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# Living with disability in inaccessible housing: social, health and economic impacts

**Final Report** 

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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 data about the lived experience and social, health and economic benefits of accessible housing.

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 home-care 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 support needs, with lower income, or renting privately were most likely to live in inaccessible housing.
- Compared to housing constructed to minimum accessibility 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.
- Survey respondents living in homes that were not modified or were modified to meet only some needs, reported inaccessible housing features reduced their ability to move into and out of their home, and to complete self-care and home-care activities. Home-care activities (such as home cleaning) were the most limited by housing design, and movement inside the home was the least limited.
- 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 reported difficulties finding accessible homes close to employment opportunities, while fatigue from living in an inaccessible home and the additional time and energy spent on self-care and home-care, reduced productivity, motivation, self-confidence and capacity to work, study or volunteer.
- Inaccessible housing increased support needs for most (65.8-67.1%) respondents with high support needs, including both paid and unpaid support. Just over half (51.2%) of the respondents with low support needs living in inaccessible housing reported an increase in need for informal care, and 42.0% reported an increase in paid disability support. Participants reported spending high proportions of their NDIS support funding on support for self-care activities they could have done independently in a more accessible home. 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.
- 80.8% of survey respondents agreed or strongly agreed with the statement "I can't visit friends and family whose homes are inaccessible".

- 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 the respondents 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.

# The report concludes that:

- Inaccessible housing severely harms the dignity, freedom, social inclusion, economic productivity, health and wellbeing of people with mobility restrictions.
- The benefits identified in literature on home modifications apply to, and are even exceeded in, new homes built to accessible standard.
- Voluntary construction of accessible homes without regulation, funding for postconstruction home
  modifications, and provision of accessible social housing have failed to deliver accessible housing
  for most people with mobility restrictions.
- Including minimal accessibility standards in the National Building Code is necessary to achieve greater independence, dignity, freedom, social inclusion, economic productivity, and improved health and wellbeing for people with mobility restrictions.

# 1. Background

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 (CIE, 2020). Existing literature highlights the myriad social, health and economic benefits of accessible housing for people with mobility restrictions (see review in Chapter 2), however Australian researchers and advocates have raised concern about the inadequate supply of accessible housing to meet current and future demand. Under current legislation, public venues in Australia are required to meet minimum accessibility standards, however existing and new dwellings are exempt.

The Australian Government's commitment to people with disabilities' rights for inclusion and participation is enshrined in its ratification of the 2008 United Nations Convention on the Rights of People with Disabilities (CRPD), as well as the Australian National Disability Strategy (NDS) (Australian Government, 2011). The NDS lists "Inclusive and accessible communities" as the first of its six areas for policy action, and specifically highlights the importance of "Improved provision of accessible and well-designed housing with choice for people with disability about where they live." (Australian Government, 2011, p. 32). However, rather than regulating accessibility standards, the NDS relied on voluntary market-led take up driven by demand across the general population, which will increase the supply of accessible housing for those with mobility restrictions (p. 32).

This voluntary approach to provision of accessible housing derived from a National Dialogue on Universal Housing Design (or 'the Dialogue'). The Dialogue involved negotiations between disability rights advocates, community sector leaders, the housing industry and government, and was concluded with an agreement focused on voluntarily provision of accessible housing, with the aim of reaching 'visitable' standard (see Chapter 2 for discussion on accessibility standards) in all new housing constructed by 2020. A not-for-profit organisation, Livable Housing Australia (LHA), was established to develop guidelines, educate the public and building industry, and oversee accreditation of accessible housing as the key strategies towards achieving the target (Ward and Franz, 2015).

The voluntary approach has failed to deliver the targets set out in the Dialogue. ANUHD & RI Australia (2015) estimated that by 2015 take up has achieved less than 5% of the target. A more recent study by Winkler et al. (2020) examined the design of twenty popular project home designs currently offered by Australia's largest builders and found that while many accessibility features were included in most designs, none were fully compliant with LHA's silver level accessibility standard.

In 2017, the Building Ministers' Forum (BMF), with the support of the Council of Australian Governments (COAG), directed the Australian Building Codes Board (ABCB) to undertake a regulatory impact analysis on the possible inclusion of minimum accessibility standards for housing in the National Construction Code (NCC). In response, ABCB initiated public consultation in 2018, engaging the Centre for International Economics (CIE) to develop the Consultation Regulatory Impact Statement (RIS) (CIE, 2020).

The CIE (2020) Consultation RIS focused on quantifying the economic costs and benefits of regulation, in the absence of any qualitative analysis, as required by the Office of Best Practice Regulation (2020) in their Guidance Note on Cost-Benefit Analysis:

- 'CBA [Cost Benefit Analysis] requires you to identify explicitly the ways in which the proposal makes individuals better or worse off.' (p. 4)
- 'You should report cost and benefit estimates within three categories:
  - o monetised
  - quantified, but not monetised
  - o qualitative, but not quantified or monetised.' (p. 11)

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 1187 survey responses, and 45 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.

Building on, and adding to, existing literature on the benefits of accessible housing for people with mobility restrictions (see Chapter 2), the analysis presented in this report is focused on measuring and understanding:

- accessibility and inaccessible features in the homes of people with mobility restrictions in Australia
- mental health and wellbeing outcomes of living in accessible or inaccessible homes
- impacts of housing accessibility on ability to perform self-care and home-care 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.

Specifically, the report addresses three significant gaps in existing literature. Firstly, most existing literature on the social and health impacts of accessibility is focused on homes that have been modified to address specific individual needs, rather than new homes built to general accessibility standards. The current study compares homes that are modified (partly or fully addressing residents' personal needs) with those that were built accessible, or neither modified nor built accessible. Secondly, the relationship between housing accessibility and employment outcomes remains a critical gap in the literature, and this report provides important new qualitative and quantitative data on employment effects of accessible and inaccessible homes. Thirdly, the report presents new data and insight on the range of pathways through which housing accessibility, or lack thereof, impact on mental health.

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 experienced by informal carers of people with mobility restrictions, in-depth analysis focused on the perspective of carers was beyond our 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.

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. Effects of housing accessibility: previous studies

Inaccessibility occurs due to mismatches between a person's body, the activity they wish to perform, and the environment in which that activity is pursued (Fange and Iwarsson, 2003). Although definitions of housing accessibility, usability and livability vary (Fange and Iwarsson, 2003; LHA, 2017), they typically revolve around the following principles: easy entry and exit; easy navigation and functionality in and around the home; and potential for easy and cost-effective adaptation in response to changing needs of occupants over time.

In Australia, housing accessibility is often assessed in relation to Livable Housing Australia's (LHA) three-tiered standard of silver, gold and platinum:

- *Silver Level* is focused on seven core structural and spatial elements that are critical to enable easy and cost-effective home modifications over time.
- Gold Level requires more generous dimensions for most of the core silver level features, as well as additional elements in areas such as kitchens and bedrooms.
- Platinum Level involves further enhanced requirements for both the silver and gold livable housing
  design elements and introduces additional elements such as the living room and flooring. Platinum
  homes are designed for people with higher mobility needs, and to allow aging in place.

The three Australian LHA level correspond with, but are not identical to, the three levels specified in UK accessibility standards (UK Government, 2020, p. 9):

- *Visitable Dwellings*, under current regulation, are the minimum standard for all new homes in the UK, with requirements relating to level access, level thresholds, door and corridor widths, entrance level toilets and accessible heights for controls.
- Accessible and Adaptable Dwellings are currently optional in the UK and provide enhanced
  accessibility in circulation spaces (e.g. entrances, hallways) and bathrooms, as well as features to
  make homes more easily adaptable over time.
- Wheelchair User Dwellings are also optional, and provide a standard for either a wheelchair
  adaptable home (with design features to make a home easy to convert to be fully wheelchair
  accessible) or a wheelchair accessible home (which includes the most common features required by
  wheelchair users). The standard covers private outdoor spaces, parking and other communal
  facilities in the building.

For a detailed comparison of Australian and other international accessibility standards, see Bo'sher et al., (2015).

Much of the research on the effects of housing accessibility and inaccessibility derives from data on people's experiences before and after home modifications. Positive effects of home modifications have been documented across a range of interconnected life domains:

Improved function, independence and freedom: Home modifications improve people's ability to conduct everyday activities at home – from moving around, through to self-care and caregiving for others, and care of the home itself – with reduced difficulty, stress and fatigue (Alpin et al., 2015, p. 127; Lau et al., 2018, p. 240; Petersson, 2008, p. 256). Reduced effort on such everyday tasks frees up energy and time for other activities that are more meaningful to people (Norin et al., 2017, p. 233). Lau et al. (2018, p. 240) identified six activities most significantly affected by home modifications: getting in and out of home; bathing and showering; grooming; transferring to toilet; walking a block; and moving in and out of bed. Accessible housing is associated with a sense of independence and freedom, as described by Alpin et al. (2015, p. 126): "To be able to do things for one self, to choose activities freely, to move from room to room and to come and go as one pleases was extremely important to participants." (Alpin et al., 2015, p. 126)

**Support needs**: Improved accessibility at home is also associated with reduced need for paid and unpaid support. Carnemolla and Bridge (2019, p. 7) found that home modifications reduced informal care hours by

an average of approximately 6 hours per week, and formal care by approximately 0.36 hours per week, for participants in their sample. Sinclair et al.'s (2020, p. 5) survey of informal carers found the vast majority (97%) agreed that the home design had a significant influence on the level of support required. Reduced reliance on formal or informal support increases the sense of independence, and privacy when performing personal self-care activities (Lau et al., 2018, p. 240), and more freedom in choosing when and how people do things such as taking a shower or toileting, without having to ensure a spouse or a family member is present (Alpin et al., 2015, p. 126).

**Health & safety**: Home modifications are associated with improved physical and mental health. Mitoku and Shimanouchi (2014) found that modifications slow the progression of frailty. Heywood (2004) identified mental health effects of home modifications, associated for example with reduced fear of falling, and reduced depression. Many studies identified an enhanced sense of safety and a decrease in injuries and falls following home modifications (Chang et al., 2004; Clemson et al., 2008;, Tse, 2005; Turner et al., 2011; Powell et al., 2017; Lau et al., 2018, p. 240; Petersson, 2008, p. 256). However, in some documented cases, poorly designed or executed modifications, such as installation of slippery ramps, have sometimes increased risk of injury (Alpin et al., 2015, p. 126)

Social participation: Home modifications have been found to serve as a catalyst for improved social and family relations, due to improved ability to leave the home to engage in social activities, and improved ability to have friends and family members with a disability visit one's own modified home (Alpin et al., 2015, p. 127). White et al. (1995) found a 60% mean increase in reported trips out of the house following ramp installation. Home modifications contributed to family relations by enabling people to take on caregiving roles – such as a parent being able to cook for his children – and being less reliant on other family members' help in everyday activities (Aplin, 2015).

**Employment**: Bishop et al. (2013), in a US survey of over 4200 adults with Multiple Sclerosis, compared employment outcomes for those living in accessible and inaccessible homes. Among those with accessible homes 43.3% were employed, while among those living in homes that do not meet their accessibility needs, only 23.0% were employed. The study found a significant difference in the mean number of accessibility features that participants needed but did not have between employed and unemployed survey respondents.

**Housing security and choice**: Home modifications are associated with improved housing security and choice: ability to move home, or to stay put, at will rather than necessity. Alpin et al. (2015, p. 127) report that people who modified their homes experienced an enhanced sense of permanency and a feeling that their home was now a "home for life... where ageing, deteriorating or improving health or the growth of children was accommodated for." Conversely, Kim (2020, p.20) found elderly people with unmet accessibility needs in their home were more likely to move home.

A longitudinal study by Petersson et al., (2009) found that the positive effects of home modifications, as elaborated above, are sustained over time. In contrast, those waiting for home-modification with unmet need experience increased difficulty over time: "For each month's wait for a home modification, the person's difficulty in performing everyday life tasks increased".

While evidence is accumulating on the various themes noted above, the current study address three significant gaps in existing literature. Firstly, most existing literature on the impact of accessibility is focused on home modifications rather than new homes built to accessible standards. This is not surprising considering the very limited supply of new accessible housing stock in many countries. However, concerns have been raised (CIE, 2020, p. 140) that the effects identified for modified homes – which were modified to address specific individual needs – may not necessarily be applicable to houses built to a more general accessibility standard. The current study compares homes that are modified (partly or fully addressing residents' personal needs) with those that were built accessible, or were neither built accessible nor modified. Secondly, except for Bishop et al. (2013) we have not found other studies addressing the relationship between housing accessibility and employment outcomes. The current study provides important new qualitative and quantitative data on employment effects of accessible and inaccessible homes. Thirdly, our

| study presents new important qualitative data that deepens the understanding of the relationship between housing accessibility and mental health. |
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# 3. Method

The study method consisted of two primary elements: an online questionnaire (1,178 responses) and 45 indepth follow-up interviews.

## 1.1. Online questionnaire

An online questionnaire was distributed on 17<sup>th</sup> August 2020 and closed for responses on 28<sup>th</sup> August 2020. A link to the survey was circulated widely via email, with assistance from disability services and advocacy groups in distributing the survey through their 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 their current home's accessibility on:
  - o ability to perform domestic activities (moving around, self-care, home care)
  - o ability to study, work, or volunteer
  - o need for paid or unpaid support
  - o social and family relations
  - o health and wellbeing, including risk of injury
  - o 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; and, employment opportunities.
- interest in participating in follow up interview.

Between the 17<sup>th</sup> and 28<sup>th</sup> August 1178 responses to the survey were received. 100 responses were excluded from analysis due to insufficient data.

The sample represent a diverse cross-section of the population of people with mobility restrictions in Australia, including diversity in gender, age, level and type of disability, housing and living arrangements, and employment status (Table 1). The two most common physical conditions among people with disability – arthritis and back problems – were also the two most common in the sample. However, people with severe or profound disability, women, unemployed (64 years old and under), younger people, and people living in homes that have been modified were over-represented in the sample. (Table 2).

The large number of responses allowed differentiating results for people living in accessible homes and those living in inaccessible homes; and, for people with different levels support needs. Respondents' level of support need 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. 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.

Table 1: Survey sample characteristics

|  | Category                     | Count | Column % |
|--|------------------------------|-------|----------|
| 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         | Never                        | 114   | 11.8%    |
| self-care?   | Sometimes                    | 395   | 40.8%    |
|  | Often                        | 460   | 47.5%    |
|  | Total                        | 969   | 100%     |
| Do you receive individual funding from the NDIS?         | Yes                          | 616   | 63.6%    |
| σ, · · · · · · · · · · · · · · · · · · ·                 | 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%    |
| 110 w long have you lived in your cultone nome.          | 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%     |
| what is your employment status:                          | Employed part time           | 141   | 16.8%    |
|  | Receiving Disability Support | 358   | 42.8%    |
|  | Unemployed - seeking work    | 36    | 4.3%     |
|  | Unemployed - not seeking     | 76    | 9.1%     |
|  | Retired                      | 134   | 16.0%    |
|  | Other                        | 113   | 13.5%    |
|  | Total                        | 837   | 100%     |
| What is a second as a second in a second (hafe as too) 0 |                              |       |          |
| What is your personal annual income (before tax)?        | \$37,000 or less             | 466   | 58.5%    |
|  | Between \$37,001 and         | 69    | 8.7%     |
|  | Between \$48,001 and         | 77    | 9.7%     |
|  | Between \$90,001 and         | 40    | 5.0%     |
|  | between \$126,001 and        | 13    | 1.6%     |
|  | \$260,0001 or more           | 1     | 0.1%     |
|  | Prefer not to say            | 131   | 16.4%    |
|  | Total                        | 797   | 100%     |
|  | Arthritis                    | 238   | 24.6%    |
|  | Back problems                | 251   | 26.0%    |
|  | Knee problems                | 183   | 18.9%    |
|  | Epilepsy                     | 76    | 7.9%     |
|  | Acquired brain injury        | 81    | 8.4%     |
| What type of impairment do you have? (tick all that      | Multiple sclerosis           | 58    | 6.0%     |
| apply)   | Spinal cord injury           | 123   | 12.7%    |
|  | Spina bifida                 | 45    | 4.7%     |
|  | Cerebral palsy               | 115   | 11.9%    |
|  | Cystic fibrosis              | 5     | 0.5%     |
|  | Muscular dystrophy           | 49    | 5.1%     |
|  | Tourette syndrome            | 1     | 0.1%     |

| Dwarfism                 | 6   | 0.6%  |
|--------------------------|-----|-------|
| Amputation               | 43  | 4.5%  |
| General lack of mobility | 259 | 26.8% |
| Polio                    | 18  | 1.9%  |
| Other                    | 364 | 37.7% |
| Total                    | 966 | 100%  |

Table 2: Sample representativeness

|                            | % of sample | % of all people with disability | % of all<br>Australians |
|----------------------------|-------------|---------------------------------|-------------------------|
| Severe/profound disability | 69.50%      | 28%                             | 5.70%                   |
| Male                       | 30.60%      | 49%                             | 49.60%                  |
| Employed (15-64)           | 29.20%      | 47.80%                          | 80.30%                  |
| Arthritis                  | 24.60%      | 12.70%                          | 2.20%                   |
| Back problems              | 26.00%      | 12.60%                          | 2.20%                   |
| Over 65 y/o                | 15.70%      | 44.50%                          | 15%                     |
| Living in modified housing | 46.50%      | 16%                             | ?                       |

#### 1.2. Remote interviews

In-depth interviews were conducted with 45 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 19<sup>th</sup>-28<sup>th</sup> 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
- personal characteristics (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, the availability of participants and researchers was also a key factor in selection of participants. Table 3 presents some relevant information about the 45 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 preconceived 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

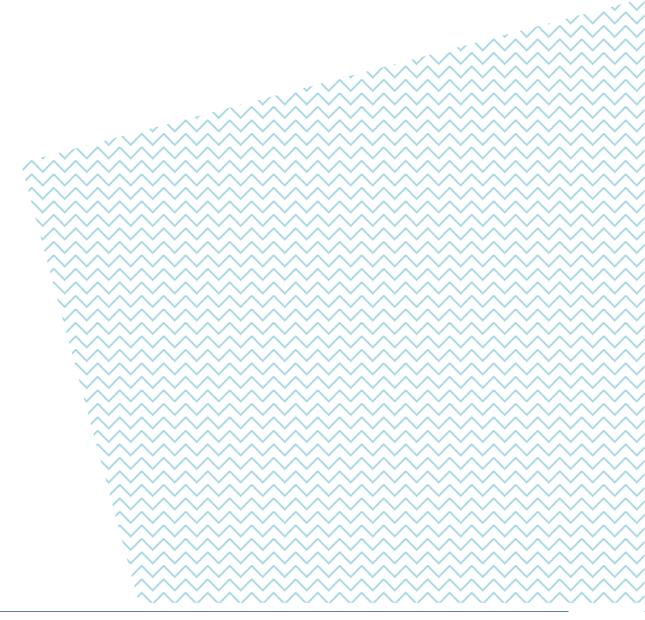
- home? What are the main features of your home that limit your ability to move around and carry out domestic activities? What are the main features of your home that enhance your ability to move around and carry out domestic activities?)
- Home modifications (e.g. Have you done any home modifications 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, study or volunteer?)
- 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.

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    |

# 4. Results



# 4.1. 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 (Table 6), possibly because of ineligibility for funds for home modifications, or for social or specialist housing. Private renters were most likely to live in inaccessible or homes modified to meet only some needs (87.6%), but high incidence of inaccessible or homes modified to meet only some needs 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.

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 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     | 100   |                |

Table 5: Does your home contain any of the following features?

|   | Built<br>accessible | Modified<br>to meet<br>all needs | Not built<br>accessible<br>or<br>modified | Modified<br>to meet<br>some<br>needs |
|---|---------------------|----------------------------------|---|--------------------------------------|
| Safe continuous step-free path from the street or parking to the entrance                           | 79.1%               | 71.6%                            | 26.3%                                     | 48.5%                                |
| At least one step-free entrance   | 57.7%               | 59.7%                            | 23.5%                                     | 51.0%                                |
| Internal doors and corridors that facilitate comfortable and unimpeded movement                     | 86.5%               | 77.6%                            | 25.9%                                     | 37.7%                                |
| A toilet on entry level that is easy to access  | 86.5%               | 83.6%                            | 51.0%                                     | 68.5%                                |
| A bathroom that contains a hobless shower recess  | 79.1%               | 83.6%                            | 15.1%                                     | 58.0%                                |
| Grabrails in the toilet, shower or bath   | 57.1%               | 61.2%                            | 23.9%                                     | 67.0%                                |
| Reinforced walls around the toilet, shower and bath that may allow future installation of grabrails | 39.3%               | 31.3%                            | 8.0%                                      | 20.6%                                |
| Stairways with a handrail   | 18.4%               | 16.4%                            | 27.9%                                     | 19.7%                                |
| Stairways without a handrail  | 2.5%                | 3.0%                             | 16.3%                                     | 4.5%                                 |

Table 6: Housing accessibility by support needs

|                    | Built<br>accessible | Modified to<br>meet all<br>needs | Accessible (total) | Not built accessible or modified | Modified to meet some needs | Inaccessible<br>(total) | Total |
|--------------------|---------------------|----------------------------------|--------------------|----------------------------------|-----------------------------|-------------------------|-------|
| Low support needs  | 17.4%               | 4.2%                             | 21.5%              | 45.1%                            | 33.3%                       | 78.5%                   | 100%  |
| High support needs | 19.5%               | 9.0%                             | 28.5%              | 29.7%                            | 41.9%                       | 71.5%                   | 100%  |
| Total              | 18.8%               | 7.5%                             | 26.3%              | 34.6%                            | 39.1%                       | 73.7%                   | 100%  |

Table 7: Housing accessibility by tenure

|  | Built<br>accessible | Modified to meet all needs | Accessible (total) | Not built accessible or modified | Modified to meet some needs | Inaccessible<br>(total) | 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<br>Residential<br>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%  |

# 4.2. Barriers and limits to home modifications

The survey and interview data highlighted five issues related to home modifications as the most common strategy to address housing accessibility needs. First, participants faced a range of barriers to home modifications:

- Affordability: Most survey respondents expressed concern about ability to afford necessary home modifications. These concerns were strongest for people living in inaccessible or homes modified to meet only some needs (81.6% of those with low support needs, and 85.7% of those with high support needs). Yet such concerns were also reported by those living in accessible homes (44.2% and 47.5% respectively) highlighting changing accessibility needs over time (Table 8).
- *Funding ineligibility*: Some participants did not meet eligibility criteria for NDIS or other funding for home modifications (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 barriers to modifications, including difficulty getting landlord approval, home modification funding restrictions for renters, and housing precarity heightening the risk of financial investment in home modifications. Just over a quarter of private renters lived in homes that were modified (compared to 46.6% of all respondents), and only 2.6% in homes modified to meet all needs (compared to 7.5% of the full sample (Table 7).
- 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

|         |                                  |     | ery<br>erned |    | newhat<br>cerned | 1 7 7 . | cerned<br>otal) |    | t too<br>erned |    | at all<br>erned | Conc | ot<br>erned<br>tal) | To | otal |
|---------|----------------------------------|-----|--------------|----|------------------|---------|-----------------|----|----------------|----|-----------------|------|---------------------|----|------|
|         |                                  | С   | %            | С  | %                | С       | %               | С  | %              | С  | %               | С    | %                   | С  | %    |
| Low     | Built accessible                 | 6   | 17.6         | 10 | 29.4             | 16      | 47.1%           | 11 | 32.4           | 7  | 20.6            | 18   | 52.9                | 34 | 100  |
| support | Modified to meet all needs       | 1   | 11.1         | 2  | 22.2             | 3       | 33.3%           | 2  | 22.2           | 4  | 44.4            | 6    | 66.7                | 9  | 100  |
| needs   | Accessible (total)               | 7   | 16.3         | 12 | 27.9             | 19      | 44.2%           | 13 | 30.2           | 11 | 25.6            | 24   | 55.8                | 43 | 100  |
|         | Not built accessible or modified | 48  | 49.5         | 29 | 29.9             | 77      | 79.4%           | 12 | 12.4           | 8  | 8.2%            | 20   | 20.6                | 97 | 100  |
|         | Modified to meet some needs      | 38  | 48.1         | 28 | 35.4             | 66      | 83.5%           | 7  | 8.9%           | 6  | 7.6%            | 13   | 16.5                | 79 | 100  |
|         | Inaccessible (total)             | 86  | 48.9         | 57 | 32.4             | 143     | 81.3%           | 19 | 10.8           | 14 | 8.0%            | 33   | 18.8                | 17 | 100  |
|         | Total                            | 93  | 42.5         | 69 | 31.5             | 162     | 74.0%           | 32 | 14.6           | 25 | 11.4            | 57   | 26.0                | 21 | 100  |
| High    | Built accessible                 | 20  | 18.7         | 28 | 26.2             | 48      | 44.9%           | 36 | 33.6           | 23 | 21.5            | 59   | 55.1                | 10 | 100  |
| support | Modified to meet all needs       | 14  | 26.4         | 14 | 26.4             | 28      | 52.8%           | 11 | 20.8           | 14 | 26.4            | 25   | 47.2                | 53 | 100  |
| needs   | Accessible (total)               | 34  | 21.3         | 42 | 26.3             | 76      | 47.5%           | 47 | 29.4           | 37 | 23.1            | 84   | 52.5                | 16 | 100  |
|         | Not built accessible or modified | 110 | 65.9         | 39 | 23.4             | 149     | 89.2%           | 11 | 6.6%           | 7  | 4.2%            | 18   | 10.8                | 16 | 100  |
|         | Modified to meet some needs      | 125 | 52.1         | 75 | 31.3             | 200     | 83.3%           | 29 | 12.1           | 11 | 4.6%            | 40   | 16.7                | 24 | 100  |
|         | Inaccessible (total)             | 235 | 57.7         | 11 | 28.0             | 349     | 85.7%           | 40 | 9.8%           | 18 | 4.4%            | 58   | 14.3                | 40 | 100  |
|         | Total                            | 269 | 47.4         | 15 | 27.5             | 425     | 75.0%           | 87 | 15.3           | 55 | 9.7%            | 142  | 25.0                | 56 | 100  |

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%), suggesting that building to accessible standard is more effective in meeting needs than post-construction modifications.

Homes modified to meet all individual needs of occupants are almost as accessible as homes built to accessible standards in the first place, but slightly inferior with respect to features that require more structural modifications (e.g. 7.5% lower rates of step-free paths to entrance, 8.9% lower rates of internal doors and corridors that facilitate comfortable and unimpeded movement, 8% lower rates of reinforced walls around the toilet, shower and bath that may allow future installation of grabrails).

Homes modified to meet only some needs are significantly inferior in their accessibility to those built accessible (e.g. 30.6% lower rates of step-free paths to entrance, 48.8% lower rates of internal doors and corridors that facilitate comfortable and unimpeded movement, 18.7% lower rates of reinforced walls around the toilet, shower and bath that may allow future installation of grabrails). On average, homes modified to meet only some needs contain 19.4% fewer accessibility features compared to homes built accessible.

As elaborated in the following sections, when measuring the impacts of inaccessibility on ability to perform core activities, on support needs, on mental health and risk of injury, homes modified to meet only some needs perform far worse than homes built accessible. Compared with those living in homes built accessible, those living in homes modified to meet only some needs were:

- 32.8% (high support needs) or 46.2% (low support needs) more likely to have limitations entering/exiting the house due to its design
- 25.5% (high support needs) or 44.4% (low support needs) more likely to have limitations in internal mobility due to housing design
- 37.9% (high support needs) or 42.1% (low support needs) more likely to have limitations in personal care due to housing design
- 43% (high support needs) or 55.5% (low support needs) more likely to have limitations in home care due to housing design
- 34.7% (low support needs) or 44.3% (high support needs) more likely to be limited by their homes in their ability to have paid employment.
- 17.6% (low support needs) or 44.0% (high support needs) more likely to report worsened mental health due to the inaccessibility of their home.
- 13.4% (low support needs) or 20.3% (high support needs) more likely to be concerned about risk of injury due to the inaccessibility of their home.
- 20.2% (high support needs) more likely to be concerned about being forced to move to a nursing home due to the inaccessibility of their home.
- 13.3% (low support needs) or 29.7% (high support needs) more likely to report increased need for paid support due to the inaccessibility of their home.
- 29.4% (low support needs) or 38.4% (high support needs) more likely to report increased need for unpaid support due to the inaccessibility of their home.

Third, when modifications are undertaken exclusively in the homes of people who have mobility restrictions, most housing stock remains inaccessible, preventing people with mobility restrictions from visiting the homes of 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 housing stock remains 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.

# 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 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.

# 4.3. Barriers to building accessible homes under current building code

A small number of studies conducted outside Australia point to the difficulties experienced by people with disability when engaging with builders to construct new-build accessible homes, which exceed the building code requirements (Thomas, 2004; Burns, 2004; Nasar & Elmer, 2016). Our own survey and interviews in Australia also demonstrate that consumers with mobility restrictions who sought to build new accessible homes face significant barriers. Of 45 participants with disability we interviewed, 9 lived in homes that were built to be accessible and another participant was in the process of building an accessible home. Five of these ten participants reported difficulties negotiating their home design with builders, or errors made by builders, leading to reduced accessibility outcomes. This high proportion of participants who encountered such difficulties is indicative of systemic suppression of demand for accessible housing. We provide three illustrative examples as follows:

**Perry**: Perry reported a building process that was protracted and draining, to a large part because of the difficulty working with builders. The first builder, whom he eventually replaced, tried to convince Perry to make-do with access to the back of his house only. When the plans were finally approved with the second builder, unbeknown to Perry subsequent modifications to the design raised the house and rendered the front door inaccessible. Expensive, additional work was then undertaken to make it "barely" accessible. Other expensive blunders – such as installing the basins at the wrong height or reducing the size of the elevator – demonstrate the challenge Perry faced finding builders who could deliver the accessibility features of the plan:

"this made some outside area inaccessible and some other areas dangerous, such as driveway for wheelchair transfer from chair to car (this now takes place in the street). Overall, the house works, and I spent some \$50k post-handover to resolve some inaccessible areas... I am totally frustrated and a bit narky even after five years that some of the areas that I had agree to with the builder were changed during the build reducing my access to my carefully though about and agree to design"

**Jenny**: In 2014, after many years renting places that where not fully accessible for her, she and her family decided to rebuild a home. Jenny described a difficult process including engagement with builders who didn't follow the plans designed with the help of an accessibility consultant:

"We built this house through a project home builder. We amended design to allow for wheelchair clearances. Not all plans were followed. Complete lack of knowledge on the building company's part regarding universal and accessible design. We engaged an access consultant to go over the design for us."

See also Kelly's story (Box 6), whose father 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.

In our survey, several text responses to open-ended questions commented on similar difficulties working with builders to build new accessible homes:

"Our experience with builders, knowledge of accessibility was extremely poor, and they weren't at all interested in finding out."

"It's like builders know they are supposed to put in accessible features, but they have no idea what's practical. Ramps are placed in unsafe areas, or don't give enough room to manoeuvre."

"I am in the process of building a new home. The entire purpose was to get a house that is accessible now and in the future as these are not readily available on the open market. Unfortunately, because accessibility is poorly understood I have ended up with a less accessible house than I requested. I requested flat access however there are still threshold steps. I requested sliding door tracks to be set into the concrete to create flat access however this was not done in error as it was done how it is usually done and now it is too late to fix. While I have cavity slider doors and requested adequate circulation space for a wheelchair this is questionable. I feel that if accessibility were standard then I would not have been in a position where I had little option to build and builders would have a greater understanding of accessibility requirements without it being a constant battle of what is usually done and what is required....It is not as easy as making an exception when required. The building industry has a very poor understanding of what is considered accessible. As such when people do go down the path of purpose built it quite often still ends up being inappropriate due to breaking the well-entrenched ways it has always been done."

"There are far too few project home builders prepared to make sustainability and accessibility both the absolute minimum and reasonably priced."

"My own sibling built a new home, and I cannot access it. She did not mean to exclude me- the builder just didn't know what to do to allow for my disability. Legislation would include guidelines and standards. Very much needed and should be a requirement."

Several interview and survey participants described working with builders who were supportive, but then facing barriers to building accessible homes in the planning approval process:

"Our home was purpose built for me, so we saw how all the builders had to fight the council for common sense plan changes that people without disability would absolutely love: e.g. a sloped garage slab that removes the step into the house."

"My family has just built me a new fully accessible house for me, and it took a long time to get plan drawn up and to then get plans through council because what we required had to be discussed at great length to get what I needed. The builder was good in doing what we required but still had things he couldn't change because of the regulations."

## 4.4. Ability to perform domestic activities

Survey respondents living in homes that were not modified or modified to meet only some needs, 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. As expected, inaccessible homes or homes modified to meet only some needs were more limiting for people with high support needs, especially in relation to movement inside the house (Table 9). Some participants reported prioritising certain activities to reserve their energy for other activities, for instance by giving up showers (see for example box 3, Rowena's story).

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

| Low support needs              | Built<br>accessible | Modified to meet all needs | Not built<br>accessible<br>or modified | Modified to meet some needs | Total |
|--------------------------------|---------------------|----------------------------|--|-----------------------------|-------|
|                                | Low                 | support needs              | :                                      | :                           |       |
| Entering and exiting the house | 13.5%               | 0.0%                       | 74.0%                                  | 46.3%                       | 48.4% |
| Internal Mobility              | 0.0%                | 0.0%                       | 52.2%                                  | 25.5%                       | 25.7% |
| Personal Care                  | 9.8%                | 0.0%                       | 72.9%                                  | 47.7%                       | 48.2% |
| Home care                      | 29.7%               | 25.0%                      | 77.4%                                  | 72.7%                       | 65.9% |
|                                | High                | support needs              | <u> </u>                               | <u> </u>                    |       |
| Entering and exiting the house | 4.7%                | 8.0%                       | 87.8%                                  | 50.9%                       | 48.4% |
| Internal Mobility              | 0.9%                | 3.8%                       | 82.6%                                  | 45.3%                       | 41.0% |
| Personal Care                  | 8.1%                | 16.7%                      | 87.0%                                  | 50.2%                       | 49.7% |
| Home care                      | 31.6%               | 38.8%                      | 87.9%                                  | 87.1%                       | 73.2% |

# 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."

# 4.5. Ability to study, work, or volunteer

While many respondents and interview participants were unable to study or work for reasons other than housing accessibility, for others housing accessibility 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 (partly or not modified) 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 have paid employment?

|                                  | Limits           | Enables | Total | Count |
|----------------------------------|------------------|---------|-------|-------|
|                                  | Low support nee  | eds     | :     | ;     |
| Built accessible                 | 5.3%             | 94.7%   | 100%  | 19    |
| Modified to meet all needs       | 0.0%             | 100.0%  | 100%  | 7     |
| Accessible (total)               | 3.8%             | 96.2%   | 100%  | 26    |
| Not built accessible or modified | 53.5%            | 46.5%   | 100%  | 43    |
| Modified to meet some needs      | 40.0%            | 60.0%   | 100%  | 30    |
| Inaccessible (total)             | 47.9%            | 52.1%   | 100%  | 73    |
| Low support needs (total)        | 36.4%            | 63.6%   | 100%  | 99    |
|                                  | High support ned | eds     |       |       |
| Built accessible                 | 7.3%             | 92.7%   | 100%  | 55    |
| Modified to meet all needs       | 18.2%            | 81.8%   | 100%  | 33    |
| Accessible (total)               | 11.4%            | 88.6%   | 100%  | 88    |
| Not built accessible or modified | 77.9%            | 22.1%   | 100%  | 86    |
| Modified to meet some needs      | 51.6%            | 48.4%   | 100%  | 122   |
| Inaccessible (total)             | 62.5%            | 37.5%   | 100%  | 208   |
| High support needs (total)       | 47.3%            | 52.7%   | 100%  | 296   |

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   | 16.8% |
| Reduced your hours of work?        | 168   | 17.7% |
| Reduced your productivity at work? | 194   | 20.4% |
| Led to losing or giving up a job?  | 120   | 12.6% |
| Total                              | 327   | 34.4% |

<sup>\*</sup> of 948 respondents with enough data

Survey respondents who were younger, in part-time employment, with low support needs, and currently living in inaccessible or homes modified to meet only some needs, were more likely to have ever experienced negative impact of housing accessibility on their ability to enter or maintain paid employment and productivity (Table 12).

Table 12: Housing accessibility impact on employment by selected characteristics

|   | No impact on<br>work or<br>productivity | Reduced work opportunities or productivity |
|---|---|--|
| % employed full time                          | 7.0%                                    | 11.9%                                      |
| % employed part time                          | 12.1%                                   | 26.9%                                      |
| % unemployed seeking work                     | 45.4%                                   | 42.5%                                      |
| % unemployed not seeking work                 | 3.1%                                    | 6.8%                                       |
| % receiving DSP                               | 10.3%                                   | 7.8%                                       |
| % Retired                                     | 20.9%                                   | 9.2%                                       |
| % part time with DSP                          | 3.3%                                    | 6.8%                                       |
| median age                                    | 51                                      | 34   |
| % male  | 31.4%                                   | 28.7%                                      |
| % female                                      | 66.6%                                   | 67.0%                                      |
| % Non-binary                                  | 2.0%                                    | 4.3%                                       |
| % high support needs                          | 33.2%                                   | 27.0%                                      |
| % low support needs                           | 66.8%                                   | 73.0%                                      |
| % home built accessible                       | 21.0%                                   | 14.5%                                      |
| % home modified to meet all needs             | 8.0%                                    | 6.5%                                       |
| % home modified to meet some needs            | 32.5%                                   | 38.5%                                      |
| % home not built or modified to be accessible | 38.5%                                   | 40.6%                                      |

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 already employed. Survey respondents with both low (40.4%) and high (53.4%) support needs living in inaccessible or homes modified to meet only some needs, reported housing design features limiting their ability to work or study from home (table 13). 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.

Second, many respondents and participants reported difficulties finding accessible homes close to employment opportunities. Those who already lived in accessible homes – often after significant investment in home modifications – were especially 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 home-care, 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 14).

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 that this has enabled their informal carers to take on more paid work.

Table 13: To what extent does the design of your home enable or limit your ability to work or study from home

|  | Limiting  | Enabling | Total |          |
|--|-----------|----------|-------|----------|
|  | Row %     | Row %    | Row % | Count    |
| Low suppo  | ort needs | <u> </u> |       |          |
| Built in a way that meets my accessibility needs     | 10.7%     | 89.3%    | 100%  | 28       |
| Modified to meet all of my accessibility needs       | 0.0%      | 100.0%   | 100%  | 8        |
| Accessible (total)                                   | 8.3%      | 91.7%    | 100%  | 36       |
| Not built or modified to meet my accessibility needs | 53.7%     | 46.3%    | 100%  | 54       |
| Modified to meet some of my accessibility needs      | 24.4%     | 75.6%    | 100%  | 45       |
| Inaccessible (total)                                 | 40.4%     | 59.6%    | 100%  | 99       |
| Low support needs (total)                            | 31.9%     | 68.1%    | 100%  | 135      |
| High suppo   | ort needs | !        |       | <u> </u> |
| Built in a way that meets my accessibility needs     | 12.7%     | 87.3%    | 100%  | 71       |
| Modified to meet all of my accessibility needs       | 16.7%     | 83.3%    | 100%  | 36       |
| Accessible (total)                                   | 14.0%     | 86.0%    | 100%  | 107      |
| Not built or modified to meet my accessibility needs | 71.6%     | 28.4%    | 100%  | 88       |
| Modified to meet some of my accessibility needs      | 42.7%     | 57.3%    | 100%  | 150      |
| Inaccessible (total)                                 | 53.4%     | 46.6%    | 100%  | 238      |
| High support needs (total)                           | 41.2%     | 58.8%    | 100%  | 345      |

Table 14: Survey respondents' comments on housing accessibility impacts of work and study

| Inaccessible housing  | Accessible housing   |
|---|--|
| Working f   | rom 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 beendifficult 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<br>my hyperacusis. [Otherwise], high temperatures (due to<br>poor shading on windows) worsen my body's heat<br>regulation and therefore drain my limited energy.                                   |
|--|--|
| When the house is inaccessible, the time it takes to access the shower and toilet prevents 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   | I could be more independent and focus time and energy<br>on family and work instead of worrying how I get around<br>my house.  |

perform other typical household chores once I get inside

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

accessible thought process

| Indepe  | ndence  |
|---|---|
| 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<br>others for assistance, therefore limiting my ability to<br>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<br>and go freely without having to wait on others to assist<br>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<br>not be a PhD or a senior public servant. My study and<br>career over 30 years depended on it. |
| It takes a significant amount of time to get prepared to<br>leave the home with required assistance to bathe due to<br>the design of the bathroom. I would not require<br>assistance if the bathroom had been designed with an  | 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<br>because all rental housing was either luxury or<br>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."

# 4.6. Need for paid or unpaid support

Inaccessible housing increased need for both paid and unpaid support by most survey respondents.

Among people with low support needs, 18.9% of those living in homes built accessible, and 25% of those living in homes modified to meet all needs, reported decreased support needs thanks to the accessibility of their home. In contrast, 38.9% of those living in homes not built or modified for accessibility, and 45.7% of those whose homes were only modified to meet only some needs, reported increased need for paid disability support due to the inaccessibility of their home. Similar results were found in respect for decrease/increase in unpaid support.

Among people with high support needs, 23.9% of those living in homes built accessible, and 21.2% of those living in homes modified to meet all needs, reported decreased paid support needs thanks to the accessibility of their home. In contrast, 73.3% of those living in homes not built or modified for accessibility, and 60.9% of those whose homes were modified to meet only some needs, reported increased need for paid disability support (an impact significantly stronger compared to those with low support needs) (Table 15). One striking result is that 32.4% of people with high support needs living in homes built accessible reported a decline in need for unpaid support (Table 16).

Although there was a proportion of people living in homes built accessible or modified to meet all needs who reported increased support needs due to the design of their homes – indicative that even homes designed to a minimum accessibility standard can create barriers – their proportions were lower compared to those living in homes that were only partly or not at all accessible, and offset by the numbers of those who reported reduced support needs (Tables 15 and 16).

Some interview 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, increased reliance on support in inaccessible homes negatively impacted on relationships with relatives 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 participants' sense of independence.

Table 15: To what extent does the design of your current home affect your need for paid disability support?

|                  |                                  | My need for | paid disability | y support has |       |       |
|------------------|----------------------------------|-------------|-----------------|---------------|-------|-------|
|                  |                                  | increased   | neither         | decreased     | Total | Count |
| Low              | Built accessible                 | 32.4%       | 48.6%           | 18.9%         | 100%  | 37    |
| support<br>needs | Modified to meet all needs       | 0.0%        | 75.0%           | 25.0%         | 100%  | 8     |
|                  | Not built accessible or modified | 38.9%       | 57.9%           | 3.2%          | 100%  | 95    |
|                  | Modified to meet some needs      | 45.7%       | 49.4%           | 4.9%          | 100%  | 81    |
|                  | Total                            | 38.9%       | 53.8%           | 7.2%          | 100%  | 221   |
| High             | Built accessible                 | 31.2%       | 45.0%           | 23.9%         | 100%  | 109   |
| support<br>needs | Modified to meet all needs       | 30.8%       | 48.1%           | 21.2%         | 100%  | 52    |
|                  | Not built accessible or modified | 73.3%       | 23.0%           | 3.7%          | 100%  | 161   |
|                  | Modified to meet some needs      | 60.9%       | 31.9%           | 7.3%          | 100%  | 248   |
|                  | Total                            | 56.0%       | 33.3%           | 10.7%         | 100%  | 570   |

Table 16: To what extent does the design of your current home affect your need for informal care?

|                                       |                                  | My need for | informal ca | re has    |       |       |
|---------------------------------------|----------------------------------|-------------|-------------|-----------|-------|-------|
|                                       |                                  | Increased   | Neither     | Decreased | Total | Count |
| Low                                   | Built accessible                 | 25.6%       | 56.4%       | 17.9%     | 100%  | 39    |
| Low support needs  High support needs | Modified to meet all needs       | 11.1%       | 66.7%       | 22.2%     | 100%  | 9     |
|                                       | Not built accessible or modified | 47.8%       | 48.9%       | 3.3%      | 100%  | 90    |
|                                       | Modified to meet some needs      | 55.0%       | 37.5%       | 7.5%      | 100%  | 80    |
|                                       | Total                            | 45.0%       | 46.8%       | 8.3%      | 100%  | 218   |
| High                                  | Built accessible                 | 22.9%       | 44.8%       | 32.4%     | 100%  | 105   |
|                                       | Modified to meet all needs       | 28.3%       | 52.8%       | 18.9%     | 100%  | 53    |
|                                       | Not built accessible or modified | 75.8%       | 19.9%       | 4.3%      | 100%  | 161   |
|                                       | Modified to meet some needs      | 61.3%       | 32.9%       | 5.8%      | 100%  | 243   |
| support                               | Total                            | 55.2%       | 33.3%       | 11.6%     | 100%  | 562   |

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.

# 4.7. 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 17). 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 17: 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 | Co<br>unt | Agree<br>(total) | Disagree (total) |
|--------------------------|----------------|----------------|----------------------------|-------------------|-------------------|-----------|------------------|------------------|
| Low<br>support<br>needs  | 29.9%          | 36.3%          | 18.4%                      | 10.3%             | 5.1%              | 234       | 66.2%            | 15.4%            |
| High<br>support<br>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 18).

# Table 18: 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 can therefore 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 19)

Table 19: Impact of inaccessible housing on social and family relations

| Inaccessible housing  | Accessible housing  |  |  |  |
|---|---|--|--|--|
| Lack of energy, injured self-confidence, and mental healt maintain relationships  | th pressures due to inaccessible housing makes it difficult to  |  |  |  |
| 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<br>my wellbeing and mood, so I didn't have energy to have<br>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, and therefore were less likely to agree with the statement "Friends and family can't visit me because my home is inaccessible" (Table 20). Qualitative data suggested many people have friends or relatives with a disability, and thus the inaccessibility of their home is a barrier to having these 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 20: To what extent do you agree or disagree with the statement "Friends and family can't visit me because my home is inaccessible"

|  | Agree | Neither | Disagree | Total |     |
|--|-------|---------|----------|-------|-----|
| Built in a way that meets my accessibility needs     | 9.7%  | 13.2%   | 77.1%    | 100%  | 144 |
| Modified to meet all of my accessibility needs       | 6.3%  | 10.9%   | 82.8%    | 100%  | 64  |
| Accessible   | 8.7%  | 12.5%   | 78.8%    | 100%  | 208 |
| Not built or modified to meet my accessibility needs | 43.9% | 25.0%   | 31.1%    | 100%  | 264 |
| Modified to meet some of my accessibility needs      | 23.0% | 22.1%   | 54.8%    | 100%  | 330 |
| Inaccessible   | 32.3% | 23.4%   | 44.3%    | 100%  | 594 |
| Total  | 26.2% | 20.6%   | 53.2%    | 100%  | 802 |

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.

#### 4.8. 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 wellbeing (Table 21).

Table 21: 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 |          |     |  |  |  |
|----------------------------------|-------------------|-----------|----------|----------|-----|--|--|--|
|                                  | Row N %           | Row N %   | Row N %  | Total    | N   |  |  |  |
|                                  | Low support needs |           |          |          |     |  |  |  |
| Built accessible                 | 19.4%             | 13.9%     | 66.7%    | 100%     | 30  |  |  |  |
| Modified to meet all needs       | 0.0%              | 66.7%     | 33.3%    | 100%     | 10  |  |  |  |
| Accessible (total)               | 15.6%             | 24.4%     | 60.0%    | 100%     | 39  |  |  |  |
| Not built accessible or modified | 61.1%             | 33.7%     | 5.3%     | 100%     | 38  |  |  |  |
| Modified to meet some needs      | 37.0%             | 35.8%     | 27.2%    | 100%     | 52  |  |  |  |
| Inaccessible (total)             | 50.0%             | 34.7%     | 15.3%    | 100%     | 89  |  |  |  |
| Low support needs (total)        | 43.0%             | 32.6%     | 24.4%    | 100%     | 127 |  |  |  |
|                                  | High support      | needs     | <u>:</u> | <u> </u> | 1   |  |  |  |
| Built accessible                 | 20.2%             | 21.1%     | 58.7%    | 100%     | 88  |  |  |  |
| Modified to meet all needs       | 9.3%              | 27.8%     | 63.0%    | 100%     | 50  |  |  |  |
| Accessible (total)               | 16.6%             | 23.3%     | 60.1%    | 100%     | 137 |  |  |  |
| Not built accessible or modified | 82.7%             | 11.9%     | 5.4%     | 100%     | 30  |  |  |  |
| Modified to meet some needs      | 64.2%             | 19.1%     | 16.7%    | 100%     | 89  |  |  |  |
| Inaccessible (total)             | 71.7%             | 16.2%     | 12.1%    | 100%     | 118 |  |  |  |
| High support needs (total)       | 56.2%             | 18.2%     | 25.6%    | 100%     | 254 |  |  |  |

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 associated with increased need for informal care due to inaccessible housing
- anxiety about risks posed by inaccessible housing, including risk of injury (table 22), being forced to move into a nursing home or another 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. One participant who moved out of shared supported accommodation to more independent living, noted experiences of abuse in support accommodation, increasing their current anxiety about 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 23)

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 22).

Table 22: How concerned are you about risk of injury because of difficulty getting in and around your home related to the accessibility of your home?

|                                  | Very<br>Concerned | Somewhat<br>Concerned | Concerned | Not<br>Concerned | Total    |     |
|----------------------------------|-------------------|-----------------------|-----------|------------------|----------|-----|
|                                  |                   | Low support needs     |           |                  |          |     |
| Built accessible                 | 17.1%             | 25.7%                 | 42.8%     | 57.1%            | 100%     | 35  |
| Modified to meet all needs       | 0.0%              | 11.1%                 | 11.1%     | 88.9%            | 100%     | 9   |
| Accessible (total)               | 13.6%             | 22.7%                 | 36.3%     | 63.6%            | 100%     | 44  |
| Not built accessible or modified | 26.3%             | 51.6%                 | 77.9%     | 22.1%            | 100%     | 95  |
| Modified to meet some needs      | 17.7%             | 55.7%                 | 73.4%     | 26.6%            | 100%     | 79  |
| Inaccessible (total)             | 22.4%             | 53.4%                 | 75.8%     | 24.2%            | 100%     | 174 |
| Low support needs (total)        | 20.6%             | 47.2%                 | 67.8%     | 32.1%            | 100%     | 218 |
|                                  |                   | High support needs    |           |                  | <u> </u> |     |
| Built accessible                 | 16.3%             | 13.5%                 | 29.8%     | 70.2%            | 100%     | 104 |
| Modified to meet all needs       | 15.4%             | 21.2%                 | 36.6%     | 63.4%            | 100%     | 52  |
| Accessible (total)               | 16.0%             | 16.0%                 | 32.0%     | 68.0%            | 100%     | 156 |
| Not built accessible or modified | 64.7%             | 25.1%                 | 89.8%     | 10.2%            | 100%     | 167 |
| Modified to meet some needs      | 39.7%             | 39.7%                 | 79.4%     | 20.6%            | 100%     | 242 |
| Inaccessible (total)             | 49.9%             | 33.7%                 | 83.6%     | 16.4%            | 100%     | 409 |
| High support needs (total)       | 40.5%             | 28.8%                 | 69.3%     | 30.6%            | 100%     | 565 |

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 23: 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  | on / 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 force 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<br>rather than just sponge baths, so has made me feel<br>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 agoknowing 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<br>by low accessibility; It usually leaves me in more pain<br>and being less productive, which makes me anxious, and<br>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 builfully accessible home of my own. I feel safer, more secure, it has led me to feeling free and liberated.   |
| Bathing and self-care are 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<br>my study or hobbies, I have become more depressed as I<br>feel the environment has taken me from rather<br>independent to fully dependant beyond need, general<br>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 mor<br>things independently which has a positive impact on<br>mental health. I don't feel like a burden anymore.   |
| I look at the steps to my front door from my wheelchair<br>and I am defeated. There is no way around it and you<br>can't sugar-coat it.   | It feels wonderful to be able to enter and leave my hom<br>independently without assistance. This is something<br>everybody should be able to do.  |
| Sense o   | 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 see<br>every inch of the house you live in. Having a house that<br>allows me to get to every part of it means I am included<br>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.   |

#### 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.

#### 4.9. Housing choice and control

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) (Table 24), or to a nursing home (58.9% and 45.0% respectively, Table 25). This compares with a minority of people living in accessible homes who reported similar concerns, demonstrating that accessible home significantly reduces such risks.

Table 24: How concerned are you about being forced to move to another residence because of difficulty getting around your home?

|                                  | Very<br>Concerned | Somewhat<br>Concerned | Concerned | Not<br>Concerned |          |     |
|----------------------------------|-------------------|-----------------------|-----------|------------------|----------|-----|
|                                  | Low s             | support needs         | !         | :                |          |     |
| Built accessible                 | 17.1%             | 22.9%                 | 40.0%     | 60.0%            | 100%     | 35  |
| Modified to meet all needs       | 0.0%              | 11.1%                 | 11.1%     | 88.9%            | 100%     | 9   |
| Accessible (total)               | 13.6%             | 20.5%                 | 34.1%     | 65.9%            | 100%     | 44  |
| Not built accessible or modified | 28.7%             | 29.8%                 | 58.5%     | 41.5%            | 100%     | 94  |
| Modified to meet some needs      | 30.5%             | 22.0%                 | 52.5%     | 47.5%            | 100%     | 82  |
| Inaccessible (total)             | 29.5%             | 26.1%                 | 55.6%     | 44.3%            | 100%     | 176 |
| Low support needs (total)        | 26.4%             | 25.0%                 | 51.4%     | 48.6%            | 100%     | 220 |
|                                  | High :            | support needs         | .1        |                  | <u> </u> |     |
| Built accessible                 | 12.1%             | 13.1%                 | 25.2%     | 74.7%            | 100%     | 107 |
| Modified to meet all needs       | 19.2%             | 3.8%                  | 23.0%     | 76.9%            | 100%     | 52  |
| Accessible (total)               | 14.5%             | 10.1%                 | 24.6%     | 75.4%            | 100%     | 159 |
| Not built accessible or modified | 53.8%             | 22.5%                 | 76.3%     | 23.7%            | 100%     | 169 |
| Modified to meet some needs      | 32.4%             | 29.9%                 | 62.3%     | 37.7%            | 100%     | 244 |
| Inaccessible (total)             | 41.2%             | 26.9%                 | 68.1%     | 31.9%            | 100%     | 413 |
| High support needs (total)       | 33.7%             | 22.2%                 | 55.9%     | 44.1%            | 100%     | 572 |

Table 25: How concerned are you about being forced to move to a nursing home because of difficulty getting around your home

|                                  | Very<br>Concerned | Somewhat<br>Concerned | Concerned | Not<br>Concerned | Total    | Count    |
|----------------------------------|-------------------|-----------------------|-----------|------------------|----------|----------|
|                                  | Low .             | support needs         |           |                  |          | <u> </u> |
| Built accessible                 | 20.0%             | 8.6%                  | 28.6%     | 71.5%            | 100%     | 35       |
| Modified to meet all needs       | 11.1%             | 11.1%                 | 22.2%     | 77.7%            | 100%     | 9        |
| Accessible (total)               | 18.2%             | 9.1%                  | 27.3%     | 72.7%            | 100%     | 44       |
| Not built accessible or modified | 18.5%             | 23.9%                 | 42.4%     | 57.6%            | 100%     | 92       |
| Modified to meet some needs      | 26.6%             | 21.5%                 | 48.1%     | 51.9%            | 100%     | 79       |
| Inaccessible (total)             | 22.2%             | 22.8%                 | 45.0%     | 55.0%            | 100%     | 171      |
| Low support needs (total)        | 21.4%             | 20.0%                 | 41.4%     | 58.6%            | 100%     | 215      |
|                                  | High              | support needs         | <u>i</u>  |                  | <u> </u> | 1        |
| Built accessible                 | 17.0%             | 7.5%                  | 24.5%     | 75.5%            | 100%     | 106      |
| Modified to meet all needs       | 26.4%             | 11.3%                 | 37.7%     | 62.3%            | 100%     | 53       |
| Accessible (total)               | 20.1%             | 8.8%                  | 28.9%     | 71.1%            | 100%     | 159      |
| Not built accessible or modified | 36.4%             | 25.5%                 | 61.9%     | 38.2%            | 100%     | 165      |
| Modified to meet some needs      | 37.2%             | 19.7%                 | 56.9%     | 43.1%            | 100%     | 239      |
| Inaccessible (total)             | 36.9%             | 22.0%                 | 58.9%     | 41.0%            | 100%     | 404      |
| High support needs (total)       | 32.1%             | 18.3%                 | 50.4%     | 49.6%            | 100%     | 563      |

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 an inaccessible housing stock. Difficulty finding accessible housing was the most significant barrier to moving home. Nearly half (48.5%) of respondents 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 26). Private renters were three times more likely than homeowners to want to move home and to be limited because of difficulty finding accessible housing (Tables 27 and 28).

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

|                                  | I would like to move<br>home, but limited<br>because of difficulty<br>finding accessible<br>housing | I would like to move<br>home, but limited<br>for reasons other<br>than accessibility | I am not<br>interested in<br>moving home<br>right now | Total | Count |
|----------------------------------|---|--|---|-------|-------|
|                                  | Lov   | v support needs  |   |       |       |
| Built accessible                 | 12.1%   | 3.0%   | 84.8%   | 100%  | 33    |
| Modified to meet all needs       | 11.1%   | 11.1%  | 77.8%   | 100%  | 9     |
| Accessible (total)               | 11.9%   | 4.8%   | 83.3%   | 100%  | 42    |
| Not built accessible or modified | 29.0%   | 22.6%  | 48.4%   | 100%  | 93    |
| Modified to meet some needs      | 16.9%   | 6.5%   | 76.6%   | 100%  | 77    |
| Inaccessible (total)             | 23.5%   | 15.3%  | 61.2%   | 100%  | 170   |
| Low support needs (total)        | 21.2%   | 13.2%  | 65.6%   | 100%  | 212   |
|                                  | Hig   | h support needs  | .å.   |       | i     |
| Built accessible                 | 31.4%   | 8.8%   | 59.8%   | 100%  | 102   |
| Modified to meet all needs       | 30.8%   | 7.7%   | 61.5%   | 100%  | 52    |
| Accessible (total)               | 31.2%   | 8.4%   | 60.4%   | 100%  | 154   |
| Not built accessible or modified | 56.6%   | 10.7%  | 32.7%   | 100%  | 159   |
| Modified to meet some needs      | 43.0%   | 6.4%   | 50.6%   | 100%  | 235   |
| Inaccessible (total)             | 48.5%   | 8.1%   | 43.4%   | 100%  | 394   |
| High support needs (total)       | 43.6%   | 8.2%   | 48.2%   | 100%  | 548   |

Table 27: Does a difficulty finding accessible housing limit your ability to move home? By tenure: Homeowners only

|                                  | I would like to<br>move home, but<br>limited because of<br>difficulty finding<br>accessible housing | I would like to move<br>home, but limited for<br>reasons other than<br>accessibility | Not<br>interested in<br>moving<br>home right<br>now | Total | Count |
|----------------------------------|---|--|---|-------|-------|
| Low support needs                |   |  |   |       |       |
| Built accessible                 | 9.1%  | 0.0%   | 90.9%   | 100%  | 22    |
| Modified to meet all needs       | 14.3%   | 0.0%   | 85.7%   | 100%  | 7     |
| Accessible (total)               | 10.3%   | 0.0%   | 89.7%   | 100%  | 29    |
| Not built accessible or modified | 10.3%   | 20.5%  | 69.2%   | 100%  | 39    |
| Modified to meet some needs      | 12.7%   | 0.0%   | 87.3%   | 100%  | 55    |
| Inaccessible (total)             | 11.7%   | 8.5%   | 79.8%   | 100%  | 94    |
| Low support needs (total)        | 11.4%   | 6.5%   | 82.1%   | 100%  | 123   |
| High support needs               |   |  |   |       |       |
| Built accessible                 | 15.2%   | 0.0%   | 84.8%   | 100%  | 33    |
| Modified to meet all needs       | 22.6%   | 3.2%   | 74.2%   | 100%  | 31    |
| Accessible (total)               | 18.8%   | 1.6%   | 79.7%   | 100%  | 64    |
| Not built accessible or modified | 23.1%   | 7.7%   | 69.2%   | 100%  | 39    |
| Modified to meet some needs      | 25.3%   | 5.3%   | 69.5%   | 100%  | 95    |
| Inaccessible (total)             | 24.6%   | 6.0%   | 69.4%   | 100%  | 134   |
| High support needs (total)       | 22.7%   | 4.5%   | 72.7%   | 100%  | 198   |

Table 28: Does a difficulty finding accessible housing limit your ability to move home? By tenure: Renters only

|                                  | I would like to<br>move home, but<br>limited because of<br>difficulty finding<br>accessible housing | I would like to move<br>home, but limited for<br>reasons other than<br>accessibility | Not<br>interested in<br>moving<br>home right<br>now | Total | Count |
|----------------------------------|---|--|---|-------|-------|
|                                  | Low   | v support needs  | :   |       |       |
| Built accessible                 | 9.1%  | 0.0%   | 90.9%   | 100%  | 22    |
| Modified to meet all needs       | 14.3%   | 0.0%   | 85.7%   | 100%  | 7     |
| Accessible (total)               | 10.3%   | 0.0%   | 89.7%   | 100%  | 29    |
| Not built accessible or modified | 10.3%   | 20.5%  | 69.2%   | 100%  | 39    |
| Modified to meet some needs      | 12.7%   | 0.0%   | 87.3%   | 100%  | 55    |
| Inaccessible (total)             | 11.7%   | 8.5%   | 79.8%   | 100%  | 94    |
| Low support needs (total)        | 11.4%   | 6.5%   | 82.1%   | 100%  | 123   |
|                                  | Hig   | h support needs  | .i.   |       |       |
| Built accessible                 | 15.2%   | 0.0%   | 84.8%   | 100%  | 33    |
| Modified to meet all needs       | 22.6%   | 3.2%   | 74.2%   | 100%  | 31    |
| Accessible (total)               | 18.8%   | 1.6%   | 79.7%   | 100%  | 64    |
| Not built accessible or modified | 23.1%   | 7.7%   | 69.2%   | 100%  | 39    |
| Modified to meet some needs      | 25.3%   | 5.3%   | 69.5%   | 100%  | 95    |
| Inaccessible (total)             | 24.6%   | 6.0%   | 69.4%   | 100%  | 134   |
| High support needs (total)       | 22.7%   | 4.5%   | 72.7%   | 100%  | 198   |

#### 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."

## 5. Discussion

# 5.1. Voluntary construction of accessible homes, postconstruction home modifications and provision of accessible social housing have failed to deliver accessible housing for most Australians with mobility restrictions.

In the absence of regulated minimum accessibility standards for dwellings, the provision of accessible homes for people with mobility restrictions in Australia is currently primarily reliant on voluntary construction of accessible homes, or postconstruction modification of inaccessible homes. These strategies have failed to deliver accessible homes for most people with limited mobility.

The voluntary construction of new homes designed to achieve minimal accessible standard is well below target (5%). The data presented in this report suggests the low uptake is a consequence of supply failure, rather than the absence of demand. Consumers with mobility restrictions who sought to build new accessible homes have faced significant barriers. Participants reported difficulties negotiating their accessibility requirements with builders, indicative of systemic suppression of demand for accessible housing (section 4.1). These findings add to a small body of international literature that also highlights the difficulties experienced by people with disability when engaging with builders to construct new-build accessible homes (Thomas, 2004; Burns, 2004; Nasar & Elmer, 2016).

Meanwhile, post-construction home modifications offer a partial and unevenly distributed solution to housing accessibility needs. Many people with mobility restrictions face barriers to home modifications in private rental, or in homes with structural physical constraints (section 4.2). Where modifications have taken place, in most cases they only partly address the accessibility needs of people with mobility restrictions, and do not adequately address changing needs over time. Modifications only in the homes of people with mobility restrictions limit their housing choice and increase their social isolation (section 4.7).

Provision of accessible social housing is one strategy to increase supply of accessible homes, and address the barriers faced by low-income households in need. However, there is a severe shortfall in social housing in Australia, and our study also found that the majority of people with mobility restrictions in social housing still live in homes that do not meet their accessibility needs (section 4.1).

# 5.2. Inaccessible housing severely harms the dignity, freedom, social inclusion, economic productivity, health and wellbeing of people with mobility restrictions.

Adding to the existing evidence base (reviewed in Chapter 2), the report presented quantitative and qualitative evidence of the harms caused by inaccessible housing.

Employment: The impact of housing accessibility on employment outcomes is a critical gap in existing literature (Bishop et al., 2013, a notable exception). Addressing this gap, this study found that close to one-third of people with mobility restrictions surveyed reported job losses, missed job opportunities, reduced working hours, or reduced productivity at work. Many survey respondents and interview participants reported difficulties finding accessible homes close to employment opportunities. Those who lived in accessible homes – often after significant investment in home modifications – were reluctant to leave their home for a job opportunity. 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."

For those who lived in inaccessible homes, fatigue and the additional time and energy spent on self-care and home-care, reduced motivation, self-confidence, and capacity to work, study or volunteer. For example, one

participant explained how the inaccessibility of her home forces her to skip showers, leading to insecurity about her bodily odour which prevents her from taking on paid employment. 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 (section 4.5).

Social isolation: living in inaccessible homes leads to social isolation in a number of ways, including reliance on family members for support putting strain on relationships, difficulty getting in and out of the house for social activities, inaccessibility-induced fatigue reducing energy for social activities, and difficulty hosting guests with mobility restrictions. Whether or not their own homes are accessible, the lack of accessible housing across the housing stock is socially isolating for most people with mobility restrictions. 80.8% of survey respondents agreed or strongly agreed with the statement "I can't visit friends and family whose homes are inaccessible". The qualitative data highlighted the experience of people who are unable to visit their elderly parents, or have lost connection with siblings and close friends; who are not being invited to family gatherings, and miss out on social events; and live 'hermit' lives that many participants have described in terms of deep loneliness and isolation. Home modifications restricted only to the homes of those with mobility restrictions cannot fix this problem, which requires a substantial increase to the supply of accessible homes across the housing system (section 4.7).

Mental health: The survey and interviews provided new data on the extent to which housing inaccessibility impacts on mental health, and the pathways that produce such effects. 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 due to the design of their homes. Living in inaccessible housing is detrimental to mental health in various ways, including social isolation and loneliness; 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."). (section 4.8)

**Housing choice:** 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%). The risk of falling into homelessness was also mentioned by many, and 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 (section 4.9).

# 5.3. The benefits identified in literature on home modifications not only apply to, but are exceeded in, new homes built to accessible standard.

Existing literature on the benefits of accessible housing draws primarily on data relating to people who have undertaken home modifications addressing their specific individual needs (Chapter 2). It was therefore not yet established whether these benefits would also apply to people living in homes built to general accessible standard (CIE, 2020, p. 140).

In our study, homes built to accessible standard were found to be equivalent in their accessibility to homes that were modified to meet all individual occupant's needs, and superior in terms of features that require more structural modifications, as well as adaptability for future modifications due to changing needs. Across

the various life domains examined in the study, the positive outcomes for people living in homes built accessible were equivalent to those living in homes that have been modified to meet all individual occupant's needs, and far superior to those who lived in homes that have been modified to meet only some needs (who represent the majority of participants living in modified homes). For instance, Carnemolla and Bridge's (2019) found that home modifications reduce need for both paid and unpaid support. The data presented in section 4.6 demonstrates that the reduction in support needs associated with accessible housing applies to both newly built accessible housing and modified housing.

Homes labelled by occupants as modified to meet only some needs were significantly inferior in the number of accessible features to those homes that were built to accessible standard. On average, homes modified to meet only some needs contained 19.4% fewer accessibility features compared to homes built to accessible standard. When measuring the impacts of inaccessibility on ability to perform core activities, on support needs, on mental health and risk of injury, homes modified to meet only some needs perform far worse than homes built accessible (section 4.2).

### 6. Conclusion

The report presented evidence that inaccessible housing severely harms the dignity, freedom, social inclusion, economic productivity, health and wellbeing of people with mobility restrictions; and, that housing built to accessible standard can deliver substantial benefits for people with mobility restrictions, across all these life domains. These findings have both economic and social justice implications, which, as argued by Dalton and Carter (2020), are closely interconnected.

Key findings from this research detail how the failure to set minimum standards for accessible housing are undermining the objectives of the National Disability Strategy and the National Disability Insurance Scheme, as well as contributing to poorer quality of life for people with disability. Specifically:

- 80.8% of survey respondents agreed or strongly agreed with the statement "I cannot visit friends and family whose homes are inaccessible".
- 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.
- Close to one-third of survey respondents reported lack of accessible housing has resulted in job loss, miss job opportunities, reduced work hours or reduce productivity at work.
- Participants reported spending high proportions of their NDIS support funding on support for selfcare activities they could have done independently and more accessible homes.

The study therefore further adds to the mounting evidence that the current strategy of relying on voluntary construction of accessible homes, on postconstruction home modifications, and on provision of accessible social housing, has failed to deliver accessible housing for most people with mobility restrictions. All in all, these findings provide strong support in favour of introducing minimum accessibility standards to the Australian National Construction Code.

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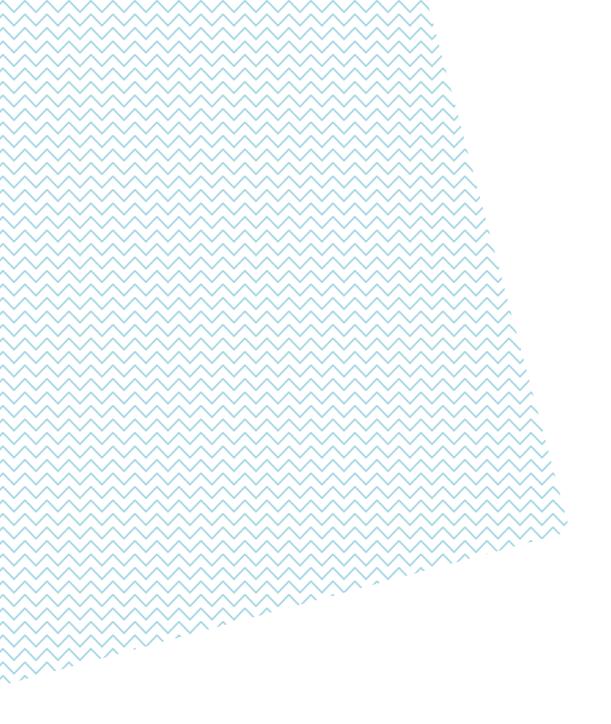
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