

11 Overview of relevant data sources

This chapter provides an overview of nationally significant data sources relevant to the ageing and disability project. The chapter begins with a review of the ABS population surveys and other data relating to disability, followed by a discussion of data relating to services provided for people with a disability. Data gaps and limitations are examined.

11.1 ABS population surveys of relevance to disability

The ABS national disability surveys

The ABS disability surveys provide cross-sectional data collected at four points in time (1981, 1988, 1993 and 1998) over a period of 17 years. The ABS disability surveys are an important source of national population data on disability, covering both rural and urban areas in all States and Territories. Data are gathered from both household and cared accommodation (establishment) samples.

In the 1998 Survey of Disability, Ageing and Carers, the household sample included about 15,300 private dwellings and 400 non-private dwelling units, while the cared accommodation sample included approximately 800 establishments. The effective sample resulted in about 37,000 persons for the household component and 5,700 persons for the cared accommodation component (ABS 1999: 52–53).

The operational definitions of disability used in the surveys were adapted from the definition of disability of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO 1980). The survey definitions are relatively broad, aiming to ensure that all people with a disability are identified by the survey. Unlike administrative agency records, the surveys rely on respondents' self-reported information.

In the 1998 disability survey a person is considered to have a disability if he/she has a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities (ABS 1999: 67). A 'specific restriction' is defined as a restriction in core activities (self-care, mobility and communication), schooling or employment (ABS 1999: 72). This corresponds with the concept of 'handicap' used in the previous surveys. 'Handicap' was identified where a person had a limitation in performing certain tasks associated with daily living in the areas of self-care, mobility and verbal communication, schooling or employment, due to their disability (ABS 1993).

In the 1981 and 1988 surveys, three levels of severity of handicap (mild, moderate and severe) were determined on the basis of the person's ability to perform tasks relevant to self-care, mobility and verbal communication and the amount of assistance they required. In the 1993 survey the severe handicap category was further divided into severe handicap and profound handicap (ABS 1993).

Similarly, in the 1998 survey four levels of core activity restriction are determined, based on whether a person needs help with, has difficulty with, or uses aids or equipment for any of the core activities. A person's overall level of core activity restriction is determined by the highest level of restriction they experienced in any of the core activity areas. Profound core activity restriction refers to a person who is unable to do, or always needs help with, a core activity. Severe core activity restriction refers to a person who sometimes needs help with a core activity, or has difficulty understanding or being understood by family or friends, or, who can communicate more easily using sign language or other non-spoken forms of communication (ABS 1999: 66).

In the survey, respondents were also asked to indicate their long-term condition. A long-term condition is defined in the survey as a disease or disorder that has lasted or is likely to last for at least six months; or a disease, disorder or event (e.g. stroke, poisoning, accident, etc.) that produces an impairment or restriction that has lasted or is likely to last for at least six months. A main condition is a long-term condition identified by a person as the one causing the most problems. Where only one long-term condition is reported, it is recorded as the main condition (ABS 1999: 69).

The 1998 disability survey has also included questions on self-perceived health for people with a disability and primary carers. A 12-item short form (SF-12) health survey instrument was used in the survey questionnaire. People interviewed were asked to rate their own health on a five-point scale and were asked questions about the extent to which they were limited by their health in the four weeks prior to the interview (AIHW 1999a; Ware et al. 1996).

The ABS National Health Surveys

The National Health Surveys obtain information about the health status of Australians, their use of health services and facilities, and health-related aspects of their lifestyle such as smoking, alcohol consumption and exercise (ABS 1979, 1991 and 1997). These surveys have been used as a major source for the analysis of health and health service use differentials in Australia.

Information most relevant to disability in the National Health Surveys comes from the data item about long-term conditions. In the Surveys, long-term conditions are defined as medical conditions (illness, injury or disability) that have lasted or are expected to last six months or more.

Unlike the disability surveys, the long-term conditions recorded in the National Health Surveys are not necessarily associated with disabilities. According to the survey data coding rules, long-term conditions are coded as medical conditions using ICD-9 codes. Only impairments or disorders that cannot be classified using ICD-9 medical condition or injury categories are coded using a 'residual' category—'disability not elsewhere classified' (e.g. incomplete use of arms or fingers) (ABS 1996, 1997). As with many sources of health data, there is a limited amount of information on the disabilities in terms of consequences of the conditions and impairments reported.

The National Health Surveys cover only people in households and exclude people in hospitals, nursing homes and other institutions. This may contribute to an underestimation of the prevalence of long-term conditions in the general population.

Nevertheless, morbidity data on long-term conditions collected from the Surveys can assist in explaining the prevalence, demographic pattern and cause of disability in Australia, and looking at trends over time.

The National Survey of Mental Health and Wellbeing of Adults

The National Survey of Mental Health and Wellbeing of Adults (SMHWB) was conducted in 1997 as an initiative of the National Mental Health Strategy. The purpose of the survey was to collect information from adults aged 18 years and over about the prevalence of a range of major mental disorders, the severity of disability associated with these disorders, and health service usage and needs for assistance as a result of mental disorders (ABS 1998e).

The SMHWB used a number of different measures of disability and health outcome: the Brief Disability Questionnaire (BDQ), the Short Form 12 (SF-12) and Days Out of Role. The BDQ is a standard questionnaire that contains eight questions emphasising physical aspects of disability (Ormel et al. 1994). Respondents were asked whether they had limitations in a number of activities such as running or sports, carrying groceries, climbing stairs, bending, lifting, walking long distances and bathing or using the toilet. They were also asked whether they had cut down or stopped activities, had decreased motivation or personal efficiency, or experienced deterioration in their social relations. The Medical Outcome Study method of scoring (scale of 0–16) was used as a measurement for the BDQ, with a high score indicating that respondents have been limited in their activities due to health problems (ABS 1998e: 50).

The SF-12 is a commonly used international instrument consisting of 12 questions that provide a generic measure of health status. The SF-12 contains eight concepts: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality (energy/fatigue), social functioning, role limitations due to emotional problems, and mental health (psychological distress and psychological wellbeing) (ABS 1998e: 52). The SF-12 has two measures: the physical component summary (PCS) and the mental component summary (MCS).

Days Out of Role measures the number of days, in the four weeks prior to interview, when respondents were unable to carry out usual activities fully (ABS 1998e).

Some caveats should be noted when the SMHWB information about disability is used:

- The BDQ differs from the measures of disability used in the ABS disability surveys in terms of the conceptual framework and definition of disability used. Although the BDQ measures activity limitations, the scope of activity in the ABS disability surveys is much broader than that of the BDQ. The eight items of the BDQ mainly focus on physical functioning, although the ABS disability survey screening questions are also somewhat focused on physical abilities of daily living.
- The empirical basis of the two SF-12 summary measures (PCS, MCS) is not necessarily appropriate for the Australian population. The two measures were developed on the basis of physical and mental health data relating to the US population (ABS 1998e: 52).
- All three disability measures (BDQ, SF-12 and Days Out of Role) focus on disability present during the four weeks prior to the interview, while the ABS disability surveys focus on disability that has lasted, or is likely last, for at least six months.
- Information about dementia-related disorders was not collected by the SMHWB, although it contributes significantly to mental health problems and disorders among older people (AIHW 1999b).
- The exclusion of people living in any type of institution from the SMHWB means that a significant group of people with mental disorders was not captured.

The ABS national time use surveys

The ABS time use surveys conducted in 1992 and 1997 examine how people allocate their time to different activities. The surveys provide information about time spent on activities such as personal care, employment, education, community participation (including voluntary work), leisure activities, travel, fitness and health activities, together with people's use of technology and their outsourcing of domestic tasks. These surveys also contain information about time spent on caring for people with disability and children. The data were collected partly by interview and partly using self-completion diaries. First, information was collected from an adult member of the selected household for all persons aged 15 years and over in the household. A diary was then left for each of these persons to record their activities over two specified days (ABS 1998c, 1998d).

An ABS 'disability module' was used in the surveys to collect basic information about disability status. The module used, which is not the same as BDQ in the mental health survey, consisted of a series of questions about health conditions associated with disability. These questions were based on the screening questions used in the ABS disability surveys. The disability module has been used in a number of ABS household surveys not primarily designed to collect disability information but rather to identify respondents with a disability.

Data from the time use surveys could be used to monitor overall outcomes for people with a disability, in particular their level and pattern of participation in a range of activities. The surveys could also be used to compare aspects of the lives of people with a disability and people in the broader community (AIHW 1997b, 1999a).

Nevertheless, caution should be exercised in interpreting time use survey data about disability status for a number of reasons:

- While there is a disability module on the survey form, far fewer questions on disability are asked in the time use surveys than in the disability surveys.
- Information about disability status obtained from the two surveys are not directly comparable.
- The sample size (over 4,500 households or 8,600 persons) is markedly smaller than that of the disability surveys.
- The time use surveys cover only people living in private dwellings, while the disability surveys also collect information about people living in institutions and cared accommodation (ABS 1998c, 1998d).

11.2 Administrative data relating to services provided for people with a disability

The following national administrative data sources contain information about services provided for people with disability, and are relevant to this project:

- CSDA MDS and associated collections of disability administrations in all jurisdictions;
- various databases of the Department of Family and Community Services;
- residential aged care data collections;
- HACC service provision data collection; and
- HACC user characteristics data collection.

The CSDA MDS collections are under the guidance of the National Disability Administrators. The purpose of the CSDA MDS collection is to facilitate the annual collation of reliable, consistent and nationally comparable data from CSDA-funded services. The information is used for disability service planning and national program evaluation. The data are collected using two forms: a service form and a consumer form. The collections are 'snapshot' day collections, which ask for data about services on a specific day during the year. The most recent snapshot day was specified for May 2000, although the specific day varies depending on the State or Territory funding department. The first full pilot test of the CSDA MDS collection was conducted in late 1994 and the first annual collection was conducted in the second half of 1995. Data items include not only demographic characteristics but also disability group, need for support or assistance, main source of income and living arrangement. Some of the data items for consumers were designed to relate to the ABS population census and disability survey data (Black & Madden 1995; Black & Maples 1998; AIHW 1999c).

In the 1998 collection of the CSDA MDS, a linkage key was pilot tested to statistically record use of multiple services by individuals on the 'snapshot' day. The aim was to overcome the problem of double-counting clients who receive services from more than one outlet, enabling estimation of the number of individual consumers on the snapshot day, as opposed to the number of services received. All States participated in the linkage key trial in the 1999 CSDA MDS collection (AIHW *Disability Data Briefing* Number 17, March 2000).

The databases of the Department of Family and Community Services include information on recipients of disability-related pensions and benefits, such as the Disability Support Pension, Carer Pension and Child Disability Allowance. Data on recipients include demographic characteristics, impairments and medical conditions. The databases provide useful information for assessing the implications of population ageing on the number of recipients of the Disability Support Pension and the number of people likely to require disability support services. The CSDA MDS 1997 collection showed that 86% of adult clients (aged 16 years or over) of CSDA-funded services are recipients of the Disability Support Pension.

The residential aged care data collections include information about all residents admitted to a residential care facility. The residential aged care structural reform policy introduced in October 1997 has merged nursing homes and hostels into a single residential care system. As a result, the two previous data collection systems (the Nursing Home Payment System and the Commonwealth Hostel Information Payment System) were replaced by a single system—the System of Payment for Aged Residential Care (SPARC) (AIHW 1999a).

The HACC service provision data collection obtains information from HACC-funded service outlets on recipient profiles and the amount of service provided. The information is collected twice a year (May and November) from all HACC-funded service outlets by State Governments and provided to the Commonwealth Government for coordination and monitoring. The data have been used to compare a region's share of the service target population (people with a profound, severe or moderate handicap) with its share of HACC services (Department of Health and Aged Care 1998).

The HACC user characteristics data collection provides data used to monitor access of the HACC target group and special needs groups to HACC-funded services. The collection obtains client information by surveying a 10–20% sample of HACC recipients from all services participating in the HACC service provision data collection (a higher proportion of recipients is selected in the Northern Territory and the Australian Capital Territory). Service providers complete client survey forms using their client records. States are responsible for collecting data and providing it to the Commonwealth for national coordination and

monitoring. Over 28,000 survey forms were completed in 1989–90 and 41,600 in 1993–1994 (Department of Health and Aged Care 1998).

There are several limitations that need to be taken into account in the analysis of the HACC data. There are duplicate records for clients who receive services from more than one outlet; forms with any data missing are not included in the collection; sampling methods, service type definitions and data quality vary between jurisdictions. The current data cannot provide definitive answers to such questions as:

- How many people receive HACC services at any given time or over a set time period?
- How much HACC service is provided in a particular region?
- What combinations of service types might one client use over a specific period?

A new HACC MDS, developed by the AIHW for Commonwealth and State/Territory HACC officials in 1998, and pilot tested nationally in 1999, is scheduled for full implementation from 1 January 2001. The HACC MDS collection is a client-centred data collection that will replace the previous HACC Service Provision, HACC User Characteristics and Community Options data collections. It is designed to answer the sort of questions listed above (Ryan et al. 1998: 1).

11.3 Data limitations and key data sources for analysis

This chapter has reviewed some significant national data sources currently available. Other data sources relating to disability prevalence and disability groups have been reviewed in a number of AIHW reports (e.g. Madden et al. 1996; Wen 1997; Mathers et al. 1999; Fortune & Wen 1999; Wen & Fortune 1999). These data sources include special studies providing health or epidemiological information of possible relevance to disability, registration data and hospital morbidity data.

One of the major limitations of the data currently available is the difficulty in making comparisons between population and administrative data sources, and between different administrative collections. The underlying purposes of surveys and data collections are diverse, and thus the data collection methods vary.

For this project, therefore, a key population data source and a key administrative data source were identified and relied on. Other data sources were used as supplementary information. The key data sources chosen are those most recent and readily available and most relevant to the current project.

Of the national population surveys, only the ABS disability surveys are designed specifically to generate a comprehensive national overview of levels and patterns of disability in Australia. The surveys contain useful information on people with a disability and their needs for assistance. The survey definition of severe or profound core activity restrictions is based on the need for frequent or continual personal support in three areas of activity (self-care, mobility and communication). This corresponds quite closely to the 'target population' of CSDA services (AIHW 1997b). The information collected by the survey is also relevant to the analysis of aged care services. Therefore, the ABS disability surveys will be used in this project as the key population data source for conducting analyses and producing estimates at the national level.

The CSDA MDS collections are used in this project as the key administrative data source for information about disability service provision and usage, since this project focuses on CSDA

services. The Department of Family and Community Services databases provide information on recipients of income support programs and service programs. HACC service data and residential aged care data provide supplementary information on services used by people with a disability, especially as they age.