two cycles of monitoring were common to all interviews. That is, the housing experiences reported by family/whānau members of people with complex disabilities, reflected the experiences reported by disabled people. These include limited choice and control, access to the housing market, affordability, access within the home, community access and belonging, wellbeing, support services, and awareness. Although the key themes manifested in different ways, the commonality of rights violations were found throughout the entire community. In this way, the two housing reports serve to enrich and support each other in the shared aim of progressively realising the UNCRPD.

However, it might also be noted that there were unique and additional layers of complexities affecting people with multiple and complex disabilities and their families and whānau. For example, the dependency of disabled people with significant health needs on family/whānau and service providers was lifelong. Family/whānau members were often unemployed, meaning there was a total reliance on government welfare as the only income for entire families. In many cases, the caregiver role was carried out by the mother, casting a further

gendered lens on the rights violations. Additionally, the uncertainty around the health and life expectancy, and/or behavioural needs, of people with complex disabilities had a significant and direct impact on the social, psychological and economic experiences of entire families. Although these experiences are not unique to people with complex disabilities, these challenges were reported with greater consistency and severity throughout the interviews in this report, than were shared in the wider housing report.

12. Best Practice and Recommendations

As was articulated throughout the interviews - just as family/whānau members are in the best position to inform and guide the support and services provided to their family member, family/whānau members and close supporters are also in the best position to recommend how best to ensure the UNCRPD is being progressively realised when a disabled person cannot express their own will and preference. Outlined below are a selection of recommendations and examples of best practice which demonstrate the benefits of families and support people contributing to the progressive realisation of housing-related rights.

12.1 Embrace a kaupapa Māori approach to ensuring people with multiple and complex disabilities can enjoy adequate housing and living conditions.

“[W]hat I’m hoping is that solutions or answers will come from the Māori community and that the rest of us will learn from that. Because I don’t think that community has lost it’s community links in the same way that perhaps other ethnic groups have. And that’s a really long bow to draw but the more we bring Māori concepts into our delivery of services, the more I think the wellbeing of the disabled person and their family is safe guarded.”
(Interview #3)

12.2 Take a life-long approach to improving housing and living conditions that includes close family/whānau members as co-designers.

“I always talk about a corporate model when I talk about this, you are doing all of the operational type of support so you’re doing the feeding, the toileting, the laundry, the housework, you’re taking the child to school, you’re doing all the school notices and all that sort of thing and that’s just part and parcel of being a parent and as your child gets typically bigger and you’re starting to older and a bit more tired particularly if you’ve had a family member with extreme sleep disturbances and you just start ticking by. Then you start getting support into the house, and your role as a parent, you’ve still got a big chunk of all that operational stuff but then you start taking on a management role and that is finding the staff, training the staff, paying the staff, deciding what their role is going to be and what you want your child to be achieving and that role becomes bigger and bigger as your child gets older so there’s a whole lot of things, for example, that I can’t do with my son any longer. He’s much taller and bigger and faster than I am and so we have more staff coming into that space and taking on more of that operational role and then the tier to that model is the strategic role and that’s the creation and holding of a vision and in my view, parents will be able to be involved with that level for the rest of their lives. So, this is the mirror that I hold up to our current model of cope cope cope and then tip into crisis rather than start moving out of operational

and support staff come in there then having more of a management role till maybe your own health or cognitive functioning means that you can't do that management role. But I think that parents will be able to stay at that strategic role and I think this is where support services should come in and start moving with the families, not just the parents but sibling or cousins or whoever else is involved in holding that strategic space for that person and with that person, the disabled person. So, that's what I think the government should be looking at, understanding the life trajectory of the parents and siblings as well as the disabled person." (Interview #3)

12.3 Increase accessible state housing stock and incentivise accessible housing in the private rental market.

"They could provide some incentives to private landlords. Those who are providing accessible homes to a person with disability, perhaps there could be tax incentives. Those kinds of things. Or maybe the government could subsidise some portion of the rent. These landlords are human beings, they have hearts, they will try and keep people there longer. No landlords want to have a frequent turnover of tenants. So, in return the disabled renter will have permanent stable housing and landlord should provide accessibility, provide a ramp, make bathrooms wider, that will keep them there longer and make the house warmer. Then the landlord could get some kind of incentive. Well it should be. If a house is not accessible, or someone wants some kind of unique house which needs to be built on a slope or with nice views, maybe they should have extra charges or fees so those charges or fees can go towards building better homes. Something like that." (Interview #7)

"Not everyone can afford to buy, let alone build, an accessible home. So, if someone takes initiative and decides to build an accessible home, this should also be supported. The government should be like, this mother or this family is going to provide an accessible home and this home will be someone's in the future. They could perhaps arrange for banks to give low interest rates, that kind of thing. A set of things, not just the one thing. One side there is builders, construction industry. One side there is creditors, also which the government can push creditors to do those things. Government can push construction industries, private landlords. It's not only the government responsibility. They can do a lot of things to improve this situation." (Interview #7)

"I think what they probably need to be doing is making universal design with new housing. And I know it's a tricky one because it adds to the price of new housing but all the houses that are going up now, I would say, what they need to be doing is making a greater stock of houses that are universal design. Or that disabled people can live there and I don't think they're committed to that

are they? When you look at these houses going up they don't seem to be following the principle of universal design." (Interview #8)

"If there is a facility, a funder of this housing provision, if they do support rental for him, maybe we can find some relatives who are willing to let the property be renovated for that purpose. The provider can help subsidise for the rental or something. So maybe that is one way to find a house for her, housing provision for her." (Interview #9)

12.4 Engage close family/whānau and supporters of people with multiple and complex disabilities as co-designers when discussing the amount of funding that is needed for adequate housing, what the funding is needed for, and when the funding is needed. It is important to acknowledge that a disabled person's needs change over time.

"I guess they just need to, it's all about money isn't it? They just need to provide more money [...] Cause right now it is, you've got to apply and all that to get told no no. So so many of my friends, out of five friends I can think of with disabled children, only one has got a proper bathroom. And this child's nineteen and she's just got it. So it just takes forever!" (Interview #10)

"I guess surveying the people that are using those facilities [group homes and other residential facilities], ask the questions of the people who are actually using whatever it is and finding out what they actually want, so that they're not spending money in areas that don't need it. In the whole disability sector, there's so much wastage of money just spent and frittered away on things that someone has decided it's a good idea but isn't actually where it's needed. Right from equipment right through to housing and stuff. So asking what they actually want, what they actually need, rather than someone with no experience or a very narrow experience assuming that they know what's required for everybody. And making sure there's enough funding. But like I said earlier, there's never enough for everybody to get everything they want. And then maybe having some sort of checking to make sure that things are happening how they said that they're happening." (Interview #11)

"You know all that needs to happen is just, I don't know, there's pretty small governmental changes that they could make to make it happen. It's kind of just attitude. Make it part of their policies and systems that it is a priority if someone has got a disability. It's little things. I was thinking about it the other day, I went to get my boy's hair cut and I just thought, I'll go in quickly, whip in, get his haircut and go home. And I got there and said to the woman, "I've got a boy in a wheelchair, I just want to check out what the wait was." And she said, an hour and a half to two hours. And I just, now I have to hang out with him here for up to two hours and he doesn't have cognitive flexibility so couldn't cope with the fact that the haircut wasn't going to be straight away, screamed

his head off and I was just thinking, for most people, you'd tell them [the child] that we have to wait for an hour to get a haircut and then think oh well, we'll go to the Warehouse or something. But when you've got a child with a disability, it's a lot more complicated. I've got this child who is screaming his head off because he doesn't understand why we have to wait for an hour and a half and I can't just drive home and wait for a bit and then come back because he's in a chair and it's taken a lot of effort to get him in that chair and here. And I just thought, if people in society just understood and thought, oh she's got a child with disability, we'll just put them through straight away. I'd never ask for that, but it would make things so much easier. Because the effort for me to manage that situation. And I think it's the same for housing. If someone turns up in need, then they should be helped." (Interview #8)

"To give you an example, we tried a power chair, an electric wheelchair. We gave it a go, and it became obvious that my daughter wasn't going to master it. [...] They finally took it away. \$20,000 worth of power chair sitting there that we couldn't use, but we can't have half of that much money to put a ceiling hoist in. There're so many examples like that that I could give you. There's money, but never in the area you actually want it. Someone else out there, they'll be given a ceiling hoist, but they want a power chair, they'll be being told, "Oh no, you can't have a power chair but we can give you a ceiling hoist." It's just weird." (Interview #11)

12.5 Ensure access to more supported living options and respite services, with increased choice and control.

"And we need to have a respite [...] that parents can get easy access to. And maybe if the parents can't afford transport they could have transport for them to be transported to the respite and then back home. That would mean a lot for us and would make things so much easier. Because that's the thing I'm struggling with and I'm sure there are a lot more parents out there struggling as well, like me not having a respite close by." (Interview #6)

"To really provide us enough facilities, home care or in the residential, that disabled people can have a choice, to live in an accommodation of their choice. To enjoy life just like other people do. In whatever way, even in a home care setting, the Government should come up with something, subsidy, house rental, enough housing to house these people in a home setting, with their family, that is important. Otherwise if they are single, they can be quite used to living together with other people. But with the family, like [name] has a family with a baby, not many with babies or small children around in that situation. But for this small group of people, that needs to be looked at in greater detail and compassion, to consider aspects of needs, to live together, to see their

children growing, that's important. How the government will come up with whatever idea, I'm not sure, but that needs to be done, more needs to be done on that aspect." (Interview #9)

12.6 Ensure families/whānau and close supporters can easily access information in a timely manner so that they have a complete understanding of what people with complex disabilities are entitled to, and why, without having to seek out the information themselves.

"When you think you know the rules, and then you find out that somebody else got something that it was against something you were told what the rules were, then you don't know the rules, the rules seem to change from one person to the next. It's odd. I do find they often ask is there anything you need or anything you want or whatever. My reply is usually, "I don't know everything that's available." And you don't know what you been doing and just coping with, without even realising that there's something out there that will make it so much easier. Because you've just been doing it, you don't even realise how hard it is. Does that make sense? You're just doing something and someone comes along and says, "Why are you doing that the hard way?" "That's just the way we've always done it, I didn't know that there was an easier way." But they will never, they always ask you what you want, never, "Hey, here's this new thing that's been developed, I think that might be useful to you, do you want to explore that?" That doesn't happen." (Interview #11)

M: [T]hat's a lot of information for you to have to process also.

I: Some of them I really don't... We are not familiar also with all the processes. At the moment, the ACC part is represented by lawyers, the claim is. The rest, the funders, they will have to find a place, will have to work out a plan for [Name]'s care." (Interview #9)

"I didn't really have any concept or understanding of disability at all so I would never have heard of the word inclusion at all" (Interview #3)

12.7 Provide age-appropriate care for people with complex health needs to ensure families can remain together post-injury.

I: Definitely I think moving her to a private hospital [aged care facility] where she would mix with all the elderly people it's not an ideal place. It's not a good setting for her.

M: She's too young to be spending time there.

I: Correct.

M: There aren't so many other choices with the limited funding.

I: Yeah, for the limited care you know? Not complete care to meet her needs, to care for her the needs is really high." (Interview #9)

“It’s not an ideal situation for her to be separated from the family. For this group of people with young children especially, they need to be together. It’s quite inhuman to separate them, they can’t be staying at home, so by whatever means the government needs to come up with something to help this group of people. As I myself got in this situation so I can understand the frustration and people who needs this to be resolved.” (Interview #9)

12.8 Prioritise disabled people and their families/whānau in accessible state housing.

“I think if you do have a family member with a disability, people who are in state housing, I was thinking about this the other day because sometimes you see these programs with people in these horrible houses and I just think that there should be some priority for people so that they can get the houses that are going to work for them. Even if it means, and I know this sounds really rough, but moving other people on that don’t have disabilities and put them in houses that... because a lot of time, it’s not necessarily a better house, just that there are certain features in a house that lead themselves to being accessible. Like having a bathroom that is reasonably big, and having the bedrooms positioned fairly strategically towards that bathroom, you know there can just be some little features. I do think that if you have a child with a disability then you go to the top of the list particularly in the state housing.” (Interview #8)

12.9 Address the inequalities between funding models.

“I’ve got friends [...] they have a lot of trouble but not ACC. And their houses just... they don’t have the ceiling hoist like we do. They have mobile hoists and they have a lot of trouble getting bathroom modifications and yeah they have to put their own ramps in and they can only have one sort of like seating option. So, they can have only a wheelchair whereas, we’ve got a wheelchair and a nice comfy chair that she sits in. And yeah there’s just there’s not the options. The difference between ACC and Ministry of Health is huge!” (Interview #10)

12.10 Provide extra financial support for women caring for disabled children and single parents.

“I mean having a disabled child means a lot of mothers can’t work and that immediately puts the whole family at a financial disadvantage. So, I think there is a lot of people with disabled family members who probably are lower socio economic but in places that don’t work for them. And I think that should be a priority. [...] I shouldn’t say just women, but they can’t work and they do need to be giving them a wage I think. And I’m not talking for myself. Because to be honest, I know I’m privileged. But I do think that women, particularly from

poorer areas, they should have a wage so that they can save for a house for themselves, or they can save to rent somewhere a bit more decent. They need to have an income coming through because they need to have housing options. Because if you're on even one income, but if you're a solo mum and you're not even on one income and you're just relying on benefits, you've got no way of getting yourself into the housing market. So, you don't have any choices about having an accessible home. You probably just have to take what is going. And that's probably not going to be good. [...] If people were like, oh you've got a child with a disability, we're going to totally support you so your life is going to carry on at least financially, in terms of your ability to have time out and have as much as normal. It could take the stigma away too, that whole thing of looking at it as such a terrible thing. But the truth is, it does drive you into some negative statistics or it has the potential to throw you into negative statistics in terms of poverty and lifestyle. If you have to do it without support. I guess it can put you into some undesirable categories. Which doesn't help with that whole valuing of disabled people." (Interview #8)

12.11 Update the Building Act (2004) and Building Code to align with the UNCRPD.

"[I] very much hoped that this report will help to accelerate potential changes to the Building Act to enable accessible housing and a submission on potential changes to the Building Code to regulate for accessible housing." (Interview #7)

13. Strengths and Limitations

The greatest strength of monitoring research is that it is led by disabled people. Both of the primary researchers/authors of this report have lived experience of disability and were supported by a wider team of scholars with extensive experience in inclusive research methodologies, and research collaborations with families and people with complex disabilities. The researchers also had the benefit of recently completing the wider housing report, which had already provided insight into the rights violations affecting disabled people's access to adequate housing in Aotearoa New Zealand.

Limited capacity and resources meant that Interviews were initially restricted to two geographical locations (Auckland and Dunedin). However, Covid-19 restrictions meant that to ensure physical distancing could be maintained, all interviews were conducted remotely using phone and video conferencing technology. While this introduced new challenges, such as the necessity of having access to a phone, laptop and WIFI, it also allowed for the scope of recruitment to be broadened to include participants from anywhere in Aotearoa New Zealand.

A further challenge associated with virtual or remote interviews was the lack of face-to-face engagement between researchers and Interviewees. Virtual Interviews require a unique skill set, particularly when discussing sensitive subjects. The inability to make eye contact, sit comfortably, interject, and so on, are known to cause fatigue and difficulties engaging in an effective way. Covid-19 restrictions also meant that families who were isolated at home without their usual support workers and networks, were often unable to dedicate time to an interview. This had a negative impact on participant recruitment efforts. In particular, the recruitment of Māori and Pasifika Interviewees was hindered, with several interviews falling through at the last minute due to the stressful nature of Covid-19 and social distancing.

Finally, as with most research endeavours, this research was limited by the capacity and resources afforded to this project. This research would have benefitted from a wider scope of Interviewees, increased participation of Māori and Pasifika family/whānau/aiga members and supporters of people with complex needs, and the engagement of Interviewees over a longer period of time to ensure that the experiences of a wider range of people with complex disabilities were captured in greater depth.

14. Conclusion

This monitoring report has only just begun to scratch the surface of the housing experiences of people with multiple and complex disabilities, with there being much more still to be learned. Inequitable funding and support systems, barriers in all facets of life, and exclusion from the dominant disability narrative, all points towards something that most families and supporters already know: people with multiple and complex disabilities are amongst the most systematically marginalised groups in Aotearoa New Zealand, especially when it comes to housing. Indeed, while Aotearoa New Zealand may have made significant progress since the days of mass institutionalisation, as a nation we are still a far cry from ensuring that all disabled people have adequate housing and an adequate standard of living.

Throughout the interviews, family/whānau members and close supporters articulated the challenges and barriers they had experienced and continue to experience - all of which had stopped their disabled family member from the full enjoyment of their rights. From access to the housing market, affordability, in-home and community access, to physical injury and psychosocial distress, complex relationships with providers and people in positions of authority, and a lack of awareness about what supports their family member is entitled to under New Zealand law. The findings of this report closely align with the experiences reported by disabled people themselves. However, additional layers of complexities relating to the nature of impairment, the ability to exercise choice and control or express will and preference (with or without support), the often strained relationships with service providers, and carer exhaustion, all suggest that when it comes to the progressive realisation of the right to adequate housing for people with multiple and complex disabilities, the Government of New Zealand still has a lot to achieve.

Even so, much like the wider housing report, solutions to the reported challenges can be found in the wisdom of those who live through the aforementioned challenges every day. Not only has this report highlighted rights violations and problematic accommodation arrangements that fail to align with the ethos of the UNCRPD, Te Tiriti o Waitangi, the Disability Strategy, and the Action Plan, but the report has also served to amplify the voices of people with multiple and complex disabilities through those who know them best - their family/whānau members and close supporters. Throughout the Interviews a range of solutions and recommendations were provided as to how best progressively realise the housing rights of people with multiple and complex disabilities. Despite only having only scratched the surface, this report demonstrates the potential for disability and family/whānau/aiga-led progressive realisation of the UNCRPD in Aotearoa New Zealand and a future where all people, including those with multiple and complex disabilities, can enjoy their rights, freedoms, and dignity in a full and meaningful way.

Appendix A: Monitoring Team

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Appendix B: Interview Questions

On the Participant Interest Form, you indicated that [insert specified situation]. Tell us about where you live now:

- Where do you live?
- Where does [insert person's name] live?
- When did you/they move here/there?
- How easy was it to find this place?
- Are you happy with your living arrangement? If not, what do you think would be the ideal living situation for you/ [insert person's name]?

Tell us about how disability has impacted you/ [insert person's name] ability to access adequate housing...

SAFETY (PSYCHOLOGICAL AND PHYSICAL)

- How do you feel about the people [insert person's name] lives with?
- Does your/ [insert person's name] home have water, hot water and electricity all the time? If not, why not?
- Is your/ [insert person's name] home warm?
- Is your/ [insert person's name] home free of hazards?
- Is your/ [insert person's name] home big enough for the number of people that live here? If you don't feel it is big enough, please explain.
- Does [insert person's name] have a safe and private space to go to if they need to?

SELF DETERMINATION

- Who made the decision for [insert person's name] to live here/ there?
- Who does [insert person's name] live with?
- What are the advantages of living here/ there?
- What makes this/ it a good home to live in?
- What makes this/ their home less than ideal for you as a parent/support person?
- Were you able to easily understand the information or legal documents you were given about the housing arrangement of [insert person's name]? (for example lease, banking information etc.)

RHYTHMS AND ROUTINES

- What kind of things do you like to do with [insert person's name] at home?
- What kind of things can't you do with [insert person's name] at home, but would like to do?
- Who controls what happens in your/ their home?

COMMUNITY CONNECTION

- How easy is it for you/ [insert person's name] to get to, and use, facilities where you/ they live? For example, shops, healthcare, school, community centre, cultural spaces etc.

HOMELINESS

- What do you think your/ [insert person's name] home says about you/ them?
- Do you/ [insert person's name] invite friends or family to your/ their home? Why? Why not?

PHYSICAL NEEDS

- What modifications and/or assistance does your/ [insert person's name] have at home? Please explain what you/ they currently have, and what else is needed.
- What difference do these things make in your life as a parent/support person? (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 [insert person's name] need but don't have. How does this impact your everyday life as a parent/support person?

AFFORDABILITY AND AVAILABILITY

- 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?

SECURITY OF TENURE

- Has your tenancy/ [insert person's name]'s 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 disability has ever impacted on your/ their ability to find a house (now or in the past)? If yes, why?
- Are you afraid that your/ [insert person's name] 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 New Zealand Government must recognise the right of disabled people to an adequate standard of living.

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

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

- What does this mean for you and [insert person's name]? Where will you/ they 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?

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