WHERE WILL WE LIVE IN THE FUTURE?

“Tā tātou kainga e noho ana ki hea ā te wā heke mai”

Research into the Unmet Housing Needs of People with Disabilities, their Family and Whānau

MARCH 2021

disability connect. helping families

ABOUT THE COMMUNITY HOUSING COLLECTIVE

Our organisations, led by Disability Connect, have formed a collective advocating for the housing needs of our communities with disabled people and their families. This research is the product of our collaboration together.

Front Cover: If 100% of new public housing doesn't use universal building principles like in other jurisdictions, New Zealand will not have homes and communities suitable for all disabled people, let alone an aging population with physical disabilities.

Photo Credit: Disability Connect

ACKNOWLEDGEMENTS

This research was largely undertaken on a voluntary basis. It engaged people living with disabilities on a voluntary basis in telling us something about their lives and struggles. We would like to thank all those involved for the generosity and goodwill they showed toward this project and to our kaupapa.

We would also like to thank the agencies which supported this project for this support and access to their networks and influence. In particular we wish to thank Child Poverty Action Group for the significant financial contribution it made to the research and report production.

To all of those whose stories are represented here we thank you for the trust you showed in us in sharing these stories and we hope that you are satisfied with the way they have been represented here.

To all participants, readers and those interested in the wellbeing of New Zealanders living with disabilities we welcome your feedback.

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Respite Care

COMPLEX CARE GROUP

yes
YOUTH EMPOWERMENT SERVICES

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INTRODUCTION

This report and the research behind it outline the housing and living circumstances of people living with disabilities in Aotearoa – New Zealand in 2020. Both the research and the report were undertaken by a small team of people with connections to disability advocacy groups, community-based services and anti-poverty groups. The intention of the research was to give a voice to disabled people over their housing problems and their care needs. Such a voice is considered necessary by those who undertook this project because they believe that people living with disabilities as well as their whānau are amongst the most socially marginalised in Aotearoa and as such deserve to be heard.

The research reported here was undertaken during 2020 through self-motivated on-line surveys, and voluntary interviews or focus groups/hui. Those participating included people living with disabilities and/or chronic health conditions as well as their parents, other whānau members and caregivers. The research was undertaken in two phases one in February to March 2020 and was nearing completion just before the first Covid19 lockdown on 23rd March.

Because of Covid19 and its potential impact of peoples' wellbeing, it was decided to undertake a second phase of research. This was undertaken between July and September 2020 and included a further on-line survey as well as face to face interviews. The intention of this second research phase was to gain some understanding of the impact of Covid19 on respondents' wellbeing including their living and housing circumstances.

Disabled people need housing in communities close to work, schools and medical centres. Houses on popular routes are either unaffordable or inappropriate for their needs.

Photo Credit: Jo Currie/Disability Connect.

Two types of objectives are anticipated for this research project – one type relates to the information which is being sought and the other to how the information is sought. These objectives are as follows:

To provide an opportunity for people with disabilities and their whānau, including carers, to discuss and record their housing experiences and their housing related problems.

To undertake analysis based on these experiences and reported problems which might provide insights for policy advocacy to central and local government agencies and to the UN review on the Convention of the Rights of People with Disabilities.

To use this analysis for more general public advocacy around the unmet housing needs of people with disabilities and their families and whānau.

To build social research capacity within the disability sector including providing people who have disabilities, their families, carers and whānau with useful experience in research and analysis techniques.

This report and the results of this research are intended to be used by the report's authors to advocate for greater planning for and provision of appropriate housing opportunities for people living with disabilities. Such planning appears almost non-existent within the several public agencies which might be expected to have some responsibility towards promoting and supporting the wellbeing of people with disabilities. Because of this, the provision of housing for people living with disabilities is haphazard and incidental since these needs are not specifically considered in planning for social housing and for income and personal support services which might serve disabled people.

As part of this advocacy purpose the report's authors offer this report as a resource to support advocacy for the rights and needs of disabled people and their whānau and welcome your feedback and involvement in any further work.

A SUMMARY OF THIS RESEARCH

The research involved two on-line surveys as well as interactions with respondents through two focus groups and a small number of one-to-one phone interviews. Because of the limited agency[1] of many people with disabilities it was most often the case that the people participating in this research were doing so on behalf of a relative or friend with a disability. This was clearly the case for parents responding on behalf of their children.

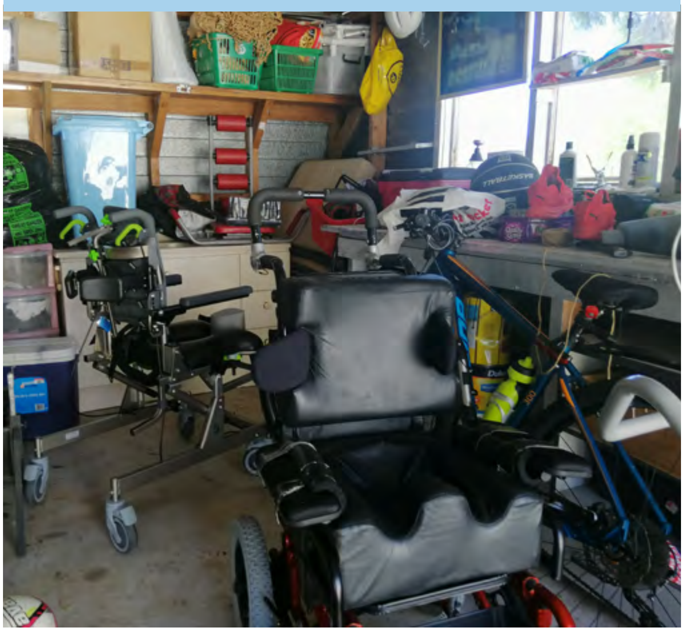
There is probably nothing new in the results of this research reported here. This lack of novelty can be seen as cause for concern. Although, as a national community we may know quite a lot about the experiences and needs of people with disabilities, their poor experiences continue to be overlooked by those making policy so their needs remain inadequately addressed.

In many respects the background problem is one of agency. The lack of agency of many people with disabilities to affect the changes in their lives which they need and desire. Their inability to express their needs effectively or at all. The apparent silence of families with disabled children who are so unimportant in the large cast of social policy that they are not even seen. It is probably the definition of marginalisation that you and your loved ones are so unimportant that your basic needs are not fully met and your frustration, anger and hurt are not heard. These are the experiences emerging from some of this research.

This lack of agency from people with disabilities reflects an absence of systemic and comprehensive policies at government level.

Disabled people are living longer and have more equipment. Children with physical disabilities need storage space for a shower chair inside the house, not in a garage separate from a house.

Photo Credit: Disability Connect



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[1] The term agency here refers to a person's ability to make sound decisions for themselves and so act as their own agent

Comparison of surveys

Two surveys were conducted as part of this research – both online and drawing from volunteer respondents who found out about the surveys through social networks and particularly social media networks within the various disability communities.

The first survey was conducted in March 2020, just prior to the nation-wide COVID-19 lockdown. This survey sought details of respondents' housing and living arrangements, their satisfaction with these, their general sense of wellbeing and the nature of any unmet housing need. In total 512 people participated in the survey although there was a high attrition rate during the survey with just over three quarters of respondents completing the whole survey.

The second survey was conducted during July and August 2020 following the nation-wide COVID-19 lockdown and prior to the subsequent Auckland one. The point of the second survey was to establish how the lockdown and subsequent policy responses had impacted on those living with disabilities as well as their families. This survey asked respondents if the lockdown and following arrangements had impacted on their housing and general wellbeing and if so how. This survey drew a more modest response of 144 and had a slightly lower in-survey attrition rate to that of the first survey at 23%.

Only 37% of those responding to the first survey did so on their own behalf while 56% of respondents were family members participating on behalf of a person with a disability and 7% were carers of such people. Efforts were made in the framing of the questions to ensure that those participating on behalf of others had a duty to answer the questions from the interests/needs of their family member or friend. Of those responding to the second survey 62% did so on their own behalf. Perhaps related to this higher rate of self-reporting in the second survey is the higher proportion of respondents reporting having a physical disability – 76% in the second survey against 56% in the first.

Both surveys drew the same ethnic mix of respondents and this was generally close to the ethnic mix of the New Zealand population. The first survey had equal numbers of males and females while the respondents in the second survey 59% were male. Respondents in the second survey tended to be more middle aged than in the first where 70% were aged between 30 and 65 years old compared with 49% in the first survey.

> *'Where do you start to find out what is available and who is also looking for a home for their children similar to mine?'* Nadia

Summary of results from the first survey

The first survey found that those responding were slightly more likely to live in rented accommodation -36% compared with 33% for the whole population. Attempts were made to identify those living in social housing but the responses to this question were somewhat inconsistent. Almost one quarter of respondents (23%) reported that they had little or no choice over where or how they lived.

The survey asked respondents a number of questions about their housing and their living arrangements including their satisfaction with these. Overall people were happier with their housing (where they lived) than their living arrangements (who they lived with).

Two thirds of respondents reported that their home was very comfortable while a clear majority (62%) believed that their home supported their health and wellbeing. A similar proportion (60%) said that they were very happy and satisfied with their housing. Conversely around one in five people were unhappy with their housing – 16% disagreed or strongly disagreed that their home was comfortable, 24% were similarly critical of the extent to which their housing met their wellbeing needs while 21% were not happy with their housing overall.

Respondents' satisfaction with their living arrangements were less pronounced. Just 44% of respondents to the first survey agreed or strongly agreed with the statement that they were satisfied with their living arrangements although only 15% disagreed or strongly disagreed with this statement. Those who lived in supported living arrangements with family/whānau were more likely to be happy with their living arrangements while those living with non-whānau members were less happy.

Those living in housing they owned (alone or with whānau) had satisfaction levels 1.5 times that of the average overall while those living in rented accommodation had half the average level of satisfaction. This difference is consistent with the tenure insecurity felt by a large minority of people with disabilities. Forty one percent of respondents were unsure or worried about the permanence of their housing and living arrangements.

There are no reliable comparisons of these housing satisfaction results with similar indicators for the general population. This means that it is not possible to assess whether or not people with disabilities experience poorer housing than the more abled population of New Zealanders. The General Social Survey for instance records peoples' satisfaction with their lives but does not report this in relation to housing or record the contribution which housing makes to peoples' wellbeing.

Despite being generally happy with their house/home the vast majority of respondents to the first survey (70%) identified at least one aspect or element of it that could be improved. Most respondents identified at least two shortcomings in their home. People with intellectual disabilities were less likely than others to identify something wrong with their house and in general those with intellectual disabilities (or those reporting for them) said that they were satisfied with their housing despite identifying shortcomings. A larger majority of people with a chronic illness (82%) identified at least one shortcoming with their house although the majority of people with chronic illness (59%) were still satisfied with their housing.

Although the respondents to the first survey were able to identify one and most often two shortcomings with their housing, they remained happy with it despite these shortcomings. Why this was so is not known. Living with family/whānau and living in a house which you or your family/whānau own appear to make the biggest difference to a person's satisfaction with their housing or living arrangements.

Intensive urban housing can create barriers for people like Melanie who need natural light and disabled children like Karl and Simon who require live in support workers.

Photo Credit: Disability Connect

Summary of results from the second survey

As mentioned above the second survey did not seek to repeat the first one as it was a post-COVID-19 lockdown check-in. Instead, it set out to establish if COVID-19 had detrimentally impacted the wellbeing of people living with disabilities. The survey comprised 14 questions of which seven sought responses to changes in the respondents housing or living arrangements as a result of the pandemic and shutdown. These responses asked for descriptions of changes as well as changes in how people felt about their wellbeing. As mentioned above 144 people responded to the second survey of whom 78% answered every question.

Only a small proportion of respondents reported material changes due to COVID-19. Fourteen percent reported having to shift house as a result of the pandemic while 11% reported changes in the living arrangements. What these changes were is hard to identify from the responses and no significant patterns can be identified.

The majority of respondents reported either no change in their wellbeing (48%) or an improvement (13%) due to COVID-19. Of the remaining 39% of respondents just less than one third (or 12% of all respondents) reported that their wellbeing had become much worse since the national-wide shut down.

When asked what had contributed to changes in their wellbeing around one quarter reported deteriorated health (23%) or poorer care and support (24%) or feeling lonelier (28%) or being bored (28%). Fourteen percent of respondents attributed a decline in their wellbeing due to a change in the housing arrangements. On the positive side 26% of respondents said that they liked having more time to do activities which they valued while 14% said that their health had improved and 14% said that they had improved social contacts.

The significance of these results in terms of how they compare with the general New Zealand population is unknown. A comparable and representative survey of this population has not been undertaken and on any account the response totals were low for the total population of people with disabilities[2].

‘We empower our children to be independent, but who provides the support and co-ordination to make it work when we are no longer around to make it happen?’ Grace

Discussion of results from interviews and focus groups

Between May and September 2020 fourteen individual interview participants and two focus groups were asked questions about their current living situation along with the challenges they had getting that home or faced in the future. They were also asked what their ideal home would look like and how they had fared under the Covid-19 restrictions.

The majority of people interviewed were doing so on behalf of a disabled family member many of whom had high and complex needs. There was representation from all major ethnic groups.

The narratives revealed a number of consistent concerns not just about housing. Interviewees spoke about feelings of exhaustion and defeat. Whilst on paper the living arrangements might appear adequate when compared to other families struggling in the current housing market, the interviews revealed a level of anxiety and desperation about the future for their adult dependants. Disabled people voiced concern at the lack of options for them and the tenuousness of their current living arrangements.

Disabled people and whānau spoke about the lack of choice and the lack of information available to them.

There was a sense that regardless of what was offered to them, a disabled person or their family should be ‘grateful’ for whatever accommodation was offered. Without exception the participants sought basic requirements – to be near to public transport and family/whānau; to have a home that was warm, dry and accessible; secure and well managed; to be in an age-appropriate facility for the disabled person if that was needed.

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[2] One survey of a representative sample of New Zealanders reported that 30% of respondents had moderate to severe psychological distress (K10), 16% moderate to high levels of anxiety, and 39% low wellbeing. This low wellbeing rate compared with ‘base’ low wellbeing rate of 25% reported in the 2018/19 General Social Survey.

Interviewees were challenged by working with government agencies responsible for their welfare. They also spoke about the lack of forward planning and that there was no one place they could go to for information and support.

Interviewees wanted a quality of life and parents in particular spoke about their fear of what would happen to their dependant adult child once they were dead or could no longer advocate for them.

A key issue was accessibility in a home and forward planning to accommodate a disabled person being able to age in place.

Our housing doesn’t meet our changing needs as we age. Joan feels unsafe getting in and out of her shower.

Photo Credit: Jo Currie/Disability Connect.

Recommendations offered below include having a holistic view of housing disabled people and their whānau. Their lack of agency and voice means that in order for the current situation to change consideration must be made to the whole of life needs of a family and/or disabled person. This will require a considerable shift in current thinking and policy making by government agencies.

Additional recommendations require a single government agency to collect long term data with disabled people and their whānau to prepare and plan for housing and community needs in the future. It is the view of these researchers that the Ministry of Social Development is the best placed agency to collect information to inform not only government house builds but those of NGOs. Parents are prepared to assist with housing. Not all housing needs are directed at social housing and/or government provision.

In order to affect change and to give agency back to disabled people and their whānau, clear information and workable processes must be made available so informed decisions can be made by those seeking housing options.

Concluding comments

The two surveys and face to face research reported here are not particularly comparable given that they sought different types of responses and most likely tapped different parts of the disabled community within Aotearoa. This lack of compatibility makes it difficult to draw strong conclusions from the results discussed above and as reported in more detail later in this paper.

As might be expected people living with disabilities have poorer housing than those without seriously impairing disability or illness. They are more likely to rent their home, their security of tenure is poorer and they spend a higher proportion of their income on housing. Notwithstanding this disadvantage those responding to the surveys showed some resilience as they were mostly happy with their housing and living arrangements despite this housing most often not meeting all of their physical needs. Unsurprisingly disabled peoples' self-assessed wellbeing is positively related to their connection with family/whānau.

Disabled peoples' housing and living arrangements generally remained intact since the first COVID-19 lockdown. A significant minority of respondents reported diminished wellbeing as a result of the lockdown but this deterioration appears to be at a similar proportion as those within the general population. This may also reflect the resilience of those participating in the survey.

The face to face interactions offer greater insight into the nature of the struggles and concerns of whānau with disabled children and siblings. The security of their housing and living arrangements are a source of major concern for them. This security is both around the adequacy and permanence of their present housing/living arrangements and the absence of a viable future pathway for many.

Those with disabilities most often lack any agency to make informed and realistic choices over their future housing and care and this lack of agency extends to many of their families as well. This later agency problem is both economic and material in nature – there are just not sufficient viable options for housing and care and whānau lack the economic and organisational resources to change this.

Disabled people and their families have a number of rights guaranteed to them under such international frameworks as Convention on the *Rights* of *Persons* with *Disabilities* and the International Covenant on Economic, Social and Cultural Rights, as well as through national policy frameworks such as the New Zealand Disability Strategy. Given these guarantees, their inability to secure adequate housing and personal care must be seen as a long-term failure of public policy. This failure is not one of ignorance (we didn't know) or even wilful ignorance (we didn't want to know) but an admission of neglect (we knew and did very little). This is so given that these needs are already well known and are in many instances quite calculable and predictable.

The following recommendations are designed to address this commission of neglect by focusing on enhancing the agency of those living with disabilities and their families and on an obligation for the Crown to support this agency.

RECOMMENDATIONS

That the housing needs of disabled people be seen as an issue of rights rather than as a social or a health need. As a basic human right which is acknowledged by international conventions and national policy frameworks a single Crown agency – such as the Ministry of Social Development, should have the statutory obligation to ensure that people with disabilities are always adequately housed.

In fulfilling this obligation Ministry of Social Development would ensure that people who are living with disabilities have sufficient agency to be able to make informed and adequate choices over their housing and personal care.

A disabled person’s wellbeing is most often closely linked to that of their family or whānau so it is important that the question of agency takes account of the role which family/whānau play in making choices and in providing support for disabled people.

That Ministry of Social Development has a statutory responsibility to plan for the housing and care needs of New Zealanders with disabilities and that it does so from a sound evidence base and with respect to the principles set out in the New Zealand Disability Strategy.

That information on housing and personal care options for disabled people is freely available and accessible so that those with disabilities and their families/whānau can make informed choices over their housing and care needs and can plan adequately for these needs as they change.

That the government sets a target for 100% of new public housing to fully include universal design, following similar initiatives in the UK, Ireland and Norway, to ensure that this housing is always available for use by people with disabilities and able to cater for the access and functional needs of New Zealand’s aging population.

> *‘I don’t know where he will live when we die.’*
>
> *Priya*

RESEARCH OBJECTIVES AND METHODOLOGY

This report presents the results of research into the housing and living needs of people living with disabilities in Aotearoa-New Zealand. Initially one sequence of research was planned to be undertaken during February and March 2020 which involved on-line surveys, focus groups/hui and person to person interviews. The first COVID shutdown commenced 26th March 2020 by which time this initial research had largely been finished. Given the possible impacts of this shutdown on peoples' housing and living arrangements, it was decided to more or less repeat the research sequence with a further on-line survey and more person-to-person interviews. The purpose of this second sequence was to ask about the impact of the shutdowns on the lives of people with disabilities and in particular if their housing and living arrangements had changed as a consequence of the shutdowns. This second sequence of research was undertaken during June to August 2020.

Two types of objectives were anticipated for this research project – one type relates to the information which is being sought and the other to how the information is sought. These objectives are as follows:

To provide an opportunity for people with disabilities and their whānau, including carers, to discuss and record their housing experiences and their housing related problems.

To undertake analysis based on these experiences and reported problems which might provide insights for policy advocacy to central and local government agencies and to the UN review on the Convention of the Rights of People with Disabilities.

To use this analysis for more general public advocacy around the unmet housing needs of people with disabilities and their families and whānau.

To build social research capacity within the disability sector including providing people who have disabilities, their families, carers and whānau with useful experience in research and analysis techniques.

A white screen mesh safety screen keeps parents and children with intellectual disabilities safe at home. Families with disabled children need homes with the flexibility for equipment like screens and space for adaptive children's tables and seats.

RESULTS FROM FIRST ON-LINE SURVEY

Methodology and responses

An on-line survey through Survey Monkey was promoted within the various disability communities through social media in March 2020. The survey invited people with disabilities or their whānau or caregivers to discuss their housing and living arrangements and the level of satisfaction and/or problems they experienced with these. The survey was conducted anonymously although it asked participants to tell us about the disabilities they had and their gender, age and ethnicity.

The survey involved 19 questions and a copy of this is attached as Appendix 1. Potential respondents were provided with a summary of a privacy/ethic statement which is attached as Appendix 2 and they were advised of who was conducting the survey and its purpose. Participants were made aware that undertaking the survey was purely voluntary and that participation provided no promise that their housing or living circumstances might be improved by their participation.

A total of 512 people participated in the survey although the responsiveness to questions waned as people worked their way through the survey. Question 1 had a 100% response rate, Question 4 a rate of 84%, Question 8 a rate of 79% while by Question 18 the response rate had fallen to 73%. Generally, those respondents who offered an answer to the last few questions had answered the previous one consistently so there was an attrition as people worked their way through the survey with about 100 respondents effectively abandoning the survey before completing it.

Who participated?

The majority of participants in the survey (56%) were responding on behalf of a whānau member who had a disability while 7% were responding on behalf of someone they were a care giver for. Just 37% of respondents did so on their own behalf. The survey was framed to allow this to happen, but where the respondent was answering on behalf of someone else they were reminded that responses should represent the views and interests of the person they were participating for.

Half the respondents answering the survey were female (n=187) while 49% were male (n=181) and 1% were an otherwise defined gender (n=2).

The age distribution of respondents is offered in the following table. This shows that most of the respondents were working age adults with an even spread of ages between 20 and 64 years old. Few people were aged 65 or older.

Table 1: Age distribution of respondents

Age distribution	Number	% of those responding to question
Under 20 years	83	22%
20 to 29 years	77	21%
30 to 49 years	109	29%
50 to 64 years	74	20%
Over 65 years	28	8%
No response	141	

Māori were proportionately represented within the survey at 15% of responses to the ethnicity question while Pākehā/European are slightly over represented at 70%. The reported ethnicity of respondents is offered in Table 2 below. Note the number of responses to this ethnicity question is 422 which suggests that as many as 51 respondents reported two ethnicities.

Table 2: Ethnicity of respondents

Ethnicity	Number	% of those responding to question
Māori	59	16%
Pākehā/European	268	72%
Pacific Island	33	9%
Asian	25	7%
Other ethnicities	37	10%
Total respondents	371	
Total responses	**422**	
No response	141	

Question 1

Table 3 reports the types of disabilities encountered by respondents. The numbers of people with a physical disability narrowly exceeded those with an intellectual disability and at least half the responded reported more than one disability.

Table 3: Disability encountered by respondents

Disability encountered	Number	% of those responding to question
Physical	208	33%
Intellectual	173	27%
Sensory	99	16%
Mental health related	65	10%
Chronic health condition	85	13%
No response	141	
Total responses	**630**	

Responses to questions on housing and living arrangements

The following tables report the responses to questions on people’s housing and living arrangements.

Question 2

Table 4: Agency in choice of living situation

What choice did you have in deciding your current living situation? (tick one)	Number	% of those responding to question
Full and free choice	176	38%
Some but limited choice	184	39%
No choice	109	23%
No response	43	
Total responses	**469**	

Question 3

Table 5: Nature of living situation

Describe the arrangements which best describe your current living situation: (tick one)	Number	% of those responding to question
Living independently and alone	43	10%
Living independently with my family/whānau	111	25%
Living independently with non-family/whānau members	17	4%
Supported living alone	27	6%
Supported living with my family/whānau	202	46%
Supported living with non-family/whānau members	42	10%
No response	70	
Total responses	**442**	

Question 4

Table 6: Tenure of accommodation

Under what arrangements do you occupy or use your accommodation: (tick one)	Number	% of those responding to question
Own mortgage free	39	9%
Own with a mortgage	51	12%
Live with my family/whānau who own mortgage free	44	10%
Live with my family/whānau who own with a mortgage	80	19%
Rent alone	62	14%
Rent and share with others	60	14%
Rent free with family/whānau	36	8%
Rent free with non-family/whānau members	1	<1%
Hostel or residential facility	24	6%
Other	31	7%
No response	84	
Total responses	**428**	

Question 5

Table 7: Nature of tenancy

If you rent your house, flat or apartment who is your landlord? (tick one)	Number	% of those responding to question
A family member	67	24%
A private person (not family) or a business	108	39%
Housing New Zealand/Kāinga Ora	47	17%
City or district council	5	2%
A community organisation or charitable trust	20	7%
Not sure	32	11%
No response	233	
Total responses	**279**	

Question 6

Table 8: Personal income spent on housing

What share of your income do you pay toward your housing? (tick one)	Number	% of those responding to question
None	61	15%
< 20%	63	15%
20% to 30%	44	11%
30% to 40%	29	7%
40% to 50%	52	13%
>50%	93	23%
Don’t know/not sure	70	17%
No response	100	
Total responses	**412**	

Question 7

Table 9: Security of tenure

How sure are you that you can stay in your home for as long as you want? (tick one)	Number	% of those responding to question
Very sure	137	34%
Quite sure	94	23%
No sure/worried	122	30%
Very unsure	48	12%
Not applicable	6	1%
No response	105	
Total responses	**407**	

Question 8

Table 10: Length of tenure

How long have you lived in your present house, flat or apartment? (tick one)	Number	% of those responding to question
Less than 1 year	67	17%
1 to 2 years	44	11%
2 to 5 years	88	22%
5 to 10 years	80	20%
More than 10 years	124	31%
No response	109	
Total responses	**403**	

Question 9

Table 11: Home comfort

To the statement 'My home is very comfortable' do you (tick one)	Number	% of those responding to question
Strongly agree	128	32%
Agree	134	34%
Neither agree nor disagree	70	18%
Disagree	36	9%
Strongly disagree	27	7%
No response	117	
Total responses	**395**	

Question 10

Table 12: Home health and wellbeing

To the statement 'My home supports my health and wellbeing' do you (tick one)	Number	% of those responding to question
Strongly agree	111	28%
Agree	136	34%
Neither agree nor disagree	55	14%
Disagree	58	15%
Strongly disagree	35	9%
No response	117	
Total responses	**395**	

Question 11

Table 13: Need for home modifications

Does your house, flat or apartment have features or alterations built into which cater for your disability related needs? (tick one)	Number	% of those responding to question
Yes	173	44%
No	131	33%
Nothing is required	88	22%
No responses	120	
Total response	**392**	

Question 12

Table 14: Disability related modifications

Does your house, flat or apartment have features or alterations built into which cater for your disability related needs? (tick one)	Number	% of those responding to question
None - it is fine as it is	117	30%
Better insulation	95	24%
Better safety features	90	23%
More space	114	29%
A better bathroom which is easier to use	130	33%
A better kitchen which is easier to use	109	28%
Better access in and out of the building	114	29%
Wider doors	69	18%
Better fencing	69	18%
No response	122	
Total responses	**907**	

Question 13

Table 15: Contentment with location

How happy are you with where your present home is located? (tick any)	Number	% of those responding to question
Its location is fine and I am happy with it	277	72%
Closer to my job or to employment opportunities	44	11%
Closer to the health and support services I need	53	14%
Closer to my family and friends	51	13%
In a neighbourhood where I knew more people	46	12%
Closer to shops and entertainment opportunities	42	11%
Closer to schools	19	5%
Closer to public transport	48	12%
No response	127	
Total responses	**580**	

Question 14

Table 16: Housing satisfaction

To the statement 'I am very happy and satisfied with my current housing' do you (tick one)	Number	% of those responding to question
Strongly agree	102	27%
Agree	125	33%
Neither agree nor disagree	78	20%
Disagree	49	13%
Strongly disagree	29	8%
No response	129	
Total responses	**383**	

Question 15

Table 17: Ideal living arrangements

What is your ideal housing or living arrangement? (tick any)	Number	% of those responding to question
Happy with what I have already	119	31%
More independence and/or privacy	93	25%
Bigger house	88	23%
Closer to my family/whānau and friends	44	12%
More secure tenure	117	31%
A house which better meets my needs	121	32%
To own my house	124	33%
No response	133	
Total responses	706	

CROSSTABULATIONS

Further analysis of the survey results was undertaken to see if a person's level of satisfaction with their housing or living arrangements varied according to their living arrangements, housing tenure, the disabilities they had or various demographic characteristics. This analysis was done through cross-tabulation of the data set of individual responses to count how many people answered two questions in the same way. For example, how many people lived with whānau members and expressed satisfaction with their housing. The results for eight cross-tabulations are presented in the following tables.

Living arrangements and housing satisfaction

Table 18: Satisfaction with housing by a respondent's living arrangements

To the statement I am satisfied with my housing/living arrangements **Living arrangement of respondent**	Agree or strongly agree	Disagree or strongly disagree	Number
Living independently and alone	51%	23%	43
Living independently with my family/whānau	55%	12%	111
Living independently with non-family/whānau members	24%	47%	17
Supported living alone	63%	15%	27
Supported living with my family/whānau	50%	17%	202
Supported living with non-family/whānau members	50%	21%	42
Total	44%	15%	442
Living independently	51%	18%	171
Living with family/whānau	52%	15%	313

Housing tenure and housing satisfaction

Table 19: Satisfaction with housing by a respondent’s housing situation

Living arrangement of respondent	Agree or strongly agree	Disagree or strongly disagree	Number
I live in a hostel or residential facility	42%	33%	24
I live rent free with family/whānau	33%	19%	36
I live rent free with non-family/whānau members	0 %	100%	1
I live with my family/whānau who own the house/flat/apartment mortgage free	75%	2%	44
I live with my family/whānau who own the house/flat/apartment with a mortgage	59%	11	80
I own the house/flat/apartment mortgage free	72%	10%	39
I own the house/flat/apartment with a mortgage	66%	8%	50
I rent my house/flat/apartment alone	44%	32%	62
I rent my house/flat/apartment and share the rent with others	41%	26%	61
Other	39%	26%	31
No response	0%	0%	84
Total	**44%**	**15%**	**512**
Owned with or without family/whānau	**66%**	**9%**	**213**
Rented with or without family/whānau	**42%**	**29%**	**123**

Housing satisfaction and housing needs

Table 20: Satisfaction with housing by agreement that housing meets wellbeing needs

Satisfaction with housing or living arrangements **My home supports my health and wellbeing**	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	No response	Total
Strongly agree	77.5%	20.8%	6.4%	4.1%	0.0%	2.3%	23.5%
Agree	21.6%	64.8%	34.6%	2.0%	0.0%	3.9%	23.3%
Neither agree or disagree	1.0%	9.6%	38.5%	16.3%	6.9%	1.6%	11.2%
Disagree	0.0%	4.8%	20.5%	59.2%	20.7%	0.8%	11.8%
Strongly disagree	0.0%	0.0%	0.0%	18.4%	72.4%	0.8%	6.3%
No response	0.0%	0.0%	0.0%	0.0%	0.0%	90.7%	23.9%

Housing satisfaction and gender

Table 21: Satisfaction with housing by gender of respondent

Satisfaction with housing or living arrangements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	No response	Total
Female	52%	44%	47%	59%	50%	0%	49%
Male	48%	55%	52%	41%	50%	0%	50%
Other	0%	1%	1%	0%	0%	0%	1%

Housing satisfaction and respondent's age

Table 22: Satisfaction with housing by age of respondent

Satisfaction with housing or living arrangements **Age of respondent**	Agree or strongly agree	Disagree or strongly disagree	Number
20 to 29	61%	23%	77
30 to 49	57%	18%	109
50 to 64	59%	24%	74
Over 65	68%	7%	28
Under 20	57%	23%	83
Not stated	**6%**	**1%**	**141**
Total stated	**61%**	**21%**	**371**

Housing satisfaction and respondent's ethnicity

Table 23: Satisfaction with housing by ethnicity of respondent

Satisfaction with housing or living arrangements	Agree or strongly agree	Disagree or strongly disagree	Number
Māori	53%	29%	59
Pākeha/European	63%	20%	268
Pasifika	33%	21%	33
Asian	64%	12%	25
Other Ethnicity	59%	24%	37
Not stated	5%	7%	0
Total stated	**59%**	**21%**	**0**

Housing satisfaction and respondent's disability

Table 24: Satisfaction with housing by type of disability/impairment of respondent

Satisfaction with housing or living arrangements **Type of disability**	Agree or strongly agree	Disagree or strongly disagree	Number
Physical	40%	30%	208
Intellectual	49%	27%	173
Sensory	47%	31%	99
Mental health related	52%	34%	65
Chronic illness related	59%	29%	85
Not stated	3%	3%	137
Total stated	47%	30%	630
Total responses	39%	25%	767

Housing satisfaction and agency of respondent

Table 25: Satisfaction with housing by the agency of the person responding to the survey

Satisfaction with housing or living arrangements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	No response	Total
Carer	3%	12%	21%	6%	9%	49%	33
Family/Whānau member	18%	25%	16%	9%	4%	29%	288
My self	26%	26%	13%	12%	8%	15%	190
Totals	20%	24%	15%	10%	6%	25%	511

Housing improvement required by type of disability

Table 26: Requirement for housing improvement by the type of disability/impairment of respondent

Type of disability	Nothing required	Something required	Total	Satisfied with housing (Table 24)
Physical	25%	75%	208	40%
Intellectual	35%	65%	172	49%
Sensory	23%	77%	99	47%
Mental health	22%	78%	65	52%
Chronic health	18%	82%	85	59%

Main points to take from these results

Most respondents apparently had some choice in their housing/living situation (77%) although this result needs to be tempered by the fact that a minority (37%) of respondents participated in the survey on their own behalf. (Q2|Table 4)

While the majority of responses were from whānau members on behalf of a person with a disability, it appears that when respondents answered for themselves, they tended to report a more positive view of their housing. Fifty-two percent of respondents answering for themselves said that they agreed or strongly agreed with the statement that they were satisfied with their housing or living arrangements while 43% of whānau members reported this on behalf of their relative. On the negative side 21% of self-respondents said that they weren't satisfied with their housing while just 13% of whānau respondents did. (Cross-tab Q1:Q14|Table 25)

Most respondents (71%) lived with whānau in an independent or supported living arrangements while 10% of respondents lived in supported accommodation outside of their whānau (Q3|Table 5)

While 50% of respondents live in housing which is owned by the occupants (with or without a mortgage) nationally this ownership rate is 63%. This means that respondents were more likely to live in rented accommodation than the general population. (Q4|Table 6)

Over one third (36%) of respondents reported paying more than 40% of their income as housing costs (Q6|Table 8). The 2018 Household Economic Survey from Statistics New Zealand reported that nationally 12% of households paid more than 40% of income on housing while 21% of tenants did so.

Forty two percent of respondents are unsure or very unsure about the security of their housing tenure while 57% of respondents were confident of the security of their tenue (Q7|Table 9)

Two thirds of respondents (66%) find their home very comfortable while a clear majority (62%) believe that their home supports their health and wellbeing. Nearly a quarter of respondents (24%) however believe that their home doesn't do so. (Q9|Table 11 and Q10|Table 12)

Despite being generally happy with their house/home the vast majority of respondents (70%) identified at least one aspect or element of it that could be improved. Most respondents identified at least two shortcomings in their home. (Q12|Table 14). People with intellectual disabilities were less likely than others to identify something wrong with their house and in general those with intellectual disabilities (or those reporting for them) said that they were satisfied with their housing despite identifying shortcomings. The majority of people with a chronic illness (82%) identified at least once shortcoming with their house the majority (59%) were still satisfied with it. (Cross-tab Q14:Q19|Table 26)

Of those responding to the question, 72% were happy with the location of their home while between 10% and 15% identified at least one shortcoming with the location of their home (Q13|Table 15).

A modest minority of respondents (21%) are unhappy with their housing or living situation while a clear majority (60%) are happy and satisfied with it. (Q14|Table 16).

Just less than one third (31%) of respondents were unreservedly happy with their current housing while the remainder of respondents could identify at least one feature which could be improved. The most important thing to improve an individual's housing was security of tenure – cited by nearly one third of respondents (Q15|Table 17).

People living independently and those living with whānau (dependently or independently) tended to be slightly more satisfied with their living arrangements or housing. Those living with people who were not their whānau were more likely to be dissatisfied with their housing. (Cross-tab Q3:Q14|Table 18)

People who lived in housing which they or their whānau owned (with or without a mortgage) were 50% more likely than respondents overall to be satisfied with their housing or living arrangement and half as likely to be dissatisfied. People who lived in rented accommodation were twice as likely as respondents overall to be dissatisfied with their housing (Cross-tab Q4:Q14|Table 19).

Unsurprisingly a person's satisfaction or dissatisfaction with their housing or living arrangements was related to their assessment of whether or not the housing met their wellbeing needs. Those who agreed that their housing met their wellbeing needs were almost always likely to be satisfied with their housing or living arrangement. Conversely those who felt that their housing did not meet their wellbeing needs were almost entirely likely to be dissatisfied with their housing (Cross-tab Q10:Q14|Table 20).

Female respondents are slightly more likely than males to be dissatisfied with their housing. (Cross-tab Q14:Q16|Table 21). People aged over 65 years old were more likely to be satisfied with their housing or living arrangement and less likely to be dissatisfied with it than those of other ages. (Cross-tab Q14:Q17|Table 22).

Māori were less likely than Pākehā/European to be satisfied with their housing or living arrangements and more likely to be dissatisfied with them. The same pattern of lower dissatisfaction emerged for Pasifika and Asian respondents although the numbers of these respondents make this result not reliable statistically (Cross-tab Q14:Q18|Table 23).

A home facilitates community connection. Barriers to community include no accessible toilet downstairs or covered parking for disabled visitors.

Photo Credit: Disability Connect.

RESULTS FROM SECOND ON-LINE SURVEY

With the emergence of COVID-19 and the related nationwide shut down in March and April 2020, the researchers appreciated that many peoples' living circumstances may have changed and that the survey conducted in March may no longer have relevant results. A decision was made at this stage to conduct a second survey in order to gain an understanding of how COVID-19 had impacted on the lives of people living with disabilities.

This second survey used the same on-line networks within the disability community as the first to elicit participation of people with disabilities or their whānau and carers. The second survey consisted of 14 questions – five of these dealt with demographic characteristics of the respondent while nine asked people about how COVID-19 had impacted on their living arrangements and wellbeing. A copy of this survey is attached as Appendix 3.

Responses and respondents to the second survey differed significantly so there is little association able to made between the two. They should most appropriately be seen as representative snapshots of the lives of those participating at different points in time and under different circumstances. As snapshots they may also be seen as being indicative of the lived experiences of people with disabilities under these circumstances. The second survey had just 30% of the responses of the first and respondents tended to be older, more male, and more likely to be living with a physical disability. Respondents in the second survey were also more likely to be representing themselves than have someone else respond for them. This higher rate of self-representation is consistent with the higher rate of people with physical rather than intellectual and perhaps mental health related disabilities. Comparisons of the demographics of the two surveys are presented in the following tables.

> *'I couldn't have international students as flatmates to subsidise my rent. They have all gone home or won't be returning for some time'*
>
> *Melanie*

Table 27

Agency of respondents to on-line surveys	Survey 1	Survey 2
For myself	37%	62%
For a family/whānau member	56%	33%
Carer	7%	5%
Number of respondents	512	144
No response to question	0	0

Table 28

Gender of respondents to on-line surveys	Survey 1	Survey 2
Female	49%	41%
Male	50%	59%
Other	1%	0%
Number of respondents	371	111
No response to question	141	33

Table 29

Age of respondents to on-line surveys	Survey 1	Survey 2
Under 20	22%	5%
20 to 29	21%	16%
30 to 49	29%	41%
50 to 64	20%	29%
Over 65	8%	8%
Number of respondents	371	111
No response to question	141	33

Table 30: Ethnicity of respondents

Proportion of respondents	Survey 1	Survey 2
Māori	16%	18%
Pākeha/European	72%	74%
Pacific Island	9%	11%
Asian	7%	3%
Other ethnicities	10%	9%
Number of responses	422	127
Number of respondents	371	111
No response to question	141	33

Table 31: Disability encountered by respondents

Proportion of respondents	Survey 1	Survey 2
Physical	56%	76%
Intellectual	47%	27%
Sensory	27%	15%
Mental health related	18%	9%
Chronic health condition	23%	14%
Number of responses	630	164
Number of respondents	371	111
No response to question	141	33

It is clear from the data offered above on respondents' demographic characteristics and their agency, that the second survey was contributed to by more people with a physical disability who had sufficient agency to respond for themselves. We have no way of knowing why this shift in participation occurred between surveys as the method of recruiting participants was passive and informal and participation was entirely voluntary.

Respondents to the second survey were more likely to own their home in comparison with those responding to the first survey as reported in the following table. This is consistent with respondents to the second survey being older and may be related to the higher proportion with physical disabilities. Because of the small numbers involved in the second survey, cross-tabulations of housing tenure with the following wellbeing indicators was not done as the results would not be statistically significant.

Table 32: Comparison of housing tenure across surveys

Proportion of respondents	Survey 1	Survey 2
In a home I own	21%	35%
In a rented property	36%	24%
In supported living	6%	4%
With family/whānau in a home we own	29%	27%
Other	7%	11%
Number of respondents	344	135
No response to question	84	9

> *‘What will happen to David when I die?’*
>
> *Grace*

The majority of respondents to the second survey (86%) reported that their housing had not changed as a result of COVID-19. Responses to a subsequent question to those 18 people who reported some change were not able to identify any reason for their shift or changed housing circumstances. Four people reported higher housing/living costs as a result of COVID-19 the majority (11) of those effected indicated a non-specific impact or reason for the change. From this result it would appear that COVID-19 at the stage of the pandemic when the survey was undertaken, had not impacted much on the housing arrangements of respondents.

A similar question asked about changes in people’s living (rather than housing) arrangements. That is who they were living with rather than where they were living. Once again COVID-19 had a limited impact of those responding. Just 11% (14 respondents) reported changed living arrangements with five reported having different people in their household and seven indicating that they had less access to the outside world.

The majority of respondents reported that their wellbeing was the same or better during the first COVID-19 lockdown. Fifty eight people (48% of responses) indicated no change in their sense of wellbeing while 16 (13%) said that they felt their lives had improved. Conversely 39% of respondents indicated that their wellbeing had deteriorated while 12% indicated that it had got much worse.

When asked how or why their wellbeing had changed respondents offered the responses outlined in the following table. Around one in four respondents indicated that things had got worse for them especially around having poorer health, worse care and support, being lonelier or bored. About one in eight people reported that things had got better for this as a result of COVID-19.

Table 33

Contributors to your changed sense of wellbeing	Survey number	% of those responding to a question
My state of health has improved	14	14%
My state of health has got worse	22	23%
I am struggling more with my finances	15	15%
My care and support arrangements have improved	12	12%
My care and support arrangements have got worse	23	24%
Improvements with my housing situation	5	5%
Problems with my housing	14	14%
Positive changes in my relationships	11	11%
Negative changes in my relationships	11	11%
I have improved connections with others	14	14%
I am lonelier	27	28%
I have more time to do the things I want to do	25	26%
I am bored	27	28%
Total number of people responding	97	
No response to question	47	

RESULTS AND RESPONSES FROM INTERVIEWS AND FOCUS GROUPS

Introduction

Fourteen telephone interviews took place between May and August 2020, conducted by two trained interviewers. Two focus groups were also held. The first focus group on the 11th March 2020 in the Frankton area, in Hamilton was for people with spinal impairments. The second focus group comprised of twenty Tongan elders and their supporters living in Kainga Ora homes in the Glen Innes, Tamaki community in Auckland. This group met on the 11th August in the Glen Innes Community Hall.

With the fourteen interviews, nine people were interviewed on behalf of a disabled family member. The remaining five interviews were from people advocating for themselves. Most of the interviews were for people with high and complex needs. While most of the participants identified as Pakeha, there was representation from Māori, Pacifica, Asian and one who identified as ‘other’.

The semi-structured interviews took place after the first Covid-19 nation-wide lock-down and before the 11th August level three lock-down. Some participants referred to the impact this period had on their families.

Interview questions

Question One centred on the participant talking generally about their current home. They were asked about the tenure of their home and who lives with them. They were encouraged to discuss the positives and negatives about their home, including physical barriers, lighting, safety, and repairs and the impact on them. The interviewees were asked about the impact of their impairment on their daily living in their home.

Question two asked them to reflect on the challenges they faced and do face in finding a home.

Question three centred on the impact of Covid-19 on their lives with regard to their housing.

Question four asked the participants to talk about what their ideal home would look like. They were asked what amenities they would like, the cost of their ideal home, adding in issues like carer support, and to think about the next 10, 20, 30 years.

Narrative Results from Interviews

General comments from the interviewees:

Many families had tried a variety of housing options for their disabled family member and for the most part they were disillusioned with what was offered to them or what their final choice had been. The disabled people who were interviewed had also experienced a variety of living options with varying success. There was a sense that regardless of what was offered to them, a disabled person or their family should be 'grateful' for whatever accommodation was offered. Without exception the participants had basic requirements – to be near to public transport and family/whānau; to have a home that was warm, dry and accessible; secure and well managed; in an age-appropriate facility for the disabled person if that was needed.

One homeless interviewee had concerns about Work and Income staff's competency and understanding of disability when dealing with him.

One family has been living in cold damp conditions in a Kainga Ora home for eight years. Despite the government agency knowing about their severely disabled daughter, they have little optimism that anything will change for her and indeed for them in the near future. Trying to work with a government agency has been frustrating and has affected their mental health and well-being.

Threaded throughout the interviews were comments about what the lack of forward planning had meant for their housing aspirations from both personal and systemic agency points of view. Participants, especially the families, were concerned that there wasn't one place they could go to for clear information and direction as to what their options could be.

Those participants who had researched various options stated their concern over the length of time arranging accommodation could take and the energy and focus required from parents who were already stretched and possibly lacking the necessary contacts to make it happen. One parent said, 'It takes too much work, it would be like a part-time job with all the organisation required.'

'Only one provider will offer him sufficient safety and a decent quality of life. The waiting list for that provider is over 30 years or more,' says Jenny on behalf of her son Joseph who has high and complex needs requiring 24/7 care. Jenny and her husband are already struggling and will be very unlikely to live that long.'

When negotiating a living arrangement for her son Simon who has a profound disability and Autism, his mother Lesley was unaware of the low level of funding for adult residential care. Although Simon receives funding for his living situation it is not enough to give him an option that delivers 'choices, dignity and respect.'

Nadia who owns her home wants to organise a living arrangement for her son Jason who is 20 and has Global Development Delay. Jason requires constant supervision for routine tasks such as personal cares, reading and writing. Nadia wants to meet other parents to help find a house but is perplexed at where to start. 'Where do you start to find out what is available and who is also looking for a home for their children similar to mine?'

Sanjay and Jasmina care for their daughter Mary who is in her late 20s. Mary needs constant support for all areas in her life. Sanjay said,' I am frustrated that there is not better support for families like ours. There is no database of available housing for people looking for independent and residential living. We would like to create something from our own pocket which gives us some control but we need help to make it happen. How can we connect with families with similar issues? There is no place currently available for her (Mary's) future and it is up to parents like us who are already tired and worn out from care to create a space for their children.'

'Work and Income staff's adversarial attitude towards assisting people with chronic illness and disabilities will reduce Thomas to tears and cause a major relapse in his condition.'

Shared recurring concerns centred on 'who would look after a disabled son or daughter after they had died.' Many are aware that this is a tough conversation to have with their wider family and an area that concerned many family members who were interviewed.

Priya and her husband share their home with their daughter and son Rahul. Rahul, aged 22 is on the autism spectrum, and is prone to anger, physical responses and violence if bullied or anxious. Priya asks, 'I don't know where he will live when we die'. She knows of other families struggling with this question. Priya thinks, 'It is probable that Rahul's sister will look after him after they die.'

Grace is concerned about what will happen to her son David when she dies. 'We empower our children to be independent, but who provides the support and co-ordination to make it work when we are no longer around to make it happen?'

Grace and her husband think he will stay on in the house with support. 'We have family friends who have said they will look after him when we are no longer around. I am grateful for that.'

Susan and Timothy are unsure whether extended family would be interested or able to assist their family going forward.

Nadia has two elderly parents and a sister nearby. She feels that her sister could step in to support Jason if anything happened to her. She has realised that she has to make arrangements for Jason's guardianship going forward.

> *'How can we connect with families with similar issues?'*
>
> *Sanjay*

Some families with children on the autism spectrum need safe spaces where parents can keep a watch on them and fences to keep them from running across the street.

Photo Credit: Disability Connect.

Question One – Current living arrangements.

Many parents interviewed had been caring for their now adult children for many years. Some were single parents and a number of them appeared to only have one child. Many admitted to feelings of exhaustion and defeat. Whilst on paper the living arrangements might appear adequate when compared to other families struggling in the current housing market, the interviews revealed a level of anxiety and desperation about the future for their adult dependants. A number of parents had already tried a variety of housing options and held informed views about the current prospects for their adult children. Disabled people voiced concern at the lack of options for them and the tenuousness of their current living arrangements. The majority of the interviewees had struggled with housing concerns for a number of years.

Jenny lives with her husband Hemi and son Joseph in a rural area near Auckland. Their son is 19 years old, non-verbal and wears nappies. According to Jenny, Joseph would not survive without 24/7 care. The family is at breaking point from sleep deprivation which impacts their health. ‘Attending ordinary events is near impossible as Joseph will not go where you want him to go, instead he sits down and refuses to move. If Joseph is left to his own devices, he would make noise all night, smear poo, escape and lie on the road. He needs a secure safe place to wander outside.’

Jenny is concerned that a typical house functioning as a group home would be totally inadequate for Joseph. ‘It would be like a small prison for him.’

Joan who is 67 has progressive health conditions which has led to limited mobility and extreme fatigue. She is estranged from most of her family and has limited support. She has lived in Kainga Ora homes for 20 years, and her current one for 15 years. The home she lives in needs painting. It has never been painted in the 15 years she has lived there despite promises that it would be done. She feels, ‘the house is literally rotting away and no one seems to be concerned. They wouldn’t look after their own places like that.’ Joan has a number of progressive health issues that cause her to fatigue easily and she lives with constant pain. Due to the progressive nature of her medical needs she requires additional modifications to be carried out on the house. The house is cold without a heat pump and she relies on a small blow heater for warmth.

Lesley’s son Simon is 23, is totally blind, has a profound intellectual disability and Autism, is non-verbal with no reliable system of communication. He has major gut issues and is underweight and easily stressed, incontinent and a poor sleeper. Simon receives funding for his living situation but it is not enough to give him an option that delivers choices, dignity and respect. From the age of 14 to 22 Simon boarded in a home providing respite care. Despite the fact that he was over the cut-off age of 18 years the respite provider agreed that they would provide a transition option for Simon to then move into a permanent home. The plan fell through for a number of reasons, including a lack of funding and carer training. Simon is now back living at home.

Thomas has lived in a van since 2002 and more recently in a car after selling his house due to a catastrophic collapse in his health in 2001. After a number of mis-diagnoses Thomas finally knows that his condition is caused by his exposure to chemicals and pollutants. Thomas suffers from memory loss and cognitive impairment. His rare disorders and sensitivities have made it impossible for Thomas to find suitable housing. He has tried everything, from house-sitting to living rurally, however any spray or perfume, chemical cleaners and Wi-fi signals leave him incapacitated.

Grace lives with her husband in a large family home in a central Auckland suburb. They own their own home. Her son, David aged 32 lives downstairs. David has a mild intellectual disability. David's main challenge is his lack of motivation. He needs guidance and help to make sure he gets tasks like cleaning done and to actually start chores. If left to himself David will spend all day on media or on his computer. He doesn't have a wide range of friends.

Grace says she is tired. 'I need a team of people to take over the role of guidance and support. Someone who can help him to live his life in the best way possible.' 'I want to be a mother, not a nagging co-ordinator for my son when he is middle-aged. David is happy living in the family home. Grace and the family are working to renovate the flat downstairs for him. Whilst David has been flatting in the past, it didn't work out and he came home for a temporary stay. Three years later he is still living at home because he has realised, he can still have his independence by living there.

Susan and Timothy live with their 14-year-old son Karl in a four bedroomed house in Auckland. Karl has Global Developmental Delay. He attends a near-by special school and goes to a respite care house four nights a month. Karl has just started wearing underwear and wears nappies at night. The house meets the family's current needs with its proximity to work, leisure activities and school.

Priya and her husband care for their adult son Rahul (22) who is Autistic and prone to getting angry, with physical responses and violence if bullied or experiencing high anxiety. Whilst Rahul enjoys a range of social activities, he needs someone to organise them for him. He wouldn't live in residential care as he needs more independence and someone to take him for walks. Currently they do not feel as though Rahul has many living choices at all, so he remains living at home with his parents. Whilst Rahul wants to live away from home, he lacks the living skills to do so. It took Priya two and a half months to teach him how to make his own breakfast.

Nadia (60) has owned her four bed-roomed home for 25 years which she shares with her Samoan children, Saskia (17) and son Jason (20) and an international student. Jason has Global developmental Delay which impacts on his daily life. Jason can drive a car but cannot navigate, he is very particular and quirky. He doesn't like talking on the phone, won't use public transport and easily offends people as he doesn't understand social cues. Jason has a girlfriend Tatiana who also has impairments. Currently Jason and Tatiana spend a lot of time at Nadia's place. They rely on Nadia to organise their lives. Jason needs support in his personal cares and to organise his day.

Aziz has lived in New Zealand for around ten years. He is married to Farah and they have two children Jana aged 11 and Hamed aged nine. Jana has a number of serious health and neurological problems. She is tube fed and monitored 24 hours a day as she vomits and can die through choking. Aziz refused the Kainga Ora home they now live in as it was filthy. He was told to take it as there was nothing else on offer. He repainted the interior but still has to combat mould on a regular basis. The house is on a steep hill so Jana cannot be taken up it by family members.

There is a wooden ramp at the back of the house for access as the front has steps. Jana needs sunlight as she has significant Vitamin D deficiencies, her feet and arms are twisted, she has had breaks in both her arms and her legs and she is waiting surgery on both her hips and feet to correct them. Due to the site Jana cannot be taken outside to sit in the sun. Jana has a lot of equipment. As the house is small the only place to store them is the open external garage which is no good in the rain. Aziz's wife is pregnant with their third child and is on medication for depression. Jana relies on her parents to turn her each night and change her nappies. She often misses school due to chest infections and vomiting. Despite many complaints about the house Aziz and his family have been told that there is nothing else available due to the housing crisis. Some modifications have been carried out to the house but Aziz suspects that the repair work was not to a high standard as the floor is soft to walk on and the original water-related problems within the structure have not been found or rectified.

Fraser lives in his office which is in a converted garage next to the family home. He is 24 years old, and is a self-taught game developer. He uses the internet to connect with people, to learn and to upload his gaming creations. Fraser has been diagnosed with ASD, Dyspraxia and ADHD. He has Misophonia, a disorder in which certain sounds trigger emotional or physiological responses that some might perceive as unreasonable given the circumstances. He sleeps on a mattress next to his desk. He does this because his brother who lives in the main house, makes noises that trigger responses in Fraser. His Mum, Margot, is converting a storage area in the garage into a bedroom for him, by sealing the floor, fixing holes and has had new glass put in the windows.

Margot has lived in the Whangaparoa area for 22 years where she has raised four sons, including Fraser, virtually on her own in a two-bedroomed home. Two sons live away from home. Fraser's brother Nigel (26) returned home during the Covid-19 lock-down and both sons are currently living with her. Margot says Fraser has little realisation of how his actions impact on others. Fraser can have bursts of outrage which are unpredictable. He broke his hand when he punched the wooden floor in February. Fraser can't stand public transport; he doesn't drive and he walks mainly at night time when less people are around. Margot feels that 'there is nowhere for people with ASD to live away from their parents.'

Question Two – Challenges in finding their current houses

Examples from the interviews surrounding the lack of disabled people's choices in their living arrangements were intertwined with a paucity of information about how they could possibly be more assertive and decisive around how they exercised choice.

Not being told about the right to appeal a Kainga Ora decision.

Denise, a wheelchair user with progressive multiple sclerosis living with her son who attends university and a daughter still at secondary school along with her mobility assist dog, found she had few living choices when her husband left her. Denise was assessed and found that she wasn't in a high priority position for a Kainga Ora house. Denise reduced the hours she worked, in order to strengthen her housing case. She tried again to get onto the Kainga Ora wait list but was informed that the agency did not add registrations during 'lock-down'. No one told Denise that she could appeal the original Kainga Ora decision.

Denise has now appealed the original decision and Kainga Ora has subsequently back-dated her home search registration to more aptly reflect how long she has been waiting.

The lack of information

Sanjay and Jasmina now feel that they are ready to make a more informed choice about the type of home Mary would enjoy living in, however they are frustrated by the lack of information to enable them to do that. Sanjay and Jasmina are looking for other families who might want to work with them to create a combined home for their adult disabled children. They can now identify some of the barriers facing them.

Buying a home.

Melanie has previously lived in rented accommodation for eleven years which was ideal for her. She has low vision and is in her early 60s. When her flat was sold, Melanie's life was turned upside down. She could not find a flat in Ellerslie where she had lived. A temporary renting arrangement has morphed into a three-year tenancy. The cost of renting is now prohibitive in Ellerslie. Whilst she is prepared to have international students in her home to off-set the costs, the current Covid-19 pandemic has effectively stopped that from being an option. Being in her 60s she fears that her age is against her if she wanted to buy a home – who would lend money to her? In addition, during the lock-down rental agents have set short viewing time frames around potential rentals and that plus the challenge of actually getting to the viewing using public transport has meant more delays for Melanie in moving out of her 'temporary' accommodation.

Thomas has some money for a house, but not enough to buy a property outright and his income is insufficient to service a mortgage as well as meeting his health needs. Work and Income do not recognise Thomas's diagnosis of Myalgic Encephalomyelitis, a disease recognised by the World Health Organisation, and classify him as having Chronic Fatigue Syndrome. Whilst Thomas receives the Supported Living Allowance and the Disability Allowance which is capped at $65 a week it cannot meet his dietary requirements and supplements needed to support his health condition. Visiting Work and Income offices is a challenge for Thomas due to the range of perfumes, cleaning agents and toxins present. He has been refused a case manager and despite his doctor asking for any interviews to be held outside Work and Income offices, this request has been denied.

Nadia would like the opportunity to meet other parents to help find a house for Jason. 'Where do you start to find out what is available and who is also looking for a home for their children similar to mine?

The interview participants were also concerned by the lack of trained carers available to care for their dependants based on their own experience.

Lesley found that 'trained staff simply were not able to be recruited and agency staff and temps exacerbated the situation.'

Susan and Timothy's son Karl aged fourteen requires help with most of his personal cares and communicates through his talk link device and sign language. His parents are concerned that the carers at his respite home all have English as a second language and may not understand Karl's signing. 'The carers don't seem to understand his needs as well as they could.'

Joan's support workers are paid through Individualised Funding (IF). Her current carer can only help Joan once a week. If Joan uses agency carers it means she has to pay them more than her regular carer. In Joan's experience the pool carers arrive late and leave early, not leaving an invoice so she cannot determine how much of her Individualised Funding she has left to spend on her care until over a month later when her statement arrives.

Question Three – Covid-19 challenges.

Sanjay and his wife Jasmina who are in their late 50s, early 60s live with their daughter Mary who is in her late 20s. They live in a provincial New Zealand city. Mary has carers to help her with personal cares, cooking and cleaning. Mary is a social person who likes communal activities. During the lock-down period Mary missed the connection she has with the local day programme she normally attends.

Thomas was offered a place in a motel during the Covid-19 lock-down period. He had to refuse due to the health effects on him of the number of cleaning products used in the motel unit.

When Covid-19 struck, Grace took over the role of support person for her son David as his support workers were unable to come to the house. All David's activities stopped. He stayed inside for most of the lock-down period. He refused to accompany the family on their daily walks.

Lock-down was easy for Susan and Timothy. They managed financially as Timothy could work from home, Karl was happy on his computer and accompanied his parents on their daily walks.

Joan coped well with the lock-down restrictions but found it very challenging when all her support workers were withdrawn as the agency did not consider her needs essential to her health and well-being. Joan found this distressing and felt very vulnerable during this period.

Lock-down was a blessing because the family could be calm, study and work at home. Priya was able to work with Rahul on his domestic skills. Coming out of lock-down was challenging for Rahul. He was anxious, staying at home and not going to his internship, so Priya had to stay home from work to be with him.

Covid-19 worked well for the family, as Jason got a job removing rubbish from a hospital site four days a week. Jason works well on routine tasks and is very reliable. Nadia feels that she avoided some of the stresses which would have occurred had he not had the job which started before the first lock-down occurred.

Aziz and Farah stayed home during the lock-down. Medical appointments were postponed or cancelled, Aziz was unable to work and medications for both Jana and Farah were difficult to access due to limited pharmacy opening hours. Community nurses were able to visit twice a week with full PPE gear.

Fraser missed the pub quiz night he attended when it was cancelled during lock-down. It provided a social outing for him. He spent a lot more time at home than usual which has impacted on his mental health and well-being.

> *Melanie is unsure whether she has been unsuccessful in getting a flat because of her disability.*

Question Four - What is your ideal housing or living arrangement

The interviewees and members of the focus groups knew exactly what they needed in order to live in a safe, secure home. The list of requirements was modest. An accessible bathroom, somewhere near to whānau, somewhere warm, close to a GP, friends, public transport and shops were some of the typical requests. People spoke about the need for a mix of cultural living options and the expansion of the enabling GoodLives model.

Families and disabled individuals spoke about some of the living situations either their adult child or they had been in.

For those who were renting, life was precarious.

Melanie has looked for rentals near her friends and work but nothing has worked out. She needs a sunny flat where she can use a second bedroom as a music therapy room, and it needs to be near public transport. The light in the flat is critical as Melanie is unable to read using artificial light for any length of time. Transferring from one form of public transport to another is challenging. Many of her possessions are in boxes and she is dislocated from the normal pattern of her life. The cost of renting keeps climbing. Melanie is frustrated and disillusioned with the whole house hunting process.

Being close to whānau is important

Sanjay and Jasmina's requirements of a home for Mary are simple. They would like her to live near them in a small house in the community. The home would need to be easy to maintain, be warm, dry and secure. They would like Mary to be able to walk to the shops, and to her GP in the company of her support workers.

People are seeking innovative solutions to their housing concerns which should include different cultural options.

For Priya and her husband, having their son Rahul living nearby is an essential part of his housing solution. 'He would be uncomfortable if he had to live in another area.' Priya believes that the government should help with innovative accommodation options for families like hers. Priya would like a two bedroom sleep out or flat for her now adult son. Rahul would also need support but she is firmly of the opinion that parents want to be involved in their adult children's care if they have the support to do so. The cost of housing is still a challenge for them. 'Rahul needs to be somewhere safe, a place where his independence is not compromised. He needs supervision, not baby-sitting. He needs reliable support as he is vulnerable.'

Outings to "ordinary" events are near impossible for Jenny's family as Joseph won't go where you need him to go, instead he sits down and refuses to move. Jenny believes that, 'We should be talking about quality of life and well-being, not just an 'ordinary' [living] solution, particularly with respect to those with high and complex needs.' Jenny feels that, 'ordinary' may well be a Pakeha construct of our times. Other community or multi-generational/tribal based forms of living on communal land is not seen as 'ordinary', but these can be superior in terms of the presence of larger numbers of permanent adult supporters, as opposed to a roster of young single caregivers.' Jenny dreams of a beautiful village-like community of residential units, with appropriate facilities staffed by lovely residents in an open rural environment.

Grace believes Individualised Funding has the potential to make a difference for her son David, but that it is limited in its current form. 'I am hopeful that Enabling Good Lives will make the difference that will allow me to step back from the present requirement of such a hands-on role. We need it to be available nationally not just in trials.'

Grace and her family are part of a family collective recently formed whose aim and vision is for it to be set up in such a way that it will maintain David's and the other family members' independent community-oriented life style to which they are accustomed. The collective will endure after the family members are no longer around to ensure that this happens.'

Fraser hopes to be in his own home in four years' time. He is quite specific about the type of people he would like to live with who must be able to tolerate his conditions. His ideal home would have sound proofing and excellent wi-fi connections. He could not live in a house that had a toilet in the bathroom where he brushes his teeth. He would not use gas to cook with as he finds gas confusing, difficult and potentially dangerous. He would need supervision to manage and maintain a home.

Margot believes that 'Fraser would be best suited to a flat with people with mixed abilities with someone 'in charge' to manage the social and communication aspects of living.' Each person would have their own personal space to withdraw into when they needed it. He needs to live with people who are sympathetic to his needs in a 'disability house, flanked by neurotypical houses; and this is as much of a priority as finding a suitable house.'

Skilled knowledgeable staff are a critical link to successful living options.

‘Lesley knows that her son needs highly skilled multi-disciplinary specialist care with suitable programmes. At present he sits at home rocking on a sofa. Lesley feels that Simon could thrive with a holistic personal programme for in-home support. Lesley looks to the government to provide people like Simon with more options than those currently available with a greater focus on their well-being. At present the economic pressure and social impacts on families of those with complex needs to be alleviated.

Families and disabled people would like to have accessible homes – physically and financially.

Thomas would like to live in a house built based on eco-friendly building principles in an affordable rural town.

The family sees two options for Karl in adulthood and for them in retirement. Firstly, Karl could go into full-time residential care on his various disability allowances. The second option is for one of them to become a full-time carer. Timothy worries that the second option would be too hard financially.

Joan’s ideal living situation is a two-bedroom home on a flat section that she can easily navigate. She would like modifications carried out to her current home if she is to continue living there. An accessible bathroom with a seat would be useful, along with her cupboards converted to drawers and a pull-out pantry.

Aziz and Farah would like a four bedroomed home house on a flat section with space for equipment inside and a big bathroom that could be modified to include a ceiling hoist. They would like to have wider doorways and bigger door frames to accommodate Jana’s wheelchair.

Nadia is prepared to move out of her home to provide a house for Jason as she knows it is very familiar for him and he would be reassured by that. Nadia wants Jason to be independent and to grow in caring for himself. ‘In ten years’ time I would like him to be living with other people. It wouldn’t be good for him to be living alone. He will always need someone to watch over him for decision-making especially for finances.’

Are these houses created for community?
Can family whānau and friends visit? Do they have accessible downstairs bathrooms? Is there space for a visiting support dog to drink and toilet?

Photo Credit: Disability Connect.

Narrative Results from Focus Group Meetings

The focus group meetings and interviews were held on March 11th for people with spinal impairments and their families (13 people) and 11th August for the Tongan participants (20 people) with a total of thirty-three people attending. Eight of the Tongan participants had hearing impairments or used assistive mobility devices. There were four younger people attending the meeting who were supporting their elders. All sixteen Tongan elders were regarded as 'seniors' and many had associated health concerns. All lived in Kainga Ora homes.

The focus groups were asked four questions.

What do you like about your current place?

What would you like to improve about it?

What barriers do you experience in getting the housing you want?

What are your hopes for your own housing in the future?

Focus Groups' responses

The focus group with spinal impairments responses centred on their lack of power and control to influence their needs in a timely manner. Participants commented on the complexity of dealing with ACC, real estate agencies and landlords along with the unaffordability of buying their own home that then has to be modified to suit their physical needs.

The Tongan focus group had an interpreter and some family members to support their conversation about their homes and their hopes and dreams.

Question One – What do you like about your current place?

Those with physical disabilities rated their homes more highly when they had easy access and some modifications made to make daily living easier. Owning the home made a difference to the level of satisfaction as well.

Leighton (in his mid-20s) noted that his current 'home' was a rest-home that he was living in until he could get a home.

'I have lived here a long time.' – comment by a Tongan elder.

Robyn commented that her home had been specifically built for her and that her disability was the result of an accident sixty years ago.

'I am close to my family.' – comment by a Tongan elder.

> *'It's worrying that the housing we need for the future isn't being built and even if it was, I can't afford it.'*
>
> *Brent – a manual wheelchair user with a spinal cord impairment.*

Question Two – What would you like to improve about it (your home)?

There were a range of comments about narrow passageways, small rooms, insufficient space to store equipment and small bathrooms along with observations concerning the lack of foresight.

‘I can’t use my kitchen. I used to be a chef but I can’t access it, benchtops, storage, oven, hob are not accessible to me.’ – comment by Sally.

‘The house needs repairs.’ – comment by a Tongan elder.

‘I will need a modified house in a couple of years, more suited to my needs, hopefully close by with no steps.’ – comment by Tahu.

‘The ramp is too steep and sliding doors would be better for my needs.’ – comment by Brett.

‘I need a place with no stairs.’ – comment by a Tongan elder.

‘The rest-home is not suited to my height, makes transferring difficult as the hoist is not tall enough. I need a ceiling hoist but the ceilings aren’t high enough and I’m in temporary accommodation so we can’t do anything about it.’ – comment by Leighton.

‘The house is cold. It needs heat.’
– comment by a Tongan elder.

Question three – What barriers do you experience in getting the housing you want?

Participants reflected on the difficulty of arranging loans given the 80% compensation to people after an injury by ACC, particularly in a buoyant housing market. From their collective experience they felt that with their list of needs they were hard work for real estate agents who were reluctant to have them as clients. In addition, finding out what housing is available to them under various government policies is also a challenge. There was also the challenge of finding a rental property with enough features so that you could live there without the tension of asking a landlord to make modifications risking ending up with no home at all.

‘We are worried that we will never afford the place we need and none will be built to suit us where we live.’ – comment by Rhonda and Brent.

‘Housing is just unaffordable. It’s so expensive and then we would need modifications on top.’
– comment by Brent.

‘We don’t know who to talk to.’ – comment by a Tongan elder.

‘Agents keep telling us, ‘sorry that home is not suitable for you.’’ – comment by Kevin.

‘There is simply not enough housing suitable for me – or my family.’ A comment shared by four participants – Brett, Brent, Leighton and Kevin.

‘My parents won’t complain. They put up with it. They have trouble with the language barrier and need someone who is Tongan to visit and hear them.’– comment by the son of a Tongan elder.

‘I don’t know what is possible with ACC – it takes work to find out.’– comment by Brett.

‘I’m not sure what A18 means other than I am near the top of the list.’ – comment by Leighton.

‘I don’t usually come to this group. I am here to bring my aunt. The people here are older. They won’t complain. They are living in terrible housing but they find it too difficult to talk about it because English is not their language. I’m worried because my aunt’s house is not in good condition and their health is not good. I can’t do anything about it.’ – comment by a young Tongan man providing whānau support.

‘It doesn’t seem fair that State Housing gets adjusted to what you can afford, but under ACC we have to find housing that works for our budget with no assistance if we are on 80% of our weekly earnings.’ – comment by Brent and Rhonda.

> *‘I want to be a mother, not a nagging co-ordinator for my son when he is middle-aged.’*
>
> *Grace*

Question Four – What are your hopes for your own housing in the future?

Participants had modest requests; accessibility topped their list with the paramount desire being to stay and fully participate in their own home. A number of participants recognised that their needs had changed over the years and they had not anticipated that, for example, they may need to transition from a manual wheelchair to a power chair.

‘A new accessible bathroom with a shower chair.’ – a request from Robin

‘A modified kitchen that I can cook in.’ – a request from Kevin

‘A three-bedroom place would be nice with high ceilings and an accessible bathroom I can use.’ – a comment by Leighton who is over 6’ 5” tall

‘A house with sliding doors.’ – a request from Brett

‘A more accessible home for my disability.’ – a request from John E

‘We need housing that everyone can use – wider doors can be used by everyone. ‘- a comment by Brent.

‘A kitchen I can enjoy cooking in.’ - a request from Sally

Referred to but not elaborated on:

The impact on the main carer in a family – usually a woman with her own health, work prospects compromised and feeling total responsibility for the disabled person.

Powerlessness of disabled people and family members at times caught between what they considered to be an indifferent social welfare system and their lack of knowledge about their own or their dependant’s living options.

A feeling of fear sitting within the interviews and focus groups – how tenuous and fragile their lives and the lives of their dependants were.

The lack of vision by successive governments to assist with housing needs for the disabled community.

Crisis-driven decision-making by people such as themselves.

Aziz regularly takes his 12 year old daughter to hospital in the middle of the night. She needs 24 hours 7 day a week care and has vitamin D deficiencies that Aziz attributes to their house having no outdoor access for her wheelchair.

Photo Credit: Disability Connect.

SUMMARY AND CONCLUSIONS

A summary of this research and this attendant report is provided at the beginning of this paper along with recommendations for addressing the gaps and shortcomings identified here. These gaps and shortcomings are well enough known and are somewhat predictable. People living with a disability, either personally or through kinship, are because of this disability, more likely to have low incomes. In an increasingly expensive and restrictive housing market and unless the person has access to social housing, this low income is likely to translate into poor housing outcomes. This possibility is somewhat borne out by the results of the surveys conducted in this research which showed that respondents were more likely than other New Zealanders to rent and more likely to pay more than 40% of their income toward housing costs. While a small majority of respondents were satisfied with their housing, a significant minority weren't. Whether this level of dissatisfaction is significant is not known because we have not asked a sample of people without disabilities the same questions.

The policy and provision gaps were most notable from the narratives emerging from the interviews. These showed the personal costs of unresolved housing and care issues for the families of people with disabilities. None of this should be surprising to policy makers because these stories have been told before and the circumstances of the thousands of families affected by problems is able to be estimated from what public agencies know of peoples' needs and their entitlements. The gaps here are filled by families' love, care and sense of obligation to their children and siblings. Whether such reliance is fair and reasonable in a society such as ours which has resources to assist more generously is in many respects a matter of what individuals see are the legitimate roles for families and the state.

The narratives offered here suggest that the current level of reliance on families' love, care and sense of obligation is not sustainable. There appears to be little planning or forethought by policy makers to the problem of aging parents caring for their disabled children. As noted above this problem is measurable and predictable. It is difficult not seeing this policy neglect as wilful and symptomatic of the powerlessness of those concerned.

The recommendations offered above are made in part to address this neglect.

Thomas lives in this car. He could buy a house if he could afford and find one that meets his complex needs.

Photo Credit: Thomas

APPENDIX 1:
Sample of On-line Survey 1

Thank you for your interest in participating in this on-line survey of the housing experiences of people with disabilities and their families/ whānau.

This survey is being conducted by Disability Connect and a number of partner organisations which are involved in advocacy for people with disability and for child poverty.

The purpose of this survey is to gain information on the housing experiences of people with disabilities and their families. This information will be put together for a report to the United Nations for its investigation into New Zealand's efforts at supporting the rights of people with disabilities. This survey is independent of Government and the results of the survey, and of a face to face survey also being undertaken, will be used for public advocacy for better housing provision for people with disabilities. Participating in this survey will not lead to you gaining better housing or supported living. If you need assistance with your housing you can contact one of the organisations which offer this service.

This survey is confidential and no details of your answers to the following questions will be published or shared with anyone outside of the small group of people conducting this research. If you participate in this survey you have a number of rights under the Privacy Act 1987 which must be respected. How we will do this is set out in the Privacy Statement which is **available in appendix 2 on page 64.**

SURVEY 1

If you are doing this survey on behalf of a family/whanau member or friend who has a disability but is unable to participate in the survey themselves, please answer the questions as best you can from their perspective and as if he or she was doing the survey.

Question 1

**Are you participating in this survey for you,
for a family/whānau member or for someone you care about?**

	FOR MYSELF	FOR A FAMILY/ WHĀNAU MEMBER	CARER
TICK ONE			

YOUR HOUSING CHOICES

Question 2

What choice did you have in deciding your current living situation?

	FULL AND FREE CHOICE	SOME BUT LIMITED CHOICE	NO CHOICE
TICK ONE			

YOUR LIVING ARRANGEMENTS

Question 3

Please describe the arrangements which best describe your current living situation:

	TICK ONE
Living independently and alone	
Living independently with my family/whanau	
Living independently with non-family/whanau members	
Supported living alone	
Supported living with my family/whanau	
Supported living with non-family/whanau members	

YOUR HOUSING TENURE

Question 4

Under what arrangements do you occupy or use your accommodation:

	TICK ONE
I own the house/flat/apartment mortgage free	
I own the house/flat/apartment with a mortgage	
I live with my family/whānau who own the house/flat/apartment mortgage free	
I live with my family/whānau who own the house/flat/apartment with a mortgage	
I rent my house/flat/apartment alone	
I rent my house/flat/apartment and share the rent with others	
I live rent free with family/whānau	
I live rent free with non-family/whānau members	
I live in a hostel or residential facility	

LANDLORD

Question 5

If you rent you house, flat or apartment who is you landlord?

	TICK ONE
A family/whānau member	
A private person (not family/whānau) or a business	
Housing New Zealand/Kāinga Ora	
City or district council	
A community organisation or charitable trust	
Not sure	

HOUSING COSTS

Question 6

What share of your income do you pay toward your housing?

	TICK ONE
None	
Less than 20%	
More than 20% but less than 30%	
More than 30% but less than 40%	
More than 40% but less than 50%	
More than 50%	
Don’t know or not sure	

HOUSING SECURITY

Question 7

How sure are you that you can stay in your home for as long as you want?

	TICK ONE
Very sure and confident that I can stay as long as I want to	
Quite sure	
Not very sure and worried sometimes that I may have to move out	
Very unsure and always worried that I might lose my housing	

HOUSING HISTORY

Question 8

How long have you lived in your present house, flat or apartment?

	TICK ONE
Less than one year	
More than one year but less than two years	
More than two years but less than five years	
More than five years but less than ten years	
More than ten years	

HOUSING ADEQUACY

Question 9

To the statement 'My home is very comfortable' do you;

	TICK ONE
Strongly agree	
Agree	
Neither agree nor disagree	
Disagree	
Strongly disagree	

Question 10

To the statement 'My home supports my health and wellbeing' do you;

	TICK ONE
Strongly agree	
Agree	
Neither agree nor disagree	
Disagree	
Strongly disagree	

DISABILITY NEEDS

Question 11

Does your house, flat or apartment have features or alterations built into which cater for your disability related needs?

	TICK ONE
Yes	
No	
Nothing is required to be done	

HOUSING IMPROVEMENTS

Question 12

What sorts of improvements does your house, flat or apartment need?

	TICK ONE
None - it is fine as it is	
Better insulation	
Better safety features	
More space	
A better bathroom which is easier to use	
A better kitchen which is easier to use	
Better access in and out of the building	
Wider doors	
Better fencing	

HOUSING LOCATION

Question 13

How happy are you with where your present home is located?

	TICK ONE
Its location is fine and I am happy with it	
I would like to be closer to my job or to employment opportunities	
I would like to be closer to the health and support services I need	
I would like to be closer to my family/whānau and friends	
I would like to live in a neighbourhood where I knew more people	
I would like to be closer to shops and entertainment opportunities	
I would like it to be closer to schools	
I would like it to be closer to public transport	

HOUSING SATISFACTION

Question 14

To the statement 'I am very happy and satisfied with my current housing' do you;

	TICK ONE
Strongly agree	
Agree	
Neither agree nor disagree	
Disagree	
Strongly disagree	

*If you urgently need help with your present housing or living arrangements please contact one of our advocacy organisations. Their contact details can be found at;

https://www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/needs-assessment-and-service-coordination-services

HOUSING ASPIRATIONS

Question 15

What is your ideal housing or living arrangement?

	TICK ONE
I am happy with what I have already	
I would like more independence and/or privacy	
I would like a bigger house	
I would like to be closer to my family/whānau and friends	
I would like to feel more secure and not have to worry about having to move out sometime	
I would like a house which better meets my needs	
I would like to own my house	

SOME DETAILS ABOUT YOU WHICH WILL REMAIN CONFIDENTIAL

If you are doing this survey for a family member please answer these questions for them

GENDER	FEMALE	MALE	OTHER
TICK			

AGE	Under 20	20 to 29	30 to 49	50 to 64	Over 65
TICK					

ETHNICITY	Māori	Pākeha/ European	Pacific Island	Asian	Other ethnicity
TICK ANY					

TYPE OF DISABILITY	Physical	Intellectual	Sensory	Mental health related	Chronic health condition
TICK ANY					

APPENDIX 2:
Privacy and ethics statement

Ethics and Privacy Statement for Disability Housing Survey

This statement provides those people participating in the Community Housing Collective's Disability Housing Research Project with a description of the ethical and privacy standards that will be applied to this research and a description of the expected behaviour of those people undertaking this research project

- Participants in the research project will at all times be treated with dignity and respect. They will have the nature of the project accurately described to them before their consent to participate is requested. This description of the project includes the project objectives, timeframes and the uses to which the research may be put.
- Participants in the research project have the right to withdraw from the project at any time and may ask that their responses to questionnaires are deleted from the collection of data at any time up until the research is published. Researchers will leave their contact details with all participants to allow this to happen.
- Researchers will at no time offer guarantees, promises or implications of assistance to potential participants as a means of gaining their participation. Researchers will make all potential participants aware of the fact that this research project is independent of any agency whose help they may be seeking.
- Participants in the research project will have their identity protected at all times during the research project and following its completion. Personal details which may allow for the identification of individual respondents will not be recorded. This includes the respondent's name, date of birth and place of birth as well as any other distinctive characteristic of any respondent which might possibly be used to identify them.
- All completed questionnaires will be destroyed once the results of the research project are completed and published. Until they are destroyed questionnaires will not be available to any person outside the research team.
- Information gathered from this research project will only be used in support of the research objectives and for no other purpose. The researchers and the Community Housing Collective provide guarantees that they will at all times comply with the legal requirements of the Privacy Act 1993.
- As a record that this ethics and privacy statement has been discussed with the respondent each interviewer should ask the respondent if they wish to sign copies of the statement or provide consent by return email to acknowledge that the respondent has agreed to participate in this survey based on the guarantees offered in this statement.

………………………………………………………

SURVEY RESPONDENT

………………………………………………………

INTERVIEWER

………………………………………………………

DATE

APPENDIX 3:
Sample of On-line Survey 2

Thank you for your interest in participating in this on-line survey of housing and living experiences of people with disabilities and their families/whānau during the COVID-19 shutdown.

This survey is a follow-up survey to one which was done within the wider disability community in early 2020 – prior to the COVID-19 shutdown. Clearly much has changed since the shutdown and some of these events and their consequences will tend to reduce that value of a housing survey undertaken before these happened. For this reason, the housing survey is being continued in order to gain some understanding about how the shutdown has impacted on people with disabilities and their family. Most likely a third survey will be undertaken at the end of 2020 to see what has happened to your housing and living arrangements after COVID-19. You can take part in this survey whether or not you took part in the earlier one.

This survey is being conducted by the Community Housing Collective; Disability Connect, Mangere East Family Services, Otara Health Charitable Trust, Complex Care Group, Yes Disability, Childrens Autism Foundation, IHC, Cerebral Palsy Association, Te Manawa Respite Care and Auckland Disability Law.

The purpose of this survey is to gain information on the experiences of people with disabilities and their families during the COVID-19 shutdown. In particular the survey covers changes in these peoples' housing, living arrangements and wellbeing during this period. This information will be put together with information from the previous housing survey for a report to the United Nations for its investigation into New Zealand's efforts at supporting the rights of people with disabilities. This survey is independent of Government and the results of the survey will be used for public advocacy for better housing provision for people with disabilities.

Participating in this survey will not lead to you gaining better housing or supported living. If you need assistance with your housing you can contact one of the organisations which offer this service. Their contact details are at this link;

https://www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/needs-assessment-and-service-coordination-services

This survey is confidential and no details of your answers to the following questions will be published or shared with anyone outside of the small group of people conducting this research. If you participate in this survey you have a number of rights under the Privacy Act 1987 which must be respected. How we will do this is set out in the Privacy Statement which is in **Appendix 4.**

SURVEY 2

If you are doing this survey on behalf of a family/whanau member or friend who has a disability but is unable to participate in the survey themselves, please answer the questions as best you can from their perspective and as if he or she was doing the survey.

If you would like to provide more detailed feedback on the impacts of the COVID-19 shutdown on your housing, care or wellbeing please contact one of the following people for this.

Mike Potter
Disability Connect
admin@disabilityconnect.org.nz
09 636 0351

Rachel Peterson
Yes Disability Resource Centre
Rachelp@yesdisability.org.nz
0274 355651

Lisa Martin
Complex Care Group
complexcaregroup@xtra.co.nz
0272 667690

Mark Simiona
Otara Health
Mark@otarahealth.org.nz
09 390 4169

Question 1

Are you participating in this survey for you, for a family/whānau member or for someone you care about?

	FOR MYSELF	FOR A FAMILY/ WHĀNAU MEMBER	CARER
TICK ONE			

YOUR HOUSING OR LIVING SITUATION PRIOR TO THE COVID-19 SHUTDOWN

Question 2

Please describe your housing or living situation prior to the COVID-19 shutdown;

	IN A HOME I OWN	IN A RENTED PROPERTY	IN SUPPORTED LIVING	WITH FAMILY IN A HOME WE OWN	OTHER
TICK ONE					

RECENT CHANGES TO YOUR HOUSING

Question 3

Has your housing (the place where you live) changed since the COVID-19 shutdown?

	YES	NO
TICK ONE		

If you answered NO to this question please go to Question 5

Question 4

If your housing has changed how has it changed?

	TICK ONE
I needed to move for financial reasons	
I needed to move for family/whānau reasons	
My housing costs have **INCREASED** but I am still in the same place as before the shutdown	
My housing costs have **DECREASED** but I am still in the same place as before the shutdown	
I was evicted by the landlord	
I needed to move for other reasons	

CHANGES IN YOUR LIVING ARRANGEMENTS

Question 5

Have your living arrangements (who you live with for example) changed since the COVID-19 shutdown?

	YES	NO
TICK ONE		

If you answered NO to this question please go to Question 8

Question 6

If your living arrangements have changed, HOW have they changed?

	TICK ONE
I needed to move house	
I have new people living with me now	
I have **REDUCED** access to care and support	
I have **IMPROVED** access to care and support	
I have less access to life outside my home	
I have fewer people living in my home	

Question 7

If your living arrangements have changed, WHY have they changed?

	TICK ANY
Because I needed to move house	
Because I have new people living in my house	
My care and support arrangements have been changed by the agency offering this	
Because I have less access to life outside my home	
Financial difficulties or hardship	

CHANGES IN YOUR WELLBEING

Question 8

Regardless of whether or not your housing or living arrangements have changed, how has your wellbeing been affected by any changes brought about by the COVID-19 shutdown?

	TICK ONE
Overall, I feel that my wellbeing has improved	
Overall, I feel that my wellbeing is much the same as before	
My wellbeing has got a little worse since the shutdown	
My wellbeing has got much worse since the shutdown	

Question 9

What has contributed to any changes in your wellbeing or sense of wellbeing?

	TICK ANY
My state of health has improved	
My state of health has got worse	
I am struggling more with my finances	
My care and support arrangements have improved	
My care and support arrangements have got worse	
Improvements with my housing situation	
Problems with my housing	
Positive changes in my relationships	
Negative changes in my relationships	
I have improved connections with others	
I am lonelier	
I have more time to do the things I want to do	
I am bored	

SOME DETAILS ABOUT YOU WHICH WILL REMAIN CONFIDENTIAL

If you are doing this survey for a family member or friend, please answer Question 10 about your relationship with them.

If you are answering this question on your own behalf please go to Question 11.

Question 10

For the person I am answering this survey for, I am;

	TICK ANY
Their primary care giver	
Their parent	
A family/whānau member but not a parent	
Employed to offer them care and support	
Volunteering to offer them care and support	
A friend	

If you are doing this survey for a family member, please answer these questions for them;

Question 11

	FEMALE	MALE	OTHER
GENDER			

Question 12

	Under 20	20 to 29	30 to 49	50 to 64	Over 65
AGE					

Question 13

ETHNICITY	Māori	Pākeha/ European	Pacific Island	Asian	Other ethnicity
TICK ANY					

Question 14

TYPE OF DISABILITY	Physical	Intellectual	Sensory	Mental health related	Chronic health condition
TICK ANY					

We are keen to share the results of this survey and the overall research project with you if you are interested. Please send an email to admin@disabilityconnect.org.nz to register your interest for this.

If you have any questions about this survey or the overall research project please contact;

Mike Potter
Disability Connect
admin@disabilityconnect.org.nz
64 9 636 0351

PO Box 13385
Onehunga 1643
Auckland
New Zealand

APPENDIX 4:

Ethics Statement for Disability Housing Research Project

This statement provides those people participating in the Community Housing Collective's Disability Housing Research Project with a description of the ethical standards that will be applied to this research and a description of the expected behaviour of those people running the project

1. Participants in the research project will at all times be treated with dignity and respect. They will have the nature of the project accurately described to them before their consent to participate is requested. This description of the project includes the project objectives, timeframes and the uses to which the research may be put.

2. Participants in the research project have the right to withdraw from the project at any time and may ask that their responses to questionnaires are deleted from the collection of data at any time up until the research is published. Researchers will leave their contact details with all participants to allow this to happen.

3. Researchers will at no time offer guarantees, promises or implications of assistance to potential participants as a means of gaining their participation. Researchers will make all potential participants aware of the fact that this research project is independent of the work of the agency whose help they are seeking.

4. Participants in the research project will have their identity protected at all times during the research project and following completion of the project. Personal details which may allow for the identification of individual respondents will not be recorded. This includes the respondent's name, date of birth and place of birth as well as any other distinctive characteristic of any respondent which might possibly be used to identify them.

5. All completed questionnaires will be destroyed once the results of the research project are completed and published. Until they are destroyed questionnaires will not be available to any person outside the research team.

6. Information gathered from this research project will only be used in support of the research objectives and for no other purpose. The researchers and the Community Housing Collective provide guarantees that they will at all times comply with the legal requirements of the Privacy Act 1993.

CHiLD
POVERTY
ACTION
GROUP

Thank you Child Poverty Action Group for generously supporting this research.

disability connect. *helping families*