

Better information and statistics for better health and wellbeing

# Aboriginal and Torres Strait Islander people with disability

Wellbeing, participation and support

May 2011

Australian Institute of Health and Welfare Canberra

Cat. No. IHW 45

# The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is better information and statistics for better health and wellbeing.

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**Board Chair** 

Hon. Peter Collins, AM, QC

Director

David Kalisch

Any enquiries about or comments on this publication should be directed to: Communications, Media and Marketing Unit Australian Institute of Health and Welfare GPO Box 570

Canberra ACT 2601 Phone: (02) 6244 1032 Email: info@aihw.gov.au

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## **Abbreviations**

ABS Australian Bureau of Statistics

AIHW Australian Institute of Health and Welfare

CSTDA NMDS Commonwealth State/Territory Disability Agreement - National

Minimum Data Set

## **Symbols**

nil or rounded to zero

not applicablen.a. not available

n.p. not publishable because of small numbers, confidentiality or other concerns about the

quality of the data

## **Summary**

- Census 2006 data suggest that Indigenous Australians aged 0-64 years are 2.4 times as likely to need assistance with the core activities of daily living than non-Indigenous people.
- Among Indigenous Australians aged 45–54 years the rate of need for assistance with core activities is almost 3 times that of non-Indigenous Australians.
- The employment rate among Indigenous people with disability aged 15–64 years (13%) is significantly lower than among Indigenous people without disability (51%).
- Reliance on Government pensions and allowances as the principal source of income among Indigenous people (aged 18–64 years) with severe or profound disability is similar to that for all Australians (of similar age and severity of disability).
- Indigenous households with a member with severe or profound core activity limitations are clustered in the lowest income levels, in contrast to households without a member with disability which have a more even spread across low- and middle-income levels.
- Indigenous Australians with severe or profound disability have very low rates of year 12 high school attainment (16%) compared with Indigenous Australians without disability (28%) in the same age range (18–64 years).
- 30% of Indigenous Australians aged 18–64 years with the most severe levels of disability wanted to pursue further study in the 12 months prior to survey and 13% were unable to do so because of caring or family reasons.
- On average 14% of Indigenous women and 9% of Indigenous men have caring responsibilities.
- There are 12,068 Indigenous users of specialist disability services in Australia aged 0–64 years, comprising 5% of all service users. This equates to a service level of about 329 per 1,000 potential population, almost identical to the non-Indigenous service level.
- Case management (as part of community support) and open employment support are the most commonly used service types by Indigenous Commonwealth State/Territory Disability Agreement-funded service users.
- 46% of Indigenous Australians aged 18–64 years with severe or profound core activity limitations report problems accessing service providers.
- Daily smoking is found more commonly among Indigenous Australians with more severe disability (52%) than Indigenous Australians without disability or long-term health conditions (42%) in the 18–64 years age group.

## Introduction

It is well established that Aboriginal and Torres Strait Islander people experience significantly poorer health outcomes than other Australians, with rates of disability (when defined as needing assistance with a core activity) 2.4 times that of non-Indigenous people (AIHW 2009a). This report delves further into this statistic, providing more detailed information on their situations and experiences.

The International Classification of Functioning, Disability and Health (ICF) describes functioning and disability in terms of three key components: body functions and structures, activities and participation. These components are part of a complex interplay of individual health conditions and environmental factors, which together profoundly influence a person's experience of functioning and disability.

This paper focuses on Aboriginal and Torres Strait Islander people with severe or profound core activity limitation (Box 1). Note that the terms 'severe or profound disability' and 'the more severe disability' are sometimes used for brevity.

#### Box 1: Measuring disability

'Severity of disability' is a measure based on the level of limitation a person experiences for any tasks relating to the core activities of self-care, communication and mobility. There are four levels of limitation:

- profound the person always needs help with at least one core activity
- severe the person needs help with at least one of the core activities some of the time
- moderate the person has difficulties with at least one of the core activities but does not need assistance
- mild the person uses aids but does not have difficulties with core activities.

Indigenous people with severe or profound core activity limitations often face considerable difficulties, many of which appear to be shared by all Australians with this severity of disability. This paper addresses how Indigenous Australians with severe or profound disability are faring in terms of the five key areas of economic wellbeing, education, health and wellbeing, services and support, and accessible communities. It explores the experience of Indigenous Australians with disability compared to those without disability as well as all Australians with similar severity of disability. In order to compare rates and aspects across population groups a number of data collections are used in this paper:

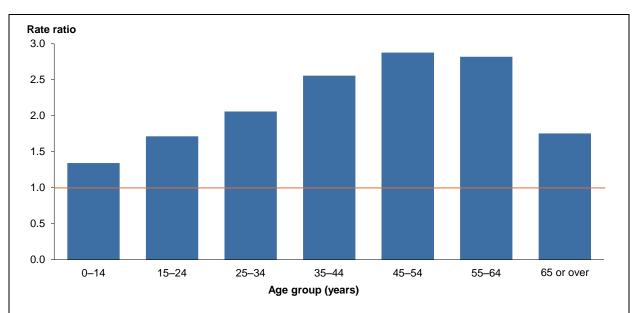
- Census data are used to compare Indigenous and non-Indigenous disability rates.
- Survey data from the ABS 2008 National Aboriginal and Torres Strait Islander Social Survey (NATSISS) are used to compare Indigenous Australians with and without disability and is also compared with ABS 2006 General Social Survey (GSS) data for all Australians.
- Administrative data is used to compare users of disability services.

See Appendix 1 for more detail on the various data sources and their particular limitations.

# Disability in the Australian Indigenous population

Consistent with the experience of indigenous people around the world (Gracey & King 2009), Indigenous Australians have rates of ill-health and disability substantially higher than other Australians. The 2006 Census revealed that Indigenous Australians aged under 65 years were 2.4 times as likely as non-Indigenous Australians of the same age to need assistance with activities of daily living. This figure takes into account differences between the two populations both in terms of age structure and the rate of 'unstated' need for assistance (AIHW 2009a).

Figure 1 shows that the disparity in the rates for Indigenous and non-Indigenous Australians needing assistance with core activities was greatest in the 45-54 and 55-64 year age groups, with Indigenous Australians almost 3 times as likely to require assistance as non-Indigenous Australians. This reflects the pattern of premature ageing seen among the Indigenous population, expressed in a greater chronic disease burden in middle and later life, and shorter life expectancy (Vos et al. 2009).



#### Notes:

- 1. Based on rates standardised to the age- and sex-distribution of the Australian population.
- 2. Excludes people who did not respond to the Census questions about disability.
- 3. A rate ratio greater than 1 means that Indigenous Australians were more likely than non-Indigenous Australians of the same age to need assistance with core activities. Higher rate ratios mean larger differences

Source: AIHW 2009a.

Figure 1: Need for assistance with core activities by Indigenous Australians: rate compared to non-Indigenous Australians, 2006

## **Disability group**

Physical disability is the most common type of disability group among Indigenous Australians with severe or profound core activity limitations, consistent with the experience of Australians generally (AIHW 2009a). Among Indigenous Australians aged 15–64 years with severe or profound disability, 82% experience physical disability. Sight, hearing and speech related disability is the next most common, at 42%, among those with severe or profound core activity limitations (Table 1).

Table 1: Indigenous Australians aged 15-64 years with severe or profound core activity limitations, disability group, 2008

Disability group	Number	Per cent
Sight, hearing, speech	9,167	41.6
Physical	18,061	82.0
Intellectual	6,362	28.9
Psychological	6,196	28.1
Total	22,015	

#### Notes:

Source: AIHW analysis of ABS 2008 National Aboriginal and Torres Strait Islander Social Survey confidentialised unit record file.

<sup>1. 2008</sup> NATSISS excluded special dwellings where higher proportions of people with severe and profound disability may be found.

<sup>2.</sup> The disability types are not mutually exclusive.

## Profile of Indigenous people with disability

## **Economic wellbeing**

Financial circumstances strongly influence the degree to which an individual with disability can participate in society. People with disability tend to have fewer financial resources than those without disability. In particular, those with severe or profound core activity limitations are much more likely to be found in lower income households (AIHW 2009a).

## **Employment**

The level of employment among Indigenous Australians aged 15–64 years with core activity assistance needs was only about one-quarter that of other Indigenous Australians of the same age (13% and 51% respectively). Although employment levels were higher, a similar pattern was evident among non–Indigenous people aged 15–64 years, where 17% of those with a need for assistance were employed, compared with 73% of those without need for assistance (Table 2).

Table 2: Employment status by Indigenous status and need for assistance, aged 15-64 years, 2006

	Need for as	sistance	No need for a	assistance
	Indigenous Australians	Non-Indigenous	Indigenous Australians	Non-Indigenous
Employed	12.9	16.5	51.3	73.2
Unemployed	3.4	2.5	9.4	3.9
Not in the labour force	83.7	81.0	39.3	22.9
Sub-total - not participating in the labour force	87.1	83.5	48.7	26.8
Total number	11,592	285,198	230,723	11,711,602

Source: AIHW analysis of ABS 2006 Census of Population and Housing.

These data suggest that disability strongly influences employment outcomes among Indigenous people, to a degree similar to that experienced by non-Indigenous people with the same severity of disability.

## Household income

With such low employment it is not surprising that there is a much greater reliance on government pensions and allowances among Indigenous Australians with severe or profound disability. Nearly two-thirds (64%) of Indigenous Australians aged 18–64 years with severe or profound core activity limitations relied on government pensions and allowances as their principal source of income — double that of Indigenous Australians without disability or long term health conditions (32%) (Table 3).

The ABS 2006 General Social Survey of all Australians found 56% of those aged 18–64 years, with severe or profound disability, relied on government pensions and allowances as their principal source of income, compared with 10% of those without disability (Table 3).

Table 3: Principal source of income by disability level and Indigenous status, 2006 and 2008

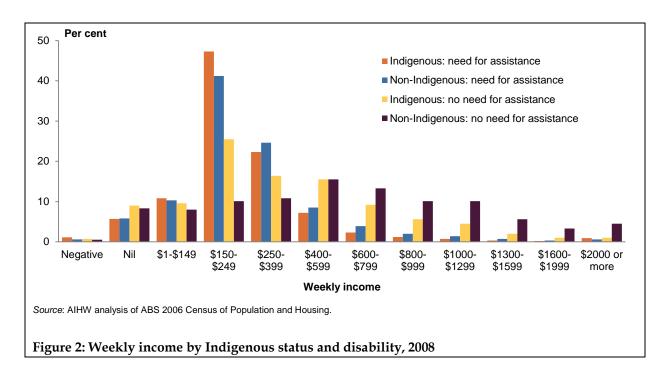
	Severe or prof	ound core activity limitations	No disability o	r long-term health conditions		
	Indigenous Australians	All Australians	Indigenous Australians	All Australians		
Principal source of income	Per cent					
Employee income	20.2	20.2	50.9	66.7		
Government pensions & allowances	64.4	56.3	31.9	9.9		
Other <sup>(a)</sup>	15.4	23.5	17.2	23.4		
Number	20,721	516,487	135,441	8,477,923		

(a) Includes unincorporated business income, CDEP income, investment income, other income and undefined.

Note: 2008 NATSISS and 2006 GSS excluded special dwellings where higher proportions of people with disability may be found and 2006 GSS excluded very remote and sparsely settled areas.

Source: AIHW analysis of ABS 2008 National Aboriginal and Torres Strait Islander Social Survey confidentialised unit record file and ABS 2006 General Social Survey confidentialised unit record file.

These findings are consistent with 2006 Census data indicating that people with disability are clustered at the lower income levels. The income patterns for Indigenous and non-Indigenous Australians with disability are very similar, reinforcing the suggestion that disability strongly influences income (Figure 2).



#### Financial stress

Low household income is often associated with financial stress. This can be measured, for example, by difficulty paying bills (16% of Indigenous Australians with more severe disability, compared to 8% without disability); or the inability to raise \$2,000 in an emergency (57% compared with 44%) (Table 4). While all Australians also experienced financial stress, the proportions were much lower. Less than one-third (29%) of all

Australians with the more severe disability could not raise \$2,000 in an emergency compared with 11% of those without disability (Table 4).

Table 4: Experience of financial stress factors in the previous 12 months, by disability and Indigenous status, ages 18-64 years, 2006 and 2008

_	Severe/prof	ound core activity limitations	No disability or long-term health conditions		
	Indigenous Australians	All Australians	Indigenous Australians	All Australians	
Financial stress factor		nt			
Difficulty paying bills >5 times	16.3	10.2	7.7	4.1	
Could not raise \$2,000 in an emergency	57.3	28.7	44.2	10.6	
Total number	20,722	516,487	135,441	8,477,923	

Note: 2008 NATSISS and 2006 GSS excluded special dwellings where higher proportions of people with disability may be found and 2006 GSS excluded very remote and sparsely settled areas.

Source: AIHW analysis of ABS 2008 National Aboriginal and Torres Strait Islander Social Survey confidentialised unit record file and ABS 2006 General Social Survey confidentialised unit record file.

## Housing

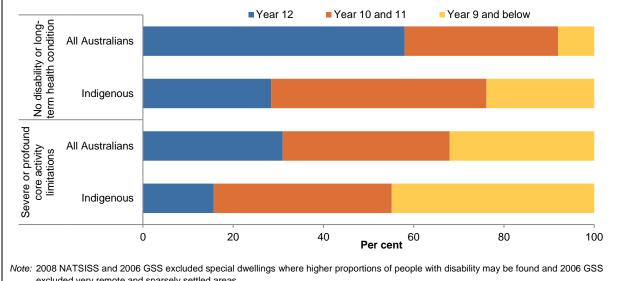
The AIHW (2009a) has previously reported that over 30% of social housing includes a member with a disability. In particular, over 2,500 state owned and managed indigenous housing households include a member with a disability. In addition, the 2003 Survey of Disability, Ageing and Carers (SDAC) (ABS 2004) demonstrated that people with severe or profound core activity limitation are often found in special dwellings, such as residential institutions, hostels, group homes and boarding houses, which are outside the social housing classification.

## **Education**

Education plays a significant role in developing the skills and abilities of people with disability; supporting them in their learning goals, providing a foundation for breaking free from the type of entrenched disadvantage financial hardship causes and fostering their participation in Australian society (AIHW 2008; AIHW 2009a; National People with Disabilities and Carer Council 2009).

As seen in Figure 3, Year 12 attainment rates were much lower among 18–64 year old Indigenous Australians with severe or profound disability (16%) compared with Indigenous Australians without disability (28%). The rates for all Australians are significantly higher and the 2006 GSS showed that 31% of all Australians with more severe disability and 58% of those without disability completed Year 12 (Figure 3).

Of particular note is that an estimated 45% of Indigenous Australians aged 18–64 years with severe or profound disability left school at Year 9 or below, almost double that of other Indigenous Australians (24%). This pattern is even more pronounced among the Australian population generally (Figure 3).



excluded very remote and sparsely settled areas.

Source: AIHW analysis of ABS 2008 National Aboriginal and Torres Strait Islander Social Survey confidentialised unit record file and ABS 2006 General Social Survey confidentialised unit record file.

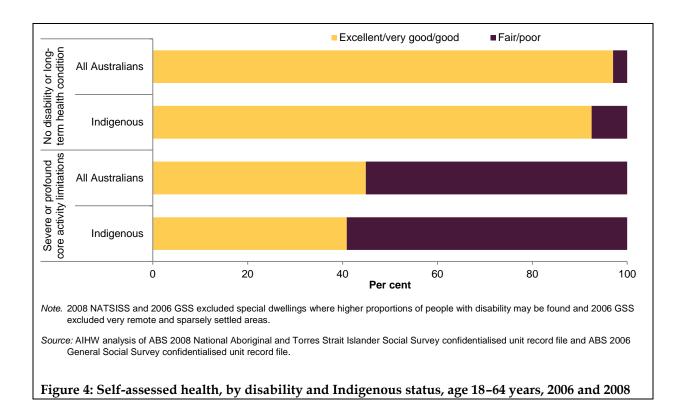
Figure 3: Highest school attainment, by disability and Indigenous status, age 18-64 years, 2006 and 2008

Just under a third (30%) of Indigenous Australians aged 18-64 years with severe or profound core activity limitations had an interest in further study in the 12 months preceding survey. This is slightly higher than Indigenous people without disability in the same age range (27%). The most-often cited reason among Indigenous Australians with severe or profound disability for not studying further was personal caring and other family reasons (Table A1).

## Health and wellbeing

#### Self-assessed health status

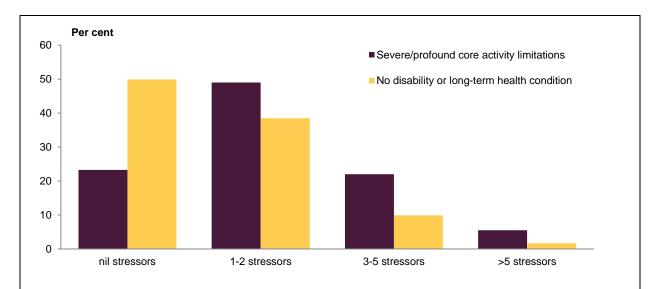
While self-assessed health status is a subjective measure, perceptions of health are important to mental and physical well-being. Moreover, it has been established that self-assessed health status is a good predictor of actual health (AIHW 2010). As Figure 4 reveals, Indigenous Australians with severe or profound core activity limitations are far more likely to assess their health as fair or poor (59%) than Indigenous Australians without disability (8%). This is consistent with the pattern seen among the Australian population generally, where 55% of all people with severe or profound disability assess their health as fair or poor compared with 3% of all people without disability.



Clearly among Indigenous Australians without disability, perceptions of health are more closely aligned with those of Australians without disability than with Indigenous Australians with severe or profound disability.

#### **Stressors**

Stressors have a significant impact on quality of life and over time may influence mental and physical wellbeing. They include stressful life events such as divorce, domestic violence, losing one's job and overcrowding at home. Along with lower perceptions of health, Indigenous Australians with severe or profound core activity limitations experience such events at greater rates than other Indigenous Australians (Figure 5). This is consistent with findings from the 2007–08 National Health Survey (NHS) that among all Australians, people with disability are more likely than those without disability to experience stressful life events (AIHW 2010).



Note: 2008 NATSISS included remote, very remote and indigenous communities but excluded special dwellings where higher proportions of people with severe and profound disability may be found.

Source: AIHW analysis of ABS 2008 National Aboriginal and Torres Strait Islander Social Survey confidentialised unit record file.

Figure 5: Number of stressors experienced in the previous 12 months, Indigenous Australians, 2008

#### **Health risk factors**

It has been reported elsewhere that Indigenous Australians are more likely than non-Indigenous Australians to be smokers, and that among Australians generally, people with a disability are more likely than those without disability to smoke (AIHW 2010). Consistent with this evidence, the 2008 NATSISS shows that Indigenous Australians aged 15-64 years with severe or profound core activity limitations have higher rates of daily smoking (52%) compared with Indigenous Australians without disability (42%) (Table 3). The latest ABS figures suggest that Indigenous Australians aged 15 years and over were twice as likely as non-Indigenous people to be current daily smokers (ABS 2010b).

Rates of risky alcohol consumption and substance use have also been found to be slightly higher among Australians aged 15–64 years who have severe or profound disability, (AIHW 2010), however this pattern is not seen among Indigenous Australians (Table 5).

Table 5: Indigenous Australians aged 15-64 years, health risk factors by disability status, 2008

	Severe/profoun	d core activity limitations	No disability or long-term health conditions		
Factor	Number	Per cent	Number	Per cent	
Smoker daily	11,380	52	67,989	42	
Medium to high risk alcohol consumption	3,134	14	26,893	17	
Substance use in last 12 months	4,665	21	32,181	20	
Total	22,015	100	160,990	100	

#### Notes:

Source: AIHW analysis of ABS 2008 National Aboriginal and Torres Strait Islander Social Survey confidentialised unit record file.

 <sup>2008</sup> NATSISS included remote, very remote and indigenous communities but excluded special dwellings where higher proportions of people with severe and profound disability may be found.

<sup>2.</sup> Totals may not be the sum of components as individuals may be exposed to more than one risk factor during the period.

## Services and support

Individuals with disability, both Indigenous and non-Indigenous, have general needs which can be met by accessing mainstream services. However, people with severe or profound disability have unique needs that can be more appropriately met by specialist disability services. The purpose of such services is to support and enhance the participation of individuals with disability in their communities, in ways that are most effective for the individual. In particular, the purpose of specialist disability services funded under the National Disability Agreement (NDA) (formerly the Commonwealth State/Territory Disability Agreement (CSTDA)) is that:

People with disability and their carers have an enhanced quality of life and participate as valued members of the community.

Despite the higher prevalence of disability among Indigenous Australians, the rate of specialist service use among Indigenous Australians with disability is similar to that for non-Indigenous people (329 Indigenous service users per 1,000 potential population, compared with 330 non-Indigenous service users per 1,000 potential population, see 'Access' on p12).

### Box 2: Disability support service data terminology

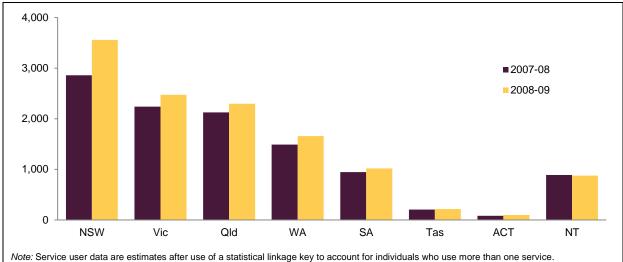
As this report presents data collected under both the CSTDA and the NDA, the following terminology will be used throughout:

- CSTDA NMDS refers to the *National Minimum Data Set* throughout the reporting period. The NMDS was renamed the *Disability Services National Minimum Data Set* (DS NMDS) from 1 July 2009; that is, after this reporting period.
- CSTDA/NDA refers to both agreements under which the data was collected.
- *Disability support services* refers to services provided under both CSTDA and NDA.

## **Support services**

In 2008-09 there were 12,068 Indigenous people aged 0-64 who used specialist disability services funded under the NDA. However, this figure may be understated because of the high number of service users (14,000) where Indigenous status is not stated. The number of service users increased from 10,633 to 12,068 between 2007-08 and 2008-09, with increases in most states and territories (Figure 6). Over this period, the rates of Indigenous status recorded as 'not stated/not collected' have remained stable at around 5%.

The proportions of disability groups among Indigenous and non-Indigenous service users aged 0–64 years are similar. Intellectual disability is the most common primary disability among service users, with 34% of Indigenous service users and 31% of non-Indigenous service users reporting this as their primary disability (Table A2).



Source: AIHW analysis of CSTDA NMDS 2007-08 and 2008-09.

Figure 6: CSTDA-funded services, Indigenous service users 0-64 years, by state/territory, 2007-08 to 2008-09

## Service types used

Community support is the most commonly used service type among Indigenous people, followed by employment support (Figure 7).

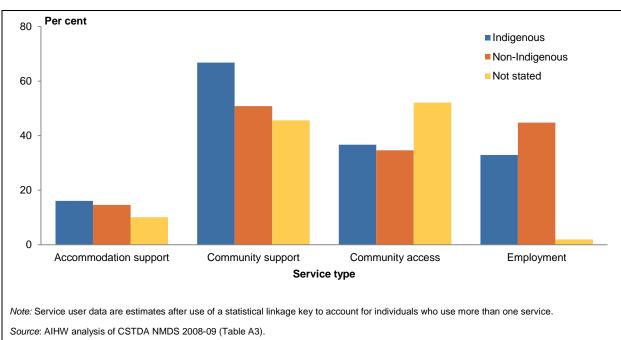


Figure 7: Users of CSTDA-funded services by type and Indigenous status, aged 0-64 years, 2008-09

The *community support* broad service type includes individual therapy, early childhood intervention, case management, behaviour management and counselling. Case management was the main service used at a rate of 31% (Table A3). Case management is used to assist people to access services, to coordinate care where multiple services are in use and in care planning.

Accommodation support services in the form of institutions, hostels and group homes were provided to a similar proportion of both Indigenous and non-Indigenous service users (6% versus 7%) (Table A3). Indigenous service users were slightly more likely than non-Indigenous service users to receive in-home accommodation support (10% and 8% respectively).

*Employment* services include open employment services which assist people with disability to find or retain employment in the open job market. Over one-quarter (27%) of Indigenous service users received open employment services compared with 36% of non-Indigenous users.

## **Access**

The NDA incorporated a series of performance indicators, results against which are published annually by the COAG Reform Council. Performance Benchmark (e) seeks:

An increase in the proportion of Indigenous people with disability receiving disability services (COAG, 2008: 7).

Further analysis of service data against potential population estimates reveals some state/territory-based variations, although caution should be exercised in interpreting these data as service models vary across jurisdictions and may affect comparability (see Appendix 1).

Data for 2007–08 and 2008–09 suggest that while New South Wales and Queensland have the largest populations of Indigenous people with severe or profound core activity limitations, according to the potential population estimates, their rates of service provision to Indigenous service users, per 1,000 population, fall somewhat below the Australian average. Indigenous under identification may have influenced this rate as the number of service users with Indigenous status recorded as 'not stated/not collected' is over 2,000 in NSW and almost 1,500 in Queensland.

A small increase in the proportion of Indigenous people with disability receiving services occurred in every state and territory of Australia, except the Northern Territory, in the previous two years.

The rate of service use for both Indigenous and non-Indigenous Australians with disability is highest for the 15–24 year age group (Table A5).

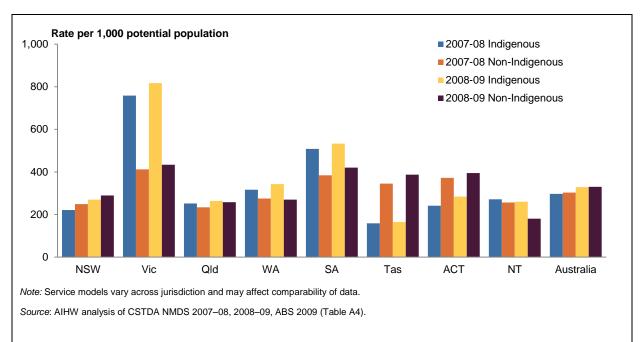


Figure 8: Users of CSTDA-funded services per 1,000 potential population, by Indigenous status and state/territory, aged 0-64 years, 2007-08 and 2008-09

## Service provider access difficulties

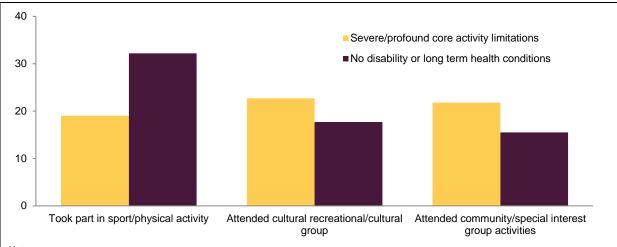
The 2008 NATSISS found that nearly half of Indigenous Australians with severe or profound core activity limitations identified having problems accessing service providers. These problems are not limited to specialist disability service providers but include doctors, hospitals, dentists, as well as legal, employment and other services (Table A9. These rates are similar to those of Australians generally, with almost half of people in Australia with severe or profound disability experiencing problems accessing services (Table A10).

## Participation and accessible communities

Appropriate access to support and assistance for people with a disability is a pre-condition both to acquiring services and to participation in society. Levels of participation may be gauged by looking at involvement in the community and barriers or facilitators, such as transport or having an informal carer can also be identified.

## Involvement in the community

Among the Indigenous population, apart from sporting or physical activity, disability status did not appear to be related to participation in community activities. According to the 2008 NATSISS, Indigenous Australians with the most severe disability enjoy higher rates of participation in cultural or recreational groups, and attending community or special interest groups for example, than Indigenous Australians without disability (Figure 9).



- 2008 NATSISS included remote, very remote and indigenous communities but excluded special dwellings where higher proportions of people with severe and profound disability may be found.
- 2008 NATSISS and 2006 GSS data are not directly comparable in this area as different categorisations of sport, recreational and cultural activity were used in each.

Source: AIHW analysis of ABS 2008 National Aboriginal and Torres Strait Islander Social Survey confidentialised unit record file.

Figure 9: Participation in physical, social and recreational activities by disability status, Indigenous Australians aged 18-64 years, 2006 and 2008

According to the 2006 GSS, a considerable difference in participation in sporting and recreational activities exists between all Australians with and without disability, with very much lower rates among those with more severe disability (45% compared with 69%). It is difficult to achieve a robust comparison of Indigenous and non-Indigenous people with disability in this area, as the relevant datasets do not provide directly comparable data.

## **Transport**

An essential facilitator of community participation and involvement is adequate transport to events and activities. As Table 4 shows, Indigenous people with severe or profound core activity limitations experience some degree of difficulty with transport at rates roughly double that of Indigenous people without disability (46% and 21% respectively).

The 2006 GSS indicates that Australians generally with severe or profound disability do experience difficulties with transport at rates well beyond those of people without disability (41% and 12% respectively; Table 6).

The Aboriginal Disability Network's (ADN 2007) consultations among Aboriginal people with disability in NSW found that many communities visited had little or no access to public transport. Participants identified lack of transport as a major barrier to inclusion in 'mainstream' and their own community activities. The consequences of lack of public transport infrastructure included: people confined to homes, no access to employment, education etc, poor health outcomes (p.19).

Table 6: Indigenous Australians aged 18-64 years, transport difficulties, by disability, 2008

	Severe or profound core activity limitations		No disability o	or long-term health conditions		
	Indigenous	All Australians	Indigenous	All Australians		
		Per cent	1			
Can easily get to places as needed	54 59 79					
Sometimes have difficulty getting to places as needed	22	23	12	10		
Often have difficulty getting to places as needed	21	13	8	1.8		
Cannot get to places needed, housebound, never go out	3	5	0	0.4		
Total per cent having difficulty	46	41	21	12		
Total number	20,722	516,487	135,441 8,477,923			

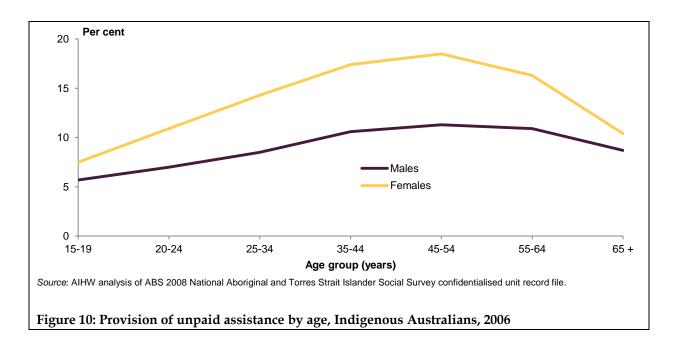
Note: The 2008 NATSISS and 2006 GSS excluded special dwellings where higher proportions of people with disability may be found and the 2006 GSS excluded very remote and sparsely settled areas.

Source: AIHW analysis of ABS 2008 National Aboriginal and Torres Strait Islander Social Survey confidentialised unit record file and ABS 2006 General Social Survey confidentialised unit record file.

## Indigenous carers

In 2009 the House of Representatives Standing Committee on Family, Housing and Youth Affairs released a report on the inquiry into better support for carers (HRSCFCHY 2009). The Committee made particular note of the absence of information available related to Indigenous carers and called for research into the profiles and specific needs of Indigenous carers.

Census 2006 data reveal that, on average, 14% of Indigenous women and 9% of Indigenous men had caring responsibilities. The peak in provision of unpaid assistance (20%) occurred among women aged between 45 and 54 years (Figure 10).



Among CSTDA-funded disability service users, 49% of Indigenous Australians had a carer, compared with 41% of non-Indigenous people. Among both Indigenous and non-Indigenous Australians, mothers were most frequently the primary carer (29% Indigenous service users and 28% non-Indigenous service users; Table A7).

The House of Representatives inquiry into carers (HRSCFCHY 2009:165) observed that many Indigenous carers 'see caring as a natural extension of family duty also [reducing] the likelihood of their seeking any assistance'.

## **Appendix 1: Disability data issues**

## **Current dataset limitations**

#### Commonwealth State/Territory Disability Agreement - National Minimum Data Set

The CSTDA NMDS provides data only on people receiving services and hence these data cannot address either the characteristics or the service and support needs of people not receiving services.

In the 2008–09 CSTDA NMDS a change was made to the processes used to link data using the statistical linkage key to address concerns raised by data providers. To allow comparison with previous period data the 2007–08 data set was recreated on the same basis. These changes resulted in a revised number of Indigenous service users to that reported in the 2007–08 Annual report (AIHW 2009b, AIHW forthcoming).

#### ABS data

Population data may be collected by complete enumeration (census) or survey. Data related to Indigenous Australians with disability are found in a number of ABS collections, each of which experiences certain limitations.

#### Census of Population and Housing

A measure of disability was developed for the 2006 Census, conceptually similar to the Survey of Disability, Ageing and Carers (SDAC) but telescoped into four questions, for practical administration within a national census. These questions identified those people with a 'need for assistance' in one of the core activities of self-care, communication or mobility, similar to those identified as having severe or profound core activity limitations in SDAC.

However, a census requires the individual household to complete a form. Ascertainment of Indigenous status tends to be lower in self-report forms (ABS 2007; SCRGSP 2009) and the non-response rate on the 'need for assistance' among those who do identify as Indigenous was 7% in 2006 compared with 2% for non-Indigenous people (ABS & AIHW 2008). Hence under-representation of Indigenous people with disability may have occurred.

Surveys: 2008 NATSISS, 2006 GSS and 2003 SDAC

The ABS conducts a number of surveys that provide data on disability at the population level. The most comprehensive is the Survey of Disability, Ageing and Carers (ABS 2010a), which collects information about a wide range of impairments, activity limitations and participation restrictions, and their effects on the everyday lives of people with disability, older people and their carers. This survey has the advantage of covering special dwellings, such as cared accommodation, as well as private dwellings. The most recent data available are for 2003, but it did not collect Indigenous status. While data collected in 2009 did collect Indigenous status its findings were not released in time for inclusion in this material. Also, the SDAC does not collect data in very remote areas and is therefore limited in comparisons that can be undertaken between Indigenous and non-Indigenous people (ABS 2010a).

A short Disability Module, based on SDAC, is used within other ABS surveys, such as the NATSISS and the GSS. It identifies those with disability and the 'severity of disability' experienced, as described above. However these surveys do not include people who live in special dwellings, such as institutions, group homes and hostels, where people with the

more severe disability are often found (ABS 2004). The ABS (2010a) has recently produced a paper on sources of disability data and their uses. It cautions users of disability data not to use surveys employing the short disability module to update prevalence estimates in the period between SDACs.

## Specific data collection issues

There are also limitations on the degree to which survey data that is collected on Indigenous Australians with disability is comparable to data collected on either non-Indigenous people or all people with disability. Apart from differences in the actual data items collected between different groups there are a number of issues specific to Indigenous Australians with disability.

#### These include:

- identification of relevant participants for survey
- culturally appropriate content of the survey instrument
- culturally appropriate administration of the survey instrument.

The first issue–identification of who should participate–is confounded in various ways. Indigenous perceptions of disability and caring may be different to the assumptions upon which statistical surveys used in this publication are based. As an example, many Indigenous languages do not contain words for 'disability' or 'caring' and hence potential participants may well self-exclude because the concepts are alien and not consistent with Indigenous world views (ADN 2007; Disability WA 2008; Helps & Moller 2007:44–46; NSW Ombudsman 2010; Parliament of the Commonwealth of Australia 2009; Senior 2000).

The second issue-culturally appropriate content-concerns concepts such as 'disability', 'caring', and 'need for assistance'. Surveys tend to assume a shared perception of these terms, however, this is not always the case. Hence, efforts to quantify these areas, unless carefully developed in the context of Indigenous understandings and experience, may be difficult.

## **Appendix 2: Additional tables**

Table A1: Indigenous Australians aged 18-64 years, reasons for not studying further in the previous 12 months although wanted to, by disability, 2008 (per cent)

	Per cent of people with severe or profound core activity limitations	Per cent of people with no disability or long-term health condition
Too much work or other work reason or no time	7.0	8.6
Personal caring or other family reasons	12.7	8.5
Course related reasons	2.6	3.2
Too expensive or financial reasons	5.3	5.0
Other	1.8	2.1
Total per cent wanting to study further	29.5	27.2
Total number	20,722	135,441

Note: 2008 NATSISS included remote, very remote and indigenous communities but excluded special dwellings where higher proportions of people with severe and profound disability may be found.

Source: AIHW analysis of ABS 2008 National Aboriginal and Torres Strait Islander Social Survey confidentialised unit record file.

Table A2: CSTDA service users aged 0-64 years, primary disability, by Indigenous status, 2008-09

			Se	rvice users			
_	Indigeno	us	Non-Indige	Non-Indigenous		tus not	
Primary disability type	number	%	number	%	number	%	Total (number)
Intellectual	4061	33.7	72102	30.7	1328	9.7	77491
Specific learning	533	4.4	8944	3.8	155	1.1	9632
Autism	541	4.5	16145	6.9	311	2.3	16997
Physical	2171	18.0	39495	16.8	821	6.0	42487
ABI	670	5.6	9185	3.9	242	1.8	10097
Neurological	432	3.6	10661	4.5	342	2.5	11435
Deaf/blind	27	0.2	453	0.2	21	0.2	501
Vision	234	1.9	5961	2.5	1066	7.8	7261
Hearing	228	1.9	4682	2.0	266	1.9	5176
Speech	149	1.2	2815	1.2	97	0.7	3061
Psychiatric	1918	15.9	43544	18.6	2379	17.4	47841
Developmental delay Not stated/not	535	4.4	8124	3.5	193	1.4	8852
collected	569	4.7	12453	5.3	6473	47.3	19495
Total	12,068	100.0	234,564	100.0	13,694	100.0	260,326

#### Notes

Source: AIHW analysis of CSTDA NMDS 2008-09.

<sup>1.</sup> Service user data are estimates after use of a statistical linkage key to account for individuals who use more than one service.

In tables the term 'Indigenous' refers to service users who identified as Aboriginal and/or Torres Strait Islander people. 'Non-Indigenous' refers to service users who reported not being of Aboriginal or Torres Strait Islander background.

Table A3: Users of disability support services aged 0-64 years, service type use, by Indigenous status, 2008-09

Service type	Indigenous users as a percentage of all service type users	Usage rate among Indigenous service users (%)	Usage rate among non- Indigenous users (%)	Usage rates among not stated users (%)	Total users for service type
Accommodation support					
Residential institutions, hostels and group homes	4.0		0.0	0.4	40.474
• •	4.2	5.7	6.6	2.1	16,474
Personal care and in-home support	5.8	9.5	7.5	7.8	19,756
Alternative family placement and	5.0	9.5	7.5	7.0	19,730
other accommodation support	8.9	0.9	0.5	0.2	1,207
Community support	0.9	0.9	0.5	0.2	1,207
Therapy support	5.1	10.2	9.1	12.1	24,248
Early childhood intervention	4.5	8.6	8.9	6.4	22,908
Regional resource teams	6.5	10.1	7.3	3.2	18,665
Case management	6.9	31.1	20.2	21.6	54,073
Behaviour/specialist intervention, counselling and other community support	6.0	6.8	5.3	2.3	13,521
Community access					
Learning/life skills development	4.5	12.8	13.0	15.5	34,172
Recreation/holiday programs and other community access	2.8	4.5	6.7	23.2	19,540
Respite					
Centre-based	6.0	6.8	5.3	3.8	13,690
Flexible	6.2	9.6	7.0	7.2	18,658
Own home, host family and other	5.3	3.0	2.6	2.4	6,808
Employment	0.0	3.0	2.0	2.4	2,000
Open employment	3.8	27.2	35.8		87,230
Supported and targeted	0.0	27.2	23.0	•	37,200
employment	3.1	5.7	9.0	1.9	22,079
Total users	4.6	12,068	234,564	13,694	260,326

Source: AIHW analysis of CSTDA NMDS 2008-09.

<sup>1.</sup> Service user data are estimates after use of a statistical linkage key to account for individuals who use more than one service

<sup>2.</sup> In tables the term "Indigenous" refers to service users who identified as Aboriginal or Torres Strait Islander people. Non-Indigenous refers to service users who reported not being of Aboriginal or Torres Strait Islander background.

Table A4: Users of CSTDA-funded services aged 0-64 years per 1,000 potential population, by Indigenous status and state/territory, 2007-08 and 2008-09

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
Service users					2007-08				
Indigenous	2,860	2,240	2,125	1,491	945	205	82	890	10,633
Non-Indigenous	56,171	72,951	32,616	19,175	20,391	5,583	4,336	1,153	211,394
Not stated/not collected	1,528	8,152	996	137	1,038	153	89	111	12,202
Total	60,559	83,343	35,737	20,803	22,374	5,941	4,507	2,154	234,229
Potential population (0-64 y	years)								
Indigenous	12,912	2,953	8,434	4,703	1,860	1,293	340	3,277	35,772
Non-Indigenous	225,809	176,972	139,202	69,636	53,026	16,160	11,642	4,500	696,946
Service users per 1,000 pot	ential population	on (0–64 ye	ears)						
Indigenous	221.5	758.6	252.0	317.0	508.1	158.5	241.2	271.6	297.2
Non-Indigenous	248.8	412.2	234.3	275.4	384.5	345.5	372.4	256.2	303.3
					2008-09				
Service users									
Indigenous	3,558	2,474	2,297	1,657	1,020	217	100	876	12,068
Non-Indigenous	66,422	78,356	36,858	19,344	22,532	6,318	4,662	834	234564
Not stated/not collected	2,015	8,857	1,414	137	832	166	139	136	13,694
Total	71,995	89,687	40,569	21,138	24,384	6,701	4,901	1,846	260,326
Potential population (0-64 y	/ears)								
Indigenous	13,181	3,026	8,702	4,831	1,912	1,320	352	3,361	36,684
Non-Indigenous	229,314	180,519	142,803	71,699	53,635	16,320	11,808	4,621	710,720
Service users per 1,000 pot	ential population	on (0–64 ye	ears)						
Indigenous	269.9	817.7	264.0	343.0	533.6	164.5	284.1	260.6	329.0
Non-Indigenous	289.7	434.1	258.1	269.8	420.1	387.1	394.8	180.5	330.0

Source: AIHW analysis of CSTDA NMDS 2007-08, 2008-09, ABS 2009.

Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Totals for Australia may not be the sum of components because individuals may have accessed services in more than one state or territory during the 12-month period.

<sup>2.</sup> In tables the term 'Indigenous' refers to service users who identified as Aboriginal and/or Torres Strait Islander people. 'Non-Indigenous' refers to service users who reported not being of Aboriginal or Torres Strait Islander background.

<sup>3.</sup> Indigenous potential population estimates are experimental.

<sup>4.</sup> Indigenous potential population estimates are calculated by applying Indigenous/non-Indigenous sex and 10-year age group rates of severe/profound disability in each state/territory to Indigenous and non-Indigenous population data in each state/territory by sex and 10-year age group for people aged 0-64.

Indigenous population figures are based on revised ABS Series B projections of the Indigenous population by state/territory for June 2008 (ABS 2009).

TableA5: CSTDA service use rates, by age and Indigenous status, 2008

		Indigenous A	Australians	Non-	Non-Indigenous Australians			
Age range	Severe/ profound core activity limitation	Service users	Service rate (%)	Severe/ profound core activity limitation	Service users	Service rate (%)	Not stated, not collected	
0-4	2,567	882	34.4	37,952	16,205	42.7	884	
5-14	8,590	2,122	24.7	127,066	31,073	24.5	2,741	
15-24	4,010	2,999	74.8	62,512	42,830	68.5	2,644	
25-34	3,452	1,819	52.7	65,453	37,642	57.5	2,113	
35-44	5,569	1,914	34.4	97,553	39,993	41.0	1,944	
45-54	6,525	1,549	23.7	136,896	40,484	29.6	1,957	
55-64	5,971	783	13.1	184,625	26,337	14.3	1,411	
Subtotal (0-49)	27,396	10,601	38.7	454,020	189,152	41.7	11,445	
Total (0-64)	36,684	12,068	32.9	712,057	234,564	32.9	13,694	

- In tables the term 'Indigenous' refers to service users who identified as Aboriginal and/or Torres Strait Islander people. 'Non-Indigenous' refers to service users who reported not being of Aboriginal or Torres Strait Islander background.
- 2. Indigenous potential population estimates are experimental.
- Indigenous potential population estimates are calculated by applying Indigenous/non-Indigenous sex and 10-year age group rates of severe/profound disability in each state/territory from SDAC 2003 to Indigenous and non-Indigenous population projection data for 2008 in each state/territory by sex and 10-year age group for people aged 0-64.
- Indigenous population figures are based on ABS Series B projections of the Indigenous population by state/territory for June 2008 (ABS 2009).

Source: AIHW analysis of CSTDA NMDS 2008-09 and revised ABS Series B projections of the Indigenous population by state/territory for June 2008 (ABS 2009).

Table A6: Indigenous Australians provision of unpaid assistance by age, 2006

	Provided unpaid assistance	No unpaid assistance	Not stated	Total	Provided unpaid assistance (excluding not stated)
			Males		
15-19 years	5.7	76.4	17.9	100.0	7.0
20-24 years	7.0	77.5	15.5	100.0	8.3
25-34 years	8.5	75.0	16.5	100.0	10.2
35-44 years	10.6	75.0	14.4	100.0	12.4
45-54 years	11.3	76.7	12.1	100.0	12.8
55-64 years	10.9	77.2	11.9	100.0	12.4
65 years or over	8.7	70.7	20.6	100.0	10.9
Total per cent	8.8	75.8	15.4	100.0	10.4
Total number	12,003	103,603	21,087	136,693	12,003
			Females		
15-19 years	7.5	76.9	15.5	100.0	8.9
20-24 years	10.9	79.9	9.2	100.0	12.0
25-34 years	14.3	76.4	9.3	100.0	15.8
35-44 years	17.4	73.5	9.1	100.0	19.1
45-54 years	18.5	72.3	9.2	100.0	20.4
55-64 years	16.3	71.5	12.2	100.0	18.6
65 years or over	10.4	69.1	20.5	100.0	13.1
Total	14.0	74.9	11.1	100.0	15.7
Total number	20,578	110,289	16,354	147,221	20,578
			Total		
15-19 years	6.6	76.7	16.7	100.0	7.9
20-24 years	9.0	78.7	12.3	100.0	10.2
25-34 years	11.5	75.7	12.8	100.0	13.2
35-44 years	14.2	74.2	11.6	100.0	16.1
45-54 years	15.1	74.4	10.6	100.0	16.8
55-64 years	13.8	74.2	12.0	100.0	15.7
65 years or over	9.7	69.8	20.6	100.0	12.2
Total	11.5	75.3	13.2	100.0	13.2
Total number	32,581	213,892	37,441	283,914	32,581

Source: AIHW analysis of ABS 2006 Census of Population and Housing.

Table A7: CSTDA service users aged 0-64 years, existence of carer by Indigenous status, 2008-09

Carer relationship	% of Indigenous service users	% of non-Indigenous service users	% of service users with not stated Indigenous status
Wife/female partner	1.4	1.3	0.6
Husband male partner	1.2	1.3	0.7
Mother	29.3	28.1	11.0
Father	2.5	2.3	0.7
Daughter	0.4	0.5	0.2
Son	0.2	0.1	0.0
Daughter-in-law	0.0	0.0	0.0
Son-in-law	0.0	0.0	0.0
Other female relative	6.8	2.5	3.2
Other male relative	1.3	0.4	0.1
Friend/neighbour - female	1.3	0.5	0.2
Friend/neighbour - male	0.2	0.1	0.1
Other	0.0	0.0	0.1
Not stated	5.0	3.6	6.6
No carer	50.5	59.2	76.6
Total service users	12,068	234,564	13,694

Source: AIHW analysis of CSTDA NMDS 2008-09.

Table A8: Need for Assistance compared with Severe/Profound Core Activity Limitation, by age, 2006 and 2008.

	Needs assistance with core activities (Census 2006 <sup>1.</sup> )			
Age group (years)	Indigenous	Non-Indigenous	Indigenous Australians (NATSISS 2008)	All Australians (GSS 2006)
0-4	620	10,467	not collected	not collected
5-14	3,025	49,467	not collected	not collected
15-24	4,133	68,096	5218	15-17 not collected
18-24			3925	39388
25-34	1,522	31,911	3904	62056
35-44	2,533	51,110	4223	114503
45-54	3,116	74,377	4676	112025
55-64	2,991	105,588	3994	188515
Sub total 18-64			20722	516487
Total	15,705	356,651	22015	516487

#### Notes

Source: AIHW analysis ABS Census 2006, ABS 2008 National Aboriginal and Torres Strait Islander Social Survey confidentialised unit record file and ABS 2006 General Social Survey confidentialised unit record file.

<sup>1.</sup> Service user data are estimates after use of a statistical linkage key to account for individuals who use more than one service.

In tables the term 'Indigenous' refers to service users who identified as Aboriginal and/or Torres Strait Islander people. 'Non-Indigenous' refers to service users who reported not being of Aboriginal or Torres Strait Islander background.

<sup>1.</sup> Self-reported.

<sup>2.</sup> Survey administered by interviewer. NATSISS 2008 did not collect disability status 0-14 years, GSS 2006 reports 18 years onward.

Table A9: Indigenous Australians aged 18-64 years, problems accessing service providers, by Indigenous status and disability, 2008

	Per cent of people with severe or profound core activity limitations	Per cent of people with no disability or long-term health condition
Had problems	46	27
Did not have problems	54	73
Total number	20,722	135,441

Note: 2008 NATSISS included remote, very remote and indigenous communities but excluded special dwellings where higher proportions of people with severe and profound disability may be found.

Source: AIHW analysis of ABS 2008 National Aboriginal and Torres Strait Islander Social Survey confidentialised unit record file.

Table A10: All Australians aged 18-64 years, problems accessing service providers, by Indigenous status and disability, 2006

	Per cent of people with severe or profound core activity limitations	Per cent of people with no disability or long-term health condition
Had problems	49	22
Did not have problems	51	78
Total number	516,487	8,477,923

Note: 2006 GSS excluded very remote and sparsely settled areas and excluded special dwellings where higher proportions of people with severe or profound disability may be found.

Source: AIHW analysis of ABS 2006 General Social Survey confidentialised unit record file.

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