



# Data Starter

A project of the Disability Data Reference Advisory Group

# 1



## How to find and use disability data

This Data Starter aims to help those who use or intend to use disability data, for example, people with disability, staff of non-government organisations, government officials, researchers and students. The Starter will help you find relevant existing data collections, understand and interpret the data, and give you a guide for presenting the data to suit your purpose.

### Inside Issue 1

- 1 Why use disability data?
- 2 Finding existing data
- 3 Understanding data
- 4 Presenting data
- 5 Data dictionaries and standards

## 1 Why use disability data?

To improve and/or inform a range of activities, including:

- advocacy;
- understanding the extent of need for a particular group, area or service;
- service delivery;
- planning and evaluation;
- advertising and promotion;
- preparing funding submissions; and
- study and research on disability issues.

To answer questions about:

- characteristics of the community you live in or serve;
- whether there is evidence that changes in government policies have resulted in changes in your circumstances or the service you provide to people with disability; and
- whether you or the people with disability you provide a service to are served as well as other groups in the community.

## 2 Finding existing data

The following table gives an overview of national or other large disability-related data collections in Australia. Some national special-interest collections are also included. Many other disability-related data collections are beyond the scope of this document.

The best digest of data of these collections is the AIHW's *Australia's Welfare: Services and Assistance*. This publication is compiled every two years, the latest one being for 1999. The document can be viewed on the Institute web site at <http://www.aihw.gov.au>

COLLECTION NAME	DATA CUSTODIAN	FREQUENCY OR TIMING	COLLECTION METHODS	TARGET POPULATION	OBJECTIVE OR PURPOSE	SELECTED KEY CONTENT OR ELEMENTS	ACCESSIBILITY
<b>Major national disability-specific collections</b>							
Survey of Disability, Ageing and Carers	Australian Bureau of Statistics <sup>1</sup> PO Box 10, Belconnen ACT 2616 Ph. 02 6252 6627 www.abs.gov.au	1981, 1988, 1993, 1998	Estimates based on the responses to sample surveys of households with interviewers, and cared accommodation establishments with administrator-completed mail-back forms	People residing in dwellings (not prisons or boarding schools)	To obtain data about people with a disability, ageing people and their carers	Prevalence; Disability status, types; Support needed and received	Publications; Tables on request; Confidentialised Unit Record File; Modelled small area data
Commonwealth/State Disability Agreement Minimum Data Set collections	Australian Institute of Health and Welfare PO Box 570 Canberra ACT 2601 Ph. 02 6244 1000 www.aihw.gov.au	1995, 1996, 1997, 1998, 1999; Snapshot day	National collection of surveys by jurisdictions of service providers that they fund under the CSDA	Service outlets and people receiving services under the CSDA	To obtain data about providers and recipients of specialist disability support services	Service details, types; Disability status, types; Support needed; Performance indicators	Publications; Tables on request*
State and Territory CSDA MDS collections	State and Territory departments responsible for disability services	Variable since 1995; Snapshot day or 'continuous'	Surveys of service providers that jurisdictions fund under the CSDA	Service outlets and people receiving services under the CSDA	To obtain data about providers and recipients of specialist disability support services	As for the CSDA MDS collections. Jurisdictions add-on data items for their own use	Publications for some jurisdictions
Disability Services Census (Commonwealth)	Dept. of Family and Community Services PO Box 7788 Canberra Mail Centre ACT 2610 Ph. 02 6244 6867	1986, 1991, 1993, 1995, 1997, 1998, 1999; Snapshot day; on the books	A survey of specialist disability support service providers funded by the Commonwealth	Service outlets and people receiving Commonwealth CSDA-funded employment services	To obtain data about clients, staff, operations and finances of services under the Disability Services Act 1986	Service details; Disability status, types; Support needed; Performance indicators	Publications
National Information Management System (NIMS) for open employment services	Australian Institute of Health and Welfare PO Box 570 Canberra ACT 2601 Ph. 02 6244 1000 www.aihw.gov.au	Quarterly March 1995–June 1999; ceased 1999	A survey of open employment service providers funded by the Commonwealth	Service outlets and people receiving CSDA-funded open employment services	To obtain data about providers and recipients of specialist open employment services	Service details; Disability status, types; Support needed; Performance indicators; Jobs obtained, current	Publications
Centrelink databases: • Disability Support Pension • Carer Allowance • Mobility Allowance • Sickness Allowance • Carer Payment	Centrelink PO Box 7788 Canberra Mail Centre ACT 2610 Ph. 02 6244 7270 www.centrelink.gov.au knowledge.desk@centrelink.gov.au	Ongoing, regular downloads	Details provided by clients	Centrelink clients receiving DSP, CA, MA, SA, Carer Payment; People being cared for by CA recipients; Dependents of clients	To administer payments to people receiving income support payments and allowances	Pension types, rates, duration; Income/asset levels; Medical condition, status; Rent assistance; Dependents	Statistical summaries; Tables on request*
Department of Veterans' Affairs Client Database: • Service Pension (Permanently incapacitated veterans) • Disability Pension	Department of Veterans' Affairs 13 Keltie Street Woden ACT 2606 Ph. 02 6289 1111 www.dva.gov.au	Ongoing, regular downloads	Details provided by veterans and their dependants	DVA clients receiving Service Pension, Disability Pension, Special Disability Allowance, and dependants of veterans	To administer payments to people receiving income support and compensation payments and allowances	Pension types, rates; Qualifying war service; Special disability allowances, eligibility for treatment	Statistical summaries

Surveys of consumer satisfaction with CSDA-funded services	SCRCSPP/NDAP Productivity Commission Locked Bag 2 Collins St East Post Office Melbourne Vic 8003	1999	National collation of sample surveys by service type and state	People receiving services under the CSDA	To obtain data about the satisfaction of recipients of specialist disability support services	Satisfaction measures; Access to services; Level of choice of service; Relationships with staff; Quality of life	Publications
<b>Other related collections</b>							
National Survey of Mental Health & Wellbeing of Adults	Australian Bureau of Statistics† PO Box 10 Belconnen ACT 2616 Ph. 02 6252 6627 www.abs.gov.au	1997 May–August	Estimates based on responses to a sample survey of households with interviewers	People aged over 17 in urban or rural areas (not remote) residing in private dwellings (not special dwellings)	To monitor initiatives of the National Mental Health Strategy and provide a baseline to evaluate future activity	Prevalence of selected major mental disorders; Level of disability; Help needed; Health services used	Publications; Tables on request; Confidentialised Unit Record File
National Health Survey	Australian Bureau of Statistics PO Box 10 Belconnen ACT 2616 Ph. 02 6252 6627 www.abs.gov.au	1989–90, 1995	Estimates based on survey of households with interviewers	People of all ages residing in private dwellings in urban and rural areas (remote areas included, but not for future surveys)	To obtain data about recent and long-term illnesses, risk factors and health interventions	Prevalence of health conditions; Consultations with doctors and other health professionals; Use of medications; Alcohol consumption; Smoking and exercise patterns	Publications; Tables on request; Confidentialised Unit Record File
Australian Spinal Cord Injury Register	National Injury Surveillance Unit Flinders University Mark Oliphant Building Laffer Drive Bedford Park SA 5042 Ph. 08 8374 0970	1986–1991; Ongoing since July 1995; Reporting annually	Collation of data recorded by Australia's six hospital-based specialist spinal treatment units	People with persisting spinal cord injury	To monitor cause and severity for cases of spinal cord injury	Incidence; Cause; Clinical data; Hospital length of stay	Publications
Birth Defects collections	National Perinatal Statistics Unit Lvl 2 McNiven Dickson Bldg Sydney Children's Hospital Randwick Hospital Campus Randwick NSW 2031 Ph. 02 9382 1014	Ongoing since 1981; Reporting on an annual basis	National collation of data on births notified to perinatal data units, including birth defects registers, in States and Territories	Children born with major congenital abnormalities	To monitor the incidence of major congenital abnormalities	Incidence; Malformations; Trends: time and place; Evaluation of diagnosis or interventions	Publications
Home and Community Care Program Data Collections	Dept. of Health and Aged Care GPO Box 9848 Canberra ACT 2601 Ph. 02 6289 1555 www.health.gov.au	User characteristics and service provision; Annual basis	National collation of surveys undertaken by jurisdictions.	Clients accessing HACC services and receiving HACC services	To obtain data about HACC clients and the extent and type of services they receive	Services received	Publications
Supported Accommodation Assistance Program National Data Collection	SAAP NDC Agency c/o AIHW GPO Box 570 Canberra ACT 2601 Ph. 1 800 027 191 ndca@aihw.gov.au	Client collection; ongoing since March 1996, reporting annually since 1996–97	National collation of data from agencies providing accommodation and/or assistance for the homeless	Clients, agencies, support periods funded under the SAAP program	To obtain data about clients, agencies, support periods, unmet demand, etc. to inform policy, planning and service delivery	Accommodation and/or assistance for the homeless	Publications; Tables on request
Household Expenditure Survey	Australian Bureau of Statistics† PO Box 10 Belconnen ACT 2616 Ph. 02 6252 6627 www.abs.gov.au	Periodically since 1974–75	Estimates based on survey of households with interviewers or expenditure diaries	People in urban or rural areas (not remote) residing in private dwellings (not special dwellings). Identifies people with disabilities/long-term health conditions	To obtain data about expenditure and how it varies by income level and source, household size/composition, etc.	Housing; Food; Health; Medical care; Labour force status	Publications; Tables on request; Confidentialised Unit Record File

COLLECTION NAME	DATA CUSTODIAN	FREQUENCY OR TIMING	COLLECTION METHODS	TARGET POPULATION	OBJECTIVE OR PURPOSE	SELECTED KEY CONTENT OR ELEMENTS	ACCESSIBILITY
<b>Other related collections</b>							
ABS Community Services Survey	Australian Bureau of Statistics† PO Box 10, Belconnen ACT 2616 Ph. 02 6252 6627 www.abs.gov.au	1995–96	Estimates based on responses of a sample survey of providers of community services	Employing businesses and organisations providing community services, and other relevant organisations and departments	To obtain data about the size of the community services industry	Activities; Expenditure; Employees; Size of business	Publications; Tables on request
ABS Time Use Survey	Australian Bureau of Statistics† PO Box 10, Belconnen ACT 2616 Ph. 02 6252 6627 www.abs.gov.au	1992, 1997	Estimates based on responses to a sample survey of households with interviewers and activity diaries	People aged over 14 in urban or rural areas (not remote) residing in private dwellings (not special dwellings). Identifies people with disabilities/long-term health conditions	To obtain data about time spent on activities where, and with whom	Activities, including paid, unpaid and voluntary work; Study; Personal, social and leisure activities	Publications; Tables on request; Confidentialised Unit Record File
Survey of Education and Training	Australian Bureau of Statistics† PO Box 10, Belconnen ACT 2616 Ph. 02 6252 6627 www.abs.gov.au	1997	Estimates based on responses to a sample survey of households with interviewers	People aged over 15–64 residing in private dwellings in urban and rural areas, employed or employed in the last 12 months, marginally attached to the labour force, or in full- or part-time education. Identifies people with disabilities/long-term health conditions	To obtain data about education and training; access, participation and outcomes	Qualifications completed or attempted but not completed; Study intentions; Educational achievement; Training courses and on-the-job training in the last 12 months	Publications; Tables on request; Confidentialised Unit Record File
Commonwealth Rehabilitation Service Management Information System	CRS Australia GPO Box 9848 Canberra ACT 2601 Ph. 02 6212 2900 www.crsrehab.gov.au	Ongoing	Details provided by clients and administrative data	People receiving CRS services	To administer services to people receiving CRS services	Service provision data	Publications
Hearing Services Client Database	Hearing Australia Inc. 126 Greville St Chatswood NSW 2067 Ph. 02 9412 6800	Ongoing	Details provided by clients and administrative data	Clients applying for hearing services	To administer services and record client case histories	Assessment; Hearing aid fittings; Rehabilitation	Publications
Workers' compensation statistics	WorkSafe Australia GPO Box 58 Sydney NSW 2001 Ph. 02 9577 9555 www.worksafe.gov.au	Ongoing since 1986–87	National collation of details provided by WorkCover authorities	People with compensable injuries and diseases	To monitor occupational injuries and diseases	Occupation; Type of accident; Extent of disability	Publications
WorkCover	NSW 02 9370 5259 WA 08 9388 5555 ACT 02 6205 0200 TAS 1300 366 322 QLD 1300 362 128 NT 08 8999 5026 VIC 03 9641 1444 SA 08 8233 2222	Continuous	Details provided by insurers	Employees	To monitor occupational injuries, the WorkCover program and identify areas for prevention	Financial Information; Injury; Accident; Plans to return to work; Injured person and employers details	Publications; Data requests

Motor Accident Authority (NSW)	Level 22, 580 George Street Sydney NSW 2000 Ph. 1300 137 131 www.maa.nsw.gov.au	Continuous	Insurers provide quarterly data	Motor accidents resulting in a claim on insurance	Monitoring the scheme; Research; Strategies for road safety	No of claims; Costs involved; Payments made; Type of injury	Annual publications; Data requests
Transport Accident Commission (Victoria)	222 Exhibition Street Melbourne VIC 3001 Ph. 03 9664 6098 www.tac.vic.gov.au	Continuous	Data entry from claims	Insurance claims for accidents involving a Victorian registered vehicle	Accident prevention; Claims management	Claims form data; Accounts data from service providers	Annual reports; Data requests
Motor Accidents Insurance (Tasmania)	1st Floor, 33 George Street Launceston TAS 7250 Ph. 03 6336 4800 www.malb.tas.gov.au	Continuous	Data entry from claims	Motor accidents involving Tasmanian registered vehicles	Claims management	No. of claims; Type of injury; Costs of injury; Whether injured person was driver, pedestrian or passenger	Annual report; Data requests
Territory Insurance Office (Northern Territory)	66 Smith Street Darwin NT 0801 Ph. 08 8946 2222 www.tiofi.com.au	Continuous	Data entry from claims	All people injured by a Territory registered vehicle	Claims management	Claims data; Injury codes; Accounts data	Annual report
Motor Accident Insurance Commission	Level 18 288 Edward Street Brisbane QLD 4001 Ph. 07 3227 8088 www.maic.qld.gov.au	Continuous	Insurers provide data monthly	Motor accidents resulting in a claim for personal injury	Scheme monitoring and research	Claims, vehicles, injury coding, costs, accidents and role data	Annual report; Data requests
Insurance Commission of Western Australia	22nd Floor The Forrest Centre 221 St George's Terrace Perth WA 6000 Ph. 08 9264 3333 www.icwa.wa.gov.au	Continuous	Data entry from claims	Claimants on insurance of motor vehicles in Western Australia	Claims management	Claims data; Type of injury; Costs of injury	Annual report; Data requests
SGIC (on behalf of the Motor Accident Commission)	211 Victoria Square Adelaide SA 5000 Ph. 08 8223 1188 www.sgic.com.au (under construction)	Continuous	Data entry from claims	Motor accidents involving South Australian registered vehicles	Claims management	No. of claims; Type of injury; Costs of injury; Whether injured person was driver, pedestrian or passenger	Data requests
Non-government Schools Census	Dept. of Education, Training and Youth Affairs PO Box 9880 Canberra ACT 2601 www.detya.gov.au	Biennial	Survey of non-government primary and secondary schools	All non-government school children	To administer grants to educational authorities	Includes question on the disability status of children	Tables on request
Government Schools Censuses	Education authorities in each State/Territory	Various	Census	All government school children	To administer grants to educational authorities	Includes question on disability status	Tables on request
Technical and Further Education commencements	National Centre for Vocational and Educational Research Ph. 08 8333 8432	Annual	Details of course enrolments provided by educational institutions	All people enrolled in TAFE courses	To administer TAFE courses	Includes question on disability status	Tables on request
Apprentices in training	National Centre for Vocational and Educational Research Ph. 08 8333 8432	Quarterly	Details provided by apprenticeship authorities	All apprentices	To monitor apprenticeships	Includes question on disability status	Tables on request

† There are regional offices in capital cities

\* There may be a charge if expensive analyses are required

**The information in a data publication may look useful, but it is wise to check some details about the data before quoting from it.**

## 3 Understanding data

---

The information in a data publication may look useful, but it is wise to check some details about the data before quoting from it. Go to where there is detail about how and when the data were collected and who supplied the data (that is, who answered the questions). Be sure that you know exactly what was being counted, for example, clients, service occasions, beds, places in use, places available for use, etc. There can be subtle differences, so look for definitions of these. Are the numbers estimates or actual counted things? Check the following:

- The definitions of terms used, such as 'disability', 'mobility difficulty', 'high support needs', 'severe disability', 'neurological disability';
- The meaning of the terms used, such as 'prevalence', 'rate', 'labour force', 'unemployed';
- Over what time period the counting happened, for example, a year, a day, the last six months before the survey, etc.;
- The geographic area, for example, Australia, all States except one, a region;
- What questions were asked to get the data. The actual survey form or interview questionnaire can be very useful, though they are often difficult to obtain. Again, subtle differences can greatly affect the way data should be interpreted. For example, counting the people who answer 'yes' to the question 'Do you have a disability?' is entirely different to counting people who answer 'yes' to a range of disability-related questions like 'Do you have problems hearing?'
- Who supplied the data. There is a difference in the way questions are answered depending on whether the person directly involved answers or whether someone else answers on their behalf.

Often data publications will give you exactly what you want; but sometimes data appear to be very complex or you would like the information presented in a slightly different way or tailored to a more specific purpose. You will then need to know more about the collections and about who holds them (refer to the table for contacts). Source organisations should be able to provide assistance and advice in terms of interpreting data. It is also important to provide comments to source organisations where you feel data collected have not met your needs or have not been presented in a user-friendly way.

## 4 Presenting data

---

Once you have located your data, think about what is relevant for your purpose and how to present it in a useful and accurate way.

### **DATA USED SHOULD BE:**

- Relevant, for example:
  - ▶ if you are talking about the needs of older people with disability, use data appropriate to that age group (e.g. over 65 years) and define the specific disability group you are talking about; and
  - ▶ if you are talking about employment for people with disabilities, use data appropriate to people of employment age, e.g. 15–64.
- Reliable, so check all the notes in the publication about reliability (e.g. the ABS uses asterisks, one or two, to indicate how cautious you need to be with a particular bit of data);
- The most up-to-date data available.

## **DATA PRESENTED TO OTHERS SHOULD:**

- Be defined in the precise terms as used by the original data collectors. For example, if you are talking about people with physical disability, define which people come under this general term, and which don't;
- State the population covered (e.g. all people with disability, or a group with one type of disability, or people living at home, or a particular age-group, or the geographical coverage). Use table or graph captions and footnotes to show precisely what group of people the data cover;
- State the sample size and date that the data were collected (e.g. 'A survey of 140 families receiving services from the ...Association in the western Sydney area in 1997 showed that...');
- State what the numbers are, for example, percentages, actual numbers, estimates of numbers, and the units being used are, for example, thousands (often shown in a table by using '000 in the column or row labels), millions of dollars (often expressed as \$m);
- State the source and page or table number of any information, so that the reader can verify or get extra information. You can do this in the text, below a table, or on an overhead.

If you use a graph, make the actual numbers used in it also available (usually in a table), so people interested in your data can do further analysis.

If you use data to show trends over time, use as long a data series as possible, and show the time intervals.

When rounding figures, use standard rules and be consistent throughout your document.

When you are comparing data from a variety of sources, think about whether you are comparing 'like' with 'like' in terms of, for example:

- content (i.e. counting the same thing using the same definition);
- time frame (e.g. annual figures); and
- geographical coverage (e.g. same State, or the whole of Australia).

## **WHEN USING DATA:**

- Don't generalise from a small sample to a larger sample, or from a small region to a larger region (e.g. data from NSW cannot be generalised to the whole of Australia without checking a range of possibilities, such as demographic variables, that could mean that NSW is different from Australia).
- Don't jump to conclusions about the data you have found (e.g. changes in disability rates over time could be due to population ageing, greater readiness to identify as having a disability, or both, or something else entirely).
- In the same vein, don't assume a cause and effect relationship where there is no evidence that one exists. Correlation is the way to measure the strength of the relationships between two or more variables (e.g. the relationship between number of hours of therapy and the amount of improvement in functioning). It is important to consider that there are other factors involved such as the natural course of recovery and the hours of therapy from carers.
- Don't use data from different years, or collected over a different length of time, without stating that—always check the year of collection, and the collection period.

**The aim of the Data Dictionaries is to provide a 'common language' for the various agencies and organisations.**

## 5 Data dictionaries and standards

---

Under the National Information Agreements the *National Community Services Data Dictionary* and the *National Health Data Dictionary* are the authoritative sources for data definitions where national consistency is required or desired. The dictionaries are designed to improve the comparability of data. They are also designed to make data collection activities more efficient, reducing duplication of effort by providing standards for core data items, and more effective, by ensuring that information to be collected is appropriate to its purpose. The dictionaries may also be useful in providing a checklist for those developing data collection tools, such as surveys, to ensure that all possible responses are covered, at least in aggregate form. The aim is to provide a 'common language' for the various agencies and organisations.

### DATA DICTIONARIES

Australian Institute of Health and Welfare 2000. *National Community Services Data Dictionary*. Version 2. AIHW cat. no. HWI 27. Canberra: AIHW.

National Health Data Committee 1999. *National Health Data Dictionary*. Version 8.0. AIHW cat. no. HWI 18. Canberra: AIHW.

### OTHER RESOURCES

#### Catalogues

Australian Bureau of Statistics. *Catalogue of Publications and Products*. No. 1101.0 July 2000. Canberra: ABS.

Australian Institute of Health and Welfare *Publications and Services Catalogue* 2000. Canberra: AIHW.

#### Your local library

Library searches on AUSTROM, APAIS, Social Sciences Citation Index, and Family. A range of ABS publications are available—contact your librarian.

### THE KNOWLEDGEBASE

This is an Internet-based electronic storage site for Australian national health metadata (that is, data about data), and includes a powerful query tool. It can be accessed through the AIHW's internet site. You can use the Knowledgebase to find out what data collections are available on a particular health-related topic or term, and any related official national agreements, definitions, standards and work programs, as well as any linked organisations, institutions, groups, etc. It does not (currently) make actual data available. This is a technical site. It is not intended for the beginning disability data user!

## Acknowledgments

---

#### Catherine Sykes

Australian Institute of Health & Welfare

#### Joanne Maples

Australian Institute of Health & Welfare

#### Ros Madden

Australian Institute of Health & Welfare

#### Chrysanthe Psychogios

Australian Institute of Health & Welfare

#### Helen McAuley

ACROD

#### Gerry Brophy

National Caucus of Disability Consumer Organisations

Thank you for contributing to the preparation of this document.