Positioning Paper

Housing and Indigenous people living with a disability: lived experiences of housing and community infrastructure

authored by

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ACRONYMS

AATSIHS	Australian Aboriginal and Torres Strait Islander Health Survey
ABS	Australian Bureau of Statistics
ABCB	Australian Building Codes Board
AHURI	Australian Housing and Urban Research Institute Limited
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
AIHW	Australian Institute of Health and Welfare
ANAO	Australian National Audit Office
ANUHD	Australian Network for Universal Housing Design
CAEPR	Centre for Aboriginal Economic Policy Research
CAT	Centre for Appropriate Technology
COAG	Council of Australian Governments
CHINS	Community Housing and Infrastructure Needs Survey
CMHC	Canada Mortgage and Housing Corporation
DSS	Department of Social Services (Australian Government).
GSS	General Social Survey
HACC	Home and Community Care program
HNZC	Housing New Zealand Corporation
HREOC	Human Rights and Equal Opportunity Commission
ICF	International Classification of Functioning, Disability and Health
NATSIHMS	National Aboriginal and Torres Strait Islander Health Measures Survey
NATSIHS	National Aboriginal and Torres Strait Islander Health Survey
NATSINPAS	National Aboriginal and Torres Strait Islander Nutrition and Physical Activity Survey
NATSISS	National Aboriginal and Torres Strait Islander Social Survey
NCC	National Construction Code of Australia
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NIHG	National Indigenous Housing Guide
NIIG	National Indigenous Infrastructure Guide
NPDCC	National People with Disabilities and Carer Council
OECD	Organisation for Economic Cooperation and Development
PDF	Practical Design Fund
RCAP	Royal Commission on Aboriginal Peoples (Canada)
SDAC	Survey of Disability, Ageing and Carers

SNZ   Statistics New Zealand
WHO   World Health Organization

EXECUTIVE SUMMARY

Good quality, safe and appropriate housing and living environments are fundamental factors shaping individuals' wellbeing and quality of life (OECD 2011; Howden-Chapman & Caroll 2004). Having limited or no choice at all about where one lives, or residing in inappropriate housing, has a profound impact on an individual's physical and mental health (NPDCC 2009; Baker et al. 2014). This relationship between housing and health is increasingly being recognised in academic, political and practice circles (e.g. see, Phibbs & Thompson 2011 for AHURI) and particularly for vulnerable groups within the population, including for people living with a disability (NPDCC 2009; also Mason et al. 2013; Bentley et al. 2012; Bentley et al. 2011) and for Indigenous peoples (Ware 2013; also Grant et al. 2014). Yet, the stark reality remains that many people living with disabilities face multiple barriers to securing appropriate housing and finding and negotiating living environments that meet their needs. Barriers to finding appropriate housing and living environments seemingly apply across all types and degrees of disability (NPDCC 2009; Tually et al. 2010, 2011). It is also increasingly apparent that Indigenous Australians living with disabilities face multiple barriers in accessing appropriate and adequate disability supports. When coupled with known issues around access to, and the quality of, housing and community infrastructure, this puts this population group at an even more disadvantage in terms of health, wellbeing and social, economic and community participation. Current reforms around the provision of disability services—through the significant social policy change that is the National Disability Insurance Scheme (NDIS)—offers real potential to transform the living circumstances and social and economic outcomes for Indigenous people living with disabilities.

This research project explores the nexus between housing, community infrastructure and quality of life for Indigenous people living with disabilities. The housing and community infrastructure needs of this population group have not been previously studied. This Positioning Paper is the first published step of the project. It presents background information and reviews the relevant literature and data to inform the study which is being undertaken during the implementation phase of the National Disability Insurance Scheme. An important part of this study is the collection of narratives from Indigenous people living with disabilities, which will be collected alongside baseline data on the quality, quantity and condition of housing and community infrastructure in three case study communities—Yalata and Point Pearce in SA, and Geelong in Victoria. The study has this focus in order to understand the cultural, physical, social and functional issues of housing and infrastructure and the impacts these have on people's lives.

This research has been timed to coincide with the roll out of the ground breaking policy that is the NDIS; the implementation of which is a response to the previously fragmented and inefficient nature of the delivery of disability services in Australia. The NDIS is an important break away from past approaches to the delivery of disability services. Its core tenet is to ensure eligible Australians living with a disability have access to whole-of-life supports focussed on meeting their life goals and aspirations (NDIS 2015d). The Scheme is a social insurance program, supporting 'people with a permanent and significant disability that affects their ability to take part in everyday activities' (NDIS 2015d). For eligible 'participants', NDIS providers will work with them to identify the supports they need for daily life, centred around assistance to meet life goals in areas such as achieving and maintaining independence, community involvement, education, employment and health and wellbeing. The Scheme emphasises participant 'choice and control', expressed in its person-centred focus, and has been designed to give certainty in terms of supports across participants' lifetime. Notably also, and particularly important in the context of this research, the NDIS will fund 'reasonable and necessary supports' for participants where required and to achieve participants' stated goals. This includes in areas such as 'therapies, equipment, home modifications, mobility equipment, taking part in community activities or assistance with employment' (NDIS 2015d). The Scheme

is also an information and referral service for people living with a disability who do not meet the eligibility requirements to be participants, as well as for carers and families of all people living with disabilities in Australia.

The NDIS was launched in four 'stage one' areas: Tasmania, South Australia, the Barwon area in Victoria and the Hunter region in New South Wales (NDIS 2013) and will be progressively implemented across other states and territories. The government has stated that lessons learnt from the trial areas will be implemented in other locations. One estimate has suggested the NDIS will have 410 000 participants when fully operational in 2019 (Bonyhady 2014a). The housing issues that arise in association with the NDIS are yet to be addressed. This study has the capacity to inform policy in this area.

There are a range of data regarding the number of Indigenous Australians living with a disability. Census data indicate that 19 600 Indigenous Australians need assistance with one or more core activities and may be assumed to be living with a profound or severe disability. The National Aboriginal and Torres Strait Islander Social Survey (NATSISS) records 26 000 Indigenous Australians aged 15 years or over with profound or severe limitations in performing core activities (ABS 2013b). Notably, the National People with Disabilities and Carer Council (NPDCC), the Australian Productivity Commission (2011b), the First Nations Disability Network and the Australian Institute of Health and Welfare (AIHW) have all questioned the accuracy of the current data on the prevalence of disability within the Indigenous population. Underreporting or non-reporting of disability within the Indigenous population also appears common due to historical, cultural and linguistic factors. Much of the literature indicates that Australian Bureau of Statistics (ABS) figures are the 'tip of the iceberg', with evidence from one ABS survey (the NATSISS—the National Aboriginal and Torres Strait Islander Social Survey) noting that in the order of 50 per cent of Indigenous people (some 163 000 people at the time of the NATSISS in 2008) were living with some form of disability (Biddle et al. 2014). Physical disability appears to be the most common disability type reported by Indigenous Australians at this point in time (AIHW 2011b, p.47).

Living with poor health and disability is commonplace for many Indigenous Australians. Approximately 30 per cent of Aboriginal and Torres Strait Islander people report living with high or very high levels of distress while only 11 per cent of the non-Indigenous population report living with similar levels of distress (ABS 2013b). Across the range of reported disabilities, Indigenous Australians living with a disability are at least twice as likely as members of the non-Indigenous population to need help with a core activity (AIHW 2011b, p.46).

The Aboriginal and Torres Strait Islander population face a complexity of housing issues:

→ Rates of homelessness among Aboriginal and Torres Strait Islander people are significantly higher than for non-Indigenous Australians. At Census 2011, 488 Indigenous people per 10 000 were recorded as homeless versus 35 per 10 000 for non-Indigenous Australians (14 times the rate) (AHIW 2014a, p.7).

→ Indigenous households are much more likely to live in overcrowded conditions than non-Indigenous households, with data noting rates of overcrowding of somewhere between 3 and 10 times higher overall among Indigenous people than other household types (AIHW 2014b, p.18).

→ The standard and condition of dwellings available to many Indigenous Australians is generally considered to be well below that available to, and occupied by, the non-Indigenous population, particularly in remote and very remote regions (Walls & Bridge 2011; Walls et al. 2013).

→ The poor condition of community infrastructure in discrete Indigenous communities (e.g. see, Mines 2011a & b; Senior 2000).

This study will shed further light on these housing complexities, revealing the housing and community infrastructure related issues for Indigenous people living with a disability and their impacts on individuals' health and wellbeing and their capacity to participate economically and socially. These impacts are key concerns for people living with disabilities as noted in the NPDCC report *Shut Out: The Experience of People with Disabilities and their Families in Australia* (2009).

People living with a disability face major housing issues (NPDCC 2009; Tually et al. 2011). Public housing stock is often of poor standard or inaccessible for those with mobility impairments. People living with disabilities often require housing with certain attributes to meet their needs. In particular, it has been noted that housing needs to:

→ be located close to hospitals and specialist health services

→ have access to public transport

→ include accessibility features and technologies (McConkey & Keogh 2014; NPDCC 2009; Tually et al. 2011; Tually & Beer 2010; Wiesel et al. 2012).

Housing strategies under the NDIS include home modifications for privately-owned dwellings, as well as private rentals and social housing (NDIS 2015b). The literature notes that there may be major constraints in modifying Indigenous housing due to the poor condition of housing, environmental conditions and other health and safety issues (Pholeros & Phibbs 2012; Walls et al. 2013; Walls & Bridge 2011).

Notably also, the Productivity Commission has noted in their background work and conceptualisation of the NDIS that there may be significant barriers to accessing disability support services for Indigenous people without specific attention being paid to the needs of this group, particularly because of issues such as 'remoteness, social marginalisation, cultural attitudes towards disability and culturally inappropriate services' (Productivity Commission 2011a, p.53). Such well documented barriers to disability support lead the Productivity Commission (2001a, pp.53–54) to comment that:

> … the service delivery model underpinning the proposed NDIS may not, on its own, deliver adequate care and support to Indigenous people with a disability. While Indigenous Australians would have access to individual support packages on the same basis as non-Indigenous Australians, it may also be necessary to block fund some services in order to overcome the additional barriers that Indigenous Australians face. In addition, Indigenous people with disabilities often do not make claims for support. These distinctive aspects suggest that disability support for some Indigenous communities will probably need to take a different form.

These insights form the basis for the fieldwork to be conducted as the next and final stage of this project.

While there is a large body of knowledge on the cultural design of housing to meet Indigenous users' socio-spatial needs, domiciliary behaviours, cultural values and aspirations (e.g. Heppell 1979; Memmott 1988, 1991, 2003, 2004, 2007; Ross 1987; Keys 1996; Read 2000; Fantin 2003; Long et al. 2007; Milligan et al. 2011), few studies have been conducted nationally or internationally examining 'best-practice' housing for Indigenous people living with a disability. This reality is evident from this report, with the review of the relevant literatures from Australia, New Zealand and Canada in this regard showing a dearth of literature. This review, however, does show a number of key ways of working within, between and among Indigenous communities to ensure appropriate design, construction, maintenance and modifications for housing and community infrastructure (see Chapter 5).

It is clear that a range of cultural factors are central to understanding and determining housing options (and outcomes) for Indigenous people. These include such things as housing design

that pays attention to customary behaviours around avoidance, household structures, sleeping and eating, as well as cultural constructs around crowding and privacy and responses to death. Additionally, the literature is unequivocal on the need to approach the provision and design of housing independently, recognising diversity in Indigenous cultures, values, laws and customs in Australia (Grant et al. 2015). Moreover, the key to any model or approach for the improvement of housing for Aboriginal people living with a disability must facilitate and work within a framework emphasising community ownership, community engagement, community participation and community empowerment to ensure that initiatives and development plans (and decision-making processes) drive sustainable and appropriate housing models (Davidson et al. 2011). Importantly, it is clear that there is no one solution to providing and designing housing for Indigenous people. In the course of this research, it is anticipated that some preferred models of housing for Indigenous people living with a disability may be revealed.

Seven research questions have been devised to respond to the apparent knowledge gaps around this research area:

1. What are the housing experiences of Indigenous people living with a disability in the case study locations?

2. What are the types of housing and housing modifications and the condition of housing available for Indigenous people living with a disability in each of the case study areas?

3. How do Indigenous people respond to the housing options available to them?

4. How does the housing available measure up against the available guides and legislation?

5. What community infrastructure is present in the case study locations to support Indigenous people living with disability?

6. How does the community infrastructure measure up against the available guidelines and legislation?

7. Are there more appropriate housing and community infrastructure models for Indigenous people living with a disability?

To address the research questions, workshops and qualitative interviews with individuals and stakeholders will be conducted in three separate locations: Yalata (a discrete remote Aboriginal community), Point Pearce (a discrete rural Aboriginal community) and Geelong (a major urban area). These case studies have been chosen as they are examples of urban, rural and remote communities, allowing us to document the different types of housing options available to Indigenous people living with a disability in such communities. They were also chosen as they are in stage one NDIS launch regions and governments have stated the lessons learnt in these areas will be applied elsewhere.

Notably also, this research and that choice of case study locations have been informed by consultations between the research team and the First Nations Disability Network—the peak body representing Indigenous people with a disability.

Some of the housing issues that will be explored in depth in the interviews to be undertaken in the final stage of this research, include:

→ The benefits and/or constraints of people's current housing in terms of disability.

→ Whether modifications have been made to people's homes and how these have worked and played out.

→ The appropriateness of such modifications.

→ Impacts on quality of life related to disability and housing.

→ Whether people have thought about/had to move or reside elsewhere because of unsuitable housing.

→ Whether people would like to live in different housing and aspirations in terms of such housing.

→ Whether current community infrastructure enables people to access the community and surrounding areas.

The study will also evaluate the existing housing and infrastructure in terms of the capacity of Indigenous people living with a disability to access housing, the condition and location of housing and the availability, appropriateness and suitability of housing modifications and community infrastructure, measured against the National Construction Code of Australia (NCC) and key guidelines for Indigenous housing and infrastructure, namely the National Indigenous Housing Guide and the National Indigenous Infrastructure Guide. The NCC contains minimum requirements to address the needs of people with disabilities that must under law to be addressed in all construction projects. The National Indigenous Housing Guide and the National Indigenous Infrastructure Guide, on the other hand, are neither developed specifically for people with disabilities, nor binding in legal terms, but are generally considered the best resource available for assessing (and developing) housing and infrastructure in Indigenous communities. As per the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) publication *Guidelines for Ethical Research in Australian Indigenous Studies* (2012), this research and the fieldwork is being conducted in partnership with communities.

The results of this study will provide a picture of the characteristics of the housing environment and the cultural, physical, social and functional issues related to housing for Indigenous people living with a disability. These results will be able to inform policy decisions regarding the housing and community infrastructure needs of Indigenous Australians living with a disability, as well as funding, allocations and housing modifications processes.

1 INTRODUCTION

1.1 Research and policy significance

The National Disability Insurance Scheme (NDIS) provides new arrangements for meeting the needs of (eligible) people living with a disability. The objective of the NDIS is to improve the wellbeing and social and economic participation of people with a disability and to remedy the existing arrangements found to be '… inequitable, underfunded, fragmented, and inefficient' leaving many people with a disability little choice regarding their support needs (Productivity Commission 2011a, p.5). From mid–2013, the NDIS was launched in four 'stage one' areas:

→ across the whole of Tasmania (for people aged 15 to 24 on day of access request)

→ across the whole of South Australia (for children aged 13 and under on 1 July 2014)

→ the Barwon area in Victoria (people aged under 65)

→ the Hunter region in New South Wales (people aged under 65) (NDIS 2013).

While many details around the full roll out of the NDIS are yet to be determined, it is clear that there are some major gaps in support for people living with a disability nationally, and especially for some groups within the disabled population. As this report notes, one such gap is around the adequacy and appropriateness of support for Indigenous Australians living with disabilities. This research will contribute to our understanding around the needs of Indigenous Australians living with a disability, particularly from the perspective of presenting the lived experiences of housing and community infrastructure among this often multiply-disadvantaged population group. As the roll out of the NDIS in stage one areas coincides perfectly with the roll out of this study, this research can contribute important new insights and information on this topic that can then shape the further roll out of the Scheme and specifically in terms of how it will meet the needs of Indigenous people living with a disability.

The ethnographic research method known as 'lived experience' has been adopted as part of the methodology of narrative inquiry used for this project (and alongside observational methods) as it allows 'representation and understanding of a … research subject's human experiences, choices, and options and how those factors influence one's perception of knowledge' (Boylorn 2008; van Manen 1990 for further discussion of the method). The notion of lived experience explores how the people and the environment intertwine and the impact that one has upon another (Clandinin & Rosiek 2006). Narrative inquiry was adopted to preserve the voices of Aboriginal people living with a disability and their carers. It has been used in other major investigations such as in *Bringing them home*, the report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families (HREOC 1997) and in capturing voices for the Royal Commission into Aboriginal Deaths in Custody. It is considered an effective methodology for preserving Indigenous viewpoints.

This research is specifically focused on lived experiences of housing and infrastructure for Indigenous people living with a disability. It has this focus as having access to appropriate housing is proven to be integral to the physical and mental health of people living with a disability (Baker et al. 2014; Bentley et al. 2012, 2011; Grant et al. 2014). How the NDIS will fit with concerns and challenges regarding housing for people living with disabilities though remains somewhat unclear. The limited literature available on housing support under the NDIS notes that responsibility for the provision of housing will continue to rest with current housing providers and the NDIS will not provide funding for housing for individuals. It also notes that the National Disability Insurance Agency (the statutory body overseeing the implementation of the NDIS) and NDIS providers will act as an advocate for the promotion and procurement of housing for people with a disability generally, and NDIS providers will assist with referrals and linkages regarding housing and housing issues for people living with a disability, their carers and families (Bonyhady 2014b; NDIS 2015b). Where the current NDIS model sits on other

housing-related matters raised by the Productivity Commission in their background work for the NDIS and conceptualisation of the NDIS model remains to be seen. This includes in terms of the housing strategies they mentioned in passing that will be funded under the Scheme (in areas such as group housing and home modifications for eligible NDIS participants), plus with regard to the various funding models housing for initiatives (individual financial support and block funding for housing providers) mentioned (Productivity Commission 2011a, p.471).

The First Peoples Disability Network (the peak Australian body representing Indigenous people living with a disability) had developed a 10-point plan noting that the lived experiences of Indigenous people with a disability need to be documented urgently (First Peoples Disability Network 2013a). In reviewing the literature, it apparent that little is known by policy-makers and researchers about the housing experiences of Indigenous Australians living with a disability. There are anecdotal reports of people being trapped physically in their homes as houses are not modified for their disability (Mines 2011a, p.11, 2011b; see also Senior 2000). Other commentators have reported on incidents of people encountering issues with basic community infrastructure impacting on access to necessary services for Indigenous people living with a disability. The MJD Foundation Limited (2013), for example, highlights such concerns in relation to lacking or inappropriate kerbs and gutters, street lighting and ramp accesses to buildings and the like. Additionally, unpaved roads and poor drainage have also been identified as particular challenges for Indigenous people with disabilities in some communities (Burns 2006, p.17; MJD Foundation Limited 2013, pp.5, 94). The Aboriginal Disability Network of NSW also identified access and service issues for this cohort, reporting that an Aboriginal man living in a discrete Aboriginal community with poor community infrastructure stated:

> I can't get down to the shops and go to places I want to go because the footpath is too bad. (2007, p.2)

The lack of disability-friendly housing, disability services and transport in regional and remote areas means people are often forced to leave their communities in order to access services and appropriate housing (Biddle et al. 2014, p.ix; O'Neill et al. 2004). This forced mobility is commonplace for many residents of rural, regional and remote Australia generally—and magnified for those with more complex needs requiring specialist services—and reflects the well documented lack of services in such areas of Australia and the continual battle for resources to adequately provide basic, let alone specialist, services in non-metropolitan areas (Beer et al. 2003). These challenges are worthy of brief mention here as the context in which people with a disability in non-metropolitan areas live and disability and other support providers operate. The investigations of lived experiences of Indigenous people living with a disability will be situated in these wider contexts affecting individual and community experiences where appropriate.

Deficiencies in information and the broader knowledge base around disability and disability services in Indigenous communities were acknowledged in the lead up to implementation of NDIS and consequently a handful of important projects were initiated through the Practical Design Fund (PDF)—a grants program developed to identify practical ways to enable the transition to the NDIS—to work toward remedying these deficiencies. For the purposes of this study, three projects are of particular interest:

→ Small-scale research conducted to identify the issues in the modification of remote Indigenous housing for people living with a disability by Walls and Bridge (2011) and Walls et al. (2013).

→ A disability audit of communities within north east Arnhem Land and the Northern Territory Gulf was completed (see MJD Foundation Ltd. 2013).

→ Research examining Indigenous concepts of impairment undertaken (see Motivation Australia 2013).

This research project is driven by an evidence based approach to problem solving. The AHURI 2014 National Research Agenda stated that the 'repackaging [of] housing and support services in response to national disability reforms' is a priority area for research and it is evident there are major issues in the provision, location and suitability of housing for Indigenous people with a disability, as well as clear funding constraints in this area of social policy. Given that the lived housing experiences of Indigenous Australians with a disability are unknown, the need to collect baseline information to provide understandings of the issues to inform policies and funding models is imperative. This research will examine:

→ The ability of Indigenous Australians living with a disability and residing in stage one NDIS areas (Tasmania, South Australia and the Barwon area of Victoria) to access appropriate housing.

→ The condition and location of housing and the availability and suitability of housing modifications.

→ The availability and suitability of community infrastructure.

This study will provide data to enable informed policy decisions regarding the funding and allocation for housing, housing modification, housing options and needs and community infrastructure for Indigenous Australians living with a disability. Possible cost effective models for the delivery of supported accommodation and respite care may arise from the research. The research also has the capacity to provide further data on Indigenous homelessness and mobility patterns with possible implications for policy relating to Indigenous people living with a disability. It will also provide understandings on the manner in which Indigenous people living with a disability use other services, adapt behaviour and access other housing services in the absence of appropriate housing or community infrastructure.

1.2   Research themes and questions

This research will document the lived housing experiences of Indigenous people living with a disability. It will examine the characteristics of their housing environments and the cultural, physical, social and functional issues related to housing. This will provide baseline data and recommendations for the provision of housing and community infrastructure within the NDIS implementation.

The project team will respond to seven key research questions:

1. What are the housing experiences of Indigenous people living with a disability in the case study locations?

2. What are the types of housing and housing modifications and the condition of housing available for Indigenous people living with a disability in each of the case study areas?

3. How do Indigenous people respond to the housing options available to them?

4. How does the housing available measure up against the available guides and legislation?

5. What community infrastructure is present in the case study locations to support Indigenous people living with disability?

6. How does the community infrastructure measure up against the available guidelines and legislation?

7. Are there more appropriate housing and community infrastructure models for Indigenous people living with a disability?

It is anticipated that the results will inform policy decisions regarding the funding and allocation for housing, housing modifications, housing options and needs and community infrastructure for Indigenous Australians living with a disability. Possible models for the delivery of supported

accommodation and respite care may arise from the research, along with, potentially, further data on homelessness and mobility.

1.3   Structure of the Positioning Paper

The remainder of this Positioning Paper is structured into six more chapters. Chapter 2 outlines the history of the development of the National Disability Insurance Scheme and its core tenets. It provides a précis of the background, aims and implementation of the NDIS and notes that the housing issues in regard to the NDIS are yet to be addressed. Chapter 3 reviews the data available on the occurrence of disability in the Indigenous population to provide estimates of the number of Indigenous people living with a disability who may encounter issues with housing. Chapter 4 discusses initiatives within the NDIS with regard to housing. Chapter 5 examines the literature on culturally responsive housing models for Indigenous people living with a disability on a national and international level. Chapter 6 provides an overview of the guidelines and recommendations that are applied to housing developments within the Indigenous communities. It contrasts these with the National Construction Code. The various guidelines and codes will be used as benchmarks for the evaluation of housing and infrastructure in this study. Chapter 7 focuses on the research program to examine the lived experiences of housing and infrastructure of Indigenous people living with a disability. The chapter describes the research methodology aimed at documenting the characteristics of the housing environments and the cultural, physical, social and functional issues related to housing. It notes that the study's aim is to provide baseline data and recommendations for the provision of housing and community infrastructure within the NDIS implementation.

2   REVIEW OF POLICY DEVELOPMENTS

2.1   Background to the NDIS

Reform of disability services in Australia has long been called for. The most recent (and successful) lobbying for such change—which ultimately saw the development and then establishment of the NDIS—emerged out of the so called 2020 Summit convened by the then Labor Prime Minister Kevin Rudd (Every Australian Counts 2014). Through this Summit Rudd brought together more than 1000 participants from all areas of the community to raise, debate and discuss issues of national significance under 10 key policy areas of national significance (see Appendix 1). Under the policy area 'strengthening communities, supporting families and social inclusion' the development of a National Disability Insurance Scheme was raised, debated and unanimously put forward as a 'big idea' in need of further investigation (Department of Prime Minister and Cabinet 2008, pp.173, 175, 193). The response to move this idea forward was the Australian Government's commissioning of an inquiry into the 'costs, cost effectiveness, benefits, and feasibility' of a national disability long-term care and support scheme in 2010 (Productivity Commission 2011a, p.iv). The Terms of Reference for that inquiry—known as the Disability Care and Support Inquiry—reflected the strong social inclusion focus of the then Rudd Government and asked the Commission to report on an approach which:

→ provides long-term essential care and support for eligible people with a severe or profound disability, on an entitlement basis and taking account the desired outcomes for each person over a lifetime

→ is intended to cover people with disability not acquired as part of the natural process of ageing

→ calculates and manages the costs of long-term care and support for people with severe and profound disability

→ replaces the existing system funding for the eligible population

→ ensures a range of support options is available, including individualised approaches

→ includes a coordinated package of care services which could include accommodation support, aids and equipment, respite, transport and a range of community participation and day programs available for a person's lifetime

→ assists the person with disability to make decisions about their support

→ provides support for people to participate in employment where possible (pp.iv, v).

Ultimately, the Productivity Commission called for the establishment of a National Disability Insurance and National Injury Insurance Scheme after conducting its comprehensive inquiry into the delivery of services for people living with a disability (see Productivity Commission 2011a, especially Section 1.2). The Commission made the calls after labelling the existing disability support system '… underfunded, unfair, fragmented, and inefficient' (Productivity Commission 2011a, p.2). Within the inquiry, the need for a system that promoted choice for the individual was highlighted (Productivity Commission 2011, vol. 1, p.12). The current NDIS was developed out of these debates and investigations, under the premise of providing '… a new way for people to get disability support that takes an individualised approach to providing care and support over a person's lifetime' (NDIS 2013, p.1). The Productivity Commission inquiry also noted that 'Funding of the scheme should be a core function of government (just like Medicare)' (Productivity Commission 2011a, p.2).

It is also important to mention here that much of the impetus for the need to make wholesale changes to the delivery of disability services in Australia as reported in the Productivity Commission inquiry emerged from a groundswell of support for such change from the disability

and community sectors and the community generally, focused through the 'Every Australian Counts' campaign (launched on Australia Day 2011) and its recognised activists and supporters, among other avenues. The Every Australia Counts campaign continues to focus attention on the NDIS, with their actions now sharply focussed on the refinement and roll out of the NDIS and as they note 'making the NDIS the best it can be' (Every Australian Counts 2014). The 610 initial and 452 post draft submissions received by the Disability Care and Support inquiry also stand as testament to the strength of the campaign for disability sector and services reform.

The NDIS is an important break away from past approaches to the delivery of disability services. Its core tenet is to ensure eligible Australians living with a disability have access to whole-of-life supports focussed on meeting their life goals and aspirations (NDIS 2015d). The Scheme is a social insurance program, supporting 'people with a permanent and significant disability that affects their ability to take part in everyday activities' (NDIS 2015d). For eligible 'participants' NDIS providers will work with them to identify the supports they need for daily life, centred around assistance to meet life goals in areas such as achieving and maintaining independence, community involvement, education, employment and health and wellbeing. The Scheme emphasises participant 'choice and control', expressed in its person-centred focus, and has been designed to give certainty in terms of supports across participants' lifetime. Notably also, and particularly important in the context of this research, the NDIS will fund 'reasonable and necessary supports' for participants where required and to achieve participants' stated goals. This includes in areas such as 'therapies, equipment, home modifications, mobility equipment, taking part in community activities or assistance with employment' (NDIS 2015d). The Scheme is also an information and referral service for people living with a disability who do not meet the eligibility requirements to be participants, as well as for carers and families of all people living with disabilities in Australia.

The establishment of the NDIS in Australia follows international trends in the manner support services are provided to people living with disability (Alakeson 2010; Dixon & Alakeson 2010; Williams 2014). A number of countries have moved beyond passive welfare models to involving people living with a disability in decision making processes (Power et al. 2013). This approach to disability support is underpinned by the United Nations Convention on the Rights of Persons with Disabilities. As part of this Convention, signatories—which include Australia— have committed to 'recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community' (United Nations 2006 Article 19).

The concepts of 'choice' and 'control' are the cornerstones of current reforms to disability support programs nationally. And, these tenets are underpinned by two key policy directions as summarised by Williams (2014, p.30):

1. Personalised support services that are consumer-directed and designed to support each individual's life goals and aspirations.

2. Individualised funding with a personal budget based on each person's assessed needs to enable that person to control the purchase of agreed supports.

The NDIS in Australia follows these principles and is designed to be people-centred and to respond to the diverse needs of participants. Notably, Bruce Bonyhady, Chairman of the NDIA, further adds that in recognising such client diversity and diversity in person-centred needs, the NDIS must also take into account co-morbidities such as psychosocial and intellectual disabilities as well as the functional impairments of people living with disabilities rather than the 'diagnostic labels' they have been given (Bonyhady 2014a, p.7).

The *National Disability Insurance Scheme 2013* (Cwlth) became fully operational on the 1 July 2013. The Act creates '… the framework for the NDIS, including access criteria, age

requirements, how a person with disability works with the National Disability Insurance Agency to draw up a plan to help meet their goals and aspirations, and what constitutes reasonable and necessary support' (Children with Disability Australia 2015).

The rules that accompany the legislation cover issues such as: becoming a participant; representatives of children; when a child can represent themselves; the appointment of nominees; registered providers; plan management; protection and disclosure of information; government agreements; rules for the scheme actuary; risk management rules; and facilitating the preparation of participants' plans in Tasmania, South Australia, New South Wales and Victoria (NDIA 2014). Within the *National Disability Insurance Scheme Act 2013* (Cwlth), the NDIS Launch Transition Agency (now known as the National Disability Insurance Agency) was established to implement the legislation.

2.2 The concepts of disability and permanent impairment

Under the NDIS legislation disabilities are classified according to the type of impairment (e.g. intellectual, cognitive, neurological, sensory or physical), the severity of disability and the degree of assistance required performing core activities (communication, social interaction, learning, mobility, self-care, self-management). Where there are no limitations in performing core activities, the level of disability is considered in terms of whether someone has restrictions impacting on their ability to participate in social and economic activities and whether they are likely to require support for their lifetime (*National Disability Insurance Scheme Act 2013* (Cwlth), sect. 24).

Eligibility for the NDIS is based on participants demonstrating that their disability is the result of an 'impairment or impairments are, or are likely to be, permanent' (*National Disability Insurance Scheme Act 2013* (Cwlth), sect. 24). Additionally, access to early intervention and ongoing support through the Scheme requires that 'there is no known, available and appropriate evidence based clinical, medical or other treatments that would be likely to remedy the impairment(s); and the impairment(s) do not require further medical treatment or review in order to demonstrate permanency (or likely permanency)' (NDIS 2014a, p.2). The NDIS does not assume responsibility for either the medical or health needs of participants, with these remaining the responsibility of the broader health system (see Crowther & Collister 2014 for further discussion).

2.3 Implementation of the NDIS

The NDIS was launched in 'trial' areas administered by National Disability Insurance Agency (NDIA) which is jointly funded by Commonwealth, state and territory governments. From the 1 July 2013, the NDIS began in Tasmania for young people aged 15–24 years, in South Australia for children aged 0–14 years, and in the Barwon area of Victoria and the Hunter area in New South Wales for people up to age 65 years. From 1 July 2014, the NDIS was implemented in the Australian Capital Territory, the Barkly region of the Northern Territory and the Perth Hills area of Western Australia. Most recently (1 July 2015) 'early transition' work around the Scheme for a limited number of people aged 18 was rolled out in NSW in the Nepean Blue Mountains area (NDIS 2013). Roll out of the full scheme in other areas nationally is indicated to progressively happen from July 2016. The Council of Australian Governments have noted that the trial sites '… will be subjected to intensive scrutiny and evaluation. Information of the outcomes achieved, what works well and what requires modification will be provided to COAG for its consideration of any further roll out of the NDIS' (COAG 2012, p.7).

NDIA service providers are tasked with working with individuals living with significant and permanent disability to develop individualised plans to meet their needs and support their life aspirations (NDIS 2015b). This process has been implemented as a foundation of the NDIS to ensure that participants have greater choice and control over their supports, as well as how they are provided, who delivers them and how they wish to manage their funding. Flexibility to

review support plans in the light of changing needs and circumstances is also built into the NDIS process for participants (Australian Government 2013).

The NDIA estimates that some 410 000 people will be participants of the NDIS by 2019 when it is fully operational. Among these participants some 154 000–193 000 will be low or very low-income households, probably requiring housing assistance. Notably, through extrapolation of data on current levels of provision of housing assistance for people living with a disability, the NDIA predict a deficit of affordable housing in the order of 83 000 to 122 000 NDIS participants (Bonyhady 2013, p.3).

2.4 Summary

The establishment of the NDIS is a watershed in social and disability policy in Australia. The Scheme offers hope that for many of the most vulnerable in the community disability services will be more appropriate, timely and consistent. This said, there remain many gaps in information around the Scheme, its reach and execution. Two of such gaps are critical in terms of this research. The first, being how housing issues for people with a disability will be addressed, given the known role of stable and appropriate housing in shaping health and wellbeing outcomes for individuals, and especially for those with more complex needs, such as those relating to disability. The second notable gap around the implications of the NDIS for Indigenous Australians. On this issue it is clear that the reality at the current time is that we know very little about how the Scheme recognises, will work with and/or meet the needs of Indigenous people living with disability. This research aims to shed much needed light on the nexus between lived experiences of disability and housing among Indigenous Australians in order to inform how the NDIS could best meet the needs of this overlooked group within the population.

3 PROFILE OF THE AUSTRALIAN INDIGENOUS POPULATION, HOUSING MEASURES AND INDIGENOUS PEOPLE LIVING WITH A DISABILITY

3.1 Introduction

This chapter examines various types of statistical data to form a clear picture of the Australian Indigenous population, the number of Indigenous people living with a disability and the types of housing they occupy. Data in this chapter are drawn from the Australian Bureau of Statistics, particularly the Australian Health Survey (AHS), which includes information on a representative sample of Aboriginal and Torres Strait Islander peoples, known as the Australian Aboriginal and Torres Strait Islander Health Survey (AATSIHS) (ABS 2014a). The AATSIHS has collected important information on Indigenous Australians in remote and non-remote communities since 2012 and incorporates data measures formerly collected as part of the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS), the National Aboriginal and Torres Strait Islander Nutrition and Physical Activity Survey (NATSINPAS) and the National Aboriginal and Torres Strait Islander Health Measures Survey (NATSIHMS). Helpfully, the most recent AATSIHS (collected 2012–13) presents data from 9300 respondents, focussing on long-term health conditions and health risk factors (ABS 2014c).

3.2 An overview of the Australian Indigenous population

3.2.1 Demographics

The estimated Indigenous population of Australia at 30 June 2011 was 669 900 people or 3 per cent of the total Australian population (ABS 2013a). This population estimate represents a large increase from the population estimate of 517 000 in the 2006 Census, which is considered to have been a significant undercount for a range of reasons including natural population growth, improved Census estimates and an increase in people identifying as Indigenous (AIHW 2014a, p.2).

The Indigenous population has a much younger age profile than that of the non-Indigenous population. This is reflected in the median age of the Indigenous population, which at 30 June 2011 was 21.8 years of age, compared with 37.6 years for the non-Indigenous population (ABS 2013a). Fertility rates among this cohort are and remain higher than for the non-Indigenous population.

While the majority of the Indigenous population lives in major cities (32%), inner regional (21%) and outer regional (22%) areas, a substantial proportion live in remote (10%) and very remote areas of Australia (16%). In comparison with the total Australian population, Indigenous Australians are much more likely to live in remote parts of the country.

The geographical distribution of Indigenous Australians differs from state to state (Figures 1 and 2). And, as shown in Figure 2, the largest population of Indigenous Australians in absolute numbers resided in New South Wales at Census 2011 (208 500 people), the majority in major cities or outer regional areas. Queensland was home to the next largest population at the state level, with 189 000 Indigenous Australians, many living in remote and very remote regions. The smallest population of Indigenous Australians lived in the Australian Capital Territory (6200 people). Indigenous Australians comprised 30 per cent of the population of the Northern Territory, by far the highest proportion of any state or territory population (ABS 2013a).

Figure 1: 2006 Indigenous population clusters
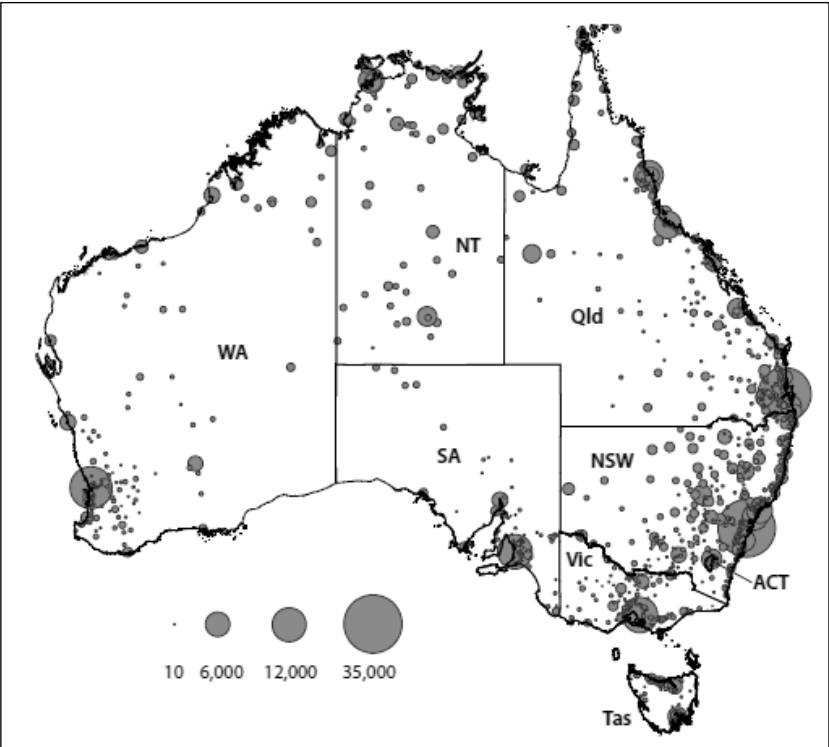
Source: AIHW 2011b, p.9

Figure 2: 2011 Distribution of the Indigenous population
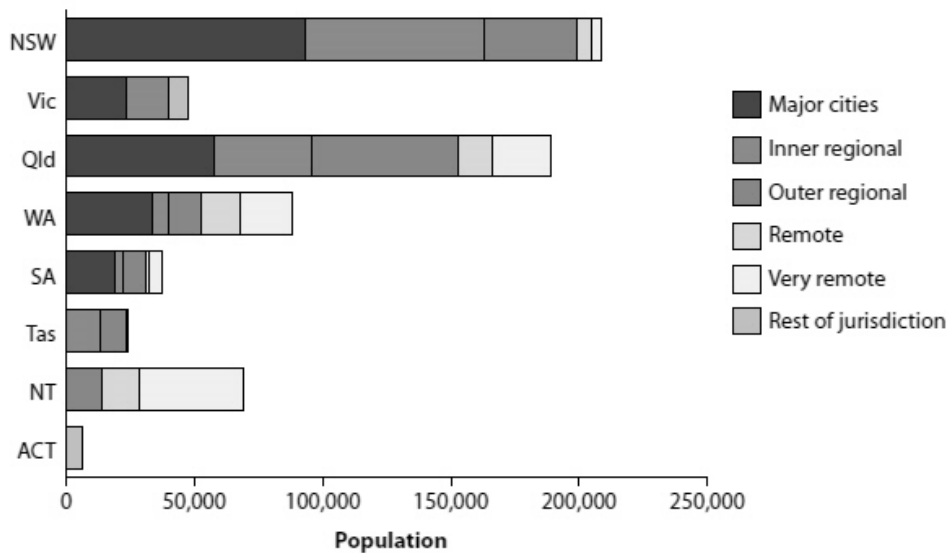
Source: ABS 2013a

The locations in which people live has implications for service delivery and people's overall quality of life. For Indigenous people living in remote communities, the key issues in this regard centre around health outcomes related largely to the quality of housing and infrastructure. Senior (2000) discussed these issues some 15 years ago with respect to one Aboriginal community. She noted the clear limitations placed on residents living with disabilities because of 'place':

The physical environment of the community is limiting to people with disabilities. The roads are dirt and deeply corrugated causing great difficulties for those in wheelchairs or who are unsteady on their feet. In the wet season the roads are often flooded and always boggy. Moving around the community can be very difficult. Transport is also a problem for members of the community. Very few people have cars and public transport is limited. (Senior 2000, p.10)

Knowing where Indigenous people living with a disability reside is important as it has implications for the provision of appropriate housing and community infrastructure. How the different housing and disability related needs of Indigenous people vary by geographic area will be touched on in the research.

3.3   Indigenous housing

Many challenges have been noted in the design, delivery and development of Indigenous housing in Australia (e.g., see, work for AHURI by Fien et al. 2007, 2008; also Long et al.'s almost 10-year-old but just as pertinent and useful *Audit and review of Australian Indigenous housing research* (2007)). These have included concerns over the cultural appropriateness of housing, issues with continuity in the delivery of Indigenous housing, as well as problems relating to the provision of essential services such as power, water and waste and other community infrastructure. These concerns have particularly been expressed in relation to discrete Indigenous communities as they are necessary for maintaining the health and well-being of residents of such communities (The Australian Institute of Architects 2008). Such are the concerns with the state of Indigenous housing that the Australian Institute of Architects have noted that:

The standard of housing and essential infrastructure available to Indigenous communities is well below that which is generally available to the non-Indigenous population. There is clear evidence that the failure of governments to provide a reasonable standard of housing design, construction and maintenance has direct and immediate consequences for the health and well-being of Indigenous people. The inadequate supply of housing, which leads to overcrowding, aggravates these problems. (2008, p.1)

Evidence shows the prime causes for concerns about Indigenous housing stem from poor quality initial construction exacerbated by irregular and inadequate maintenance (The Australian Institute of Architects 2008, p.2; see also Neutze 2000; Nganampa Health Council et al. 1987; Pholeros 2002; Pholeros et al. 1993).

3.3.1   Home ownership

Bailie and Wayte (2006) suggest 'owning rather than renting a home may confer ontological security—a sense of security, control and mastery—which in turn may have flow on effects to health and well-being' (p.180). Unfortunately, there is no literature relating to outcomes of home ownership on the health or wellbeing of Aboriginal and Torres Strait Islander people (see Memmott et al. 2009a, 2009b for discussion of some elements of Indigenous home ownership). It is known that home ownership provides the most secure form of housing tenure (Elsinga & Hoekstra 2005; Beer & Faulkner 2009a) and secure tenure generally allows residents to undertake housing modifications for disabilities (Beer & Faulkner 2009b; Kroehn et al. 2007). Having limited or no choice at all about where one lives, or residing in inappropriate housing, has a profound impact on an individual's physical and mental health and wellbeing (NPDCC 2009; see also Baker et al. 2014; OECD 2011). Recent research by the National People with Disabilities and Carer Council (NPDCC) also notes the clear impact of unstable and inappropriate housing on social inclusion outcomes for people living with disabilities (NPDCC 2009) and a review of the key literature around *Housing strategies that improve Indigenous health outcomes* by Ware (2013) draws the same conclusions for the Indigenous population,

emphasising the bidirectional relationships between health and housing (see also Phibbs & Thompson 2011 for AHURI).

According to the 2011 Census the Indigenous population is under-represented in the home ownership and home purchase tenures and over-represented in both the private and public rental markets. Only 32 per cent of households including an Indigenous person or persons fully owned or were purchasing their home at the time of the 2011 Census—compared with 68 per cent for all Australian households—with only one-third of these homes owned outright (AIHW 2011b, p.23). There has been a gradual increase in the rate of home ownership among Indigenous households: 32 per cent owned or were purchasing their own home in 2001, 34 per cent in 2006, and 36 per cent in 2011 (AIHW 2014b, p.6). The vast majority of other Indigenous households—about three in five (59%)—rented their home. This stands in contrast to rental trends among other household types, where around one in three households (29%) rented their home at the same point in time (AIHW 2014b, p.4).

Patterns of home ownership and rental for Indigenous households vary by location. Rates of home ownership for Indigenous households are much higher in non-remote areas (36%) than areas classed as remote (16%) (AIHW 2011b, p.23). The proportion of Indigenous families owning homes is highest in Victoria, New South Wales and Queensland and lowest in the Northern Territory where there is a high proportion of Indigenous people living in discrete Aboriginal communities.

Dwellings in remote Indigenous communities are generally owned and managed by public housing providers or community bodies. A significant proportion of remote households pay rent to housing organisations (33%) when compared to Indigenous households in non-remote areas (5%) (AIHW 2011b, p.23). Analysis of data from the past three Censuses by the Australian Institute of Health and Welfare (2014b) provides further detail regarding tenure trends among households with one or more Indigenous resident and other household types (see Table 1).

Table 1: Housing tenure, Indigenous and other households Australia, 2001, 2006, 2011 Censuses (% of respective populations)

Tenure type	Indigenous households			Other households		
	2001[1]	2006	2011	2001[1]	2006	2011
Home owners						
Owned outright	12.6	11.0	11.2	41.5	34.6	32.6
Being purchased	19.4	23.2	24.8	27.8	34.4	35.2
Total home owners	32.0	34.2	35.9	69.3	68.9	67.8
Renters						
Social housing	31.3	29.0	26.3	4.8	4.4	4.1
Private renters	27.4	27.0	29.1	19.8	20.8	22.6
Other renters	4.9	4.3	4.0	2.7	2.2	2.0
Total renters	63.5	60.2	59.4	27.3	27.4	28.8
Other tenure type	1.3	0.7	0.7	1.3	0.8	0.9
Tenure type not stated	3.2	4.9	4.0	2.1	2.8	2.5
Total (%)	100.0	100.0	100.0	100.0	100.0	100.0
Total number	**144,493**	**166,659**	**206,049**	**6,600,302**	**6,977,437**	**7,551,237**

Source: AIHW 2014b, p.7

Notes: [1] AIHW explains that this data differs from that in the 2001 Census community profiles as a different definition of Indigenous was used at that time.

Understanding Indigenous ownership arrangements is important in the context of this research, as the investigations will examine whether changes in governance, funding and ownership of housing within communities, as well as among individual households (where appropriate), impacts positively or otherwise on lived experiences of disability and the provision and receipt of disability-related services.

3.3.2 Measurements of housing need

A number of data sources exist nationally highlighting specific housing needs and measures of such needs among Indigenous Australians. Such data sources and their analyses point to key concerns related to overcrowding (AIHW 2014b) and homelessness (AIHW 2011b). Other sources note the high levels of housing assistance among Indigenous households of various types (AIHW 2014c).

On the issue of overcrowding AIHW (2014b) analysis of relevant ABS 2011 Census data finds a number of key trends of concern here:

→ Indigenous households were three times more likely to be living in overcrowded situations (requiring one or more additional bedroom[s]) than non-Indigenous households (p.18) and as a population rate Indigenous people were 35 times more likely to be living in severely overcrowded dwellings than non-Indigenous people (AHIW 2014e, p.10).

→ Some 115 600 Indigenous people were living in overcrowded conditions at the time of the Census, with this equalling around 25 per cent of the total Indigenous population recorded at home in private dwellings at that point in time (p.19).

→ Incidence of overcrowding among renting Indigenous households, especially those households renting from social landlords and lowest among home owners.

→ Incidence of overcrowding had a strong geographic expression, with Indigenous households in remote and very remote areas much more likely to be living in overcrowded conditions than those in non-remote areas. In large measure this is a function of the high rates of overcrowding among Indigenous households in social housing properties in these regions (nationally 46% in regions defined as very remote and 31% in those considered remote) (p.20).

→ Rates of overcrowding (and the absolute numbers of people affected) have generally fallen across the last three Censuses for Indigenous households (p.19), although remain in an area of concern in terms of inappropriate housing and unmet housing needs.

The AIHW note multiple reasons for the much higher rates of overcrowding among Indigenous households, commenting that:

> The higher level of overcrowding among Indigenous households is associated with a number of factors, including cultural and social differences, higher levels of unmet demand for affordable housing, and lower income levels …. (AIHW 2014b, p.18)

Another key indicator and area of housing need for Indigenous Australians concerns rates and absolute numbers of people who are homeless. Analysis of 2011 Census data by the AHIW (AIHW 2014e) alarmingly finds that some 28 per cent of homeless people indicating their Indigenous status were homeless on Census night in 2011. This proportion of the homeless population is clearly well in advance of their proportion of the total population (3%). Moreover, when rates of homelessness per 10 000 persons were calculated by the AIHW, a stark picture of crisis and unmet housing needs emerged:

> Taking into account the size of the Indigenous population, 1 in 20 Indigenous people (488 per 10 000 population) were considered homeless on Census night in 2011. This is 14 times the rate for non-Indigenous people (1 in 284 people, or 35 per 10 000 population). (AIHW 2014e, p.7)

The vast majority of those enumerated as homeless at that Census (nearly three quarters) were in fact living in severely overcrowded dwellings which needed four or more extra bedrooms to accommodate residents (AHIW 2014e); thus meeting the severely overcrowded component of the ABS's statistical definition of homelessness (see Appendix 2 for a brief discussion of the ABS definition and ABS 2012b and Chamberlain 2014 for further detail). The average number of residents of Indigenous households in severe overcrowding was 12 people, three more than the average for all severely crowded dwellings (AHIW 2014e, p.8).

Table 2 outlines other key trends among homeless Indigenous people indicative of their precarious housing situation (expressed per 10 000 population for Censuses 2006 and 2011). A key data point in the table in terms of housing needs and the Indigenous population is that they are 13 times more likely than their non-Indigenous counterparts to be sleeping rough, that is living in improvised dwellings, tents or sleeping out (AIHW 2014e, p.10).

As with data for overcrowding there is a clear regional geography to homelessness for Indigenous Australians, with seven in every 10 homeless Indigenous people nationally in remote areas of the country (AIHW 2014e, p.14). This average reflects the high prevalence of severe overcrowding among Indigenous households in more remote areas.

Table 2: Population based rates of homelessness for Indigenous and non-Indigenous homeless people by type of homelessness, Australia, 2006 and 2011 (rate per 10 000 of respective populations at Census)

Type of homelessness	Indigenous		Non-Indigenous	
	2006	**2011**	**2006**	**2011**
In improvised dwellings, tents or sleeping out	46.0	30.6	2.6	2.4
In supported accommodation for the homeless	59.2	59.9	6.4	7.2
Staying temporarily with other households	19.1	18.4	9.0	8.0
Staying in boarding houses	17.2	12.4	6.8	6.9
In other temporary lodging	0.5	0.7	0.3	0.3
Living in severely crowded dwellings	428.5	365.9	6.3	10.4
All homeless people	*570.6*	*487.9*	*31.4*	*35.2*

Source: AIHW 2014e, p.10

The high level of homelessness among the Indigenous population is clearly of concern in understanding, assessing and addressing the housing needs of this population group. These concerns are further magnified when the group referred to as 'marginally housed' or at risk of homelessness by the ABS is also considered (the ABS now counts this group separately to total homelessness). As noted in the AIHW publication *Homelessness among Indigenous Australians* available data that can be gleaned from the 2011 Census suggests that there are another 12 837 individuals in selected types of marginal housing: 92.4 per cent of them in overcrowded dwellings requiring three more bedrooms; 6.2 per cent marginally housed in caravan parks with limited other alternatives based on employment status and income; and 1.4 per cent in improvised dwellings that do not meet the technical definition for inclusion in the homelessness count for this category (AIHW 2014e, pp.16–17).

Further indicators of housing need among the Indigenous population relate specifically to the quality and availability of housing (and other infrastructure) in certain Indigenous communities. Data sources in this area are somewhat dated, with the 2006 Community Housing and Infrastructure Needs Survey (CHINS) (the third CHINS to be conducted by the ABS) providing some key information regarding regional concerns. The 2006 CHINS updated information

collected previously in 2001 and 1999 relating to discrete Indigenous communities and provided information such as:

→ '… details of current housing stock, dwelling management practices and selected income and expenditure arrangements of Indigenous organisations that provide housing to Aboriginal and Torres Strait Islander peoples.

→ Details of housing and related infrastructure such as water, electricity, sewerage, drainage, rubbish collection and disposal as well as other facilities such as transport, communication, education, sport and health services, available in discrete Aboriginal and Torres Strait Islander communities' (ABS 2007b, p.iv).

In 2006, CHINS data showed that there were 17 177 permanent dwellings in discrete Indigenous communities (ABS 2007a). A key finding of this survey and important in the context of housing need is that highlighting the continuing issue of Indigenous people residing in temporary dwellings. On this point the ABS note that:

> Of the 92 960 Aboriginal and Torres Strait Islander people reported as living in discrete Indigenous communities, a total of 4039 people (4%) were reported as living in temporary dwellings. This compares with 5602 people (5% of the total population of 108 085 in discrete Indigenous communities) in 2001 (ABS 2007a, p.4).

In presenting the most recent data available here on the housing needs of Indigenous households nationally, it is important to note that there has generally been some improvement noted in the housing circumstances of this cohort in terms of overcrowding, homelessness, and, possibly, in terms of the quality of housing (and other infrastructure) (Biddle 2012). These challenges for the Indigenous population have been the target of particular policy initiatives over recent years, including actions to improve housing circumstances and options under the National Partnership Agreement on Remote Indigenous Housing (COAG 2008).

Finally, it is important to note here that while there is information on housing needs for Indigenous households (as outlined above), little information exists on housing needs for Indigenous people living with a disability or for households where one or more residents identify as Indigenous. The ABS Survey of Disability, Ageing and Carers (SDAC), last conducted in 2012, collected data from 1550 Indigenous people and 66 550 non-Indigenous people living in private dwellings (ABS 2013c). The ABS further noted that comparisons between Aboriginal and Torres Strait Islander people and non-Indigenous people are 'not necessarily representative of all people living across Australia', primarily because the survey did not capture information and experiences of Indigenous people in the most remote regions of the country:

> … the proportion of non-Indigenous people living in very remote areas is very small (less than 1%), Aboriginal and Torres Strait Islander people living in very remote areas account for around 14 per cent of that population. (ABS 2014b)

Clearly more comprehensive and representative data about the housing and other shelter-related needs of Indigenous people living with a disability, and analysis of this data—like that produced by the AIHW on *Aboriginal and Torres Strait Islander people with disability* for the domains of wellbeing, participation and support for the 2006 Census (AIHW 2011a)—is needed to progress debates and improve outcomes for this population group.

3.4   Indigenous people living with a disability

3.4.1 Defining disability

Disability is a 'concept', 'label' or 'category' that has been defined in many different ways at different times and depending on the reason for which the definition is needed. This point is emphasised upfront in the AIHW's key disability background and data publication *Disability prevalence and trends* (AIHW 2003a) which notes in particular how definitions of disability vary

(and matter) between, for example, applications in population-focused surveys and in determining eligibility for disability-related support services or income support payments (AIHW 2003a, p.4). In that publication, and in Australia generally (AIHW 2003b), the favoured definition or rather understanding of disability is based on the World Health Organisation's (WHO) interactive framework for defining and measuring health conditions (including disability) at the individual and population level known as the International Classification of Functioning, Disability and Health, referred to as the ICF (for further discussion see WHO 2001, 2014; also Madden & Dimitropoulous 2014). The ICF uses 'disability' as an umbrella term for any or all of the following:

→ 'impairments—problems in body function or structure such as significant deviation or loss

→ activity limitations—difficulties an individual may have in executing activities

→ participation restrictions—problems an individual may experience in involvement in life situations' (WHO 2001, p.10).

Environmental factors which 'make up the physical, social and attitudinal environment in which people live and conduct their lives' (WHO 2001, p.10) are also considered in terms of their negative and positive impact on the domains outlined above (pp.16–17).

The ABS considers five main concepts in its measurement of the prevalence of disability in Australia: disability; long-term health condition; specific limitation or restriction; core activity limitation and levels of restriction; and the need for assistance (ABS 2013c) (see Appendix 3). These concepts underpin data collection in the main survey instrument used to collect information about disability nationally, the ABS *Survey of Disability, Ageing and Carers* (SDAC). In the SDAC a person is considered to have a disability if '… they report they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities' (ABS 2013d). Box 1 outlines the specific limitations, restrictions or impairments in this regards.

In considering disability-related limitations, restrictions or impairments the ABS also measure the 'severity of disability'; qualifying this by determining the highest level of limitation(s) an individual may encounter in performing daily core activities such as self-care, mobility and communication into four levels of severity or limitation (and therefore need) as outlined in Box 2.

Box 1: Disability-related limitations, restrictions or impairments considered in the ABS's SDAC

Loss of sight (not corrected by glasses or contact lenses).

Loss of hearing where communication is restricted, or an aid to assist with, or substitute for, hearing is used

Speech difficulties

Shortness of breath or breathing difficulties causing restriction

Chronic or recurrent pain or discomfort causing restriction

Blackouts, seizures, or loss of consciousness

Difficulty learning or understanding

Incomplete use of arms or fingers

Difficulty gripping or holding things

Incomplete use of feet or legs

Nervous or emotional condition causing restriction

Restriction in physical activities or in doing physical work

Disfigurement or deformity

Mental illness or condition requiring help or supervision

Long-term effects of head injury, stroke or other brain damage causing restriction

Receiving treatment or medication for any other long-term conditions or ailments and still being restricted

Any other long-term conditions resulting in a restriction.

Source: ABS 2013d

Box 2: The ABS's four levels of severity of disability and related limitations

Profound	→	the person is unable to do, or always needs help with, a core activity task.
Severe	→	the person:
		→ sometimes needs help with a core activity task
		→ has difficulty understanding or being understood by family or friends
		→ can communicate more easily using sign language or other non-spoken forms of communication.
Moderate	→	the person needs no help, but has difficulty with a core activity task.
Mild	→	the person needs no help and has no difficulty with any of the core activity tasks, but:
	→	uses aids and equipment
		→ cannot easily walk 200 metres
		→ cannot walk up and down stairs without a handrail
		→ cannot easily bend to pick up an object from the floor

Source: ABS 2013d

Notably one group of researchers commentating on data issues for Indigenous people (Biddle et al. 2014, p.30) has noted that '… the most useful measure of disability from surveys is "profound/severe core activity limitation"' as service delivery for this population group is most critical. While this point is true, it is also important that due consideration is also given to both enumerating and meeting the needs of those with less 'severe' disabilities, especially in areas where services are poor. Interestingly, the same commentator also noted that the measures of 'disability' proposed by the Productivity Commission for estimating the number of people living with a disability as part of the NDIS do not always correspond to currently used survey measures (see Biddle et al. 2014, p.31). These concerns regarding data and definitions of

disability highlight the ongoing difficulties around 'disability' and its definition in a cultural context. Such issues will be given considerable attention in the conceptualisation and execution of the fieldwork component of this research.

3.4.2   Measuring the prevalence of disability in the Indigenous population

A number of surveys are used to estimate the prevalence of disability in the Indigenous population. These include the Census, the SDAC (as mentioned above) and other instruments such as the National Aboriginal and Torres Strait Islander Social Survey (NATSISS).

The 7th SDAC, conducted in 2012, is considered by some, such as Biddle et al. (2014) to be the most comprehensive source of data on the prevalence of disability. It confirms that typically, physical disability is the most common disability type experienced by Indigenous Australians overall (Figure 3). Moreover, as shown in Figure 4, in many age groups Indigenous Australians living with a disability are at least twice as likely to need help with a core activity.

Figure 3: Disability type for Aboriginal and Torres Strait Islander people aged 15–64 years with severe or profound core activity limitations, Australia, 2006 (% of all Indigenous people with such limitations)
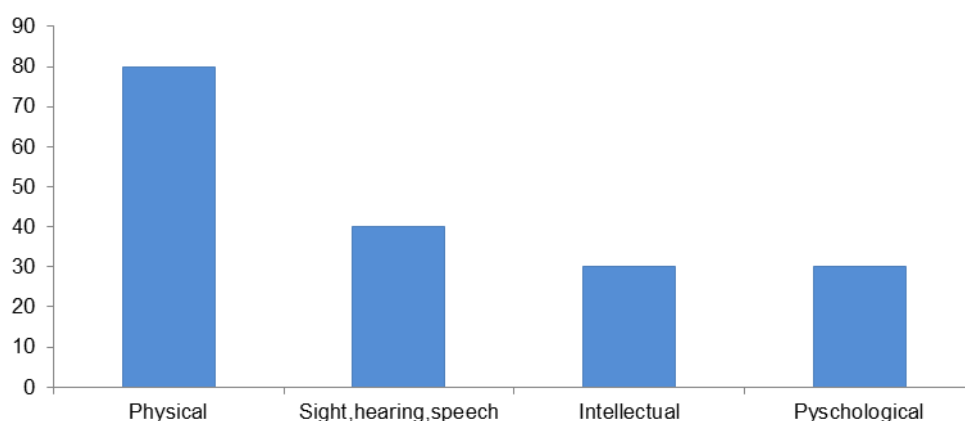
Source: AIHW 2011b, p.47

Note: Disability types are not mutually exclusive. Data based on AIHW analysis of the 2008 NATSISS.

Figure 4: Proportion of Indigenous and non-Indigenous people needing assistance with core activities, Australia, 2008 (% of respective populations)
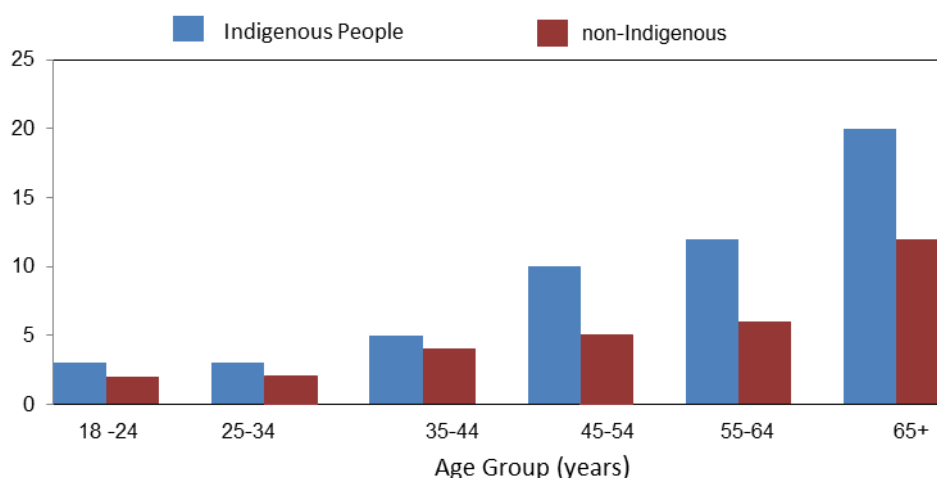
Source: AIHW 2011b, p.46

Note: Data based on analysis of 2006 Census data.

According to the 2006 Census, 19 600 Indigenous Australians need assistance with a core activity and could be assumed to have a profound or severe disability. The most recent NATSISS records 26 000 Indigenous Australians aged 15 years or over as having a profound or severe limitation on performing core activities (ABS 2013b). Biddle et al. (2014) note that in comparing this data   with the Census, the NATSISS presents superficial evidence of a much larger issue given it has been generally found that half of the Indigenous population aged 15 years and over (some 163 000 people) has some form of disability (p.38).

Some sources maintain that it is difficult to accurately quantify disability within the Indigenous community (NPDCC 2009; Productivity Commission 2011b; First Nations Disability Network 2013). This point is also raised by the AIHW (2006) who in their publication *Disability rates among Aboriginal and Torres Strait Islander people—Updating the Indigenous factor in disability services performance indicator denominators* which drew on data from the 2002 NATSISS and the 2002 ABS General Social Survey (GSS) questioned the accuracy of the current data on the prevalence of Indigenous people living with a disability on the basis of the data captured and included in those surveys and available for comparison between the two population groups. The Institute noted that as the surveys captured data for different age ranges (18+ for the GSS and 15+ for the NATSISS; meaning comparisons could only be made based on over 18 data) this saw some 45 per cent of the (structurally much younger overall) Indigenous population omitted from the survey. And, this translated to the estimates for disability derived from the AIHW's analysis representing just over half the total Indigenous population but some three-quarters of the much older non-Indigenous population (AIHW 2006, pp.5–6; see also AIHW 2011a, pp.17–18). While this issue was largely overcome in the design and conduct of the subsequent NATSISS (2008) there remain quality issues with regard to Indigenous subjects in surveys, particularly because of undercount (discussed further below) and variability/errors in surveys based on sample populations rather than universal application (see ABS 2009 for further discussion). The fact that different explanations of disability were used in the application of the NATSISS in remote versus non-remote areas has also been cited as a reason for caution in the use of disability data from that survey—with a likely undercount of rates of disability in remote areas generally, and a definite underrepresentation of rates of mental illness where an individual needs assistance as this line of questioning was overlooked in the data collection (ABS 2009).

The Productivity Commission in their inquiry into *Disability Care and Support* (2011b) also provides some commentary on the appropriateness of data about disability within the Indigenous community. They note that a key issue in this regard is that of data quality due to the known issues of undercount (as captured in the Post Enumeration Survey conducted after each Census) and the higher non-response to surveys among Indigenous people. This fact was proven for the 2006 Census, where the net undercount rate was measured at 2.7 per cent for non-Indigenous Australians and 11.5 per cent for Indigenous Australians (ABS 2012a). It is also demonstrated by the comments made by the ABS about the 2006 Census questions on need for assistance, where '[i]n the Indigenous population, the non-response rate was 7 per cent for the questions about need for assistance, and in the non-Indigenous population, non-response was 2 per cent' (AIHW & ABS 2008, p.59). Rates of undercounting for the most recent Census were indeed higher for the Indigenous population, tipping 17.2 per cent, versus 6.2 per cent for the non-Indigenous population (ABS 2012a). These much higher rates of undercounting (and non-response) clearly impact on the robustness of data about Indigenous people and Indigenous people and disability.

On the whole it is important that these known limitations to data must be considered in any investigation of the characteristics of Indigenous Australians, and prevalence of such things as disability, issues with housing and need for supports among Indigenous Australians.

Reporting of disability among Indigenous people is also influenced by cultural factors. Some Indigenous Australians find the concept of disability difficult to understand or irrelevant, thus

reducing the likelihood that the surveys accurately record the prevalence of disability. The First Peoples Disability Network emphasised this in their *Ten-point plan for the implementation of the NDIS in Aboriginal communities* (First Peoples Disability Network 2013a), with point one of the plan stating the need to:

> Recognise that the starting point is that the vast majority of Aboriginal people with disability do not self-identify as people with disability. This occurs for a range of reasons including the fact that in traditional language there was no comparable word for disability. Also that many Aboriginal people with disability are reluctant to take on the label of disability particularly if they may already experience discrimination based on their Aboriginality. In many ways disability is a new conversation in many communities therefore with regard to the NDIS we are starting from an absolute baseline position. And as a consequence change in this area may evolve on a different timeline to that of the main part of the NDIS.

Moreover, in some Aboriginal communities there are diverse and complicated understandings of the emergence and presence of disability (as there are also diversities among and between Indigenous cultures). Again the First Peoples Disability Network provided commentary in this regard to the Productivity Commission's inquiry into *Disability Care and Support*, noting that in some communities there is a stigma attached to disability; it is viewed along the lines of bad karma; and, in some cultures, disability is considered a result of 'married wrong way' (Griffis 2010, p.8). This reality was also mentioned by Senior (2000, p.17) in her now 15-year-old work *Testing the ICIDH-2 (International Classification of Functioning, Disability and Health-2) with Indigenous Australians* in two Aboriginal communities in the Northern Territory.

Examination of research relating to Indigenous disability by the Productivity Commission itself adds that 'supernatural causes' or sorcery have also been seen as a reason for incidences of disability in some communities, especially in terms of mental health issues (Productivity Commission 2011b, p.540 quoting Senior 2000, pp.15–17).

This point nicely highlights how concepts of disability can be constructed very differently between Aboriginal communities. Many Aboriginal people understand disability from a very medical standpoint, focussing on physical or visible types of impairments and failing to recognise mental illness or cognitive deficiencies as a type of disability. Bostock (2007) notes that this can result in serious under-reporting of disability in some communities. These factors are also noted in the Productivity Commission's examination of Indigenous disability as important barriers to accessing disability services among the Indigenous population generally (PC 2011b, Chapter 11). Viewing disability in a very medical way, which reflects past approaches to service delivery in such communities, presents a specific challenge in terms of the roll out of the NDIS, for as the First Peoples Disability Network highlights, there is limited understanding among many Indigenous people and communities about a social model of funding, servicing and dealing with disability (First Peoples Disability Network 2013b).

In understanding the prevalence of disability among the Indigenous population it is important to acknowledge also that for many Aboriginal people the challenges they face because of disadvantage and discrimination are considered more important than disability. This point was made more than 20 years ago in an article by Gething (1994, p.30), who noted then that:

> Problems associated with disability are widespread and accepted as part of life; they are so vast yet secondary to being Aboriginal or of Torres Strait Islander background that they do not rate a mention on any agenda of priorities or needs. Poor living conditions and their consequences are a common element with the Aboriginal experience.

There is some evidence that because of fear of stigmatisation or discrimination some Indigenous people choose not to identify as having a disability (Aboriginal Disability Network of NSW 2007; see also First Peoples Disability Network 2013a, 2013b; Griffis 2010). This of

course leads to further under-reporting of levels of disability. On the whole the reality is (and remains) that Indigenous Australians experience the worst health outcomes of any group in Australia, as evidenced over time in many publications reporting data about the health of Aboriginal and Torres Strait Islanders by the ABS and AIHW (ABS 2013b, 2014a & b; AIHW 2011b, 2014a; AIHW & ABS 2008). Despite this many Indigenous people perceive themselves to be in 'good health.' As shown in Table 3 the self-assessed health status of Indigenous people improved between the periods 2001 and 2012–13 for residents living in remote localities, while results for Indigenous people in non-remote circumstances show a general trend towards self-diagnosed 'good' health with lower levels of people reporting 'excellent' and 'fair' health. A very small percentage of people sampled in non-remote circumstances (7.5%) and remote circumstances (6.7%) perceived themselves to be in poor health. These figures are interesting given what we know from underreporting of disability and the poor health of the Indigenous community generally, as discussed throughout this section.

Table 3: Self-assessed health status, Aboriginal and Torres Strait Islander persons, Australia, 2001 and 2012–13

	2001		2012–13		Percentage point change	
	Non-remote	**Remote**	**Non-remote**	**Remote**	**Non-remote**	**Remote**
Excellent	15.7	10.8	12.9	13.1	-2.8	2.3
Very good	26.7	24.2	26.7	24.7	0	0.5
Good	29.5	42.8	34.6	41.1	5.1	-1.7
Fair	20.6	15.1	18.2	15.7	-2.4	0.6
Poor	7.5	6.7	7.6	5.5	0.1	-1.2

Source: ABS 2013b

While Indigenous people may choose not to identify as living with a disability and are reporting better self-assessed health overall and by region, there is evidence that Indigenous people are living with high levels of distress as a result of their circumstances and health conditions. This reality is demonstrated in data collected and analysed by the ABS (2013b) which notes the high proportion of Indigenous individuals reporting high or very high distress levels compared with the non-Indigenous populations: some 30 per cent of Aboriginal and Torres Strait Islander adults report high or very high distress levels while only 11 per cent of non-Indigenous adults report the same (see Figure 5).

Figure 5: Comparison of level of high and very high distress recorded by Indigenous and non-Indigenous people, Australia, 2012–13 (% of respective populations)
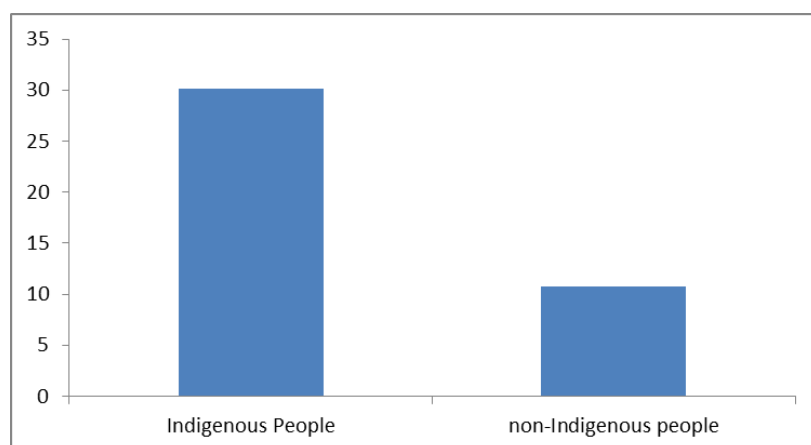
Source: ABS 2013b

3.5   Summary

As the discussion in this chapter highlights there remains a way to go nationally to determine an accurate picture of disability among Indigenous Australians living with a disability, let alone of their housing circumstances and needs. These challenges have been recognised in the research design for this project, resulting in the development of a flexible narrative inquiry methodology.

Moreover, it is clear from the discussion in this chapter that more detailed data is needed on the *impacts* of homelessness, overcrowding and other adverse circumstances on housing for Indigenous people living with a disability in particular. This population group is surely one of the most disadvantaged in the community. We know little about their access to services, and even less about how a scheme such as the NDIS could or will work to positively influence their lived experiences of disability, housing and infrastructure. As a first empirical study in this space, this research will, where able and appropriate, shed important light on how the demographic trends and other factors raised in this discussion (and subsequent chapters) impact on lived experiences of disability (through the lens of housing and infrastructure) for this group.

4 HOUSING, ACCOMMODATION AND THE NDIS

4.1 Disability and housing

The key housing requirements for most individuals are secure tenure and affordable housing. There is a robust and growing body of work for AHURI noting these requirements (e.g., see Beer & Faulkner 2009a; Beer et al. 2006; Centre for Housing, Urban and Regional Planning 2012; Hulse et al. 2015, 2012; Jacobs et al. 2004, 2005; Rowley & Ong 2012; Stone et al. 2013; Wulff et al. 2009, 2011; Yates 2006; Yates & Milligan 2007). For people living with a disability further key requirements may be necessary. Some may require housing that is designed or fitted out in a particular way to meet their disability-related needs (NPDCC 2009; McConkey & Keogh 2014; Tually & Beer 2010). Some people living with a disability may also require housing located near particular services and facilities such as hospitals, specialist health services and/or public transport. Close proximity to these amenities is necessary to manage their condition or mobility and access issues (Tually et al. 2011; Wiesel et al. 2012). Tually et al. confirmed this in their study into the nexus between disability, housing and social inclusion noting that 'Households where one or more persons is affected by a disability are often forced to choose between inappropriate accommodation in accessible locations and more appropriate housing in less accessible places' (2011, p.30). Furthermore, these factors can lead to social exclusion for what is already considered a highly vulnerable and disadvantaged group within the population (Tually et al. 2010, 2011).

As is noted throughout this chapter, the particular needs of people living with a disability are as diverse as their 'type' or 'classification' of disability. The diversity of these needs translates into specific housing requirements of people living with disabilities. People living with acquired brain injuries and psychiatric disabilities, for example, have different housing needs compared with people with physical limitations such as mobility issues (discussed further below) or those with multiple impairments. The episodic nature of such disabilities often requires people with psychiatric and cognitive disabilities to spend periods of time in care meaning that they may find it difficult to maintain a rental property (Kroehn et al. 2007; Beer & Faulkner 2009b). Inappropriate behaviour exhibited during psychiatric episodes may result in people being evicted for property damage or in response to complaints by neighbours (Morden 2014; McConkey & Keogh 2014).

By comparison, people with physical disabilities often require housing with specific accessibility features, which define such housing as so called accessible housing. This is distinct also from adaptable housing—in which features to assist residents are introduced over time as needed (Palmer & Ward 2013). Accessible housing is a design 'standard' that places disability and access at the centre of design, offering residents a range of specific features. Many of them also promoted by the Livable Housing[1] and Universal Design[2] movements, which have a broader user focus and some level of national adoption, albeit difficult to quantify (RI Australia

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[1] In their (voluntary) Livable Housing Design Guidelines, Livable Housing Australia define Livable Housing as that which 'is designed and built to meet the changing needs of occupants across their lifetime' (LHA 2015, p.8). Further, 'Livable homes include key easy living features that make them easier and safer to use for all occupants including: people with disability, ageing Australians, people with temporary injuries, and families with young children' (p.8). They are designed to: 'be easy to enter; be easy to navigate in and around; be capable of easy and cost-effective adaptation, and be responsive to the changing needs of home occupants' (p.8).

[2] Similarly, Universal Design 'is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design' (Mace 2008). Universal Design as conceptualised by The Centre for Universal Design in the US (a seminal organisation in its development and evolution as a design standard) is based on 7 principles: equitable use; flexibility in use; simple and intuitive use; perceptible information; tolerance for error; low physical effort; and size and space for approach and use (The Centre for Universal Design 1997). An Australian adaptation of Universal Design Principles is available on the Australian Network for Universal Housing Design website (http://www.anuhd.org/publications-and-resources/principles-of-design).

& ANHUD 2014) and/or technologies to improve their quality of life and participation. Examples of features that may be included in accessible housing are: lowered kitchen benches, roll-under stoves, benches and sinks, roll-out kitchen and laundry drawers, wider internal and external doorways, roll-in showers and raised power points (The Arc 2015).

Some inroads have been made in terms of delivery of some accessible homes to the market, especially among new build and upgraded social housing contributed to the market as part of the Social Housing Initiative under the Nation Building Economic Stimulus Plan[3] (AIHW 2014d). This said, for people reliant on wheelchairs or other mobility aids accessible housing or that designed to the broader Universal Design or Livable Housing design standards remains difficult to find in both the owner-occupier and, especially, the private rental market. This reality remains despite the results of the 'National Dialogue' on Universal Housing Design (2009)—an Australian Government-led initiative in responding to their requirements after ratification of the Convention on the Rights of People with Disabilities—through which:

> National Dialogue members [including housing industry peaks] … agreed to pursue an aspirational target that all new homes will be of an agreed Universal Housing Design standard by 2020 with interim targets to be set within that 10-year period. (National Dialogue Consortia 2010, p.2)

A recent assessment of the National Dialogue has noted limited progress towards these goals:

> In spite of the support of the Australian Government, and the sustained efforts of Livable Housing Australia, the housing industry has failed to show any sign of systemic transformation … [and while] … housing industry leaders continue to support the voluntary approach outlined in the National Dialogue agreement … evidence to date… indicates that the 2013 target has not been met; that the National Dialogue's targets for following years are also unlikely to be met; and that the housing industry is not sufficiently incentivised to make real progress. (RI Australia and ANHUD 2014, p.1)

Poor uptake and roll out of Universal Design standards (and indeed accessible housing generally) has clear impacts on the supply of appropriate housing for people living with disabilities. This remains an area where much greater effort and attention is needed (Anglicare 2015; Beer et al. 2011; Every Australian Counts 2015a; NPDCC 2009; Tually et al. 2011). Importantly, supply issues around accessible and adaptable housing were noted by the now disbanded National Housing Supply Council in a number of their reports (see NHSC 2010, 2013), with the council noting the clear need to address this issue given the ageing of the population and the aspirations of the 'baby boom' generation:

> … the number of people with a disability is likely to significantly increase over the next two to three decades. Many of these people will expect to remain living in the community (not in residential care) and will require a range of housing options and housing with care options, further increasing demand for such services. The distribution of services is also a key factor, the potential for people to age in their existing community, is limited in poorly serviced remote areas. (2014, p.60)

How Universal Design standards have been applied and translated among and within Indigenous housing organisations and Indigenous communities—and across tenures and governance arrangements—is an area of research in need of greater attention and will be given attention in the fieldwork for this project.

Related to concerns about the supply of appropriate housing, commentators have noted (and continue to note) concerns around the costs of appropriate housing for people living with disabilities, whether as a rental, in terms of undertaking necessary modifications or as accessible/adaptable/liveable designed new build housing (e.g. see Bridge et al. 2007). The

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[3] See Murray et al. (2013) and Tually et al. (2010) for discussion of this now completed initiative.

fact that people living with a disability generally are much more likely to be unemployed or marginally attached to the labour force and therefore, unsurprisingly, are much more likely to rely on housing assistance measures across the board, adds to concerns around housing costs. The most recent AIHW report on *Housing Assistance in Australia* (2014d, p.36) confirms this, noting that:

> In the context of housing assistance, people with disability are likely to have lower incomes than the general population as they are more likely to rely on government pensions or allowances than people without disability, and less likely to report wages or salary as their principal source of personal income … People with disability are therefore more likely than the general population to need some form of housing assistance.

Anglicare Australia's recent *Rental Affordability Snapshot* adds further weight to concerns around the availability of affordable housing for people living with a disability. The report emphasises the tiny proportion of the current housing stock (suitable) and affordable for people living on a Disability Support Pension (Anglicare Australia 2015b). A further sign of the crisis here is the current call for action by the online Every Australia Counts Campaign who is lobbying hard on this issue, calling it 'the big sleeper' and widely citing Bonyhardy's (2014) figure of the likelihood of up to 122 000 NDIS participants without affordable and appropriate housing by 2020 without expansion of current housing options and changes in current approaches to this arm of disability support. A key feature of their current campaign on this issue is increasing public awareness and putting pressure on the NDIA to release their long awaited housing options paper (Every Australian Counts 2015b).

Finally, in this brief look at disability and housing generally the recently released Reform of the Federation White Paper *Roles and Responsibilities in Housing and Homelessness* (Department of Prime Minister and Cabinet 2014) also makes some salient points in regard to housing and disability, notable for this project:

> … some groups—including Indigenous Australians, older people, young people, and people with mental illness or disability—are more likely than others to experience difficulty securing stable and affordable housing. This is complicated when individuals face multiple disadvantages and interact with multiple service systems. (p.10)

Also,

> … [people with disability] are also more likely to have lower incomes, fewer housing options, require physical modifications to their homes, and rely on social housing and support services. Appropriate housing for people with disability is a long-standing issue. The introduction of the National Disability Insurance Scheme provides an opportunity for all governments to address the issue. (p.32)

As will be noted throughout the rest of this report, opportunities for change in disability support will exist under the NDIS. Addressing the housing needs of Indigenous Australians, as a known multiply disadvantaged group (as noted in the Federation White Paper on housing and homelessness) is clearly a critical area of social policy concern in need of significant attention.

4.2 Housing and accommodation services for people living with a disability under the NDIS

Providing housing that is first and foremost 'a home', as opposed to a workplace or an institution, is accepted as 'best practice' for people living with a disability (Community Housing Federation of Australia 2014). As a whole of life support program for eligible people living with a disability, the NDIA has a role to play in ensuring that participants in the NDIS have access to all the necessary supports to assist them to live in independently if and as they desire. As noted in the NDIS Fact Sheet *Mainstream interface: housing and independent living, Supports*

the NDIS will fund in relation to housing and independent living (NDIS 2014b) the Scheme is designed to achieve this in terms of housing supports by funding:

→ supports that build people's capacity to live independently in the community, such as living skills training, money and household management, social and communication skills and behavioural management

→ home modifications to the participant's own home or a private rental property

→ support with personal care, such as assistance with showering or dressing

→ domestic assistance around the home where the participant is unable to undertake these tasks due to their disability, such as assistance with cleaning and laundry (NDIS 2014b, p.1).

Additionally, the Fact Sheet notes that the NDIS may assist with the cost of accommodation for eligible participants where they have a 'specialised' (yet to be defined) disability-related housing need and only where the cost of meeting this need '… is higher than the standard rental cost that the participant would otherwise incur' (NDIS 2014b, p.1). There is also potential for some assistance with housing through the capital funds expected to be available through the Scheme. It is hoped that these funds will be used as a catalyst for growth in the housing sector through leverage (Bourke 2014; Wiesel & Fisher 2014, p.16).

Assistance with housing is therefore one of the areas covered by the NDIS. The extent of such coverage, however, is somewhat limited, for, as the NDIS website notes:

> Housing is an important issue for the National Disability Insurance Scheme (NDIS). Affordable, stable housing is needed to support people with disability in achieving their life goals and aspirations. The NDIS will provide ongoing supports for daily living but has not been designed to take responsibility for the housing needs of participants. The NDIA recognises that housing policy is a matter for governments. (NDIS 2015b, emphasis added)

From the limited information available to date on support with housing under the NDIS, it is evident that NDIS-based housing support is focussed around 'personal care and domestic assistance' and home modifications for accessibility. As such, under the Scheme participants will continue to access housing through the private market—as renters or home owners, social housing tenants or through other housing options/programs such as emergency accommodation and specialist homelessness services and the National Rental Affordability Properties already rolled out before that program was wound back. On this point the information about housing support is again clear:

> *What happens if I can't access the housing I need through public or community housing?* If the housing system is responsible for a support, the Scheme cannot fund that support, even if the housing system does not provide it. (NDIS 2014b, p.2, original emphasis)

The NDIS will facilitate access to mainstream and specialist supports around housing for those people in need of such assistance. These linkages were identified as a key pathway into support for NDIS eligible and ineligible Indigenous Australians in research conducted under the NDIS PDS by Bohanna et al. (2013), who noted in their *Assessment of acquired brain injury in Aboriginal and Torres Strait Islander Australians: Guidance for DisabilityCare Australia* that:

> For some people this stage [assessment for support] is an opportunity for DisabilityCare to perform other important functions including referring individuals to community based and mainstream organisations that can best support their needs or connecting them to other systems, such as the health, palliative care, aged care, employment, **public housing** or education systems, that might appropriately support their needs. (p.52, emphasis added)

Bonyhady, as Chair of the NDIA, emphasised this point on many occasions, including in a recent article in the practitioner-focused journal *Parity* (2014b), where he added that there are 'complexities and challenges that need to be overcome to meet the needs of people [living with disabilities]' (p.8) and these include:

→ 'People with disability need access to tailored supports that build independence and social and economic participation.

→ The demand for affordable housing exceeds supply at a time when all governments are facing tight fiscal situations.

→ The NDIS was not designed to be a builder of homes for people with disability—but the Agency recognises that without secure and appropriate housing, it is difficult (if not impossible) for people to achieve their goals and aspirations and live an ordinary life.

→ The solution is going to involve federal, state and local governments, the community, developers and builders, church groups and disability and mental health service providers working together' (p.8).

A number of commentators, particularly from the services sector, have been vocal about the need for the housing side of the disability services equation to be more explicitly addressed within and outside the NDIS (Bourke 2014; Farrar 2014; Kelly & Sheehan 2014; Smith 2014; Wiesel & Fisher 2014). This position was evident in the debates in a recent edition of *Parity* (vol. 27, no. 5), with Smith (2014, p.38), summarising the concerns of many:

> … there needs to be leadership from the NDIA on addressing systemic barriers to accessing housing for people living with disability. This includes things like calling for an increase in the supply of public housing so that all people, including those living with disability, don't have to wait for extended periods to be allocated a property.

> There are also tenancy law reforms needed to improve the physical accessibility of private rental properties. The NDIA, as the major deliverer of disability services across Australia, has a powerful voice it can add to national debates on a wide range of issues that affect the ability of people living with disability to gain access to housing.

> The task of addressing access to housing for people living with disability will be challenging but is a vital part of delivering on the vision of the NDIS. The goals of independence, control and choice will not be achieved without it.

Smith's position was reinforced by Kelly and Sheehan in their article in the same journal:

> The social policy objectives of the NDIS—and its ability to transform the lives of people with disability—rest on a proactive response from the housing sector to the challenges ahead, not least of which is increasing overall supply. (p.34)

And,

> Achieving the right mixture of safety, appropriateness, design and property amenity, security and individual support from the right mix of services—from the provider(s) of choice—will require all stakeholders to be involved in designing the right housing choice to meet people's needs and aspirations. This is new territory for the housing sector, which traditionally designs and builds to a form, rather than to meet a need.

> The need for housing innovation into the future extends beyond the design and funding of different housing products. It will also require the housing sector to think and act differently, to see and hear people with disability and become a part of the network of stakeholders and people necessary to underpin the choices and control of a person with disability (p.34).

Notably, Kelly and Sheehan discussed a range of learnings from initiatives in the ACT that offer potential paths forward in this area. These include:

→ Placing people with a disability at the centre of housing (and other services) responses.

→ Building communities along with and through housing.

→ Ensuring new technologies are centre stage in housing design, development and execution.

→ Holding and working toward a common vision in housing support for people living with disabilities, with significant attention directed to relationship building, as well as planning and design (p.34).

Information about the NDIS also hints at providing some level of 'reasonable and necessary supports for families' around other accommodation-related support such as respite (as was considered a key element in the disability care and support (now NDIS) framework by the Productivity Commission 2011a). The details around these areas of support though are seemingly yet to be worked out. Currently, the focus of information around this area of support is centred on referral and links to existing services for families and carers outside the NDIS (NDIS 2015a).

4.3 Housing and accommodation services for Indigenous people living with a disability under the NDIS

Very little information exists on how the NDIS will assist Indigenous Australians with disabilities. Even less information exists on how housing and accommodation support will be developed, evolved and operationalised for the same group. To date, the only identifiable information on housing and accommodation services for Indigenous people living with a disability is, logically, application of the same information on supports about housing and accommodation under the NDIS generally (as outlined above) and that some 'capacity building' activity has been announced for Indigenous Australians (as well as other groups) under the NDIS framework. Such capacity building activities are part of the Disability Support Organisation Capacity Building Project under the Sector Development Fund.[4] This project has seen a number of what the NDIA call Disability Support Organisations (community organisations operating at the grass roots level) funded to work with key stakeholders (families, carers and people living with disabilities themselves) by establishing local peer/mutual support groups to help stakeholders fully engage with the NDIS and capitalise on the opportunities it offers by developing (NDIS 2015c). The Indigenous capacity building initiative under the project is being delivered by the First People's Disability Network (a recently established organisation), who are:

> … working with urban, regional and remote communities to raise awareness of the NDIS and assist Indigenous people with disability, and their families and carers, to understand and use individual packages effectively. (NDIS 2015c)

As noted in the First People's Disability Network document *Strategic Directions 2015–2020* (First People's Disability Network 2015) their activities and plans in this regard include:

→ As a Local Area Coordinator for the NDIS:

  → Establishing and operating a service for Aboriginal people in SA.

  → Pursuing the establishment and operation of similar culturally specific services across Australia.

→ As a Disability Support Organisation under the NDIS:

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[4] Established to manage the transition to the NDIS for people living with disabilities and their carers and families and the disability sector (NDIA 2014). The Sector Development Fund is structured as a competitive grant funding process with outcomes to be achieved in five primary and two secondary outcome areas as per the Fund guidelines: building community capacity and engagement; increasing individual capacity and increasing new forms of support; building disability sector capacity and service provider readiness; expansion and diversification of the workforce; and building the evidence base and emerging priorities and innovation; and quality and safeguards (DSS 2015).

→ Establishing Disability Support Organisations of the type described above for Aboriginal people in SA and the NT.

→ Working in partnership with Aboriginal Disability Network NSW to establish disability Support Organisations of the type described above for Aboriginal people in NSW.

→ Establishing culturally specific Disability Support Organisations of the type described above in all states and territories.

Working to improve access to community infrastructure, (including social housing and community and social services) and ensuring Aboriginal people living with a disability have accessible public and community transport (particularly in remote communities) are stated priorities of the organisation generally (First People's Disability Network 2015). The First People's Disability Network has also developed a *Ten-point plan for the implementation of the NDIS in Aboriginal communities* (2013a), identifying ways to move forward in supporting Indigenous people under the NDIS. The Plan does not comment on the provision of specific services such as housing and community infrastructure, but instead provides a framework for working with Indigenous people living with disabilities, their families and carers, service providers and communities about these services where they are engaged through the NDIS (and outside that support system).

How other aspects of the NDIS will assist Indigenous people living with a disability remains somewhat unknown, particularly in terms of housing and accommodation. However, some recommendations and potential avenues for support (as well as concerns and barriers) were identified in the Productivity Commission reports into Disability Care and Support that are worthy of mention here. These tend to focus on increasing the health outcomes of Indigenous peoples in general, early interventions and the provision of culturally appropriate services, at the same time acknowledging that there are major problems with housing for Indigenous people living with a disability, particularly for people living in remote locations.

Further, the Productivity Commission noted that there may be significant barriers to accessing disability support services for Indigenous people without specific attention being paid to the needs of this group, particularly because of issues such as 'remoteness, social marginalisation, cultural attitudes towards disability and culturally inappropriate services' (Productivity Commission 2011a, p.53). Such well documented barriers to disability support lead the Productivity Commission (2001a, pp.53–54) to comment that:

> … the service delivery model underpinning the proposed NDIS may not, on its own, deliver adequate care and support to Indigenous people with a disability. While Indigenous Australians would have access to individual support packages on the same basis as non-Indigenous Australians, it may also be necessary to block fund some services in order to overcome the additional barriers that Indigenous Australians face. In addition, Indigenous people with disabilities often do not make claims for support. These distinctive aspects suggest that disability support for some Indigenous communities will probably need to take a different form.

A range of strategies was identified in the Productivity Commission reports to address known barriers to the delivery of support (and being mindful of other actions to reduce Indigenous disadvantage nationally):

→ 'fostering and building capacity in community-based operations, in consultation with local communities, and through the engagement of local staff. Larger experienced service providers would provide support. This strategy would apply across all parts of Australia— urban, regional and remote communities. But the strategy would need to recognise the particular challenges of adequate support in remote locations where even mainstream services are often absent' (2011a, p.54).

And,

→ 'Block funding suitable providers where services would not otherwise exist or would be inadequate.

→ Fostering smaller community-based operations that consult with local communities and engage local staff, with support from larger experienced service providers, in particular those with a high level of community ownership.

→ Employing and developing Indigenous staff.

→ Developing the cultural competency of non-Indigenous staff.

→ Encouraging innovative, flexible and local problem solving, as well as conducting and publishing evaluations of trials in order to better understand what works and why.

→ Developing an effective and cost-effective balance between bringing services to remote areas, and bringing people with a disability in remote areas to services.

→ Working with state and territory governments, Indigenous advocacy groups and other community groups to develop and refine funding strategies, better understand local and systemic issues as well as successful (and unsuccessful) approaches and diffusing this knowledge to other service providers, researchers working in this field and the broader community' (2011b, p.561).

Discussion of these strategies has not progressed significantly beyond what was outlined in the Productivity Commission reports at the time of writing this report. And, this reality remains despite the fact that the implications for Indigenous people living with a disability in remote areas may be profound and despite the clear challenges facing Indigenous people living with a disability in terms of their disability-related housing and community infrastructure needs generally. Whether and how other housing and accommodation options such as respite housing, independent living and other care options within Aboriginal communities will be rolled out under the NDIS has not yet been addressed.

The insightful comments provided by the Productivity Commission about Indigenous people with a disability and the conceptualisation of the NDIS model outlined above will form somewhat of a thematic guide informing the lived experience fieldwork to be conducted as the final stage of this research. Such strategies and considerations will also be confirmed, given further consideration or modified in line with research findings.

4.4 Summary

This chapter has shone a light on what we know from the available information about the relationship between the NDIS and housing. Revealing that much is still to be determined with regard to how the NDIS will interact with housing agencies, the housing industry and housing-related supports for people living with a disability generally. How such relationships and interactions will manifest in terms of supports for Indigenous people living with a disability is even less clear. As is how the NDIS has been designed to take account of the particular disability, housing and infrastructure needs of Indigenous people living with a disability, particularly in remote areas where service delivery arrangements are known to be problematic. Additionally, the currently available information on the NDIS and Indigenous Australians does not provide any guidance on how the notion of person centred approaches to service delivery will dovetail with Indigenous cultures which are based around ideals of the collective and community approaches to understanding, managing and meeting individual and community needs. Notably, these realities regarding the NDIS remain despite acknowledgement by the Productivity Commission of the greater barriers this population group will face in terms of accessing disability (and other related) supports for cultural, social, geographical and financial reasons. It is important that they are addressed given the crucial role housing plays in the health and wellbeing of all Australians.

5 CULTURALLY RESPONSIVE HOUSING FOR INDIGENOUS PEOPLE LIVING WITH A DISABILITY

5.1 Introduction

This chapter examines the literature on culturally responsive housing for Indigenous people living with a disability. As noted earlier there is a paucity of research around this issue, that is for Indigenous people living with a disability in particular.

Literature from Canada and New Zealand is also reviewed in order to identify challenges in Indigenous housing for people living with a disability elsewhere and to identify, where able and appropriate, ways of working with and in Indigenous communities that support good health and wellbeing outcomes for Indigenous people living with disabilities in these countries. New Zealand and Canada were specifically chosen for this review as both have many similarities to Australia in terms of the types of housing available to their Indigenous populations, as well as having increasingly urbanised Indigenous populations and significant cultural diversity among their Indigenous populations. Conclusions about the Australian, New Zealand and Canadian literatures are drawn together in the final section of the chapter.

5.2 Culturally responsive housing for Australian Indigenous people living with a disability

A growing body of literature exists in Australia documenting and debating appropriate types of housing for Indigenous people and how these should be developed, designed, delivered, modified and maintained (see Long et al. 2007 for a comprehensive summary; also Pholeros & Phibbs 2012; Lea & Pholeros 2010). Such literature generally espouses the design and provision of housing that support Indigenous peoples' culturally-based socio-spatial needs, domiciliary behaviours, values and aspirations (Heppell 1979; Memmott 1988, 1991, 2003, 2004, 2007; Ross 1987; Keys 1996; Read 2000; Fantin 2003; Memmott et al. 2006; Long et al. 2007; Milligan et al. 2011; Grant et al. 2015). Notably, while the literature on cultural design approaches is developing, there is no literature on appropriate design for Indigenous people living with a disability.

For more than a decade now, what Memmott (2003) has labelled 'the cultural design paradigm' has been one of three paradigms dominating housing research and design for Aboriginal clients (for discussion see Fien et al. 2007, Chapter 5). And, recognising culturally specific needs around Indigenous housing have been identified as major factors in determining successful housing outcomes. Additionally, and as cited by Memmott almost three decades ago (1988), failing to recognise the varying and diverse cultural needs of Indigenous peoples around their housing has been a key reason for poor housing outcomes and housing 'failure'. On this issue, Memmott has further noted:

> [h]ousing administrators also need to recognise that housing management systems must also accommodate culturally specific behaviours. To not take cultural needs into consideration, both at the housing design and management levels may ultimately result in a service failure (Memmott 2004, p.48).

A range of values-based cultural factors is discussed in the literature as central to understanding and determining housing options (and outcomes) for Indigenous people. These include such things as housing design that pays attention to customary behaviours around avoidance, household structures, sleeping and eating, as well as cultural constructs around crowding and privacy and responses to death. In saying this the literature is also unequivocal on the need to approach the provision and design of housing independently, recognising diversity in Indigenous cultures, values, laws and customs in Australia. In short, there is no one solution to providing and designing housing for Indigenous people.

Notably, while there has been a great deal of research on the housing needs of Aboriginal people, there is a paucity of research on housing for Aboriginal people living with a disability. An important contribution to the literature by the Aboriginal Disability Network of NSW, *Telling it Like it Is: A report on community consultations with Aboriginal people with disability and their associates throughout NSW, 2004–2005* (2007) sheds some light on concerns in that state, which is based on findings from research about people living with a disability generally (e.g., see, Taleporos et al. 2013), and in light of the discussion above about Indigenous housing generally, has broader application. The notable learnings from this research are:

→ For housing, disability and social support generally:

  → A lack of culturally- and disability-appropriate housing options and services (with the same noted for other social services), especially for Aboriginal people living with a disability (pp.14–15).

  → Under-use of mainstream disability and other social support services (including disability-related housing services) by Aboriginal people generally.

  → Lack of awareness of disability-related housing needs (and available supports) among Aboriginal people living with disability, their families and some service providers (pp.14–15; see also Bostock 2007).

  → Concerns about the management of accessible housing allocations in both mainstream and Aboriginal housing agencies (p.15).

  → Negative experiences with housing agencies, impacting on people's desires to interact with them (p.15).

  → Some service providers expressing occupation, health, safety and welfare concerns entering into sub-standard housing, impacting on the delivery of supports to some people (p.16).

  → Lack of Aboriginal specific accommodation services (p.17).

  → Desire for more Aboriginal-run services for people living with disabilities (p.17).

→ For Aboriginal housing (p.14):

  → A high prevalence of sub-standard Aboriginal housing, especially in remote communities and, relatedly, the high prevalence of housing and accommodation options that are physically inaccessible for Aboriginal people living with disabilities.

  → Issues of nepotism in Aboriginal housing (p.15).

→ For public (social) housing (pp.15–16):

  → Cultural inappropriateness of much public housing, with available stock insufficient in terms of accessibility, size and number of bedrooms, as well as there being issues around tenancies because of overcrowding, mobility and 'visiting', kinship traditions et cetera.

  → Poor understanding of rights and responsibilities among public (social) housing tenants.

  → Challenges around accessing support for modifications to properties, including in public (social) housing.

→ For home owners (p.16):

  → Poor awareness of supports available to assist Indigenous people living with disabilities (and their families) in the home.

  → Questioning of the feasibility of home ownership schemes for Aboriginal people given known levels of poverty.

→ For supported accommodation (p.17):

→ Highly limited uptake of supported accommodation options by Indigenous people living with disabilities, although no clear data on this.

→ Concerns over the location of such facilities, away from communities, country, significant events.

→ Unmet need for such services, with a possible appetite for Aboriginal-run services but these must be culturally appropriate in terms of design and operation, as well as being in appropriate locations.

→ Lack of support for 'group home' models of living.

No discussion was included in the report about privately renting Indigenous people, however, it seems fair to assume that many of the same concerns and issues above would apply and be magnified given known issues around affordability of private rental, the condition of some properties, difficulties modifying such properties for disability-related needs and security of tenure.

The Aboriginal Disability Network of NSW's report also notes challenges in terms of the provision of services, including housing, due to the ongoing issues around cultural sensitivity and responsiveness and cultural awareness among mainstream service providers. And, on this point, the organisation notes that 'a comprehensive and ongoing cultural competence training program must be provided for non-Indigenous service providers' (p.18).

Research undertaken under the NDIS's own Practical Design Fund also contributes some important learnings here regarding the provision of culturally appropriate housing, in terms of construction, management, modifications and community engagement. The key documents in this regard are the publications by Walls and Bridge 2011 and Walls et al. 2013; researchers associated with the Home Modification Clearinghouse at the University of New South Wales. These publications add further information and context around Indigenous housing and disability; this time through a home modification lens. These studies provide a useful starting point for building understandings of the barriers to good housing outcomes for Indigenous people living with a disability through this study and with possible application in a revised disability services (NDIS) context.

The study on *Home modifications and inclusive design in Aboriginal housing* in remote Indigenous communities by Walls and Bridge (2011) provides some interesting insights (albeit unable to be broadly applied across all communities given the small-scale of that study). It noted major constraints in modifying some remote Indigenous housing, primarily because such dwellings have 'historically been fraught with problems arising from poor construction and maintenance', have what they refer to as 'a remarkably short life cycle' and therefore '… may be in a dilapidated condition' resulting in 'instances where homes are unsuitable for habitation, much less modifications' (p.1).

They further noted real concerns in terms of the characteristics of the environment in which some (primarily remote) Indigenous housing is located. Such challenges pertain to the basic health and safety of residents (as well as those undertaking modifications of homes), and include:

→ poor, absent or failing utility supply and sewage systems

→ presence of uneven internal floor surfaces (a falls hazard), with brushed concrete floors commonplace

→ presence of biofilms on concrete surfaces leading to issues with bacteria and potential for health issues and food contamination

→ impacts from humidity and salinity problems, causing issues with corrosion and mildew (2011, p.1).

Importantly, the research by Walls and Bridge also suggested that the benefits of modifications may be limited given the existing dilapidated state of many houses (see also Walls et al. 2013; Pholeros & Phibbs 2012; Lea & Pholeros 2010).

On a practical level, and arguably with application in non-remote communities where the standard of housing stock is generally better, Walls and Bridge's work emphasised the need for development of appropriate assessment tools in consultation and collaboration with Aboriginal community groups in the first instance. And, as part of this, common issues need to be clarified in terms of the housing environment and modifications including use of the domestic environment, engagement with extended family/community and personal functional barriers to independent living within the living space (Walls & Bridge 2011, p.1). Here their research emphasises the strong need for a 'rigorous methodology involving sound anthropometric and cultural data collection', as 'Inclusive design practices including participatory and co-design strategies are capable of providing solutions that truly assist clients both with immediate and potential future needs' (Walls & Bridge 2011, p.1). It also highlighted four inter-related factors which appear to need to be addressed to achieve more effective housing and home modification interventions for Aboriginal people with a disability, their families and carers:

1. Disability characteristics of the Aboriginal population.

2. Characteristics of the housing environment.

3. Cultural, physical, social and functional issues.

4. Linking housing interventions to culturally appropriate housing and home modification solutions.

Many of these findings are also reported in the other work by Walls and Bridge (and other colleagues)—*Home Modification in Aboriginal Housing* (second edition)—also for the NDIS PDF (Walls et al. 2013). A number of key learnings about modification of dwellings for Indigenous people living with a disability (and the related issues of design, construction and maintenance) are outlined in this Occasional Paper. Many of these are summarised in the following excerpts from the report, drawn from their review of the relevant literatures:

> … current housing provision for Aboriginal people in remote/rural Australia is inappropriate due to its lack of cultural relevance, incompatibility with the geographic landscape, poor design and state of disrepair, and its inability to cater to the functional impairment of Aboriginal older people and people with disabilities … (p.5)

> Inadequate housing supply, inappropriate home environments and a high incidence of disability and long-term health issues has led to compounded disadvantage for Aboriginal Australians living in remote areas … People living in remote areas face a number of challenges in accessing vital health and housing services. The availability of and accessibility of health and disability services is extremely limited in remote communities … which means that many Aboriginal people with disabilities may face heightened difficulties with regards to mobility around the home and neighbourhood and daily living activities. People can also be isolated from services by lack of transport and limited mobility due to disability. Language, gender issues and lack of information about or understanding of treatment or modification options may be further limiting factors in seeking assistance …. (p.5)

And, in terms of disability-specific modifications:

> The issues of inappropriate housing design and construction for people with functional impairment are intensified by deterioration of their home environment, and this can perpetuate a negative cycle for people unable to maintain inappropriate dwellings due to ageing or disability and because of their social and financial situation. The ability to implement retrofitting and home modifications services are [sic] heavily influenced by

and dependent on the existing structure in place, and in instances where that structure is dilapidated, it may not be safe to undertake modifications. Where no home modifications are possible due to the conditions of the home premises, the client's ability to live at home is severely jeopardised, and in the worst cases, it is not possible for the client to receive home-based health and care services at all. (p.9)

Ultimately, they note that:

An undersupply of appropriate, accessible housing in remote Aboriginal communities limits the ability of Aboriginal people with a disability or long-term illness to participate in activities of daily life and in their community. (p.6)

This is a key justification for the need to investigate and ameliorate housing conditions in communities, in a culturally appropriate manner.

Walls et al.'s contribution to the scant literature around housing and disability for Indigenous people is particularly helpful for this research, not only for the summary it provides of the literature outlined above, but also for a core purpose of the paper—the development of a checklist of the 'key issues and design elements to consider when designing effective home environments for Aboriginal people who are ageing or who have a disability, particularly in remote areas' (p.6). This checklist is developed from their review of the relevant literatures, data and building codes and guidelines. It builds upon Fien et al.'s (2008) work for AHURI outlining *A new design framework for remote Indigenous housing* which identified six dimensions of sustainability for housing[5] (including the role of 'healthy living practices' which are a focus of this research on lived experiences of housing and community infrastructure as discussed in Chapters 6 and 7 of this report). Walls et al.'s checklist is conceptualised in terms of similar areas of 'specificity' to Fien et al., emphasising the importance of five domains for the quality and appropriateness of housing for Indigenous people that need to be incorporated, addressed and accounted for in the whole process of housing design, construction, maintenance and modifications:

→ cultural appropriateness

→ eco efficiency

→ employment opportunities

→ lifecycle costing

→ innovation in procurement, ownership and construction systems.

Within the checklist, a category is included to highlight the impact of certain design attributes and elements in functional terms for people living with a disability (or who are ageing or ageing with a disability). Box 3 outlines some examples from the checklist.

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[5] Cultural appropriateness; environmental sustainability; healthy living practices; employment opportunities and economic development; life-cycle costing; and, innovation in procurement, ownership and construction systems (Fien et al. 2008, pp.104–105).

Box 3: Examples of design elements and attributes and their meanings from the checklist developed by Walls et al.

In terms of cultural appropriateness in design:

→ [Recognise the] Location of family and kinship groups when designing settlements and township.

Meaning in terms of function:

→ Visitability is possible for elders and family/kin relations regardless of ability set.

→ Family and kin can be contactable and close by for support and assistance.

→ Family and kin can visit each other's homes without physical barrier to the home (e.g. no stairs).

In terms of 'life cycle costing:

→ House is easy to maintain—materials are common/durable/available if need to be replaced.

Meaning in terms of function:

→ Resident is not reliant on external contractors for basic maintenance procedures.

In terms of innovation in procurement, ownership and construction systems:

→ Dwellings are procured by management agencies that will support the residents with tenancy and/or ownership in a culturally relevant way.

→ Dwellings are built from easy to assemble materials.

Meaning in terms of function:

→ Increased likelihood of timely build, repair and modification.

→ Decreased likelihood of resident needing to seek interim (accessible) housing while awaiting repairs.

Source: Walls et al. 2013, pp.32, 36, 37

Walls et al.'s checklist will also be referred to in the fieldwork stage of this report; fundamentally, as it provides a more disability specific focus to the whole process of housing design, construction, maintenance and modifications.

Notably also, Walls et al.'s research concludes with two important statements in the context of this research in particular. That, improving the housing situation facing Indigenous communities, and people living with disabilities within these communities ….

> … will require innovation from both industry and policy-makers in investing in creative strategies for the provision of housing and home modifications to Aboriginal groups and to undertake true community and stakeholder consultation to ensure this provision is executed in a meaningful and successful manner. In particular, policies to identify and manage the specific and unique difficulties faced by Aboriginal Australians with a disability and who are ageing (or both) will be critical to a meaningful and ongoing dialogue with service providers and tenants with the ultimate goal of effective and appropriate housing for Aboriginal people regardless of their location in Australia.

Also, as this Positioning Paper shows overall,

> The complex relationship between inadequate housing supply, poor housing conditions, overcrowding, and health and disability needs to be explored further in order to design the most effective home environments in remote Aboriginal communities. (p.39)

Delivery of services to Indigenous people living with disabilities under the NDIS (and through other mechanisms outside the Scheme) will need to take these complexities, learnings and approaches into account.

Challenges around the modification of dwellings for Indigenous people living with a disability are also noted in research by Jung and Bridge (2009) on rural home modifications for the same

Clearinghouse. In analysing the Australian Government's Minimum Data Set for the Housing and Community Care (HACC) program[6] Jung and Bridge found that:

> Indigenous people account for a very small minority (1.2%) of home modification users. Considering that Indigenous people [at that time made] … up 2.5 per cent of the total Australian population their home modification service usage was significantly low and this indicates that Indigenous people tend to use home modification services less than non-Indigenous people. (p.14)

Before moving on to examine the literature around the nexus between housing and disability for Indigenous people in New Zealand and Canada, it is pertinent to point out here the conclusions regarding Indigenous housing generally in two Resource sheets produced for the *Closing the Gap* Clearinghouse; the first by Pholeros and Phibbs (2012) and the second by Ware (2013). These works outline a series of important perspectives regarding what works and what doesn't in *Constructing and maintaining houses* (Pholeros & Phibbs) and in terms of *Housing strategies that improve Indigenous health outcomes* (Ware), recognising the clear importance of, and bidirectional relationship between, housing and health. Both of these plain English resources reference the National Indigenous Housing Guide which is discussed in Chapter 6 of this report, with elements of this Guide forming the foundation of assessments of housing in Indigenous communities that will be undertaken in the final stage of this research. Box 4 outlines Pholeros and Phibb's key commentary and Box 5 that of Ware.

Arguably many of these learnings and approaches apply to building, maintaining or modifying appropriate housing for Indigenous people living with disabilities.

The lack of research in the area highlights the importance of this and other studies, as well as genuine culturally-sensitive and appropriate consultation with Indigenous people living with a disability and their families to ensure they understand and can access the full gamut of supports they need. Such supports include those offered or to be offered directly as part of the NDIS and mainstream and specialist supports that sit outside the (yet to be clearly defined) bounds of the Scheme.

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[6] The Australian Government's HACC program 'provides funding for services which support frail older people and their carers, who live in the community and whose capacity for independent living is at risk, or who are at risk of premature or inappropriate admission to long term residential care. Older people are people aged 65 years and over and Aboriginal and Torres Strait Islander people aged 50 years and over' (DSS 2012, p.8). Aboriginal and Torres Strait Islander people are an identified special needs group under the program (p.13).

Box 4: Pholeros and Phibbs' commentary on Constructing and maintaining houses in Indigenous communities

Commonalities of successful construction and maintenance projects/approaches:

→ Designing and constructing housing based on the established standards and accumulated knowledge in the *National Indigenous Housing Guide* … This includes a process of consultation with the local community, and designing housing that meets the social and cultural needs of occupants.

→ Targeting limited-maintenance budgets for safety and health items to improve the functional performance of the house.

→ Using appropriate construction methods and materials, given the particular local environment, especially in rural and remote locations.

→ Involving Indigenous communities in planning and implementing programs for construction and maintenance.

→ Using local community Indigenous labour to assist with construction and maintenance programs.

Carefully documenting the performance of Indigenous housing using a set of standard, repeatable tests linked to the principles outlined in the National Indigenous Housing Guide.

→ Having rigorous inspection programs at handover after completion of building or major upgrade, to ensure that construction complies with the drawings and specifications and that all aspects of the house work properly.

Commonalities of 'troubled' construction and maintenance projects/approaches:

→ A one-size-fits-all approach that doesn't allow for particular local cultural, social and environmental circumstances.

→ Short-term or piecemeal interventions that are not implemented for long enough to make a significant impact.

→ Fixed, short-term deadlines for any construction program.

→ Interventions that are adopted without collaborating with Indigenous communities to provide a real opportunity for them to let their views be known.

→ Maintenance programs for rural and remote areas based on models that apply in capital cities.

→ Programs that are based on 'responsive maintenance' (that is, when repair and other work only occurs when a tenant notifies the landlord), rather than on periodic or cyclical maintenance supplemented with local, ongoing testing of houses.

Source: Pholeros and Phibbs 2012, pp.1–2

Box 5: Ware's commentary on Housing strategies that improve Indigenous health outcomes

Key *learnings* from the literature and data:

→ Housing is a key social determinant of health.

→ The relationship between housing outcomes and health outcomes is bi-directional: housing affects health outcomes, and health affects housing outcomes.

→ There are clear links between the quality and location of housing and health outcomes.

→ The impacts of housing on health vary between geographic and climatic locations and contexts.

→ There is a wide range of housing interventions that positively impact Indigenous health. One way of categorising these is: infrastructure improvements; addressing behavioural factors; and adjustments to policy environments.

Elements of successful housing strategies for good health:

→ Addressing infrastructure, health promotion and the policy environment simultaneously.

→ Effective policy environments that administer and enforce appropriate housing standards and design guidelines, while allowing sufficient flexibility to tailor designs and materials to local conditions.

→ Indigenous environmental health workers are vital for ongoing housing maintenance and the promotion of healthy living practices.

→ High-quality, well-maintained health hardware such as taps, toilets, showers and sinks, coupled with attention to safety of a house, can make a major positive impact on Indigenous health for any age group.

→ Improving indoor temperature regulation, as well as preventing damp, mould and fungi, reduces respiratory and skin diseases.

→ Involving communities in the design, construction and maintenance of housing empowers them and builds capacity for improved housing-related health outcomes.

Approaches that don't work in terms of housing strategies for good health:

→ Imposing housing and health promotion programs or housing design that is inappropriate for the physical, climatic and social context.

→ Using low-quality materials and construction to generate initial cost savings increases the costs of maintenance and housing replacement in the longer term.

Source: Ware 2013, pp.1–2

5.3 International literature on housing for Indigenous people living with a disability

5.3.1 New Zealand/Aotearoa

As with Australia's Indigenous population the Māori of New Zealand experience higher rates of disability when compared with New Zealand's general population. Data from the 2013 Disability Survey conducted by Statistics New Zealand (SNZ) revealed that 26 per cent of the Māori population overall reported a disability (up from 20% of the population in 2001) and compared with a total disability rate of 24 per cent in 2013 (up from 20% in 2001) (SNZ 2015, p.10). For the other First People's group in New Zealand—the Pacific population—the disability rate overall (19%) is actually lower than the total disability rate (SNZ 2014). Age adjusted disability rates by ethnic group reveal the true extent of disability for each population: Māori 32 per cent; Pacific 26 per cent; European 24 per cent; and Asian 17 per cent. Physical disabilities were the most reported disability type overall among Māori (SNZ 2015, pp.10–11).

Again as in Australia, the literature around housing in New Zealand shows that living in substandard and overcrowded housing are key challenges for Māori (and Pacific populations),[7] with such conditions experienced more frequently, and to a greater extent, by these population

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[7] See Bierre et al. (2007) for a detailed tracing of the history of Māori housing in New Zealand, including discussion of the reasons why their housing conditions are so much worse than those experienced by other New Zealanders.

groups than other New Zealanders (McDermott Miller 2005 Chapter 9; see also the documents associated with the then New Zealand Housing Strategy—HNZC 2004, pp.75–76, HNZC 2005, pp.65–67; Koloto & Associates Ltd et al. 2007; Hall 2008; Marriott and Sim 2014). The fact that these issues impact disproportionately on Māori and Pacific populations makes them an important area of social policy concern given the clear associations between housing and health and the identified role of housing as a social determinant of health in New Zealand (as elsewhere), where a significant body of literature on this topic exists (e.g. see, Howden-Chapman et al. 2012, 2011, 2008; Howden-Chapman & Carroll 2004; also Keall et al. 2010).

The diverse housing needs of the Māori population have been outlined in a number of publications (Hoskins et al. 2002; Faumuina & Associates 2002; Waldegrave et al. 2006; Hall 2008). Hall (2008), in particular, notes some key considerations in her literature review around *Maori and Pacific Peoples' Housing Needs in the Auckland region* for the Auckland Regional Council:

> Cultural and demographic differences have implications on the housing designs required by both Maori and Pacific groups. For example, the concept of tapu and noa in Maori culture, and the importance of extending hospitality in Pacific culture have impacts on space requirements. Differences in the demographic and household characteristics of these population groups also impact on housing requirements. Maori and Pacific households tend to be large and to have many children. (p.18)

(For further discussion of Pacific peoples housing experiences see also Koloto & Associated Ltd et al. 2007, especially Chapter 11.).

The literature notes that dwellings designed for Māori living with disability and/or their whanau (family) need to have certain features (Davey & Barrington 1979; Hoskins et al. 2002; McKinlay Douglas Ltd & Etain Associates 2006; James 2007; Saville-Smith 2007), including that housing needs to be:

→ accessible

→ constructed with low maintenance, hard wearing materials

→ designed to incorporate wider halls and doors and non-skid surfaces

→ designed with wet areas such as bathrooms on the ground floor.

These considerations are important given the fact that (as noted in the then New Zealand Housing Strategy) that the majority of the housing stock in New Zealand was designed for able-bodied people and as the terrain in many places across the country makes single storey, accessible dwellings challenging to construct.

Further complexity around the issue of disability and housing for Māori and Pacific peoples in New Zealand comes from the literature exploring issues related to children (James 2007; McKinlay Douglas Ltd & Etain Associates 2006; Saville-Smith et al. 2007), with proportionately many more dependent children of Māori and Pacific background in New Zealand living in overcrowded and substandard housing than dependent children of other ethnic backgrounds. This literature reinforces general concerns in New Zealand about the environmental health-related impact of poor quality and overcrowded housing; housing conditions that Māori and Pacific peoples occupy more frequently as noted above. Important concerns for children (and others) here include the need for houses to be warm, dry and relatively dust-free (Saville-Smith et al. 2006; see also Howden-Chapman et al. 2012, 2011, 2008), and where necessary, include special structural features such as sound proofing, strengthened walls, reinforced glass and increased safety features for children with behavioural issues and protection from accessible risks for households accommodating people with intellectual disabilities (McKinlay Douglas Ltd & Etain Associates 2006, p.37).

The size of dwellings has also been raised in the literature as of paramount importance for Māori and Pacific populations, not only because of the larger size of these families generally, but also in households where there is an older person with a disability, so that room is available to accommodate a caregiver where necessary. This is an important consideration for all housing accommodating people living with a disability, and is a practical need that is counter to the general trend in New Zealand towards models of housing for people living with a disability that are smaller (driven by affordability issues). Other important considerations raised in the New Zealand literature around disability and Māori and Pacific peoples' households (and applicable to all people living with a disability) include the need for housing that provides:

→ for those with some types of mental health issues: a low stimulation environment and space that is theirs (especially if living with others)

→ for those with vision impairments: good lighting, non-shiny surfaces and/or different surface textures

→ for those with hearing impairments: facilities to support communication equipment (McKinlay Douglas Ltd & Etain Associates 2006, pp.36–37).

As in Australia, limited literature exists in New Zealand around 'best practice' culturally responsive housing models for Māori and Pacific peoples living with a disability. Some insights around housing needs, however, are able to be drawn out of the piecemeal literature. A paramount consideration in terms of 'best practice' is clearly the design, development and construction of accessible housing[8] and housing where extended families can reside together, avoiding high levels of overcrowding. This latter consideration was especially highlighted in research by Koloto and Associates Ltd et al. (2007) for Pacific peoples as there may be as many as three generations living in one dwelling, and more than one family member with a disability (see also Faumuina & Associates 2002; McDermott Miller 2005). The enduring themes within the literature with regard to models of appropriate housing for Māori and Pacific peoples living with disabilities centre on issues such as security of tenure, affordability, difficulties accessing dwelling modifications and the location of housing in relation to social and health supports (see particularly McKinlay Douglas Ltd & Etain Associates 2006; Saville-Smith et al. 2007). And, as James and Saville-Smith note in their study of *Children's Housing Futures* (2010), the suitability of existing housing stock remains a significant challenge in New Zealand, with the issue here being:

> … accessibility and flexibility of dwelling design, not only to better accommodate children with disability, but also to allow for much more dynamic family and household structures. There is little evidence of take-up of flexible design in New Zealand in response to either disability or changing household dynamics. (p.48)

From a cultural standpoint, it is also clear from the literature that 'best practice' housing for Māori and Pacific peoples living with disabilities needs to recognise their spiritual and practical needs, therefore should include such things as outdoor living space and space for communal gatherings, gardens and safe play spaces for (many) children (Hoskins et al. 2002). Further, the literature on Māori notes the importance of housing initiatives on Māori ancestral lands (Hoskins et al. 2002), including within or adjacent to a marae,[9] a particular tribe's, subtribe's or whanau's meeting place (McKinlay Douglas Ltd & Etain Associates 2006, p.45). The same literature also notes, however, the need for regular review of the accessibility and appropriateness of older style marae-related housing, especially Kaumātua (Māori elder) housing, as such housing is traditionally very small and therefore may not be suitable for frail and/or disabled Māori. as such dwellings are.

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[8] With moves towards improved accessibility in some public and private dwellings through the introduction of the Lifemark (universal) home design standards (http://www.lifemark.co.nz/home.aspx).

[9] See http://www.newzealand.com/au/feature/marae-maori-meeting-grounds/ for further explanation of this important structure within Māori culture.

Finally, it is important to note that the New Zealand literature, and particularly the publications for the Centre for Housing Research Aotearoa New Zealand (e.g., Saville-Smith et al. 2007; James & Saville-Smith 2010) promote the importance of appropriate housing in preventing the exacerbation or acceleration of disability. Such literature discusses the manner in which the housing needs of people living with a disability may change at any point in time or over the course of their lives, because of the multiple and multigenerational needs of Māori and Pacific households and during the life cycle of the whanau and household. Changes in the type, severity or progression of disability often lead to a household needing to secure different supports, such as housing, care and/or equipment. These circumstances can also occur where an individual's disability leads to them acquiring or developing other disabilities or where a young person with a disability starts and then progresses through school and into adulthood (McKinlay Douglas Ltd & Etain Associates 2006, p.33). Such changes related to disability highlight the need for a range of housing options, and flexibility and adaptability in housing design, to ensure the lifelong needs of people living with a disability are met, including their needs relating to cultural background.

5.3.2 Canada

As in Australia and New Zealand, particular culture-related challenges in terms of housing are documented in the literature around Aboriginal people in Canada living with a disability. The key issues for the Indigenous populations of Canada—known collectively as the Aboriginal people of Canada (and comprising First Nations (North American Indian), Métis and Inuk (plural: Inuit)) (Statistics Canada 2015a)—are briefly discussed here, with particular attention paid to lessons in the relevant literature about culturally-responsive housing models or approaches to the delivery of housing. Before moving on to this discussion it is pertinent to first outline the extent of disability among Indigenous people in Canada. It has been shown that, as in Australia, the rate of disability among Aboriginal people in Canada is higher than that for the non-Aboriginal and total populations generally. Succinctly summarising the rate of disability among Aboriginal peoples in Canada, however, is difficult.[10] In large measure this is because findings from the first Canadian Survey on Disability (2012) by ethnic group have not yet been publicly released (see Arim 2015 for discussion of the general findings). Notably, this new Survey also uses a different definition of disability from Statistics Canada survey instruments, meaning direct comparisons about data over time cannot be made (Statistics Canada 2014, p.44).

It is also evident from a cursory examination of the data on disability that different survey instruments also focus on, include or exclude different cohorts within the population surveyed. Some surveys, for example, exclude all children or those aged under 15, and others include only certain sub-groups within a population, such as Aboriginal people living off-reserve. Such inclusions and exclusions again complicate the disability data picture, especially for people unfamiliar with the ins and outs of the geography, demography and definitions of Aboriginal people in Canada. The Aboriginal Peoples Survey (which is conducted every five years, with the fourth cycle and latest version undertaken in 2012) is a case in point here. It is described as 'a national survey of First Nations people living *off-reserve*, Métis and Inuit aged six years and over' (Statistics Canada 2012). Data from the most recent of these Surveys was not able to be located for this report, however, widespread reference[11] seems to be made to now dated data from the 1991 Survey, which reported age standardised disability rates for the total Aboriginal population of 31.4 per cent for all ages 15 and over versus 12.6 per cent for the total

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[10] Contact was made with Statistics Canada to determine current rates but was not forthcoming by the time of printing.

[11] Reference to what we assume are these figures is made in a number of publications including those by Durst and colleagues over time (2004; 2006a, 2006b) and Wearmouth and Wielandt (2009).

population[12] (Ng 1996, p.27). And, for subgroups within the total Aboriginal population: North American Indians on-reserve (31.7%) and off-reserve (31.0%), Métis (32.0%) and Inuit (29.9%), with prevalence of disability increasing with age and remaining significantly higher with age than for the total Canadian population (p.27). According to these figures, rates of disability among Aboriginal Canadians are double those of the total population, with severity increasing significantly with age (Ng 1996, p.28).

The most up to date single national disability figure available is from the 2012 Canadian Survey of Disability—which reports a national disability rate of 13.7 per cent (Statistics Canada 2013). This figure tallies somewhat with that reported by Ng (1996) above, but differs from the population rate in both New Zealand and Australia. These data also differ from statistics presented in other publications such as Health Canada's 2008 publication *A Statistical Profile on the Health of First Nations in Canada, Self-rated Health and Selected Conditions, 2002– 2005* which outlines findings from Statistics Canada's Canadian Community Health Survey, reporting an overall rate of disability[13] of 22.9 per cent for adult First Nations people living on-reserve (p.13), and, age adjusted figures for the same population group as 28.5 per cent versus 25.8 per cent for the general population (p.14).[14] Accordingly, it is fair to state that somewhere in the order of a third of Aboriginal people in Canada report having a disability, and this figure is above the average for the Canadian population as a whole. Notably, on this difference in rates of disability the 1996 *Royal Commission into Aboriginal Peoples* (RCAP) noted that:

> The disparity between Aboriginal and non-Aboriginal rates of disability corresponds to disparities in rates of injury, accident, violence, self-destructive or suicidal behaviour and illness (such as diabetes) that can result in permanent impairment. (p.148)

There is a dearth of literature around housing issues and housing models for Aboriginal people living with a disability in Canada. In many ways this is unsurprising given the dearth of literature around housing and Aboriginal people generally. A small number of reports by housing agencies and other national peak bodies, as well as researchers for these organisations, have explored particular elements of the nexus between housing and culture and circumstances for Aboriginal people (Hill 2010; Durbin 2009; Carter & Polevychok 2004). Other more grey-type literature also exists on broader housing issues such as homelessness and Aboriginal people (Patrick 2014; Thurston et al. 2011), as well as exploring gender needs in terms of Aboriginal housing (Native Women's Association of Canada 2004; Centre for Equality Rights in Accommodation 2002). The complexity of political and financial changes around support for Aboriginal people (including in terms of their housing), controversy over 'defining' Aboriginal Canadians and their 'sub' populations (particularly Status versus non-Status Indians[15]), the geography and demography of Aboriginality and of housing (by province and region, urban versus non-urban living and on-reserve versus off-reserve living) and, simply, the lack of data and information about disability, housing and lived experiences of culture, housing and disability, are key themes underpinning all of the literature reviewed here. Useful summaries of these issues can be found in, for example, Urban Aboriginal Knowledge Network (2013); also Craig and Hamilton 2014; MacTavish et al. (2012), Belanger et al. (2012); Hill (2010); Durbin

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[12] Comparison data for the total Canadian population drawn from the (then) 1991 Health and Activity Limitation Survey (Ng 1996, p.27).

[13] Of at least one disability condition and with disability in this context being self-defined and what Health Canada call a much more sensitive measure as it is medical 'diagnosis-free' (p.14). Major revisions to the methodology for the annual component of the Canadian Community Health Survey and its content, including questions around health and health conditions, occurred in 2015, with application from 2016 (Statistics Canada 2015b).

[14] The data limitations discussed here must also be considered when using particular survey tools to examine the housing-related data for Canada. This said, such data does provide at least indicative information about challenges facing Aboriginal Canadians in comparison with their non-Aboriginal counterparts.

[15] See Statistics Canada 2015a for explanation.

(2009); Carter and Polevychok (2004) and Centre for Equality Rights in Accommodation (2002).

As in Australia and New Zealand, housing for Indigenous people in Canada generally has long been recognised as a critical issue which has not been addressed through adequate funding for supply and repairs and maintenance. This situation was acknowledged in the 1996 RCAP which made numerous conclusions regarding Aboriginal people, their culture, health, housing and wellbeing, which are of ongoing relevance (RCAP 1996 Vol III, Chapter 4). It strongly emphasised 'the intolerable housing and living conditions of many aboriginal people' and the fact that 'aboriginal housing and community services are in a bad state, by all measures falling below the standards that prevail elsewhere in Canada and threatening the health and well-being of Aboriginal people'. Additionally, 'the inadequacy of these services is visible evidence of the poverty and marginalisation experienced disproportionately by Aboriginal people'. At the same time, the RCAP noted that by addressing the national 'housing crisis' for Aboriginal people—through adequate financial investment, culturally appropriate governance of housing and community services and removal of the bureaucratic and political barriers to the provision of services based on ethnicity—major gains could be made in terms of culture, economic and social outcomes for this group as a whole:

> An underlying Aboriginal expectation is that better housing and community services, as well as the processes and activities leading to them, will improve community morale and increase every individual's sense of self-worth and identity, and that these services will be a central part of the healing process as people rebuild their lives and their cultures simultaneously, in both social and physical forms.

And,

> Aboriginal people see housing improvements as means of simultaneously increasing control over their own lives, developing increased capacity to manage complex programs and businesses, providing meaningful jobs, sustaining Aboriginal lifestyles, cultures, and generally better health, and strengthening Aboriginal communities.

The need to address the housing needs of Aboriginal peoples in the RCAP was noted as necessary for all Aboriginal peoples—for First Nations on- and off-reserve, as well as for Métis and Inuit—and for Aboriginal peoples regardless of geography.

Much more recent literature about Aboriginal housing in Canada shows that the situation described in the RCAP remains in large measure, with the significant challenges in terms of housing for Indigenous Canadians being both the quality and availability of good quality, safe and affordable housing. These challenges apply on- and off-reserve and in Métis and Inuit communities (Belanger et al. 2012; MacTavish et al. 2011; also Patrick 2014 in the context of housing and homelessness).

In discussing the housing situation facing Aboriginal Canadians it would be remiss not to mention here that almost all discussions and evaluations of the suitability of housing in Canada reference and present data using a locally-developed and understood model or framework of housing status known as 'core housing need' The components of this model are outlined and explained in Box 6.

Box 6: Explanation of Canada's core housing need model of housing status

A household is said to be in core housing need if its housing falls below at least one of the adequacy, affordability or suitability, standards *and* it would have to spend 30 per cent or more of its total before-tax income to pay the median rent of alternative local housing that is acceptable (meets all three housing standards).

→ Adequate housing are [sic] reported by their residents as not requiring any major repairs.

→ Affordable dwellings costs less than 30 per cent of total before-tax household income.

→ Suitable housing has enough bedrooms for the size and make-up of resident households, according to National Occupancy Standard (NOS) requirements.

A household is not in core housing need if its housing meets all of the adequacy, suitability and affordability standards.

Or,

If its housing does not meet one or more of these standards, but it has sufficient income to obtain alternative local housing that is acceptable (meets all three standards).

Note: Regardless of their circumstances, non-family households led by maintainers 15 to 29 years of age attending school full-time are considered to be in a transitional stage of life and therefore not in core housing need.

Source: CMHC 2014b

This model of housing status highlights the relative disadvantage faced by Aboriginal peoples in Canada in terms of their housing costs and conditions.

Detailed analysis of 2011 Census and/or 2011 National Housing Survey data by the CMHC (2014a) reveals a number of issues around housing and housing need:

→ For off-reserve Aboriginal households:

  → An incidence of core housing need of 19.0 per cent (representing 96 000 households in core housing need), compared with 12.2 per cent for non-Aboriginal households (1.456 million households in need) and down from 20.4 per cent at Census 2006 versus 12.4 per cent for non-Aboriginal households and 24.0 per cent versus 13.5 per cent at Census 2011 (pp.1–10 & 1–36).

  → Much higher rates of core housing need among all housing types, such as 16.3 per cent for Aboriginal family households (63 000 households in core housing need) versus non-Aboriginal family households of 8.6 per cent (710 000 households in need); lone parents 40.4 per cent (33 000 households) versus 25.2 per cent (295 000 households) (pp.1–36).

  → Much higher rates of core housing need for all types of renter households (versus owners), such as among all Aboriginal households a 7.9 per cent incidence of core housing need for owners versus 34.7 per cent for renters (corresponding figures for non-Aboriginal households of 6.4% and 25.9%); for family households, owners 6.7 per cent versus renters 34.0 per cent (4.8% versus 23.6% non-Aboriginal households) and for lone parent households, owners 20.4 per cent versus renters 51.8 per cent (14.2% versus 40.6%) (pp.1–37)[16].

Off-reserve Aboriginal households in core housing need comprised a larger proportion of the total population in core housing need in 2011 compared with 2006, with the CMHC attributing this to the much more rapid population growth among off-reserve Aboriginal households over this time (CMHC 2014a, pp.1–10).

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[16] See CMHC (2014a, pp.1–37) for further core housing need statistics by household type.

For on-reserve Aboriginal households[17]:

→ About one in every three households on-reserve (33.4%) living below standards for adequacy and suitability and with incomes insufficient to meet costs for 'acceptable' housing.

→ Most on-reserve households lived below the adequacy standard (i.e. housing condition standard) (28.9%), with 10.4 per cent living below the suitability standard (overcrowding) and 10.5 per cent below both standards (pp.1–11).[18]

Analysis of on-reserve household data from the 2006 Census (only) by the CMHC noted similar trends in core housing need among Aboriginal households (CMHC 2011a). Research by Durst (2006a), an active researcher in the field of Aboriginal disability, reiterates many of the key messages about Aboriginal housing here, with specific reference to reserve communities:

Housing on many remote and rural reserves is inadequate, failing to meet basic housing standards for amenities and structure. (Durst 2006a, p.15)

MacTavish et al. (2011) note similar concerns:

First Nation (Indigenous) on-reserve housing in Canada is in crisis due to severe shortages, high reported instances of mould contamination, overcrowding and structural deficiencies. (p.207)

Data around housing need record an apparent improvement in core housing need over time, although there is a way to go to see significant improvements in housing conditions. The still significant proportion of Aboriginal houses needing major repairs, let alone minor repairs and regular maintenance (Statistics Canada 2010; National Aboriginal Housing Association 2009) or disability-related modifications (Durst 2006a, 2006b) shows the clear need for further attention to this issue.

Notably, the need for better understanding of the nexus between housing, disability and other health related concerns for Aboriginal Canadians has been identified in a number of circles, including in the context of health promotion through understandings of the social determinants of health; with housing identified as a key determinant (see the systematic review conducted by Kolahdooz et al. 2015 for discussion; also Carter & Polevychok 2004). Additionally, specific concerns regarding health and housing for Aboriginal peoples generally has been raised by the Urban Aboriginal Knowledge Network noting in their review of the literature on concerns for urban Aboriginal peoples that one of the future directions in housing research is 'research on intersections between housing and mental health, addictions, physical health, and education in an urban context' (p.20). The National Aboriginal Housing Association has also strongly directed debates about housing and other services for Aboriginal people living off-reserve (as the majority of Aboriginal households in Canada; and households that generally do not receive Indigenous specific housing and other assistance from the federal government) putting forward *A National Plan to Address Aboriginal Housing* with the minimum requirements of:

→ Redressing disparities around the supply and availability of adequate, affordable and suitable off-reserve housing, particularly social housing.

→ Addressing the much higher prevalence of homelessness among Aboriginal Canadians.

→ Reducing overall incidences of core housing need to 'a level no higher than that among the non-Aboriginal population (National Aboriginal Housing Association 2009, pp.i, ii).

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[17] Core housing need cannot be calculated for Aboriginal people living on-reserve as housing costs are not collected by the NHS due to payment arrangements on-reserve. However, some needs calculations related to adequacy and suitability were able to be calculated for households using data on income collected on-reserve (CMHC 2014a, pp.1–11).

[18] See also Durbin (2009) for a history and assessment of current issues regarding health and housing for Aboriginal people on-reserve.

Data analysis by Belanger et al. (2012) supports the National Aboriginal Housing Association call for action and also traces much of the policy context around the need for these directions.

Concerns about housing among Aboriginal people in Canada is acknowledged by the Canada Mortgage and Housing Corporation (CMHC); Canada's federal authority on housing[19] (CMHC 2015e). In recognition of the challenges facing them the CMHC provides specific assistance for Aboriginal people in Canada, including: assistance to fund and support the operations of projects to build and rehabilitate suitable, adequate and affordable rental housing for eligible First Nations people; subsidies and direct loan finance for eligible social housing projects; seed funding and funding for the development of proposals for initiatives to provide affordable housing; and advice on a range of housing related matters (CMHC 2015b). They also provide a range of information-based tools and resources for First Nations people, including tools to help address known housing-related health and safety concerns, such as mould and fires (CMHC 2007, 2011b). CMHC also provide two on-reserve assistance programs with clear impact on people living with disabilities, including age-related needs. The first of these is the Residential Rehabilitation Assistance Program On-Reserve which provides funding to repair substandard homes so that they meet health and safety requirements as well as to improve accessibility for residents with disabilities. The other key CMHC program is the Home Adaptations for Seniors' Independence Program On-Reserve, which assists older low-income people on-reserve with modifications to their home to facilitate ongoing community living. CMHC also provides assistance to Aboriginal people living off-reserve through their other housing assistance programs, such as through financial aid for certain social housing providers and via CMHC funds directed to provinces and territories for their own housing programs (CMHC 2015b).

As a key contributor to the field of Aboriginal people living with a disability and housing, Durst has provided important commentary around the issue of disability and housing for Aboriginal people in Canada, albeit in this case specifically for urban Aboriginal people living with a disability. In his work on *Urban Aboriginal Families of Children with Disabilities* (Durst 2006a) Durst succinctly summarised the situation facing many as follows:

> Many First Nations people with disabilities move to urban areas to obtain treatment or to be closer to services. They find that accessible housing is scarce, education and training opportunities are inadequate, as are home care services, employment opportunities, and transportation. In addition, they are isolated and have limited opportunities for social interaction. (p.16)

Importantly, he also noted that for many Aboriginal people living with a disability, '[t]hey are clearly affected by disabilities because of poor economic, political, and social living conditions' (p.15). The importance of these factors in determining the poor housing conditions facing Aboriginal Canadians generally, and particularly those living with a disability, is a key theme in almost all of the literature reviewed here.

On the whole, the scant literature around disability, housing and Aboriginal peoples in Canada concedes that many in this group face multiple challenges in their attempts to live an independent lifestyle, with the state of housing and lack of resources and knowledge about improving its appropriateness shaping these challenges. This reality is demonstrated in recent research by Wearmouth and Wielandt (2009) who in a small scale study of physical disability and on-reserve housing in First Nations communities in western Canada found on-reserve

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[19] The CMHC is a corporation of the Crown, set up by an Act of Parliament in the immediate post-war period, with parliamentary reporting responsibilities (CMHC 2015c, 2015d). The CMHC describes its roles as helping 'Canadians meet their housing needs' (CMHC 2015e). They further note that their role is to '… contribute to the stability of the housing market and financial system, provide support for Canadians in housing need, and offer objective housing research and advice to Canadian governments, consumers and the housing industry' (CMHC 2015e). The CMHC provides a range of housing-related services and products for the Canadian housing system, including mortgage loan insurance, subsidies for social housing and matching funds (with province and territory governments) for social housing and other bricks and mortar and housing assistance measures to assist people in need (CMHC 2015e).

homes were not generally wheelchair accessible and modifications, if and when completed, took considerable lengths of time to complete.

In examining the Canadian literature, it is clear that there is a dearth of research on culturally responsive models of housing for Aboriginal Canadians, let alone for people living with disabilities. As in Australia and New Zealand, the literature around Indigenous people and disability and around Indigenous people and housing notes the crucial role of community and the communitarian focus of Indigenous peoples for addressing challenges and meeting individual needs (Durst & Bluechardt 2004, p.5) As such, the key to any model or approach for the betterment of housing for Aboriginal people living with a disability must facilitate and work within a framework emphasising community ownership, community engagement, community participation and community empowerment to ensure that initiatives and development plans (and decision-making processes) drive sustainable and appropriate housing models (MacTavish et al. 2011; issues also noted in the Australian context by Davidson et al. 2011).

5.4   Conclusions

This chapter has highlighted the paucity of international and national research on housing for Indigenous people living with a disability. Apart from a small body of research on the housing needs of Maori living with disabilities from New Zealand (which does not identify best practice models), little research had been undertaken. The lack of material identifying culturally responsive housing (and infrastructure) models for Indigenous people across New Zealand, Canada and Australia living with a disability demonstrates the need for further attention, research and resources in this area.

The material presented in this Chapter does, however, highlight that there is no 'one size fits all' approach regarding the type(s) of housing needed for Indigenous people living with disabilities and that housing choices for people living with disabilities are limited at every level; across types of disability, degrees of disability and regionally, nationally and internationally.

The discussion in this chapter demonstrates that housing for Indigenous people living with a disability is a major challenge. It is a challenge that nations with similar governance structures are grappling to come to terms with. Comparative analysis is therefore difficult. This means that Australia must chart its own course to develop appropriate solutions and best practice models of culturally appropriate housing for Indigenous people who are living with a disability. The NDIS is a massive social policy change and a potential impetus for addressing many of the gaps in understanding of the role of housing and infrastructure for Indigenous people living with a disability in Australia. Continuing work in the area is imperative given the NDIS legislation and Australia's obligations as a signatory to the United Nations Convention on the Rights of Persons with Disabilities.

6 GUIDELINES AND STANDARDS FOR HOUSING FOR INDIGENOUS PEOPLE LIVING WITH A DISABILITY

6.1 Introduction

Alongside the scant literature about housing for Indigenous people living with a disability it is important to note there exist a number of guides and guidelines for housing and infrastructure in Indigenous communities. Like the increasing body of mainstream research on disability and housing (NPDCC 2009; also, e.g. Baker et al. 2014; Mason et al. 2013; Bentley et al. 2012, 2011; Phibbs & Thompson 2011), these documents (and the scant literature discussing their development and application) acknowledge the central importance of housing and living environments and amenity to health and safety, quality of life, social inclusion, economic participation and overall wellbeing (OCED 2011). It is important to review and provide some context around these documents here as they will be referred to in the fieldwork for this study; shaping and providing benchmarks for the evaluation of housing and community infrastructure in case study locations to be undertaken in the final stage of this research (as outlined in the final chapter of this Positioning Paper). The key documents in this regard are:

→ The *National Indigenous Housing Guide* (NIHG) (2007).

→ The *National Indigenous Infrastructure Guide* (NIIG) (2010).

→ The newly developed *National Construction Code* (NCC) (2015)—specifically for its guidelines around access for people living with a disability.

The chapter considers each of these documents in turn.

6.2 Indigenous housing and infrastructure guidelines

The *National Indigenous Housing Guide* (NIHG) (2007) and the *National Indigenous Infrastructure Guide* (NIIG) (2010) provide guidelines for healthy living through the design, construction and maintenance of sustainable housing and infrastructure for Aboriginal and Torres Strait Islander peoples. These Guides are important in the context of this study as they recognise the clear connection between the built environment and health and wellbeing for Indigenous Australians; which are obviously also important connections, with functional implications, for people living with disabilities.

6.2.1 The National Indigenous Housing Guide (2007).

The NIHG (2007) is a government endorsed resource, including an assessment tool and checklists, for all stakeholders involved in the design, provision and maintenance of housing in Indigenous communities. As noted upfront in the NIHG it:

> … provides practical information on the design, selection, installation, construction, renovation and maintenance of housing health hardware and other aspects related to environmental health, for example dealing with dust, insects and dogs. It is a resource for everybody involved in providing housing to Indigenous people, including community councils, Indigenous housing workers, council staff, architects, project managers, tradespeople and government officials. (FaHCSIA 2007, p.9)

A key influence on the development of the Guide is the concept of 'health hardware' a term coined by Dr Fred Hollows to refer to 'the physical equipment necessary for healthy, hygienic living' (FaHCSIA 2007, p.9). That this is a central tenet underpinning the Guide, is also reflective of its environmental health focus.

The NHIG comprises four parts, each covering a particular element of importance in terms of Indigenous housing. These are (including their overarching preambles):

→ A. Safety—'When designing, upgrading or maintaining a house, immediate, life-threatening dangers must be given the highest priority' (p.18).

→ B. Health and housing—'Poor environmental and living conditions promote the spread of infectious diseases. To achieve good health outcomes, most houses in a community must have health hardware functioning most of the time. Houses must be designed well, soundly constructed and regularly maintained' (p.57).

→ C. Healthy communities—'Individual houses depend on the availability and function of community infrastructure such as water, waste water disposal and power supply. If these essential services are not functioning properly, the health hardware in the house will be compromised' (p.209).

→ D. Managing houses for safety and health—'A cyclical maintenance program is essential for sustaining the safety and health of houses and yard areas in a community' (p.255).

The NIHG was been designed to be 'used in tandem with local knowledge' to '… help to improve housing and health outcomes' and to inform the development and success of community development activities (FaHCSIA 2007, p.9). Its introduction notes that it has been informed by the needs and experiences of local communities with regard to their housing, as well as reflecting the experiences of relevant design consultants and builders, research, and relevant building codes and standards. The Guide forms the basis for the quality assurance framework outlined in the *National Partnership Agreement on Remote Indigenous Housing* (ANAO 2010, p.9; Healthabitat 2015); the key reform agreement negotiated between the states and territories and Australian Government for the 'provision of housing for Indigenous people in remote communities and to address overcrowding, homelessness, poor housing condition and severe housing shortage in remote Indigenous communities' (COAG 2008, p.1). All of these factors contribute to the Guide's practical nature, widespread reference and application and therefore its relevance to any research examining Indigenous housing.

The 2007 Guide is the third edition of the document (following editions in 1999 and 2003).[20] It reflects experiences in surveying and then working to fix 3600 homes in 'urban, urban fringe, regional, remote and very remote regions covering desert, temperate and tropical conditions' (FaHCSIA 2007, p.17), with these dwellings home to some 25 000 residents (FaHCSIA 2007, p.5). Notably while the NIHG is backed by a database of experiences with the maintenance of dwellings, Pholeros and Phibbs (2012) rightly point out that a similar data set does not exist for newly constructed homes in Indigenous communities, leaving a gap in our understanding around culturally appropriate design standards for newly constructed Indigenous housing, as well as around 'the performance of different housing designs and construction methods' and their endurance/longevity and cost-effectiveness (p.2). Pholeros and Phibbs' work on *Constructing and maintaining houses* for the *Closing the Gap* Clearinghouse offers some important insights into Indigenous housing that is referred to in this research generally (see Chapter 5), and references the important and necessary role of the NIHG in assessing, and working to improve, the standard of housing in Indigenous communities nationally.

The data and experiences that form the foundation for the NIHGs are drawn from a series of government funded projects investigating and promoting health through housing (and other related infrastructure) at the household level. These projects, known as the Fixing Houses for Better Health projects or simply the Health for Housing projects (see Healthabitat website for further information; also ANAO 2010; NSW Department of Health 2010), were designed and delivered by Healthabitat during the 2000s and emphasise a survey-fix approach for housing and communities. They are based on Healthabitat's almost 30 years of experience in delivering such programs in Indigenous communities. All of these projects and the NIHG reflect key learnings about individual and community health through housing in a seminal piece of work in

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[20] The 1999 edition contained no data and the 2003 edition contained data on 800 houses only (Healthabitat 2013b; FaHCSIA 2007, p.17).

this regard conducted in the APY Lands (Anangu Pitjantjatjara Yankunytjatjara) in far north western SA in 1987 (by Healthabitat). This work, known as the UPK Report (Uwankara Palyankyu Kanyintjaku) put forward nine (prioritised) essential Healthy Living Practices for households and communities:

→ washing people

→ washing clothes/bedding

→ waste removal

→ nutrition

→ reduce crowding

→ separation of dogs and children

→ dust control

→ temperature control

→ reduced trauma (Nganampa Health Council 1987, p.2).

The development of the NIHGs was also informed originally by the key principles of safety, health, quality control and sustainability underpinning the then National Framework for the Design, Construction and Maintenance of Indigenous Housing (1999). These principles emphasised that:

1. 'Houses for Aboriginal and Torres Strait Islander peoples will be designed, constructed and maintained for safety.

2. Houses will be designed, constructed and maintained to support 'healthy living practices'.

3. Quality control measures will be adopted in the design, construction and maintenance of houses.

4. Houses will be designed and constructed for long-term function, and ease and economy of maintenance' (Fien et al. 2007, p.25).

(John Fien and colleagues (Fien et al. 2007, 2008) provide further discussion of the relationship between key housing-related documents and policies, in their now almost decade old research for AHURI outlining a holistic design 'system' or 'framework' for remote Indigenous housing and to supplement the strong safety, health and sustainability focus of the NIHG (see particularly Fien et al. 2007, Chapter 3)).

The NIHG continues to be structured around Healthabitat's 'Healthy Living Practices' (see especially Part B and C) and together with the documents informing its development[21] (and the then *National Framework for the Design, Construction and Maintenance of Indigenous Housing* (1999)) has elevated these as the preferred methodology for approaching many critical safety- and wellbeing-related housing and infrastructure surveys and fixes in Indigenous communities. Since the inception of the *Health for Housing* initiative, Healthabitat have delivered over 180 separate projects in Indigenous communities (Australian Indigenous HealthInfoNet 2015a); contributing to efforts to improve housing through the *National Partnership Agreement on Remote Indigenous Housing* and feeding in to the Closing the Gap strategy (COAG 2008).

At the practical level the NIHG provides an approach for tackling (first) larger safety issues in construction around electrical safety, fire prevention, gas leaks and structural collapse. Following this the Guide outlines good practices to maintain healthy living including washing and cleaning. These sections are followed by further guidelines on development of community infrastructure dealing with waste water and energy management, and recommendations on routine maintenance. While the recommendations are not directed specifically at people with

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[21] Pholeros et al. 1993, 2000; Torzillo and Pholeros 2002.

disabilities, a series of the recommendations do take into account the needs of disabled people in addressing issues around safety and healthy living. The general thrust of these recommendations is ensuring accessibility for people with physical disabilities. Other sections use the relevant Australian Standards to specify dimensional requirements. The relevant sections of the Guide in this regards are identified in Appendix 4. (Helpfully, the Guide indicates (with the use of symbols) the strength of evidence around each guideline under the four key areas covered.).

In addition to guidelines concerning requirements for people with disabilities, the Guide also provides recommendations on universal access. This focus within the Guide recognises that dwellings may be occupied or visited by people with different access needs and different levels of mobility (FaHCSIA 2007, p.284). Universal access standards as per the Guide are divided into three categories as outlined in Box 7.

Box 7: Universal access standards, NIHG, Australia, 2007

'Fully accessible'—a house in which the bathroom, laundry, kitchen, living areas, external areas and at least one bedroom are designed so that they can be accessed and used by a person with a disability (to comply with AS 1428.1 Design for access and mobility and AS 4299 Adaptable housing).

'Adaptable' housing—houses that can be modified easily in the future to be fully accessible, for example, room and door sizes comply with AS 1428.1 and AS 4299 but fittings and fixtures may need to be modified in the future (refer to AS 4299 Category C).

'Visitable'—housing where visitors with a disability can enter the house and use the main living area and the toilet'.

Source: FaHCSIA 2007, p.284

In recognition of disability-related access and mobility needs, as a minimum the NIHG suggests houses should be surveyed and fixed to provide:

→ access from the street to the house by a continuous, slip resistant, accessible path

→ no barriers and step free entry to the house

→ wider doorways (minimum 870mm wide door leaf) and lever handles to doors

→ at least one toilet, size of shower and hand basin, including barrier free access to shower

→ grab rails, or provision for future grab rails

→ laundries and kitchens designed with 1550mm clear circulation space in front of benches and fixtures, and accessible taps, power points, fixtures, appliances and shelves accessible to a person in a wheelchair (otherwise they need to be easy to alter)

→ interiors and hall ways that provide adequate circulation space

→ correct height of power points and light switches (between 900mm and 1100mm and set out at least 600mm from corners of rooms)

→ full access to car parking areas, clothes drying and bin storage

→ provision to modify the house to accommodate access needs of residents (FaHCSIA 2007, p.285).

The importance of the work conducted by Healthabitat should be acknowledged here. For, in addition to the community work done by the organisation, they have produced a range of tools to promote healthy living within Indigenous communities. Notable amongst these is a new version of the NIHG known as *Housing for Health: the Guide. The Housing for Health Guide* is an interactive online resource underpinned by the same health and safety principles as the NIHG. It includes data on some 7500 houses and is a living resource, designed to be updated continuously and reviewed periodically. Unlike the NIHG it does not have government

endorsement. Healthabitat note that they developed this Guide when the fourth edition of the NIHG was not forthcoming (due 2012) (Healthabitat 2013b). Like the NIHG it provides a series of practical tools based on their survey/fix methodology to improve health and housing outcomes for Indigenous people (Healthabitat 2013a).

6.2.2   The National Indigenous Infrastructure Guide (2010).

The NIIG is a complementary document to the NIHG,[22] and is a framework currently used in remote Indigenous communities to improve the quality and sustainability of what is referred to in the NIIG as 'community level infrastructure' (Elvin & Hogan 2010). Like the NIHG, the NIIG was developed out of evolving experience in improving such infrastructures; this time by the Centre for Appropriate Technology (CAT)[23] based in the Northern Territory. Elvin and Hogan (2010) helpfully summarise the relationship between this NIHG and NIIG:

> In short, the *Housing Guide* stops at the front gate, while the Infrastructure Guide goes beyond the front gate, and even includes the roads out of town.

Development of the NIIG was funded by the Australian Government. The CAT (2014) note that it is:

> … an integrated framework for understanding major infrastructure provision issues for remote communities … Integral to it is an emphasis on involvement of community members, especially in the maintenance and management of infrastructure.

Rather than being a comprehensive 'how to' manual, it seeks to provide community managers, local and state government officers, and those working in planning and developing infrastructure projects with an awareness of the issues that need to be considered when working with various aspects of infrastructure. Its modest technical scope can be expanded as demand requires. The NIIG comprises two distinct parts:

Part A: covering issues and approaches in terms of engaging communities, project and asset management and maintenance (FaHCSIA 2010).

Part B: covering seven specific areas of community level infrastructure, reflecting ongoing learnings about common issues in remote communities:

→   water

→   stormwater

→   wastewater

→   waste

→   energy (including renewables)

→   telecommunications (roads, aerodromes, waterways)

→   transport (see also Elvin & Hogan 2010).

Helpfully the document cites relevant Australian standards for each community level infrastructure area, as well as providing pointers on choosing appropriate solutions, management and maintenance of systems and items and outlines relevant research and evidence (FaHCSIA 2010). In contrast to the NIHG though the NIIG contains limited references to specific issues in terms of infrastructure for Indigenous people living with a disability. The NIIG does note, however:

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[22] And the *Environmental Health Handbook: A Practical Manual for Remote Communities* developed nearly 15 years ago now by the Menzies School of Health Research in Darwin (Australian Indigenous HealthInfoNet 2015b).

[23] The CAT website notes the organisation's core capabilities for assisting Indigenous people and communities as: community engagement and relationships; technology innovation; housing and Infrastructure services; project management; capacity building and training and employment (as a Registered Training Organisation) (CAT 2014).

→ Consideration of demographic needs including disability in deciding on community sanitation systems (p.149).

→ Provision of services for people with disabilities to ensure they can also participate in recycling schemes (p.208).

→ The need for accessible telecommunications systems and essential services telecommunications for all community members, including those with special needs (pp.257, 260, 264).

→ Access to appropriate transport infrastructure for medical and health needs (including roads for community transport and medical evacuations, airports for medical-related freight et cetera) (pp.293, 294 & 298).

While the disability focus in the NIIG is not as obvious as that in the NIHG there is also a general acknowledgement of the need to meet, plan for and engage, the many and varied needs of community members in the planning and maintenance of new and existing infrastructure.

6.3 National Construction Code and Australian Standards

The previous discussion has been limited to guidelines and recommendations that are applied to developments within Indigenous communities. However, these are neither developed specifically for people with disabilities, nor are they binding in any legal sense. In contrast, Volumes One and Two of the performance-based National *Construction Code of Australia* (NCC)[24] which 'provides 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) throughout Australia' (ABCB 2011), set up certain minimum requirements when addressing the needs of people with disabilities in all construction projects across the nation. While the NCC is not specific to the requirements of any individual community, it does provide basic minimum standards for ensuring general safety and well-being of people, with, arguably, need to extend these to all community projects in a timely fashion. The NCC allows for consideration of structure, weatherproofing, fire safety, health and energy; all general requirements for safe construction.

A number of provisions in the NCC are of particular importance in meeting the needs of people living with a disability, which by default then extend to developments for people living in Indigenous communities. The provisions around Safe Movement and Access under Section 3.9 of the Code are notable in this regard (NCC Vol. 2). So too are the performance provisions under SA 5.1, which focuses on equitable and dignified access, requiring wheelchair access from road boundary to and within buildings (NCC Vol. 2, p.495). Areas such as kitchens and bathrooms should also be wheelchair accessible.

The Code also specifies provisions for accessibility in relation to certain developments of 20 or more dwellings, namely that:

→ '(a) Access for people with a disability must be provided from the entrance doorway to areas normally used by the occupants. A path of travel providing required access must not include a stairway or other impediment which would prevent a person in a wheelchair using it.

→ (b) Access, finishes and fittings must comply with the provisions of *AS 1428.1*.

→ (c) In every class one building to which access for people with a disability is required, one closet pan and washbasin and one shower must be provided for use by people with a disability' (NCC Vol 2, p.495).

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[24] The NCC is the name given to the single national construction code, developed out of a Council of Australian Governments initiative. It comprises three volumes: Volumes One and Two of the *Building Code of Australia* (BCA) and, as Volume Three, the *Plumbing Code of Australia* (PCA) (ABCB 2011).

Like the NIHG the NCC also references the Australian Standard *AS 1428.1* document (part of the *AS 1428* suite of standards related to disability access), which sets out standards for 'Design for Access and Mobility' (Standards Australia 2009). This document provides practical normative guides for construction of new facilities to allow for the following:

→ Continuous accessible paths of travel and circulation spaces for people who use wheelchairs:

   → access and facilities for people with ambulatory disabilities

   → access for people with sensory disabilities (Equal Access Australia 2015).

In addition to outlining a range of technical requirements relating to sizing of particular design elements, the *AS 1428 Standards* also provide information on signage and materiality. It must be noted, however, that these are based on international standards and may not be directly applicable to the culturally specific requirements of an Indigenous community (an area in need of further investigation). The Standards therefore need to be assessed and interpreted in relation to the specific requirements of each community. Compliance with the NCC also helps achieve compliance with the *Disability (Access to Premises—buildings) Standards 2010*, known as the Premises Standards.

6.4 Summary

The NIHG and NIIG are two important documents in terms of understanding and working to improve both housing and infrastructure in Indigenous communities. Such improvements to housing and infrastructure are crucial given known issues with the quality and sustainability of these important influences on the health and wellbeing of Indigenous people and their communities. The NCC and Australian Standards documents provide additional guidance on meeting the needs of people living with disabilities through new and existing construction, however, it is evident that many gaps remain in terms of the cultural-appropriateness, reach and application of these documents and other relevant standards for Indigenous people, and especially for Indigenous people living with disabilities.

The fieldwork component of this research will pay specific attention to the guidance and learnings in the NIHG, with reference also paid to relevant sections of the NIIG and NCC (and the Australian Standards they reference) where applicable for profiling and understanding housing and community infrastructure needs for people living with a disability. Chapter 7 discusses the fieldwork stage of this project in further detail.

7 RESEARCH PROGRAM

7.1 Introduction

The housing experiences of Indigenous people living with a disability are largely unknown in the research literature, to the research team brought together to undertake this research and probably to most policy-makers. Additionally, the ability of Indigenous individuals living with a disability to access appropriate housing, the condition and location of housing generally, as well as the availability of housing modifications and appropriate community infrastructure is also largely unknown. This research aims to shed light on these unknowns, providing robust information on Indigenous people living with a disability and their lived experiences of housing and community infrastructure. As noted in this chapter the research will do this by undertaking workshops with stakeholders, semi-structured interviews with Indigenous people living with a disability, their carers and families, and evaluating housing and community infrastructure in three case study sites within the stage one NDIS launch regions. In these locations the research team will document the characteristics of the housing environment, paying attention to cultural, physical, social and functional issues related to housing to provide baseline data and recommendations for the provision of housing and community infrastructure for Indigenous people living with a disability within the NDIS. The results of this research will be able to inform policy decisions regarding the housing and community infrastructure needs of Indigenous Australians living with a disability, as well as funding, allocations and housing modifications processes.

This final chapter of the Positioning Paper sets out the way forward for this research, outlining the methodology to be employed to garner necessary data on lived experiences; the location of the case studies upon which the research will be based; and proposed data collection and analysis methods.

7.2 Fieldwork

Fieldwork for this research will be undertaken in the three case study areas—Yalata and Point Pearce in SA and Geelong in Victoria. Fieldwork will be undertaken in two stages as discussed below.

The case study areas chosen for the project are examples of urban, rural and remote communities, allowing us to document to different types of housing options available to Indigenous people living with a disability in such communities. The areas were also chosen as they are all in stage one NDIS trial regions where eligible people are able to become NDIS participants (children aged 13 and under in the case of SA) and governments have stated the lessons learnt in these areas will be applied elsewhere.

Fieldwork for the project will be conducted as follows:

Stage one

→ Yalata: a discrete remote Aboriginal community located approximately 740 kilometres north-west of Adelaide. The community has a fluctuating population of between 220 and 1000 people (approximately 265 residents at Census 2011 (ABS 2012e)). All housing is community owned and independent living units have been constructed for people living with a disability.

Stage two

→ Point Pearce: a discrete rural Aboriginal community located 194 kilometres from Adelaide, with a population of approximately 120 people at Census 2011 (ABS 2012d). All housing is community owned.

→ Geelong: located 75 kilometres south-west of Melbourne with a population of approximately 1560 Aboriginal people at Census 2011 and originating from many places around Australia (ABS 2012c). Public housing is available to Indigenous residents through the Department of Human Services. There is a range of disability support services available within the Geelong community for people living with a disability, including supported accommodation, group and respite housing.

Notably also, this research was instigated by initial work by the First Nations Disability Network and refined through discussions between the researchers and the First Nations Disability Network, as the peak body representing Indigenous people with a disability. The First Nations Disability Network have been an active partner in the research and assisted in identifying case study areas.

As per the AIATSIS *Guidelines for Ethical Research in Australian Indigenous Studies* (2012), the methodology for the research has been devised to include 'meaningful engagement and reciprocity between the researcher and Indigenous people' (AIATSIS 2012, p.3). The methodology has been devised in consultation with the National First Peoples Disability Network and other stakeholders and adheres to the AIATSIS guidelines and requirements of the University of Adelaide Human Ethics Research Committee.

7.3 Documentation of the lived housing and community infrastructure experiences

The research involves documenting the lived housing and community infrastructure experiences of Indigenous people and communities in the three case study communities outlined above.

In the first instance, workshops will be held with community leaders, staff, housing and health service providers and other relevant community stakeholders at each location. The research questions posed in the workshops will focus on ascertaining the following information about each community:

→ A local estimate of the number of people living with disability in the community (to compare against available data).

→ Types of disabilities.

→ With whom people with a disability are living.

→ The number of people who have moved elsewhere for disability-related reasons.

→ Major housing issues for all people living in the community.

→ Housing issues for people living with a disability.

→ Community infrastructure being used by people living with a disability.

→ Community responses to the issues of disability, housing and community infrastructure.

→ Details of housing modifications that have been undertaken.

→ Details of community infrastructure modifications that have been undertaken.

→ Current and future projects to accommodate people with a disability.

→ Constraints to delivering accessible housing and community infrastructure.

Preliminary meetings will also be held in each community with community leaders, staff, stakeholders, housing and health service providers. At these meetings stakeholders will be asked to identify any potential participants and families/carers who may be interested in being interviewed for the study. Notices advertising the research will also be placed around the communities calling for interview participants. Particular attention will be paid to developing relationships with health services in preliminary meetings as the research teams feel that these

services are the most likely to have an existing and on-going relationship with individuals and families affected by disability.

Semi-structured interviews will be held with people with a disability and their families/carers (identified by HACC and health workers) to outline their lived housing experience. These interviews will be held over two periods in 2015. The focus of these interviews will be:

→ The benefits and/or constraints of people's current housing in terms of disability.

→ Whether modifications have been made to people's homes and how these have worked and played out.

→ The appropriateness of such modifications.

→ Impacts on quality of life related to disability and housing.

→ Whether people have thought about/had to move or reside elsewhere because of unsuitable housing.

→ Whether people would like to live in different housing and aspirations in terms of such housing.

→ Whether current community infrastructure enables people to access the community and surrounding areas.

To allow participants time to contemplate the issues being discussed in interviews all participants will have the opportunity to participate in a second interview if they desire. Participants will be given a store voucher as partial reimbursement for their time. It is anticipated that 20 interviews will be conducted for each case study area. The views and experiences of residents currently living outside the community due to health issues, lack of housing or for other reasons will be included wherever possible.

The fieldwork component of the research will involve four researchers and is to be conducted over six months to allow necessary time for organisation and conduct of the fieldwork.

The draft Final Report will be sent to key stakeholders (including the First Nations Disability Network, community leaders and the Policy Group) for discussion. This is an important step in the research methodology which has been designed to be respectful and inclusive of Indigenous cultural norms, knowledge and viewpoints.

7.4   Evaluations of housing and community infrastructure

For each community data will be collected on the types of housing, housing modifications, community infrastructure, and infrastructure modifications relating to needs of people living with a disability. A framework for collection and interpretation of such data will be developed through a review of standards available from the *National Construction Code of Australia* (NCC), *National Indigenous Housing Guide*, *National Indigenous Infrastructure Guide*, *Housing for Health* and other studies of remote housing. The collection and interpretation of these data will follow these processes:

1. Visual inspection:

The first stage of data collection will include a site visit and visual inspection of the housing and community infrastructure available at each case study location. Access to the houses will be arranged through appropriate processes, giving due regard to cultural sensitivities and the privacy of the residents. During visual inspections initial notations will be used to record the condition of properties and to identify specific details that require further inspection.

2. Photographic survey:

Following an initial visual inspection, a more detailed photographic survey will be carried out that records the existing condition of dwellings and infrastructure, noting any modifications.

3. Spot measurements and comparison against original proposed designs:

During the visual inspection and photographic survey specific details will be captured through spot measurements, including, where relevant, laser measurements to capture accurate data. These spot measurements will help identify how modifications have been made in relation to proposed designs and by comparison with existing plans and detail drawings.

4. Semi-structured interviews:

Once the general condition of housing, infrastructure and modifications have been identified and documented, residents will be asked a series of semi-structured questions to document how these meet their disability-related needs. Undertaking these interviews will help annotate the record regarding modifications and give insight into the way the needs of people with disabilities are incorporated into the existing housing and community infrastructure.

5. Evaluation against standards and proposed guidelines:

As a final step, the data collected will be evaluated against the framework extracted from the NCC as well as other guides. Such a comparison against the various proposed guidelines will not only help identify any limits of the existing designs, housing types and incorporated modifications, but also help formulate an understanding of needs that should be further reflected in the standards for future proposals.

7.5   Data analysis

Data collected from participants in the course of this research will be analysed using Nvivo 10 software to find common themes and trends. These themes and trends will then be compared with those discussed in this Positioning Paper to form a picture of the lived housing experiences of Indigenous Australians living with a disability. Importantly, by sorting material into themes (using Nvivo) and preserving the spoken word through quotations we hope to preserve the experiences of the participants in the research.

Housing will be evaluated against the NCC. The NCC provides nationally consistent, minimum standards as a benchmark for evaluating Indigenous housing in terms of use by Indigenous people living with a disability.

A template to record details of housing type, conditions, modifications and suitability for use by people with various disabilities will be developed. Similarly, a template for recording type and condition of community infrastructure will also be developed. These templates will assist the research team in meeting one of their goals for the research; to inform the evolution of standards and guidelines for housing for Indigenous people living with a disability. This is an important contribution to the Indigenous housing literature; adding to an area of knowledge where more research is clearly needed.

7.6   Conclusion

> Aboriginal people with disability often face multiple layers of discrimination at the intersection of their Aboriginality and disability. If we add further dimensions such as gender or age for example, then the degree of discrimination experienced by many Aboriginal people with disability is particularly acute. (Aboriginal Disability Network of NSW, p.11)

It is clear from this review of the literature and data around housing and disability among Indigenous Australians that there is still much to learn and understand. And, importantly, there is also much to gain from illuminating the housing, community infrastructure and disability nexus for Indigenous Australians, specifically in terms of improving health, wellbeing and social inclusion outcomes for this group.

The NDIS has been widely heralded as a watershed in the structure and delivery of supports for people living with a disability; a transformational opportunity for those eligible for services

under the Scheme and a way to strongly influence governments, the community, mainstream and other specialist services to truly recognise and meet the needs of some of the most vulnerable and excluded within the community. This reality is even more so among Indigenous people living with disabilities, particularly in rural and remote communities, where we know from the scant literature available that there are layers of disadvantage and numerous barriers in terms of service access and delivery, with whole of life implications. In many instances even basic services are not available to support community living for Indigenous people living with disabilities, let alone to let them thrive among their own families, communities and culture. Given these realities it is important that we capture the lived experiences of this group through research such as this, to allow us to emphasise their housing and related support needs. Accommodating these needs either within or in loose association with the NDIS—something we hope we will better understand as lessons are learnt from the NDIS trial sites, as well as research about the Scheme and disability generally (such as this project)—is an important way forward in acknowledging the all-encompassing impact of disability on people lives. As many commentators have stated it is also crucial for ensuring the NDIS delivers on its mandate of promoting individual choice and control to improve the lives of all people living with a disability.

The results of this study will provide a picture of the characteristics of the housing environment and the cultural, physical, social and functional issues related to housing for Indigenous people living with a disability. These results will be able to inform policy decisions regarding the housing and community infrastructure needs of Indigenous Australians living with a disability, as well as funding, allocations and housing modifications processes.

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APPENDICES

Appendix 1

The 10 major policy challenges facing Australia debated at the Rudd Government's 2020 Summit in Canberra April 2008:

1. the productivity agenda—education, skills, training, science and innovation

2. the future of the Australian economy

3. population, sustainability, climate change, water and the future of our cities

4. future directions for rural industries and rural communities

5. a long-term national health strategy

6. strengthening communities, supporting families and social inclusion

7. options for the future of Indigenous Australia

8. towards a creative Australia—the future of the arts, film and design

9. the future of Australian governance—renewed democracy, a more open government (including the role of the media, the structure of the federation, and the rights and responsibilities of citizens

10. Australia's future security and prosperity in a rapidly changing region and world.

Source: Department of Prime Minister and Cabinet 2008, p.1

Appendix 2

Box A1: Elements of the ABS definition of homelessness

The ABS definition of homelessness is informed by an understanding of homelessness as 'home'lessness, not rooflessness. It emphasises the core elements of 'home' in Anglo American and European interpretations… includ[ing] a sense of security, stability, privacy, safety, and the ability to control living space. Homelessness is therefore a lack of one or more of the elements that represent 'home'.

[T]he ABS definition has been built from three key conceptual elements. These elements are used to assess whether someone in a particular living condition can be defined as homeless.

In brief, the ABS statistical definition is that:

When a person does not have suitable accommodation alternatives they are considered homeless if their current living arrangement:

→ is in a dwelling that is inadequate; or

→ has no tenure, or if their initial tenure is short and not extendable; or

→ does not allow them to have control of, and access to space for social relations.

The definition has been constructed from a conceptual framework centred around the

following elements:

→ adequacy of the dwelling

→ security of tenure in the dwelling

→ control of, and access to space for social relations.

The ABS definition does not include those people who are 'at risk of homelessness' nor does it include housing situations that put them at risk of homelessness.

[Homelessness is considered in the context of choice (and some level of control over access to other accommodation alternatives].

Accommodation alternatives

People must lack one or more of the three elements listed above to be defined as homeless. However, the elements are considered in the context of an overarching consideration of accommodation alternatives. People who lack one or more of these elements are not necessarily classified as homeless …. People's exercise of choice in not accessing accommodation alternatives is contingent on them having each of the financial, physical, psychological and personal means necessary to provide access to these alternatives.

Adequacy of the dwelling

[A dwelling must be fit for human habitation (meets building codes, have access to basic facilities and not be improvised].

If the dwelling is inadequate by lacking in any of the aspects outlined above and the person also lacks accommodation alternatives, the person would be considered to be homeless.

Security of tenure in the dwelling

… covers a person's legal right to occupy a dwelling, with stability and security of tenure such as owning (with or without a mortgage the dwelling and/or land, or renting with a formal lease or similar right that could be enforced by the tenant.

Those people who have no tenure or tenure that is short and not extendable would be considered to be homeless if they also lack accommodation alternatives.

Control of, and access to space for social relations

… covers whether a person or household has control of and access to space so they are able to pursue social relations, have personal (or household living space, maintain privacy and the household has exclusive access to kitchen facilities and a bathroom.

Those households (or people for those who are living in accommodation such as boarding houses etc. which do not have their own living space that enables them to maintain privacy or do not have exclusive access to kitchen facilities and a bathroom, would, if they also lacked accommodation alternatives, be considered to be homeless.

Specific exclusions

The ABS has identified and excluded specific living situations from the definition of homelessness. While these living situations lack one or more of the key elements of 'home' identified in the definition of homelessness, the people occupying these places are not regarded as homeless. People in these living situations are not classified as homeless because:

→ they may have chosen to live in these circumstances and have accommodation

→ alternatives; or

→ are required by law to live in these circumstances; or

→ are acceptable temporary living arrangements (such as student halls of residence; or

→ it is essential for their broader health and wellbeing to be living in these situations.

The specific exclusions are:

→ People confined in prisons, detention centres and other institutions such as juvenile correctional facilities or hospitals.

→ Students living in halls of residence.

→ Members of religious orders such as monks and nuns living in seminaries and nunneries and similar establishments.

Severe crowding

People living in crowded dwellings represent a continuum within the scope of those who are marginally housed … In terms of the key elements in the ABS definition, all people living in the severely overcrowded dwelling do not have control of, or access to space for social relations.

Marginal housing

Homelessness is a component of marginal housing. Other marginal housing outside the concept of homelessness will be reported separately where available.

Source: ABS 2012b, pp.11–15

Appendix 3

Table A1: ABS table of limitations, restrictions, activities and tasks (Survey of Disability, Ageing and Carers)

Limitation or restriction	Activity	Tasks
Specific limitation or restriction		
Core activity limitations	Communication	Understanding family or friends
		Being understood by family or friends
		Understanding strangers
		Being understood by strangers
	Mobility	Getting into or out of a bed or chair
		Moving about usual place of residence
		Moving about a place away from usual residence
		Walking 200 metres
		Walking up and down stairs without a handrail
		Bending and picking up an object from the floor
		Using public transport
	Self-care	Showering or bathing
		Dressing
		Eating
		Toileting
		Bladder or bowel control
Schooling or employment restrictions	Schooling	Unable to attend school
		Attends a special school
		Attends special classes at an ordinary school
		Needs at least one day a week off school on average
		Has difficulty at school
	Employment	Permanently unable to work
		Restricted in the type of work they can or could do
		Need, or would need, at least one day a week off work on average
		Restricted in the number of hours they can, or could, work
		Requires special equipment, modified work environment or special arrangements
		Needs ongoing assistance or supervision
		Would find it difficult to change jobs or get a preferred job
		Needs assistance from a disability job placement program or agency

Limitation or restriction	Activity	Tasks
Without specific limitation or restriction		
Other activities	Health care	Foot care
		Taking medications or administering injections
		Dressing wounds
		Using medical machinery
		Manipulating muscles or limbs
	Reading or writing	Checking bills or bank statements
		Writing letters
		Filling in forms
	Transport	Going to places away from the usual place of residence
	Household chores	Washing
		Vacuuming
		Dusting
	Property maintenance	Changing light bulbs, taps, washers or car registration stickers
		Making minor home repairs
		Mowing lawns, watering, pruning shrubs, light weeding or planting
		Removing rubbish
	Meal preparation	Preparing ingredients
		Cooking food
	Cognition or emotion	Making friendships, interacting with others or maintaining relationships
		Coping with feelings or emotions
		Decision making or thinking through problems

Source: ABS 2013c

Appendix 4

Guidelines contained in the *National Indigenous Housing Guide* pertinent to this study

A1.1 Safety switches

→ checking the location and height of safety switches, so they can be reached by people with disabilities, but out of children's reach (see AS/NZS 3000 Electrical installations.

A1.4 Power points, lights and other fittings

→ The recommended height of switches and power points for use by people with disabilities is in line with door handles (900mm to 1100mm above floor level. A 'rocker' action, toggle, or push-pad switch with a width of 35mm is recommended.

→ locating light switches and power points away from corners and doors so that they can be reached by people with disabilities.

A3.2 Fire and smoke detection

→ specifying a smoke alarm with a wall mounted hush or pause button that automatically resets after five minutes, or installing a timer switch to the smoke alarm so that it automatically resets (confirm hush buttons, if installed, are easy to reach by people with disabilities.

A3.3 Escape in the event of fire

→ door handles are located between 900 to 1100mm above the floor level and can be operated by one hand and are within easy reach for people with disabilities.

→ sizing all doorways and hallways on exit routes to comply with AS 1428.1 Design for access and mobility for people with disabilities.

→ doors, hallways and windows are large enough to allow escape, including for people with disabilities.

B1.1 Wet area design

→ ensuring wet areas are accessible to elderly people and people with disabilities.

→ there are floor drains in the bathroom and the falls to these drains are clearly specified and allow access by people with disabilities.

→ the wet area can be accessed discreetly and independently by all members of the household including young children, frail aged people and people with disabilities.

→ designing all wet areas so that they can be easily adapted to allow frail aged people or people with disabilities full access to, and use of, wet areas (AS 1428.1 Design for access and mobility.

→ incorporating a bench seat next to the shower for use by children, the frail aged and people with disabilities.

B1.3 Taps

→ how and where the tap is mounted, for example bench mounted taps are easier to maintain than wall mounted taps and may be easier for people with disabilities to use but bench mounted taps can cause water damage to the bench if not well installed.

→ whether the tap uses a washer or ceramic disc, washers are cheap and easy to replace and tend to be longer lasting in water that contains sand, grit or other particles (river water but ceramic disc taps are easier for children and people with disabilities to use and can have fewer maintenance requirements if the water is free of particles.

→ the handle type, lever handles and 'flick' mixers are easier for people with disabilities to use and plastic handles should be avoided.

→ tap ware is standardised for easy maintenance and allows for handles to be changed to capstan or lever handles if required to meet the needs of residents with disabilities.

→ in the laundry, taps are positioned at the side of the tub within easy reach for people with disabilities.

B1.4 Washing young children—baths and tubs

→ If incorporating a bath tub in the wet area, avoid using a combination shower/bath as this can be difficult and dangerous to use, particularly for older people or people with disabilities.

B1.5 Showers

→ shower trays, hobs and showers over baths can limit accessibility for elderly people and people with disabilities (51% of houses that have a bath have a combined shower and bath.

→ providing at least one shower in each house that can be accessed by people with disabilities that complies with AS 1428.1 Design for access and mobility.

B2.1 Laundry design

→ providing circulation space into and within the laundry for use by a person with a disability, 1550mm clear space in front of fixtures, and locating the taps and power points within reach for a person in a wheelchair.

B2.2 Drying clothes and bedding

→ installing a lower level clothes line, or a line that can be lowered, for use by people with disabilities.

B3.1 Flush toilets

→ if the toilet is in a separate cubicle, the cubicle has a minimum depth of 1250mm in front of the toilet and 900mm clear width excluding door swings and fixtures, to allow use by people with disabilities and an adult assisting a child

→ fitting hand rails next to the toilet for the frail aged and people with disabilities.

→ providing at least one toilet that complies fully with AS 1428.1 Design for access and mobility, or that can be adapted in the future for use by the frail aged and people with disabilities.

B3.5 Dry toilets

→ building a path between the house and the toilet, which is slip resistant and accessible to people with disabilities designing the cubicle to comply with AS 1428.1 Design for access and mobility, and locating the hand washing point that can be accessed by people with disabilities.

B4.2 Food storage

→ The refrigerator and food storage cupboards need to be accessible for all members of the household, including people with disabilities.

→ there are at least two linear metres of cupboards or shelves built above bench height for storage of food or utensils out of the reach of children and animals, and that under-bench storage with doors is accessible for people with disabilities.

→ fitting a high level, secure cupboard for dangerous items such as cleaning products and medicines, and having a secure cupboard that is accessible for people with disabilities.

→ Consider making provision for people with disabilities to access storage areas, including:

→ providing a clear circulation space of at least 1550mm in the kitchen;

→ having lower or adjustable benches;

→ providing removable or mobile under-bench cupboards;

→ providing refrigerators with the freezer located under the fridge compartment to provide better access.

B4.3 Preparing food—sinks and benches

→ designing some parts of the under-bench cupboards to allow easy removal to provide access for people with disabilities.

→ planning the kitchen with a continuous bench top between the fridge and stove/oven to allow people with disabilities to safely slide hot or cold items from the fridge or the stove/oven along the bench.

→ using a kitchen sink bowl that is a maximum of 150mm deep, can be adjusted to heights from 750mm to 850mm or can be replaced to allow access for people with disabilities.

→ providing a bench area for a microwave oven at a height of 750mm to 1200mm above floor level that can be easily reached by people with disabilities.

B4.4 Cooking

→ the need to provide separate cooktops and wall ovens that can be accessed by people with disabilities.

→ installing ovens between 400mm and 1000mm above the floor, with side-opening doors and a bench immediately next to the oven to allow access for elderly people and people with disabilities.

→ a model that has controls at the front or side of the stove with raised crossbars for safe grip by people with disabilities.

→ providing a clear circulation space of 1500mm x 820mm to allow a forward approach to the cooktop by people with disabilities, no more than 500mm of this clear floor space should extend under the cooktop.

→ the isolation switch and check it has been installed in a location that can be reached by people with disabilities.

→ installing a stove with side or front controls with raised crossbars, which are easier for people with disabilities to grip.

B4.5 Kitchen design generally

→ locating the kitchen where it is easily accessed from inside and outside eating areas, and can be accessed by people with disabilities.

→ selecting and locating power points, switches, stove controls and taps to allow people with disabilities to reach and use them.

→ providing a slip resistant path between indoors and the outdoor cooking area, which is accessible to people with disabilities.

B5.1 Performance of health hardware in large households

→ health hardware such as taps, shower fittings, laundry tubs, washing machines, power points and light switches are good quality, will withstand high usage in large households and can be used by people with disabilities

→ at least one toilet and shower area is sized to be accessible to people with disabilities or can be adapted in the future to be fully accessible.

B5.2 Developing the edges of the house and the yard

→ house edges are accessible to people with disabilities.

→ Consider designing the yard area so that it is accessible to people with disabilities, by:

  → selecting a level or gently sloping site with up to 1:14 gradient

  → providing a well-lit, continuous, accessible path of travel and clear line of sight from street frontage and vehicle parking to entry, complying with AS 1428.1 Design for access and mobility

  → providing additional paths and walkways which are continuous, slip resistant and hard surfaced, with gradients complying with AS 1428.1

  → pathway lighting which is at a low height to avoid glare and provides a minimum of 50 lux at ground level

  → building wide pathways to suit people using a walking frame

  → locating drainage grates so they do not run parallel to the direction of travel and can be crossed in a wheelchair

  → ensuring the width of car parking spaces, garages and carports suit people using wheelchairs or prams.

B5.3 Storage

→ some secure storage is provided that could be used by people with disabilities providing cupboards that can be accessed by people with disabilities, including using D‑handles on cupboards and locating them to allow people with disabilities to reach them.

→ providing storage areas for food, clothes, bins that are accessible to people with disabilities by locating handles and locks 900mm to 1100mm above the floor or ground level, ensuring the paths to bin areas are at least 1 metre wide and specifying circulation around cupboards and bin enclosures to allow access.

B9.3 Preventing slips, trips and falls

→ stair and ramp hand rails are structurally sound, protected from the weather, have a non-slip finish, and are designed to suit the needs of children, the frail aged and people with a disability.

C6 Landscaping

→ planning to make the public areas and houses more accessible to people with disabilities.

Source: FaHCSIA 2010

AHURI Research Centres

AHURI Research Centre—Curtin University

AHURI Research Centre—RMIT University

AHURI Research Centre—Swinburne University of Technology

AHURI Research Centre—The University of Adelaide

AHURI Research Centre—The University of New South Wales

AHURI Research Centre—The University of Sydney

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