Dr Ilan Wiesel
School of Geography

Lived experience and social, health and economic impacts of inaccessible housing

Report submitted to the Australian Building Codes Board RIS

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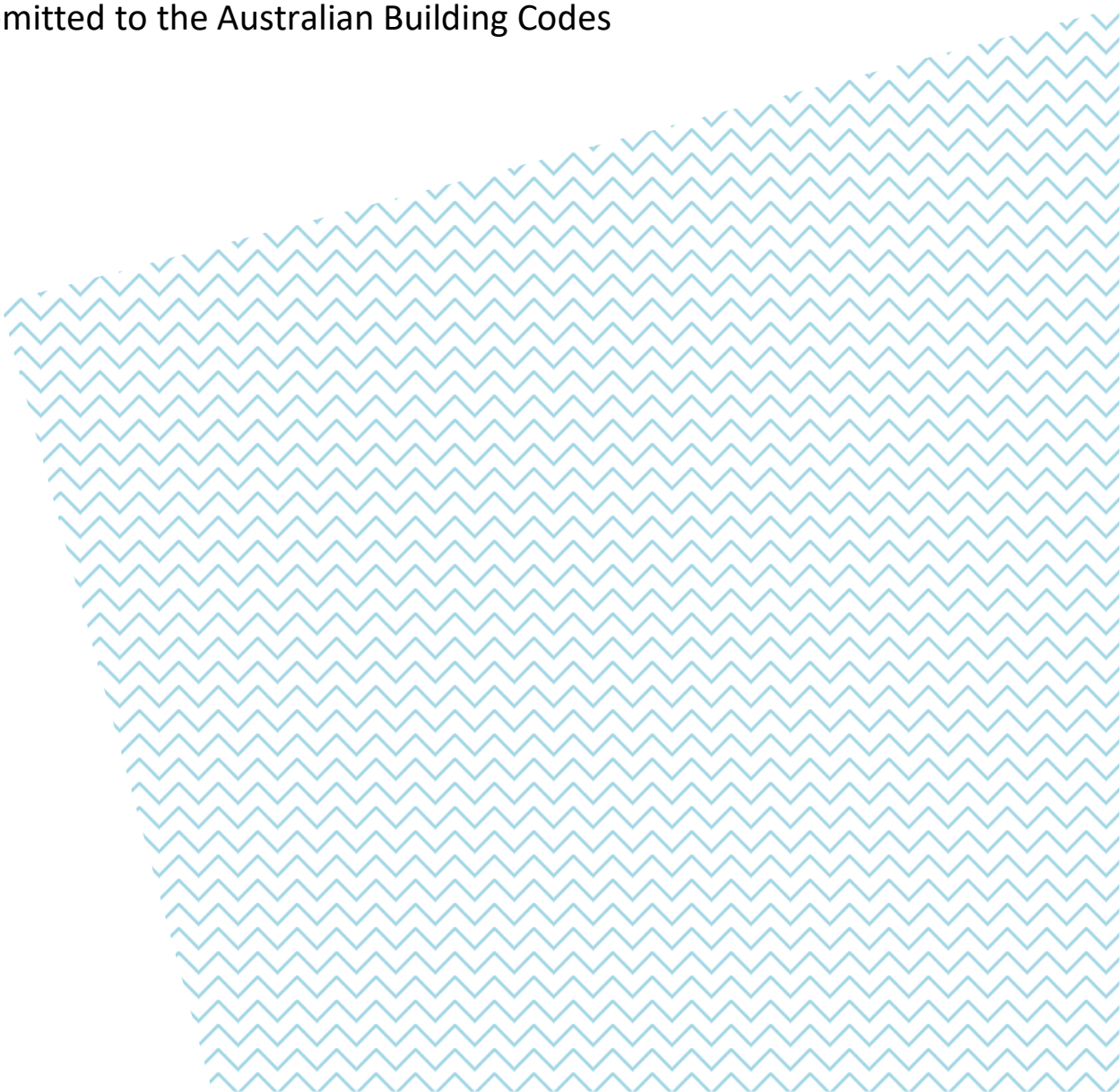

Table of Contents

Table of Figures

Acknowledgments

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Executive summary

The study included an online questionnaire that elicited 1,187 responses, followed by 45 in-depth interviews, conducted in August 2020. It was initiated in response to the Australian Building Codes Board's (ABCB) consultation on a proposal to include minimum accessibility standards for housing in the National Construction Code. The aim of the study was to address a gap in both qualitative and quantitative (but not monetised) data about the lived experience and social, health and economic benefits of accessible housing. It brings the voices of hundreds of Australians with disability and other mobility limitations into the ABSB consultation.

The analysis presented in this report is focused on measuring and understanding:

- accessible and inaccessible features in the homes of people with mobility restrictions
- mental health and wellbeing outcomes of living in accessible or inaccessible homes
- impacts of housing accessibility on ability to move around the house and perform self-care and homecare activities
- impacts of housing accessibility on social and family relations
- impacts of housing accessibility on need for paid and unpaid support
- impacts of housing accessibility on employment and productivity
- impacts of housing accessibility on housing choice and mobility, including ability to move to another home and ability to stay home and avoid forced moves to other residences or supported accommodation.

Key findings from the study are summarised as follows:

- The majority (73.6%) of respondents live in housing that does not meet, or only partly meets, their accessibility need. People with lower level of impairment were more likely to live in inaccessible housing, possibly because of ineligibility for funds for home modifications, social housing, or specialist housing. People with lower income were more likely to live in inaccessible housing, due to affordability barriers to purchase or rent an accessible home, or to modify their homes. Private renters were most likely to live in inaccessible home (87.6%), but high incidence of inaccessible homes was also recorded for homeowners (71.5%) and social renters (74.8%). Although significantly more accessible than mainstream housing, partial inaccessibility was surprisingly high even in specialist disability housing such as group homes (47.1%) and supported residential services (46.2%).
- Compared to housing constructed to affordability standards, post-construction modifications were more likely to only partly meet people's accessibility requirements. While close to half (46.6%) of survey respondents lived in homes that were modified, most of those (39.1%) reported these modifications met only some of their accessibility needs.
- When modifications are undertaken exclusively in the homes of people who have mobility restrictions, they are unable to visit the homes of their family and friends, resulting in significant social isolation. 80.8% of survey respondents agreed or strongly agreed with the statement "I can't visit friends and family whose homes are inaccessible".
- Individuals' accessibility needs change over the life course, due to ageing, injuries (often due to inaccessibility of homes), and deterioration of disability or illness, requiring ongoing modifications, highlighting need for houses as adaptable as possible, such that they can continue to be modified more effectively and cheaply over time.
- The proportion of survey respondents who lived in housing that was built in a way that meets all their accessibility needs (18.7%), was more than twice as high as those who lived in housing modified to meet all their accessibility needs (7.4%), demonstrating that building to accessible standard is more effective than post-construction modifications.

- Survey respondents living in homes that were not modified or only partly modified, reported inaccessible housing features further limited their ability to move into and out of their home, and complete self-care and home-care activities. Home-care activities (such as home cleaning) were most limited by housing design, and movement inside the home was the least limited. Inaccessible housing was more limiting for people with high support needs, especially in relation to movement inside the house and home care activities.
- Close to one-third of survey respondents reported lack of accessible housing has resulted in job loss, missed job opportunities, reduced work hours, or reduced productivity at work.
- Many survey respondents and interview participants reported difficulties finding accessible homes close to employment opportunities, while fatigue from living in inaccessible home and the additional time and energy spent on self-care and home-care, reduces productivity, motivation, self-confidence and capacity to work, study or volunteer.
- Inaccessible housing increases support needs for most (65.8-67.1%) of people with high support needs, including both paid and unpaid support. Just over half (51.2%) of people with low support needs living in inaccessible housing reported an increase in need for informal care, and 42.0% of those reported an increase in paid disability support.
- Approximately a quarter (23.0-27.8%) of people with high support needs, and a fifth (20.0-18.8%) of people with low support needs living in accessible or modified homes reported a decrease in their paid and unpaid support needs thanks to accessible design.
- Participants reported spending high proportions of their NDIS support funding on support for self-care activities they could have done independently in more accessible homes.
- Unnecessary reliance on paid or unpaid support for such activities is not only economically inefficient, but bears additional social and health costs, such as adverse impacts on relations with family members providing informal care; on employment opportunities (e.g. reliance on availability of support to be able to get organised in the morning for work); and on sense of independence and dignity.
- Housing accessibility or inaccessibility has significant impact on self-reported mental health and wellbeing. 60.0% of people with both low and high support needs living in accessible housing reported improved self-reported mental health and wellbeing, thanks to the accessibility of their home. In contrast, 71.7% of people with high support needs, and 50.0% of people with low support needs, living in inaccessible housing reported worsened mental health and wellbeing.
- Participants with high support needs living in inaccessible homes were more likely to express concern about risks such as difficulty affording necessary home modifications in the future (85.7%), being forced to move to another residence (68.0%), or to a nursing home (58.9%). This compares with a minority of people living in accessible homes who reported similar concerns. However, ability to afford home modifications remains a concern even for those living in accessible homes (47.5% of those with high support needs, and 44.2% of those with low support needs) indicating that needs change over time, highlighting the importance of adaptable housing.
- The shortage in accessible housing significantly limits housing choice for people with mobility restriction, especially those with high support needs. Nearly half (48.1%) of people with high support needs living in inaccessible homes, and close to a third (30.7%) of those living in accessible homes, reported a desire to move home but being limited by difficulty finding accessible housing elsewhere. Difficulty finding accessible housing was the key barrier to moving home. People who have already made a substantial investment in modifying their residence are discouraged from moving home when their household or employment circumstances change.

The report concludes that:

1) Existing strategies such as a voluntary building code, reliance on home modifications or provision of accessible social housing have failed to deliver accessible housing for most people with mobility restrictions. Building all new homes to accessible standard will be the most effective way to address the shortage in accessible housing.

2) The impact of inaccessible housing on dignity, freedom, social inclusion, health, and workforce participation is profound, and the report presents robust quantitative and qualitative evidence of these. Such impacts must not be measured exclusively in dollar value; rather, the social justice argument for addressing the indignities experienced by people with mobility restrictions must be front and centre to the RIS Consultation considerations.
3) Notwithstanding the above, the data indicates the CIE RIS Consultation report has underestimated the economic costs of inaccessible housing, by ignoring impacts on workforce participation and productivity of people with mobility restrictions; underestimating the impact on paid and unpaid support needs; underestimating adverse impacts on mental health and wellbeing; and, underestimating the extent to which a shortage in accessible housing limits housing choice and mobility.
4) The range of domestic activities for which paid support is provided, and which can be reduced by accessible housing is broader and more significant than estimated by CIE. The CIE only focused on paid and unpaid assistance with mobility tasks[1], whereas inaccessible housing also significantly increases need for assistance with self-care and homecare. Furthermore, in estimating the impact on support needs, the CIE excluded those living in housing that has already been modified due to disability or age, assuming that modified housing is fully accessible[2]. However, the qualitative survey shows that most people whose homes have been modified, consider these modifications to only partly address their needs, and they too require additional paid or unpaid support due to inaccessible homes.

1 The CIE Proposal to include minimum accessibility standards for housing in the National Construction Code, July 2020, p140
2 *ibid*, p140

1. Introduction

Extrapolating from Australian Bureau of Statistics (ABS) data and population projections, the Centre for International Economics (CIE) estimated that the number of Australians with a mobility-related disability will increase from 2.9 million in 2018 to around 4.7 million people over the next 40 years, due to population growth and an ageing population. Many people with mobility restrictions have trouble finding housing that meets their accessibility needs. The Australian Building Codes Board (ABCB) is currently investigating options to address this problem and has engaged CIE to develop a Regulatory Impact Statement (RIS) Consultation.

The CIE analysis[3] is focused on quantifying the economic costs and benefits of regulation, with limited reference to equity considerations and in the absence of any qualitative analysis. The Office of Best Practice Regulation in their Guidance Note on Cost-Benefit Analysis[4] states:

- 'CBA [Cost Benefit Analysis] requires you to identify explicitly the ways in which the proposal makes individuals better or worse off.'[5]
- 'You should report cost and benefit estimates within three categories:
    - monetised
    - quantified, but not monetised
    - qualitative, but not quantified or monetised.'[6]

The study reported here was initiated in response to the CIE Consultation RIS, and was designed to address a gap in both quantitative (but not monetised) and qualitative (but not quantified or monetised) data about the social, health and economic benefits of accessible housing.

With over 1187 survey responses, and 40 in-depth interviews, the report presents some the most comprehensive data ever collected in Australia about the lived experience of people with mobility limitations living in accessible or inaccessible housing. It brings the voices of hundreds of Australians with disability into the RIS Consultation and the policy debate about the need for regulatory reform in housing accessibility standards.

The analysis presented in this report is focused on measuring and understanding:

- accessibility and inaccessible features in the homes of people with mobility restrictions
- mental health and wellbeing outcomes of living in accessible or inaccessible homes
- impacts of housing accessibility on ability to perform self-care and homecare activities
- impacts of housing accessibility on social and family relations
- impacts of housing accessibility on need for paid and unpaid support
- impacts of housing accessibility on employment and productivity
- impacts of housing accessibility on housing choice and mobility, including ability to move to another home and ability to stay home and avoid forced moves to other residences or supported accommodation.

Although this report does not seek to directly translate findings into monetary costs or benefits, some of the findings presented challenge the assumptions underpinning the CIE analysis. The report also addresses the following questions raised by RIS Consultation:

- The impact of a lack of accessible housing on equity, dignity and employment outcomes is difficult to fully measure. How does a lack of accessible housing contribute to these issues?
- What other information could be used to estimate the costs associated with a lack of accessible housing to make estimates more reliable?

[3] The Centre for International Economics (CIE), Proposal to include minimum accessibility standards for housing in the National Construction Code, Consultation Regulation Impact Statement, 2020

[4] Office of Best Practice Regulation, Department of the Prime Minister and Cabinet, Cost-Benefit Analysis Guidance Note, February 2016

[5] p. 4

[6] p. 11

- Do you have information about the type and cost of home modifications that are made to improve the accessibility of a home?
- In your opinion what is the main contributor to a lack of uptake of universal design principles in new dwellings?
- Are our assumptions relating to the occupation of accessible housing by owner occupiers and renters over time reasonable? What additional evidence could we consider to make these assumptions more robust?
- To avoid attributing benefits to accessibility features already installed in dwellings under current arrangements, the impacts of the proposal have been reduced in proportion to those elements assumed prevalence and weighted average cost. What additional evidence could we consider to make this assumption more robust?

The scope of the study was limited to understanding the lived experiences of adults with mobility limitations. While some evidence presented is indicative of major impacts of inaccessible homes on informal carers of people with mobility restrictions, in-depth analysis of such impacts was beyond its scope. Further research is needed on the impact of inaccessible housing on wellbeing, physical and mental health, social inclusion, economic productivity and personal freedom and empowerment outcomes for informal carers. Further research is also needed on the impact of inaccessible housing on families with children with disability.

This report presents only a first cut of the data, and further work will be undertaken to analyse at more depth the extensive interview and survey data that has been collected. A key focus of the work will involve analysis of how specific accessibility features impact on specific activity restrictions at home, and the impacts on social, health and employment outcomes. A second report will be published in November 2020, followed by a series of scholarly publications.

The study was co-sponsored by the Summer Foundation and Melbourne Disability Institute (MDI). It was given ethics approval by the University of Melbourne, Science Faculty Human Research Ethics Committee (approval number 2057641).

2. Method

The study method consisted of two primary elements: an online questionnaire (1,178 responses) and 40 in-depth follow-up interviews.

1.1. Online questionnaire

An online questionnaire was distributed on the 17th August 2020 and closed for responses on the 28th August. A link to the survey was circulated widely via email through disability services and advocacy networks.

The questionnaire targeted people over 18 years old with a mobility impairment. It could be filled by the person with a disability or another person assisting them.

The questions included:

- standard demographic information about the respondent (age, gender, occupation, income).
- information about their disability (impairment type and severity, need for assistance with mobility and self-care, and use of mobility aids).
- information about their housing situation (dwelling type, tenure).
- the accessibility of their home (accessibility features; modifications undertaken).
- impact of accessibility in their current home on:
    - ability to perform domestic activities (moving around, self-care, home care)
    - ability to study, work, or volunteer
    - need for paid or unpaid support
    - social and family relations
    - health and wellbeing, including risk of injury
    - risk of being forced to move home
- wider shortage in accessible housing and its impacts on ability to move home; ability to visit friends and family in their home; employment opportunities.
- interest in participating in follow up interview.

The response to the online questionnaire was overwhelming, with 1,178 responses between the 17th and 28h August. 100 responses were excluded from analysis due to insufficient data.

Analysis of the survey data was undertaken by a statistician (Liss Ralston), and sought to identify patterns in the social, economic and health impacts of housing accessibility or inaccessibility. The large number of responses allowed differentiating results for people living in accessible homes VS those living in inaccessible homes; and, for people with different levels of disability and support needs.

Respondent's level of support needs was assessed based on their responses to two questions: frequency of need for support with body movement and self-care; and, whether they receive NDIS funding.

Table 1: Survey sample characteristics

	Category	Count	Column N %
What is your age?	18-30	184	17.1%
	31-50	374	34.8%
	51-65	349	32.4%
	66-75	126	11.7%
	76 or older	43	4.0%
	Total	**1076**	**100%**
What gender do you identify with?	Male	330	30.6%
	Female	719	66.7%
	Non-binary	29	2.7%
	Total	**1078**	**100%**
How often do you need help with body movement or self-care?	Never	114	11.8%
	Sometimes	395	40.8%
	Often	460	47.5%
	Total	**969**	**100%**
Do you receive individual funding from the NDIS?	Yes	616	63.6%
	No	339	35.0%
	Not sure	14	1.4%
	Total	**969**	**100%**
How long have you lived in your current home?	Less than a year	82	10.1%
	1-4 years	216	26.6%
	5-9 years	162	20.0%
	10-19 years	176	21.7%
	20 years or more	175	21.6%
	Total	**811**	**100%**
What is your employment status?	Employed full time	71	8.5%
	Employed part time	141	16.8%
	Receiving Disability Support Pension	358	42.8%
	Unemployed - seeking work	36	4.3%
	Unemployed - not seeking work	76	9.1%
	Retired	134	16.0%
	Other	113	13.5%
	Total	**837**	**100%**
What is your personal annual income (before tax)?	$37,000 or less	466	58.5%
	Between $37,001 and $48,000	69	8.7%
	Between $48,001 and $90,000	77	9.7%
	Between $90,001 and $126,000	40	5.0%
	between $126,001 and $260,000	13	1.6%
	$260,0001 or more	1	0.1%
	Prefer not to say	131	16.4%
	Total	**797**	**100%**

Table 2: Classifying 'High' and 'Low' support needs

		House Design			
		Enabling	Limiting	Total	
Disability level	Low	21.5%	78.5%	100%	288
	High	28.5%	71.5%	100%	657
	Total	26.3%	73.7%	100%	945
		249	696	945	

1.2. Remote interviews

In-depth interviews were conducted with 40 participants who expressed an interest and provided their contact details in the online questionnaire. Due to COVID19 social distancing restrictions in Melbourne, all interviews were conducted remotely over the phone or videoconference (using Zoom). Most interviews lasted between 45-60 minutes, and were conducted between the 19th-28th August, by a team of four research assistants. With participants' consent, all interviews were audio recorded for transcription. Each interviewee received a $50 shopping e-voucher as a recompense for their time.

Survey data allowed us to select of participants based on their questionnaire responses. In selection of participants we sought a diversity of people in terms of:

- housing tenures – with a focus on homeowners and private renters
- demographics (age, gender, disability type and severity)
- accessibility features and barriers in their home
- impacts of accessibility or inaccessibility on daily life, social relations, work opportunities and health.

Due to the short timeframe for the interviews, logistics such as the availability of participants and researchers also played a key role in selection of participants.

The interviews were semi-structured, with the focus of questions adjusted to each participant's individual circumstances, allowing participants to construct narratives in ways that are less restricted by a pre-conceived format. The themes covered in the interviews corresponded with those of the online questionnaire, but more open-ended in their style to allow participants to share further detail about their housing and life circumstances.

- About the person (e.g. Where do you live? What is your main occupation?)
- About the person's disability and mobility limitations (e.g. What kind of physical impairment do you have? How long have you had it? How does your impairment impact on your mobility, support needs?)
- About the person's home (e.g. When and why did you move into this home? Who do you live with and what is their relationship to you? How would you describe the accessibility standard of your home? What are the main features of your home that limit your ability to move around and carry out domestic activities? What are the main features of your home that enhance your ability to move around and carry out domestic activities?)
- Home modifications (e.g. Have you done any home modifications to improve the accessibility of your home? If so, what and why? What were the main difficulties in getting these or other modifications done? In what ways did these modifications change your life? Do you expect that you will need to take home modifications in the future?)
- Impacts of housing design on study, work, and volunteering (e.g. Does the accessibility of your home or difficulty finding accessible housing limit your opportunities to work or volunteer? Does the accessibility of your home or difficulty finding accessible housing limit your opportunities to study?)

- Impact on social life (e.g. How does accessibility or inaccessibility of your own home impact your ability to have a social life, maintain social connections with friends and family – within and outside your household? How does accessibility or inaccessibility of other people's home impact your ability to have a social life, maintain social connections with friends and family?)
- Impact on support needs (e.g. Do you need support from other people to do certain things at home? What if any modifications to your home might reduce your need for support?)
- Other impacts (e.g. Have you ever experienced injury because of difficulty getting in and around your home? How concerned are you about the risk of future injury for that reason? Are you concerned that you might be forced to move to another residence or a nursing home because of accessibility issues? Have you ever had trouble moving home because of difficulty finding accessible housing?)
- Concluding question (All things considered, how does the accessibility/inaccessibility of your home impact on your health, wellbeing, and life opportunities? How different would your life be if you had a more/less accessible home?)

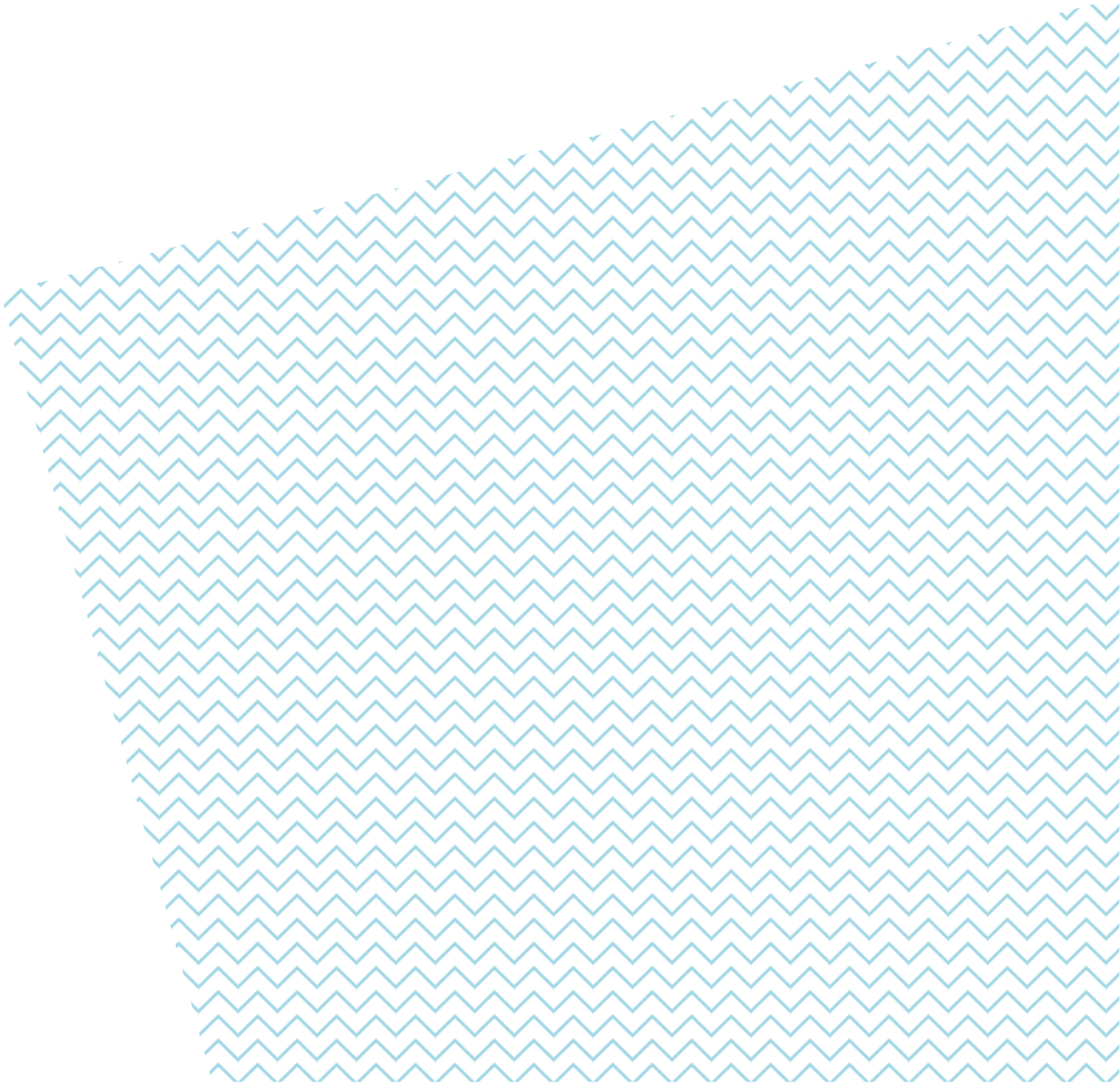
A 2-3-page interview summary was completed by the interviewer for every participant they interviewed. The summary was structured around the 9 interview themes. In this report we draw on these summaries to present some participants' stories as 'case studies' that illustrate how accessibility or inaccessibility features impact on a person's social, health and economic outcomes in a more holistic context of a person's life.

In Phase 2 of the study, which will commence in September 2020, all interview recordings will be fully transcribed and coded using NVivo software, to allow more comprehensive thematic analysis of the interview data.

Table 3: Interview participants, selected characteristics

	Category	Count
What is your age?	18-30	10
	31-50	15
	51-65	11
	66-75	7
	76 or older	2
What gender do you identify with?	Male	14
	Female	27
	Non-binary	4
Which of the following best describes your home…	Built accessible	14
	Modified fully accessible	6
	Modified partly accessible	11
	Not built or modified accessible	14
Tenure	Homeowner	15
	Private rental	11
	Social housing	12
	Group home	1
	Living with parents	4
	Living in partner's home	2
	Total	**45**

3. Results



1.3. Prevalence of accessibility and inaccessibility features

The majority (73.6%) of respondents live in housing that does not meet, or only partly meets, their accessibility need (Table 4). People with lower support needs were more likely to live in inaccessible housing, possibly because of ineligibility for funds for home modifications, or for social or specialist housing (Table 6). Private renters were most likely to live in inaccessible home (87.6%), but high incidence of inaccessible homes was also recorded for homeowners (71.5%) and social renters (74.8%). Although significantly more accessible than mainstream housing, partial inaccessibility was surprisingly high even in specialist disability housing such as group homes (47.1%) and supported residential services (46.2%) (Table 7). People with lower income face significant affordability barriers to purchase or rent an accessible home, or to modify their homes, resulting in higher proportions of people on lower income living in inaccessible homes (despite a higher proportion of low income people living in social housing).

Table 4: Housing accessibility classification

	Count	%	Classification
Built in a way that meets my accessibility needs	178	18.7%	Accessible
Modified to meet all my accessibility needs	71	7.4%	Accessible
Not built or modified to meet my accessibility needs	328	34.5%	Inaccessible
Modified to meet some of my accessibility needs	372	39.1%	Inaccessible
Total	949		

Only 21.3% of all respondents – including 37.0% of those who rated their home accessible – had reinforced walls around the toilet, shower and bath that may allow future installation of grabrails, indicating low level of adaptability to changing future needs. The features least often included in dwellings ranked as 'inaccessible' were wide internal doors and corridors, and hobless shower recesses (Table 5).

Table 5: Accessibility features in respondents' homes

	Self-Rated Home Accessibility				All respondents	
	Accessible		Inaccessible			
	Count	%	Count	%	Count	%
Safe continuous step-free path from the street or parking to the entrance	177	77.0%	238	39.3%	417	49.5%
At least one step-free entrance	134	58.3%	240	39.6%	375	44.5%
Internal doors and corridors that facilitate comfortable and unimpeded movement	193	83.9%	199	32.8%	394	46.8%
A toilet on entry level that is easy to access	197	85.7%	371	61.2%	569	67.6%
A bathroom that contains a hobless shower recess	185	80.4%	244	40.3%	430	51.1%
Grabrails in the toilet, shower, or bath	134	58.3%	298	49.2%	433	51.4%
Reinforced walls around the toilet, shower and bath that may allow future installation of grabrails	85	37.0%	93	15.3%	179	21.3%
Stairways with a handrail	41	17.8%	140	23.1%	185	22.0%
Stairways without a handrail	6	2.6%	57	9.4%	63	7.5%
	230		606		842	

Table 6: Housing accessibility by support needs

	House Design			
	Accessible	Inaccessible	Total	
Low support needs	21.5%	78.5%	100%	288
High support needs	28.5%	71.5%	100%	657
Total	26.3%	73.7%	100%	945
	249	696	945	

Table 7: Housing accessibility by tenure

	Built in a way that meets my accessibility needs	Modified to meet all my accessibility needs	***Accessible***	Not built or modified to meet my accessibility needs	Modified to meet some of my accessibility needs	***Inaccessible***	**Total**
Homeowners	17.7%	10.8%	28.5%	26.0%	45.5%	71.5%	**100%**
Private rental	9.8%	2.6%	12.4%	64.2%	23.3%	87.6%	**100%**
Social housing	23.5%	1.7%	25.2%	30.4%	44.3%	74.8%	**100%**
Living with parents or other relatives in their home	20.1%	9.8%	29.9%	29.3%	40.8%	70.1%	**100%**
Other	29.4%	0.0%	29.4%	35.3%	35.3%	70.6%	**100%**
Group home	35.3%	17.6%	52.9%	11.8%	35.3%	47.1%	**100%**
Supported Residential Service	46.2%	7.7%	53.8%	11.5%	34.6%	46.2%	**100%**
Hostel	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	**0%**
Total	18.8%	7.5%	26.3%	34.6%	39.1%	73.7%	**100%**

39.1% of survey respondents lived in homes fully modified to meet their accessibility needs, more than twice as many as those who lived in homes that were built in a way that meets their accessibility needs (18.7%). The survey and interview data highlighted five issues related to such reliance on home modifications to meet accessibility needs.

First, participants faced a range of barriers to home modifications:

- Affordability and funding restrictions: many people with disability have low incomes and therefore often cannot afford to pay for home modifications on their own. Most survey respondents expressed concern about ability to afford necessary home modifications. These concerns were strongest for people living in inaccessible homes (81.6% of those with low support needs, and 85.7% of those with high support needs). Yet concerns about ability to afford necessary home modifications remains a concern even for those living in accessible homes (44.2% and 47.5% respectively) highlighting changing accessibility needs over time, and the need for adaptable housing (Table 8).
- Many people are ineligible for NDIS or other funding for reasons such as low assessment of support needs or living in private rental. (see Rachel's story in box 1).
- Structural restrictions such as homes and rooms that are too small, or doorframes and hallways too narrow, preclude home modifications or limit their efficacy.
- Private renters face significant barriers to modifications, including difficulty getting landlord approval, home modification funding restrictions for renters, and housing precarity heightening the risk associated with personal financial investment in home modifications.
- Body corporate approval is required for structural modifications in apartments.
- Shortage in skilled builders for modifications (see Rachel's story in box 1 and Andrea's story in box 2).

Table 8: Ability to afford home modifications, by support needs

	Housing	Very Concerned	Somewhat concerned	Concerned (total)	Not Concerned	Total	N
Low support needs	Accessible home	16.3%	27.9%	*44.2%*	55.8%	100%	43
	Inaccessible home	49.4%	32.2%	*81.6%*	18.4%	100%	174
High support needs	Accessible home	21.3%	26.3%	47.5%	52.5%	100%	160
	Inaccessible home	57.7%	28.0%	85.7%	14.3%	100%	407

Second, compared to housing constructed to accessibility standards, post-construction modifications were more likely to only partly meet people with disabilities' accessibility requirements. While close to half (46.5%) of survey respondents lived in homes that were modified, most of those (40.2%) reported these modifications met only some of their accessibility needs. The proportion of survey respondents who lived in housing that was *built* in a way that meets all their accessibility needs (18.7%), was more than twice as high as those who lived in housing *modified* to meet all their accessibility needs (7.4%), demonstrating that building to accessible standard is more effective than post-construction modifications.

Third, when modifications are undertaken exclusively in the homes of people who have mobility restrictions, they are unable to visit the homes of their family and friends, resulting in significant social isolation. (see data and discussion in section 3.5).

Fourth, the reliance on modifications restricts people with disabilities' residential mobility (see section 3.7), as most dwellings are inaccessible. People who have already made a substantial investment in modifying their residence will be discouraged from moving home when their household or employment circumstances change. As commented by one survey respondent:

"I have thrown so much of my savings and you making my current home accessible that should I sell it I wouldn't be making a large profit margin that could be used to add accessibility and the new home. Modifications are made didn't add value to the property but have cost me over $100,000. Therefore, trying to buy a new property and repeat this is financially disadvantageous"

Fifth, individuals' accessibility needs change over the life course, due to ageing, injuries (often due to inaccessibility of homes, see section 3.6), and deterioration of capacity, requiring ongoing modifications, highlighting need for houses as adaptable as possible, such that they can continue to be modified more effectively and cheaply over time (see Andrea's story in box 2).

Box 1: barriers to home modifications

Rachel's story

Rachel, in her 60s, works as an artist, and lives with her partner in a house that they own in Melbourne. Rachel had polio as a child and now lives with post-polio syndrome. Her mobility is significantly impaired by partial paralysis, and she can only walk short distances (up to 30 metres), has difficulties sitting up, lifting herself from a sitting to standing position, dressing and showering, though she continues to perform many of these activities independently. Her mobility is significantly declining over time and she expects to be in a wheelchair later in life.

Rachel and her partner bought a house in Melbourne twenty years ago and have continuously modified their home to meet her changing accessibility needs. These included installing a handrail next to three steps at the front of the house and constructing a ramp at the back to create level entry, which now serves as her entrance into the home. She has also modified the toilet, raising it six inches, and installed a hand shower on a sliding pole and a seat in the bath (her shower is too small to sit in). They have also modified the kitchen to increase the amount of accessible storage.

They have taken loans to finance these modifications, which otherwise they could not have afforded. But with limited income, Rachel had difficulty sourcing a competent and reliable builder for these modifications, instead compromising for an 'informal' and cheaper provider who delivered work of poorer quality.

"I was on a knife edge of anxiety the whole time … It wasn't a very big loan but to me it was just terrifying. Because on the disability support pension it's very low fixed income. And to get into any kind of debt on that is scary."

Despite these compromises, home modifications have made a substantial difference to Rachel's life. Rachel converted her carport into an accessible artist's studio and commented: "An accessible home means an accessible workspace." Having an accessible home is also fundamental to connecting with her family and friends because she cannot meet them in their inaccessible homes. Her support needs are kept low, and independence high, thanks to accessibility features a home. Had Rachel's home not been accessible, she would have been forced to live in specialist disability housing, rather than living with her partner.

"I wouldn't be able to live in a home that was not accessible. I'd have to live in some kind of supported accommodation. So, accessibility in the home means that I can live with my family in my house and be independent. That's the main impact."

As Rachel's mobility continues to deteriorate, further modifications will be required in her bathroom, which she describes being in a "makeshift" condition at present. She would also like to create an accessible emergency exit from her home in case of a fire. But there are challenges getting modifications done. It is difficult to source an NDIS approved builder due to there being so few of them. Another challenge is finding accessible accommodation to live in while the bathroom modifications are being done. Furthermore, there is a limit to how much Rachel's home can be modified to adapt to her changing conditions: once she requires a wheelchair, she will need to move, as the house's hallways and doorframes are too narrow.

Box 2: barriers to home modifications

Andrea's story

Andrea, in her 20s, is a university student who lives in Melbourne with her family. Andrea fell ill almost a year ago with a disease that causes her to tremble and to experience seizures. She can walk on a flat surface for up to twenty metres using a frame for support. As her current home cannot accommodate a wheelchair, at present she only uses one when she is outdoors. She has difficulty independently carrying out daily activities such as getting her own food or showering. She uses two shower chairs to assist her with the latter task. She has not been approved for NDIS and she relies entirely on her family for daily support.

Andrea lives with her parents, siblings, and dog in a two-story house. The house has wide hallways and some wide doorframes that she can easily walk through using her walking frame. However, her bedroom is located on the second floor of the house and cannot be moved downstairs as she would then no longer have easy access to a bathroom. As a result, she must sit and use her arms to push herself up and down the stairs, a tiring process that restricts her to descending only once per day.

Within her home, a step into the shower makes it difficult for her to access the shower and old, uneven carpet has caused frequent falls – Andrea sustained four concussions in the past year as a result of tripping and hitting her head on her bedframe. Getting in and out of her home is also a challenge as every entrance into the house has steps. Her family investigated installing a ramp, but the cost was too prohibitive. Her father tried to fabricate a ramp himself, but it did not function well. Andrea's father – who works in construction - had previously registered for a course on accessible housing design, but the program was never run due to a lack of interest or no one qualified to teach it. Due to the difficulty in getting outside with her dog, Andrea often crawls around her house and backyard in order to spend time with him.

To solve these problems, her parents decided to move home. Finding a more accessible home was not easy, and Andrea commented: "Everywhere has steps. You don't realise until you actually have to look."

Eventually they found and bought a new single-story house that is not accessible but can be modified to meet Andrea's accessibility needs. Unfortunately, it is further away from public transport which will limit Andrea's ability to travel independently to study or work. The family intends to undertake modifications, including a ramp in the entry, a double shower bathroom with a built-in seat and a lower basin, and railings to the walls, and a modified kitchen with lower countertops. However, due to both financial constraints and difficulty finding builders who are qualified and willing to do this work, renovations will be completed progressively after the family moves in. Andrea is particularly anxious about climbing the three steps to enter the house, and says that while renovations are underway, she will "hide in my room the entire time." When the renovations are completed, Andrea hopes that she will be more independent, and need to ask for less help.

1.4. Ability to perform domestic activities

Survey respondents living in homes that were not modified or only partly modified, reported inaccessible housing features further limited their ability to move into and out of their home, and perform self-care and home-care activities. Home care activities (such as home cleaning) were most limited by housing design, and movement inside the home was the least limited. Inaccessible housing was more limiting for people with high support needs, especially in relation to movement inside the house and home care activities (Table 9).

Table 9: Housing design limitations on activities, by self-rated housing accessibility and support needs

	Low support needs			**High support needs**		
Activities limited	Accessible housing	Inaccessible housing	Total	Accessible housing	Inaccessible housing	Total
Entering and exiting the house	10.9%	60.7%	48.4%	5.7%	66.2%	48.4%
Internal Mobility	0.0%	37.6%	25.7%	1.9%	60.5%	41.0%
Personal Care	7.8%	60.1%	48.2%	10.9%	65.0%	49.7%
Home care	28.9%	75.1%	65.9%	34.0%	87.4%	73.2%
	51	181	232	165	398	563

Some participants reported prioritising certain activities over other – for instance by giving up showers - to reserve their energy for other activities (see for example box 3, Rowena's story).

Box 3: Domestic activities limitations and trade-offs

Rowena's story

Rowena, in her 50s, lives in Brisbane and works part-time as a consultant. Prior to falling ill, she worked in executive roles in the public sector. Rowena was diagnosed with chronic fatigue syndrome at the end of 2016. Her condition causes debilitating fatigue and limits the amount of energy she can expend over a day. Every action she takes involves a trade-off whereby, for example, the choice to prepare a meal, or work from home, means doing without a shower that day.

The inaccessibility of her home further limits her choices. To enter or exit her home, Rowena must climb one flight of stairs – there is no elevator – adding a significant drain on her limited daily energy. Each time she enters or exits her home means another activity that she needs to forego (e.g. washing up or spending time with friends or family). She is also concerned about the risk of having difficulty evacuating in the event of an emergency. Other inaccessible design features include her kitchen. It is draining for Rowena to lift her arms to reach the shelves. The height of her microwave is causing particular concern as it requires lifting hot food and could lead to an injury.

As Rowena depends on her livelihood, she prioritises her work when it comes to her energy levels, meaning that she ends up foregoing other aspects of her life, such as showering, when necessary. However, her latest medical results suggest that eight hours of work a week is currently too debilitating for her health. Rowena feels that if her home was designed in a way that enabled her to better balance her energy across the week, she may be able to sustain the eight hours without compromising her health.

There is no single design feature in her home that renders Rowena's life impossible, but the culmination of a number of poorly designed features results in her having to make impossible tradeoffs, give up fundamental activities, leading to a significantly depleted quality of life. Having to choose between activities that most people take for granted (e.g. preparing meals versus showering) is an ongoing source of stress in its own right.

"Because I have a limited energy envelope, and because I'm expending energy from the climbing of stairs and lifting and so forth, that means I have less energy to do everything else."

1.5. Ability to study, work, or volunteer

While many survey respondent and survey participants were unable to participate in study or paid/unpaid employments for reasons other than housing accessibility, for those who could participate housing design played an important role in either limiting or enabling work or study.

Excluding those for whom this question was inapplicable (i.e. other reasons preventing paid employment), 96.2% of survey respondents with low support needs, and 88.6% of those with high support needs, living in accessible homes reported their homes were 'enabling' to having paid employment. In contrast, 47.9% of survey respondents with low support needs, and 62.5% of those with high support needs, living in inaccessible homes reported their homes were 'limiting' their ability to have paid employment. Similar results were recorded for study and volunteer work (table 10).

Table 10: To what extent does the design of your home enable or limit your ability to work, study or volunteer

Low support needs		Limiting	Enabling	Total	Count
Study in secondary, tertiary, or continuing education	Accessible home	6.1%	93.9%	100%	33
	Inaccessible home	39.7%	60.3%	100%	63
Have paid employment	Accessible home	3.8%	96.2%	100%	26
	Inaccessible home	47.9%	52.1%	100%	73
Do volunteer work	Accessible home	11.1%	88.9%	100%	27
	Inaccessible home	44.8%	55.2%	100%	67

High support needs		Limiting	Enabling	Total	Count
Study in secondary, tertiary, or continuing education	Accessible home	13.5%	86.5%	100%	89
	Inaccessible home	58.3%	41.7%	100%	192
Have paid employment	Accessible home	11.4%	88.6%	100%	88
	Inaccessible home	62.5%	37.5%	100%	208
Do volunteer work	Accessible home	8.0%	92.0%	100%	88
	Inaccessible home	57.9%	42.1%	100%	197

Over a third of all survey respondents reported lack of accessible housing has resulted in loss of job opportunities, loss of existing work, reduction in work hours, or reduced productivity at work (Table 11).

Table 11: Has a lack of accessible housing ever...

	Count	**%***
Prevented you taking a job?	160	48.9%
Reduced your hours of work?	168	51.4%
Reduced your productivity at work?	194	59.3%
Led to losing or giving up a job?	120	36.7%
Total	327	34.4%

* of 948 respondents with sufficient data

Qualitative and quantitative data suggested housing accessibility reduces productivity and work opportunity for people with mobility restrictions in four primary ways.

First, limitations or enablers to work or study from home influenced both employment opportunities and work productivity for those in employment. Survey respondents with both low (40.4%) and high (53.4%) support needs living in inaccessible homes, reported housing design features limiting their ability to work or study from home (table 12). In contrast, those who were able to create modified workstations in their home had significantly improved work opportunities and productivity (see for example box 4, Jack's story). Qualitative data suggested limitations working from home have become especially restricting during

COVID19 lockdowns and the requirement to work or study remotely. However, some participants have been working primarily from home even before the pandemic.

Table 12: To what extent does the design of your home enable or limit your ability to work or study from home

	Low support needs			**High support needs**		
	Accessible home	Inaccessible home	Total	Accessible home	Inaccessible home	Total
Work or study from home	8.3%	40.4%	31.9%	14.0%	53.4%	41.2%

Second, many survey respondents and interview participants reported difficulties finding accessible homes close to employment opportunities. Those who have lived in accessible homes – often after significant investment in home modifications – were reluctant to leave their home for a job opportunity.

Third, fatigue from living in inaccessible home and the additional time and energy spent on self-care and homecare, reduces productivity, motivation, self-confidence, and capacity to work, study or volunteer. For example, difficulty showering because of an inaccessible bathroom limits capacity to take on any work outside the house (see box 7, Edna's story).

Forth, inaccessible housing increased reliance on paid or unpaid support with personal and domestic activities, limiting ability to take on employment, for example due to reliance on assistance in preparation in the morning. Those living in accessible homes reported independence in everyday activities, such as self-care, which also provided greater capacity to take on work or study outside their home (Table 13).

The productivity of informal carers of people with mobility restrictions living in inaccessible homes is also harmed. Several participants commented on the burden of care placed on relatives – especially parents and partners – including impact on their ability to work. Some participants who were able to move into more accessible homes commented this has had enabled their informal carers to take on more paid work.

Table 13: Survey respondents' comments on housing accessibility impacts of work and study

Inaccessible housing	Accessible housing
Working from home	
Limited facilities to provide room for study materials, laptop etc.	Accessible housing mean I can work or study whenever I want.
Study room not modified in any way. [Neither] ADHC nor NDIS are willing to subsidise modification to my desk area nor study area itself.	Accessibility makes it possible. Cannot consider moving without considering modifying a house
I have owned and lived in my house for some 20 years, which was purchased and (partially) modified soon after my spinal cord injury (T6 complete paraplegia). I do hold a permanent part-time job and have done over this period. Until 2020, this had little detrimental effect on my working life. However, with the COVID pandemic, I have found that my house (in terms of appropriate desk and more particularly "physical space") is NOT meeting my needs and is limiting my work productivity.	I certainly was unable to attend work or study as because the house was inaccessible, I wasn't even able to return home let alone return to work or study. We had to move to another town and purchase a home. The home needed a lot of modifications and once this was all done, I was just then able to return to study.
I have a micro business and the lack of space to do my sewing, so it means I have to go to different places to work. Loss around 15 hours a week	Working from home has been a dream
Working from home during COVID has been ...difficult because of lack of space for an ergonomic accessible work desk.	Having my modified apartment enabled me to return to work full time, despite my injury.
Time and energy available for work	
Time and energy spent getting prepared for work can take an overall toll on energy left to get to/from work and around the workplace.	A quiet environment at home, e.g. thick walls, supports my hyperacusis. [Otherwise], high temperatures (due to poor shading on windows) worsen my body's heat regulation and therefore drain my limited energy.
When the house is inaccessible time it takes to access the shower and toilet prevented me from taking on paid employment.	I have a home that makes life easy for me, so I am able to think and plan for things outside the home. Also, I can come home to a place that renews me.
Suitable private rental housing was much further away from work/study so lost 2 hours a week to travel time. Energy required to live/clean/cook/shower in rental housing that didn't meet my access needs meant I decided to work part time (4 days a week). So, I lost 1 day a week wages + associated superannuation, leave entitlements + missed promotion opportunities at work due to being part time employee.	Ease of living at home and entering/exiting home improves energy levels to be able to maintain employment
Accessibility directly affects my physical emotional and mental wellbeing and health. Bad design means extra effort which means less capacity for work or study. Bad design means social isolation, and poor mental health. Good access means equity if enjoyment of space and relationships.	If our home was not accessible it would severely limit social, mental and creative wellbeing which would impact on ability to sleep/et/bathe suitably and therefore be in a positive way able to attend waged work and thereby contribute to paying taxes.
My apartment has incredibly limiting space in the bathroom in particular, and this has meant that I have been late for things, especially when work was still in an office. The space between the wall, my wheelchair and the bed is narrow. My closet is largely inaccessible. Getting ready for anything, but work especially, takes a long time.	Without somewhere to shower or sleep, good *** luck trying to hold down a job or focus on other things
The energy which navigating these stairs takes is something which I have to factor into every day... That is not even considering the energy needed to cook dinner or perform other typical household chores once I get inside	I could be more independent and focus time and energy on family and work instead of worrying how I get around my house.

after work. This takes a significant toll on the extent to which I can be productive during the workday.

Independence

Being unable to shower or dress myself has caused issues on keeping my employment	If my home was not accessible, I would rely heavily on others for assistance, therefore limiting my ability to work or study
When I lived in a rental that had a step at the front door I really needed other people to always be able to be there to get in and out of the house which meant there were times I couldn't leave the house so I couldn't work	My accessible home enables me to live independently and safely on my own.
I find it hard to lock and open the front door	Living in an accessible home means I'm able to come and go freely without having to wait on others to assist me
Difficult moving in house doorways narrow no safe access into/out of house.	If I did not have safe, secure, accessible housing I would not be a PhD or a senior public servant. My study and career over 30 years depended on it.
It takes a significant amount of time to get prepared to leave the home with required assistance to bathe due to the design of the bathroom. I would not require assistance if the bathroom had been designed with an accessible thought process	Gaining entry and exit of house enables me to participate in full-time work and occasionally socialise

Accessible housing close to work

I chose a house that was accessible but when work relocated the drive was quite far. Expensive by taxi but to find another accessible house precluded a desire to move closer to work.	It is sheer luck that I found a ground floor Villa. Now they are all high-rise apartments. I only want to live on ground floor due to access and safety concerns. If I didn't find this home close to public transport, I may not have been able to work as taxi fares are too expensive (compared to bus/train)
Due to a lack of even minimal accessible housing I have had to spend all my disposable income travelling to work in a taxi because no accommodation was closer.	If I did not have a fully wheelchair accessible home in a location of my choosing I would have had huge difficulty finding a job, keeping a job due to the fact it takes me a long time to get ready in the mornings and need to be close to my place of work.
Location of houses a long distance away from work, therefore taking 3 hours get ready for work, 1 hour for travel so I need to live closer to the city where my work is. Not enough property close to work.	
Having limited accessible housing available means it is not easy to find a suitable living arrangement that is close to work, which causes me to have to travel long distances to my parent's home, limiting the number of hours I can work each week.	
I found it hard to find housing without stairs very limited as I have had a few falls from being unsteady on my feet. Spent over two months not being able to work while looking for accommodation.	
I couldn't take internships that would have been excellent because all rental housing was either luxury or inaccessible.	

Box 4: Accessible housing and work

Jack's story

Jack, in his 40s, lives in Sydney. He works part-time for government, studies part-time, and is an active volunteer in disability advocacy. As a result of a spinal injury twelve years ago, Jack has no feeling from the neck down, and no capacity to use his arms and legs. He uses a motorised wheelchair and uses his head to drive the chair and activate other equipment. Since 2010, Jack lives in a group home with three other residents. The house has been purpose-built for people with spinal injuries and is therefore fully accessible.

Each resident has their own bedroom and ensuite. Accessibility features include wide doors and hallways and large living spaces that provide ample room for wheelchairs. The front door has a scanner to allow easy entry. Jack's ability to use assistive technology within his home has reduced his need for paid support. In addition, the house is very centrally located providing easy access to footpaths, transport, shops, amenities, and specialist health services.

Despite its accessibility, living in a group home is challenging. Jack noted the bland, sterile atmosphere of the house that does not feel homely. Another key challenge relates to working from home. Jack notes that unlike an able-bodied person who can just open their laptop in the kitchen, for him, working from home requires an elaborate set-up. He needs a high, adjustable table, multiple computer screens, a microphone for dictation, and adequate space for his wheelchair. As his bedroom is too small, he has set this up in a shared room at the front of the house. On the one hand, working and studying remotely from his accessible workstation at home during COVID19 has allowed Jack to be more productive. On the other hand, he is worried about the impact his work in a shared space has on his flat mates.

Jack has been approved for NDIS Specialist Disability Accommodation and has begun looking into options to live on his own. One of the challenges to finding a suitable SDA home is that those available have been too far from his workplace. Because it takes Jack three hours to get ready in the morning, he cannot afford to lose additional time traveling to work.

Jack's experience has also allowed him to appreciate the ways in which accessible design creates opportunity, as he eloquently articulated:

"I always look at design, not only for the visual things, but also for the hidden things that it brings out and encourages people to do things. We look at design and think oh yeah, just get him through a door. But no, get him through a door to get to work, to get on the train. That's what the right door does, it provides an opportunity. It's all about opportunities. And that's what design does."

"You've got to have a house that helps you produce, helps you participate. Having a house like this, it's like an encouragement. It encouraged me to participate. I get up in the morning and I go: jeez, I can get out the door. And then I went down the road and I volunteered for my Council because I was able to have a good shower, get in my chair, out the door. It induces me to be productive in the community. That's what this house did."

1.6. Need for paid or unpaid support

Inaccessible housing increased need for both paid and unpaid support by most (65.8-67.1%) survey respondents with high support needs. Just over half (51.2%) of respondents with low support needs living in inaccessible housing reported an increase in need for informal care, and 42.0% of those reported an increase in paid disability support. Roughly a quarter (23.0-27.8%) of respondents with high support needs, and a fifth (20.0-18.8%) of those with low support needs living in accessible or modified homes reported a decrease in their support needs thanks to accessible design (Table 14).

Table 14: To what extent does the design of your current home affect your need for paid disability support or informal care?

	High support needs	Increased	Neither	Decreased	Total	Count
Accessible home	My need for paid disability support has...	31.1%	46.0%	23.0%	100%	161
	My need for informal care has...	24.7%	47.5%	27.8%	100%	158
Inaccessible home	My need for paid disability support has...	65.8%	28.4%	5.9%	100%	409
	My need for informal care has...	67.1%	27.7%	5.2%	100%	404

	Low support needs	Increased	Neither	Decreased	Total	Count
Accessible home	My need for paid disability support has...	26.7%	53.3%	20.0%	100%	45
	My need for informal care has...	22.9%	58.3%	18.8%	100%	48
Inaccessible home	My need for paid disability support has...	42.0%	54.0%	4.0%	100%	176
	My need for informal care has...	51.2%	43.5%	5.3%	100%	170

Qualitative data from the survey and interviews indicated the ways in which inaccessible housing increases support needs, and how accessible housing might reduce these. Participants reported spending high proportions of their NDIS support funding on support for self-care activities they could have done independently in more accessible homes (see box 5, Miriam's story). Beyond the public costs of increased reliance on paid support, the survey and interview pointed to additional social and health costs borne by those living with a disability in inaccessible homes, including negative impacts on relationships with relatives providing informal care; impact on employment opportunities (e.g. reliance on availability of support to be able to get organised in the morning for work); and reduced sense of independence.

Box 5: Inaccessibility and support needs

Miriam's story

Miriam, in her 40s, lives on her own in a social housing unit in Melbourne. She is a Paralympic athlete, but she has been unemployed since March. She has had Epilepsy and cerebral palsy since birth, and as a result has trouble walking and occasionally uses a wheelchair, a mobility scooter, or crutches. She used to receive support from the NDIS but now, due to COVID19, she cannot engage workers.

Although she previously lived in a social housing unit that was accessible, she was transferred to the current unit which is not. There are two steps in the entry, and there is not enough space to build a ramp. The unit's shower is over a bathtub, which she cannot safely use without support. The only modification she organised was adding handrails.

This inaccessible feature increases her need for paid support, and effectively drains her full NDIS funding package:

"On the topic of NDIS: because my housing is inaccessible I have basically 25000 a year funding purely to supervise me [while] showering, which would be completely unnecessary if I had an actual accessible bathroom. It is completely bonkers".

Miriam notes it would have been cheaper for the NDIS to pay the difference in rent if she had moved into an accessible private rental unit, compared to the cost of paid support resulting from housing inaccessibility. Being dependent on support workers to shower is limiting in many ways, and Miriam highlights the risk of exposure to staff coming in during a pandemic.

Miriam complained about this situation to the Office of Housing but heard in response that they will not modify the bathroom and that there is no other unit she could be transfer to. Because of how poorly accessible her current home is, her isolation has increased. She has less energy to go out. Miriam explained that most of her energy is spent compensating for inaccessible home design, when she could be using that energy for improving herself, taking care of her personal appearance, and increasing her self-confidence.

1.7. Social and family relations

The majority (80.8%) of survey respondents agreed or strongly agreed with the statement 'I cannot visit friends and relatives whose homes are inaccessible'. People with high support needs were more likely to agree with the statement (86.5%) than those with low support needs (66.2%) (Table 15). The level of agreement ('strongly agree' as opposed to 'somewhat agree') was also substantially stronger for people with high support needs. This finding highlights the limits of home modifications in producing a built environment that provides inclusion for people with mobility restrictions, as even those with accessible homes remain socially isolated due to limits on visiting others.

Table 15: To what extent do you agree or disagree with the statement "I can't visit friends and relatives whose homes are inaccessible"

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Count	**Agree (total)**	**Disagree (total)**
Low support needs	29.9%	36.3%	18.4%	10.3%	5.1%	234	66.2%	15.4%
High support needs	63.7%	22.8%	5.9%	5.2%	2.4%	593	86.5%	7.6%
Total	**54.2%**	**26.6%**	**9.4%**	**6.7%**	**3.1%**	**827**	**80.8%**	**9.8%**

Hundreds of survey respondents added written comments on how being restricted from visiting loved relatives and friends impacts their sense of inclusion, health, and dignity (Table 16).

Table 16: Selected comments on difficulty visiting friends and relatives

I'm unable to enter any of the homes of friends or families. The only way I can engage with my 92-year-old mother is either by phone or by meeting her at a cafe somewhere.
Very simple: the only people I can visit are other physically disabled people who live in accessible homes. This means I can't visit family and friends, who stop inviting me to their homes (pre COVID) and often ends up in lack of inclusion in most social activities outside the home. If I'm out of sight, I'm out of mind.
I cannot visit anyone that is in an inaccessible house. I miss out on being with family and friends and they meet without me or we all do not get together. My social and family life is significantly impaired by lack of accessible buildings every day.
It has a profound effect on friendships in particular as my family make the effort to see me despite their homes being inaccessible. I have lost touch with friends due to their houses being inaccessible - I have had to turn down invitations due to inaccessibility, and the embarrassment of their houses not being accessible means I don't get invited any more.
Unable to visit children in two story houses.
I am a hermit! I communicate with the outside world via computer. Occasionally friends drop by, but rarely.
I feel sad and sometimes depressed that I just can't visit people I love as I can't get into their house.
I have one child, who is married with a child... to see my granddaughter… far less often than I wish… causes me great pain and misery, envying friends and neighbours who spend a lot of time with their grandchildren, and can choose to drop in on them, offer to babysit, take them out, etc I feel that my later years of life will remain emotionally barren and both my grandchild and I will miss out on so much.
I can't visit my family... I miss out on building a relationship with my nieces because I can't access their house... I don't really have a close relationship with them at all and I feel like, to some extent… I feel like I've been a bit frozen out at times. So, it's really important that it's not just my home that needs to be accessible. It needs to be other people's homes.

Beyond the difficulty of visiting friends and relatives in their own homes, survey respondents and interviewees noted other impacts inaccessible housing has on their social and family relations. Many noted the struggle of living in inaccessible homes leaves them devoid of energy, and with injured self-confidence and mental health, impacting their ability to socialise. Many have also commented that inaccessible housing creates increased reliance on others – especially parents and partners – for support with everyday tasks, and the burden of care can severely strain relationships. Restricted housing options due to housing inaccessibility (see section 3.7) also isolates people with mobility restrictions from their family and social networks, including barriers to living together with an intimate partner (see box 6, Kelly's story).

Having an accessible home thus can relieve some of the pressures on social and family lives, by reducing reliance on family for support with everyday domestic tasks; freeing up energy previously spent on negotiating inaccessible homes for socialising; improving self-confidence to socialise; and creating a space where friends and family both with and without disability can visit (Table 17)

Table 17: Impact of inaccessible housing on social and family relations

Inaccessible housing	Accessible housing
Lack of energy, injured self-confidence, and mental health pressures due to inaccessible housing makes it difficult to maintain relationships	
The less accessible my house is, the more energy it takes for me to do the most basic things, leaving no energy left for social relationships or a life in general.	[social life improved] Immensely! Good access means good self-worth, self-capacity, independence and, self-motivation, energy for life rather than struggling for day to day tasks.
Living in inaccessible housing has negatively affected my wellbeing and mood, so I didn't have energy to have friends and family over	Without accessible housing I would not have the freedom of movement or energy to care for my children
Living in inaccessible housing increases the care burden on family and friends, straining relationships	
Struggle to maintain relationships due to accessibility issues or lack of accessibility, entirely. Too much strain on other person to do tasks that I otherwise am fully capable of doing, had there been minor adjustments. Leads to "carers" having resentment and leaves Self vulnerable to neglect and abuse.	When living with my parents I couldn't always have friends at home but now in my own fully accessible house and without my parents (24/7 Support workers instead) I can have friends over or I can go out to social events my parents couldn't take me to. Now my parents can be Mum & Dad not my carers.
The less accessible my house is the more I depend on my family for help, which definitely hinders our relationships on multiple levels.	Having an accessible home enables me to independently assist around the home, decreasing my reliance upon others to assist me, thereby improving my relationship with my wife and children.
Having an accessible home makes it easy to be visited by friends and family	
My elderly parent and my sister cannot visit due to the stairs, as they both have bad backs. My mother also has problems with her hips.	Having an accessible bathroom on the entry level means that my friends with mobility impairments can visit me.
I have many friends in wheelchairs who cannot visit my home. We have to pay for venues if we want to do an activity, which usually means we don't do them.	We built this house specifically for access and have a brilliant toilet design which means, two friends with wheelchairs can visit for a long time (pre COVID19) as they are able to use our toilet

The pain of not being able to visit family and friends in their homes was equally shared by research participants who lived in accessible homes, and those who did not. However, those who lived in accessible homes had greater capacity to host friends and family in their home. Those living in inaccessible housing – low and high support needs alike – were more likely to agree with the statement "Friends and family can't visit me because my home is inaccessible" (Table 18). Qualitative data suggested many people who have friends or relatives with a disability, and thus the inaccessibility of their home is a barrier to having friends over. One participant commented: ""it is disappointing that my friends with disabilities can't come

over to my house because it is inaccessible. It disconnects me from my community, my disability community".

Table 18: To what extent do you agree or disagree with the statement "Friends and family can't visit me because my home is inaccessible"

	Agree (total)	Disagree (total)
Accessible housing	8.7%	78.8%
Inaccessible housing	32.3%	44.3%
Total	**26.2%**	**53.2%**

Box 6: Housing accessibility and social and family relationships

Kelly's story

Kelly, in her 40s, is a mental health professional. She was born with spina bifida and has severe scoliosis, and uses a manual wheelchair since she is not able to stand or walk.

Kelly rents a detached social housing unit, in which she has been living on her own for close to 20 years. The unit was built to standard accessibility specifications. However, some features of the house do not meet her personal needs, including the laundry trough and kitchen shelves that are too high, and insufficient space to comfortably maneuver her wheelchair, especially in the bathroom. Nevertheless, Kelly says the house is good enough for her to get around to do what she needs to do.

Her main concerns relate not the accessibility of her own home, rather those of her family and friends. Kelly is a very social person, but access barriers significantly restrict her from spending time with her family and friends. She cannot visit her friends at their inaccessible homes without assistance to be able to move around and use their toilets. She commented:

"… we are no longer stuck in institutions, but we are stuck at home because of poor design."

Her father recently contracted builders to construct a new home that was supposed to be fully accessible, yet his plans were met with pushback from the builders who rejected critical accessible design features he asked for. This was extremely disappointing for Kelly who had been eagerly looking forward to finally be able to gather with her extended family in her father's home. Kelly is convinced this would not have happened if minimum accessibility standards were included in the building code.

Housing accessibility also impacted her long-term intimate relationship with an able-bodied partner of 20 years. They have not been able to move in together due to the difficulty finding housing that is designed for an inter-abled couple. For example, her kitchen bench has been lowered to meet her needs but would be uncomfortable for her partner to use. The unit is also too small, and with another person around it would be difficult for her to move around.

1.8. Health and risk of injury

Housing accessibility or inaccessibility has significant impact on self-reported mental health and wellbeing. 60.0-60.1% of respondents living in accessible housing reported improved mental health and wellbeing, thanks to the accessibility of their home. In contrast, 71.7% of people with high support needs, and 50.0% of people with low support needs, living in inaccessible housing reported worsened mental health and well-being (Table 19).

Table 19: To what extent has the accessibility standard of your current home - and ability to get in and around the home - affected your mental health and wellbeing?

		Worsened	**No Impact**	**Improved**	Total	Count
Low support needs	Accessible home	15.6%	24.4%	60.0%	100%	45
	Inaccessible home	50.0%	34.7%	15.3%	100%	176
High support needs	Accessible home	16.6%	23.3%	60.1%	100%	163
	Inaccessible home	71.7%	16.2%	12.1%	100%	414

Worsened mental health was a consequence or culmination of the various impacts discussed in other sections:

- fatigue caused by spending more time and effort completing everyday self-care and home-care chores due to inaccessible housing features (especially stairs, and inaccessible bathrooms and kitchens)
- social isolation due to difficulty socialising with friends and family
- strained relations with family members providing additional informal care due to inaccessible housing
- anxiety about risks posed by inaccessible housing, including risk of injury (table 20), being forced to move into a nursing home or other residence; or being unable to escape the house in the event of fire or another emergency. Such anxieties were reinforced by past traumatic experiences of injury. Some participants who moved out of shared supported accommodation noted experiences of abuse in such settings, increasing their current anxiety of being forced to move back to shared accommodation due to accessibility constraints in their own home.
- reduced self-confidence and sense of self-worth due to increased dependence on formal and informal support for everyday chores (table 21)

Inaccessible housing design also posed physical health hazards, and many participants reported repeated injuries in their homes (see boxes 7 and 8, Edna's and Ian's stories). Most survey respondents (75.9% of those with low support needs, and 83.6% of those with high support needs) living in inaccessible homes reported concern about the risk of injury in their home, compared to only 36.4%/32.1% of those living in accessible homes. The level of concern reported ('very concerned' as opposed to 'somewhat concerned') was substantially higher for people with high support needs.

Table 20: How concerned are you about risk of injury because of difficulty getting in and around your home related to the accessibility of your home?

	Housing	Very Concerned	Somewhat concerned	***Concerned (total)***	**Not Concerned**	Total	N
Low support needs	Accessible home	13.6%	22.7%	***36.4%***	63.6%	100 %	44
	Inaccessible home	22.4%	53.4%	***75.9%***	24.1%	100 %	174
High support needs	Accessible home	16.0%	16.0%	**32.1%**	67.9%	100 %	156
	Inaccessible home	49.9%	33.7%	**83.6%**	16.4%	100 %	409

One participant interviewed commented that the health impacts of inaccessible homes are often overlooked by health professionals, or are inadequately addressed through medical interventions rather than design interventions, because of the nature of clinical assessments:

"So often people who are seen in the medical sector, are only seen in their clinical situation, or their surgery, they are not seen in their home, but when you actually go to somebody's house and see what the access is like within it, it has huge implications on how they live and how they get around. And a lot of people don't understand that's the barrier, and that it can be removed, you know?"

Table 21: Selected quotes on mental health impacts of accessible and inaccessible homes

Mental health deterioration in inaccessible homes	**Mental health improvement in accessible homes**
Social isolation / belonging	
It is very depressing to not be able to go out easily, or have friends visit because my house is inaccessible. It makes me feel very isolated and alone.	We have a home that is easily accessed by anyone, so visits by other people with disabilities are easy, and they find that rare.
I feel isolated, because it takes so much energy and effort to get in and out of my home. ... I feel hopeless sometimes because housing accessibility is probably my biggest barrier to achieving independence, but I'll never get there if houses aren't built with disabled people in mind.	The fact that my apartment is accessible, improved my mental health tremendously! I feel included in the community. I can go anywhere, invite my friends, etc.
Not being able to fully access my friend's homes and have them access my homes has had a huge impact on my mental health. It feels like it is my fault for not being able to find an accessible place. I also feel disempowered because when my health is bad, I have to ask friends and family for help because my own home is not fully accessible.	Because I was able to easily modify my existing family home, I have been able to remain at home with my young family despite my increasingly poor mobility. This has given my life meaning. We also welcome family and friends to our house... Without the modifications to our own home I would have been forced to move to a nursing home because of my high needs.
Access to my shower and toilet isn't easy and it's hard as my partner needs to help me shower. This often makes me procrastinate showering/self-care etc as showering already makes me unwell and fatigued as it is which then makes me feel horrible and gross.	Means I can live a near to normal life and have time with my baby daughter.
It has dehumanised me to the point that I have become a recluse and am suicidal.	It has allowed me to have showers with an attendant rather than just sponge baths, so has made me feel cleaner.
Anxiety / Security	
My greatest fear is becoming homeless due to the inaccessibility of housing. It has led to suicidal thoughts.	Happy, knowing I have future options that can be used to allow me to stay in my home longer if my condition deteriorates.
If I can open the front door I won't burn to death… it is really frightening. That one modification would be fantastic. I would really like to be able to get out of the front door.	It is an enormous relief to live in an accessible house and I know that as my condition is most likely to worsen, I am still secure here in my home with my husband.
I'm not confident in my ability to stop myself falling it's made me fearful and reclusive.	Having a house of my own that is modified to meet all my accessibility needs has given me a feeling of stability and confidence for my future that I have never felt since I acquired my disability 24 years ago…knowing that my everyday life is so much easier, my physical needs are met and this will be my home for the rest of my life.
When my ability to move around my house is hampered by low accessibility; It usually leaves me in more pain and being less productive, which makes me anxious, and makes my depression worse.	If I can move easily around my home and attend to all my daily living requirements, like everyone else can, I feel more relaxed, independent, and resilient.
I worry now that I won't get better or more mobile so will I be able to keep living at home? Going into aged care terrifies me, especially now with the pandemic.	I feel grateful every day that I now live in a purpose built fully accessible home of my own. I feel safer, more secure, it has led me to feeling free and liberated.
Bathing and self-care is traumatic and upsetting with physical risk which is stressful and makes me anxious and upset leading to self-harm.	Because I am lucky to live in an accessible home with my daughter, I am actually more mobile which has helped improve my independence which has been wonderful for my mental health. Also, the fact that I don't live with the constant fear of falling.
Withering / Flourishing	
The less accessible my house is, the more I am reliant on carers and loved ones, which has a huge impact on my mental health and wellbeing. I highly value my independence.	I am more in control of my life and that means everything.

Mental health deterioration in inaccessible homes	Mental health improvement in accessible homes
I've felt stuck and limited by my home. I get frightened by the insular nature of staying home. Unsettled sleep I find I get headaches stress and anxieties.	Being able to enter and exit my home, and shower independently, has improved my sense of self-worth.
I used to have a passion for cooking and can't, nor to do my study or hobbies, I have become more depressed as I feel the environment has taken me from rather independent to fully dependant beyond need, general apathy and frustration.	My current house is very accessible and located near town and activities I enjoy.
Not being able to turn on taps results in me crying every day.	Living in an accessible home means I'm able to do more things independently which has a positive impact on mental health. I don't feel like a burden anymore.
I look at the steps to my front door from my wheelchair and I am defeated. There is no way around it and you can't sugar-coat it.	It feels wonderful to be able to enter and leave my home independently without assistance. This is something everybody should be able to do.
Sense of home	
It just feels awful. It feels like I'm fighting the space that's supposed to be a sanctuary for me.	We adapted this house to serve us in this period of our lives. is very comfortable so we are content.
It is extremely depressing to be incapacitated by the limitations of your own house. To own rooms you cannot go into, to not be able to exit from all areas, to not be able to access the backyard. To not be able to get a drink from the fridge or use the stove.	I can't imagine living in a house where you haven't seen every inch of the house you live in. Having a house that allows me to get to every part of it means I am included in every part of day to day life.
Not being able to access all of my garden, watching my lawns get full of weeds and overgrown. Unable to reach areas in my house to clean, frightened of falling in my shower… Not being able to get to the pantry because the doors open outwards and block access. I don't know what is in the pantry until someone comes and I can ask them. I cannot access furniture in bedroom because I am in a wheelchair. I don't know what is in them anymore... I find the whole situation very depressing.	Having an accessible house makes even my worst days not as bad as I can still function around the house without any issue or frustration.
My home is supposed to be my space and yet even here I can't do basic things. It weighs hard on your heart.	I was very happy when I moved into my home because everything from showering to watering my garden was so easy... I had not been able to water a garden for 20 years.

Box 7: Health and risk of injury

Edna' story

Edna is a self-employed professional working from home – a private rental unit - on a casual basis. She's lived with muscular dystrophy for her entire life. It is a progressive disease that has become more debilitating over time. When Edna moved into the unit, she was still able to walk, and the unit seemed to meet her needs at that time. However, within fifteen months an injury in her home led to her losing the ability to stand and walk. She was pulling a trolley carrying her meal over a slight step, lost her balance and fell. This accident could have been prevented if there had been a step-free threshold. The unit is poorly designed to meet her current needs and abilities, significantly enhancing her need for paid support funded by the NDIS. More so, Edna is anxious about the risk of another injury at home.

Edna worries that if she were to fall within the cramped conditions of her shower and toilet, she might seriously injure herself or become stuck and unable to ask for help. She is also worried that the set up in her home could lead to her support workers being injured. For example, while Edna's unit has two bathrooms, both are too small to accommodate the mobility aids that she requires. Entering and exiting without a rolling chair demands too much effort and is so time consuming and exhausting that she skips showering when she needs to go out in the morning. This gives rise to anxiety about her hygiene and odor throughout the entire day and restricts her ability to work outside her home.

Her ensuite bathroom has been set up for toilet use, however as there is inadequate space for her toilet transfer bench, she has to reverse on her wheelchair out of the bathroom, often hitting the door on her way out. These safety hazards due to the cramped conditions and lack of accessibility features prey on her mind: if she falls, she could get stuck without no one to assist.

Edna's housing choices are highly restricted. Many of the design problems in her home are structural in nature and thus not easily modifiable, especially given that this is a private rental unit. She cannot afford to buy her own home, even with the assistance of family members who are willing to contribute. She cannot return to her parents' home - while they had thought that they were building her an accessible home, now that she is in a wheelchair, this is no longer the case. Edna has been approved to move into Specialist Disability Accommodation (SDA) but has many concerns about this transition, particularly around lack of choice over housemates, being forced to move further away from her family, a perceived loss of freedom and autonomy as well as health concerns relating to group living during a pandemic. Edna has already spent three months in a transitional nursing home and describes a lingering feeling of being "fenced in".

Edna describes her home as a prison and points out the kinds of restrictions many Australians experienced for the first time during COVID19 lockdowns, for her are just an ordinary routine:

"I came home and there were months at a time when I was stuck at home. I couldn't go to my friends' place because I couldn't use their toilets, or I couldn't get in the door or whatever it was. All I could see out the backyard at that time was a dead garden and a fence and no view to the outside world and that was really isolating. And people would say, 'I'll come around and visit you.' It didn't make any impact on my mental health because I still had that same feeling when I came home that my home was a prison and not a home. So, the joy of moving out and being by myself and getting my own space just disappeared after that experience. And I felt like it was a prison. This lockdown is not my first rodeo. I've built resilience prior to this."

Box 8: Health and risk of injury

Ian's story

Ian is a retired homeowner and has lived with his partner and his two sons in a freestanding house in Melbourne for twenty years. He has paraplegia due to a spinal cord injury that occurred 35 years ago. He uses a manual wheelchair for his daily activities.

He has been able to modify his current home to meet his accessibility needs, at a cost of approximately 28,000 AUD funded by insurance compensation. He fully renovated the bathroom with a flat entry for the wheelchair, a rolling shower chair, and reinforced floor and walls to support the hoist and handrails. He has also installed ramps in the front and back door and widened a few doorways. The modification that most reduced his need for assistance from others was an overhead hoist that allows him to go into bed without help despite his arms and shoulder muscles' deterioration. Nevertheless, he still needs assistance transferring into a seat, accessing the shower, for dressing and undressing.

Before the modifications of his home, Ian broke his leg several times from falls when transferring to a seat, but thanks to the modifications he is no longer concerned about such injuries. However, he expects his sons to move out of the house, and the need to relocate with his wife to a smaller home, which might require further investment in home modifications.

1.9. Housing choice: Ability to stay or move home

The shortage in accessible housing limits housing choice for people with mobility restrictions in two ways: firstly, by increasing the risk of forced moves due to the inaccessibility of their own homes; and secondly, by limiting the range of housing options they can choose from should they move home on their own volition.

Participants living in inaccessible homes were more likely to express concern about the risk of being forced to move to another residence (68.0% of those with high support needs, and 55.7% of those with low support needs), or to a nursing home (58.9% and 45.0% respectively). This compares with a minority of people living in accessible homes who reported similar concerns, demonstrating that accessible home significantly reduces such risks (Table 22).

Table 22: How concerned are you about the following impacts related to the accessibility of your home?

Low support needs	Housing	Very Concerned	Somewhat concerned	***Concerned (total)***	Not Concerned	Total	N
Being forced to move to another residence because of difficulty getting around your home	Accessible housing	13.6%	20.5%	***34.1%***	65.9%	100%	44
	Inaccessible housing	29.5%	26.1%	***55.7%***	44.3%	100%	176
Being forced to move to a nursing home because of difficulty getting around your home	Accessible housing	18.2%	9.1%	***27.3%***	72.7%	100%	44
	Inaccessible housing	22.2%	22.8%	***45.0%***	55.0%	100%	171

High support needs	Housing	Very Concerned	Somewhat concerned	***Concerned (total)***	Not Concerned	Total	N
Being forced to move to another residence because of difficulty getting around your home	Accessible housing	14.5%	10.1%	**24.5%**	75.5%	100%	159
	Inaccessible housing	41.2%	26.9%	**68.0%**	32.0%	100%	413
Being forced to move to a nursing home because of difficulty getting around your home	Accessible housing	20.1%	8.8%	**28.9%**	71.1%	100%	159
	Inaccessible housing	36.9%	22.0%	**58.9%**	41.1%	100%	404

For people with mobility restrictions who do wish to move home, the shortage in accessible housing significantly limits the choices available, especially for those with high support needs. Most (56.6%) people with high support needs living in inaccessible housing wanted to move home but were limited in doing so, reflecting again the detrimental effects of housing inaccessibility. Difficulty finding accessible housing was the most significant barrier to moving home. Nearly half (48.5%) of people with high support needs living in inaccessible homes, and close to a third (31.2%) of those living in accessible homes, reported a desire to move home but being limited by difficulty finding accessible housing elsewhere (Table 23). Private renters were three times as likely to want to move home but be limited because of difficulty finding accessible housing than homeowners (Table 24).

The difficulty finding an accessible home is evident in both Ken's story (box 9) and the quotes below:

"*There is not great awareness within the broader community about how little accessible housing is available. I think that there is an expectation that people with a disability… don't have a family or don't have pets or don't have a job and so can live in an apartment by themselves. However, we have families, we have jobs and we have pets and we have a right to have all those things, but that means that we should have housing options that suit us."*

"When I went through a property settlement and the court ordered me to sell my accessible house, I was very anxious and quite terrified that I would not find an accessible home with the amount [of time] the court gave me… there was insufficient stock of accessible homes available. It was a terrifying time and caused me great anxiety, depression and sleepless nights."

Other interview participants and survey respondents pointed out the difficulty to hold on to jobs – or to seek new ones – while searching for an accessible home in a market where these are a rare commodity.

Table 23: Does a difficulty finding accessible housing limit your ability to move home? By support needs

		I would like to move home, but limited because of difficulty finding accessible housing	I would like to move home, but limited for reasons other than accessibility	I am not interested in moving home right now	Total	Count
Low support needs	Accessible housing	11.9%	4.8%	83.3%	100%	42
	Inaccessible housing	23.5%	15.3%	61.2%	100%	170
High support needs	Accessible housing	31.2%	8.4%	60.4%	100%	154
	Inaccessible housing	48.5%	8.1%	43.4%	100%	394

Table 24: Does a difficulty finding accessible housing limit your ability to move home? By tenure

			I would like to move home, but limited because of difficulty finding accessible housing	I would like to move home, but limited for reasons other than accessibility	I am not interested in moving home right now	Total
I own this home	Low level	Accessible housing	10.3%	0.0%	89.7%	100%
		Inaccessible housing	11.7%	8.5%	79.8%	100%
		Total	11.4%	6.5%	82.1%	100%
	Severe level	Accessible housing	18.8%	1.6%	79.7%	100%
		Inaccessible housing	24.6%	6.0%	69.4%	100%
		Total	22.7%	4.5%	72.7%	100%
I rent this home (private rental)	Low level	Accessible housing	0.0%	0.0%	100.0%	100%
		Inaccessible housing	39.5%	18.4%	42.1%	100%
		Total	36.6%	17.1%	46.3%	100%
	Severe level	Accessible housing	33.3%	16.7%	50.0%	100%
		Inaccessible housing	70.1%	9.3%	20.6%	100%
		Total	66.1%	10.1%	23.9%	100%

Box 9: Lack of accessible housing and housing choice

Ken's story

Ken moved out of supported accommodation (group home) after experiencing abuse. To avoid Ken moving into a nursing home – and while waiting on an NDIS decision on SDA funding - his mother searched for a private rental unit where Ken could live. His mobility is very limited. Ken uses an electric wheelchair outside the house and a walking frame inside the house. He needs an accessible home with a fully accessible bathroom and a Hi-Lo bed, in addition to 24/7 support.

The search for an accessible and affordable home in a location that was easily accessible to a pool of support workers, took almost a year, and involved inspections of 32 rental listings. Eventually they found and compromised on a standalone house that was modified to be only partly accessible, with a ramp at the entry into the house and a small partly accessible bathroom. The internal layout means Ken cannot use his electric wheelchair inside the house, and his walker only narrowly fits through the doorways and hallways, leaving only an inch on either side. Ken likes to help with meal preparation, but the kitchen design does not allow him to do that. The bathroom is partly accessible, but there is barely enough room to fit in a shower chair, Ken's incontinence aids or a support worker to safely assist him. Ken's mother invested time and money in small modification to the house, including a ramp in the rear entry to facilitate backyard access. The landlord approved those modifications because they were planning to knockdown and rebuild the house anyway. However, this of course creates uncertainty about the long-term sustainability of Ken's tenancy. In these circumstances the NDIS will not approve funding for further modifications, even if recognized as necessary.

With the outbreak of COVID19, because of difficulty getting support workers to visit his home, as well as his being highly immunocompromised, Ken moved back to live with his mother temporarily. He continues to pay rent on the now vacant property to maintain the lease, since finding an alternative home that meets Ken's accessibility requirements will be again extremely difficult and long.

Trapped in a home that does not meet some of his basic needs, but unable to find alternatives, Ken's mother commented: "A safe home to stay happy and healthy shouldn't be impossible to do."

4. Conclusions

1) **Existing strategies such as the voluntary building code, reliance on home modifications or provision of accessible social housing have failed to deliver accessible housing for most people with mobility restrictions. Building all new homes to accessible standard will be the most effective way to address the shortage in accessible housing**.

The existing reliance on voluntary construction of accessible homes, or postconstruction modification of inaccessible homes has not delivered accessible homes for people with limited mobility, leaving most people with mobility restrictions in homes that do not meet their needs. Ability to finance or access funds for home modifications is unequally distributed, and there are major barriers to home modifications in private rental, or in homes with structural physical constraints. Most modifications undertaken only partly address the accessibility needs of people with mobility restrictions. Home modifications do not adequately address changing needs over time. Most importantly, modifications only in the homes of people with mobility restrictions limit their housing choice and increase their social isolation.

CIE[7] notes provision of accessible social housing as a strategy to improve housing accessibility for people with mobility restrictions, however there is a severe shortfall in social housing; and our study also found the majority of people with mobility restrictions in social housing still live in homes that do not meet their accessibility needs.

2) **Inaccessible housing severely harms the dignity, freedom, social inclusion, health and wellbeing of people with mobility restrictions**.

The report presented robust quantitative and qualitative evidence of the harms caused by inaccessible housing.

- 80.8% of survey respondents agreed or strongly agreed with the statement "I can't visit friends and family whose homes are inaccessible". The stories behind this statistic are profoundly disturbing: people with mobility limitations unable to visit their elderly parents, losing connection with siblings and close friends; not being invited to family gatherings; missing out on social events; and living 'hermit' lives that many participants have described in terms of deep loneliness and isolation.
- 71.7% of people with high support needs, and 50.0% of people with low support needs, living in inaccessible housing reported worsened mental health and wellbeing. The difference accessible housing can make was illustrated starkly in contrasting comments made by two participants. One, living in an inaccessible home vividly described the despair she feels because she is not able to access rooms and the garden in her own home, "watching my lawns get full of weeds and overgrown". The other woman moved into a new accessible home and expressed the joy of being able to water her garden for the first time in 20 years.
- Participants with high support needs living in inaccessible homes were anxious about the possibility of being forced to move to another residence (68.0%), or to a nursing home (58.9%). One participant said: "My greatest fear is becoming homeless due to the inaccessibility of housing. It has led to suicidal thoughts." For another participant, having an accessible home meant she was able to remain at home with her young family despite increasing support needs, which otherwise would have forced her to move into a nursing home. The accessibility of her home, and the things it made possible, "has given my life meaning."
- Nearly half (48.1%) of people with high support needs living in inaccessible homes, and close to a third (30.7%) of those living in accessible homes, reported a desire to move home but being limited by difficulty finding accessible housing elsewhere.

[7] CIE, 2020, p. 2

Such impacts must not be measured exclusively in dollar value; rather, the social justice argument for addressing the indignities and harms experienced by people with mobility restrictions must be front and centre to the RIS Consultation considerations.

3) **CIE's cost-benefit analysis underestimated the economic costs of inaccessible housing, by ignoring impacts on workforce participation of people with mobility limitations; underestimating the impact on paid and unpaid support needs; underestimating the negative impacts on mental health and wellbeing; and, underestimating the extent to which a shortage in accessible housing limits housing mobility**.

3a) CIE discounted the impact of inaccessible housing on workforce participation by people with mobility limitations

In estimating the 'size of the problem' and quantifying costs of inaccessible housing, the CIE did not consider impact on workforce participation of people with mobility limitations. Our data shows close to one-third of people with mobility restrictions surveyed reported job losses, missed job opportunities, reduced working hours, or reduced productivity at work.

Excluding those for whom this question was inapplicable (i.e. other reasons preventing paid employment), 96.2% of survey respondents with low support needs, and 88.6% of those with high support needs, living in accessible homes reported their homes were 'enabling' to having paid employment. In contrast, 47.9% of survey respondents with low support needs, and 62.5% of those with high support needs, living in inaccessible homes reported their homes were 'limiting' to having paid employment. As one respondent to the survey stated: "Without somewhere to shower or sleep, good *** luck trying to hold down a job or focus on other things."

Many survey respondents and interview participants reported difficulties finding accessible homes close to employment opportunities. Those who have lived in accessible homes – often after significant investment in home modifications – were reluctant to leave their home for a job opportunity. For those who lived in in inaccessible homes, fatigue and the additional time and energy spent on self-care and homecare, reduced motivation, self-confidence, and capacity to work, study or volunteer.

CIE also ignore that the monetary benefits from work can largely be removed because of a lack of accessible housing close to work or public transport. As one respondent stated: "Due to a lack of even minimal accessible housing I have had to spend all my disposable income travelling to work in a taxi because no accommodation was closer."

3b) CIE underestimated the impact of inaccessible housing on support needs.

CIE expressed scepticism as to the relevance of Carnemolla and Bridge's[8] evidence that housing with accessibility features reduces care needs. The CIE questioned whether the sample investigated by Carnemolla and Bridge is representative of the general population with mobility limitations living in inaccessible housing. It also argued Carnemolla and Bridge's findings relate to home modifications, which are tailored to the specific needs of the recipient and are not always aligned with the proposed universal accessibility standards for new build.

Addressing both CIE concerns, our report presented data on a much larger sample of participants than those examined by Carnemolla and Bridge, and still validates their conclusion, demonstrating that the reduction in support needs associated with accessible housing – including both newly built accessible housing and modified housing – is widely applicable for the general population of people with mobility restrictions.

8 Carnemolla, P. and Bridge, C., Housing Design and Community Care: How Home Modifications Reduce Care Needs of Older People and People with Disability, *International Journal of Environmental Research and Public Health*, 2019.

Furthermore, our findings suggest CIE underestimated the range of everyday activities for which paid support is provided[9], and which can be reduced by accessible housing. The CIE has focused exclusively on paid and unpaid assistance with mobility tasks. In contrast, our analysis shows that inaccessible housing also significantly increases need for assistance with self-care and other domestic activities (Table 9).

In estimating impact on support needs, CIE excluded those living in housing that has already been modified due to disability or age, assuming that modified housing is already accessible (p. 140). However, our analysis shows that most people whose homes have been modified, consider these modifications to address their needs only partly, and they too require additional paid or unpaid support due to inaccessible homes (Tables 4 and 14).

3c) CIE underestimated the impact of inaccessible housing on mental health.

Our findings point to two shortcomings in the way CIE estimated the impact of inaccessible housing on mental health.

Firstly, CIE only measured impacts on mental health as an indirect outcome of loneliness. The evidence in our study demonstrates that living in inaccessible housing is detrimental to mental health in many other ways, including the frustration, fatigue and indignity of not being able to complete everyday tasks of movement, self-care and home-care; being reliant on others for support, and the strain this puts on family relations; the ongoing anxiety associated with fear of injury, forced removal from home, or inability to escape home in the event of fire or another hazard; and an undermined sense of home, security and self-worth ("My home is supposed to be my space and yet even here I can't do basic things. It weighs hard on your heart.").

Secondly, CIE underestimated the extent to which inaccessible housing contributes to loneliness and social isolation of people with mobility restrictions. Drawing on SDAC data, CIE[10] commented as follows:

"There were a further 309 000 people who reported avoiding visiting family and friends due to their disability (this excludes the overlap between those that also had difficulty accessing another person's house). However, it is not clear that they avoided visiting family and friends because their housing was inaccessible or for some other reason related to their disability."

Our data removes any doubt as to whether inaccessible housing is the primary barrier to visiting family and friends: 80.8% of survey respondents agreed with the statement that they cannot visit friends or family living in inaccessible housing. Comments made in the survey and interviews also confirmed that inaccessibility was the primary reason for not being able to visit friends or family.

3d) CIE underestimated lack of accessible housing impact on residential mobility

CIE[11] argued that "even if more accessible dwellings become available, there are a range of factors that suggest that the number of people who would choose to move to a more accessible dwelling would likely be relatively low for owner-occupiers."

CIE[12] based their analysis on SDAC data on those who have already moved homes and their reasons to do so. However, as acknowledged by CIE, this method discounts those who wish to move but are unable to do so due to lack of accessible housing. Our data presents strong evidence that most people with mobility restrictions living in inaccessible housing wish to move home, and the primary reason they are unable to do so is difficulty finding accessible housing (table 22).

[9] CIE, 2020, p. 140
[10] p. 157
[11] p. 91
[12] p. 146-7

Challenging the CIE assumptions, while desire to move home is stronger among private renters than it is among owner occupiers, 22.7% of homeowners with high support needs would like to move home but are limited because of difficulty finding accessible housing (table 23). This data suggests the ‘sorting’ process that will see new accessible housing stock allocated to people with mobility limitations can be faster than the CIE assumptions, and the associated benefits thus higher.

Contact: Dr Ilan Wiesel, School of Geography, ilan.wiesel@unimelb.edu.au