

2 Introduction

This report presents data about services directly provided or funded by government in 2000 under the Commonwealth/State Disability Agreement (CSDA). This agreement, signed in 1998, places responsibility for planning, policy setting and management of employment services with the Commonwealth, whilst the States and Territories are responsible for all other disability services. Advocacy, print disability and information services are considered shared responsibilities under this agreement. Services provided under the CSDA are designed for people who need ongoing support with everyday life activities.

2.1 CSDA MDS collections

The CSDA MDS collections are conducted under the auspices of the National Disability Administrators (comprising the heads of government disability services throughout Australia). The purpose of the CSDA MDS is to collate national data relating to services under the CSDA and their consumers, and to facilitate the exchange of information between jurisdictions by the design and use of standard core data items and agreed definitions. This 2000 collection is the sixth annual collection and the fourth fully national collection.³

Data are collected about service providers and about people receiving a service from a service provider on a 'snapshot' day, that is, on a single day during each year. Data are collected by each jurisdiction in relation to services provided under the CSDA. Services included under the CSDA umbrella vary slightly from State to State. Section 2.3 outlines where these differences occur.

2.2 Collection method and data included

Service providers completed a Service Form⁴ and multiple Consumer Forms to produce the data. In general, a Service Form is completed for each service type at each outlet and a Consumer Form is completed for each person receiving that service type at the outlet on a snapshot day (see Appendix 3 for the 2000 forms). Each year the AIHW develops, in cooperation with all jurisdictions, standard versions of a Service Form, a Consumer Form and a Data Guide.

3 In 1995, data on services funded by the Western Australian Government were not included. In 1996, data on services funded by the Australian Capital Territory and on some services funded by the Commonwealth Government were not included. These variations are significant for the purposes of comparability with this 2000 collection.

4 Some information on the Service Forms is completed by the funding organisation. This includes service type, auspicing organisation and geographic location of the service.

The snapshot day was Wednesday, 24 May 2000 for all but three jurisdictions. These were:

- Western Australia – Wednesday, 14 June 2000;
- Northern Territory – Wednesday, 7 June 2000; and
- the Commonwealth – Friday, 30 June 2000.

The data items collected on the 2000 Consumer Form included demographics, selected letters of the consumer's name for the linkage key, Indigenous status, communication method, primary and other significant disabilities, support needs, and living arrangements. The data items collected on the 2000 Service Form included information about service type provided, hours worked by staff (both paid and unpaid), annual funding under the CSDA, times of operation and number of recipients.

Forms are completed by service providers and sent (as hard copy or electronic file) to the government funding organisation in each jurisdiction. Here, data are edited and a data file finalised for each jurisdiction.⁵ This file is used for analysis by each jurisdiction, and a copy containing the nationally agreed CSDA MDS data items is sent to the AIHW for further editing and national collation.

2.3 Scope of the collection

The collection covers disability support services receiving some funding under the CSDA in 2000, and the consumers of those services. It does not include services that do not receive CSDA funding – for instance, many services in the areas of rehabilitation, hearing services, aids and appliances – or those funded solely through the Home and Community Care Program. It excludes residential aged care facilities, hospitals and any services that receive no government funding. In the context of this collection CSDA-funded services generally consist of:

- those services for people with a disability that were funded or provided by the 'disability program area' of each State and Territory before the first CSDA, and which were considered to be of a type to be included in the initial 'CSDA base';
- those services for people with a disability that were transferred between the Commonwealth, States and Territories at the start of the first CSDA in 1991; and
- services provided or funded under the CSDA since the signing of the first CSDA and included under the second agreement signed in 1998.

There is some variation between jurisdictions in the services included under the CSDA. Therapy services are not included separately in the collection by all jurisdictions, although some therapy services may be included as a component within other service types. Not every State or Territory includes psychiatric services or early childhood intervention services:

- In New South Wales, psychiatric disability services are provided by the New South Wales Department of Health.
- In Victoria, early childhood intervention services were included under the CSDA and hence are included in this collection. Psychiatric disability services are also included.

⁵ Some jurisdictions add data items of particular interest to them, sometimes for a single year.

- In Queensland, psychiatric disability services funded and provided by the Mental Health Branch of Queensland Health are included in the CSDA MDS collections, but services funded under the 'Gaming Machine Community Benefit Fund' are not.
- In the Australian Capital Territory, only some mental health services are included in the CSDA MDS collections.
- In the Northern Territory, some mental health services and early childhood intervention services are included.
- In Western Australia, only some psychiatric disability services are included in the CSDA MDS collections. The Health Department is the main provider of services for people with a psychiatric disability and these services are not included.

2.4 Counts in the collection

The main counts of the MDS collection in 2000 are service outlets and consumers (see also Box 2.1). In addition, previous reports up to 1998 and some tables in this report are based on counts of services received.

A service outlet is a service provider funded to provide a particular CSDA service type at a discrete location. In general a separate service form is completed (usually by service providers) for each service outlet, but in some instances more than one outlet will be included on the one service form. That is, in some cases a 'service outlet' may in fact represent two or more outlets.

The CSDA MDS is progressing towards an outlet-based collection, but this has not been completely achieved in all jurisdictions due to some of the complexities of funding processes. Aggregation may occur because (a) two or more service types are combined together at the one location and recorded on the one form or (b) multiple sites providing the same type of service are recorded as one outlet. For example, a single site mainly providing accommodation, and recorded as such, may also be providing respite services; or a number of group homes of one organisation may be combined on one service form.

A service provider is an organisation that delivers one or more CSDA-funded service types to consumers. The service provider has an administrative base from which services of one or more service types are delivered to consumers, or from which a team operates when it delivers services to consumers at other locations.

The response rate for return of all Service Forms sent out by jurisdictions was 98% (see Section 6.1).

A person may receive more than one service over any time period, including on the snapshot day itself. For each service type (and consequently for each service outlet), a Consumer Form is completed for every consumer receiving a service of that type on the snapshot day (see Box 2.1). This means that the number of consumer *forms* represents the number of services received on the snapshot day, but not the number of consumers. That is, services received are not counts of individual consumers since a person may have received (or been allocated) resources from more than one service outlet on the day and hence may be counted more than once.

Box 2.1: Definitions and major counts of the CSDA MDS collection

<i>Consumer</i>	<p><i>A consumer is a person who receives a CSDA service.</i></p>
<i>Service</i>	<p><i>A service is a support activity delivered to a consumer, in accord with the CSDA. Services within the scope of the collection are those for which funding has been provided by a government organisation operating under the CSDA.</i></p> <p><i>A consumer may receive more than one service over any time period, including on the snapshot day itself.</i></p>
<i>Service type</i>	<p><i>Service type is the support activity which the service outlet has been funded to provide under the CSDA.</i></p> <p><i>The MDS classifies services according to 'service type'. The 'service type' classification groups services into six categories: accommodation support, employment support, community access, community support, respite and other support (see Box 2.2 for definitions). Within each of these categories there are subcategories (see for example Table 3.3).</i></p>
<i>Service outlet</i>	<p><i>A service outlet is a service provider funded to provide a particular CSDA service type at or from a discrete location.</i></p> <p><i>If a service provider provides, say, both accommodation support and respite services, it is counted as two outlets. Similarly, if a service provider is funded to provide more than one accommodation support service type (for example, group homes and attendant care) then it is providing (and is usually separately funded for) two different service types, that is, there are two service outlets for the provider.</i></p>
<i>Service provider</i>	<p><i>A service provider is an organisation that delivers one or more CSDA service types.</i></p> <p><i>It is service providers generally that fill out CSDA MDS forms:</i></p> <ul style="list-style-type: none"><i>• a Service Form for each service type funded (that is, a Service Form for each outlet); and</i><i>• for each service type (or outlet), a Consumer Form for each consumer receiving that service type on the snapshot day (except for advocacy, information, print disability).</i>
<i>Auspicing organisation</i>	<p><i>Some service providers are part of a wider organisation – either non-government or government – that has some management control over the provider.</i></p>

For the first four CSDA MDS collections (1995 to 1998) there was no way to determine consumer counts from the data on services received. Thus the reports for these years presented tables for services received (termed 'service recipients' in these reports) but not for consumers. In 1999 all jurisdictions except Western Australia collected a statistical linkage key on the Consumer Form and in 2000 all jurisdictions did so. The statistical linkage key enables the number of consumers to be estimated from the data on services received (see Box 2.3). Data collected for each service received include characteristics of a person at the collection time and place (that is, on the snapshot day, at each service outlet). Consumer counts for these characteristics can be estimated by using the linkage key.

The 1999 report presented tables for both consumers and services received. For 2000 it is possible to estimate the number of consumers across all jurisdictions; thus, the focus of this report is on consumer counts. For both 1999 and 2000 the number of services received was about 20% greater than the estimated number of consumers.

Data on consumers are presented in Sections 1 and 3 of this report. It is not appropriate to sum data from service type categories and label them as total numbers of consumers, since a consumer may be in more than one category if he or she received multiple services (see, for example, Table 1.1, where the 'totals' in the table are not the sums of the components.). Section 4 examines the patterns of multiple service use by consumers on the snapshot day.

It is important to remember that consumer counts relate to a particular day. The use of a snapshot day permits the number of consumers to be estimated at a single point in time. To the extent that the snapshot day was not an average day, this count differs from a weekly or annual average. This is likely to be more significant for particular service types, such as employment, recreation and respite services.

Consumer Forms were not required for some service types – such as advocacy, information/referral, combined advocacy and information, print disability services – where there may be no direct contact with individual people with a disability, or where contact with consumers is transient, for example giving a telephone referral.

Box 2.2: Definitions of service types covered by the Commonwealth/ State Disability Agreement

<i>Accommodation support</i>	<i>Services that provide accommodation to people with a disability and services that provide the support needed to enable a person with a disability to remain in his or her existing accommodation.</i>
<i>Community support</i>	<i>Services that provide the support needed for a person with a disability to live in a non-institutional setting (not including support with the basic needs of living such as meal preparation and dressing included under accommodation support).</i>
<i>Community access</i>	<i>Services designed to provide opportunities for people with a disability to gain and use their abilities to enjoy their full potential for social independence. People who do not attend school or who are not employed full time mainly use these services.</i>
<i>Respite</i>	<i>Respite services provide a short-term and time-limited break for families and other voluntary care givers of people with a disability, to assist in supporting and maintaining the primary care giving relationship, while providing a positive experience for the person with a disability. While there are therefore two clients – the carer and the person with a disability – in this report the person with a disability is regarded as the primary client. Statistical tables in this report reflect this perspective.</i>
<i>Employment</i>	<i>Services that either provide employment assistance to people with a disability in obtaining and/or retaining paid employment in another organisation (open employment), and/or that support or employ people with a disability within the same organisation (supported employment).</i>
<i>Other</i>	<i>Other services, including service evaluation and training, peak bodies, and research and development.</i>

Box 2.3: Statistical linkage key

To link records within the data set, the linkage key part of each record for a service received is compared electronically with the linkage key part of all other records. Records that have matching linkage keys are assumed to belong to the same individual consumer and are 'linked'. Some degree of false linking is expected. Because the linkage key is not a unique identifier, there is a small probability that some of the linked records do not actually belong to the same individual, and, conversely, that some records that did not link do belong to the same individual. For privacy reasons, the linkage key is not constructed to enable the linking of records to the extent needed to be totally certain that a 'consumer' is one individual person.

Linkage can identify two, three or more records as probably relating to the same person. These linked records are assumed to be for one person and are counted as one consumer. Thus the total number of consumers can then be estimated.

Missing or invalid linkage keys cannot be linked to other records and so must be treated as belonging to separate individual consumers. This may result in the number of consumers being overestimated.

Most linked records specify a response for each data item consistently, and the appropriate response for the consumer (now counted as one) is easily determined. Sometimes linked records have inconsistent responses for some data items. Rules to resolve these inconsistencies have been used. Further details of the linkage processes, including a discussion of these issues, are given in Appendix 4.

The AIHW Ethics Committee approved a trial in July 1998. The Committee reviews its approval regularly – most recently in August 2000 – and has noted that the linkage key is now being collected routinely and data sets (with the consumer's name reduced to only the linkage key components) are being transmitted to the AIHW. All State and Territory jurisdictions have signed assurances in relation to the CSDA MDS collections that:

- consumers will be informed about the information being recorded and its purpose;*
- each consumer's information will not be electronically matched with other information in an attempt to identify that consumer, and no other attempt will be made to identify individuals;*
- no access to the collection will be given, except as statistical information that does not identify an individual; and*
- the information will be used for statistical purposes only.*

The Commonwealth undertakes its collection, used for CSDA MDS purposes, as well as policy development and program management purposes, meeting its legislative obligations under the Privacy Act 1988, Information Privacy Principles, and Guidelines under the Data Matching (Assistance and Tax) Act 1990.

The statistical linkage key used in the CSDA MDS was initially developed for the Home and Community Care (HACC) Minimum Data Set. The HACC MDS collection began on 1st January 2001 and will be downloaded every quarter.