VACCHO Project: "No One's Left Out": Improving Support For Aboriginal People With Disability

Literature Review, February 2018
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1. **INTRODUCTION**

The Victorian Aboriginal Community Controlled Health Organisation (VACCHO) has received funding from the National Disability Insurance Agency (NDIA) to implement a trial project called "No One’s Left Out: Improving Support For Aboriginal People with Disability". The South Australian Health and Medical Research Organisation (SAHMRI) has been commissioned to carry out the evaluation of the project.

The aim of "No One' Left Out" is to establish ways of working with Aboriginal people with disability that result in change in the capacity and capability of ‘mainstream’ community services, within both Aboriginal Community Controlled and non-Indigenous organisations, to demonstrate and embed inclusive practices in their services. In the context of the NDIA and this project, it is important to remember that the term 'mainstream' refers to non-disability services, rather than non-Indigenous services.

The project is being implemented and trialled through two Aboriginal Community Controlled organisations in different parts of regional Victoria. These organisations will work both internally and with external health and community service providers in their local areas to effect consultation, education and, hopefully, instigate changes that will support Aboriginal people with disability receiving improved access to mainstream services.

The two organisations that are participating in the trial are:
- Bendigo and District Aboriginal Cooperative (BDAC).
- Ramahyuck Aboriginal Cooperative, through their Morwell site only.

This document provides the outcomes of a targeted literature review, which is designed to bring together information about the NDIS and Aboriginal people with disability, to assist VACCHO and the participating organisations, BDAC and Ramahyuck, to learn from work that had been published in the previous five years.

The key search terms included combinations of:
- Aborig*
- Torres Strait Island*
- Indig*
- Disab*

There was a primary, but not exclusive, focus on publications that addressed conditions within Australia.
2. ABOUT THE NDIS
Reviewed/Gathered 8-16/01/18

The National Disability Insurance Agency (NDIA) is an independent statutory agency. Its role is to implement the National Disability Insurance Scheme (NDIS), which is designed to support a better life for Australians with a significant and permanent disability, and their families and carers. The scheme is being introduced gradually, aiming for a smooth transition for people with disability and support providers.

For reference, the principles of the National Disability Insurance Scheme Act, 2013 are as follows:

(1) People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development.

(2) People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability.

(3) People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.

(4) People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.

(5) People with disability should be supported to receive reasonable and necessary supports, including early intervention supports.

(6) People with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect and exploitation.

(7) People with disability have the same right as other members of Australian society to pursue any grievance.

(8) People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.

(9) People with disability should be supported in all their dealings and communications with the NDIA so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs.

(10) People with disability should have their privacy and dignity respected.

(11) Reasonable and necessary supports for people with disability should:
    a) support people with disability to pursue their goals and maximise their independence; and
    b) support people with disability to live independently and to be included in the community as fully participating citizens; and
    c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment.
(12) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected.

(13) The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:
   a) promoting their independence and social and economic participation; and
   b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and
   c) maximising independent lifestyles of people with disability and their full inclusion in the mainstream community.

(14) People with disability should be supported to receive supports outside the National Disability Insurance Scheme, and be assisted to coordinate these supports with the supports provided under the National Disability Insurance Scheme.

(15) Innovation, quality, continuous improvement, contemporary best practice and effectiveness in the provision of supports to people with disability are to be promoted.

(16) Positive personal and social development of people with disability, including children and young people, is to be promoted.

Broadly: the NDIA allocates each client a planner (local area coordinator or something similar in some states). Their job is to help clients put in place the disability support arrangements they need to live a better life, planning for immediate and longer term needs and as their circumstances change over time.

The NDIS will fund what it calls “reasonable and necessary supports”. This means supports that relate to a person’s disability are value for money and not day-to-day living costs. Some specific examples of support and services include:

- Personal care.
- Work and study.
- Mobility and technological aids.
- Living skills like shopping or cooking.
- Connecting you with support groups and mentors.
- Support for family and carers.
- Therapy help like occupational therapy or physiotherapy.
- Community and sports activities.
- Accommodation services.

Assistive technology (AT) may:
- be custom made or ‘off the shelf’ but configured uniquely for the person.
- require interconnection or integration with other AT or the person’s home/work/place of study.
- carry significant risk (hospitalisation or death).

Assistive technology examples:
- Mobility: power wheelchairs with integrated controls; motor vehicle AT (operator); highly configurable manual wheelchairs; electronic mobility AT for person who is blind.
- Adaptive seating and positioning system for complex posture: within wheelchair; vehicle passenger seat/tie down; static seating; bed systems.
- Complex bathing and toileting devices: bathing devices including shower commodes.
- Complex pressure care management: high-level pressure cushions and pressure care sleep systems.
• **Bed systems for complex need**: full mattress replacements; bed rails & bedrail covers.
• **Respiratory devices**.
• **Prosthetics** complex/myoelectric; **orthotics/footwear** complex, high-risk.
• **Hearing**: hearing aids and accessories (complex need); cochlear implant speech processors, BAHA.
• **Specialised ICT access**: specialised software; alternate access & mounting systems etc.
• **Complex home modifications**: modifications that require structural changes to building and/or require council permits.
• **Communication devices** (initial / complex): electronic voice/voice prostheses; equipment for Deafblind individuals.
• **Continence**: initial supply/review of anal devices and intravaginal bladder supports.
• **Enteral nutrition**.
• **Environmental control units**: multifunction complex control ECUs.

2.1. **How is the NDIS being implemented?**

In Victoria, the plan has been designed around services that are currently being delivered by the Victorian Government. It also includes people who are waiting for supports on the Disability Support Register (DSR) and Early Childhood Intervention Services (ECIS). People on the DSR and the ECIS waitlist will enter the scheme as the first groups in each geographical area.

The NDIS is being introduced by region in Victoria. This means that in some parts of the state the NDIS is already available, while in others it has yet to begin.

2.1.1. **Bendigo:**

The Greater Bendigo area is part of the Loddon region, which includes the local government areas of:

- Campaspe.
- Central Goldfields.
- Greater Bendigo.
- Loddon.
- Macedon Ranges.
- Mount Alexander.

The NDIS became available in the Loddon area from 01 May 2017. People in those areas and already receiving support from the Victorian Government, or who were waiting for supports on the Disability Support Register (DSR) or Early Childhood Intervention Services (ECIS), should have been contacted by the National Disability Insurance Agency (NDIA) and given access to the new NDIS.

**Order of transition**

The Loddon region was subject to the following agreed phasing plan:

- **From May 2017**:
  - DSR Waitlist.
  - New clients and other Commonwealth clients.
  - Commonwealth - Residential aged care (young people).
  - Commonwealth - Home care (young people).

- **From June 2017**:
  - Supported Accommodation.
  - Individual Support Packages.
  - Futures for Young Adults.

- **From August 2017**:
  - Early Childhood Intervention Services.
~ Student Transport.
~ Attendant Care.
~ Other disability activities (Community and Facility Based Respite, Flexible Support Packages, Outreach, Behaviour Intervention Services, Case Management, Recreation, Therapy, and Independent Living Training).

- From September 2017
  ~ Mental Health Community Support Services (MHCSS).
  ~ Home and Community Care (HACC).

If a person receives support from more than one of these activities, they will enter the NDIS when the first activity is phased in. For example, in Loddon, a person receiving both an Individual Support Package and Home and Community Care would transition to the NDIS from June 2017. Clients residing together in shared supported accommodation will be transitioned at the same time where possible.

2.1.2. Morwell:

Morwell is a town in the Latrobe Valley, therefore part of the Inner Gippsland region, which covers the local government areas of:

- Bass Coast.
- Baw Baw.
- Latrobe.
- South Gippsland.

The NDIS became available in the Inner Gippsland area, from 01 October 2017. People in the region already receiving support from the Victorian Government, or who were waiting for supports on the Disability Support Register (DSR) or Early Childhood Intervention Services (ECIS), should have been contacted by the National Disability Insurance Agency (NDIA) and given access to the new NDIS.

Order of transition

The Inner Gippsland region was subject to the following agreed phasing plan:

- From October 2017
  ~ Attendant Care in Schools.
  ~ DSR Waitlist.
  ~ Mental Health Community Support Services Needs Register waitlist.
  ~ Student Transport.

- From November 2017
  ~ Futures for Young Adults.
  ~ Supported Accommodation.

- From December 2017
  ~ Other disability activities (Community and Facility Based Respite, Flexible Support Packages, Outreach, Behaviour Intervention Services, Case Management, Recreation, Therapy, and Independent Living Training).

- From January 2018
  ~ Home and Community Care Program for Younger People.
  ~ Mental Health Community Support Services (MHCSS).

2.1.3. List of NDIS qualifications:

- People must be under 65 years of age when applying to join the Scheme.
• They must live in Australia and: be an Australian citizen OR hold a Permanent Visa OR hold a Protected Special Category Visa, that is they were in Australia on a Special Category Visa on 26 February 2001 or had been in Australia for at least 12 months in the 2 years immediately before 26 February 2001 and returned to Australia after that day.

• They may meet the disability requirements if:
  ~ they have an impairment or condition that is likely to be permanent (i.e. it is likely to be life-long) and their impairment substantially reduces their ability to participate effectively in activities, or perform tasks or actions unless they:
  ~ have assistance from other people or
  ~ have assistive technology or equipment (other than common items such as glasses) or
  ~ can’t participate effectively even with assistance or aides and equipment and
  ~ their impairment affects your capacity for social and economic participation and
  ~ they are likely to require support under the NDIS for their lifetime.

• An impairment that varies in intensity, e.g. because the impairment is of a chronic episodic nature, may still be permanent and people may require lifetime support under the NDIS despite the variation.

Additional early intervention supports may be available if certain criteria are met.
2.2. **Disability within the Indigenous community**

Last updated: 13/07/17
Reviewed 8/1/18


In this webpage, Australian Indigenous HealthInfoNet reproduces an "excerpt from Productivity Commission (2011) Disability care and support: draft report [vol 1 & 2]. Canberra: Productivity Commission (section 9)", making it easier to access the section of the Productivity Commission's report most relevant to the current search.

### 2.2.1. Summary

This web page provides a large amount of key information on disability among Indigenous Australians, highlighting the differences between Indigenous and non-Indigenous people. For example, Indigenous Australians are more likely to require assistance with a core activity than non-Indigenous Australians, in all states and at all levels of remoteness. The gap is greatest in the Northern Territory and Western Australia, and in remote and very remote areas. The report also makes it quite clear that the measures of disability among Indigenous people are known to be undercounting and that allowances need to be made for that.

The web page mainly supplies the reader with key statistics, rather than an in-depth analysis of the roots of solution to the health gap problems. However, there is a section on Indigenous peoples' perceptions of disability "Some Indigenous Australians, particularly those living a more traditional way of life, have a different perception of disability to non-Indigenous Australians. Indigenous views on disability are diverse, matching the diversity of Indigenous cultures and beliefs, the diversity of individual lived experience with disability and individual's economic and social standing."

One of the report's conclusions that is particularly relevant to the No One's Left Out project is that: "A key challenge to achieving this goal is overcoming the barriers to accessing services experienced by Indigenous people experience".

The following sections are lifted directly from HealthInfoNet and, therefore, reproduce the whole of Chapter 9 of the Productivity Commission's 2011 report. While lengthy, the Chapter has been reproduced here in full, both for completeness and to enable VACCHO and the two No One's Left Out trial sites to review individual parts of the more comprehensive information that may be more specifically relevant to them, without SAHMRI applying selective analysis.

### 2.2.2. Key Points

- After correcting for differences in age structure, Indigenous Australians require assistance with a core activity at almost twice the rate of non-Indigenous Australians. In part, this is driven by socio-economic disadvantage and exposure to risk factors such as smoking, high body mass, physical inactivity, poor nutrition and substance abuse.

- There is some scope for the National Disability Insurance Agency, in cooperation with government agencies, to attempt to address the high rate of Indigenous disability through prevention and early intervention. However, addressing the socio-economic disadvantage that underlies the higher rate of Indigenous disability is an issue for all of Australian society and requires a long-term whole-of-government approach.
• Indigenous Australians also face significant barriers to accessing disability support services. This occurs due to insufficient services in metropolitan and regional areas, social marginalisation, cultural attitudes towards disability and culturally inappropriate services.

• These barriers to service delivery access suggest that the market based service delivery system underpinning the proposed National Disability Insurance Scheme may not deliver adequate care and support to Indigenous people with a disability. While Indigenous Australians will have access to individualised funding on the same basis as non-Indigenous Australians, it may also be necessary to block fund some service providers in order to overcome the additional barriers that Indigenous Australians face.

• A number of strategies can be used to improve accessibility of services for Indigenous people, including embedding services within local communities, employing Indigenous staff and developing the cultural competency of non-Indigenous staff.

Indigenous Australians have high rates of disability but access relatively few services or supports. The consequences of this are compounded by broad socio economic disadvantage and the geographical isolation that many Indigenous Australians experience. This chapter highlights the importance of addressing Indigenous disability, and provides a starting point for developing a strategy to best support Indigenous Australians under the NDIS. It does so by examining

- the extent and nature of Indigenous disability (section 9.1)
- some of factors underlying Indigenous rates of disability and preventing the uptake of existing supports (section 9.2)
- some of the options available to the NDIA in response to this challenge (section 9.3).

A snapshot of Indigenous disability

It is very difficult to provide an accurate depiction of disability within the Indigenous community. Prior to the 2002 National Aboriginal and Torres Strait Islander Social Survey (NATSISS), there were no national surveys of Indigenous disability. Two further data collections have occurred since this time, the 2006 Census and the 2009 NATSISS. However, there is reason to suggest that these surveys understate the extent of disability amongst Indigenous Australians.

First, surveys of Indigenous Australians are affected by higher rates of non-response. The estimated undercount (not responding to survey at all) in the 2006 Census was 2.7 per cent for non-Indigenous Australians and 11.5 per cent for Indigenous Australians (ABS 2006a). In addition, the non-response rate for the question about the need for assistance was 2 per cent for non-Indigenous Australians and 7 per cent for Indigenous Australians (ABS and AIHW 2008). This reduces the general accuracy of the estimate of disability and can also introduce sample selection bias. For example, if Indigenous people with a disability are less likely to respond to a survey than those without a disability, then the overall disability rate will tend to be underestimated.

Second, some Indigenous Australians find the concept of disability hard to understand or irrelevant, reducing the likelihood that the surveys accurately recorded disability. For example, the First Peoples Disability Network suggested that ‘in traditional language there was no comparable word to disability which suggests that disability may have been accepted as part of the human experience’ (sub. 542, p. 8).

While the existing data may tend to understate the problem, they still suggest that disability is a serious issue for Indigenous Australians. There are two main dimensions to this:

- the reported rate of disability is considerably higher for Indigenous Australians than non-Indigenous Australians
- Indigenous Australians face greater barriers to accessing disability supports than non-Indigenous Australians.
Disability amongst Indigenous Australians

It is estimated that there are around 19,500 Indigenous Australians that need assistance with a core activity (Census 2006). This represents 4.6 per cent of the Indigenous population, which is higher than the rate of 4.4 per cent for the non-Indigenous population. However, Indigenous Australians have a much younger age profile than non-Indigenous Australians (due to a combination of a higher fertility rate and lower life expectancy). As disability rates tend to increase with age, unadjusted population estimates of disability rates will understate the difference between Indigenous and non-Indigenous Australians. Indigenous Australians between the age of 15 and 24 require assistance with a core activity at around 1.7 times the rate of non-Indigenous Australians, and this gap widens as they grow older. After standardising for differences in age structure, estimates based on the 2006 Census suggest that the rate of the need for assistance with a core activity is almost twice as high overall for Indigenous Australians as it is for non-Indigenous Australians (figure 9.1).

Figure 9.1 Needs assistance with core activities

Source: SCRGSP (2009)

Indigenous Australians were more likely to require assistance with a core activity than non-Indigenous Australians in all states and at all levels of remoteness. The gap is greatest in the Northern Territory and Western Australia, and in remote and very remote areas (figure 9.2).

A range of health conditions and disabilities underlie the aggregate rate:

- Despite comprising only 3.8 per cent of the Western Australian population, Aboriginal children make up 8.4 per cent of all children born there between 1980 and 1999 with cerebral palsy (sub. 290, p. 3).
- Indigenous children (under 15) are 3.4 times more likely to be deaf (SCRGSP 2009 - Table 5A 7.2). Over 70 per cent of Indigenous children in remote communities suffer from chronic otitis media that can cause permanent hearing loss and inhibit language and literacy development. (Department of Education and Training, Western Australia 2006)
- In non-remote areas, Indigenous people are twice as likely to be obese as non Indigenous people (SCRGSP 2009).
- Indigenous Australians are almost 12 times as likely to be hospitalised for care involving dialysis (SCRGSP 2009).
- Indigenous Australians are nearly four times as likely to have an intellectual disability (ABS 2006b).
- 28.2 per cent of Indigenous Australians self-reported their health as fair/poor, as compared with 14.5 per cent of non-Indigenous Australia’s (ABS 2008b).
Considerable resources are dedicated to supporting Indigenous Australians with a disability. In 2001-02 a total of $95.7 million was spent on Indigenous welfare services (CSDA funded disability services and HACC). This represents 3 per cent of total expenditures and around 30 per cent more was spent on Indigenous Australians per person, than non-Indigenous (table 9.1). However, given the higher rate of disability and multiple disability, as well as the significantly higher costs involved in servicing remote Indigenous communities, it is likely that this level of expenditure is still associated with significant under-servicing.
## Table 9.1 Total recurrent health-related expenditure, by program and Indigenous status, 2001-02

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<td><strong>Total welfare services for people with a disability a</strong></td>
<td>95.7</td>
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<td>89.1</td>
<td>29.87</td>
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Source: AIHW 2006, Expenditures on health for Aboriginal and Torres Strait Islander peoples, 2001-02.

Notes:

a  Includes Australian Government administrative costs, excludes state and territory administrative costs, concession expenditure and services for older people.

b  Excludes state and territory government expenditure on ACCHSs.

### Use of services

The main source of data on the use of disability support services is the Disability National Minimum Data Set (NMDS). The NMDS data suggests that, given the underlying population with a disability, less Indigenous Australians with a disability use accommodation and community access services than non-Indigenous Australians. However, the gap is relatively small (figure 9.3). Use of community support services appears greater for Indigenous Australians than non-Indigenous Australians (SCRGSP 2010).
This is somewhat at odds with the broad anecdotal evidence that Indigenous people with a disability face significant barriers when trying to access support (particularly in rural or remote settings) and are marginalised within the disability sector more generally (First Peoples Disability Network, sub. 542, p. 6, Australian Disability Network 2007, NSW Ombudsman 2010, Stopher and D’Antoine 2008). This view was echoed in consultations between the Productivity Commission and State and Territory government agencies, as well as Indigenous-focused service providers.

The NDMS may inadequately reflect Indigenous Australians' access to disability services (or conceal the barriers that some Indigenous Australians face):

- as noted above, it is likely that the estimated number of Indigenous people with a disability significantly understates the real figure. If this is the case, the rate that Indigenous Australians access services will be overstated.
- there are wide variations in Indigenous service use by state, suggesting that access may be more of an issue in some areas than others (notably access is relatively low in New South Wales and relatively high in Victoria).

Challenges to supporting Indigenous Australians with a disability

High level of Indigenous disadvantage

Indigenous disadvantage across a range of indicators is broad in scope, profound and entrenched. In addition to higher rates of disability and chronic disease described above, gaps persist between non-Indigenous and Indigenous Australians in terms of life expectancy, child mortality, education attainment, income, employment and interactions with the justice system. Socio-economic disadvantage interacts with disability in a circular fashion (SCRGSP 2009). On the one hand, socio-economic factors contribute to the higher incidence of disability in the same way as they do in other disadvantaged groups in society. For example, low education attainment is linked to a higher rate of smoking, excessive alcohol consumption and poor nutrition amongst Indigenous Australians (ABS and AIHW 2008). These risk factors increase the chance of acquiring a disability. On other hand, disability entrenches socio-economic disadvantage. For example, Indigenous
children with hearing loss suffer poorer education outcomes, which in turn limits their employment and income prospects.

Both socio-economic disadvantage, and higher levels of exposure to risk factors (such as tobacco, alcohol and violence) have been linked to the history of dispossession and marginalisation that has contributed to the breakdown of traditional family or societal structures, feelings of loss or despair and the social dysfunction that afflict some Indigenous communities (Salvatori 2010, Bostok 2004, sub. 542, p. 7). Indigenous Australians are twice as likely (on average) to engage in or be exposed to a range of activities that can lead to disability, including smoking, binge drinking, using illicit drugs, and being victims of violence. Indigenous Australians are also more likely to be physically inactive and subject to more than one of these risk factors (AIHW 2008). These risk factors explain a large proportion of the difference in health outcomes and rate of disability between Indigenous and non-Indigenous people (table 9.2).

Table 9.2 Risk factors contributing to the difference in Disability Adjusted Life Years between Indigenous and non-Indigenous Australians

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Percentage contribution to the gap in DALYs between Indigenous and non-Indigenous Australians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tobacco</td>
<td>17.4</td>
</tr>
<tr>
<td>High body mass</td>
<td>15.9</td>
</tr>
<tr>
<td>Physical inactivity</td>
<td>11.6</td>
</tr>
<tr>
<td>High blood cholesterol</td>
<td>7.1</td>
</tr>
<tr>
<td>Alcohol</td>
<td>6.8</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>5.7</td>
</tr>
<tr>
<td>Low fruit and vegetable intake</td>
<td>5.1</td>
</tr>
<tr>
<td>Illicit drugs</td>
<td>3.8</td>
</tr>
<tr>
<td>Intimate partner violence</td>
<td>3.3</td>
</tr>
<tr>
<td>Child sexual abuse</td>
<td>1.5</td>
</tr>
<tr>
<td>Unsafe sex</td>
<td>1.6</td>
</tr>
<tr>
<td>11 Risk factors combined</td>
<td>48.5</td>
</tr>
</tbody>
</table>

Source: Calculations based on Vos et al. 2003.

Notes:
- a Disability Adjusted Life Years are a measure of the burden of disease that takes into account the effect on life expectancy and the amount of time spent with a disability
- b This estimate takes account of the combined causal pathways between many of these risks factors, and thus is lower than the sum of each effect considered in isolation.

Social marginalisation and mistrust of authority
Numerous participants in this inquiry noted that negative experiences within communities and with government agencies or service providers can make Indigenous Australians with a disability reluctant to seek support. As noted in the NSW Ombudsman’s report:

For Aboriginal people, a collective legacy of negative experiences with mainstream agencies and services has led to a significant degree of fear and mistrust (2010, p. 27)

This issue was also noted at the first state conference of the Aboriginal Disability Network of New South Wales was that:

Some Aboriginal people retain the fear that their children will be removed by government authorities. Furthermore that Aboriginal children remain over represented as wards of the state and that Aboriginal children with disability and Aboriginal parents with disability remain vulnerable to this fact. (ADN 2002, p. 8)

Even in the absence of specific negative experiences, Indigenous Australians may be reluctant to seek services because of a general sense of social exclusion, or a feeling that services are there for white people and not them. Hepburn (2005) relates the following view from a rural worker:

Indigenous people in rural country areas don’t feel they are part of, or are welcome, in the rural towns. They feel that mainstream services do not or are not willing or able to provide a service for them. If they need assistance or support they are afraid to ask for help or they feel that it would be a waste of time and effort. Many people have a defeatist attitude towards services. They are more likely to say things like ‘They won’t help me’. (p. 20)

Similarly, Stopher and D’Antoine (2008) quoted once participant in their study who stated ‘Aboriginal people are reluctant to use services as they feel they are for whitefellas’. (p. 13).

In other situations, some mainstream providers may be unwilling to take on Indigenous clients because they feel there are specialised services funded to do so (NSW Ombudsman, p. 30).

Indigenous perceptions of disability

Some Indigenous Australians, particularly those living a more traditional way of life, have a different perception of disability to non-Indigenous Australians (First Peoples Disability Network, sub. 542, p. 8). Indigenous views on disability are diverse, matching the diversity of Indigenous cultures and beliefs, the diversity of individual lived experience with disability and individual’s economic and social standing (Senior 2000). Nevertheless, two frequently cited generalisations about Indigenous perception of disability may be relevant to the delivery of disability support services in some areas:

• some Indigenous people may not have a general concept of disability, which can result in under-reporting (as noted above) and, potentially, under utilisation of the available supports from government or service providers.

• some Indigenous communities view some types of disability (such as congenital disabilities) as a consequence of ‘marrying wrong’ (First Peoples Disability Network, sub. 542. p. 8), or attribute it to supernatural causes stemming from eating certain foods or doing certain activities while pregnant (Senior 2000). While this is a potential source of shame that may dissuade some Indigenous Australians from seeking support, Elliot (1994) and Senior (2000) suggest that stigmatisation within communities is limited.
Like many groups in Australia, Indigenous Australians have a strong cultural belief that it is the responsibility of family to provide care and support. As noted by O’Neil, Kirov and Thomson (2004), ‘throughout Australia - in remote, rural and urban areas - most Indigenous people with a disability were, and are, cared for within their extended family’. This presents a particular challenge for supporting Indigenous Australians with a disability. On the one hand, a core component of a ‘good’ disability system is respecting the wishes of people with a disability and those who care for them - including the cultural beliefs about the appropriate role of family. On the other hand, there is a risk that assumptions about Indigenous family care could result in an excessive burden of caring, and/or inadequate levels of care. This is a particular issue when families’ capacity to offer care and support is affected by socio-economic disadvantage (such as poverty), carers’ own health problems, family breakdown or social dysfunction. The death of Kate Bugmy in 2007 presents a tragic example of this. As noted by State Coroner Mary Jerram (2010):

The extreme disabilities with which Kate Bugmy was born required fulltime care, with which her family struggled to cope, staunchly resisting alternative, outside care. Although that resistance clearly arose from love, it came at a price and may not have been best for Kate, at least in her later years (p. 11).

**Cultural competence**

The norms, beliefs and expectations embodied within a culture have value within their own right. They also make it easier for people within a cultural group to communicate, and for human interaction and ordinary social exchange to take place (including marketplace exchange). Conversely, people from different cultural backgrounds may find such interactions more difficult and miscommunication more frequent. Many Australians who identify as Aboriginal or Torres Straight Islander experience little difficulty in understanding or interacting with non-Indigenous Australians, including those providing disability support services. However, in some cases, differences in cultural background between service providers and Indigenous Australians can form an impediment to effective delivery of support services. Indigenous culture is diverse (meaning cultural competence within one area may not be relevant to another), but some commonly identified areas where cultural differences impact on the delivery of disability support services include:

- perception of disability (discussed above)
- relationship to the land
- triggers and responses to shame (O’Neill, Kirov and Thomson 2004; Jenkins and Seith 2004)
- rules governing the interactions between men and women, and within kinship systems (SNAICC 2010)
- styles of communication, including the use of eye contact, silence within conversation, and appropriate ways of requesting information (Pheonix consulting, sub. 311, p. 1; Jenkins and Seith 2004; McConnel 2010; SNAICC 2010)

Such cultural differences can result in service offerings that are not attractive to Indigenous Australians, or misunderstandings that give Indigenous Australians a negative impression of disability support services. It can also make service providers tentative about proactively seeking Indigenous clients. As noted by Regan and Harriden (2008):

In general, non-Aboriginal service providers appeared to be anxious about their ability to engage with Aboriginal people and services in a culturally appropriate manner. This idea is perhaps best summed up by a respondent who noted that the “fear of ‘doing the wrong thing’ by non- Aboriginal service staff” was one of the dominant issues limiting their work with Aboriginal communities. (p. 14)

Conversely, some Indigenous Australians who want to engage with the disability system may be constrained by a lack of knowledge about the necessary requirements (such as paper work and personal information), or lack confidence or understanding of their rights or entitlements.
Salvatori (2010), describes how the feeling of cultural misunderstanding, combined with broad disadvantage and negative past experiences can be a powerful deterrent to seeking support:

When accessing mainstream services, the effects of trans-generational trauma can be evidenced when clients feel inferior, shamed, misunderstood, not educated enough and feel that they have no voice. Aboriginal people have different ways of communicating and thinking and feel that the Aboriginal 'way of being' is not understood. Feelings of intimidation, racism and fear due to past history often stand in the way and keep our clients from using mainstream services. Many do not feel safe.

Isolation

Almost half of Indigenous Australians live in outer regional, remote or very remote areas, compared to around 10 per cent of non-Indigenous Australians (figure 9.4). There is significant variation across jurisdictions. For example, Victoria has a relatively urban Indigenous population, with 84 per cent living in a major city or inner regional area. Conversely, around 80 per cent of Indigenous Australians in the Northern Territory and 42 per cent of in Western Australia, live in remote or very remote areas.

Figure 9.4 Proportion of the population by remoteness area, 2006

As with other services (such as health and education) remoteness creates particular difficulties in providing disability services to Indigenous Australians. These difficulties are compounded by

- lower levels of vehicle ownership by Indigenous Australians (77 per cent versus 90 per cent). In very remote areas vehicle ownership is 47 per cent for Indigenous people
- inadequate or no public transport options (with taxi drivers sometimes reluctant to enter Indigenous communities - Australian Disability Network 2007)
- difficult weather conditions in some areas, including regular periods of heavy rain and flooding.
- lack of access to appropriate housing and urban infrastructure (including clean water and sanitation)
- lack of access to specialists.

Remoteness reduces the scope of the services that can be delivered, and dramatically increase their costs. In some communities, only ‘fly in fly out’ services are available - for example for respite or specialists. This approach cannot provide adequate support for people with a high level or complex needs on an ongoing basis.
and Indigenous Australians with disabilities will sometimes need to move to regional centres to receive the supports they need. However, as many Indigenous Australian's have a strong bond with both the land and their local community, they may be very reluctant to do so.

Language barriers

For many Indigenous Australians, particularly in remote areas and among older people, language can be a barrier to accessing services, or can lead to misunderstandings or ineffective service provision. For some Indigenous Australians, English was not the first language learnt, nor is it the main language used. In other areas, local varieties of English are spoken, which can also make communication difficult. The NATSISS (2008) suggests that around 11 per cent of Indigenous Australians aged 15 and over speak an Aboriginal or Torres Straight Islander as their main language overall, and around 40 per cent in remote areas.

Indigenous disability and the NDIS

Addressing the high rate of Indigenous disability

The most important issues surrounding Indigenous disability is its relatively high incidence compared with the non-Indigenous population. This gap is driven by complex combination of socio-economic disadvantage and exposure to a broad range of risk factors (such as smoking, binge drinking, obesity, substance abuse and violence). Addressing Indigenous disadvantage has been a longstanding (and so far largely unsuccessful) policy objective of a broad range of government initiatives. This effort was formalised in 2008, in the form of the COAG agreements that make up the Closing the Gap initiative (box 9.1). This initiative commits governments to working toward reducing Indigenous disadvantage as revealed through a set of specified indicators. Closing the Gap is aimed at providing greater transparency and accountability of government, greater coordination of effort, increased and more consistently maintained resources, and improving the knowledge base.

Addressing broad disadvantage requires the 'whole-of-government approach' contained with the Closing the Gap initiative, which raises the question as to the appropriate role of the NDIS. Many areas (such as increasing year 12 attainment rates) are clearly beyond the scope of the NDIS. However, other initiatives, particularly in the health area, are more closely aligned to the objectives of the scheme. Specifically, part of the function of the proposed NDIA is to fund early intervention and prevention approaches in areas where there is robust evidence of both effectiveness and cost effectiveness (chapter 11). While not a frontline provider of such interventions, there may be a role for the NDIA, in cooperation with other government agencies (such as the Australian National Preventive Health Agency), to fund preventative measures with an Indigenous focus. There may also be a role for the NDIA to fund or conduct research specifically directed towards the prevention or treatment of conditions that are pervasive in the Indigenous community and could potentially result in long term disability.

For example, early intervention targeting otitis media (which can lead to deafness) among Indigenous children could potentially decrease the rate of disability and have important socio-economic flow on effects (such as improved educational outcomes). The NDIA, in co-operation with Indigenous communities, state and territory health agencies and Australian Hearing, could expand initiatives aimed at reducing the incidence of otitis media in children through:
• Indigenous community led ear health education programs
• early intervention through mobile ear health clinics
• other types of preventative interventions with demonstrated benefits, such as the provision of swimming pools in local schools (SCRGSP 2009).

However, it is not obvious the extent to which responsibility for such prevention activities should lie with the NDIA or with existing government agencies, or how collaborative efforts could be encouraged and facilitated. It would obviously be undesirable for the NDIA to duplicate the efforts of existing agencies with greater expertise, or to run programs that are inconsistent or conflict with existing ones.

The Commission seeks further feedback on the merits of the NDIA funding prevention and early intervention measures specifically targeting Indigenous communities, and how this could work in practice.

Box 9.1 Closing the Gap

The Closing the Gap initiative is a joint effort by all levels of government to reduce the disadvantage experienced by Indigenous Australians. It is underpinned by a set of agreements by the Council of Australian Governments (COAG) to work towards reducing the disparity revealed by a set of specific indicators within a nominated time frame. The National Indigenous Reform Agreement (NIRA) commits COAG to
• closing the life-expectancy gap within a generation
• halving the gap in mortality rates for Indigenous children under five with a decade
• ensuring access to early childhood education for all Indigenous four year olds in remote communities within five years
• halving the gap in reading, writing and numeracy achievements for children within a decade
• halving the gap for Indigenous students in Year 12 (or equivalent) attainment rates by 2020 (amended to 2015 in April 2009)
• halving the gap in employment outcomes between Indigenous and non-Indigenous Australians within a decade.

NIRA also contains the over-arching framework for Closing the Gap, including the service delivery principles that should be adhered to and the basic 'building blocks' that governments should focus on in order to make progress on the Closing the Gap targets. These are early childhood, schooling, health, economic participation, healthy homes, safe communities and governance and leadership.

These objectives are pursued through a number of specific agreements that commits governments to a common framework of outcomes, progress measures and policy directions' and 'builds on current initiatives, address shortfalls and in many cases provide significant additional funds' (FaHCSIA 2011). These agreements relate to health, housing, early childhood development, economic participations, remote service delivery, remote internet access, and closing the gap in the Northern Territory.

Source: (FaHCSIA 2011).

Getting services to Indigenous people with a disability

While the obstacles to service delivery described in section 9.2 are frequently noted in the literature, there is no clear guide as how prevalent or important they are in practice. For health services, it appears that scarcity and proximity are more important issues than mistrust or culturally inappropriate services (table 9.3).
To the extent that this holds true for disability services, the increased resources under the proposed NDIS, combined with support from case managers and advocacy groups, will bring about a dramatic increase in the supports they receive. Indigenous Australians living in rural areas will be supported by regional NDIS offices and will be able to access self-directed funding on the same basis as all other Australians. More generally, the increased choice and flexibility of the proposed scheme will empower many to seek out the supports that best suit their individual situation.

Nevertheless, the cultural appropriateness of disability services and perceptions of government, service providers and the NDIA itself may become relatively more important as shortages in the disability sector are eased. It is not clear that the proposed consumer choice model would, on its own, adequately facilitate the delivery of such services. The remoteness of some Indigenous communities is one factor inhibiting the emergence of a competitive market for disability support services. However, in both rural and urban settings, socio-economic disadvantage, marginalisation and a lack of culturally appropriate services are a major barriers inhibiting many Indigenous Australians from accessing the services and supports available to them and exercising their consumer rights effectively.

For this reason, block funding the provision of disability support services specifically focussed on ensuring Indigenous people with a disability can access the supports they need, is likely to remain a feature of the disability system under the NDIS, at least over the short to medium term. In order to make good funding decisions and provide guidance for service providers, the NDIA will need to develop an understanding of the characteristics of effective service delivery to Indigenous Australians. While the experience of state and territory government agencies will be a valuable source of expertise, the Commission recognises the difficulty and complexity of this task. There are no easy or comprehensive answers. Moreover, it is often unclear how broadly the lessons from local solutions can be applied - often solutions will be specific to circumstances of a specific community and place based planning will be the appropriate approach. Nevertheless, there is a growing literature describing the basic strategies that can assist in meeting the needs of Indigenous people. Some of these are discussed in the following section.

**Embedding services within the community**

<table>
<thead>
<tr>
<th>Table 9.3 Types of problems faced by Indigenous Australians aged 15 years and over seeking health services years, 2008</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-Remote</strong></td>
</tr>
<tr>
<td>%</td>
</tr>
<tr>
<td>Waiting time too long/not available when needed</td>
</tr>
<tr>
<td>No services in the area</td>
</tr>
<tr>
<td>Not enough services in area</td>
</tr>
<tr>
<td>Transport/distance</td>
</tr>
<tr>
<td>Cost of service</td>
</tr>
<tr>
<td>Don’t trust services</td>
</tr>
<tr>
<td>Services not culturally appropriate</td>
</tr>
</tbody>
</table>

The extent to which disability services are ‘in and of’ the Indigenous communities they serve is a critical factor to their acceptance and success. The capacity of not-for-profit providers to be representative of the communities they serve suggest they may have an advantage over government run services in this area (Productivity Commission 2010a), particularly if they are managed by the Indigenous community themselves. Also, having staff that are culturally competent or Indigenous themselves is clearly an important part of service providers gaining acceptance (discussed below).

Beyond this, establishing trust and rapport with Indigenous communities is a long-term task involving integration into the social, political and economic activities of the community (NDS 2010, Gilroy 2008). While there is no one way to achieve this, some common strategies includes:

- participating in local events and community meetings
- establishing relationships with other Indigenous services providers, schools and medical centres. In particularly, in remote communities Aboriginal Medical Services’ may be a hub of ‘community activity connection and organisation’ - making them a useful contact point for newly established disability support service providers (SNAICC 2010, p. 41). However, an evaluation of coordinated care trials suggested that the effectiveness and community acceptance of these organisations themselves can be mixed DOHA (2007).
- using existing networks, getting referrals from trusted sources within the community and establishing a mechanism through which ongoing communication with key elders, community workers and other service providers can occur (Regan and Harriden 2008).
- effective and authentic consultation with the community. 8 The Community Health Committees used in the Sunrise Health trial is useful example of this (DOHA 2007)
- developing an understanding of local community. This includes community and family structure, the identification of influential community members and elders and an awareness of community politics and factions (NDS 2010).

**Indigenous staff**

The value of Indigenous staff to service providers and their clients is widely acknowledged (O’Neil, Kirov and Thomson 2004). Gilroy (2008) outlines a number of reported benefits to service providers from having Indigenous staff, including:

- increased-cross cultural awareness of the organisation
- greater awareness of local indigenous issues (both cultural and political)
- greater capacity to network with Aboriginal community services and develop programs that effectively target and cater for Indigenous clients.

While hiring Indigenous staff members may lead to complications arising from broader community tension in some areas (for example between kinship factions) 9, overall the presence of Indigenous staff appears to have a strong affect on use of services by Indigenous people (NDS 2010, p. 28). Similarly, the NSW Ombudsman (2010) states:

> While it is a myth that Aboriginal people will not utilise mainstream services simply because they do not employ Aboriginal staff, it is clear that employing Aboriginal workers is one of the most effective ways for organisations to demonstrate that they welcome Aboriginal clients and are capable of providing culturally responsive services. (p. 23)
For this reason, there is merit in both the NDIA (for example as case managers attached to regional NDIS offices), and service providers in communities with substantial Indigenous populations, establishing dedicated positions for Indigenous people within their organisations.

Success in recruiting Indigenous staff is dependent on a number of factors, such as reputation in the community (NDS 2010) and whether there are already Indigenous staff within the organisation (Gilroy 2008). The NDS (2010) provided a number of recommendations to assist recruitment, including having Indigenous Australians on the recruitment panel, working with Aboriginal job network services and offering traineeships. Gilroy (2008) argued that a lack of skills or qualifications is common barrier to recruiting Indigenous Australians and suggested a greater role for government to assist service providers with the costs of training and development.

Working conditions can also be difficult for Indigenous staff, which can cause problems with staff retention. This has a number of facets:

- Indigenous staff being 'pigeon holed' into positions that solely deal with indigenous communities. This can reduce career opportunities and impact upon workplace satisfaction (NDS 2010).
- A shortage of Indigenous staff can result in them being overloaded with work, which, combined with cultural expectations, can lead to staff working significant unpaid overtime (Hepburn 2005).
- Indigenous staff may be caught between the conflicting demands of their employers and their community. For example, member of the Indigenous community may ask Indigenous staff for things that agency policy forbids from providing, such as money, transportation or simply taking the time visit elder groups and socialise with Aboriginal community members while at work (O'Neil, Kirow and Thomson 2004; NDS 2010). However, refusing such requests may undermine their standing in the community.
- standard working conditions may be difficult to reconcile with personal cultural responsibilities (such as attending funerals). Conversely, Indigenous staff who can access more flexible working conditions may experience friction with non-Indigenous staff, who feel they receive preferential treatment (ARP 2010).

Appreciating the additional pressures that Indigenous staff may be facing will be an important factor in developing strategies for staff retention. Beyond this, the NDS (2010) also recommended building the capacity for non-Indigenous staff to serve the needs of the Indigenous community, thereby alleviating some of the demands made on Indigenous staff. This is reliant on non-Indigenous staff developing a sufficient level of 'cultural 'competence' and understanding of the Indigenous community they serve. This is discussed in the following section.

**Indigenous Cultural Awareness Training**

Cultural competency arises from a number of sources, including

- individual staff experience with Indigenous communities
- the institutional knowledge base developed by providers as to what service delivery strategies are most effective and appropriate in meeting the needs of Indigenous clients in different situations (itself derived through organisational experience and consultation).

Beyond this, Indigenous Cultural Awareness Training (ICAT) is an important and widely used strategy for improving cultural competency in dealing with Indigenous clients or staff. It is offered within the mainstream education system (such as university and TAFE), by specialist training providers and sometimes 'in-house' by organisations themselves. In some cases, funding agreements between government agencies and disability service providers require a certain proportion of staff to have undertaken ICAT (Gilroy 2008). Courses tend to
follow a short workshop format and aim to provide a better understanding of Indigenous culture and history, to develop skills and strategies for better service provision and to improve cross cultural communication skills.

Whilst an important strategy, a number of studies caution against assuming that ICAT can provide a stand alone solution to the achieving cultural competency and that a tokenistic, 'rubber stamp' approach to ICAT is contrary to its stated objectives (NDS 2010, Gilroy 2008). Moreover, like other education and training services, the quality of ICAT providers, and the applicability of course content to disability support services providers, is likely to be varied. In particular, the NDS (2010) noted that courses with generalised (rather than specific to disability support services) and non-local content were less effective. In some instances, ICAT appeared to have been counter-productive:

Many disability services reported that aboriginal cultural awareness training (ACAT) can make disability workers feel intimidated and apprehensive in working with Aboriginal people. The ARP received reports of disability service staff leaving ACAT feeling averse and disinclined to engage with the Aboriginal community for fear of insulting people. Some disability service staff reported that ACAT reinforces the perception that Aboriginal people are difficult service users. (pg. 18)

These issues highlight the point that the ICAT should be an output, rather than input based exercise (that is the goal should not be to ‘tick the box’ but rather to develop cultural competence in a practical way that improves the service offering). Nevertheless ICAT should remain a key tool to improving cultural competency, alongside an ongoing commitment by service providers to developing their own local knowledge base about cultural competent services practices that can be used as guide by staff. Gilroy (2008) and the NDS (2010) suggest a number of features that are likely to increase the usefulness of ICAT to service providers, including:

- being locally focused
- being practical in nature and relating specifically to disability services
- involving the local community in training
- providing information on important people (such as elders) and organisations (such as other not-for-profit service providers or aboriginal-owned business) with whom to establish networks
- covering other relevant topics such as appropriate communication styles, appropriate topics for conversation, myths and misconceptions, cultural taboos or sensitivities, and gender roles (such as men’s business and women’s business).

Conclusion

Supporting Indigenous Australians with a disability should be an important, specific goal of the NDIS. A key challenge to achieving this goal is overcoming the barriers to accessing services experienced by Indigenous people experience. The market based service delivery system underpinning the proposed NDIS will not always be the most appropriate funding method, at least for the medium term. In such cases, the NDIA should block-fund service providers to deliver disability supports to Indigenous Australians. In doing so, it should work with existing government agencies, Indigenous advocacy groups, funded service providers and the Indigenous community.

Indigenous people themselves are a key resource in addressing Indigenous disability. There are considerable advantages in employing Indigenous staff, and from fostering the development of not-for-profit service providers managed by Indigenous members of the local community. However, this can present governance and accountability challenges where the skills and experience necessary to run such organisations are limited. One potential response to this is to use a lead agency type model, whereby a larger experienced service provider supports smaller community based operations that engage local staff. This could allow local
Indigenous service providers to build their administrative and organisational capability, with the long-term objective of handing over control entirely.

While the proposed scheme will seek to dramatically improve the standard of living for many Indigenous Australians with a disability, there are limits to what can realistically be expected to be achieved. First, the diversity and level of care and support available in major cities cannot be replicated in very remote areas. In some cases, Indigenous Australians with complex needs will have to move to regional centres or major cities to receive the appropriate care and support (as is also the case with non-Indigenous Australians). Additionally, in some cases non-government service providers may be unable or unwilling to service very remote communities. In such cases government run service providers may be the only practical option. Similarly, in remote settings, sharing infrastructure (for example with health or aged care), while not ideal, may also be necessary.

Second, as the NDS is (by definition) primarily focused on offering support to people with a disability, it does not directly address the underlying issue of the relatively high rate of Indigenous disability. The causes of this lie in the socio-economic disadvantage and marginalisation experienced by many Indigenous Australians and the risk factors to which they are exposed. While the NDS may have a role in funding early intervention and prevention approaches, it is not a panacea for broad Indigenous disadvantage. Addressing Indigenous disadvantage is an issue for all of Australian society and requires an ongoing cooperative approach from all levels of government and the Australian people (both Indigenous and non-Indigenous) more generally.

The Australian Government and state and territory governments should consider the feasibility of overcoming the barriers to service delivery in the NDIS for Indigenous people with a disability by:

- fostering smaller community-based operations that consult with local communities and engage local staff, with support from larger experienced service providers
- employing Indigenous staff
- developing the cultural competency of non-Indigenous staff.

In its initiatives for delivering disability supports to Indigenous people, the NDIS should be mindful of the wider positive measures addressing Indigenous disadvantage being adopted throughout Australia.

Endnotes [N.B. for this Productivity Commission report only]

1. Similarly Arioti (1999) finds that while there are Pitjantjatjara word for specific impairments, there is no traditional word for the general concept of disability.

2. ABS and AIHW (2008), have a slightly higher estimate, with Indigenous Australians requiring assistance with a core activity at 2.1 times the rate of Non-Indigenous Australians.

3. As expected given the higher incidence of disability, Indigenous people access CSTDA funded services at a considerably higher rate per 1000 population. If Indigenous people face additional barriers to access, it would be expected that this gap would also be observed in terms of the estimated population of people with a disability - referred to as the potential population. The NMDS data suggest that per 1000 potential population fewer Indigenous people with a disability access accommodation support (39.5 per cent versus 41.3 per cent) and community access (49.0 per cent versus 58.9 per cent) (SCRGSP 2010).

4. For example culturally inappropriate activities at day care centres (O’Neill, Kirov and Thomson 2004, p. 7).

5. Interestingly, Victoria has a dramatically higher rate of usage of CSTDA funded services by Indigenous Australians than other states and territories.

6. For example, based on insights yielded from the NDIS database.

7. Sometimes referred to as Aboriginal Community Controlled Health Organisations.
8. The NSW Ombudsman (2010) noted that a common criticism by Indigenous people is that communities are not consulted until after decisions are made about the development and implementation of programs (p. 7).

9. The NDS (2010) suggested that in areas where kinship factions are prominent, employing an Indigenous Australian from one family group can reduce the prospect of recruiting from or delivering services to another. The NDS (2010) and ADN (2007) suggest that in some cases Indigenous run service providers face similar issues. Potential responses to this is are deliberately hiring from multiple family groups, and involving elders in conflict resolution. ADN (2002).
2.3. **Aboriginal and Torres Strait Islander Engagement Strategy, NDIS, Australian Department of Human Services**

Published: 2017; Reviewed: 9/1/18


### 2.3.1. Summary

This Engagement Strategy is the National Disability Insurance Agency’s commitment to Aboriginal and Torres Strait Islander community to acknowledge and deliver the National Disability Insurance Scheme to all parts of Australia. The Strategy is informed by our ongoing interaction and engagement with Aboriginal and Torres Strait Islander people with disability, their families, carers, communities and supporting organisations to clearly understand and respond to issues affecting access to the NDIS. There is a clear aim to develop a collaborative planning and working model to inform practice which can meet the needs of Aboriginal and Torres Strait Islander peoples with disability, their families, carers and communities. The Strategy describes our engagement approach and reflects the different needs of Aboriginal and Torres Strait Islander peoples with disability living in urban, rural and remote areas across Australia.

### 2.3.2. Key Information

**Section 3: Key Principles**

- **Centrality of Country, Culture and Community** – Aboriginal and Torres Strait Islander peoples with disability and their representatives have emphasised that Country, Culture and Community should be central to any policy that affects Aboriginal and Torres Strait Islander peoples with disability.

- **Human rights** – Aboriginal and Torres Strait Islander peoples and people with disability should be afforded the same rights as other Australians.

- **Inclusion in mainstream services is as important as specialist disability services** – the NDIS will provide an opportunity for specialist providers to cater to the individual specialist support needs of Aboriginal and Torres Strait Islander peoples with disability.

- **Universal consideration of disability** – the impact of disability should be addressed as a matter of course within policy deliberations and governance for all policies affecting Aboriginal and Torres Strait Islander peoples.

- **Meaningful engagement with Aboriginal and Torres Strait Islander peoples with disability** – the views of Aboriginal and Torres Strait Islander peoples with disability are central to the design, delivery and evaluation of policies and services which affect them.

- **Improving the evidence base on Aboriginal and Torres Strait Islander peoples with disability** – Improvements in data collection are needed with respect to Aboriginal and Torres Strait Islander peoples with disability across a range of portfolio areas, to help build the NDIA’s capacity to track and measure outcomes.

**Section 4: Engaging in the ‘proper way’**

This section is quite large; it provides a lot of information on the importance of cultural competence, understand country, community, communication and language. The ‘proper way’ is a colloquial phrase used to describe a way of doing business in Aboriginal and Torres Strait Islander communities in a manner which is compatible with the community’s values and customs. It can be difficult to define in conventional terms, as in addition to observable behaviours, it encompasses an intangible, spiritual aspect.
The overall message of the document is that the key to success is to understand the deep diversities in Aboriginal and Torres Strait Islander communities; for example, this information on location:

- **Urban areas** – are not always based around family or language groupings; therefore, it can be more difficult to locate Aboriginal and Torres Strait Islander people with disability and it is important to make use of the Aboriginal and Torres Strait Islander networks. In urban areas there is generally greater access to disability services than in rural and remote areas; however, there may still be a fear of discrimination or issues around stigma.

- **Rural areas** – long distances between service centres mean that many Aboriginal and Torres Strait Islander people with disability face an undesirable choice – either move off Country to a regional centre to access services or stay on Country and face limited services, limited opportunities for flexibility in service offerings and a lack of transport. The NDIA also acknowledges that in rural (and remote/very remote) areas family members often take on the care role without training or support.

- **Remote/ very remote areas** – due to limitations of current research and data collection the true need of disability and potential solutions for Aboriginal and Torres Strait Islander people living in remote and very remote areas is not fully understood. Data collected by the NDIA will help inform the level of demand and characteristics of participants accessing the NDIS, such as whether they have previously been in receipt of disability supports.

**Section 5: Aboriginal and Torres Strait Islander engagement approach**

The NDIA recognises that in the important process of establishing a relationship with an individual and their family, it is also important to build a relationship with the relevant community for that person. There is an emphasis on the importance of building the necessary relationships, knowledge, confidence and rapport and that this takes time. The Agency is adopting an ‘I’ model phased approach for initiating a sustainable relationship with Aboriginal and Torres Strait Islander communities. The three phases of the ‘I’ model are:

- **PHASE 1:** Introduction by a trusted local community member. This phase involves the community leaders getting to know the NDIA and staff, during which the purpose and aims can be introduced.

- **PHASE 2:** Initiate follow up contact to demonstrate commitment in the longer-term benefit of the community. This will enable the community to ask specific questions about the NDIS and how it will be conducted, once they have had time to reflect on the purpose and aims during the introduction phase.

- **PHASE 3:** Invitation to return by the community – this is a sign that trust is being established sufficient to progress a two-way engagement and meeting with participants to collect the narratives.

**Section 6: Aboriginal and Torres Strait Islander engagement priorities**

The NDIA has identified ten key priority areas for Aboriginal and Torres Strait Islander peoples with disability, these are:

- Communication and sharing of information.
- Cultural competency.
- Sharing Best Practice.
- Local solutions.
- Participant-centric design.
- Market enablement.
- Leveraging and linking.
- Cultural Leadership.
- Supporting internal infrastructure.
- Tracking progress

Each of these points is then expanded on briefly, for example:

**Communication and sharing of information:**
Communication and information sharing refers to ensuring the key messages about the NDIS are developed and delivered in the ‘proper way’. Effective communication and information sharing directly educates and informs participants, the community, and stakeholders about how to access the NDIS and the supports and services available. It also builds trust through participation in and support of community events and activities. All effective communication recognises and reflects the diversity that exists within Aboriginal and Torres Strait Islander communities and across Aboriginal and Torres Strait Islander peoples.
2.4. **NDIA's Rural and Remote Strategy 2016-2019**  
Published: February 2016  
Reviewed: 9/1/18  

The NDIA’s Rural and Remote Strategy should be considered within the overarching framework of the National Disability Strategy 2010-2020 (NDS), to ensure the NDIS is responsive to and appropriate for people with disability, their families and carers living in rural and remote areas. The intention is to explain how the NDIS is going to be implemented in rural and remote areas, giving a more in-depth explanation of what will be implemented in the 2016-19 period.

2.4.1. **Summary**

The Strategy clearly states that it is aspirational, that achievements will be gradual and that communities will be the government’s collaborators, working together to improve the lives of people with disability within their communities. It anticipates that actions will become more tailored for rural and remote communities, will support local planning that builds on existing strengths and will develop creative ways to best support people with disability as the NDIS is delivered.

The Strategy recognises the challenges for rural and remote people accessing services and acknowledges the diversity and varying needs of people with disability who reside in rural and remote areas, particularly those communities that include a higher proportion of Aboriginal and Torres Strait Islander peoples. It uses the example that, in 2011, about one-fifth of Aboriginal and Torres Strait Islander people lived in remote or very remote areas (7.7% in remote and 13.7% in very remote areas) compared with only 1.7% of other Australians. Aboriginal and Torres Strait Islander peoples represent 16% and 45% of all people living in Remote and Very remote areas respectively.

The Strategy also recognises the challenges for service providers, i.e. limited opportunities for economies of scale; greater administrative burdens associated with multiple accreditation, accountability and reporting requirements; the need for a broader diversity of service models and tailored responses; fewer employment opportunities and greater social disadvantage increase the risk of mental illness and harm from tobacco, alcohol and drug misuse. The Strategy notes “the need to work across different sectors, including mental health and develop solutions which involve interaction with mainstream services to support the delivery of vital services and provide opportunities to build the marketplace.”

The one-page summary of the Strategy is replicated overleaf, to facilitate review of local implementation within a larger context.
NDIA’s Rural and Remote Strategy One Page Summary

2.4.2. Key Information

Not a lot of Key Information is given on Aboriginal and Torres Strait Islanders; the data presented are for the larger Rural and Remote population of Australia. The Strategy has been developed by the same organisation as the ‘Aboriginal and Torres Strait Islander Engagement Strategy’, so a lot of the dialogue from this report is connected or points to that report. Also, any data that is presented in this report is referenced by the ‘Aboriginal and Torres Strait Islander Engagement Strategy’.

Section 9 of the NDIA’s Rural and Remote Strategy provides Key lessons the NDIA has learned from initiatives across Australian states and territories. Two of these are particularly relevant to the current context.

9.1 Australian Capital Territory

9.1.1 NDIS Outreach to Members of the Aboriginal and Torres Strait Islander Community

This service delivered by Gugan Gulwan commenced as a six month project in July 2014. Funding was increased to employ additional staff and to extend the program to March 2017.

The service provides outreach to promote understanding and awareness about the NDIS among Aboriginal and Torres Strait Islander peoples across the Australian Capital Territory (ACT) community, including:

- The local communities have heard about and have a general understanding of what the NDIS is;
- Community members with disability and their families are enabled and/or assisted to find out whether they may be eligible for NDIS and what types of supports and services the NDIS might provide them;
- Eligible people are supported to consider their whole of life needs and make a participant plan that outlines their goals and their disability related needs;
- Eligible community members are supported to meet and engage with the NDIA to get the best package of supports and services to achieve the goals in the participant plan; and
- The benefits and successes of the NDIS for local communities’ members are promoted.

Additionally, Gugan Gulwan hosted gatherings in partnership with other community providers who engaged with local community by recruiting family leaders who talked to other families about their NDIS /NDIA experience.

9.7 Victoria

Victoria’s Disability Act 2006 provides a person centred and whole-of-community approach to supporting people with a disability in which supports are built around the person on the basis of their individual needs and the resources of the communities within which they live and move.

The Department of Health and Human Services supports inclusive local communities by working with local government and communities to improve access to local resources and supports.

The RuralAccess initiative gives people with a disability more opportunities to join in the life of their community through a range of arts, cultural, sport, tourism and leisure activities, as well as by improving access to education, health and other services in local communities. RuralAccess workers are located in 25 local governments and community health services across rural and regional Victoria.

The Victorian Parliamentary Inquiry into Social Inclusion for People with a Disability (2014) acknowledges the important contributions made by people with a disability, their families and carers, local governments and service providers about what works well and what needs to change. It also confirmed that the Victorian Disability Act 2006 and the State Disability Plan provide a strong basis for Victoria’s social inclusion agenda. The next State Disability Plan 2017-2020 will incorporate Victoria’s transition to the NDIS and a continued role for the Victorian Government in enabling people with a disability to participate and contribute to social, economic and cultural life, including those in regional communities.
3. **DISABILITY IN VICTORIA:**

3.1. **Victorian State Disability Plan 2017-2020, Victoria State Government**

Published: May 2016  
Reviewed: 9/1/18  

3.1.1. **Summary**

This plan was developed throughout 2015 by the State of Victoria’s Department of Health and Human Services. Information was gathered and analysed from 775 people, peak bodies, statutory authorities, advocacy organisations and over two hundred people with a disability. The information gathered outlined five key areas for the Department of Health and Human Services to focus on during the 2017-20 period.

- Inaccessible environments, structures, systems and services continue to exclude people from truly being a part of the community.
- Negative community attitudes have a far-reaching and pervasive effect on people’s lives.
- People with a disability continue to struggle to be independent and have more say over their lives and the things that are important to them.
- Economic participation is vital – for identity, security and social inclusion.
- There is a need for greater accountability, including measures and targets, to drive change.

These five key points have been divided and addressed in four ‘Themes’.

3.1.2. **Key Information**

**Theme 1: Active citizenship**

- Early engagement with people with a disability reinforced that civic engagement and social inclusion are two of the most important issues to them.
- There are very few people with a disability in political, elected and other civic roles in the broader community, including committees of management and board positions.
- When it comes to social participation, people with a disability are often excluded from opportunities. Less than a third of Victorians with a disability (31 per cent) are actively involved in community groups, compared with approximately 36 per cent of the total population.
- In a study by Deakin University, only nine per cent of people with a disability said their social contact needs were fully met and only six per cent said that their community participation needs were fully met.
- The Parliamentary Inquiry into Social Inclusion and Victorians with Disability found that while mainstream settings are considered ideal for improving belonging and social inclusion, many are not fully inclusive.

**Theme 2: Rights and Equality**

- People with a disability experience significant discrimination, disadvantage and inequality. In 2014–15, disability discrimination made up one-quarter of all complaints to the Victorian Equal Opportunity and
Human Rights Commission. Furthermore, the number of complaints has increased by 10 per cent over the last two years.

- Over six per cent of Victorians with a disability rent public or social housing, compared with only one per cent of people without a disability.
- People with a disability report poorer health outcomes than people without a disability, and they report that some health service providers don’t have appropriate equipment or knowledge to provide the services they seek.
- Inequality of access to transport is a barrier for many people with a disability. The likelihood of exclusion is further compounded in regional and remote areas.
- The Royal Commission into Family Violence found that one in four women and girls with a disability are reported victims of family violence.
- The Royal Commission also found that women with disabilities experience all kinds of violence at higher rates, increased severity and for longer than other women.

**Theme 3: Economic participation**

- 43 per cent of people with a disability rely on a government pension or allowance as their main source of income, compared with only 10 per cent of people without disability.
- Underemployment is a common theme reported by people with a disability in part-time employment. This is reflected in a significantly lower average income of $400 per week for people with a disability, compared with $750 per week for people without a disability.
- Less than 27 per cent of people with a disability aged between 15 and 64 have a bachelor degree or higher, compared with about 40 per cent of people without disability.
- Only 49.9 per cent of vocational education and training graduates with a disability were employed after completing their training, compared with 76.2 per cent of graduates without a disability.

**Theme 4: Making the most of the NDIS**

- The Victorian Government is investing $2.5 billion a year in the NDIS to support Victorians with disabilities, their families, service providers and staff, and provide a disability safety net for all Victorians.
- The NDIS is a national program that will provide a new way of delivering services and support for people with permanent and significant disability in Australia.
- People with disability who participate in the NDIS can choose the supports and services that meet their individual needs, rather than have to fit into a one-size-fits-all system.
- The NDIS will be rolled out progressively in Victoria over a three-year period from July 2016.
- The scheme is available to Victorians who have a permanent impairment or condition and: - have Australian residency - are under 65 years of age - need support from a person or equipment to do everyday activities.
3.2. Strengthening aged care assessments for Aboriginal consumers: A guide for Aged Care Assessment Services in Victoria, Vic. Department of Health and Human Services

Reviewed 8/01/2018
Published January 2014

3.2.1. Summary

The aim of this guide is to develop consistency of practice by describing the issues that need to be considered to engage positively with Aboriginal consumers and Home and Community Care (HACC) Aboriginal services. Also, to describe some of the options that can be implemented to develop and put in place effective and mutually beneficial working relationships with HACC Aboriginal services. Gather information to support ACAS staff in their day-to-day practice when working with Aboriginal consumers and be an overarching guide that can be adapted to suit local processes and needs. There is a strong emphasis throughout the document on establishment of Aboriginal status and understanding of the historical and cultural background of consumers.

3.2.2. Key Information

Section 4: Understanding the Cultural Environment

• Aboriginal Family Structure
• Aboriginal Carers
• Cognitive ability and functioning
• Grief and bereavement

Section 5: Principles of best practice

• Client Focus
  ~ Aboriginal people are treated with respect and dignity.
  ~ Assessments are culturally sensitive, flexible and person focused. This includes undertaking Aboriginal-specific cognitive assessments, where appropriate. (Aboriginal-specific cognitive assessments are defined, only specified that they have reviewed the way they conduct them)
  ~ Aboriginal clients are informed and receive timely responses about aged care assessment processes and their right to be actively engaged in decision-making.
  ~ Assessments empower Aboriginal people to make informed decisions about the available care options.
  ~ Respect for the consumer’s privacy and confidentiality will be maintained by ACAS and other staff who are involved in collecting and storing information.
  ~ Consistent advice is provided about the consumer’s right to have an independent advocate attend the assessments.
  ~ Assessments will focus on the care relationship between the client and carer/s, family members or advocate, rather than the individual in isolation.

• Carer Focus
~ Family members and carers are treated with respect and dignity.
~ Family members and carers receive timely responses that are culturally sensitive.
~ Family members and carers are well informed of their role and rights in relation to the assessment process. In particular, their right to be involved in the assessment and decision-making processes – where appropriate.
~ Respect for the family’s and carer’s privacy will be maintained by ACAS and other staff who are involved in collecting and storing information.
~ An agreed care plan is formulated with the client and their family and/or carers.

- Culturally responsive services
- Culturally aware organisations

Section 6: This section is quite a large section, discussing the multiple requirements for assessing in multiple environments.

For example: **6.2.1 Assessments in hospitals**: While assessment in the person’s own home is the most desirable option, there are circumstances where it is necessary to assess an older person in hospital. Many hospitals employ an Aboriginal Hospital Liaison Officer (AHLO) to provide support for Aboriginal patients. Where the client/carer consents, the ACAS should inform the AHLO that the Aboriginal patient is participating in an aged care assessment and keep the AHLO informed about the assessment process. This will assist the AHLO to pass information onto the patient’s carer, family members and/or HACC Aboriginal services as appropriate.
Published: February 2014
Reviewed: 8/1/2018

3.3.1. Summary

Koolin balit – healthy people in the Boonwurrung language. This plan covers the period from 2013 to 2015, outlining measures planned to be taken to improve the length and quality of the lives of Aboriginal Victorians, as outlined in Koolin Balit. This action plan outlines the detail of what the Victorian Department of Health and other relevant departments such as the Department of Education and Early Childhood Development (DEECD), in partnership with organisations such as Victorian Aboriginal Community Controlled Health Organisation (VACCHO), will do in the period up to the end of 2015.

3.3.2. Key Information

• A major aim is to close the gap in life expectancy. All the measures outlined in this plan will contribute towards this. However, at the moment we are unable to measure life expectancy for Aboriginal people in Victoria due to issues relating to statistical methodology

• The Aboriginal perinatal mortality rate: 20.4 per 1,000, compared with 6.6 per 1,000 for non-Aboriginal babies (2009)

• 51.6 per cent of Aboriginal children receive the 3.5 year age and stage visits compared with 64.4 per cent for all children (2007–08)

• 47.7 per cent of young Aboriginal adults smoke, compared with 24.2 per cent of young non-Aboriginal adults (2008)

• The smoking rate is 32.8 per cent for Aboriginal adults (2008)

• Hospital data shows a substantial increase in patients identified as Aboriginal since commencing ICAP in 2004. In 2011 the accuracy of Aboriginal identification of hospital inpatients was 78 per cent

Improved quality of life

<table>
<thead>
<tr>
<th>Current status</th>
<th>What we will do</th>
<th>2015 target/milestone</th>
<th>2022 target</th>
</tr>
</thead>
<tbody>
<tr>
<td>31.3 per cent of Aboriginal adults report excellent or very good health compared with 44.0 per cent of non-Aboriginal adults. (2008)²</td>
<td>All the measures outlined in this action plan</td>
<td>Reduced gap between Aboriginal and non-Aboriginal adults reporting excellent or very good health</td>
<td>The gap between Aboriginal and non-Aboriginal adults reporting excellent or very good health on track to be closed by 2031³</td>
</tr>
<tr>
<td>22 per cent of Aboriginal adults report &quot;high or very high&quot; levels psychological distress compared with 11.4 per cent for non-Aboriginal people. (2008)⁴</td>
<td>Several of the measures outlined in this action plan</td>
<td>Reduced gap between Aboriginal and non-Aboriginal adults reporting &quot;high or very high&quot; levels psychological distress</td>
<td>The gap between Aboriginal and non-Aboriginal adults reporting &quot;high or very high&quot; levels psychological distress on track to be closed by 2031³</td>
</tr>
</tbody>
</table>
3.4. **Balit Murrup Aboriginal social and emotional wellbeing framework 2017–2027**,  
**Department of Health and Human Services**

Published: 2017  
Reviewed: 8/1/18  

### 3.4.1. Summary

Balit Murrup means 'strong spirit' in the Woi-wurring language. This report intends to outline objectives to reduce the health gap attributed to suicide, mental health and psychological distress between Aboriginal Victorians and the general population. This document doesn’t focus solely on disability, but it articulates how people with disability often encounter the key issues outlined in the report. “For Aboriginal Victorians with a disability – physical, intellectual or cognitive – the challenges to social and emotional wellbeing can be multiplied.”

### 3.4.2. Key Information

- A snapshot of the characteristics of young offenders in custody, inclusive of Aboriginal young people, showed 33 per cent presented with mental health issues, and 23 percent had a history of self-harm or suicidal ideation. Further to this, 22 per cent were registered with Disability Services; 19 per cent had a current child protection order, with 62 per cent being victims of abuse, trauma or neglect; and 60 per cent of young people presenting with a history of alcohol and drug misuse.

- Aboriginal people with severe and persistent mental illness will have a single care plan that links their physical, social and emotional wellbeing and mental health needs with other community-based social and disability support services they may require.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Description</th>
<th>Examples of protective and enabling factors</th>
</tr>
</thead>
</table>
| Connection to body         | Physical wellbeing that includes biological markers reflecting the physical health of a person such as age, weight, nutrition, illness, disability and mortality. | • A healthy diet and nutrition, access to effective health services  
                              |                                                             | • Participating in sports, exercise and healthy lifestyles  
                              |                                                             | • Non use of drugs and alcohol, and a healthy lifestyle     |
| Connection to mind and emotions | Mental wellbeing or mental health, and emotional, psychological and cognitive wellbeing. | • Having access to internal and external resources that meet core human needs, such as personal and cultural safety, security, a sense of control, self-worth, values, purpose or meaning, and motivation  
                              |                                                             | • Developing a positive mindset, managing difficult emotions, strong coping skills such as resilience, managing stress, adaptability and humour, positive mental health and wellbeing |
| Connection to family and kinship | Family and kinship systems that maintain interconnectedness through cultural ties and reciprocal relationships of sharing, caring, responsibilities and obligations. | • Understanding Aboriginal history and spending time with Elders  
                              |                                                             | • Spending time with family and kinship relations, family cohesions  
                              |                                                             | • Talking to friends, social support and not feeling lonely |
| Connection to community    | Collective spaces and places that strengthen Aboriginal identity, belonging and culture. Family and kinship networks where personal connections and socio-cultural norms are developed and maintained. | • Using Aboriginal community-controlled organisations and other Aboriginal organisations  
                              |                                                             | • Accessing Aboriginal Healing centres and Elders, men’s, women’s and children’s groups  
                              |                                                             | • Engaging in local, state and national cultural community events |
3.5. **Aboriginal and Torres Strait Islander and culturally diverse groups**

Reviewed: 9/2/18

3.5.1. **Summary**

This web page presents statistical data on Aboriginal and Torres Strait Islander and culturally diverse groups that are receiving disability advocacy services. Some of the data has been taken from the Victorian State Disability Plan 2017-20

3.5.2. **Key Information**

- On average over four years, disability advocacy organisations recorded 3.3 per cent of clients as being from an Aboriginal or Torres Strait Islander background.
- On average over four years, disability advocacy services recorded 9.3 per cent of clients as being from a culturally or linguistically diverse background.
- The number of Aboriginal and Torres Strait Islander and culturally diverse people varies from quarter to quarter, but there is no observable trend or pattern.

![Figure 8: Cultural background of people receiving disability advocacy services](image)

**Aboriginal and Torres Strait Islander and culturally diverse people in the State Disability Plan**

The Victorian State Disability Plan 2017-20 commits to a range of activities to support Aboriginal health and wellbeing, including:

- Working with the NDIA to implement strategies to support Aboriginal communities during transition by fostering and supporting self-determined, Aboriginal disability coordination and planning networks.
- Exploring options for expanding the Balit Narrum model for Aboriginal disability networks.
- Support and build the disability service capacity of Aboriginal Community Controlled Organisations.
3.6. Overcoming Indigenous Disadvantage Key Indicators 2014

Published: 2014
Reviewed: 9/1/18

3.6.1. Summary

The information in the Overcoming Indigenous Disadvantage report can be used to examine the nature of disadvantage experienced by many Aboriginal and Torres Strait Islander Australians and can help inform the design of policies. The report is designed to have a large amount of Aboriginal and Torres Strait Islander involvement.

3.6.2. Key Information

How were Aboriginal and Torres Strait Islander Australians involved in the OID Report?

- The report had its origins in a recommendation of the Council for Aboriginal Reconciliation in 2000
- Aboriginal and Torres Strait Islander individuals and organisations from cities and regional and remote areas across Australia participated in consultations and information sessions during the development of this and previous editions of the report
- the National Congress of Australia’s First Peoples is a member of the working group that advises the Steering Committee on the content of the report
- A wide range of Aboriginal and Torres Strait Islander organisations and experts reviewed relevant sections of the report, and are acknowledged in the introduction to each section of the main report.
- Aboriginal and Torres Strait Islander Australians contributed to a key development in this Report a broadening of focus from overcoming disadvantage to improving wellbeing. The report framework has been amended to highlight new indicators that focus on outcomes that Aboriginal and Torres Strait Islander Australians said are important to them (see the section on ‘Changes for this edition of the report’ for details)

Section: Things that work, pg. 13

The Clearinghouse identified the following high level factors that underpin successful programs:

- Flexibility in design and delivery so that local needs and contexts can be taken into account
- Community involvement and engagement in both the development and delivery of programs
- Trusting relationships
- A well-trained and well-resourced workforce, with an emphasis on retention of staff
- Continuity and coordination of services. The Clearinghouse factors are closely aligned to the success factors identified by the Steering Committee in previous editions of the OID report:
- Cooperative approaches between Aboriginal and Torres Strait Islander Australians and government — often with the non-profit and private sectors as well
- Community involvement in program design and decision-making — a ‘bottom-up’ rather than ‘top-down’ approach
- Good governance — at organisation, community and government levels
- Ongoing government support — including human, financial and physical resources.
3.7. **Experiences and needs of carers of Aboriginal children with a disability: a qualitative study**, *BMC Family Practice* journal

Published: November 2017
Reviewed 15/01/18
Weblink: [https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0668-3](https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0668-3)

3.7.1. **Summary**

This study aimed to better understand the experiences and needs of parents/carers/families of Aboriginal children with a disability. Australian parents/carers of a person with a disability experience higher rates of depression, more financial stress, and are twice as likely to be in poor physical health than the general population. Aboriginal and Torres Strait Islander peoples experience worse health, social and economic outcomes than other Australians, and those with a disability face ‘double disadvantage’.

Semi-structured in-depth interviews were conducted with parents or primary carers of Aboriginal children aged zero-eight with disability. Interviews were analysed using thematic analysis.

3.7.2. **Key Information**

Nineteen women (sixteen mothers and three grandmothers) were interviewed. More than half were lone carers (without a partner or spouse). Participants described their experiences, including challenges and facilitators, to providing and accessing care, impacts on their health and wellbeing, and associated economic and non-economic costs of caregiving. Financial strain and social isolation was particularly prominent for lone carers.

- Increasingly, family carers of people with a disability are subsuming greater responsibilities while caring for people at home.
- They are often required to fill in the gaps in fragmented service and support systems through their caregiving.
- Consequences of caregiving responsibilities for parents/carers include adverse health and social outcomes related to high levels of stress experienced in dealing with challenges of caring and juggling the demands of daily life.
- Parents/carers of a person with a disability have been found to experience higher rates of depression, stress, including financial stress, and are twice as likely to be in poor physical health compared to the general population.

3.7.3. **The Aboriginal context of caregiving**

Aboriginal and Torres Strait Islander peoples are one such priority population who experience worse health, social and economic outcomes than other Australians. Government policies of dispossession and racism have contributed to Aboriginal people being one of the most disadvantaged socio-economic groups in Australia. Chronic illnesses are much more prevalent among the Aboriginal population and they impact at younger ages. They are more likely than other Australians to experience poverty, unemployment, make less money, and live in rented homes and homes that are overcrowded (National Aboriginal and Torres Strait Islander Social Survey. These disparities are also apparent in disability throughout the life course. Aboriginal children aged 0–14 years are more than twice as likely as non-Indigenous children to have a disability. High educational attainment and employment is less likely in Aboriginal and Torres Strait Islander people with disability compared to non-Indigenous people with disability.
• These disparities likewise affect Aboriginal and Torres Strait Islander carers who are more likely to be an unpaid carer for a person with a disability than non-Indigenous Australians.

• The impact of caring is more pronounced for Aboriginal and Torres Strait Islander carers and their communities due to the high levels of socioeconomic and health disadvantage. Furthermore, conceptualisations of caregiving are different in Aboriginal families where family obligation is part of the culture.

• Connotations of family extend to all relatives who are nurtured within a community context, as in a kinship system, and it is appropriate for families and communities to look after one another [16]. For example, many Aboriginal carers rely on the extended family to give them a break from caring rather than approaching formal (paid) services for respite.

• Kinship care is currently the most common form of out-of-home-care (OOHC) for Aboriginal children; this has specific implications on the impact of caregiving for Aboriginal kinship carers of a child with a disability.

• Also, the term ‘carer’ may not resonate with Aboriginal carers who perceive it as reflecting formal care workers; thus, Aboriginal carers may not identify as carers despite significant care responsibilities.
4. **ACADEMIC SOURCES:**

4.1. **Accessing the NDIS - Assisting people with psychosocial disability to access NDIS: a guide for Commonwealth-funded community mental health service providers**

Last updated: 2017  
Reviewed 7/02/18  

4.1.1. **Summary**

This guide was prepared by Flinders University with funding from the Australian Government Department of Social Services. The guide has been created to assist Commonwealth funded community mental health and carer respite programs providers in supporting participants to access the National Disability Insurance Scheme. The guide was developed with collaboration with the NDIA and DSS. The guide offers a small amount of information on how the NDIS plan is intended to be implemented in Aboriginal and Torres Strait Islander communities.

4.1.2. **Key Information**

**Part E:** Assisting people who experience cultural, language and other barriers to access the NDIS.

Engaging Aboriginal and Torres Strait Islander communities: The NDIA has funded several initiatives to develop culturally appropriate ways to engage Aboriginal and Torres Strait Islander (ATSI) communities in accessing NDIS supports. The NDIA Aboriginal and Torres Strait Islander engagement strategy was launched in February 2017 and outlines how the NDIA will work with Aboriginal people with a disability. Key commitments include:

- Cultural competency for NDIA staff and partners in the community.
- Cultural leadership.
- Local solutions.
- Participant-focused design and culturally appropriate communication.

NDIS fact sheets, a poster and a planning resource have been developed for Aboriginal people and can be downloaded from the New South Wales NDIS website. The resources are designed to support Aboriginal people and communities to begin conversations around disability and what the NDIS may mean to them and their families. The following fact sheets are available:

- NDIS for Aboriginal people with disability in NSW
- Yarnin’ about disability
- What is the NDIS?
- Getting ready for the NDIS.
- Accessing the NDIS
- Carers and the NDIS
- Yarnin’ about mental health
4.2. **Making every Australian count: challenges for the National Disability Insurance Scheme (NDIS) and the equal inclusion of homeless Aboriginal and Torres Strait Islander Peoples with neurocognitive disability**

Last updated: 2016
Reviewed 7/02/18

4.2.1. **Summary**

This article is a critique on the National Disability Insurance Scheme, questioning the accuracy of prevalence rates of neurocognitive disability, homeless Aboriginal and Torres Strait Islander people. The authors report no actual or potential conflict of interest that could inappropriately influence, or be perceived to influence, this work. It provides an extensive amount of information being accurate, people under this bracket are in danger of not being counted by the NDIS and not receiving supports to which they are entitled. The article provides challenges to addressing this knowledge gap:

- The long-term effect of profound intergenerational disenfranchisement of Aboriginal and Torres Strait Islander people.
- Aboriginal and Torres Strait Islander cultural perspectives around disability.
- The generally unrecognised and poorly understood nature of neurocognitive disability.
- The use of research methods that are not culturally safe.
- Research logistics.
- The absence of culturally appropriate assessment tools to identify prevalence.

4.2.2. **Key Information**

**Section:** Disability and homelessness among Aboriginal and Torres Strait Islander people

Current estimates suggest that Aboriginal and Torres Strait Islander people experience approximately twice the rate of disability as non-Indigenous Australians. The proportion of Australia's First Peoples aged 15 years and over reporting a disability or long-term health condition has been estimated at 37% (roughly 102,900 people).

The incidence of neurocognitive disability in particular has not been accurately established, but is thought to be high. In Aboriginal and Torres Strait Islander homeless populations, the prevalence of neurocognitive disability is likely to be particularly high given:

- People with a disability are at greater risk of homelessness compared with the general population
- The proportion of homeless Aboriginal and Torres Strait Islander people is 14-fold higher than for non-Indigenous Australians.

Given the dearth of accurate evidence available to inform the NDIS regarding the extent and nature of neurocognitive disability among homeless Aboriginal and Torres Strait Islander people, it can be assumed that the level of need for disability assistance by this group has not been properly estimated.
4.2.3. Challenges for the NDIS:

Without accurate prevalence rates of neurocognitive disability, homeless Aboriginal and Torres Strait Islander people are in danger of not being counted by the NDIS and not receiving supports to which they are entitled. Addressing this knowledge gap is challenged by a range of factors, including: *

- the long-term effect of profound intergenerational disenfranchisement resulting in limited self-determination and/or fear by Aboriginal and Torres Strait Islander people to seek help.
- Aboriginal and Torres Strait Islander cultural perspectives around disability (e.g. there is no word for ‘disability’ in traditional languages; the label of ‘disability’ may be stigmatising and result in a disinclination to identify people in need of support).
- neurocognitive disability is often generally unrecognised and poorly understood.
- historically, research methods have not been culturally safe and have been negatively experienced by Aboriginal and Torres Strait Islander people.
- research logistics (i.e. difficulties in locating people, particularly those who are rough sleepers and/or are living in rural or remote areas of Australia).
- the absence of culturally appropriate assessment tools to identify prevalence.

An accurate evidence base that is informed by culturally safe research methods and assessment tools is needed. The development of a strong evidence base to inform the successful inclusion of homeless Aboriginal and Torres Strait Islanders with neurocognitive disability in the NDIS will only be achieved through ongoing, culturally safe partnerships with Aboriginal and Torres Strait Islander people and the use of culturally safe research methodologies and tools.

To identify the prevalence of neurocognitive disability within the Aboriginal and Torres Strait Islander homeless population, an appropriate assessment tool must be developed and tested for reliability and validity. Research must also investigate the viability of the NDIS model for non-urban communities and the practical challenges inherent in living in regional and remote areas of Australia.

Evidence collection must be conducted in community by people who have credibility and respect, taking into account cultural learning, the importance of family and community, the history of disadvantage and mistrust, and heterogeneous ways of knowing, thinking and doing. Respect for Aboriginal and Torres Strait Islander ways and spirituality will be paramount. Research within this framework can inform effective, culturally appropriate and safe evidence-based policy reform and development inherent within the NDIS initiative and will contribute to the realisation of a truly inclusive NDIS.
4.3. **The NDIS, Housing and Indigenous Australians Living with a Disability**

Last updated: 2016  
Reviewed 7/02/18  
Organisation: Amit Srivastava, School of Architecture and the Built Environment, The University of Adelaide  
https://search-informit-com-au.ezproxy.flinders.edu.au/fullText;dn=492646943701415;res=IELFSC

4.3.1. **Summary**

This article is an analysis of the National Disability Insurance Scheme’s section on Aboriginal and Torres Strait Islander. Giving an evaluation on its main sections and discussing how its implementation will improve Disabled Aboriginal and Torres Strait Islander lives. This article/report is valuable because it shows a strong level of understanding of the social factors/outcomes that are involved with this epidemic, rather than just basing evaluation on statistical data. “It is imperative to understand the housing experiences in order to understand and appreciate the needs and aspirations of Indigenous peoples living with a disability and to make informed policy decisions”

4.3.2. **Key Information**

**Indigenous People Living with a Disability:** The high level of disability in Indigenous populations occurs for a range of reasons, including poor health care, nutritional deficiencies, risk taking behaviours, exposure to violence and psychological trauma and substance abuse. Indigenous people living with disability are significantly overrepresented in all population cohorts.

Some Indigenous Australians find the concept of disability hard to understand or irrelevant, reducing the likelihood of reporting. In some Indigenous language there is no term for disability. Culturally, this may suggest disability may be accepted as part of the human experience or as a unique attribute of the individual.

Equally, Aboriginal people with disability are often reluctant to take on the label of disability if they have experienced discrimination based on their Aboriginality or have had experiences as members of the ‘Stolen Generation’.

**Housing Issue for Indigenous People Living with a Disability:** Housing and living environments are fundamental to the quality of life. Having little or no choice in where one lives or residing in inappropriate housing has a profound impact on physical and mental health, and the ability to participate in employment and community activities. Many Indigenous people find this integration even harder because their families live in poor, inappropriate, or overcrowded housing.

Indigenous households are 3.7 times more likely to be overcrowded. Households often include extended family members with one or more individuals having special needs (for example, frail older people, people with psychiatric disorders, physical disabilities or in poor health from chronic diseases).

**The current arrangements for the provision of public and community housing will continue under the NDIS with the exception of Disability Care acting as an advocate in procuring accommodation services. At present, the funding available is unlikely to be adequate address the shortfalls in housing provision, let alone provide Indigenous people living with a disability access to safe, appropriate housing.**

**Conclusion:** There is an urgent need for Indigenous Australians living with a disability to have equitable arrangements and appropriate housing. While a large number of Indigenous people live with a disability or disabilities, little is known of their disabilities and characteristics and their lived and housing experiences.
4.4. The Implementation of the NDIS: Who Wins, Who Loses?

Last updated: 2014
Reviewed 7/02/18
Organisation: University of Technology Sydney

4.4.1. Summary

This paper aims to identify ways of developing workforce capacity to deliver the National Disability Insurance Scheme (NDIS) to Indigenous people with disability in Australian rural and remote communities. It reviews key research and reports, analysing the potential benefits and disadvantages of the person-centred approach on which the scheme is premised. It considers these through the frame of services, employees and people with disability in the Australian context and concludes that, while there are potentially overwhelming benefits, there are also potentially major losses.

The methodology used in this paper was a directed literature review to answer the research question: What is the potential impact of the NDIS on individuals with disability, service providers and employees?

4.4.2. Key Information

The paradigm shift in person-centred approaches places the individual person with disability at the centre of service planning and delivery. The concept originated in North America in the late 1980s [the paper provides references]; it recognises people with disability as active participants and decision makers in their lives and communities. Support is conceived as enabling them to achieve their lifetime goals based on their strengths.

Person-centredness is reported to present two types of changes for service providers:

- The first is conceptual and requires new and innovative ways of thinking about service provision.
- The second is practical, being in terms of income and cash flow. Government funding will now be directed to individuals, with service providers no longer be able to rely on block funding.

In order to get the ‘conceptual’ right, service providers will need to be close and sensitive to their actual and potential service users, understand the changing landscape and participate in shaping it.

In a 2013 Australian Council of Social Services (ACOSS) community sector survey, seventy-four per cent of disability service providers reported that the cost of service delivery exceeded their revenue. It was also noted that many government contracts require the return of any surplus, leaving little if any for investment in the organisation, let alone innovation, for person-centredness and capacity to traverse funding models from pre- to post-service delivery.

The connection between an organisation’s governance and its service users is central to the voice service users have and an organisation’s responsiveness to that voice. This is particularly so in a landscape of many stakeholders such as disability services. Governance is about ends and means, what and how (Carver & Carver 2001), the key pillars of which are mission, direction and strategy. The closer the board or governance structure is to the service user, the better and more directly informed it is likely to be, and the more likely there is to be service user representation among the board members. The paper also notes that:

*It is reasonable to conclude that smaller organisations have greater connectedness with service users simply by virtue of their size, which also enables them to respond flexibly. If smaller organisations are at risk in the new person-centredness landscape then so is the strength of the voice of service users, and the strength of the connections between services users and services that goes beyond mere service delivery.*
With regard to the disability services workforce, the paper identified three major career path impediments:

1. **fewer training opportunities and career mobility** within community services. Where the primary source of income is government funds, there is little, if any, financial capacity for staff development and training. Alternatively, using the donor dollar for staff development and training is also problematic because of the expectation that donations are given specifically for service users. This results in significantly higher staff turnover in disability services compared with other service areas.

2. **low wages relative to other industries.** The complex knowledge and experiences required of care workers not only reflect the growing professionalisation of the work, but also the increasing requirement for disability service workers to deal with more complex and diverse client needs.

3. **significant and increasing casualisation of the workforce.** In 2009, the Australian Bureau of Statistics reported that sixty-eight per cent of community service workers were part-time or casual, compared to twenty-nine per cent of the workforce overall. In the same year, the Productivity Commission reported that a substantial proportion of workers reported a desire for more work. The staffing risks attached to person-centred care and direct purchasing by service users are intermittent service usage, short notice requests or cancellations of care and service user ‘churn’ as purchasers pick and choose to find the right care.

4.4.3. **Conclusions**

Bearing in mind that this paper was written during the planning and pilot phase of the NDIS, it concluded that a major concern was the potential drying up of funding for the specialist support organisations that are providers of information to, and advocates on behalf of, those with disability and their carers. Loss of these organisations, and the knowledge and human capital within, could be devastating to the disability human rights movement.

Cortis et al. (2013, p.43) summarise a way forward referred to as the ‘high road’ strategy which requires higher costs and investment in the short term to support organisations and individuals through the transition and establishment of person-centredness. The paper suggests that, if implemented effectively, it would lead to more sustainable and higher quality service delivery in the immediate and longer terms, with ‘better outcomes for people with disabilities, and a more efficient and cost-effective system of care’. 
4.5. **Will the National Disability Insurance Scheme Improve the Lives of those Most in Need? Effective Service Delivery for People with Acquired Brain Injury and other Disabilities in Remote Aboriginal and Torres Strait Islander Communities**

Last updated: 2014
Reviewed 7/02/18
Organisation: University of Technology Sydney

4.5.1. **Summary**

This report discusses the history of disability service distribution in remote and outer regional areas of Australia. It addresses how due to common social practice, these areas have consistently lagged behind less rural areas and because of the difficulty and communication problems, Aboriginal and Torres Strait Islander people are usually overlooked by disability services. It also provides an overview of acquired brain injury services for Aboriginal and Torres Strait Islanders in remote and outer regional areas and the present (2014) sets of barriers they face to obtaining quality care and effect interventions. Most importantly, its section ‘The Indigenous Concept of Health and Disability’ provides a presumption of and Aboriginal or Torres Strait Islanders outlook on their own health.

4.5.2. **Key Information**

- Census data counted the number of people living with a disability at 9,000 (46%) people in regional areas, and 3,500 (18%) people in remote/very remote areas. People in regional, remote and very remote areas are up to 2.5 times more likely, than non-Indigenous Australians.
- Physical disability is the most common type of disability group among Indigenous Australians followed by sight, hearing and speech-related limitations. 30% experience intellectual or psychological-related disability.
- Half of all Indigenous Australians aged 15 years and over had some type of disability or long-term health condition, and, disability rates increase with age with one third of Indigenous people over 65 have a core activity need for assistance.
- The prevalence of ABI (acquired brain injury) is notably higher in Aboriginal and/or Torres Strait Islander communities compared to the general Australian population (8–23% of Indigenous people affected compared to 2.2%).
- People who experience the effects of an ABI require diverse rehabilitation and care and support needs to treat multifarious and complex co-morbidities for the rest of their lives.
- People living with a disability, generally, are said to be more likely to experience stressful life events. Divorce, domestic violence, job loss, and overcrowded housing, compound the cost and impact of ABI on the individual affected, and their carer’s, families and even whole communities.

4.5.3. **Key Recommendations:**

- ABI needs to be afforded a high level of attention, as despite its high, known prevalence, it is widely under-assessed, misunderstood by communities, and under-serviced by the disability and health systems. The NDIS includes the potential to offer flexible assessment and training to this group who have evident ongoing support needs as a result of their ABI. The NDIS might be flexible enough to consider the following key aspects for service delivery in remote and very remote communities.
Indigenous Concept of Health and Disability:

- Aboriginal and Torres Strait Islander people often view health in a broad sense that includes consideration of the physical, cultural and spiritual components of wellbeing.
- Culture and identity are central to Aboriginal perceptions of health or ill health. In many cultural linguistic groups, there may not be a word that translates directly into English that means ‘disabled’ or that describes a particular type of disability.
- Being labelled with an English-speaking word or term is often undesirable and can have stigmatising effects.
- Aboriginal and Torres Strait Islander people are unlikely to engage with non-Indigenous services if they experience or perceive that the service lacks cultural competence.
- Cost barriers, favourable treatment given to some family members over others, overt racism and stereotyping and “structural racism”, where lack of cultural knowledge and sensitivity result in processes that are incompatible with the local Aboriginal or Torres Strait Islander cultural approaches and values are all known reasons for Indigenous people to turn away from a health service.

Issues with the NDIS scheme:

- Eligibility for the NDIS scheme is also complicated by the age distribution of Aboriginal and Torres Strait Islander populations. The Productivity Commissions recommended that a younger age threshold apply based on lower life expectancy. A lower threshold may create an equity issue if higher levels of support flow to people in the NDIS scheme than the aged care sector. 31% of the Indigenous disability population needing assistance were aged 45–64 years and 20% were aged 65 years.
- Similarly, lower levels of funding were recommended to children under 15 years of age based on the assumption that families provide most care to children, but this fails to account for special needs school resourcing in regional, remote and very remote communities, or, that children may be cared for by non-remote family members, communities of extended family according to local custom.
4.6. **Need for an Australian Indigenous disability workforce strategy: review of the literature**

Last updated: 2016  
Reviewed 8/02/18  
Organisation: Taylor & Francis Group  

4.6.1. **Summary**

The aim of this report is to identify workforce opportunities for Indigenous people who fall under the NDIS. The report discusses current workforce approaches looking to evaluate on how they could be evolved, whilst also providing new examples of how things could be replaced. The main conclusions the report has made about the challenges of this task in Aboriginal communities have been listed as:

- Indigenous people with disability living in rural and remote areas experience significant access and equity barriers to culturally appropriate supports and services that enable them to live independent, socially inclusive lives.
- A workforce strategy based on community-centred principles has potential for ensuring that the disability services sector meets the rehabilitation needs of Aboriginal people with disability living in rural and remote areas.
- Cultural training and development of an Indigenous disability workforce may help to ensure a culturally safe disability services sector and workforce.

4.6.2. **Key Information**

The report discusses the large lack of cultural competency of non-Indigenous Australians, then evaluates on the importance of educating Indigenous people on how to deal with that lack of respect. For example:

“Cultural awareness training aims to increase awareness of cultural, social, and historical factors applying to Indigenous peoples generally, and to specific Indigenous social groups and/or communities. Cultural awareness is often critiqued as having limited influence on shifting the attitudes and practices of non-Indigenous peoples in their engagement with Indigenous peoples. In contrast, cultural competence encompasses a set of congruent behaviors and policies that will prevent the consequences that arise from cultural disrespect in health service provision, with training aiming to improve health workers’ awareness, knowledge, and skills so that they can operate and work in a cross-cultural environment in relation to health service interventions. Downing and colleagues advocate taking a cultural safety approach to cultural training, to provide an understanding of the social, political, and historical processes that influence health and disability practice as well as informing individual attitudes, thereby addressing the need for both systemic and individual change.”

The most important information provided is the comprehensive report on workforce development to deliver the NDIS. The specific research question was “What does a culturally responsive disability services workforce for Indigenous Australians in rural and remote areas look like?” A narrative review of literature was conducted to investigate which articles/reports would meet their requirements for proper inclusion of Indigenous people into a working environment.
The main findings of this study highlighted the need for improvement but also awareness. The findings of this review were that careful and innovative workforce planning, and strategies are essential.

One of the main papers they reviewed, ‘Arafmi Mental Health Carers Western Australia’, suggested that the currently proposed NDIS (2016) must properly address the existing low levels of knowledge of disability supports, lack of private providers, and the transient nature of community members. Forcing Indigenous people to operate within a market-based service model may further disadvantage Indigenous families in resource scarce rural and remote communities.

Their main conclusions are listed as three main areas for improvement (each of these are further evaluated in the report):
1. Genuine community engagement and consultation, as may be facilitated by community-centred approaches, will help to ensure that workforce strategies actually represent a close match to the need, priorities, and preferences of Aboriginal people with disability and their families, and mitigate some of the historic disadvantage of colonization experienced by Indigenous peoples.

2. Models of cultural training that focus on development of cultural competence and cultural safety are identified in the literature as essential components of a workforce strategy.

3. The adoption of culturally appropriate and targeted recruitment and retention strategies will build the Indigenous workforce and ensure they are trained and supported to deliver disability services within local communities including the most geographically remote.
4.7. Concerns over costs of NDIS

Last updated: 2017
Reviewed 8/02/18
Organisation: The Guardian, Llina Flynn
https://search-informit-com-au.ezproxy.flinders.edu.au/fullText;dn=166180228687348;res=IEELAPA

4.7.1. Summary

This short article from the Guardian raises several issues about the funding behind the NDIS saying “the hidden costs have not been accounted for by the government.” In particular, it focuses on the difficulties of organising things in remote areas and the lack of foresight the NDIA has had when planning out how they will spread the funding. The article refers to a prior attempt to trial the NDIS on Palm Island, where the local community is “still bearing the costs of caring for people with disability.”

4.7.2. Key Information

Palm Islands Community Company (PICC) chief executive Rachel Atkinson raises issues throughout the article

- There was a three-month gap between when the block funding model ended and the money from the new NDIS packages came through, so her organisation had to keep paying salaries of the disability support staff out of there working capital.
- The costs of training staff, as well as management and support costs, were not funded by the NDIS
- If a worker works with a client for two hours all that is covered is their salary and fuel costs, when there are costs on top of that such as blue and yellow card and also the vehicles and equipment to get them there.
- “The government didn’t send any consultants to us before the trial began, but a recent report said it spent nearly $30 million on consultants over the last two years. “Where is the benefit of this consultation? It would have been smarter to have given us some money, I guarantee we would have had a better outcome.”
- Atkinsons main point was that after her experience with the trial, was that until disability is in the limelight people will keep missing out or not be treated correctly due to second-class services
- “The NDIS is going to be a challenge for our communities. The government needs to give seed funding until it becomes a viable business. If it’s difficult then it’s the clients who will miss out.”
4.9. **How well does the Australian National Disability Insurance Scheme respond to the issues challenging Indigenous people with disability?**

Last updated: 2017  
Reviewed 9/02/18  
Organisation: Deakin University  
https://anzswjournal.nz/anzsw/article/view/281/541

4.9.1. **Summary**

This report highlights the need for disability policy improvements and promotes rethinking of what is culturally appropriate healthcare for Indigenous populations, who are disabled, not only by colonised histories but also through contemporary socio-economic marginalization.

4.9.2. **Key Information**

The report breaks its sections up into barriers:

1. **Social barriers:**
   
a. Some Indigenous community’s languages do not include a word for disability.

   b. In some communities, disability is sometimes attached to traditional views about the negative consequences of human mistakes and/or communal stigmas.

   c. Even when disability is recognised, it is considered a small issue when compared with problems such as unemployment, poverty, discrimination and chronic disease.

   d. The high rate of disability in the Indigenous population also “normalises” perceptions of disability.

   e. The impact of colonisation and mistrust of governments disability services blocks Indigenous willingness to engage with disability services, and widens Indigenous reluctance to identify disability issues and negative attitudes towards “authorities”.

2. **Attitudinal barriers:**

   a. The care requirements can burden family members when the person with disability has complex and multiple requirements, or there are many persons in the family in concurrent need of such care, or other problems currently exist for the family.

   b. The need for financial assistance and additional provision of specialist aids, equipment and skill education for familial caregivers is repeatedly reported but often ignored in practice due to “inflexible rules and bureaucratic processes”.

3. **Physical barriers:**

   a. Insufficient and inaccurate statistical information regarding Indigenous people with disability is one of the major challenges in evaluating the needs of this population.

   b. Problems with cultural appropriateness of the data collection instruments, which are mainly designed for mainstream surveys, add more complexity to the issue of limited data.

   c. Western concepts, values and English language in standard assessments, which discount the cognitive risk factors of Indigenous population including poor nutrition, substance abuse, domestic violence and trauma, results in significant numbers of Indigenous people with cognitive disability being under-represented in survey outcomes and not receiving services.
d. The scarcity of services in remote areas often means that Indigenous people with chronic impairment travel frequently and/or choose to dislocate their families and leave their communities to access proper services.

4. Communication barriers:
   a. In some remote areas where English is not the first language of Indigenous people, lack of accessible information regarding disability services has been reported.

This report also raises issues of:

- **NDIS identification**: an Evaluation of The Australian Productivity Commission (PC) proposed the NDIS in the report “Disability Care and Support”:
  - Recommendations 11.1 and 11.2 neither contained a guarantee to incorporate Indigenous people’s values, language, culture and protocols into the proposed NDIS services, nor firmly empowered Indigenous people within their own communities to control planning and administration of disability services.
  - Recommendation 8.4 generally excluded close family members from being paid support workers under the NDIS. This has restrained efforts seeking alternatives to break the Indigenous families’ cycle of poor living and health conditions, particularly related to caring attitudes and geographical distance of Indigenous people with disability.

- **Gaps in NDIS response to Indigenous people living with disability**:
  - The NDIA reported that 4.6% of 28,684 participants during the three-year trial and 5.5% of 7,440 participants in the first quarter of the 2016–2017 financial year were identified as Indigenous people.
  - Quarterly reports of the NDIA demonstrated a gradual increase in the participation of Indigenous people, but the respective rates have not yet represented approximately 34,500 Indigenous Australians who suffer from a profound or severe core activity limitation.
  - Although the NDIS Act sets out assistance for people with disability, their families and carers, it does not clearly formulate what types of support, aids and/or equipment would be available in funded packages.
  - The report lacks detail relating to cultural competence, training, attraction, recruitment and retention of the workforce in Indigenous communities.
  - The NDIS will address linguistic issues of service delivery to people with disability, however, the only provision caring for the linguistic and communication issues of the NDIS participants. Therefore, it is insufficient to help Indigenous people with disability to express their needs or overcome prolonged communication barriers due to constant differences in the ways that service providers and Indigenous people define disability.
  - The policy offers no specific scheme to help Indigenous people with disability overcome social barriers, particularly relating to language and terminology used in assessment tools, planning processes, service deliveries and enabling non-discriminatory practice of disability assessors and health workers.
4.10. **Engaging Aboriginal and Torres Strait Islander peoples in the ‘Proper Way’**

Last updated: 2017
Reviewed 9/02/18


### 4.10.1. Summary

This report accesses how culturally appropriate the NDIS is and how Aboriginal and Torres Strait Islander people now have the choice to access those supports and services which they feel are culturally appropriate and which meet their needs. This article also examines the many barriers that come with engaging Aboriginal and Torres Strait Islanders with the NDIS. The report was conducted by ‘New Paradigm’ Psychiatric Disability Services of Victoria (VICSERV).

### 4.10.2. Key Information

This report suggests that Aboriginal and Torres Strait Islander people are at a high risk of being excluded from the NDIS, evaluating on what is written in Aboriginal and Torres Strait Islander Engagement Strategy

- The Engagement Strategy intends to engage successfully through what they have called the ‘Proper Way’ process.
- Implicit in the concept of Proper Way is an understanding that Aboriginal and Torres Strait Islander peoples and communities are heterogeneous, and that protocols appropriate in one context may not be so in another.
- Clinical focus of mainstream medical models, Aboriginal and Torres Strait Islander peoples’ conceptualisations of health and wellbeing have been described as holistic, with mental, physical, cultural and spiritual health seen as indivisible.
- Until mainstream services demonstrate an understanding of and respect for these understandings of health and disability, services will not meet the needs of Aboriginal and Torres Strait Islander peoples, and engagement levels may remain low.

The article offers models of culturally appropriate engagement with rural and remote Aboriginal and Torres Strait Islander communities that aim to enhance their understanding of and participation in the NDIS. These models have been based on unsuccessful attempts to implement the NDIS in Palm Island.

- ‘The Guddi Protocol’ has been assessed by Aboriginal and Torres Strait Islander peoples for its cultural safety and appropriateness, and could potentially be used as a basis for an NDIS assessment.
  - The Guddi Protocol arose from ‘Synapse’ a non-Government organisation dedicated to reconnecting the lives of people who are affected by acquired brain disorders.
  - Synapse conducted research in Northern Queensland into ATI people with neurocognitive disability.
  - The protocol consists of a culturally appropriate interview which includes questions relating to thinking skills, psychosocial functioning, depression, psychosis, and post-traumatic stress disorder. The Guddi Protocol is underpinned by a ‘yarning’ method, which has been described as an Indigenous cultural form of conversation. ‘Yarning’ facilitates trust and relationship building, and represents a culturally safe method of engagement.