

The lived experiences of housing among Indigenous people with disability

IMPROVED UNDERSTANDING AND USE OF DESIGN STANDARDS IS NEEDED FOR BETTER OUTCOMES FOR INDIGENOUS PEOPLE LIVING WITH DISABILITY.

KEY POINTS

- Formal data collections undercount the prevalence of impairment and disability, the level of need for assistance and the complexity of conditions for Indigenous people living with disability. This is because many Indigenous communities do not understand or define disability in the same ways that official counts or mainstream services do.
- Based on service use, community organisations estimated that in Yalata 60–75 per cent of the population lived with some form of disability and in Point Pearce, 75–80 per cent lived with a chronic illness that impacted their ability to complete core tasks.
- There was better access to appropriate housing in the rural community of Point Pearce than the remote and urban communities.
- Assessed against design codes, the majority of houses did not meet accessibility or visitability requirements including ‘dignified access’ which includes the ability to access building spaces and facilities using a wheelchair. There was also a lack of design provision for people with cognitive disorders, mental health issues, and for hearing and vision impairments.

This bulletin is based on research conducted by Dr Elizabeth Grant, Professor George Zillante, Dr Amit Srivastava, Dr Selina Tully and Associate Professor Alwin Chong at the AHURI Research Centre—University of Adelaide. The research explores the interconnection between housing, community infrastructure and quality of life for Indigenous people living with disability in relation to cultural, physical, social and functional issues.

- People with disability and their carers in rural and remote communities are not aware of the different types of modifications available and how to access them.
- The preferred model of housing for Indigenous people living with disability is an independent home. Design needs to consider users and carers (predominantly family) and the extended role of family members in the shared care of Indigenous people with disability.

CONTEXT

The conceptual framework of disability informing this research accords with the biopsychosocial understanding of disability informed by the World Health Organisation International Classification of Functioning, Disability and Health (ICF). The ICF model is a blend of the social and the medical models of disability and includes impairments, activity limitations and participation restrictions. It supports an approach where it is understood that interventions are required to remove environmental and social barriers as well.

RESEARCH METHOD

Three case study communities in NDIS trial sites were selected including the remote community of Yalata and the rural community of Point Pearce in South Australia, and the urban area of Geelong in Victoria. A narrative inquiry method, including the ethnographic research methodology: 'lived experience' was employed to capture the voices of participants in the study. The fieldwork included: community/carer workshops, interviews with people with disability and carers, and assessment of housing and related infrastructure against standards and codes—the Australian Standard, the National Indigenous Housing Guide (NIHG) and the National Construction Code (NCC) which sets out the minimum necessary requirements for safety, health, amenity and sustainability in the design and construction of new buildings (and new building work in existing buildings).

KEY FINDINGS

Prevalence of disability in study areas

The research found that formal data collections such as the Census reflect an undercount of Indigenous people living with disability. Community organisations estimated that in Yalata, 60–75 per cent of the population lived with some form of disability and in Point Pearce, 75–80 per cent lived with a chronic illness.

How disability was understood and what people defined as a disability varied across the locations. Geelong residents were more comfortable using the term disability and more aware due to the roll out of NDIS. In remote and rural locations, disability was attributed to physical characteristics such as being confined to a wheelchair. Restrictions which were a result of chronic diseases were not viewed as disabilities but as illness or age related.

Community members and stakeholders at Yalata held the view that psychosocial disabilities, such as cognitive disability and mental health conditions, were most prevalent among the population. Most people in Yalata also lived with chronic diseases: specifically diabetes, cardiovascular disease and renal disease. Similarly at Point Pearce, the most commonly reported disabling conditions related to chronic diseases: cardiovascular disease, diabetes and renal disease. At Geelong, psychosocial disorders and physical disability were reported.

Access to appropriate housing within communities

In the remote locality of Yalata, housing was in high demand and difficult to access. It was often of substandard condition, overcrowded and poorly maintained. In Geelong, people with disability had difficulty accessing housing and when they did it was often substandard, inappropriate or unsuitable due to a lack of repairs and maintenance or suitable modifications. In Point Pearce—the rural setting—housing was much easier to access and of good quality due to a renovation program occurring during the research period.

At Yalata, Indigenous people with disability often had to move to access housing, health services or supported living arrangements and were greatly affected by their dislocation. Communities wanted to keep people with disability living within the community and people with disability in Yalata saw family as responsible for their care.

In contrast, at the rural location of Point Pearce some people with disability had moved back to the community to access housing and health services. Community identified the need for greater support for people to remain living independently in their own homes and granny flats at the homes of family members to provide people with disability greater dignity and independence than living in supported accommodation.

In the urban setting people had access to a full range of requisite services but were struggling to access housing appropriate to their physical, social and cultural needs. There was a diversity of housing options available to people with disability in Geelong but a shortage of every form of housing. Options include shared supported accommodation facilities and disability and age-specific independent living units, but Aboriginal people with disability prefer to be supported to live in their own homes.

Availability of suitably designed housing in relation to guidelines

An assessment of houses against design codes found the majority of houses did not meet accessibility or visitability requirements (of particular significance for Indigenous communities who tend to be a highly mobile population). In all locations there was poor adherence to existing housing guidelines and non-mandatory requirements around disability access. Given the higher prevalence of disability within Indigenous populations, current guidelines had insufficient requirements for provisions such as 'dignified access' which includes the ability to 'negotiate the route from the road boundary to and within the building using a wheelchair' and access to spaces and facilities within the building (NCC). There was also a lack of design provision for people with cognitive disorders, mental health issues, and for

hearing and vision impairments.

The remote community of Yalata has a shortage of housing and the majority of stock is not designed for residents with physical disability and therefore did not aim to address issues of 'dignified access' as stipulated in the NCC. The housing assessed did not meet with NCC universal access provisions, but was generally compliant with other NCC requirements, such as toilet access. Where specialised housing for people with disability was provided (for example, independent living units), it was inappropriately designed and poorly situated in relation to community infrastructure and activities.

Point Pearce has a housing stock mismatch and affordability issues as rents are calculated against the number of bedrooms in a dwelling regardless of the number of occupants in a house. Compliance with NCC and other relevant guidelines is mixed. Overall, the houses examined were generally compliant with the NCC, performing particularly well in terms of the 'dignified access' requirement of providing an accessible internal pathway from the entrance to areas of normal use within the house.

Houses in Geelong presented deficiencies in a number of areas, none had provision for accessible wet areas and there were significant deficiencies in terms of compliance with NCC access-related recommendations and standards due to the age and poor design of dwellings.

Housing condition and modifications

In Yalata the condition of dwellings was poor lacking basic services/facilities and requiring repair and maintenance. Generally, people were unaware of housing modifications that could be undertaken to make the lives of people with disability easier. The lack of basic amenities also means that future modifications for these properties will be extensive and very expensive.

In Point Pearce, modifications to dwellings to support people living independently was a high priority for residents with issues such as narrow passageways inhibiting this. People with disability and their carers were not aware of the types

of modifications available or how they might effect these changes.

People living in private rental in Geelong reported a better experience than those in public housing particularly with repairs, maintenance and modifications. They felt more in control although this could depend on their relationship with their landlord.

POLICY IMPLICATIONS

The research found that the preferred model for housing for Indigenous people living with disability is an independent home. Housing design needs to take into account the extended role of family members in the shared care of Indigenous people with disability as well as connection to country and community. Consideration of the location of new dwellings in communities with respect to accessibility to services, supports, community and safety for a vulnerable resident population is equally important.

The following key overarching policy recommendations have resulted from the research:

- A new NCC classification for 'housing for Indigenous people'. This will allow for a national standard to be achieved addressing statewide variations and create a basic minimum guideline and account for the higher prevalence of disability among the Indigenous population.
- A separate section in Australian Standard 1428 to address the access standards of Aboriginal housing.

- Consideration of the definition of disability and the implications of hearing and vision impairments, as well as cognitive disabilities in terms of accessible housing.
- All houses should aim for universal access and provide basic access infrastructure for people with disability. All *new* housing should be designed for accessibility for people with disability, with the *Livable housing design guidelines* 'silver' standard offering a benchmark.
- A systematic inspection process for new builds to ensure compliance with standards.

The rollout of the NDIS has provided a much needed framework for eligible participants to access necessary life-long supports. It also provides the opportunity for a further alignment of standards in the building and construction industry with Article 19 of the *Convention on the Rights of Persons with Disabilities* and guidelines on accessible housing design.

FURTHER INFORMATION

This bulletin is based on AHURI Project 31030, *Housing and Indigenous disability: lived experiences of housing and community infrastructure*.

Reports from this project can be found on the AHURI website: www.ahuri.edu.au or by contacting AHURI Limited on +61 3 9660 2300.

ahuri.edu.au



ADDRESS Level 1, 114 Flinders Street Melbourne Victoria 3000 TELEPHONE +61 3 9660 2300
EMAIL information@ahuri.edu.au WEB www.ahuri.edu.au

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