











EXECUTIVE SUMMARY

Housing and Indigenous disability: lived experiences of housing and community infrastructure

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EXECUTIVE SUMMARY

This Final Report presents the findings of research exploring the interconnections between housing, community infrastructure and quality of life ('lived experience') for Indigenous people living with disability.

Two key factors have provided the impetus for this study. First, the relationship between appropriate housing, good health, wellbeing and quality of life is now well established (Baker, Mason et al. 2014; Howden-Chapman and Carroll 2004; OECD 2011; NPDCC 2009). Yet there remain many individuals and groups who face multiple barriers to accessing housing that meets their needs and is appropriate and sustainable in terms of affordability, accessibility, safety, security and housing form. Indigenous people with disability are one such group, yet we know little about their housing experiences, aspirations and needs.

Second, the development and rollout of the National Disability Insurance Scheme (NDIS) has focused attention nationally on the needs of people with disability. A watershed in social and disability policy, the NDIS offers real potential to transform the living circumstances of many people. It will provide eligible participants with assistance to access more appropriate, timely and consistent support services, and exercise choice and control over their lives. However, while the scheme's mandate is clear, there are gaps in the structures and processes and it is not yet fully implemented at this time. We know little, for example, about how the NDIS will be applied, resourced and supported across Australia's vast network of rural, regional and remote communities, where service delivery is particularly challenging.

This study used a research approach which allowed the creation of narratives of 'lived experiences' of housing and community infrastructure in three case study communities: Yalata and Point Pearce in South Australia, and Greater Geelong in Victoria. This approach allowed the voices of Indigenous people with disability to be heard. This data was recorded alongside baseline data on the quality, quantity and condition of housing and community infrastructure. Assessments of these infrastructures were made against key disabilityrelated requirements, standards and guidelines in operation for such infrastructure—for example: the National Construction Code (NCC) (ABCB 2015a; 2015b) and relevant Australian standards; the National Indigenous housing guide (NIHG) (FaCSIA 2007); and the National Indigenous infrastructure guide (NIIG) (FaHCSIA 2010). The three case study areas were selected as examples of remote (Yalata), rural (Point Pearce) and urban (Geelong) settings, and were also chosen as they are all within the stage one NDIS launch regions. A range of stakeholders were interviewed in order to garner necessary data and perspectives, including Indigenous people with disability in each community, their families and carers, other community members, health and housing workers and other service providers.

To provide a backdrop for the study, the prevalence of disability at the three case study locations was investigated. This found that poor health and disability are major issues facing the Indigenous populations in these areas. Moreover, government data has not accurately captured the prevalence of impairment and disability in the Aboriginal population, nor the level of need for assistance. It also does not capture the complexity of disabling impairments or health conditions. Co-morbidities are common among the Indigenous populations studied. The study found that people were often hesitant to access disability services outside their family networks, as this tended to result in interference in their life and a loss of personal control.

There were contrasts observed in the living circumstances of Indigenous people with disability in the remote, rural and urban locations. In remote Yalata, housing was in high demand and difficult to access. It was often of substandard condition, overcrowded and

poorly maintained. In the urban setting (Geelong) we also found that people with disability had difficulty accessing housing, and when they did the housing 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 due to a renovation program coincidentally occurring during the research period, the housing was of reasonable quality.

The research highlights the interconnections between housing, community infrastructure and quality of life. We encountered people separated from their family and country as a result of their disability; people who lacked basic amenities such as a place to cook or sleep; people who were trapped in their houses because of the failure of an agency to complete simple house modifications or make residents aware of the range and types of modifications available and the process for accessing them; and people whose housing circumstances did not, and could not, meet their health or disability needs. Other people were homeless and cycled through a series of different (and often dangerous) living circumstances due to the nature of their disability, including psychosocial conditions. People with certain disabilities fared very poorly in all locations. In particular, people with cognitive and/or psychosocial disability had great difficulties accessing safe and appropriate housing, with impacts on the wellbeing at the individual, family and community levels (see Wright, Zeeman et al. 2016 and Zeeman, Whitty et al. 2016 for a useful recent general discussion around these issues).

At the remote location we found that Indigenous people with disability often had to move to access housing, health services or supported living arrangements. When people were required to move, they were greatly affected by their dislocation. Communities wanted to keep people with disability living within the community whenever they could. People with disability in Yalata saw family as responsible for their care. Remarkably, at the rural location, we found that some people with disability had moved back to the community to access housing and health services. The rural community had become a place of refuge. In the urban setting, there were indications that people had access to a full range of requisite services however discussions with study participants in Geelong found that some were faring very poorly in terms of accessing housing appropriate to their physical, social and cultural needs.

The majority of houses examined for this study did not meet accessibility and visitability requirements for residents and guests. This was a point highlighted repeatedly by the service providers, community members and residents interviewed. In all locations there was poor adherence to existing housing guidelines and, particularly, poor adherence to non-mandatory requirements around disability access. Accordingly, we have developed a series of recommendations from the research (summarised below), headlined by three related policy recommendations.

- → Legislate that all *new* housing be designed for accessibility for people with disability, with the *Livable housing design guidelines* 'silver' standard offering a benchmark.
- → All houses should aim for universal access and provide basic access infrastructure for people with disability. The current recommended 5 per cent 'dignified access' requirement under the NCC does not adequately account for the higher prevalence of disability among the Indigenous population.
- → A new NCC classification should be instated, to be identified as 'Housing for Indigenous people'. This will allow for a national standard to be achieved that could cut across state-level variations around Indigenous housing and create a basic minimum guideline. The new classification could be administered by a relevant state government body such as South Australia's Development Assessment Commission.

The research also highlights the need for the following

- → A separate section in Australian Standard (AS) 1428 that deals with the access needs of Aboriginal housing. The definition of disability and its implications for access should be extended to include hearing and vision impairments, as well as cognitive disabilities. Further research is required to establish what the access standards for cognitive disorders might be.
- → A systematic inspection process that ensures compliance with all new policy requirements.
- → Community infrastructure that allows the participation of people with disability in the life of the community.
- → Specialist facilities for Indigenous people with disability that are designed and built in consultation with the local community and stakeholders.
- → Specialist facilities that are co-located with relevant services and supports where these exist (e.g. disability/aged care) to allow for efficient service delivery.
- → The NDIS to understand and account for the challenges facing Indigenous people with disability.

On this last point, a series of recommendations are apparent—specific in the context of the NDIS policy.

- → People with disability (and their carers/families) should be supported to negotiate their individual disability-related requirements with housing providers.
- → The negotiation of individual packages under the NDIS should include a housing assessment by a person with appropriate qualifications with the quality and appropriateness of housing assessed against the individual's needs.
- → Housing assessments focused on access, suitability and condition should be included for organisations that receive funding under the NDIS to manage housing, to ensure compliance with relevant codes and standards and also to ensure that people with disability have access to appropriate accommodation to support their life goals, social and economic participation and health and wellbeing.
- There is a capacity in the NDIS rollout process to educate people regarding housing options, modifications and technologies to allow people to live more independently. The opportunity to educate people should be planned into any future regional rollout of the NDIS.
- → People with disability and their carers should be provided with information on the variety of housing modifications available, to allow them to make informed decisions about housing modifications which may improve their quality of life and wellbeing.
- → Within the negotiation of an individual's NDIS package, the timely and appropriate completion of housing modifications should be negotiated with the relevant person or agency, such as the housing provider or landlord.
- → Where modifications are provided, the work needs to be conducted systematically and completed to the resident's and stakeholder's satisfaction.
- → Within the negotiation of an individual's NDIS package, the access of people to essential adaptive technologies (e.g. personal security alerts) that enable them to live independently should be considered.

Additionally, it is evident that the structures around the NDIS provide an important opportunity and vehicle for undertaking further research.

Research investigating why Aboriginal people with disability in some regions are hesitant to access mainstream supported accommodation services. This research should explore:

- 1. the barriers to Indigenous people accessing these options
- 2. how mainstream supported accommodation options might better meet the needs of Indigenous people with disability
- 3. whether 'Indigenous specific' supported housing options need to be made available for Indigenous people with disability.
- → Research investigating issues for Indigenous people with disability who are renting privately, including examination of minimum standards for private rental housing and the application of relevant legislative and regulatory provisions.

The rollout of the NDIS is a timely moment to examine the housing outcomes of Indigenous people with disability. Implementation of the scheme provides opportunity to illuminate the housing and living conditions of Indigenous people with disability, many of whom live in challenging circumstances. Given the importance of appropriate housing for the health outcomes and wellbeing of Indigenous people with disability, future NDIS rollouts should involve the assessment of the housing and living environments of eligible participants during the NDIS assessment and service delivery phases.

The challenges facing Indigenous people with disability in terms of housing and community infrastructure, particularly those elements that are design-related, will not lessen without these higher-level policy recommendations being formally adopted and enforced by the relevant stakeholders (including governments, government agencies, the housing industry and Indigenous communities) and through the appropriate frameworks and channels, including in legislation.

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People with disability and families considering investment in shared ownership housing are strongly encouraged to seek independent financial advice based on their personal and financial circumstances.

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