

4. Current dataset gaps and limitations

As has been seen in analysis thus far, a range of different data sets have had to be drawn upon to try to identify the level and incidence of disability amongst Indigenous people, and their level of access to support services. In discussion a number of weaknesses have been identified in the data. These are considered in more detail in this chapter.

There are a number of gaps and limitations in current data collections on disability including:

- under-identification of Indigenous Australians in administrative data and population surveys
- gaps in coverage in survey data e.g. age groups, remoteness status
- 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 data items collected between various groups, there are a number of issues specific to Indigenous Australians with disability. These include problems with the cultural appropriateness of the survey instrument content, whether the data that are being collected accurately measure the concept of disability, and culturally appropriate administration of the survey instrument. Indigenous-specific surveys such as the NATSISS are less prone than mainstream surveys and collections to such complexities as they usually involve consultations with Indigenous communities and pilot testing of questions with Indigenous persons to ensure they are culturally appropriate.

A further challenge in estimating the extent and nature of disability in the Indigenous population is that, as mentioned above, self-reported measures of disability are likely to underestimate the extent of the Indigenous population affected by disability. According to the FPDN submission to the Productivity Commission (FPDN 2011: 3), there is a 'reluctance of Aboriginal and Torres Strait Islander people with disabilities to identify as people with disability'.

Historically much of the focus on Aboriginal and Torres Strait Islander people with disability has been from a health perspective. Whilst this is essential, it fails to recognise the social aspects of Aboriginal and Torres Strait Islander disability. Furthermore, the impact of colonisation and the resultant dispossession of land

have had an impact on the lives of many Indigenous people with disability, and this is very difficult to measure as part of a survey instrument. The reasons many Indigenous people may not identify as having a disability include:

- not wishing to take on another negative label when Indigenous Australians already experience discrimination based on their Aboriginality
- no comparable word to disability existing in some traditional Aboriginal languages, suggesting that disability may have been accepted as part of the human experience
- disability being viewed as a consequence of having ‘married the wrong way’ in some communities that continue to practice a more traditional lifestyle: those with disability and their family members may experience stigma related to negative social conceptions of disability, and
- a medical model of disability, often focusing heavily on primary health interventions, which has had a profoundly negative impact on the lives of many Aboriginal and Torres Strait Islander people with disability. In particular, the model does not address the whole of life needs of Aboriginal and Torres Strait Islander people with disability.

These issues have been raised earlier in this volume. However, it is worth reiterating that these factors also have an effect on data collections. Surveys tend to assume a shared perception of concepts such as ‘disability’, ‘caring’, and ‘need for assistance’. Indigenous perceptions of these concepts may be different to the assumptions upon which statistical surveys are based (Aboriginal Disability Network New South Wales 2007; Helps and Moller 2007: 44–6; NSW Ombudsman 2010; House of Representatives Standing Committee on Family, Housing and Youth Affairs 2009; Senior 2000; Stopher and D’Antoine 2008). Unless carefully developed in the context of Indigenous understandings and experience, efforts to measure and quantify disability among the Aboriginal and Torres Strait Islander population is difficult.

Census and survey data on disability prevalence

Census of Population and Housing

The Census of Population and Housing is conducted by the ABS at five-yearly intervals, with 2011 being the most recent. As noted above, the 2011 Census data became available after the analysis for this report was completed, and while some limited 2011 Census data has been included, the majority of the census data reported here is from the 2006 Census.

A measure of disability was developed for the 2006 Census, conceptually similar to 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, the census requires a representative of the individual household to complete a form. Ascertainment of Indigenous status tends to be lower in self-report forms (ABS 2007; Steering Committee for the Review of Government Service Provision (SCRGSP) 2009) and the non-response rate on the 'need for assistance' questions among those who do identify as Indigenous was 7 per cent in 2006, compared with 2 per cent for non-Indigenous people (ABS and AIHW 2008). Hence, under-representation of Indigenous people with disability may have occurred. The census form may be completed by one household member on behalf of others. Incorrect answers can be introduced to the census form if the respondent does not understand the question or does not know the correct information about other household members.

Survey of Disability and Carers

The SDAC is the most comprehensive survey conducted by the ABS that provides data on disability at the population level. It 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 non-private and private dwellings. The most recent data available are for 2009, which for the first time collected information on Indigenous status, although the sample size was too small for any findings for Indigenous Australians to be released publicly. 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).

National Aboriginal and Torres Strait Islander Social Survey

The 2008 NATSISS collected information by personal interview from 13 300 Indigenous Australians across all States and Territories of Australia, including those living in remote areas. The sample covered persons aged 15 years and over who are usual residents in selected private dwellings. The NATSISS is conducted every six years, with the next survey in the field at the time of publication.

The NATSISS includes a short Disability Module, based on the SDAC. It identifies those with disability and the 'severity of disability' experience. However, it does not include people who live in special dwellings, such as institutions, group homes and hostels, where people with more severe disability are often located.

The 2008 NATSISS has a relatively large level of undercoverage when compared to other ABS surveys. That is, a large proportion of the Indigenous population are missed in selecting the sample. There was also an increase in undercoverage compared to previous ABS Indigenous surveys. For example, the estimated undercoverage in the 2004–05 NATSIHS was 42 per cent. The overall undercoverage rate for the 2008 NATSISS is approximately 53 per cent of the in-scope population at the national level. This rate varies across the States and Territories (ABS 2010b). Further information on NATSISS data quality issues can be found in the 2008 NATSISS *User's Guide* (ABS 2010b).

Administrative data on disability services

Disability Services National Minimum Data Set

The DS NMDS (formerly Commonwealth State/Territory Disability Agreement NMDS as described in Chapter 3) provides data only on people receiving services and hence these data can address neither the characteristics, nor the service and support needs of people not receiving services.

The collection does not include all disability support services in Australia: it includes only those where funding has been provided for the specified period by a government organisation operating under the NDA. The scope of services included in the DS NMDS therefore varies in terms of programs that receive funding across jurisdictions. For example, in 2009–10 in Victoria and Queensland, specialist psychiatric disability services were provided under the NDA. However, in all other jurisdictions specific mental health services were funded and provided under health, rather than disability, portfolios and were therefore not included in the DS NMDS. This is likely to explain some of the differences by State/Territory in 'met need' presented in Fig. 3.5.

Indigenous status information was missing/not stated for approximately 5 per cent of clients in the DS NMDS for the latest year of data available (2009–10) when this analysis was undertaken. This varied by State/Territory from 0.3 per cent in South Australia to 11.2 per cent in Victoria. Rates of missing/not stated Indigenous status have fallen markedly over the past five years from around 10 per cent in 2005–06. It should also be noted that agencies providing recreation and holiday programs are not required to collect information on clients' Indigenous

status. Although this is not considered to be 'missing/unknown/not stated' data, these programs/services contribute to the incomplete representation of the number of Indigenous people who receive disability support services in Australia.

The presence of 'not stated' Indigenous status data is an indication that identification of Indigenous people accessing the disability support services is incomplete. It is not known what proportion of clients with 'not stated' Indigenous status are of Aboriginal or Torres Strait Islander origin, or what proportion of Indigenous clients are incorrectly recorded as non-Indigenous. 'Not stated' Indigenous status data may occur due to a number of reasons. Staff members who collect data may hold negative attitudes, lack training, or have other reasons for hesitating to ask the Indigenous status question, for instance, due to concerns about provoking aggressive responses from both Indigenous and non-Indigenous clients. Staff members might make assumptions about a client's Indigenous status based upon their appearance, and therefore fail to ask the question. Finally, clients may be concerned about the differential treatment of Indigenous clients and refuse to answer the question.

The willingness of clients to identify as Indigenous may be influenced by a number of factors related to the type of the service provided, including the purpose of the service and the voluntary nature of the clients' access to the service. For instance, clients of disability support services make voluntary contact with the service, and a sense of social stigma surrounding their situation may impede clients' readiness to identify as Indigenous.

A summary table of current data sources on disability for the Indigenous population, data items of relevance to the NDIS and data quality/data gaps is available from the website for this volume in Appendix 4 Table A4.1. A summary of key questions from the data sources that will help to inform the NDIS for Indigenous persons and mapping to available data is available in Appendix 3 Table A3.1.

Other community service data collections which include an Indigenous identifier

Community service data collections (other than the DS NMDS) which contain disability-related data items are outlined in Table 4.1.

Table 4.1 Community service data collections: Scope, related data and data quality

Data collection	Scope/ population	Disability related data items	Data quality
Home and Community Age Care (HACC)	Clients accessing the HACC program which provides funding for services supporting people who live at home with decreased capacity for independent living, or who are at risk of premature or inappropriate admission to long-term residential care.	Level of functioning (functional status) up to 14 activity areas	Functional status data is poor quality—WA is the only State to collect this data for high proportion of clients (93%). There are differing requirements for collection of this data in different States.
Community Aged Care Packages (CACP)	Recipients of CACPs which target those with 'low-care' needs	Need for assistance with core activities and non-core activities by type	Need for assistance information is not a standard part of this collection—the latest available was collected from the 2008 Community Care Census, for which data by Indigenous status is not available. CACP collection does not collect data from the flexible community aged care places operating under the Aboriginal and Torres Strait Islander Aged Care Strategy or operational flexible community care places provided by Multi-Purpose Services. This, as well as the fact that responses to the Indigenous status question are not mandatory may contribute to an under-representation of the number and proportion of Indigenous clients in this data collection.
Younger People with Disability in Residential Aged Care (YPIRAC)	Younger people with disability living in residential aged care. While the initial priority of the YPIRAC initiative targets people with disability aged under 50, where possible, people with disability under the age of 65 are also targeted.	Primary disability group Other significant disability group(s)	Most data items are very well reported. In 2008–09, data were provided for all service users for the linkage key items (name, date of birth and sex), residential setting, Indigenous status, primary disability group and postcode. The largest proportion of 'not stated' responses was the principal reason for the service user's current accommodation setting, at 7.5%.
National Child Protection (NCP) Data Collection	All children and young people involved in the child protection systems throughout Australia	Need for assistance with activities in life area (ICF) Disability group	Need for assistance data has not been published from this collection to date due to quality issues. Unit record level data not currently available (therefore data not available by remoteness or lower-level geography). However, a unit-record collection is scheduled to be implemented in mid 2013.

Source: Author's analysis

Current plans for improving disability data

Disability Services data

The NDA came into effect on 1 January 2009, and called for jurisdictions to work on 'improvements in the quality of data reported under the National Minimum Data Set'. A few reported activities specifically address Indigenous identification such as the implementation of the standard Indigenous status question. Jurisdictions currently vary in their practices to collect and record Indigenous status data. Not all disability services in all jurisdictions are using the standard Indigenous status question, response options or recording categories. However, steps are being taken to ensure consistency among service providers in different jurisdictions.

The AIHW is currently working on redevelopment of the DS NMDS to enhance the content and quality of information that is currently collected about all clients, including Indigenous clients, and to provide a better picture of the needs of people with a disability by collecting information about their needs for assistance, the support they require, and the outcomes of the services they receive. Additional data elements that are proposed for inclusion in the DS NMDS are anticipated to provide better quality information about geographical location, including Remoteness Area and a State/Territory identifier. Data elements about carers (where they live, age, sex, and their relationship to the person with disability) and data elements about living arrangements, labour force status, and main source of income are also proposed.

The DS NMDS redevelopment aims to support the development and implementation of the NDIS. The redevelopment will ensure that the DS NMDS can provide the data standards required to underpin the administrative and technical systems of the NDIS in areas such as the quantification of services and the measurement of client outcomes. In addition it will seek to align the collection with the Home and Community Aged Care (HACC) and Younger People with Disability in Residential Aged Care (YPIRAC) collections and considering how the data development will support person-centred care and the NDIS.

Disability module included in ABS surveys

Work is underway to modify the Disability Module so that results for the identification of the population with disability more closely correspond to those in the SDAC. This work will require extensive consultation with stakeholders and testing of the revised module. Once a revised module is implemented, the ABS will test the results for quality and comparability with the SDAC.

Standard Disability identifier in community services collections

The AIHW is currently undertaking work to develop a recommended standard set of disability data elements for use in community services (and potentially housing) data collections. The AIHW is currently consulting on a suite of items for inclusion. Wide consultation involving support workers, policy makers, and data providers in each sector will be essential prior to any pilot test.

Addressing data gaps/improved methods of data collection

The following recommendations are made to help to address some of the data gaps and limitations outlined above.

Recommendation 1

The Disability Module included in the NATSISS and GSS should be modified to reflect the SDAC more closely in future surveys. This would involve ABS work already underway, outlined above, which will ensure that the results for the disability population correspond with those in the SDAC. It would also include an assessment of which data items included in the SDAC and not currently included in the NATSISS/GSS would provide useful information for the Indigenous population. Cost-benefit analyses would then need to be undertaken to determine whether they could be added to future NATSISS/GSS surveys.

Recommendation 2

If the above is not feasible, then the sample size for Indigenous Australians in the SDAC could be increased to enable reliable estimates for the Indigenous population at State/Territory and remoteness levels. This should be considered regardless of whether Recommendation 1 is feasible, as there are advantages to collecting detailed information on Indigenous and non-Indigenous people in the one survey.

Recommendation 3

In terms of data analysis, when analysing core activity need for assistance data from the 2006 Census, non-response (not stated) responses to the disability

status questions should be excluded, as they are particularly high compared to the other surveys e.g. NATSISS/GSS. This should also be kept in mind if this high level of non-response is replicated in the 2011 and future censuses.

Recommendation 4

Indigenous status is also under-identified in the census. Ideally, conclusions based on the census should derive from population estimates rather than population counts. Furthermore, additional work ought to be undertaken to examine methods to assess the level of Indigenous under-identification in DS NMDS data in order to gain a better understanding of the level of under-identification in this collection, as it is currently not known.

Recommendation 5

Future NATSISS surveys should collect disability information for persons of all ages—that is, collect from persons under the age of 15 years. Future surveys should consider expanding the broader criteria to remote areas to address gaps in coverage.

Recommendation 6

For future NATSISS surveys, ‘Disability services’ should be added as a specific category to the data item on types of services people have problems accessing. This will provide comparable data on the Indigenous population to that obtained for the general population from the GSS. In addition, it is also worth considering some questions on the extent to which service needs are being met, and not only problems of access.

Recommendation 7

The final recommendation with regard to data collection is for further research work to develop measures of disability that are more conceptually relevant to measuring this concept in the Indigenous population, looking at patterns of impairment and also the impact of impairment within the contexts in which Indigenous people live. This is not merely a data issue as it will involve a mixture of quantitative data collection and analysis, qualitative research, and case studies. Ideally, this research should focus not only on individuals and their families, but also service providers. Given the money to be invested in the NDIS, this would appear to be an important component of the process of ensuring that the scheme secures the maximum benefit for Indigenous Australians.

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