Aboriginal and Torres Strait Islander disability prevalence: making sense of multiple estimates and definitions

Clare Coleman,1 Nicola Wing Young Man,1,2 John Gilroy,3 Richard Madden1

Some statistical agencies in OECD countries, notably Australia and New Zealand, have made great efforts to collect data on the Indigenous peoples of their countries, while others have not done so.1 However, there are many difficulties and lessons to be learnt concerning issues such as identification of Indigenous peoples, the remote location of many Indigenous people and cultural differences affecting usual approaches. In this paper, data collected about disability in Australia are examined, in particular for Aboriginal and Torres Strait Islander (Indigenous) peoples. Data on the prevalence of disability in Aboriginal and Torres Strait Islander populations is an essential component of effective disability policy, planning and implementation;2 notably, the Indigenous analysis by the Productivity Commission in 2011 giving rise to the National Disability Insurance Scheme (NDIS).3

The United Nations Convention on the Rights of Persons with Disabilities in 2006 signalled renewed efforts at expanding data collection on people with disabilities internationally. Article 31 states that “States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention...”.4 In Australia, the Australian Bureau of Statistics (ABS) had started the collection of disability data with the Survey of Handicapped Persons in 1981, which was the International Year of Disabled Persons.5,6 The ABS has continued to conduct the Survey of Disability, Ageing and Carers (SDAC) at regular intervals. It is the standard for assessing the prevalence of disability in Australia as recommended by the ABS.5

In the 2006 Census, the ABS introduced a series of four disability questions, with the specific aim of reporting on disability in small areas of Australia.6 The ABS had also included the Short Disability Module in some of its household surveys from 2002 onwards, details of which can be found in Supplementary Appendix 1. The ABS has explained that both of these initiatives were designed to examine the characteristics of people with a disability compared to those without a disability, not for prevalence estimation.

The ABS approach to estimation of disability prevalence was in place before the Washington Group produced its approach.9 In 2016, the ABS conducted a supplementary disability survey to compare prevalence

Abstract

Objective: To analyse the multiple sources of statistics on prevalence of disability among Aboriginal and Torres Strait Islander (Indigenous) people in Australia to provide reliable headline estimates.

Methods: Survey documentation and statistics from the Australian Bureau of Statistics (ABS) were collated and comparatively analysed.

Results: Two separate concepts are defined by the ABS: ‘Disability’ and ‘Disability and restrictive health conditions’. The former is used in the Survey of Disability, Ageing and Carers (SDAC), the recommended source of disability prevalence estimates. The second is used in surveys to compare people with disability to those without. The 2014-15 National Aboriginal and Torres Strait Islander Survey (NATSISS) used a mix of these definitions, which led to differing prevalence estimates from SDAC estimates. Further, there is confusion in the NATSISS results, with ‘disability’ frequently replacing ‘disability and restrictive health condition’.

Discussion: The SDAC should be used for prevalence statistics on disability in the Indigenous population. The ABS should act to clarify or withdraw confusing results from the 2014-15 NATSISS survey.

Implications for public health: Official statistics are used to allocate resources; in particular, to and within the National Disability Insurance Scheme. These need to be accurate to ensure Indigenous people’s health needs are met.

Key words: disability, Aboriginal and Torres Strait Islander, prevalence, statistics, Indigenous, Australia

1. Sydney Centre for Aboriginal and Torres Strait Islander Statistics, University of Sydney, New South Wales
2. School of Public Health and Community Medicine, University of New South Wales
3. Faculty of Health Sciences, University of Sydney, New South Wales

Correspondence to: Dr Clare Coleman, Sydney Centre for Aboriginal and Torres Strait Islander Statistics, University of Sydney, 75 East St, Lidcombe, New South Wales 2141; e-mail: clare.coleman@sydney.edu.au

Submitted: November 2017; Revision requested: April 2018; Accepted: August 2018

The authors have stated they have no conflict of interest.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2018 The Authors

2018 Online Australian and New Zealand Journal of Public Health

© 2018 The Authors

Aust NZ J Public Health. 2018; Online; doi: 10.1111/1753-6405.12838
estimates obtained from its approach with those obtained using the Washington Group approach. The ABS noted that the Washington Group approach is intended for international comparison with countries applying similar measures, and was designed for brevity, simplicity, universality and comparability, to be suitable for countries with differing economic resources. Results were "different from other ABS disability measures, such as those in the SDAC and the Census of Population and Housing, and should not be compared."^{10}

The ABS approaches in SDAC, the Census and the Short Disability Module follow the concepts in the International Classification of Functioning, Disability and Health (ICF).^{11} The ICF describes disability as an umbrella term for impairments, activity limitations and participation restrictions arising from a long-term health condition. It describes aspects of the interaction between an individual (with a long-term condition) and that individual's contextual factors (environment and personal factors).

The ABS defines a person with a disability if they report they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities.^{12} The ABS disability data items are based on two types of questions. Firstly, screening questions are used to identify people with disability due to a long-term health condition. Secondly, there are questions to determine severity of disability according to a person's need for assistance with core activities of daily living (self-care, communication or mobility), and education and employment restrictions.^{6,13}

The first ABS survey specific to Aboriginal and Torres Strait Islander peoples, the National Aboriginal and Torres Strait Islander Survey, was conducted in 1994. This survey stemmed from Recommendation 49 of the Royal Commission into Aboriginal Deaths in Custody, which required "a comprehensive survey of Aboriginal and Torres Strait Islander people be conducted to collect the information the Commission found to be lacking and believed to be important to Aboriginal self-determination."^{14} This evolved into the National Aboriginal and Torres Strait Islander Social Survey (NATSISS) conducted in 2002, 2008 and 2014/15, and the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) conducted in 2004/05 and 2012/13.^{15,16} The 2002, 2008, 2014/15 NATSISS and the 2012/13 NATSIHS included modified versions of the ABS Short Disability Module to identify respondents with a disability. The Short Disability module enables comparisons between Aboriginal and Torres Strait Islander people and non-Indigenous people, with and without disability: NATSISS data can be compared with General Social Survey (GSS) data, and NATSIHS data compared with National Health Survey data. Further data on Indigenous people with a disability are available from the population census since 2006.

Care needs to be exercised in estimating disability in Aboriginal and Torres Strait Islander populations, and the characteristics of people with disabilities in these communities. There is diversity in cultural understanding of disability between and within different populations. Research undertaken by Gilroy and Donnelly^{18} found many unsuccessful attempts by non-Indigenous disability researchers to identify a generalisable understanding of disability in Aboriginal and Torres Strait Islander communities. The historical research of Gilroy,^{4} Gilroy and Donnelly^{16} and Gilroy et al.^{19} found that many Aboriginal and Torres Strait Islander communities living in close proximity to each other have different terms and concepts relating to disability types (such as deafness, blindness and physical disability). Attempting to apply the concept of disability on Aboriginal and Torres Strait Islander communities is regarded by many Aboriginal and Torres Strait Islander peoples as culturally insensitive, making any attempt at a universally accepted definition of disability difficult.^{17,20}

Recognising these issues, the ABS has consulted with key stakeholders and experts in the development of its surveys, including relevant government departments and organisations such as appropriate peak bodies and academic and research centres. For surveys specific to Aboriginal and Torres Straits Islanders, the consultation process included representatives from Aboriginal and Torres Strait Islander peak bodies, government departments with Aboriginal and Torres Strait Islander responsibilities, universities with a background in relevant academic research and the ABS advisory groups for Aboriginal and Torres Strait Islander statistics.^{15,16}

In spite of these acknowledged difficulties, there has not been a clearly directed approach to estimating disability prevalence in Indigenous Australia. Use of the SDAC is compromised by the coverage limitations for Indigenous people. The 2015 SDAC reports that 29% of Indigenous people aged 15 and over have a disability. In contrast, the ABS published an estimate that 45% of Indigenous people aged 15 years and over have a disability or a restrictive long-term health condition, based on the 2014 NATSISS.^{21} Long-term conditions may not cause disability and this composite definition is not used in other ABS work. Worse, much of the report refers to 'disability' only. The ABS report states that "people with disability or a restrictive long-term health condition are collectively referred to as 'people with disability'".^{21} The 45% figure has been widely reported and used as a disability prevalence estimate. The most recent Aboriginal and Torres Strait Islander Health Performance Framework data tables have used these estimates from the NATSISS, including disability and long-term health conditions to estimate prevalence.^{22}

The ABS is a trusted source of data that is used by the Australian Government and other organisations to inform their policy making, resource allocation and planning. Given the complex situation described, multiple ABS data sources, and apparently conflicting reports on Indigenous disability prevalence, the following issues are addressed:

1. What surveys provide data on disability among Aboriginal and Torres Strait Islander peoples?
2. How is disability defined and disability prevalence estimated?
3. How can reliable comparisons of disability prevalence between Indigenous and non-Indigenous Australians be made?

Method

The various ABS data collections relating to disability give rise to multiple possibilities for estimating disability prevalence, and particularly disability prevalence for Aboriginal and Torres Strait Islander peoples. The following search strategy was carried out. A search by catalogue number on the ABS website was first performed and the categories "47. Indigenous statistics" as well as "41. Social statistics – General", and "43. Health" were identified for further search. A search was also performed on the ABS website using the term "Aboriginal disability". Under each webpage for the surveys and reports identified as relevant to Indigenous
disability, “Past & future Releases” surveys and reports in the series were also searched through and collated. On the Australian Institute of Health and Welfare (AIHW) website, a search under “Reports & statistics” by topic was carried out under “Indigenous Australians” as a population group, and under “Disability” in “Health conditions, disability & deaths”. Reports that were quoting other reports in our analysis, e.g. the Aboriginal and Torres Strait Islander Health Performance Framework from the AIHW, which primarily quoted data from other reports, were excluded from the analysis in this paper.

To determine best practice, the relevant data and metadata (technical and user guides, questionnaires and results) and advice published by ABS and/or AIHW were collated to compare their coverage of the Aboriginal and Torres Strait Islander population, their definition and description of disability and the published estimates on prevalence of disability.\(^{12,22,31}\) Where a collection was specific to Aboriginal and Torres Strait Islander peoples, the data from the comparator survey (as identified by the ABS in their user and/or technical guides and confirmed by the authors) was also collated and compared. Policy impacts of different approaches were considered, and a unified approach recommended for reporting disability prevalence for the whole population and the Aboriginal and Torres Strait Islander population.

### Results

The ABS census and surveys that collect disability data on Aboriginal and Torres Strait Islander peoples are SDAC, NATSISS, NATSIHS and the Australian Census. The definitions of disability in Aboriginal and Torres Strait Islander peoples are as follows:

SDAC 2015: “A person has a disability if they report they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities.”\(^{12}\)

NATSISS 2014-15 and GSS 2014: “A disability exists if a limitation, impairment, disease or disorder had lasted, or was likely to last for at least six months or more and which restricted everyday activities.”\(^{31}\)

NATSIHS 2012-13: “A disability or restrictive long-term health condition exists if a limitation, restriction, impairment, disease or disorder has lasted, or is expected to last for six months or more, which restricts everyday activities.”\(^{16}\)

The GSS 2014 contains an explanation for differences between the GSS and other ABS surveys. Referring to the SDAC, it says:

> While both the Survey of Disability, Ageing and Carers (SDAC) and GSS collect information about disability, the SDAC 2012 used 149 questions to gather the information used to identify types of disability and the underlying conditions causing disability, compared with the standard short module containing 12 questions used in the GSS. The standard short disability module is designed to obtain data on the broad characteristics of the disability population in the particular survey in which the module is included, while SDAC produces detailed disability data and national prevalence estimates. The scope of the SDAC is also different from GSS as it collects information from people living in special dwellings in addition to those in private dwellings. These differences are likely to account for most of the differences in estimates from these sources.\(^{32}\)

This material is not repeated in the descriptions of the NATSISS 2014-15. However, the NATSISS Appendix on published estimates that was compared with other ABS surveys states: "Comparisons with the non-Indigenous population using the GSS include…Disability status.” Thus, the GSS explanation can and should be applied to the NATSISS.\(^{33}\)

The NATSISS Appendix also states, referring to long-term health conditions: “Data relating to long-term health conditions (including mental health conditions) have been collected in the 2014–15 NATSISS in order to provide information on the characteristics of Aboriginal and Torres Strait Islander people with a long-term condition, rather than prevalence estimates”\(^{30}\).

The SDAC uses a series of screening questions to determine whether a person has a disability. The survey works progressively through a series of screener questions covering a range of impairments and Activities and Participation domains. Subsequently, it asks if people have a long-term health condition.

A different approach is used in the NATSISS, based on the Short Disability Module approach. After asking about a range of specific conditions that have been identified by a doctor or nurse, the respondent is then asked to report conditions regardless of whether they have been told about them by a doctor or nurse. A prompt card is used, which contains the following broad conditions:

1. Shortness of breath, or difficulty breathing
2. Chronic or recurring pain
3. A nervous or emotional condition
4. Long-term effects as a result of a head injury, stroke or other brain damage
5. A long-term condition that requires treatment or medication
6. Any other long-term condition such as arthritis, asthma, heart disease, Alzheimer’s disease, dementia, etc.

Then it is asked if the condition(s) restrict everyday activities.

### Prevalence Estimates

The 2015 SDAC reports that 29% of Indigenous people aged 15 and over have a disability. As commented earlier, the ABS recommends use of the SDAC for estimation of disability prevalence rates.

Unfortunately, the SDAC does not include people living in very remote areas or in discrete Aboriginal and Torres Strait Islander communities. On the other hand, SDAC covers the entire population, and so lends itself to comparisons between Indigenous and non-Indigenous people.

The NATSISS does cover remote areas. There will be more discussion of definitional differences between SDAC and NATSISS later. However, the ABS reports that the 2014-15 NATSISS found “overall (disability) rates were similar in non-remote and remote areas”. This finding will be further addressed below when considering national disability prevalence rates for Aboriginal and Torres Strait Islander people.\(^{31}\)

Because of the different age structures of Indigenous and non-Indigenous Australians, disability prevalence rates can only be meaningfully compared after age standardisation. Table 1 shows the estimated age standardised prevalence of disability among Aboriginal and Torres Strait Islander peoples in SDAC 2009, 2012 and 2015, and the rate ratios for Indigenous rates to non-Indigenous rates. The rate ratio was 1.6 in 2009, 1.7 in 2012 and 1.8 in 2015.

SDAC estimated the prevalence (%) of profound or severe core activity limitations from between 2009 and 2015. The prevalence of profound or severe limitation in core activities.
activities was higher among Aboriginal and Torres Strait Islander people compared with non-Indigenous people, with the prevalence rate ratio ranging from 1.5 to 2.0. It should be noted that the comparisons are not available for very remote regions. Unfortunately, age standardised rates were not published. The NATSISS provides these estimates on an age standardised basis. In 2013-14, the rate for Indigenous people was 9.1%, for non-Indigenous 4.3%, a rate ratio of 2.1.

Discussion

The changes in scope across the surveys, and the accompanying definitions, have not been well explained by the ABS. It seems clear that two separate concepts have been applied by the ABS. The first concept is the long-established definition of disability that has been used in the SDAC. This is based on impairments, limitations and restrictions due to a long-term health condition. The second concept is “Disability and restrictive long-term health conditions”, as defined in the 2012-13 NATSISS. While the purpose for the two separate concepts is not clear, the differences in definitions and concepts are real and significant.

If the ABS had followed its position that prevalence rates should be derived from the SDAC, and the disability module be used for comparisons of the characteristics of people with disability and without disability across various surveys, these differences should not be of great importance, even though the reasons for them have not been explained. However, the concepts in the NATSISS 2014-15 are confused and mix up the two concepts. The definition used in the NATSISS is titled ‘Disability’, not ‘Disability and restrictive health condition’, but the definition is in fact that used in the NATSISS. In addition, the ABS position on prevalence estimation has not been followed. Prevalence has been estimated for ‘Disability and restrictive health conditions’, however, that estimate has been regularly mis-labelled as ‘Disability’. The result is a published prevalence estimate from the NATSISS that is incorrect in its definition. Not surprisingly, the result is very different from prevalence calculated from the SDAC.

The ABS actions are even more surprising given the clear statement in the NATSISS Appendix quoted earlier, that the NATSISS should not be used to estimate prevalence of long-term health conditions. Yet the published tables show prevalence rates for long-term health conditions.

The ABS should act to clarify that the NATSISS estimate is not an estimate of disability prevalence. If possible, it should be withdrawn, with a clear statement that the SDAC should be the source of disability estimates, including for Aboriginal and Torres Strait Islander people. As noted above, the SDAC does not cover very remote areas; whereas, the NATSISS covers all regions. While the definitional problems limit the usefulness of the NATSISS results, the impact on estimates of those with severe and profound core activity limitations should not be significant: the boundary between disability and restrictive long-term health conditions should mainly affect estimates of people with mild limitations. The estimated prevalence of people with severe or profound core activity limitations in remote areas is 7.5%, compared to 7.8% for non-remote areas. This suggests that the SDAC exclusion of very remote areas is not likely to have much impact on the prevalence rate.

In all the circumstances, for Aboriginal and Torres Strait Islander people, the SDAC prevalence rate (29%) and rate ratio (1.8) should be used for Australian disability estimates. For severe or profound disability, the prevalence rate of 9% should be used, and the rate ratio 2.1.

Implications for public health

Using reliable disability prevalence data is essential for sound policy and planning, especially in relation to early intervention and the rollout of the NDIS. Proper understanding of Aboriginal and Torres Strait Islander peoples’ concepts of disability, and relevant prevalence estimation for non-remote and remote areas, is essential for them to obtain the benefits of these disability policy reforms.

All stakeholders need to be speaking the same language in collecting, interpreting and translating these data findings.

Acknowledgements

The comments and discussion with Ros Sackley on an earlier version of the manuscript are gratefully acknowledged.

References

17. Gilroy J. The Participation of Aboriginal People with Disability in Disability Services in NSW, Australia; Sydney (AUST): University of Sydney School of Education and Social Work; 2012.

Supporting Information

Additional supporting information may be found in the online version of this article:

Supplementary Appendix 1: Screening questions to identify people with disability and/or long-term condition in the Short Disability Module.