

Research Paper

Disability Delphi study report

**National Research Venture 2: 21st
century housing careers and Australia's
housing future**

Research Report

authored by

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1 INTRODUCTION

As part of the *21st century housing careers* project, two Delphi studies were conducted, one focusing on the housing careers of the 'mainstream' population and another focusing on housing career issues for people with disabilities. This report draws on the outcomes of the study focusing on the housing careers of people with different forms of disability. The content is drawn from responses received from the thirteen housing and disability experts who participated in the study.

2 BACKGROUND

The 21st Century Housing Careers project aims to provide an understanding of the current and anticipated 21st century housing careers of selected population groups that are of critical policy importance. The overarching question for the project is:

How are housing careers changing in Australia and what are the implications of change for government policy in relation to housing?

This Delphi study is part of a broader qualitative research sub-project within the main study. Other qualitative components are interviews and focus groups held at five sites across Australia involving the following population groups:

- Those aged 55 – 64, a group that includes some retired people and those close to or considering retirement, and generally a population expected to have followed a “traditional” housing career. It also includes those at the “front edge of the baby boomers”.
- Those aged 25 – 34, who in the past would have been expected to be entering marriage, starting a family and purchasing their first home. With changes in the age of leaving home and people now delaying (or opting out of) family formation and home purchase, this is expected to be a group where housing careers are changing.
- People with disabilities, for whom it is expected that disabilities will have a very major impact on housing choices and careers. (The focus groups and interviews with people with disabilities are to be held in Victoria only. These have been postponed to a later stage of the study).

This Delphi study has focused on issues relating to the housing careers or pathways for the population of people with lifelong disabilities, across sensory, mobility and intellectual disabilities.

3 THE DELPHI METHODOLOGY

A Delphi study aims to develop a consensus (or to identify areas of disagreement) from a group of experts about opinions on a strategic issue, through anonymous contributions in response to questions, and then a further opportunity to comment on the feedback received from all respondents.

4 RECRUITMENT AND RESPONSE PROCESS

A list of diverse disability policy experts across academic, government and community sectors was contacted by e-mail and invited to participate in the study. Those agreeing to participate were sent a questionnaire of four questions for comment. Thirteen responses were received. A summary paper was then prepared drawing on the initial responses received. A second questionnaire was sent out with the summary paper to the thirteen respondents, seeking feedback on the major issues which had emerged from the initial questionnaire. A second round of responses was received from nine respondents.

5 OUTCOMES OF THE STUDY

The following four questions were developed for this Delphi study and put to the participants:

5.1 Question 1

What are the most important factors, including key constraints, which presently impact on the housing choices and careers or pathways of people with disabilities? Describe the nature of the impacts and their implications for the living standards of people with disabilities.

5.2 Question 2

What do you consider are three principal changes that have occurred to housing careers/pathways of people with disabilities in the past 10 to 15 years in Australia? (Comments might include changes in areas other than housing which have impacted on the housing pathways of people with disabilities, including, but not limited to, government policies).

5.3 Question 3

What do you think are the major changes that can be expected to occur in housing careers/pathways for people with disabilities in the next 10 years in Australia? (Comments might include changes in areas other than housing (e.g. in health or disability services provided by government or non-government sources)).

5.4 Question 4

What do you think are the main implications of these expected changes for the housing and disability services policies of Australian state/territory and national governments?

5.5 Responses to Question 1

The responses to Question 1 concerning the most important factors which presently impact on the housing careers or choices of people with disabilities ranged over the following themes:

- Access to support;
- Financial capacity of people with disabilities;
- Availability of physically accessible housing;
- Affordability of housing;
- People with disabilities remaining at home with parents;
- Inappropriate housing and location;
- Poor coordination of programs and inflexible service system;
- Inadequate funding of services;
- Demographic change; and
- Community attitudes and discrimination.

The most frequently discussed influence in the responses was that of access to support. Respondents commented on whether support was available, and if it was how flexible that support was for an individual. The general concern was that

limitations around the amount and form of support limited the housing options of people with disabilities – limiting their mobility and their choice of housing and residential location. It was noted that for many people with disabilities, services were only available in group home settings.

A second major factor mentioned by most respondents was the limited financial capacity of people with disabilities, combining limited income (because of low employment rates) with the high costs of personal support and health care. Many respondents also commented on the cost of modifying a home. A key concern was that people with disabilities had a heavy reliance on public housing. Because of limited incomes and high living costs, many people are forced to live in cheaper locations that incur additional transport costs because of the need to access health and support services in other and possibly distant locations.

Many comments were also made about the poor physical accessibility of houses and facilities within the community, including shops and transport. This lack of physically accessible housing and accessible environments also greatly limits the housing choices of people with disabilities. There was concern that information was not available to people with disabilities about the availability of suitable accessible housing as well as concerns about the lack of interest by developers in building housing suitable for people with disabilities.

Many respondents discussed issues related to adults with disabilities living at home with their parents. While this issue could be viewed as a consequence of the other major factors impacting on housing choices and the resultant limitations on the housing careers of people with disabilities, it received a lot of comment as a standalone issue. Some of the more specific matters raised under this heading were the restrictions on the freedom of choice of people with disabilities because of their dependency on parents for support, consequences of “learned helplessness”, potential conflict within the home, the reluctance of some families to seek alternatives for their son or daughter and the implications of death or disability of parent carers or when the family home is no longer available for the person with a disability.

The poor financial position of most people with disabilities and their higher housing costs in terms of desirable or needed housing features and locational requirements means that the availability of affordable housing is also a key factor impacting on their housing choices. A number of respondents commented that the drop in funding for public housing and the consequential increased in their difficulties in finding public housing were key issues for people with disabilities.

Most respondents also commented on the inappropriate housing of many people with disabilities. In particular, comments were made about people with disabilities remaining in the family home in the long term so they could gain informal support as well as people with disabilities placed in nursing homes at a younger age than the mainstream population due to the inadequate support and housing options available to them in the community. Issues were also raised about the particular vulnerabilities of women with disabilities who are at greater risk of physical, sexual and emotional abuse in their living setting. The general issue here, raised by a number of respondents, concerned the inflexibility of support services -- this inflexibility limited the housing options of people with disabilities, whether they were in appropriate housing or not.

A smaller number of comments were received that extended this concern about the rigidities or general inflexibility in the service system for people with disabilities. Comments were made that policies can have an “either or” approach, excluding some people from receiving services, and there were no mechanisms for combining private

with public resources to secure housing. A few comments were made about the group home model which, in tying housing and support together, reduces flexibility and choices for individuals.

A small number of comments were also received about the influence of:

- Implications of demographic change – an expected increase in the proportion of the population with disabilities meant there needed to be more support, a greater quantity of more accessible housing, better planning for future needs and services, and measures to support ageing in place for people with disabilities.
- Poor funding – there was concern generally with the low level of funding for housing and support, and that people accept inadequate and inappropriate arrangements, just so that they can get some level of assistance.
- Community attitudes which are not necessarily welcoming of people with disabilities.

In the second stage of the study, the second round questions sought comment on the following significant factors in the careers or pathways of people with disabilities, drawn from the most frequent first round responses:

- Access to support;
- Financial capacity of people with disabilities;
- Availability of physically accessible housing; and
- Affordability of housing.

There was agreement from most second round respondents that these represented the most significant issues, particularly access to support and the availability of accessible housing. One respondent made the comment that the response depended on which group of people with disabilities was being referred to – physical disabilities (where accessible housing is important) or intellectual (and multiple) disabilities, where access to support is the most important factor.

Other issues raised in the second round included that of the potential problems that arise with the ageing of family carers, the inability of people to leave home at an earlier stage in their lives, and the problem of the generally poor availability of information to improve knowledge of housing choices

5.6 Responses to Question 2

Closure of institutions received the most frequent comment in relation to changes that have occurred in housing careers for people with disabilities over the past 10 to 15 years. Respondents noted the inadequate housing response as institutions have closed and people have moved to other settings which may or may not meet their needs. Respondents noted in particular the emphasis on group homes as the main alternative to institutions.

It was also noted that the closure of institutions had led to a greater visibility and acceptance in the community of people with disabilities. This change of community attitudes was noted by a number of respondents who observed that there has been a growing awareness of the benefits of accessible buildings and the community was generally more accepting of the presence of people with disabilities. This has also occurred with the opening up of employment opportunities for people with disabilities in the mainstream workforce.

A number of respondents considered that measures to assist people with disabilities to remain in their home were an important recent change. The Home and Community

Care program, home monitoring services and in-home carer respite services were highlighted by respondents.

Disability legislation, at Commonwealth and State level, was also considered by some respondents to have been an important change affecting the housing careers or pathways of people with disabilities. This had emerged from and alongside a rise in disability rights. This has been accompanied by rising expectations of people with disabilities and has encouraged more visionary government policy. It was noted here that the next generation will seek housing options reflecting their aspirations to be part of the mainstream society.

Several respondents noted there had been an expansion in community based housing options including a more diverse range of options in public housing. This included the positive move by housing authorities to provide housing scattered in the community rather than based in estates. Some noted that there have been more housing options provided also through an increase in individualised services in some jurisdictions.

There has been an increase in the availability of accessible housing in the past 10 to 15 years, as well as general improvements in accessibility of public transport and buildings. There were also comments on the increased availability of accessible tourist accommodation, with recognition of the demand for accessibility in the broader market. One respondent noted the increased availability of products and fittings designed to improve the functionality of homes for people with disabilities.

Some respondents commented on the increasing population of people with disabilities over this period with the ageing of the population, increasing life expectancy of people with disabilities, some groups surviving longer (e.g. people with acquired brain injury) and the increasing incidence of psychiatric illness in the community.

There were comments about the increase in housing costs over the past decade, particularly in well located areas which have often been affected by gentrification. This has greatly limited the housing options for people with disabilities in the private market.

Finally some respondents commented on the weakening of social capital over this period with a greater policy focus on individualism and a general weakening of social capital, leading to reduced community capacity and willingness to support people with disabilities.

In the second round of the study, respondents were asked if they concurred that the principal changes in the housing careers/pathways of people with disabilities in the last 10 to 15 years had been:

- Closure of institutions;
- Positive community attitudes;
- Improved measures to support people with disabilities in their homes; and
- Commonwealth and State disability legislation

In the second round respondents agreed on the whole with these points, although two respondents did not think community attitudes were significantly more positive, observing that negative attitudes persisted about community inclusion for people with disabilities: “the NIMBY syndrome is rife”. There were also several comments about the demographic change pressures with an ageing population and the inadequacy of government resources for services: “the level of positive impact to support people in their homes and close institutions has not been fully realised” (second round respondent).

Several respondents reinforced the importance of closure of institutions as a key change, leading to new ways to support people in the community. However one respondent was concerned that “the deinstitutionalisation movement has become too much of a driving force in the development of disability and housing policies”, noting the much larger proportion of people with disabilities now being cared for in the family home. The introduction of disability legislation from the 1980s was also considered a significant change by a number of second round respondents.

5.7 Responses to Question 3

This question was about anticipated future changes in housing for people with disabilities. The two major issues which dominated responses to this question were expectations of an increase in accessible housing and the increasing need for support services.

Respondents expected to see an expansion of available options in accessible housing in the next 10 years and the introduction of building standards for private and public housing to be accessible. Some expected to see the use of private public partnerships to respond to the increasing housing needs of people with disabilities.

Respondents also noted the increasing need for support and the likely expansion of supported housing models over this period. Some respondents expected a greater emphasis on the individualisation of services and greater support for people ageing in place. However there was also pessimism about government’s level of response to the increasing need for services.

Some respondents speculated about future changes in government policy, such as accessibility of housing and other ongoing initiatives for housing for people with disabilities.

Some respondents also saw the likelihood of technological changes in this period which would assist people with disabilities, such as home environmental control systems, pre-programmed PDAs to assist with cues and reminders and general improvements in communication and therefore greater potential for participation in the wider community (i.e. improved technology across all communities).

There were comments about further declines in housing affordability and ongoing demographic change, with further medical advances increasing the population of people with disabilities and further ageing of the population.

In the second round, respondents agreed overall that the main expected changes were:

- Increased availability of accessible housing;
- Expansion of supported housing models and individualised services;
- Technological changes; and
- Continuing decline in housing affordability.

Second round respondents raised some additional issues about the future housing prospects for people with disabilities, including an expectation that eligibility will tighten for publicly funded services and there will be a greater focus by government on cost effective solutions. In this environment, some respondents expected to seek increasing use of public/private funding mixes for people with disabilities. Two respondents also commented on the need to increase the professionalism of the disability support workforce.

5.8 Responses to Question 4

The last question referred to policy implications of the changes mentioned in question 3. A number of respondents expected there to be policy and legislative change around accessible housing. Several expected expansion of supported accommodation models, more attendant care support and more flexible support service models with a greater responsiveness to individual needs. However this needed to be supported with additional funding – for transitory services, increases in attendant care and flexible support service models. Some respondents, however, were quite pessimistic about the prospects for positive policy changes, with low expectations about improvements in funding and services.

A number of respondents were hopeful of more funding for developing different housing options for people with disabilities and greater coordination between housing and disability services. However one respondent thought that policy might shift toward a return to larger congregate care facilities for some people.

Several respondents commented that there was a need to attract and maintain quality staff in the disability sector as well as mandatory registration and training.

Some commented that they expected to see community expectations of government to increase, with greater discontent with inadequate funding and services from people with disabilities and their families.

There were also comments about expectations of change in urban form, with greater densities of housing around transport hubs, increasing well located housing options for people with disabilities.

The second round of the study sought respondents' comments on the key policy implications reflected from the first round:

- Policy and legislative change around accessible housing and communities;
- Improved range of housing options and better policy coordination;
- Increasing community expectations about availability and quality of services; and
- Inadequate policy responses to growing population and service demands.

Second round respondents agreed with the implications identified, and also stressed the need for population planning and adequate resourcing for future services – although there was continuing pessimism about resource levels improving. Several respondents emphasised the need for a strengthened policy and service nexus between the disability and aged care sectors, one of the requirements for effective policy responses flowing from an ageing population. There was also recognition that the Commonwealth and State/territory governments were “joined in an uncomfortable marriage” which could lead to “buck-passing”.

Respondents acknowledged the importance of the Commonwealth government's role in these issues, particularly for population planning and establishing service standards, and the states and territories' role in service delivery. Two respondents also noted the potential role of local government – to assist with improving community attitudes to people with disabilities living in the community and to encourage private development of accessible housing.

6 CONCLUSION

The Disability Delphi study for the 21st Century Housing Careers project achieved a high degree of consensus concerning the major factors influencing housing careers or pathways for people with disabilities now and in the past 10 to 15 years, as well as what might happen in the next decade. The factors impacting on the housing careers or pathways of the people with disabilities which received the most frequent comment from respondents were:

- Access to support;
- Financial capacity of people with disabilities;
- Availability of physically accessible housing; and
- Affordability of housing.

Most respondents commented that the closure of institutions, the introduction of disability legislation at Commonwealth and State/Territory level and the expansion of options for housing people with disabilities in the community were significant changes that had occurred in the housing pathways of people with disabilities in the past couple of decades.

Future expected changes would be driven by demographic changes in the disability and mainstream population. Respondents expected to see an increase in accessible housing in the community as well as an increasing need for support services, with a greater emphasis on individualised services. However there was concern expressed (or rather some degree of pessimism) about the likelihood of public resources for future services. There was also an expectation that technology would play an increasing role in housing and living arrangements for people with disabilities.

In relation to future policy, respondents expected to see increasing community expectations and expanded housing options for people with disabilities. However public resource constraints would mean policies will emerge which sought a mix of private and public funds to address housing requirements. There is also an expectation that further legislation would be introduced to improve the supply of physically accessible housing.

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