

Indigenous disability data inventory

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Contents

- Contents 5**
- Indigenous disability data inventory 1
- General statistics and population data..... 1
- Administrative data 5
- Data development and concepts..... 6
- Quality and reporting of Indigenous data..... 9
- Policy related reports..... 11
- References 13**

Indigenous disability data inventory

This Indigenous disability data inventory provides a list of publications and other information sources which have led to, or could lead to, improved national disability data on Aboriginal and Torres Strait Islander populations. These sources may include data concerning Indigenous people with a disability or discuss Indigenous data development issues, such as Aboriginal identification. Many also consider the various ways disability is conceptualised by Indigenous people.

For ease of reference, the data have been categorised according to the main subject matter under the headings: general statistics and population data; administrative data; data development and concepts; quality and reporting of Indigenous data, and policy related reports. Within those headings, data sources are listed in chronological order, with the most recent sources listed first. Where possible the inventory includes relevant links direct to the publication or source and an EndNote reference library has been created. This EndNote library provides an index of all the resources included in the inventory and allows publications to be grouped according to author, publication date or the key subject areas listed above.

The inventory (and EndNote library) will be updated periodically and future plans for the inventory include:

- the addition of international information sources addressing Indigenous disability data, and
- the addition of further web-based information.

General statistics and population data

Title: *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2005*

Authors: ABS and AIHW August 2005

A statistical overview of the health and wellbeing of Indigenous Australians using data from the ABS Census of Population and Housing, Community Housing and Infrastructure Needs Survey, National Health Survey and a wide range of administrative by-product data sources. This edition has a special chapter dedicated to disability and ageing. Other key areas covered are: population characteristics, housing and community infrastructure, health services, community services, mothers and babies, ill health, health risk factors and mortality.

Previous publications: The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2003, 2001, 1999 and 1997. All these reports are available online at:

www.aihw.gov.au

Future publications: This report is published biennially.

Title: *Report on Government Services 2005: Indigenous Compendium*

Author: Steering Committee for the Review of Commonwealth/State Service Provision 2005

The Report on Government Services provides information on the effectiveness and efficiency of Commonwealth, State and Territory government services. This compendium provides a summary of Indigenous data in the *Report on Government Services 2005*. A summary of data from the Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS) is presented in the disability services chapter (13).

Future publications: The Report on Government Services is published annually.

Title: *Australia's Health 2004*

Author: Australian Institute of Health and Welfare (AIHW) 2004

The ninth biennial health report of the Australian Institute of Health and Welfare provides national information on the health status, needs and services of Australians. One section is dedicated to Aboriginal and Torres Strait Islander people and includes information on data quality, measures of health status, health risk factors and housing and living conditions.

The report is available at:

<http://www.aihw.gov.au/publications/index.cfm/title/10014>

Future publications: Will continue to be published biennially with the next edition published in 2006.

Previous publications: Has been published biennially since 1988.

These publications are all available online at www.aihw.gov.au from 1996 onwards.

Title: *National Aboriginal and Torres Strait Islander Social Survey (NATSISS)*

Author: Australian Bureau of Statistics (ABS) 2004

The 2002 NATSISS is the second Australian survey measuring the wellbeing, social circumstances and disadvantage among Indigenous Australians aged 15 years and over. Key findings from the survey are summarised and cover population characteristics, health, disability, education, financial situation, housing, law and justice, transport and information technology. Some tables include comparisons between the 2002 NATSISS and its predecessor (the 1994 National Aboriginal and Torres Strait Islander Survey NATSIS). Further information on the NATSIS is provided in a later entry.

Just over one-third of Indigenous people reported a disability or long-term health condition. When the effects of age differences were removed, the disability rate among Indigenous people was 1.4 times higher than among the non-Indigenous population (57% compared with 40%). A summary of the publication is available at:

<http://www.abs.gov.au/Ausstats/abs@.nsf/0/AD174BBF36BA93A2CA256EBB007981BA?Open>

Future publications: The NATSISS will be conducted every six years.

Title: *The Western Australian Aboriginal Child Health Survey: The health of Aboriginal children and young people – Volume 1*

Authors: Zubrick SR, Lawrence DM, Silburn SR, Blair E, Milroy H, Wilkes T, Eades S, D'Antoine H, Read A, Ishiguchi P, Doyle S 2004

Telethon Institute for Child Health Research

A large scale survey of 5,289 Western Australian Aboriginal and Torres Strait Islander children was conducted in 2000 by the Telethon Institute for Child Health Research and Kulunga Research Network. The survey aims to provide knowledge on the social, emotional, academic and vocational wellbeing of Aboriginal and Torres Strait Islander children to inform future policy. Specific data were collected on limitations of independent and other functions, problems and pain associated with sensory functions, and the burden of disability. A summary of results, or the complete volume is available at:

<http://www.ichr.uwa.edu.au/research/divisions/pop/projects/waachs/index.lasso>

Future publications: Volume 2 and Volume 3 are expected to be published in 2005–2006.

Title: *Australia's Welfare 2003*

Author: AIHW 2003

Australia's Welfare 2003 is the sixth edition of the AIHW's biennial report on Australia's welfare services, indicators and systems. Information on Indigenous Australians with a disability accessing Commonwealth/State Disability Agreement-funded services is included. This publication also provides information on Indigenous homelessness, housing and use of children's and aged care services. The report is available at:

<http://www.aihw.gov.au/publications/index.cfm/title/9629>

Future publication: Biennially, the next will be Australia's Welfare 2005.

Previous publications: Biennially from 1993. These reports (since 1995) are available online at www.aihw.gov.au

Australia's Welfare 1999 noted: 'three main difficulties with obtaining better data: conceptual validity, population sampling and administrative identification' and reported on initiatives in each area (p 233).

Title: *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2003*

Authors: ABS and AIHW 2003

A statistical overview of the health and wellbeing of Indigenous Australians using data from the ABS Census of Population and Housing, Community Housing and Infrastructure Needs Survey, National Health Survey and a wide range of administrative by-product data sources. Key areas covered are: population characteristics, housing and community infrastructure, health services, community services, mothers and babies, ill health, health risk factors and mortality.

Of health conditions reported, eye and vision problems are the most common (29%), followed by asthma (16%), back problems (15%) and ear/hearing problems (15%). Indigenous consumers of CSTDA services also reported a somewhat more frequent need for support than for other consumers. The report is available at:
<http://www.aihw.gov.au/publications/ihw/hwaatsip03/index.html>

A special chapter was devoted to data issues and data development.

Previous publications: The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2001, 1999 and 1997. All these reports are available online at www.aihw.gov.au

Future publications: This report is published biennially.

Title: *Prevalence of Intellectual Disability in Western Australia*

Authors: Leonard H, Petterson B, Bower C, Sanders R, 2003

Paediatric and Perinatal Epidemiology 17: 58-67

This article documents the findings of an intellectual disability prevalence study conducted in Western Australia for children born in 1983-1992. Prevalence rates are compared for males and females and Indigenous and non-Indigenous.

Title: *National Health Survey, Aboriginal and Torres Strait Islander Results, Australia, 2001*

Author: ABS 2001

Results of the 2001 National Health Survey pertaining to Aboriginal and Torres Strait Islanders are presented. Areas of reporting include health status measures, factors affecting health service use, and lifestyle factors affecting health. Of the selected long-term health conditions, eye/sight problems were the most commonly reported conditions among the Indigenous population (29%). These were followed by asthma (16%), back problems (15%), and ear/hearing problems (15%). For the first time in this survey, data on Indigenous people in remote areas were included.

Previous publication: National Health Survey, Aboriginal and Torres Strait Islander Results, Australia 1995.

Title: *Disability Counts: A profile of disability in Western Australia*

Author: Alessandri LM, Leonard H, Blum LM, Bower C 1996

Disability Services Commission, Western Australia

This report provides an overview of disability in Western Australia. A small section is dedicated to Indigenous people with a disability, and highlights the paucity of information available.

Title: *National Aboriginal and Torres Strait Islander Survey 1994*

Author: ABS 1996

The 1994 National Aboriginal and Torres Strait Islander Survey (NATSIS) provides information about the social, economic and health status of the Aboriginal and Torres Strait Islander population. The NATSIS was replaced by the NATSISS in 2002 (see earlier entry).

A summary is available at:

<http://www.abs.gov.au/Ausstats/abs@.nsf/0/368968084CA747B2CA2569DE002139C0?Open>

Administrative data

Title: *Homeless Supported Accommodation Assistance Program (SAAP) Clients with a Disability 2002–2003*

Author: AIHW: Murdoch F 2005

AIHW Bulletin no. 23. AIHW cat. no. AUS 56

Summary information on the mean number of support periods for Indigenous SAAP clients with a disability is provided in this bulletin. Indigenous clients in the 'disability' group had a higher average number of support periods per client than in the 'non-disability' group (2.4 periods compared to 1.9).

Title: *Disability Support Services 2002–2003. The first six months of data from the Commonwealth State/Territory Disability Agreement National Minimum Data Set*

Author: AIHW 2004

This report provides information on the first six months of available data from the 2002–2003 CSTDA NMDS collection, covering the period from 1 January 2003–30 June 2003. This is the first report to provide information on data collected on all service users rather than those who accessed a service on a single, 'snapshot' day. Around 3.2% of service users identified as Aboriginal or Torres Strait Islander people. Aboriginal and Torres Strait Islander service users were proportionately more likely to access community support and respite services and less likely to access employment and community access service, than indicated by their overall rate.

The report is available online at:

<http://www.aihw.gov.au/publications/dis/dss02-03/dss02-03.pdf>

Future publication: Disability Support Services 2003–2004: A complete year's data from the Commonwealth State/Territory Disability Agreement National Minimum Data Set.

Previous publications:

Disability support services 2002: National data on services provided under the Commonwealth/State Disability Agreement (CSDA)

Disability support services 2001: National data on services provided under the Commonwealth/State Disability Agreement

Disability support services 2000: National data on services provided under the Commonwealth/State Disability Agreement

Disability support services provided under the Commonwealth/State Disability Agreement: National data 1999

Disability support services provided under the Commonwealth/State Disability Agreement: National data 1998

Disability support services provided under the Commonwealth/State Disability Agreement: National data 1997

Disability support services provided under the Commonwealth/State Disability Agreement: Available data 1996

Disability support services provided under the Commonwealth/State Disability Agreement: First national data 1995

These publications (since 1998) can be located online at: www.aihw.gov.au and include information on the characteristics and service use of CSDA service recipients who identified as Indigenous Australians, and some discussion of the quality and accuracy of data collected.

Data development and concepts

Title: *Overcoming Indigenous Disadvantage: Key indicators 2003: Overview*

Author: Productivity Commission 2003

This report provides information on key indicators of Indigenous disadvantage. 'Rates of disability and/or core activity restriction' has been selected as a headline indicator. Several pages are dedicated to a discussion on the prevalence of disability amongst Indigenous people and issues associated with data collection and quality, but no data is presented. The report also considers future directions for data across health and welfare sectors.

This report is available online at:

<http://www.pc.gov.au/gsp/reports/indigenous/keyindicators2003/keyindicators2003.pdf>

Title: *Disability*

Author: Burns J & Thomson N 2003

The Health of Indigenous Australians. Melbourne: Oxford University Press, 467- 487

This chapter provides a review of Indigenous perceptions of disability, risk factors for disability, disability services and barriers for Indigenous people to access services.

Title: *Changing Perceptions of Disability*

Author: Sloane G 2003

Aboriginal and Islander Health Worker Journal March/April: 17-19

Changing Perceptions of Disability includes a discussion of Indigenous perceptions of disability and how they can impact the way people with a disability seek assistance or report their condition.

Title: *Report on the Establishment of a National Indigenous Disability Network*

Author: Aboriginal and Torres Strait Islander Commission and National Disability Advisory Council Joint Working Party, 2000

This report documents the need for a National Indigenous Disability Network, outlining the feasibility, purpose and potential benefits of such a network. The network envisaged working with Indigenous communities, services providers, and the ABS and AIHW to improve data on disability. This will involve improving the understanding of disability in Indigenous communities, the quality of indigenous disability data and the understanding of data collection purposes.

Title: *Testing the ICIDH-2 with Indigenous Australians: Results of field work in two Aboriginal communities in the Northern Territory.*

Author: Senior K 2000

A report documenting the testing and relevance of the draft International Classification of Impairment, Disability and Handicap (ICIDH-2) to Aboriginal people. Field work was conducted in two Indigenous communities and explored the relationship of individual and community perceptions of disability in the Northern Territory to the ICIDH-2. Perceptions of physical impairments (including sensory impairments), mental impairment, children born with disabilities and old age are considered. The impact of the physical environment is also discussed.

The writer concludes that the ICIDH-2 is a broad enough tool to be used to document and classify needs of the Indigenous community however:

- the classification should be used by people familiar with the Aboriginal community and,
- its use should result in significant improvements in health and welfare services.

A copy of the report is available at:

http://www.aihw.gov.au/publications/dis/ddb21/5_icidh_ind.doc

Title: *Indigenous Disability Data: Current status and future proposals. Report on workshop proceedings.*

Authors: ABS and AIHW 1998.

This publication documents key issues discussed during a two day workshop on the status of Indigenous disability data in 1998. The workshop intended to improve information on the prevalence and types of disability within Indigenous

communities. Commonwealth and State government departments, non-government agencies, statistical organisations, Aboriginal medical services, NACHHO and independent researchers were involved. The development of principles and protocols for work on Indigenous information was recommended. Chapter 4 specifically focuses on issues relating to the conceptualisation of disability and data collection.

Title: *Ideas and options for collecting disability data for Aboriginal and Torres Strait islander peoples from the population census.*

Author: Widdowson J 1998

In: ABS and AIHW, Indigenous disability data – Current status and future proposals. Report on workshop proceedings 1998.

This paper considers the feasibility of including a measure of disability in the 2001 census, and the implications for collecting Indigenous disability statistics.

Title: *Disability Definitions and Concepts: Working towards national consistency*

Author: Madden R 1998

In: ABS and AIHW, Indigenous disability data – Current status and future proposals. Report on workshop proceedings

The importance of quality, reliable and meaningful data on Indigenous people with disabilities is discussed. Operational challenges to the collection of reliable data are outlined and the potential use of the ICDH as a relevant framework to guide more consistent national data is considered. Three main challenges were identified: conceptual validity, population sampling and accurate identification. Sampling in relation to Indigenous disability was seen as problematic since in population terms, they are two 'low probability' sub-populations. The Survey of Disability, Ageing and Carers is viewed on that basis as a less useful collection vehicle, while the census and NATSISS are potentially more so.

Title: *Disability and Rehabilitation in Cross-cultural Perspective: A view from New Zealand*

Author: Gregory R 1994

International Journal of Rehabilitation Research 17 189–200

Definitions and perceptions of disability are socially constructed and vary across cultures. People with disabilities and their families, caregivers and rehabilitation professionals play a crucial role in the classification and interpretation of disability. This is considered through a discussion of the conceptual issues relating to disability and accidents and rehabilitation. Some comparison to the American experience of disability and the American health and welfare system is made.

Title: *Across the Divide: Distance, diversity and disability*

Authors: Gething L, Pointer T, Redmayne G and Reynolds, F, The Community Disability and Ageing Program, University of Sydney 1994.

This publication reports the results of a study which explored the needs of Aboriginal people with disabilities in remote and rural areas of NSW. Relevant sections include: the definition and conceptualisation of disability, and statistics and issues regarding data collection.

Title: *Disability and Handicap among Aborigines of the Taree Area of New South Wales.*

Author: Thomson N and Snow C 1994

Australian Institute of Health and Welfare Aboriginal and Torres Strait Islander Health Series No. 9

This report discusses the findings of a study which attempted to define disability prevalence among Indigenous people living in the Taree area of New South Wales. The publication was one of the first to systematically explore the level of disability amongst Aboriginal populations, using the ICIDH as a conceptual framework. Results showed that the sample Indigenous population had significantly higher levels of disability and handicap when compared with Australian population levels derived from the ABS census. Hearing loss, asthma and learning difficulties were identified as particularly disabling conditions.

Quality and reporting of Indigenous data

Title: *Data Quality of Aboriginal and Torres Strait Islander Identification: Seven Community Services Data Collections*

Author: AIHW 2004

An analysis of the data quality in seven community service data collections, including, the Commonwealth State/Territory National Minimum Data Set (CSTDA NMDS), Supported Accommodation Assistance Program, National Child Protection Data Collection, Alcohol and Other Drug Treatment Services NMDS and three Aged care collections. The publication is available at:

<http://www.aihw.gov.au/publications/index.cfm/title/10081>

A web portal which provides access to resources and information which support the improvement of Indigenous identification has been developed in conjunction with this report. It is available at:

http://www.aihw.gov.au/indigenous/national_standards.cfm

Title: *Recent developments in the collection of Indigenous statistics (Chapter 11 of The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2003)*

Authors: ABS and AIHW 2003

This chapter discusses recent developments in the reporting and collection of statistics relating to Aboriginal and Torres Strait Islanders and provides useful summaries, on the quality of information collected from census, surveys and administrative collections. A discussion of the incomplete nature and unknown

quality of data is also included in relation to the identification of Aboriginal and Torres Strait Islander. The report is available at:

<http://www.abs.gov.au/Ausstats/abs@.nsf/0/F355E877B11789E1CA256E53007BAC1D?Open>

Title: *Indigenous Identification in Administrative Data Collections – Best Practice and Quality Assurance*

Author: AIHW and ABS 1997

This report outlines the proceedings of a workshop on Indigenous identification in administrative data collections.

Title: *Assessing the Quality of Identification of Aboriginal and Torres Strait Islander People in Hospital Data*

Author: Aboriginal and Torres Strait Islander Health and Welfare Information Unit (a joint project of the ABS and AIHW) and Australian Health Ministers' Advisory Council 1999

This publication provides results of a study conducted across a sample of hospitals in various parts of Australia to assess the quality of Indigenous identification in hospitals, and proposals as to how this can be improved.

Title: *Aboriginal and Torres Strait Islander Health Information Plan... This time let's make it happen – Final report to Australian Health Ministers' Advisory Council*

Author: Aboriginal and Torres Strait Islander Health and Welfare Information Unit (A joint project of the ABS and AIHW) 1997

A review of Indigenous health information and the development of a National Plan for Aboriginal and Torres Strait Islander Health Information was commissioned to the Australian Institute of Health and Welfare (AIHW) by the Australian Health Ministers Advisory Council (AHMAC) in 1996. The project involved consultation and review of current information activities and issues across government and non-government agencies in all jurisdictions. The information was analysed to identify information 'gaps' and current 'best practice' in Indigenous health information. Recommendations to improve Indigenous information are discussed. Particular issues identified were the potential misuse of information, the need for a more supportive information infrastructure and national commitment to quality Indigenous data. This project set the scene for future improvement and co-operation in Aboriginal and Torres Strait Islander health data.

Title: *Aboriginal Perceptions of Disability and the Formulation of an Appropriate Method of Providing Rehabilitation Services to Clients on Remote Communities. Pilot project 1.*

Author: Elliot DM 1984

Commonwealth Rehabilitation Service, Northern Territory

This report discusses the findings of a project conducted at the Darwin Rehabilitation Centre. Indigenous perceptions of disability are discussed in relation to the development of more appropriate rehabilitation services.

Title: *The Identification of Aboriginal and/or Torres Strait Islander People in Administrative Data*

Author: National Centre for Aboriginal and Torres Strait Islander Statistics (NCATSIS)

The importance of health information, data collections and the identification of Aboriginal and Torres Strait Islanders are outlined in this brief pamphlet.

Policy related reports

Title: *Achievements in Aboriginal and Torres Strait Islander Health – Summary report*

Author: Cooperative Research Centre for Aboriginal and Tropical Health on behalf of the Standing Committee on Aboriginal and Torres Strait Islander Health
November 2003

This report informs health policy and planning decision-makers of the critical factors which have contributed to successful Indigenous health outcomes and initiatives. Successful programs across primary, secondary and tertiary health sectors were nominated and analysed in detail. Recommendations included: the need for continued development and support of a policy framework for Aboriginal and Torres Strait Islander health, improved collection of health outcomes and evaluation data and funding models and partnerships between a range of government and non-government organisations which focus on long term effective strategies and the involvement of local communities.

The full report is available on-line at www.crcah.org.au

Title: *Gathering people, linking voices. The State Aboriginal Disability Conference Report 2002*

National Library of Australia 2002

Major themes of the conference were: the provision of sustainable and appropriate services for Aboriginal people with disabilities and the development of strong partnerships between Aboriginal people with a disability and their families and community.

Title: *Access and Equity for the Doubly Disadvantaged*

Author: Bostock L 1991

Aboriginal and Islander Health Worker Journal 15 (4): 10-15

This article provides a discussion of the lack of services and information available for Indigenous people with disabilities. Lack of social and cultural understanding of Indigenous people often means that people with disabilities suffer considerably more disadvantage.

Title: *Development of the National Aboriginal Health Strategy*

Authors: Thomson N & English B 1992

Aboriginal Health Information Bulletin, Number 17, May

This paper outlined the development, content and implementation of the National Aboriginal Health Strategy agreed in 1990. The overall objective of the strategy was to ensure all Aboriginal and Torres Strait Islander people have equal access to health services and facilities by 2001. One objective was to provide better support in the areas of information, education, training, research and evaluation.

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