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Australian Institute of Health and Welfare

Disability Services National Minimum Data Set collection Data Guide:

Data items and definitions 2010–11

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Glossary

Reporting period	<p>National Disability Agreement (NDA)-funded agencies are asked to record key information about service users on an ongoing basis, so that they can transmit the required information at the end of each 'reporting period'. Most jurisdictions have set their reporting period (and will therefore ask for information to be transmitted) at the end of each financial year quarter. Some will still only require information to be transmitted at the end of a financial year. The national collection will be transmitted annually to the AIHW.</p> <p><i>The reporting period in [jurisdiction name] is a [financial year/6-months/quarterly].</i></p>
Reference week	<p>The annual reference week is the 7-day week preceding the end of the financial year (i.e. 24 June to 30 June).</p> <p><i>[jurisdiction to specify reference weeks for other financial year quarters if relevant].</i></p>

1 Introduction to the *Disability Services NMDS*

1.1 What is the *Disability Services NMDS*?

The *Disability Services National Minimum Data Set (DS NMDS)* is a continuation of the previous Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS) and it is a national collection that has:

- a set of nationally significant data items or pieces of information that are collected in all Australian jurisdictions.
- an agreed method of collection and transmission.

The purpose of the DS NMDS collection is to facilitate the annual collation of nationally comparable data about NDA-funded services, and to obtain reliable, consistent data with minimal load on the disability services field. Under the NDA, the Disability Administrators in all Australian jurisdictions are responsible for ensuring 'that DS NMDS information will be comparable across all jurisdictions and years'. The DS NMDS is a key way of fulfilling this responsibility, and of reporting publicly on what was, in 2007–08, a \$4.8 billion program.

1.2 A brief history of the data collection

From 1994 to 2002, the Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS) 'snapshot' collections provided funding bodies, funded agencies, service users and other stakeholders with valuable information about services delivered under the CSDA and the people receiving those services. However, up until 2002, this information had only been collected on one snapshot day in the year and had therefore not been able to represent the full picture of service use.

In recognition of the changing information needs in the disability services field, the National Disability Administrators and the Australian Institute of Health and Welfare (AIHW) began working together to redevelop the CSDA MDS collection in 1999. The Facilitation and Implementation Group (FIG) was established to coordinate developments in each state and territory and at the Australian Government level throughout the redevelopment project. The FIG comprised representatives from state/territory and Commonwealth departments with responsibility for funding under the CSDA as well as funded agency and service user representatives. The name of the Commonwealth/State Disability Agreement (CSDA) was changed to the Commonwealth State/Territory Disability Agreement in mid 2002 and the redeveloped CSDA MDS became the Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS). For more information on the 2002 redevelopment process, see *Australia's national disability services data collection: redeveloping the Commonwealth–State/Territory Disability Agreement National Minimum Data Set* (AIHW 2003).

The vision for the CSTDA NMDS was:

- a data set that meets critical information needs across the disability field and is consistent with other major data developments

- data collation methods that are integrated with the day-to-day operations of agencies and funding departments and prevent duplication of effort (e.g. via the use of statistical linkage keys).

The full financial year CSTDA NMDS collection was implemented across Australia in June 2002 (Western Australian and Commonwealth-funded agencies) and 1 October 2002 (all other state/territory-funded agencies). The first collection period for the CSTDA NMDS ended 30 June 2003, and the first full financial year of data collection took place between 1 July 2003 and 30 June 2004.

The National Disability Agreement (NDA) replaced the CSTDA on 1 January 2009. Similar to previous Agreements, the NDA outlines state/territory and Australian Government roles and responsibilities and provides agreed objectives, outcomes and national priorities for disability service delivery in Australia (COAG 2008a). Key reforms outlined in the NDA aim to improve the effectiveness, efficiency and equitability of disability services, with a focus on person-centred approaches, improved access and lifelong planning. The overarching objective of the NDA is that 'people with disability and their carers have an enhanced quality of life and participate as valued members of the community' (COAG 2008b).

As a result of the implementation of the NDA, from 2009–10 the CSTDA NMDS has been renamed 'Disability Services NMDS (DS NMDS)'. From 2009–10 the DS NMDS collection will simply be a continuation of the CSTDA NMDS. A further redevelopment of the NMDS to align with the objectives of the NDA is in the planning stages, though it is likely to be several years before any significant changes are implemented in the DS NMDS. It is expected that prior to any implementation of a redeveloped NMDS significant testing and consultation will be undertaken.

1.3 What does the collection look like?

Information on the structure of the DS NMDS, including a list of the data items collected, can be found in section 3.4 of the Data Guide. Table 3.1 contains a list of the data items collected and Figure 3.1 demonstrates the structure of the DS NMDS through a simplified version of the data model.

1.4 Accessing DS NMDS data

National information from previous CSTDA NMDS collections is available from the AIHW web site (www.aihw.gov.au/disability/publications.cfm). This information includes brief reports and full reports. Interactive data sets may also be accessed at www.aihw.gov.au/disability/datacubes/index.cfm. Data from the DS NMDS will be available from the same location following release at the completion of the collection.

1.5 What are the Disability Services NMDS data used for?

In the past, CSTDA NMDS data have been used for a wide range of purposes, such as for planning, national program evaluation and to monitor achievement of program objectives and agreed priorities. Specific examples of uses to which the data have been put, are to:

- provide data for Productivity Commission's *Report on Government Services*
- provide data for National Disability Agreement Performance Indicators presented in the COAG Reform Council National Disability Agreement: Baseline performance report
- provide national comparisons of numbers of service users living in institutional versus community-based settings
- inform decisions on possible increases in the level of service user contributions by measuring the proportion of CSTDA service users who have benefits or pensions as their main income source
- indicate whether certain groups of people (e.g. those of Aboriginal and Torres Strait Islander origin) are accessing services in proportion to their assessed level of need
- support planning for future service delivery
- support budget submissions for increased funding or changing funding emphasis.

Full-year data about service users can also provide:

- a profile of all people receiving a NDA-funded service in a financial year
- data on carer arrangements, which enables issues relating to ageing carers to be monitored and planned for
- information about the mix of services provided to some service users can be examined in relation to various characteristics of service users, such as their support needs, disability group, carer arrangements and whether they live in metropolitan or rural locations.

1.6 What is the Data Guide for and how is it organised?

The Data Guide is designed to assist all those involved in supplying or analysing DS NMDS data. It is organised in the following sections:

- Section 2 provides details of how to seek assistance with the DS NMDS collection, including the help desk contact details in your jurisdiction.
- Section 3 provides a step-by-step guide on how to prepare for and complete a DS NMDS data 'return' (the 'return' may be completed using paper forms, data extracted from your own database or via jurisdiction-specific software). Section 3 includes specific methods for dealing appropriately with the issues of privacy and service user consent.
- Sections 4 and 5 contain detailed information about every data item in the DS NMDS. For most data items, the following explanations are provided:
 - data item name
 - associated question
 - definition
 - classification (i.e. possible response options)
 - guide for use
 - why this data item is collected
 - example of how this data item is used.

- Section 6 of the Data Guide provides the detailed privacy and data principles for the NMDS collection.

1.7 Other reference material for the Disability Services NMDS

The Data Guide is one of a range of documents relating to the DS NMDS collection. Other materials which may be of interest to or provide assistance for participants in the DS NMDS collection are listed below.

AIHW on-line Metadata Registry (METeOR)

Most data elements for the DS NMDS and from the previous CSTDA NMDS are included in AIHW's on-line Metadata Registry (METeOR). See the METeOR web site for more information, <<http://meteor.aihw.gov.au/>>.

Data Transmission and Technical Guide

The Data Transmission and Technical Guide aims to assist NDA-funded agencies provide data for the DS NMDS collection. It sets out technical requirements for data structure, essential for amalgamation of the data at a jurisdiction and national level. This document is for use by agencies wishing to develop their own data transmission software, agencies wishing to purchase commercial software, and agencies wishing to update their existing databases to meet the requirements of the DS NMDS collection. The Data Transmission and Technical Guide is available from the AIHW web site <www.aihw.gov.au/disability/ds_nmlds/index.cfm>. The Data Transmission and Technical Guide should always be read in conjunction with documentation for the DS NMDS collection, particularly the DS NMDS Data Guide for your jurisdiction (note that some jurisdictions make minor additions to the national collection material to meet local information needs).

1.8 More information or comments

For further information about the DS NMDS collection or to make comments on the Data Guide or the DS NMDS collection please contact your National Disability Data Network (NDDN) member (see Section 2 for contact details) or see the AIHW web site, <www.aihw.gov.au/disability/ds_nmlds/contacts.cfm>.

2 Who to contact for help

Jurisdictions to insert help desk arrangements for both data item and software queries.

3 How to conduct your Disability Services NMDS collection

3.1 Step-by-step guide to completing your Disability Services NMDS collection

1. Establish which service types and service users are in the scope of the collection (Section 3.2).
2. Ensure you have appropriate privacy principles and practices in place (Section 3.3).
3. Establish which data items you need to collect, depending on the DS NMDS service type or service types you offer (Section 3.4).
4. Establish how you are going to record information and start collecting the requested information on an ongoing basis for transmission to your jurisdiction funding department at specified times (Section 3.5).
5. At the end of the reporting period forward to your jurisdiction funding department:
 - a Service Type Outlet Form (paper or electronic) for each CSTDA service type you are funded to provide
 - depending on your service type, a Service User Form (paper or electronic) for all service users accessing **each** service type you are funded to provide, with relevant data items completed (Section 3.5).

Note: For simplicity, in this Data Guide, all references to a Service Type Outlet or Service User 'Form' refer to either a paper or an electronic form.

3.2 Scope of the Disability Services NMDS collection

Most funded agencies provide data about all service users for each service type they receive

Box 1 summarises the key concepts of the DS NMDS collection. Briefly, **most** agencies funded under the NDA are required to provide information about:

- each of the service types they are funded to provide (i.e. service type outlets they operate)
- all service users who **received** support over a specified reporting period (e.g. financial year or quarter)
- the DS NMDS service type(s) the service user received.

However, certain service type outlets (e.g. those providing advocacy or information/referral services) are not requested to provide any service user details while other service type

outlets (e.g. recreation/holiday programs) are only asked to provide very minimal service user details (see Table 3.2, Section 3.4 for further details).

Box 1: Key definitions for the DS NMDS collection

<i>Service</i>	<i>A service is a support activity delivered to a service user, in accord with the NDA. Services within the scope of the collection are those for which funding has been provided, during the specified period, by a government organisation operating under the NDA.</i>
<i>Service user</i>	<i>A service user is a person with a disability who received one or more NDA-funded services during the reporting period (e.g. the financial year). A service user may receive more than one service over a period of time or on a single day.</i>
<i>Service type</i>	<i>Service type is the support activity which the service type outlet has been funded to provide under the NDA. The NMDS classifies services according to 'service type'. The 'service type' classification groups services into seven categories (known as 'service groups'): accommodation support; community support; community access; respite; employment; advocacy, information and alternative forms of communication; and other support services. Within each of these categories there are subcategories.</i>
<i>Service type outlet</i>	<i>A service type outlet is the unit of the funded agency that delivers a particular NDA service type at or from a discrete location. If a funded agency provides, for example, both accommodation support and respite services, it is counted as two service type outlets. Similarly, if an agency 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 type outlets for the funded agency.</i>
<i>Funded agency</i>	<i>A funded agency is an organisation that delivers one or more NDA service types (service type outlets). Funded agencies are usually legal entities. They are generally responsible for providing DS NMDS data to jurisdictions. Where a funded agency operates only one service type outlet, the service type outlet and the funded agency are one and the same entity.</i>
<i>Scope of the DS NMDS collection</i>	<i>Services within the scope of the collection are those for which funding has been provided, during the specified period, by a government organisation operating under the NDA. A funded agency may receive funding from multiple sources. Where a funded agency is unable to differentiate service users and/or staff according to funding source (i.e. NDA or other), they are asked to provide details of all service users and staff (for each service type).</i>

3.3 Ensuring you respect privacy and have appropriate information-handling practices in place

It is the responsibility of each NDA-funded agency to inform every service user that data about them will be sent to the NDA funding department, and from there to the AIHW to become part of a national data set. This is in order for the DS NMDS collections conducted in each jurisdiction to comply with Commonwealth privacy legislation and established privacy and data principles for the overall DS NMDS collection (detailed in Section 6.2).

It is important that the service users of each agency are made aware not only that data are being transmitted to the funding department and the AIHW, but that these data will be used only for statistical purposes and will not affect entitlements.¹

The following statement should appear at least on one of the standard forms each service user fills out at your agency. This might occur at the time of enrolment or admission to the agency or at the point when Service User Information is completed for transmission to the NDA funding department.

Please note that <agency name> is required to release information about service users (without identifying you by full name, or address) to <NDA funding dept name>, and to the Australian Institute of Health and Welfare, to enable statistics about disability services and their clients to be compiled. The information will be kept confidential. This information is used for statistical purposes only and will not be used to affect your entitlements or your access to services. As a user of National Disability Agreement-funded services you have the right to access your own files and to update or correct information included in the Disability Services National Minimum Data Set collection.

Service users have rights of access to their own files, whether they have completed the Service User Form (electronic or paper) themselves or not.

Under National Privacy Principle (NPP) 5.1 of the *Privacy Amendment (Private Sector) Act 2000* agencies providing disability support services must set out in a document clearly expressed policies on their management of personal information. For agencies that have not developed such a privacy policy, the DS NMDS privacy and data principles may be a useful basis for your policy on managing personal information (see Section 6.3 for details). Please note the privacy act may change as a result of the review completed in 2008 by the Australian Law Reform Commission.

¹ All funding departments have signed an undertaking to this effect and must also comply with relevant privacy legislation. The AIHW is bound not only by Commonwealth privacy legislation, but also by privacy provisions within its own legislation. The operation of the Institute's Ethics Committee ensures that each database within the Institute complies with the relevant privacy legislation, particularly concerning the obtaining, storing and release of information.

What if a service user does not consent to information about them being transmitted to the funding department and AIHW?

From time to time a service user may not wish for information about them to be forwarded to the funding department and the AIHW for national collation.

Firstly, it is important that you explain the following to service users:

- All information transmitted about service users is non-identifying (i.e. their name and address is not forwarded to anyone, except in Western Australia and Australian Government-funded agencies where such information is forwarded to the funding department under the service contract, but not to the AIHW).
- Consistent with privacy legislation, funding departments and the AIHW go to great lengths to ensure that a person's identity cannot be established in any published material. For example, data are not published according to small geographic areas (e.g. postcodes) where it may be possible that only a small number of people with certain characteristics live.
- Information about people using NDA-funded services is used to maximise the fairness with which the program is delivered (e.g. it has been used to advocate additional funds).

Where a service user is still unwilling for information about them to be transmitted, you should consult your funding department for advice. Jurisdictions vary in their approach to this issue. Some jurisdictions consider that by agreeing to receive services from a NDA-funded agency, service users also agree to provide de-identified information for its associated data collections. Further, some service contracts with service users are conditional on the client agreeing to provide information for specified data collections. Jurisdictions also vary in their approach to the collection of the statistical linkage key (SLK) for non-consenting service users. While the SLK itself is not technically personal information under the *Privacy Act 1988*², the construction of an SLK does involve the use of personal information and should be treated as such (see NCSIMG 2004 for further discussion of SLK privacy issues).

Regardless of the approach taken, at the end of the financial year each jurisdiction is required to provide the AIHW with a count of the number of service users who did not consent to be included in the DS NMDS. This is crucial for understanding the national coverage of the collection.

Jurisdiction funding departments and the AIHW are responsible for ensuring that data dissemination is carried out without compromising confidentiality of funded agencies as well as service users.

² Definition from the *Privacy Act 1988*: '*personal information* means information or an opinion (including information or an opinion forming part of a database), whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion.'

3.4 Which data items do you need to collect?

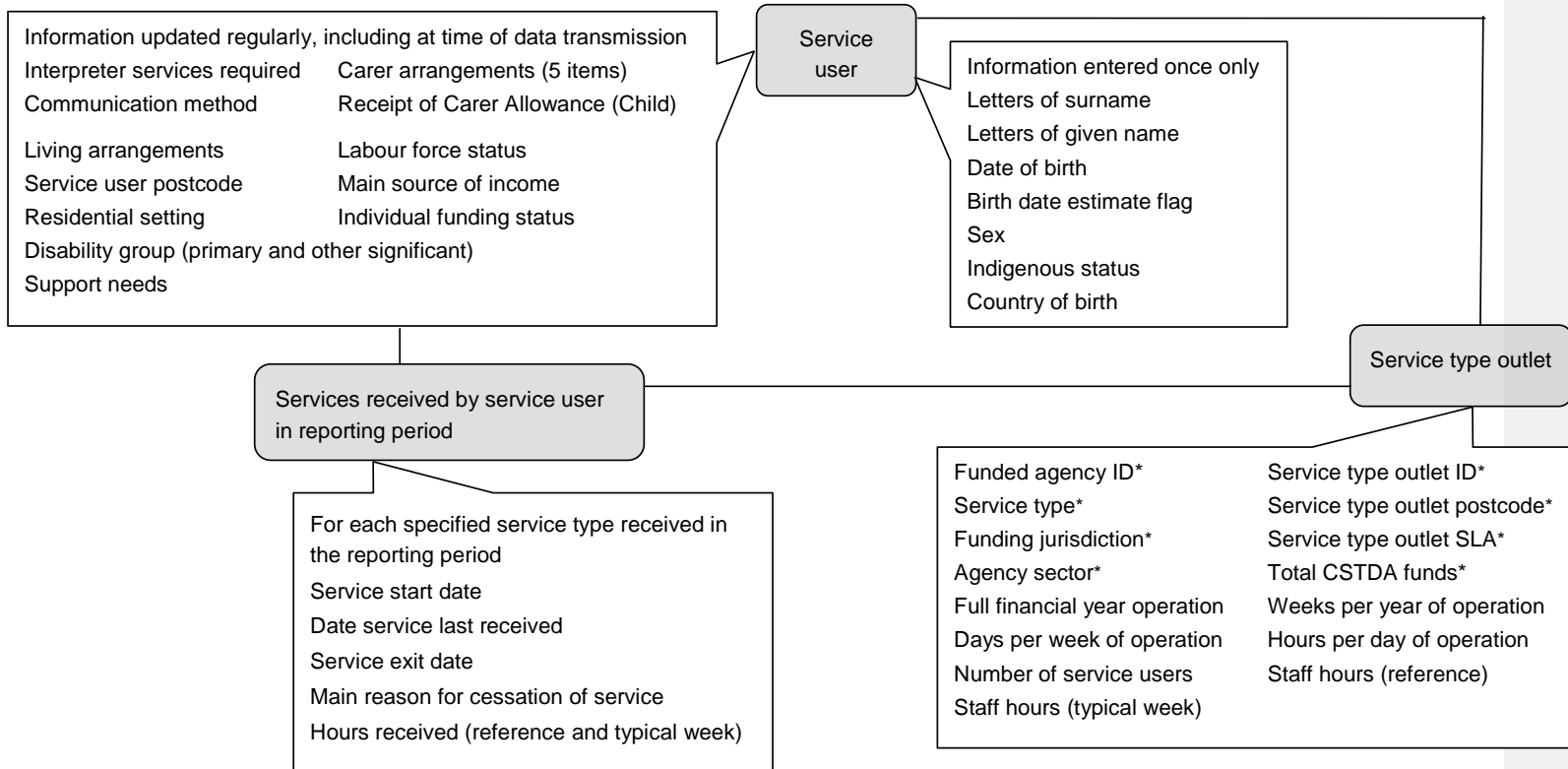
Data items in the Disability Services NMDS

Table 3.1 outlines the data items in the DS NMDS. The table highlights those data items with a related data item in the Home and Community Care Minimum Data Set (HACC MDS) and those that are provided by jurisdictions rather than funded agencies. Those data items which appear in both the DS NMDS and the HACC MDS were aligned as much as possible during the redevelopment process in order to minimise reporting requirements for agencies that submit data to both collections. Further detail about each data item is contained in Sections 4 and 5.

The data items in Table 3.1 are also detailed in the simplified information model (Figure 3.1) in this Data Guide, which also illustrates whether service user information needs regular updating.

Table 3.1: Data items for the DS NMDS

Service type outlet items	Service user items	Information required for each service type received in the reporting period (per service user)
A. Funded agency ID (J)	B. Service type outlet ID(s) (J)	17a. Service start date
B. Service type outlet ID (J)	1. Record ID	17b. Date service last received
C. Service type (J)	2a. Letters of surname (H)	17c. Service exit date
D. Service type outlet postcode (J)	2b. Letters of given name (H)	
E. Service type outlet SLA (J)	2c. Date of birth (H)	17d. Main reason for cessation of services (H)
F. Funding jurisdiction (J)	2d. Birth date estimate flag (H)	17e. Hours received (reference week)
G. Agency sector (J)	2e. Sex (H)	17f. Hours received (typical week)
1. Full financial year operation	3. Indigenous origin (H)	
2. Weeks per year of operation	4. Country of birth (H)	
3. Days per week of operation	5. Interpreter services required	
4. Hours per day of operation	6. Communication method	
5. Staff hours (reference week)	7. Living arrangements (H)	
6. Staff hours (typical week)	8. Service user postcode (H)	
7. Number of service users	9. Residential setting (H)	
	10. Disability group (primary, other significant)	
	11. Support needs (9 areas)	
	Carer arrangements (informal):	
	12a. Carer – existence of (H)	
	12b. Carer – primary status	
	12c. Carer – residency status (H)	
	12d. Carer – relationship to service user (H)	
	12e Carer – age group	
	13. Receipt of Carer Allowance (Child)	
	14. Labour force status	
	15. Main source of income	
	16. Individual funding status	
(J)	Item provided by jurisdiction rather than funded agency. In addition, jurisdictions provide information on NDA funding to agencies, defined as the total NDA dollars that the funding department has offered the service, and which the service has taken up, for the 12 months to the end of the most recent financial year.	
(H)	Related HACC data item.	



* Information provided by the jurisdiction/funding department rather than the funded agency/service type outlet.

Figure 3.1: Simplified information model of the Disability Services National Minimum Data Set data items

Which data items does your service type outlet need to complete?

The level of information a funded agency is asked to provide varies according to the particular service type (i.e. for each service type outlet). The level of information required is summarised in Table 3.2.

For example:

- if you are funded to provide residential/institutional accommodation, hostel or group home support, therapy services or early childhood intervention you are asked to provide all service user data except for the items on hours received (items 17e-f, Table 3.1)
- if you are funded to provide recreational/holiday programs you are only required to provide service user data items up to and including the linkage key components (items B, 1 and 2a-e, Table 3.1), and services received items 17a-17b
- if you are funded to provide a service in the 'advocacy, information or alternative forms of communication' service group you are not asked to provide any service user details.

Table 3.2: Information requested according to DS NMDS service type

Service type classification	Service type outlet – details required (except for those provided by the jurisdiction)	Service user – details required	Services received by each service user in the reporting period – details required
Accommodation support			
1.01 Large residential/institution (>20 people) – 24 hour care	All	All	All (except for data items on hours received – items 17e–f)
1.02 Small residential/institution (7–20 people) – 24 hour care	All	All	All (except for data items on hours received – items 17e–f)
1.03 Hostels – generally not 24 hour care	All	All	All (except for data items on hours received – items 17e–f)
1.04 Group homes (< 7 people)	All	All	All (except for data items on hours received – items 17e–f)
1.05 Attendant care/personal care	All	All	All
1.06 In-home accommodation support	All	All	All
1.07 Alternative family placement	All	All	All
1.08 Other accommodation support	All	All	All (except for data items on hours received – items 17e–f)
Community support			
2.01 Therapy support for individuals	All	All	All (except for data items on hours received – items 17e–f)
2.02 Early childhood intervention	All	All	All (except for data items on hours received – items 17e–f)
2.03 Behaviour/specialist intervention	All	All	All (except for data items on hours received – items 17e–f)
2.04 Counselling (individual/family/group)	All	All	All (except for data items on hours received – items 17e–f)
2.05 Regional resource and support teams	All	All	All (except for data items on hours received – items 17e–f)
2.06 Case management, local coordination and development	All	All (except for community development activity within this service type)	All (except for community development activity within this service type)
2.07 Other community support	All	All (except for community development activity within this service type)	All (except for data items on hours received – items 17e–f)
Community access			
3.01 Learning and life skills development	All	All	All
3.02 Recreation/holiday programs ^(a)	All	Linkage key elements only (items 2a–2e)	Items 17a–17b (service start date and date service last received)
3.03 Other community access	All	All	All

(continued)

Table 3.2 (continued): Information requested according to DS NMDS service type

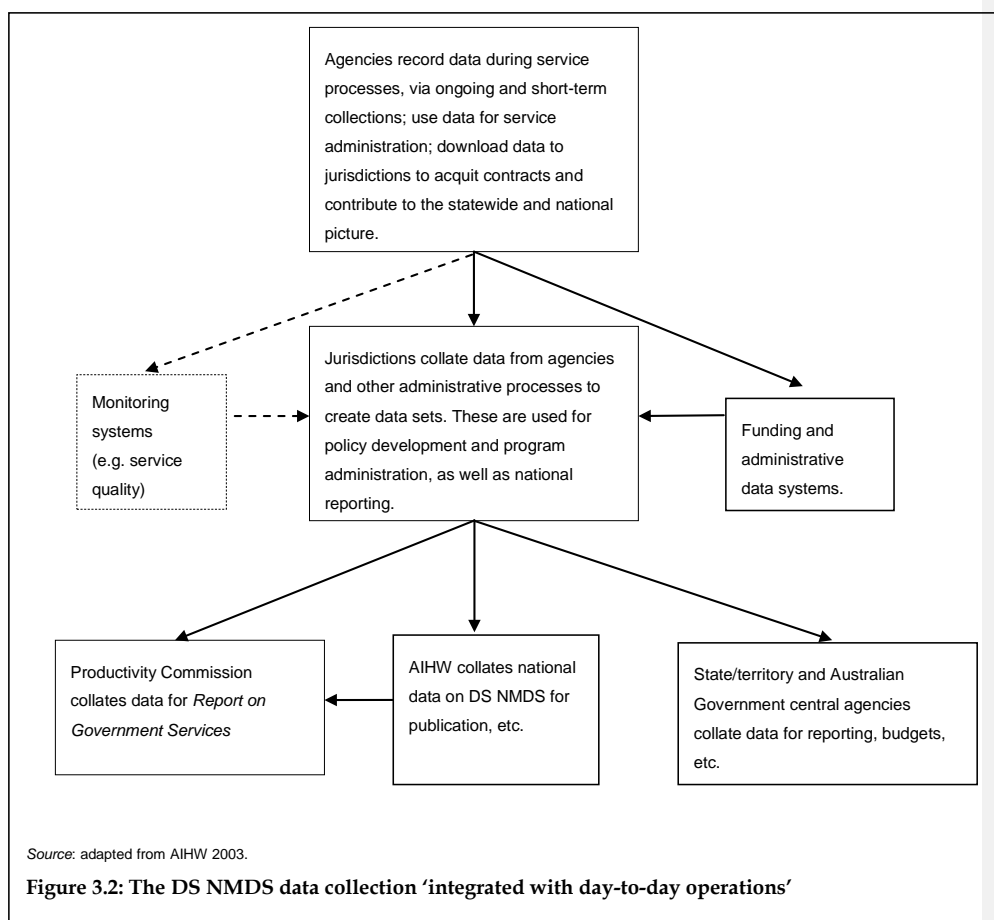
Service type classification	Service type outlet – details required (except for those provided by the jurisdiction)	Service user – details required	Services received by each service user in the reporting period – details required
Respite			
4.01 Own home respite	All	All	All
4.02 Centre-based respite/respice homes	All	All	All
4.03 Host family respite/peer support respite	All	All	All
4.04 Flexible respite	All	All	All
4.05 Other respite	All	All	All
Employment			
5.01 Open employment	All	All (except for carer – primary status, residency status, age group – items 12b,c,e)	All (except for data items on hours received – items 17e–f)
5.02 Supported employment	All	All (except for carer – primary status, residency status, age group – items 12b,c,e)	All (except for data items on hours received – items 17e–f)
5.04 Targeted support	All	All (except for carer – primary status, residency status, age group – items 12b,c,e)	All (except for data items on hours received – items 17e–f)
Advocacy, information and alternative forms of communication			
6.01 Advocacy	All	None	None
6.02 Information/referral	All	None	None
6.03 Combined information/advocacy	All	None	None
6.04 Mutual support/self-help groups	All	None	None
6.05 Alternative formats of communication	All	None	None
Other support			
7.01 Research and evaluation	All (except number of service users – item 7)	None	None
7.02 Training and development	All (except number of service users – item 7)	None	None
7.03 Peak bodies	All (except number of service users – item 7)	None	None
7.04 Other support services	All (except number of service users – item 7)	None	None

(a) Some jurisdictions require the collection of other service user/services received data items for this service type in addition to those listed here.

3.5 How to collect and transmit service type outlet and service user information

The data collection process

The figure below gives an overall picture of the collection, collation and dissemination of DS NMDS data in the context of day to day operations.



Data to be provided for each service type outlet

This data collection is based around the concept of a 'service type outlet', each of which provides only one service type from a discrete location. A funded agency may be funded to provide one or more service type through one or more service type outlets (see Section 3.2, Table 3.1). For example, an agency may be funded under the NDA to provide residential accommodation and respite services from one location or funded to provide group homes in three separate locations. It is essential for funded agencies to provide appropriate data returns for all funded service type outlets in order to avoid, for example, under-estimation of respite activity under the NDA or incorrect information about the geographic coverage of group homes in your jurisdiction.

Data to be recorded on an ongoing basis

NDA-funded agencies are asked to record key information about service users on an **ongoing basis**, so that they can transmit the required information at the end of each 'reporting period'. This information should ideally be collected on an ongoing basis (i.e. from the time new service users join your agency) as part of your general administration.

Collecting and transmitting data using paper or software

The DS NMDS collection accepts data:

- on paper forms
- entered into software tools provided by most jurisdictions specifically for the DS NMDS or the previous CSTDA NMDS
- downloaded from agency computer systems (in a specified format).

For those agencies with their own software solutions in place or those who would prefer to purchase a commercial software product, a Data Transmission and Technical Guide is available to help to ensure that your own system will produce data consistent with the DS NMDS requirements.

If your funded agency collects and collates data on behalf of all its service type outlets you may decide to forward this information on behalf of your funded agency (i.e. for a number of service type outlets). Alternatively, each service type outlet may decide to forward its data to the jurisdiction separately.

More information:

- Contact the NDDN member in your jurisdiction (see Section 2) for a copy of the Data Transmission and Technical Guide or see the AIHW web site, www.aihw.gov.au/disability/ds_nmlds/.

Which forms do you need to complete?

After considering the information in Sections 3.1 to 3.4 it is time to start collecting the information required about your service type outlet(s) and service users. As noted above, this information should ideally be collected on an ongoing basis (i.e. from the time new service users join your agency) as part of your general administration.

At the end of each financial quarter or at the end of the financial year (depending on your funding jurisdiction) you will be asked to transmit the DS NMDS information you have

collected to your funding department. This information needs to be provided in one of the following formats:

- Service Type Outlet and Service User Forms (paper)
- Service Type Outlet and Service User Forms (electronic), in the form of an automated data download from DS NMDS software provided by your jurisdiction
- a data extract or download from your own database in the format specified in the Data Transmission and Technical Guide.

Depending on the service types you are funded to provide, you need to complete:

- one Service Type Outlet Form (paper or electronic) for each service type your agency is funded to provide under the NDA
- one Service User Form (paper or electronic) for every service user accessing your agency.

There are a number of ways of providing multiple Service User Forms, for example:

- each outlet may decide to complete the entire Service User Form separately
- a central point in the agency may photocopy the Service User Form (with data items 1 to 16 completed) and ask each outlet to simply complete section B (service type outlet ID) and data item 17 (services received by the service user) at the end of the reporting period
- by using DS NMDS software provided by your jurisdiction, where the process of indicating that service users access multiple service types within an agency is automated.

Example 1

If your agency is funded under the NDA to provide residential accommodation and centre-based respite services from one location, it is necessary for you to complete:

- two Service Type Outlet Forms, one for large residential/institutional accommodation (service type 1.01) and one for centre-based respite (4.02)
- Service User Forms (electronic or paper) for all service users, including identifying the service type or types received by each service user in Section 17 of the Service User Form.

Example 2

If your agency is funded to provide learning and life skills development (service type 3.01) and counselling (individual/family/group) (2.04), it is necessary for you to complete:

- two Service Type Outlet Forms, one for learning and life skills development (service type 3.01) and one for counselling (individual/family/group) (2.04)
- Service User Forms (electronic or paper) for all service users, including identifying the service type or types received by each service user in Section 17 of the Service User Form. If there are service users who receive both service types in the reporting period (i.e. learning and life skills development and counselling (individual/family/group)) then you will need to complete section 17 on the Service User Form (about services received by the service user) separately for each service type received.

How often do you need to transmit information?

Data are to be transmitted to your jurisdiction at the end of each 'reporting period' (see Glossary, page v).

The reporting period for [jurisdiction name] funded agencies is [the financial year/ 6 - months/ quarterly]. [jurisdictions to insert please]

4 Service type outlet information

The following section contains data item definitions for service type outlet items A–G and 1–7. See also Table 3.2 in Section 3.4.

- Services within the scope of the collection are those for which funding has been provided, during the specified period, by a government organisation operating under the NDA. Therefore, if a service type outlet did not receive NDA funding for the 2010–11 collection (i.e. its NDA funding dollars for the financial year are zero), then details of this outlet should not be included in the data collection.
- All funded agencies must provide service type outlet information.
 - A separate Service Type Outlet Form (paper or electronic) must be completed for every service type outlet an agency has been funded to provide under the NDA at a specific location (see Table 3.1 in Section 3.2).
 - This is necessary in order to gain a complete and accurate picture of the types of services being received by service users under the NDA.
 - For example, where an agency is funded to provide residential/institutional accommodation support (1.01) and centre-based respite (4.02), it is essential to complete separate Service Type Outlet Forms for each service type, in order to be able to address important policy issues about the provision of each of these service types (e.g. the availability of respite beds).
- Generally, items A–G are **provided** by the jurisdiction/funding department and **verified** by the service type outlet or funded agency.
- Total NDA funds can be provided by the jurisdiction/funding department at various levels—service type outlet, funded agency, or service group level. As a result, this item does not appear on the Service Type Outlet Form or in the Data Transmission and Technical Guide.
- Service type outlet data items 1–7 are provided by the service type outlet or funded agency.
 - The following service types do **not** need to complete item 7 about the number of service users:
 - 7.01 Research and evaluation
 - 7.02 Training and development
 - 7.03 Peak bodies
 - 7.04 Other support services

A Funded agency ID

Defined as: A unique number assigned to each funded agency, by the funding department.

Classification: Numeric or alpha numeric identification.
'Not stated' is not permitted for this data item.

Guide for use

- This ID number is primarily used for the purpose of DS NMDS transmission software. Therefore it may not appear on paper forms.
- This ID number generally contains a maximum of 8 characters.
[This size is arbitrary and should be adjusted by jurisdictions to align with existing or planned administration systems.]
- The ID number can be numeric or alpha numeric, but should not identify the organisation by name.
- The funded agency ID must be included as part of the service type outlet ID.

Why is this data item collected?

Funded agency ID needs to be identified separately from the service type outlet ID in software to allow organisations running more than one service type outlet to record all details on one database. The main function of this ID is to link records once they are amalgamated into jurisdiction and then national data.

B Service type outlet ID

Defined as: A unique number assigned to each service type outlet, by the funding department.

Classification: Numeric or alpha numeric identification.
'Not stated' is not permitted for this data item.

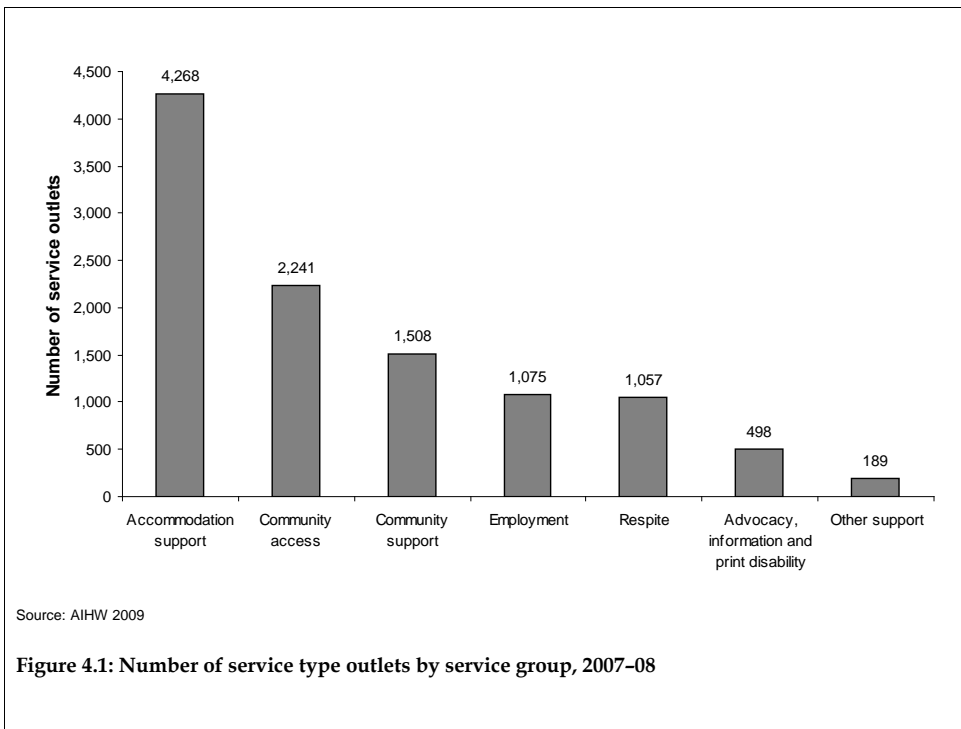
Guide for use

- This ID number generally contains a maximum of 14 characters.
[This size is arbitrary and should be adjusted by jurisdictions to align with existing or planned administration systems.]
- The ID number can be numeric or alpha numeric, but should not identify the agency by name.
- The ID number must include information to identify both the service type outlet and its funded agency, to ensure uniqueness within the jurisdiction. This means that the service type outlet ID is generally longer than the funded agency ID.
- Service type outlets should verify the service type outlet ID the funding department has assigned to their service type outlet.

Why is this data item collected?

Service type outlets deliver a particular NDA service type at or from a discrete location (see Box 1, Section 3.2). A unique identification system for service type outlets enables information to be provided about each different service type outlet under the NDA. Identifying each service type outlet also enables information to be presented about the number of service users accessing each service type. This information can then be used for future service planning at the state/territory level.

Example of how this data item is used



C Service Type

Defined as: The support activity that the service type outlet has been funded to provide under the NDA.

Classification:

Accommodation support

- 1.01 Large residential/institution (>20 places) – 24-hour care
- 1.02 Small residential/institution (7-20 places) – 24-hour care
- 1.03 Hostels – generally not 24-hour care
- 1.04 Group homes (usually <7 places)
- 1.05 Attendant care/personal care
- 1.06 In-home accommodation support
- 1.07 Alternative family placement
- 1.08 Other accommodation support

Community support

- 2.01 Therapy support for individuals
- 2.02 Early childhood intervention
- 2.03 Behaviour/specialist intervention
- 2.04 Counselling (individual/family/group)
- 2.05 Regional resource and support teams
- 2.06 Case management, local coordination and development
- 2.07 Other community support

Community access

- 3.01 Learning and life skills development
- 3.02 Recreation/holiday programs
- 3.03 Other community access

Respite

- 4.01 Own home respite
- 4.02 Centre-based respite/respite homes
- 4.03 Host family respite/peer support respite
- 4.04 Flexible respite
- 4.05 Other respite

Employment

- 5.01 Open employment
- 5.02 Supported employment
- 5.03 Open and supported employment³
- 5.04 Targeted support⁴

Advocacy, information and alternative forms of communication

- 6.01 Advocacy
- ~~6.01~~6.02 Information/referral
- ~~6.01~~6.03 Combined information/advocacy
- ~~6.01~~6.04 Mutual support/self-help groups
- 6.05 Alternative formats of communication

Other support

- 7.01 Research and evaluation
- 7.02 Training and development
- 7.03 Peak bodies
- 7.04 Other support services

Service type classification (definitions)

Accommodation support

Services that provide accommodation to people with a disability and services that provide support needed to enable a person with a disability to remain in their existing accommodation or to move to more suitable or appropriate accommodation.

1.01 Large residential/institutions (>20 places)

Large residential/institutions are usually located on large parcels of land and provide 24-hour residential support in a congregate setting of more than 20 beds. In some cases a range of residential and vocational/day services, and/or respite services are provided on the one site. (Where this is the case, each additional service type should be funded and/or reported against under the DS NMDS as a separate service type outlet.)

1.02 Small residential/institutions (7–20 places)

Small residential/institutions are usually located on large parcels of land and provide 24-hour residential support in a congregate or cluster setting of 7 to 20 beds. In some cases a range of residential and vocational/day services, and/or respite services are provided on the one site. (Where this is the case, each additional service type should be funded and/or reported against under the DS NMDS as a separate service type outlet.)

1.03 Hostels

Hostels provide residential support in a congregate setting of usually less than 20 beds, and may or may not provide 24-hour residential support. Many are situated in an institutional setting and also have respite beds included on the premises. In contrast to

³ This is now a defunct service type code. Prior to 1 December 2004, this employment service type provided a combination of both open and supported employment services.

⁴ This is now a defunct service type code. Targeted support services provided by the Commonwealth were transferred to states and territories during the 2008–09 financial year and are now distributed across various state and territory service type codes.

residential/institutions (1.01 and 1.02), hostels usually do not provide segregated specialist disability support services. (Where this is the case, each additional service type should be funded and/or reported against under the DS NMDS as a separate service type outlet.)

1.04 Group homes (usually <7 places)

Group homes generally provide **combined** accommodation and community-based residential support to people in a residential setting. Usually no more than 6 service users are located in any one house, although this can vary. Group homes are generally staffed 24 hours a day. The agency being funded to provide the service should generally have control of the residence (i.e. own, lease, hold in trust, or in other ways be responsible for the residence) not just the support to enable the residents to remain in the residence. If the only service being provided is support to enable residents to remain in their existing accommodation, then see category 1.05 'attendant care/personal care' or 1.06 'in-home accommodation support'.

1.05 Attendant care/personal care

An attendant care program provides for an attendant(s) to assist people with daily activities that they are unable to complete for themselves because of physical, intellectual or any other disability. The service is provided to people to assist them to live in the community and live on their own.

1.06 In-home accommodation support

Support involves individual in-home living support and/or developmental programming services for people with a disability, **supplied independently of accommodation**. The accommodation may be owned, rented, or otherwise provided, but should be independent of the agency providing the in-home support service, otherwise see code 1.04 'group homes'. Where an in-home accommodation support service also provides some other limited assistance, for example help with banking once a week or short-term respite for family members, then in-home accommodation should be recorded, as it is the **primary focus** of the support provided.

1.07 Alternative family placement

Placements of a person with a disability with an alternative family who will provide care and support. Includes shared-care arrangements and host family placements.

1.08 Other accommodation support

Accommodation support services that provide short-term, one-off instances of accommodation such as:

- accommodation provided so that individuals or families can access specialist services, or further education
- emergency or crisis accommodation support (e.g. following the death of a parent or carer)
- houses or flats for holiday accommodation.

If the accommodation support is primarily for respite (i.e. involves the separation of the service user from their usual support arrangements or the addition of extra support in their current environment) please refer to the relevant service type 4.01-4.05.

Community support

Services that provide the support needed for a person with a disability to live in a non-institutional setting. Support with the basic needs of living such as meal preparation, dressing, transferring etc. are included under accommodation support.

2.01 *Therapy support for individuals*

Specialised, therapeutic care services including occupational therapy, physiotherapy and speech therapy. These services are intended to improve, maintain or slow deterioration of a person's functional performance, and/or assist in the assessment and recommendation of equipment to enable people to perform as independently as possible in their environment.

2.02 *Early childhood intervention*

Support services to assist children up to (but not including) 6 years of age with a developmental delay to integrate with peers into pre-schools and the wider community. This will include the full range of services that the child receives.

2.03 *Behaviour/specialist intervention*

These include the range of services relating to the management of challenging behaviours, including dangerous antisocial behaviour. Services include intensive intervention support, training and education in behaviour management, and consultancy services for other professionals. Behaviour/specialist intervention is often provided as a by-product of other services.

2.04 *Counselling (individual/family/group)*

Services that provide counselling to individuals, families or groups.

2.05 *Regional resource and support teams*

Regional resource and support teams are generally inter disciplinary teams that provide a combination of services in the categories 2.01, 2.02 and 2.03, that cannot be broken down into the component parts. Regional resource and support teams may also assist service users to access mainstream services and/or support mainstream funded agencies. Except for early childhood intervention teams, these teams usually have an individual, rather than a family, focus.

2.06 *Case management, local coordination and development*

This is a broad service type category, including elements of individual or family-focused case management and brokerage as well as coordination and development activity within a specified geographical area. Services assist people with disabilities to maximise their independence and participation in the community through working with the individual, family and/or carers in care planning and/or facilitating access to appropriate services. If the service provided is community development **only (i.e. the service is not working with an individual)**, then it should be classified under 'other community support' (2.07).

Case management services are targeted to individuals who require assistance, for a period of time, to access necessary supports, including help with service coordination and with assisting services to respond to their service needs. Brokerage is one method of purchasing appropriate supports for an individual and should be included in this category.

Other forms of local coordination and development generally involve working with the individual, family and/or carers and at the community level to facilitate positive changes that assist people with a disability to live and participate in the community and assist families in their continued provision of care. Local coordination does not generally involve management of individuals' funds and does not generally involve ongoing case management. However, discretionary funds are sometimes available for one-off purchases (e.g. respite, therapy) to enable a quick response until longer term supports can be put in place.

2.07 *Other community support*

Community support services other than those outlined above (i.e. other than 2.01–2.06). If community development is provided as part of working with an individual, then the service should be classified under service type 2.06 (Case management, local coordination and development).

Community access

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.

The key features are that the services:

- are flexible and responsive to personal needs and interests
- range from educational to leisure and recreational pursuits
- range from facility- to home-based activities
- include supervision and physical care, and models which link people into activities which are offered to the whole community
- range from long-term day support to time-limited and goal-oriented education that maximises personal independent functioning and may complement other community services.

3.01 *Learning and life skills development*

These programs provide ongoing day-to-day support for service users to gain greater access and participate in community-based activities. Programs may focus on continuing education to develop skills and independence in a variety of life areas (e.g. self-help, social skills and literacy and numeracy) or enjoyment, leisure and social interaction. They are often called day programs. **See the 'guide for use' section on page 30 for examples of these services.**

3.02 *Recreation/holiday programs*

Recreation services and holiday programs aim to facilitate the integration and participation of people with disabilities in recreation and leisure activities available in the general community. These services may also enhance the capacity and responsiveness of mainstream sport and recreation agencies and community organisations to provide for people with disabilities.

3.03 *Other community access*

Community access services other than those outlined above (i.e. other than 3.01–3.02). For example, services offering activities designed to improve service users' physical, cognitive and perceptual abilities; encourage self-esteem growth; and provide

opportunities to socialise. This service should only be recorded where services 3.01 and 3.02 are not suitable.

Respite

Respite services provide a short-term and time-limited break for families and other voluntary care givers of people with disabilities, to assist in supporting and maintaining the primary care giving relationship, while providing a positive experience for the person with a disability.

4.01 Own home respite

Respite care provided in the individual's own home location.

4.02 Centre-based respite/respite homes

Respite care provided in community setting similar to a 'group home' structure and respite care provided in other centre-based settings. This service type includes respite care provided in any of the accommodation settings 1.01–1.04.

4.03 Host family respite/peer support respite

Host family respite provides a network of 'host families' matched to the age, interests and background of the individual and their carer. Peer support is generally targeted at children or young adults up to 25 years of age, and matches the individual with a peer of similar age and interests, usually for group activities. Usually provided on a voluntary basis.

4.04 Flexible respite

Respite services that offer any combination of own home and host family/peer support respite (service types 4.01 and 4.03). Includes respite where day outings and camping trips are taken (this service type is distinguished from service type 3.02 'Recreation/holiday programs' because the primary purpose is respite). Flexible respite to meet an individual's needs may include brokerage for respite, only when the funding dollars come from respite resources. Outlets providing centre-based respite services should be recorded separately under service type 4.02 and not under this service type.

4.05 Other respite

Respite services other than those outlined above (i.e. other than 4.01–4.04), including:

- crisis respite
- holidays for the person with the disability where the primary intention of the service is to provide respite support (rather than primarily a holiday experience) and the service user is generally separated from their usual support arrangements, e.g. family.

Employment

5.01 Open employment

Services that provide employment assistance to people with a disability in obtaining and/or retaining paid employment in **the open labour market**.

5.02 Supported employment

Services that provide employment opportunities and assistance to people with disabilities to work in specialised and supported work environments.

5.03 *Open and supported employment*

This is now a defunct service type code. Prior to 1 December 2004, these were services that provided a combination of both open and supported employment services.

5.04 *Targeted support*

This is now a defunct service type code. Prior to October 2008, Targeted support services provided people with disability structured training and support to work towards social and community participation or opportunities to develop skills, or retrain, for paid employment.

Advocacy, information and alternative forms of communication

6.01 *Advocacy*

Services designed to enable people with a disability to increase the control they have over their lives through the representation of their interests and views in the community. Examples include:

- self advocacy/individual advocacy
- citizen advocacy
- group advocacy
- system/systematic advocacy

6.02 *Information/referral*

Information services provide accessible information to people with disabilities, their carers, families and related professionals. This service type provides specific information about disability-specific and generic services, equipment, and promotes the development of community awareness. Information includes contact by phone, print or e-mail that recommends a person to another service.

6.03 *Combined information/advocacy*

Services that offer both information and advocacy services to individuals where these two components cannot reasonably be separated.

6.04 *Mutual support/self-help groups*

Focus, or special interest groups to provide support and assistance for people with disabilities, their families and carers. These groups promote self advocacy through the provision of information, support and assistance.

6.05 *Alternative formats of communication*

Includes alternative formats of communication for people who by reason of their disabilities are unable to access information provided in the standard format. May include interpreter services, radio and alternative formats of print medium, e.g. TTY, Braille etc.

Other support

7.01 *Research and evaluation*

Research and evaluation with respect to the provision of services funded under the NDA for people with disabilities. This includes the investigation of the need for new services or enhancement of existing services and the measurement of outcomes for people with disabilities using these services. Responsibility for this service type is shared between the Commonwealth and state/territory governments.

7.02 *Training and development*

Training and development services may be funded, for example, to train disability-funded agencies to deliver higher quality or more appropriate services to people with disabilities or develop materials or methods that promote service system improvements.

7.03 *Peak bodies*

Peak bodies are generally funded to support non-government disability funded-agencies in achieving positive outcomes for people with disabilities.

7.04 *Other support services*

Services that are completely outside any of the defined service types above (that is, outside service types, 1.01–1.08, 2.01–2.07, 3.01–3.03, 4.01–4.05, 5.01–5.02, 5.04, 6.01–6.05 and 7.01–7.03). This service type also includes the provision of one-off funding for a defined event (e.g. for promotional activities) or for the purchase of aids and equipment for a community facility (not for an individual).

Guide for use

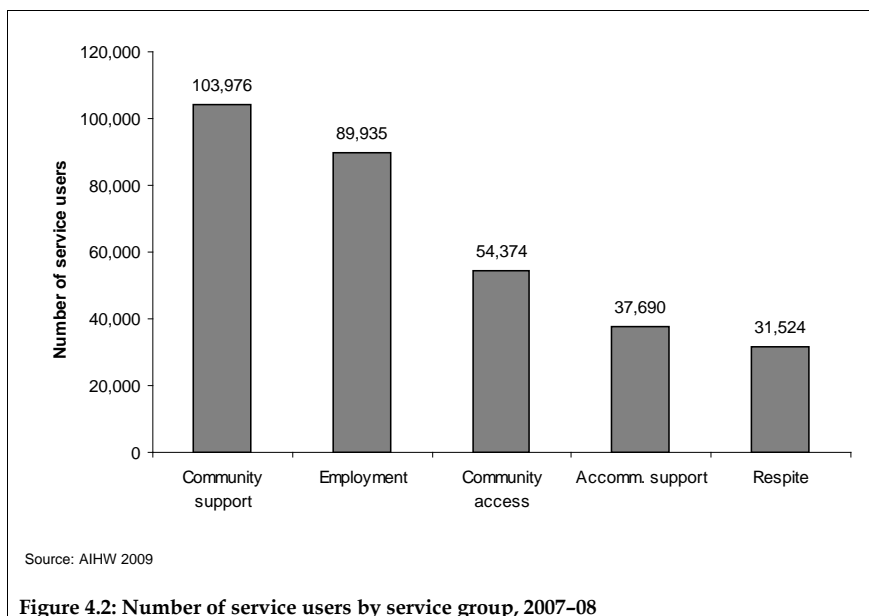
- If it is difficult to differentiate between service types 1.04 'group homes (usually <7 places)' and 1.06 'in-home accommodation support', then do so on the basis of what is **the main purpose** of the service, that is whether the service is being provided as a place to live (1.04) or to help someone live independently (1.06). Another consideration is the transportability of a service. If the service user can continue to use the service at a new residence, then the service type is 1.06. If the service is attached to the current residence and therefore cannot be used at a new residence, then the service type is 1.04. The level of staffing and support provided should also be taken into consideration – group homes (1.04) generally offer 24-hour support, and in home accommodation support services (1.06) offer more sporadic/less intense support.
- If there is some difficulty in interpreting whether an in-home service should be recorded as 1.06 or 4.01, the solution can be addressed in terms of the **primary focus** of the service. If the **primary focus** of the service is to provide respite support, then the service should be recorded as 4.01. However, if there is only a respite 'effect', and the service is mainly offered to provide in-home support, then the service should be recorded as 1.06. Alternatively, the question can be asked 'for whom is the in-home support service primarily being provided?' If the intended primary recipient of the respite support is a care-giver, then the service should generally be recorded as 4.01. However, if the recipient is the person with a disability then it can generally be recorded as 1.06.
- Where services are provided to groups or families (e.g. 2.02, 2.04, 2.05), details are only requested about the service user who is eligible for NDA services (that is, the person with a disability), not their family or other group members. For example, if a service user receives respite services, only details about the service user (i.e. person with the disability) are required, not those of the family or carer.
- For service type 2.06 'case management, local coordination and development', funded agencies are not expected to complete service user details in relation to the local development or coordination activities that do not relate to particular service users. *[In some jurisdictions, further details of these activities may be requested outside the DS NMDS.]*

- Service type 2.06 ‘case management, local coordination and development’ may include brokerage activities. For DS NMDS purposes, service user details should be recorded for all people receiving brokerage services. The details about the brokerage services received (items 17a–f) should relate only to the provision of the actual ‘brokerage’ as a service type, and not to the other service types that are purchased using brokerage funds, see items 5, 6, 17e and 17f for more details. See Appendix D for guidance and examples related to reporting on brokerage and sub-contracted services.
[In some jurisdictions, details of the services purchased via brokerage may be requested in addition to DS NMDS data items.]
- Outlets providing mainly community development services that are not linked to individuals should be coded as 2.07 service types. SU and SR data are not required for this service type. There is an assumption that many 2.07 outlets would offer services other than community development, and would therefore report on users of other service types.
- If the main focus of the service involves working with individuals, then the outlets should be classified as service type 2.06. These outlets should report SU and SR data, except where they provide community development work that is not linked to an individual.
- Activities under service type 3.01 (learning and life skills development) may include:
 - attending courses to develop literacy and numeracy, financial and household management skills or classes such as cooking, arts and crafts, water aerobics and fitness
 - undertaking trips to art galleries, libraries, movies, zoos, parks and nature reserves or outings that involve fishing or other recreational activities
 - undertaking tours to familiarise individuals with their local area and develop confidence in using public transport or visits to facilities such as hospitals, designed to alleviate the stress of future visits
 - participating in volunteer programs such as helping at the RSPCA or landscaping and gardening programs
 - attending social clubs, e.g. book, music or sporting clubs
 - going on shopping trips or eating out in various venues from food halls to restaurants.
- Recording services as 3.03 should only be done so when the service cannot be classified as 3.01 or 3.02. If the service provided is vocational in nature, though the client is not likely to ever enter the workforce the service may be more appropriately recorded as an ongoing 3.01 service, rather than a vocational service. Examples of 3.03 services include innovative services and other service mixes; for example, a mix of day programs (3.01) and therapy (2.01) services.
- State/territory-funded agencies should not use codes 5.01, 5.02 or 5.04.
- Service type outlets should verify – and correct where necessary – the service type classification that the funding department has assigned to their service type outlet.

Why is this data item collected?

The ability to output data by service type is essential. It allows for descriptive information to be presented on the types of services being received by different groups of service users and in different geographic locations.

Example of how this data item is used



D Service type outlet postcode

Defined as: Postcode of the location of the service type outlet.

Classification: Numeric 4-digit Australian postcode (Australia Post classification).

Guide for use

- If the service is provided in the person's home, the postcode of the service base from which the provider operates is to be entered, not that of the person.
- If recreation services are provided in various locations, the postcode of the service base from which the provider operates is to be entered.
- Service type outlets should verify – and correct where required – the service type outlet postcode the funding department has assigned to their service type outlet.
- The complete list of valid postcodes in the *Australia Post* classification can be downloaded from <www.austpost.com.au>.

Why is this data item collected?

This item allows data to be merged into regions for particular studies, for analysis of regional service provision using the Remoteness Areas of the Australian Standard Geographical Classification, and geographical planning for future services on the basis of need. In this way, geographical areas which may require more services can be identified.

Postcodes are widely known, and allow data to be aggregated as required, including generation of Statistical Local Area (SLA) data for transmission to the Australian Institute of Health and Welfare (if jurisdictions do not calculate SLA from full outlet address).

E Service type outlet SLA

Defined as: The Statistical Local Area (SLA) for the geographic location of the service type outlet.

Classification: Numeric 4- or 5-digit Australian SLA.

Guide for use

- Statistical Local Area (SLA) is an ABS (Australian Bureau of Statistics) geographic classification. A list of current SLA codes is available in the ABS 2009 Locality to SLA Concordance. This concordance is available on request from geography@abs.gov.au.
- Funding departments allocate SLA according to the most recent Australian Bureau of Statistics classification. This item is optional for your funding department and may not be included on your Service Type Outlet Form.

Why is this data item collected?

This data item allows data to be merged into regions for particular studies, for analysis of regional service provision using the Remoteness Areas of the Australian Standard Geographical Classification, and geographical planning for future services on the basis of need.

Statistical Local Area (SLA) is an ABS geographic classification and therefore provides planners with more useful information than postcode in terms of comparing DS NMDS data with population data.

F Funding jurisdiction

Defined as: The jurisdiction (state, territory or Australian Government) providing NDA funding to the funded agency and the jurisdiction in which the funds are allocated.

Classification:

Jurisdictions	State or territory-allocated NDA funds	Australian Government-allocated NDA funds
NSW	11	91
Vic	12	92
Qld	13	93
WA	14	94
SA	15	95
Tas	16	96
ACT	17	97
NT	18	98

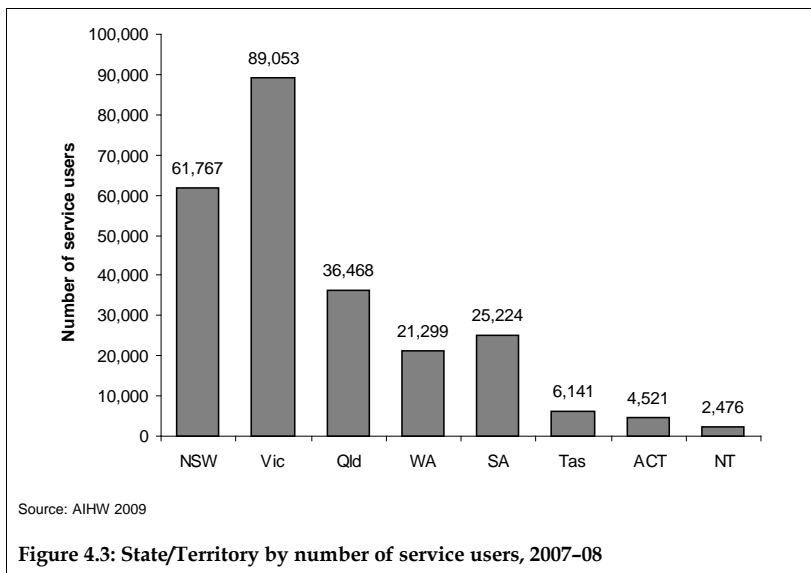
Guide for use

Funding departments allocated ‘Funding jurisdiction’ to identify their jurisdiction as the source of the NDA funding for your service type outlet and the geographic area that benefits.

Why is this data item collected?

Required to allow data to be merged to, and examined at, a state level for particular purposes, including needs-based planning.

Example of how this data item is used



G Agency sector

Defined as: The type of government or non-government sector to which the funded agency (or service type outlet) belongs.

Classification:

Government

- 1 Commonwealth
- 2 State/territory
- 3 Local

Non-government

- 4 Income tax exempt (charity)
- 5 Non-income tax exempt

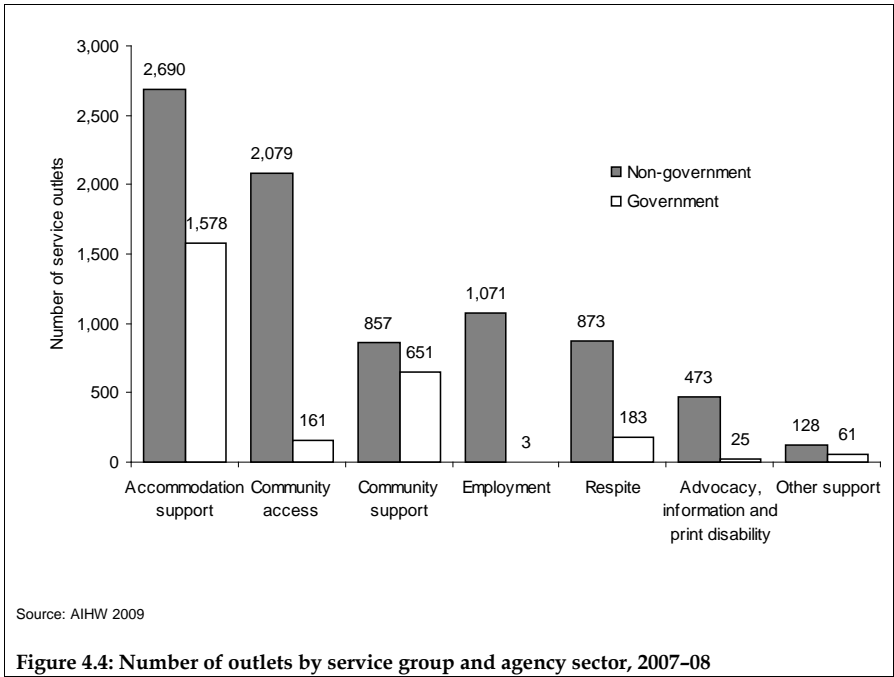
Guide for use

- Charities are not automatically exempt from income tax. There is an endorsement system under which they should apply to the Australian Tax Office to be endorsed as income tax exempt.
- **Income tax exempt charity:** an Income Tax Exempt Charity is a charity that has been endorsed by the Australian Taxation Office as exempt from income tax. As well as being exempt from paying income tax, an Income Tax Exempt Charity does not have to lodge income tax returns unless specifically requested to do so by the Australian Taxation Office <www.ato.gov.au>.
- **Non-income tax exempt charities:** charities that are not endorsed by the Australian Taxation Office as being exempt from paying income tax are classified as non-income tax exempt (code 5).
- Where a service type outlet has a formal relationship with a higher level funded agency then the agency sector of the higher level funded agency should generally be recorded.
- Service type outlets should verify – and correct where necessary – the agency sector the funding department has assigned to their service type outlet.

Why is this data item collected?

To provide a comparative break-up of the funding provided to the government and non-government sectors, and to enable analysis between and within these sectors. The example below shows the number of outlets funded by government and non-government sector, for each service group.

Example of how this data item is used



1 Full financial year of NDA funding

[Corresponds to data item 'Full financial year of CSTDA funding']

Question: Has this service type outlet been funded for the full financial year?

Defined as: Whether the service type outlet has received funding for the full financial year.

Classification: 1 Yes
2 No

Guide for use

- This data item is asking whether a service type outlet was **funded for the full financial year** (i.e. 2008–09). For example:
 - if a service type outlet received funding in December but intends subsequently to operate for 52 weeks per year, please record 'No' for this item, and record '52' for data item 2 (weeks per year of operation).
- In providing this data item do not record the weeks or days of operation of the service type outlet. The actual weeks per year, days per week, and hours per day your service type outlet normally operates across the financial year are recorded in data items 2–4.
- A service type outlet may be funded for the entire financial year but only operates for part of the year. If this applies to your service type outlet please indicate that you are funded for the full financial year and indicate (in data item 2) the number of weeks you actually operate. For example:
 - if a service type outlet receives funding for the full financial year but only operates for four school holiday periods of 2 weeks each, please record 'Yes' for this item, and record '8' for data item 2 (weeks per year of operation).
 - if a service type outlet receives funding for the full financial year but only operates for 20 weeks in the year, please record 'Yes' for this item, and record '20' for data item 2 (weeks per year of operation).

Why is this data item collected?

This question is useful for explaining variation in responses to item 7 about actual service user numbers over a financial year in relation to items 2–4 on actual hours/days/weeks of operation.

Example of how this data item is used

In 2007–08, 81% of outlets (8,748 of 10,836) reported receiving funding for the full financial year (AIHW 2009: Table A1.3).

2 Weeks per year of operation

Question: How many weeks per year does this service type outlet usually operate?

Defined as: The number of weeks per year that the service type outlet **usually** operates.

Classification: 1-52 The actual number of weeks **per year**
 90 No regular pattern of operation through a year

Guide for use

- Number of weeks of operation, rounded up to the nearest whole week.
- Please record '90' ('no regular pattern of operation through a year') if the service type outlet does not have a regular pattern of operation; for example, a recreation/holiday program which is offered only if there are sufficient numbers (i.e. program offered on demand).
- Service type outlets 7.01-7.04 may record '90' ('no regular pattern of operation through a year'), or, if it is possible and they wish to do so, they may record the actual number of weeks of operation.
- A service type outlet is considered to be operating whenever service is provided to service users e.g. if your service type outlet closes for only 2 weeks over the Christmas period you should indicate that you operate for 50 weeks per year.
- This data item is seeking information about the **usual** weeks of operation of a service type outlet. For example, if a service type outlet received funding from September but intends to operate for 52 weeks per year, please record '52' for this item, and record 'No' for data item 1 (full financial year of NDA funding).
- Data items 2-4 are asking about the amount of time the service type outlet is generally open for service provision to service users.
- Data items 2-4 are **not** asking about the amount of time a service type outlet is staffed. Information about total number of staff hours allocated to each service type outlet is requested in data items 5 and 6 (staff hours).

Why is this data item collected?

To gain a greater understanding of patterns of service delivery.

Example of how this data item is used

Table 4.1: CSTDA-funded service outlets, operating weeks per year by service group, 2007-08

	Accommodation Support	Community Support	Community Access	Respite	Employment	Advocacy, info., print	Other	Total
1 to 39 weeks	59	45	97	60	25	18	3	307
40 to 47 weeks	23	82	166	12	15	10	6	314
48 to 51 weeks	115	423	1,051	150	469	193	56	2,457
All year	3,642	676	586	570	527	193	85	6,279
No regular pattern	35	21	25	45	8	16	13	163
Total	3,874	1,247	1,925	837	1,044	430	163	9,520

Source: AIHW 2009: Table A1.3

3 Days per week of operation

Question: How many days per week does this service type outlet usually operate?

Defined as: The number of days per week that the service type outlet **usually** operates.

Classification: 1-7 The actual number of days **per week**
90 No regular pattern of operation through a week

Guide for use

- Number of days of operation, rounded up to the nearest whole day.
- Please record '90' ('no regular pattern of operation through a week') if, for example, a service will be made available to a service user after hours only upon request (i.e. an outlet operates office hours Monday to Friday and has staff on call outside these hours).
- Service type outlets 7.01-7.04 may record '90' ('no regular pattern of operation through a week'), or, if it is possible and they wish to do so, they may record the actual number of days per week of operation.
- A service type outlet is considered to be operating whenever service is provided to service users, e.g. if your service type outlet is open for 4 days per week for service provision to service users and 1 day per week for management/administration then your service type outlet should indicate that it operates 4 days per week.
- Data items 2-4 are asking about the amount of time the service type outlet is generally open for service provision to service users.
- Data items 2-4 are **not** asking about the amount of time a service type outlet is staffed. Information about total number of staff hours allocated to each service type outlet is requested in data items 5 and 6 (staff hours).

Why is this data item collected?

To gain a greater understanding of patterns of service delivery.

Example of how this data item is used

In 2007-08, most service type outlets reported operating for 5 days (4,505 of 9,391, or 48%) or 7 days (3,912, or 42%) per week (AIHW 2009: Table A1.3).

4 Hours per day of operation

Question: How many hours per day does this service type outlet usually operate?

Defined as: The number of hours per day that the service type outlet is **usually** open for the provision of service (not the number of hours staffed).

Classification: 1-24 The number of hours **per day**
90 No regular pattern of operation through a day

Guide for use

- Number of hours of operation, rounded up to the nearest whole hour.
- Please record '90' ('no regular pattern of operation through a day') if, for example:
 - the service type outlet operates for flexible hours, on call or sleepover duties
 - the service type outlet has different weekday and weekend operation patterns.
- Service type outlets that have no regular daily pattern of operation, or which have different weekday and weekend patterns, should tick the 'no regular pattern of operation through a day' box, coded as '90' (e.g. if your service type outlet operates for flexible hours, on call, or sleepover duties, please record '90' for this data item).
- Service type outlets 7.01–7.04 may record '90' ('no regular pattern of operation through a day'), or, if it is possible and they wish to do so, they may record the actual number of days per week of operation.
- Please **do not** provide the number of hours per week.
- A service type outlet is considered to be operating whenever service is open to service users (e.g. if your service type outlet is staffed between the hours of 9am–5pm but is only open for service users between 10am–3pm you should indicate that you operate for 5 hours per day).
- Service type outlets that provide facility-based accommodation (e.g. group homes) should record their hours as 24 per day if the service users reside in the facility on an ongoing basis and **can access the facility at any time**, even though the facility may not be staffed during parts of the day. In contrast, if service users are not able to stay in the residential facility during certain hours, the facility is not considered to be open or operating during these hours.
- Data items 2–4 are asking about the amount of time the service type outlet is **generally** open for service provision to service users.
- Data items 2–4 are **not** asking about the amount of time a service type outlet is staffed. Information about total number of staff hours allocated to each service type outlet is requested in data items 5 and 6 (staff hours).

Why is this data item collected?

To gain a greater understanding of patterns of service delivery.

Example of how this data item is used

In 2007–08, around one third (3,307 of 9,664, or 34%) of service type outlets reported that they operated 24 hours per day (AIHW 2009: Table A1.3).

5 Staff hours (reference week)

Question: What were the total hours worked by staff (including those worked by contracted staff) and volunteers on behalf of this service type outlet in the 7-day reference week preceding the end of the reporting period?

Defined as: The actual total hours worked by staff on behalf of the service type outlet, including contracted staff and volunteers for the **7-day reference week preceding the end of the reporting period**.

Separate figures should be entered for paid staff and unpaid staff (where applicable).

Paid staff: include paid hours worked by staff (including hours worked by contract staff) employed on a permanent, part-time or casual basis under an employment or other contract.

Unpaid staff: include unpaid hours worked by staff, volunteers or students and others who do not receive payment for the work which they perform on behalf of the service type outlet.

Classification: 5a Paid staff: 0-99999 hours worked

5b Unpaid staff: 0-99999 hours worked

Guide for use

- This item should be completed separately for both paid staff and unpaid staff (including volunteers). This item is asking for actual staff hours worked for the 7-day week preceding the end of the reporting period, not full-time equivalents or rostered weekly hours.
- **Staff hours should be rounded up to the nearest whole hour.**

Inclusions and exclusions for the calculation of staff hours worked on behalf of this service type outlet:

Include:

- Staff hours worked by administrative staff, managers etc. (i.e. indirect staff relating to this service type outlet).
- Staff hours worked by Board members relating to this service type.
- Staff hours worked on committees or at meetings relevant to this service type.
- Staff hours worked as paid overtime (to be included with paid staff hours).
- Staff hours worked as unpaid work by usually paid or contract staff (to be included with unpaid staff hours).
- Staff hours worked while staff receive payment for sleepover duties.
- Staff hours worked by staff contracted to clean premises.
- Staff hours worked by staff receiving training relevant to this service type.
- Staff hours worked while travelling to a location to assist/visit a service user.

Exclude:

- Staff hours for workers on leave (including public holidays, paid/unpaid sick leave, i.e. this data item relates to staff hours **worked**, not staff hours paid for).

- Staff hours normally worked in positions that are currently vacant.
- Staff hours allocated to non-NDA service users.
- For *agencies with multiple service type outlets* (and where staff hours per service type outlet are not known), all staff should be apportioned across service type outlets. To apportion staff across different service type outlets it is recommended that agencies.
 - use fortnightly rosters as a starting point
 - apportion total staff hours across funded service types
 - divide this figure by two to get weekly staff hours for the week preceding the end of the reporting period
 - record the apportioned staff hours to the relevant outlet on its Service Type Outlet Form.
- This item is asking for hours worked by staff on behalf of this service type outlet both directly delivered to service users and on behalf of this service type outlet more generally (i.e. indirect hours such as related committee meetings).
- A funded agency may receive funding from multiple sources, however for DS NMDS purposes, only those services provided using NDA funds should be recorded. Where a funded agency is unable to differentiate all data according to funding source (i.e. NDA or other), they are asked to provide full details (in this case, staff hours) regardless of funding source.
- If your service type outlet is funded to provide **service type 2.06 Case management, local coordination and development**, please note the following rules for calculating staff hours:
 - record staff hours relating to the case coordination/management/brokerage activities you undertake (including administrative time, board member time etc. as above)
 - do not record the staff hours for the agencies who provide any services arranged, purchased or brokered by your service type outlet as part of providing service type 2.06
 - please also see data items 17e-f 'hours received' per service user, as similar rules apply to the calculation of hours received by service users.

These rules are designed to avoid double counting and duplication of effort by funded agencies.
- If your service type outlet **sub contracts the provision of part or all of a service type (other than 2.06)** you are funded to provide to another agency:
 - you are responsible for providing relevant details about the sub contracted activity (e.g. in-home accommodation support provider sub contracting the provision of some in-home accommodation support to another agency, which may or may not be NDA-funded)
 - please include an estimate of the staff hours sub contracted in this way with the staff hours allocation for your service type outlet (and the sub contractor outlet should not include these hours in their service type outlet return, if they are also included in the DS NMDS)
 - please also see data items 17e-f 'hours received' per service user, as similar rules apply to the calculation of hours received by service users.

These rules are designed to avoid double counting and duplication of effort by funded agencies.

Please refer to Appendix D for further information and examples dealing with brokerage and sub contracted services.

Why is this data item collected?

This item is collected to assist in analysis of staffing inputs for disability support, and to enable a comparison of the staffing requirements of different service types.

It is important to include 'volunteers' due to the significant contribution they make within many agencies.

6 Staff hours (typical week)

Question: What were the hours worked in a typical (or average) 7-day week by staff (including those worked by contracted staff) and volunteers on behalf of this service type outlet?

Defined as: The **hours worked in a typical 7-day week** by staff on behalf of the service type outlet, including contracted staff and volunteers over the reporting period.

This data item is designed to enable service type outlets to reflect that the staff hours (reference week) indicated in data item 5 may not be typical.

Separate figures should be entered for paid staff and unpaid staff (where applicable).

Paid staff: include paid hours worked by staff (including hours worked by contract staff) employed on a permanent, part-time or casual basis under an employment or other contract.

Unpaid staff: include unpaid hours worked by staff, volunteers or students and others who do not receive payment for the work which they perform on behalf of the service type outlet.

Classification: 6a Paid staff: 0-99999 hours worked
6b Unpaid staff: 0-99999 hours worked

Guide for use

- This item should be completed separately for both paid staff and unpaid staff (including volunteers).
- **Staff hours should be rounded up to the nearest whole hour.**
- If your service type outlet has usual or typical weekly staff hours, please indicate this in the response to this data item.
- If the concept of a typical week does not apply to your service type and/or if your service type outlet is able to calculate this data item as an **average of actual hours worked** per week over the reporting period (i.e. you record staff hours continuously for the whole reporting period) then please do so.
- Include staff hours for staff who were on leave during the reference week and staff hours for positions that are usually filled but are currently vacant (on a short-term or temporary basis only).

Inclusions and exclusions for the calculation of staff hours worked on behalf of this service type outlet:

Include:

- Staff hours worked by administrative staff, managers etc. (i.e. indirect staff relating to this service type outlet).
- Staff hours worked by Board members relating to this service type.
- Staff hours worked on committees or at meetings relevant to this service type.

- Staff hours worked as paid overtime (to be included with paid staff hours).
- Staff hours worked as unpaid work by usually paid or contract staff (to be included with unpaid staff hours).
- Staff hours worked while staff receive payment for sleepover duties.
- Staff hours worked by staff contracted to clean premises.
- Staff hours worked by staff receiving training relevant to this service type.
- Staff hours worked while travelling to a location to assist/visit a service user.

Exclude:

- Staff hours for workers on leave (including public holidays, paid/unpaid sick leave, i.e. this data item relates to staff hours **worked**, not staff hours paid for).
- Staff hours normally worked in positions that are currently vacant.
- Staff hours allocated to non-NDA service users.
- For agencies with multiple service type outlets (and where staff hours per service type outlet are not known), all staff should be apportioned across service type outlets. To apportion staff across different service type outlets it is recommended that agencies.
 - use fortnightly rosters as a starting point
 - apportion total staff hours across funded service types
 - divide this figure by two to get weekly staff hours for the week preceding the end of the reporting period
 - record the apportioned staff hours to the relevant outlet on its Service Type Outlet Form.
- This item is asking for hours worked by staff on behalf of this service type outlet both directly delivered to service users and on behalf of this service type outlet more generally (i.e. indirect hours such as related committee meetings).
- A funded agency may receive funding from multiple sources, however for DS NMDS purposes, only those services provided using NDA funds should be recorded. Where a funded agency is unable to differentiate all data according to funding source (i.e. NDA or other), they are asked to provide full details (in this case, staff hours) regardless of funding source.
- If your service type outlet is funded to provide **service type 2.06 Case management, local coordination and development**, please note the following rules for calculating staff hours:
 - record staff hours relating to the case coordination/management/brokerage activities you undertake (including administrative time, board member time etc. as above)
 - do not record the staff hours for the agencies who provide any services arranged, purchased or brokered by your service type outlet as part of providing service type 2.06
 - please also see data items 17e-f 'hours received' per service user, as similar rules apply to the calculation of hours received by service users.

These rules are designed to avoid double counting and duplication of effort by funded agencies.
- If your service type outlet **sub contracts the provision of part or all of a service type (other than 2.06)** you are funded to provide to another agency:

- you are responsible for providing relevant details about the sub contracted activity (e.g. in-home accommodation support provider sub contracting the provision of some in-home accommodation support to another agency, which may or may not be NDA-funded)
- please include an estimate of the staff hours sub contracted in this way with the staff hours allocation for your service type outlet (and the sub contractor outlet should not include these hours in their service type outlet return, if they are also included in the DS NMDS)
- please also see data items 17e-f 'hours received' per service user, as similar rules apply to the calculation of hours received by service users.

These rules are designed to avoid double counting and duplication of effort by funded agencies.

Please refer to Appendix D for further information and examples dealing with brokerage and sub contracted services.

Why is this data item collected?

This item is requested to enable service type outlets to indicate that the staff hours worked in the reference week (i.e. 7-day week preceding the end of the reporting period) were or were not typical for the service type outlet (i.e. considerably more or less hours were worked).

This item is collected to help analysis of staffing inputs for disability support, and to enable a comparison of the staffing requirements of different service types.

It is important to include 'volunteers' due to the significant contribution they make within many agencies.

7 Number of service users

Question: How many service users received this service type from this service type outlet during the reporting period?

Defined as: Total number of people receiving a particular NDA-funded service type during the reporting period.

Classification: 1-99999

Guide for use

- **Do not complete this data item** if you are funded to provide service types **7.01–7.04** ('other support' services types such as peak bodies, research and development etc.). (See also Table 3.2 in Section 3.4.)
- The number of people is required, not instances of service. That is, each service user receiving a NDA-funded service type during the reporting period should be counted only once, regardless of the number of times they accessed the service type in that time period.
- The number of people who received a service during the whole reporting period (see Glossary, page v) is required, not just those who received a service in the reference week.
- For all service type outlets except 6.01–6.05:
 - the service type outlet must have allocated some of its resources (more than 15 minutes) to the person during the reporting period, for instance to a person residing in agency-operated accommodation, attending respite care, or attending a recreation service. Service users should not be counted if they have only made requests for information, minor phone queries etc.
- Service type outlets 6.01–6.05 should count the following:
 - 6.01 (Advocacy) – number of people who have received advocacy services in the reporting period.
 - 6.02 (Information/referral) – number of people making a request for information or referral.
 - 6.03 (Combined information/advocacy) – as for 6.01 and 6.02.
 - 6.04 (Mutual support/self-help groups) – number of people attending sessions (i.e. if an individual attends a group session every Wednesday in the reporting period, please count each person only once over the reporting period).
 - 6.05 (Alternative formats of communication) – estimated number of people accessing the output from the service.
- It may not always be feasible to count the actual number of service users receiving services from service type outlets 6.01–6.05. Where this is not possible, service type outlets are asked to estimate the number of service users accessing the service. For example, a NDA-funded radio station (6.05) should estimate the number of people who listen to the radio station. Where there is a number of people potentially receiving a 6.01–6.05 service simultaneously (e.g. an interpreter at a conference), estimate the number of people that are benefiting from the service (e.g. how many people actually need the interpreter). If this is not possible, all people present should be counted as service users.

- This data item refers to the number of service users **receiving** NDA-funded services of a particular service type, **not** those service users 'on the books', 'on waiting lists', or number of 'beds' or 'places'.
- In some cases 'number of service users' may be greater than the number of Service User Forms completed by your service type outlet. This may be because of service users who have not consented for their information to be transmitted as part of the DS NMDS; they should still be included in the 'number of service users' (see Section 3.3 about implementing privacy and data principles and Section 6 for a copy of the DS NMDS Privacy and Data Principles).
- A funded agency may receive funding from multiple sources—however for DS NMDS purposes, only those services provided using NDA funds should be recorded. Where a funded agency is unable to differentiate all data according to funding source (i.e. NDA or other), they are asked to provide details of all service users and staff (for each service type). For example, if a service type outlet providing early childhood intervention is partly funded by your agency, through donations or fund raising, and partly by NDA funds, please count all service users who receive this service during the reporting period, unless your accounting and staffing methods enable reporting separately.
- The total number of people receiving this service type (as indicated in response to this data item) will usually be equal to the number of Service User Forms completed by your service type outlet.

Why is this data item collected?

This data item has proven to be a useful check for funded agencies, jurisdictions and the AIHW to verify that service user details have been provided for the correct number of service users.

Where the calculated number of service users for a service type (derived from Service User Forms) is less than the number of estimated service users for that service type (from this data item), this question enables an understanding of the refusal rates of service users. That is, the question enables an estimate of the number of service users who did not consent to the collection or transmission of information about them.

This data item provides a vital indication of the nature of the collected data, the amount of missing information and the need to improve information to service users and funded agencies.

5 Service user and services received information

The following section contains data item definitions and information on service user items B, and 1-17f. Most service type outlets need to provide information about all service users who receive a NDA-funded service in any reporting period.

- No service user information needs to be provided if the service type is:
 - 6.01 Advocacy
 - 6.02 Information/referral
 - ~~6.026.03~~ Combined information/advocacy
 - ~~6.026.04~~ Mutual support/self-help groups
 - ~~6.026.05~~ Alternative formats of communication
 - 7.01 Research and evaluation
 - ~~7.017.02~~ Training and development
 - ~~7.017.03~~ Peak bodies
 - ~~7.017.04~~ Other support services
- For the service type 3.02 (recreation/holiday programs), service user data items up to and including the linkage key components are required (i.e. items B1 and 2a-2e – see Table 3.1), and services received items 17a-17b.
- The following service types do **not** need to complete items 12b, 12c or 12e (carer – primary status, residency status and age group):
 - 5.01 Open employment
 - 5.02 Supported employment
- The following service types do not need to complete items 17e or 17f on hours received:
 - 1.01 Large residential/institutions
 - 1.02 Small residential/institutions
 - 1.03 Hostels
 - 1.04 Group homes
 - 1.08 Other accommodation support
 - 2.01 Therapy support for individuals
 - 2.02 Early childhood intervention
 - 2.03 Behaviour/specialist intervention
 - 2.04 Counselling (individual/family/group)
 - 2.05 Regional resource and support teams
 - 2.07 Other community support
 - 3.02 Recreation/holiday programs
 - 5.01 Open employment
 - 5.02 Supported employment
- For all other service types, funded agencies are to complete all items.
See also Table 3.2 in Section 3.4.

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B Service type outlet ID

Defined as: A unique number assigned to each service type outlet, by the funding department.

Classification: Numeric or alpha numeric identification.

Guide for use

- The service type outlet is asked to relate the service user to the appropriate service type outlet ID. The service type outlet ID is the same number as that provided by the funding department and located on the Service Type Outlet Form, as data item B. This entails copying the appropriate service type outlet ID from the relevant Service Type Outlet Form.
- If an agency provides more than one service type (e.g. a therapy service and an early childhood intervention service), then the funding department will have allocated a unique service type outlet ID to each of the corresponding service type outlets. A separate Service Type Outlet Form must be completed for each of these service type outlets.
- If a particular service user accesses only one service type from a funded agency (e.g. therapy services), then the service type outlet ID number from data item B on the Service Type Outlet Form should be transcribed to their Service User Form. The remaining sections of the Service User Form should be completed in relation to the services received from the therapy service.
- If the service user also receives another service type (e.g. early childhood intervention), a separate service user form should be completed with the early childhood intervention ID number transcribed. The Service User Form is then completed for the service user in relation to the services received from the early childhood intervention.
- For further details see 'B - Service type outlet ID' listed under service type outlet data items (page 20).

Why is this data item collected?

This data item is used to identify which service type or types a service user receives in a reporting period.

Example of how this data item is used

On average, service users accessed 1.7 service type outlets and 1.3 service groups during 2007–08 (AIHW 2009).

1 Record ID

Defined as: A unique number that identifies a service user record within a funded agency.

Classification: 00001-99999999

Guide for use

- It is recommended that the record ID be a sequential number starting from 00001.
- Each service type outlet assigns the number to each completed Service User Form.
- The record ID may be an existing client number used by the service type outlet. However, note that the record ID should be numeric.

Why is this data item collected?

This data item is included for administrative purposes to assist service type outlets, funded agencies and the funding department when information is followed up, for instance when information has been omitted. The record ID, used together with the service type outlet ID, enables identification of a Service User Form without the need to identify an individual by their name, or other information.

In software this data item is used to match records between different files.

2 Statistical linkage key components

2a Letters of surname

Question: Please write in the second, third and fifth letters of the service user's surname.

Defined as: The second, third and fifth letters of the person's surname.

Classification: Alpha numeric 3 characters.

Guide for use

- Please use block capital letters.
- Do not include apostrophes, hyphens, inflections, dashes or spaces.
- If the **surname of the person is not long enough** to supply the requested letters (i.e. a surname of less than five letters) then the number '2' should be substituted to reflect the missing letters. The placement of a number '2' should always correspond to the same space that the missing letter would have within the three-digit field.
- If the surname of the person is completely absent, it should be replaced by a string of digits of value '9' to indicate 'not stated'. Please note that the use of 'not stated' for this data item is strongly discouraged and your funding department will follow up such responses. The rules for recording 'not stated' are included only to retain consistency with the HACC minimum data set.
- Often people use a variety of names, including legal names, married/maiden names, nicknames, assumed names, traditional names etc. Even small differences in recording, such as the difference between MacDonald and McDonald, can make record linkage impossible. To minimise discrepancies in the recording and reporting of name information, agencies should ask for a person's full 'surname'. This may be different from the name that the person may prefer the agency to use in personal dealings. Agencies may choose to separately record the preferred name that the person wishes to be used by agency workers.
- In some cultures it is traditional to state the surname first. To overcome discrepancies in recording/reporting that may arise as a result of this practice, agencies should always ask the person to specify their given name and their surname separately.
- Selected letters were chosen rather than initials, for privacy reasons. This information is for statistical purposes only and will not be used in data output. (See Sections 3.3 and 6 for further information about the DS NMDS Privacy and Data Principles and associated practices.)
- Some software allows for the entry of a service user's full name details; such software only exports the required letters of the service user's name for transmission.
- Note that the service user is the person with a disability, **not** the family or the carer, even in the case of respite services.

Examples of correct use

Sample name	'Surname' response						
PANG, Ho		A	N		2		
	1st	2nd	3rd	4th	5th	6th	7th
O'DOYLE, Mary		D	O		L		
	1st	2nd	3rd	4th	5th	6th	7th
De VERES, Phil		E	V		R		
	1st	2nd	3rd	4th	5th	6th	7th
MacMILLS, Jo		A	C		I		
	1st	2nd	3rd	4th	5th	6th	7th
Brian		9	9		9		
	1st	2nd	3rd	4th	5th	6th	7th

Examples of incorrect last name

Sample name	Incorrect 'Surname' response						
D'Arcy, John		D	'		C		
		D	9		C		
		D	2		C		
	1st	2nd	3rd	4th	5th	6th	7th
Heap, Sally		H	E		9		
		1st	2nd	3rd	4th	5th	6th

Why is this data item collected?

To obtain data on the number of service users accessing NDA services over the reporting period. The data item will be used in conjunction with sex and date of birth data to statistically remove the multiple counting of individuals across service types and reporting periods. Data on the number of service users accessing NDA-funded services can only be obtained by reducing multiple counting to a statistically acceptable minimum.

Example of how this data item is used

The linkage key was used to estimate that there were 245,746 service users accessing CSTDA-funded services between 1 July 2007 and 30 June 2008.

2b Letters of given name

Question: Please write in the second and third letters of the service user's given name.

Defined as: The second and third letters of the person's given name.

Classification: Alpha numeric 2 characters.

Guide for use

- Do not include apostrophes, hyphens, inflections, dashes or spaces.
- If the given **name of the person is not long enough** to supply the requested letters (i.e. a given name of less than three letters) then the number '2' should be substituted to reflect the missing letter. The placement of a number '2' should always correspond to the same space that the missing letter would have within the two-digit field.
- If the given name of the person is completely absent, it should be replaced by a string of digits of value '9' to indicate 'not stated'. Please note that the use of 'not stated' for this data item is strongly discouraged and your funding department will follow up such responses. The rules for recording 'not stated' are included only to retain consistency with the HACC minimum data set.
- If only a first initial has been provided then it should be treated as described for completely absent, that is, it should be replaced by a string of digits of value '9' to indicate 'not stated'. Please note that the use of 'not stated' for this data item is strongly discouraged and your funding department will follow up such responses. The rules for recording 'not stated' are included only to retain consistency with the HACC minimum data set.
- Often people use a variety of names, including legal names, married/maiden names, nicknames, assumed names, traditional names etc. Even small differences in recording, such as the difference between Thomas and Tom, can make record linkage impossible. To minimise discrepancies in the recording and reporting of name information, agencies should ask for a person's full 'given name'. This may be different from the name that the person may prefer the agency worked to use in personal dealings. Agencies may choose to separately record the preferred name that the person wishes to be used by agency workers.
- In some cultures it is traditional to state the surname first. To overcome discrepancies in recording/reporting that may arise as a result of this practice, agencies should always ask the person to specify their given name and their surname separately.
- Selected letters were chosen rather than initials, for privacy reasons. This information is for statistical purposes only and will not be used in data output. (See Sections 3.3 and 6 for further information about the DS NMDS Privacy and Data Principles and associated practices.)
- Some software allows for the entry of a service user's full name details; such software only exports the required letters of the service user's name for transmission.

Examples of correct use

Sample name	'Given name' response						
PANG, Ho		O	2				
	1st	2nd	3rd	4th	5th	6th	7th
O'DOYLE, Mary		A	R				
	1st	2nd	3 rd	4th	5th	6th	7th
De VERES, Phil		H	I				
	1st	2nd	3rd	4th	5th	6th	7th
NIKOV, Steve		T	E				
	1st	2nd	3rd	4th	5th	6th	7th
BEHLER		9	9				
	1st	2nd	3rd	4th	5th	6th	7th

Examples of incorrect use

Sample name	Incorrect 'Given name' response						
PANG, Ho		O	9				
	1st	2nd	3rd	4th	5th	6th	7th
BEHLER		2	2				
	1st	2nd	3rd	4th	5th	6th	7th

Why is this data item collected?

To obtain data on the number of service users accessing NDA services over the reporting period. The data item will be used in conjunction with sex and date of birth data to statistically remove the multiple counting of individuals across service types and reporting periods. Data on the number of service users accessing NDA-funded services can only be obtained by reducing multiple counting to a statistically acceptable minimum.

2c Date of birth

Question: What is the service user's date of birth?

Defined as: The day, month and year when the person was born.

Classification: ddmmyyyy

Guide for use

- If the actual date of birth is unknown, estimate the year of birth, enter 01/01 as the day and month, and tick 1 'Yes' for data item 2d 'Birth date estimate flag'.
- For privacy reasons, age in years will be the output data item rather than date of birth.

Example:

Service user born 16/2/1964

1	6	0	2	1	9	6	4
d	d	m	m	y	y	y	y

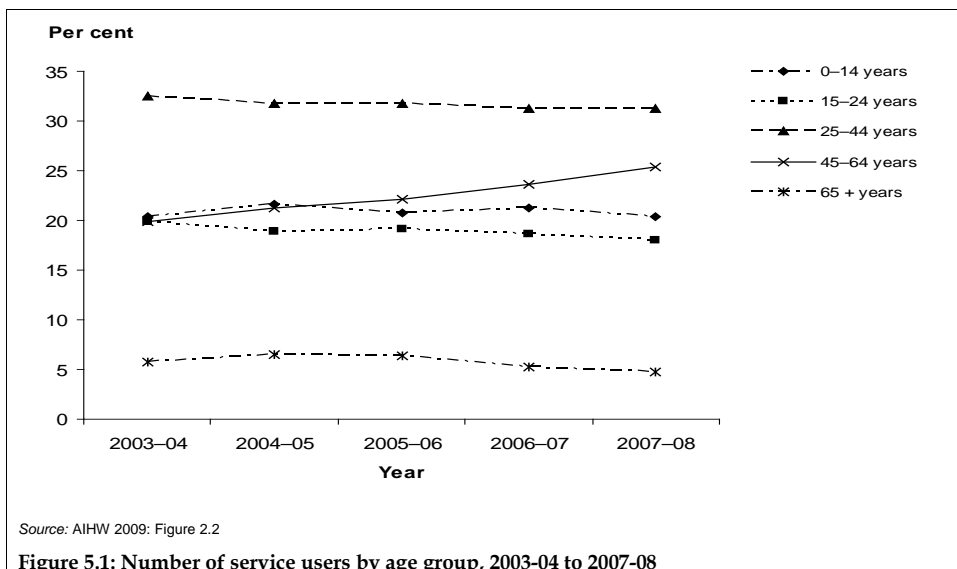
31-year-old service user, date of birth not known
(Estimated as: 2010 minus age in years)

0	1	0	1	1	9	7	9
d	d	m	m	y	y	y	y

Why is this data item collected?

Age is needed for analysis of service utilisation, and comparison with population data. Actual date of birth is used in conjunction with sex and letters of name to statistically reduce the multiple counting of individual service users across service types and over time (i.e. across reporting periods).

Example of how this data item is used



2d Birth date estimate flag

Question: Is the service user's date of birth an estimate?

Defined as: Whether or not the person's date of birth has been estimated.

Classification: 1 Yes

Guide for use

- If the service user's date of birth has been entered as 01/01, because the exact date of birth was not known, then the date estimate flag box should be ticked.

Why is this data item collected?

Date of birth is one component of the statistical linkage key, used to statistically reduce multiple counting of service users across service types and reporting periods. Date of birth is also used to generate service users' ages. By knowing that date of birth is estimated it is possible to reduce underestimation of total service user numbers and overestimation of service users' ages. Essentially, the flag is used to indicate the exact date of birth is not known.

2e Sex

Question: What is the service user's sex?

Defined as: The sex of the person.

Classification: 1 Male
2 Female

Guide for use

- Coding for this data element is based on the biological distinction between male and female. Where uncertainty exists about the sex of the person (e.g. for transvestites or transsexuals) the sex to be recorded is to be based on the sex nominated by the person themselves or on the observations/judgement of the interviewer. Although this may lead to some error, it is considered preferable to any offence that may be caused by a question that suggests that there is some doubt about the person's sex or sexuality.
- The Disability Services NMDS (July 2009) Data Set Specification entry for the Sex Data Element should be used when completing this field. For further information see the AIHW's Metadata Online Registry (METeOR) - <http://meteor.aihw.gov.au/content/index.phtml/itemId/287316>

Why is this data item collected?

This data item is needed for analysis of patterns of service use. Data can be extracted on: the age and sex of NDA service users and trends over time in these characteristics; sex variation in disability patterns of NDA service users; and access to services by different population groups. This data item is also one of the three components of the statistical linkage key.

Example of how this data item is used

In 2007–08, 145,183 (59%) of the 245,746 service users were male. (AIHW 2009: Table A1.1).

3 Indigenous status

Question: Is the service user of Aboriginal or Torres Strait Islander origin?

Defined as: Whether or not a person identifies themselves as being of Aboriginal and/or Torres Strait Islander origin.

Note: this is the Australian Bureau of Statistics 'working definition'. It does not include the concept of a need for acceptance of the person as being an Aboriginal or Torres Strait Islander by the community in which the person lives.

Classification:

- 1 Aboriginal but not Torres Strait Islander origin
- 2 Torres Strait Islander but not Aboriginal origin
- 3 Both Aboriginal **and** Torres Strait Islander origin
- 4 Neither Aboriginal origin nor Torres Strait Islander origin

Guide for use

- Responses must **not** be based on the perceptions of anyone other than the person, or their advocate. The 'look' of a person has proven to be an unreliable way for another person to assess someone's Indigenous status.
- This response should be left blank **only if**:
 - an answer was refused by the service user
 - the question was not able to be asked before data transmission because the service user was unable to communicate or a person who knows the service user was not available.

However, this item is very important and funded agencies who submit blank responses for this data item should expect to be contacted by their funding department if they continue to be unable to provide an answer.

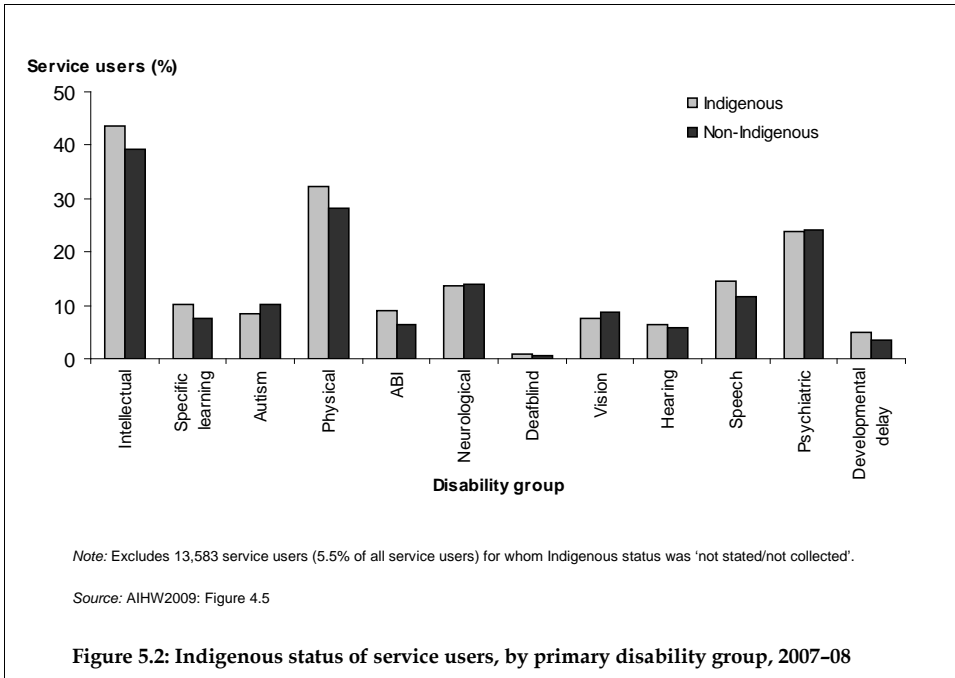
- The term 'Indigenous status' does not include 'South Sea Islander origin'. People of 'South Sea Islander origin' should be recorded as code 4 ('Neither Aboriginal origin nor Torres Strait Islander origin').

Why is this data item collected?

There is a strong case for ensuring that information on peoples of Aboriginal and Torres Strait Islander origin is collected for planning, evaluation, promotion and delivery of essential services. Accurately and consistently monitoring any inequalities in service access and wellbeing between people of Indigenous origin and others in Australia is particularly important, as is accounting for government expenditure in this area.

The health of Aboriginal and Torres Strait Islander people is of a lower standard than the health of the rest of the community. The life expectancy of Aboriginal and Torres Strait Islander people is about 20 years less than for other groups of Australians. There is some evidence that Aboriginal and Torres Strait Islander people experience higher rates of disability. Better information is needed about disability, and the needs of people with disabilities, if appropriate action is to be taken to improve the health and quality of life of Aboriginal and Torres Strait Islander people.

Example of how this data item is used



4 Country of birth

Question: In which country was the service user born?

Defined as: The country in which the person was born.

Classification:

1101	Australia	3207	Greece
2102	England	2304	Germany
1201	New Zealand	5204	Philippines
3104	Italy	7103	India
5105	Viet Nam	_____	Other country (please specify)
2105	Scotland		

Guide for use

- Where the country of birth is known but is not specified in the classification above (i.e. is 'other country'), **please specify** it in the space provided. These will then be coded by jurisdictions to the appropriate Australian Bureau of Statistics code.
- The 10 countries listed in this classification, are the 10 most frequently reported countries of birth in the 2001 Census. They are listed to simplify data collection and minimise coding load on jurisdictions.
- The codes included above are those used by the Australian Bureau of Statistics. They are included on paper Service User Forms to assist data entry by the jurisdiction (i.e. you only need to tick the relevant box, **not** enter the 4-digit code).
- For a complete listing of countries and country codes, please refer to the Australian Bureau of Statistics classification *Standard Australian Classification of Countries (SACC)* ABS cat. no. 1269.0. This classification (including latest revisions) can be downloaded for free from the ABS web site: <www.abs.gov.au>.
- SACC code 3213 (Serbia and Montenegro) was made redundant in 2006 with the independence of Montenegro. New users should be coded to either 3214 (Montenegro) or 3215 (Serbia). Also, new users should now be mapped to either 2107 (Guernsey) or 2108 (Jersey) instead of SACC code 2101 (Channel Islands).

Why is the data item collected?

Country of birth, in conjunction with data on communication method and interpreter services required is an important indicator of potential barriers to social integration.

This DS NMDS data item can be related to ABS Census data on 'country of birth'. This information can be used to generate the relevant English Proficiency Group to which the service user belongs. English Proficiency Groups can be used to examine service use in relation to cultural and language diversity.

Example of how this data item is used

The majority of service users in 2007-08 reported that they were born in Australia (203,399 of 245,746, or 83%) (AIHW 2009: Table A1.1).

5 Interpreter services required

Question: Does the service user require interpreter services?

Defined as: Requirement for interpreter services as perceived by the person seeking assistance.

Classification:

- 1 Yes – for spoken language other than English
- 2 Yes – for non-spoken communication
- 3 No

Guide for use

- This question relates to interpreter services for languages other than English, as well as interpreter services required because a person uses sign language or other form of non-spoken communication.
- If a person communicates with the assistance of a signer (i.e. not necessarily arranged by your agency) they should be recorded as 2 ‘Yes – for non-spoken communication’.
- Data item 6 ‘Communication method’, provides the opportunity to indicate the use of sign language and the level of effective communication of the service user.

Why is this data item collected?

Whether or not interpreter services are required is an important indicator of potential barriers to social integration, particularly in conjunction with data on Country of birth and Communication method.

The proportion of service users requiring any interpreter service overall will provide an indication of the support needs of service users.

Example of how this data item is used

In 2007–08, the majority of service users (209,726, or 81.5%) reported that they did not need an interpreter. A total of 12,682 service users (5.1%) did report needing an interpreter – 7,727 for non-spoken communication (3.1% of all service users) and 4,955 for spoken language other than English (2.0%) (AIHW 2009: Table 2.8).

6 Communication method

Question: What is the service user's most effective method of communication?

Defined as: The method of communication, including sign language, most effectively used by the person.

Classification:

- 1 Spoken language (*effective*)
- 2 Sign language (*effective*)
- 3 Other effective non-spoken communication (e.g. *Canon Communicator, Compic*)
- 4 Little, or no effective communication
- 5 Child aged under 5 years (*not applicable*)

Guide for use

- The communication must be **effective** in that the person must be able to communicate more than just basic needs, to unfamiliar people, using the method.
- This item is considered 'not applicable' to young children. Hence, children aged 0 to 4 years should **always** be coded as '5'.
- If communication method varies over time and it is difficult to say what the usual method is, please report the most effective method during the reference week.

Why is this data item collected?

Method of communication is an important indicator of potential barriers to social inclusion, particularly in conjunction with data on country of birth and interpreter services required.

Example of how this data item is used

In 2007–08, primary disability groups of deafblind and hearing were by far the most likely to report sign language as their main method of communication (26% and 21% respectively). Little or no effective communication was reported most frequently for those with primary disabilities of intellectual disability (26%) and autism (21%) (AIHW 2009: Table 2.7).

7 Living arrangements

Question: Does the service user usually live alone or with others? ('Usually' means 4 or more days per week on average)

Defined as: Whether the person lives alone or with other related or unrelated persons.

Classification:

- 1 Lives alone
- 2 Lives with family
- 3 Lives with others

Guide for use

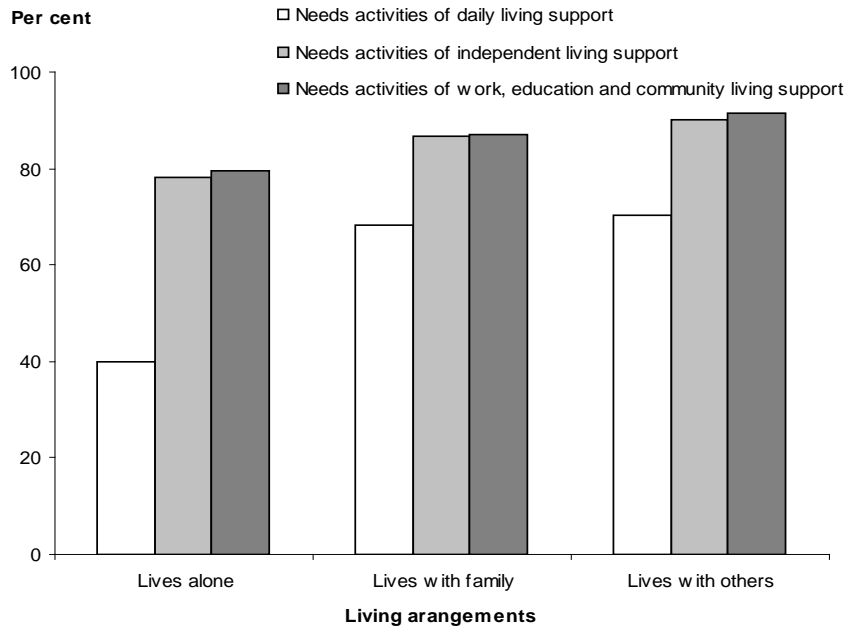
- **Lives with family** – includes living with parents, a partner (married, de facto and same sex relationships), male relatives (sons, brothers, uncles, nephews, male cousins, grandfathers, male grandchildren, step sons and so on), female relatives (daughters, sisters, aunts, nieces, female cousins, grandmothers, female grandchildren, step daughters and so on) and foster family.
- **Lives with others** – includes sharing with friends or a carer (where the carer is not a family member).
- People living in similar residential settings (e.g. hostels, group homes) may consider that they live alone or with others. The expressed views of the service user should be used to determine whether they live alone or with others.
- The service user's 'living arrangements' must relate to the same place described in 'service user postcode' (data item 8) and 'residential setting' (data item 9).
- If it is difficult to determine a 'usual' living arrangement over the reporting period, please report the living arrangement during the reference week.

Why is this data item collected?

Collection of this data item will enable the investigation of links between living arrangements and service use (e.g. are people who live alone more likely to access services?). The use of living arrangements as an indicator of potential in-home support and the ability to relate it to ABS population data are useful for planning purposes.

This data item can also relate to service users' support needs. Type of living arrangements for a person, in conjunction with carer arrangements, can indicate the level of support – both physically and emotionally – to which a person may have access.

Example of how this data item is used



Source: ALHW2009: Table A1.13 (Figure 3.5).

Notes:

1. Excludes missing data.
2. 'Needs support' refers to those that 'always and sometimes' need support.

Figure 5.3: Users of CSTDA-funded services, percentages of service users reporting always and sometimes needing support, by broad life areas and living arrangements, 2007-08

8 Service user postcode

Question: What is the postcode of the service user's usual residence? ('Usual' means 4 or more days per week on average)

Defined as: Postcode of the person's residential address.

Classification: Numeric 4-digit Australian postcode (*Australia Post* classification)

Guide for use

- Postcodes are widely known, and allow data to be aggregated as required, including generation of Statistical Local Area (SLA).
- The service user's postcode must relate to their selected 'residential setting'.

The complete list of valid postcodes in the *Australia Post* classification can be downloaded from <www.austpost.com.au>.

see: <http://auspost.com.au/products-and-services/download-postcode-data.html>

NOTE: Only residential postcodes should be recorded. Contact AIHW for exceptions.

Why is this data item collected?

Required to allow data to be merged into regions for particular analyses to monitor the availability of services in different regions across Australia. Potentially this item could also be used for analysis of distances between service users' accommodation setting and the receipt of services, and geographical planning for future services on the basis of need.

Previously, statistics on location have been restricted to service type outlets. With the collection of service user's postcode, the location of service users living in each state or territory can be more accurately classified using the Remoteness Areas of the Australian Standard Geographical Classification.

Example of how this data item is used

Table 5.1: Service users of state and territory CSTDA-funded services, service user location by state/territory, 2007–2008

Remoteness area	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
Service users per 1,000 population aged under 65 years									
Major cities	9.0	15.6	8.0	10.9	15.6	—	14.2	—	11.4
Inner regional	13.5	23.5	13.0	11.1	17.2	14.9	123.3	—	15.9
Outer regional	13.1	25.0	10.6	11.0	15.8	11.9	—	10.0	13.4
Remote	9.6	28.5	8.3	8.3	13.7	8.6	—	10.9	9.7
Very remote	17.6	—	7.7	9.0	15.4	2.7	—	8.9	8.6
<i>All remoteness areas^(a)</i>	<i>10.1</i>	<i>18.4</i>	<i>9.7</i>	<i>11.2</i>	<i>16.6</i>	<i>14.1</i>	<i>14.6</i>	<i>10.5</i>	<i>12.8</i>

Source: AIHW 2009: Table 2.14.

(a) Excludes 6,481 service users whose remoteness area is unknown (all the service user postcodes provided by all services attended by the services user were 'Not stated or not collected').

9 Residential setting

Question: What is the service user's usual residential setting? ('Usual' means 4 or more days per week on average)

Defined as: The type of physical accommodation in which the person usually resides ('usually' being 4 or more days per week on average).

Classification:

- 1 Private residence (*e.g. private or public rental, owned, purchasing etc.*)
- 2 Residence within an Aboriginal/Torres Strait Islander community (*e.g. rented private residence, temporary shelter*)
- 3 Domestic-scale supported living facility (*e.g. group homes*)
- 4 Supported accommodation facility (*e.g. hostels, supported residential services or facilities*)
- 5 Boarding house/private hotel
- 6 Independent living unit within a retirement village
- 7 Residential aged care facility (*nursing home or aged care hostel*)
- 8 Psychiatric/mental health community care facility
- 9 Hospital
- 10 Short-term crisis, emergency or transitional accommodation facility (*e.g. night shelters, refuges, hostels for the homeless, halfway houses*)
- 11 Public place/temporary shelter
- 12 Other

Guide for use

- This item should be used to record the 'usual' residential setting in which the person lives while receiving services from the service type outlet.
- If it is difficult to determine a 'usual' residential setting over the reporting period, please report the residential setting during the reference week.
- **Private residence**—refers to private residences which include a wide range of dwelling types, such as houses, flats, units, caravans, mobile homes, boats etc.
- **Residence within an Aboriginal/Torres Strait Islander community**—should be used for service users that live in this type of setting, regardless of whether the residence is a private residence or a public place/temporary shelter (codes 1 and 11). Service users living in residences within a Torres Strait Islander community should also be recorded here.

- **Domestic-scale supported living facility** – refers to community living settings in which service users reside in a facility that provides support in some way by staff or volunteers. This category includes group homes, cluster apartments where a support worker lives on site, community residential apartments, congregate care arrangements, etc. Domestic-scale supported living settings may or may not have 24-hour supervision and care. Independent living units in retirement villages should be coded to 6 and community psychiatric facilities should be coded to 8. (Service users receiving service type 1.04 ‘Group homes’ should be coded to 3).
- **Supported accommodation facility** – refers to settings in which service users reside in an accommodation facility which provides board or lodging for a number of people and which has support services provided on what is usually a 24-hour basis by rostered care workers. (Service users receiving DS NMDS service types 1.01, 1.02 or 1.03 should be coded to 4). Supported accommodation facilities include hostels for people with disabilities. This code should be used for larger supported accommodation facilities (usually 7 or more people) that provide 24-hour supervision or care. Smaller supported accommodation facilities (i.e. less than 7 people) which may or may not have 24-hour supervision or care should be coded to 3 ‘Domestic-scale supported living facility’. Aged care hostels should be coded to 7 ‘residential aged care facility’.
- **Psychiatric/mental health community care facility** – refers to community care units which provide accommodation and non-acute care and support on a temporary basis to people with mental illness or psychological disabilities.
- **Public place/temporary shelter** – includes public places such as streets and parks, as well as temporary shelters such as bus shelters or camps and accommodation outside legal tenure arrangements, such as squats.
- **Other** – includes situations such as a child under a court/guardianship order with no usual address.

Why is this data item collected?

Relating human service outcomes to peoples’ housing situations has been identified as an important step in providing better targeted services.

This data item can be used to assist in comparisons of data from administrative data collections with data from the 5 yearly Census of Population and Housing, and to assist in analyses of de-institutionalisation policies and practices.

Example of how this data item is used

This data item enables information to be provided about trends over time in the percentage of all service users living in a range of residential settings, particularly to monitor trends in people living in ‘institutional’ settings compared with community-based settings.

The three most common residential settings reported among service users in 2007–08 were private residential setting (75%), domestic-scale supported (for example, group homes; 5%) and supported accommodation facility (e.g. hostels or supported residential services; 4%) (AIHW 2009: Table A1.1).

10 Disability group

10a Primary disability group

Question: What is the service user's primary disability group? (tick one only)

Defined as: **Disability groups** are a broad categorisation of disabilities in terms of the underlying health condition, impairment, activity limitations, participation restrictions and environmental factors.

Primary disability group is the disability group that most clearly expresses the experience of disability by a person. The primary disability group can also be considered as the disability group causing the most difficulty to the person (*overall difficulty in daily life, not just within the context of the support offered by this service*).

Classification:

- 1 Intellectual (*including Down syndrome*)
- 2 Specific learning/ Attention Deficit Disorder (*other than Intellectual*)
- 3 Autism (*including Asperger's syndrome and Pervasive Developmental Delay*)
- 4 Physical
- 5 Acquired brain injury
- 6 Neurological (*including epilepsy and Alzheimer's disease*)
- 7 Deafblind (*dual sensory*)
- 8 Vision (*sensory*)
- 9 Hearing (*sensory*)
- 10 Speech
- 11 Psychiatric
- 12 Developmental delay (*apply to 0-5 year olds only, where no other category is appropriate*)

Guide for use

- A person's functioning or disability is conceived as a dynamic interaction between a person with a health condition(s) and environmental and personal factors (WHO 2001). Functioning and disability are both multidimensional concepts. Disability is the umbrella term for any or all of an impairment of body structure or function, a limitation in activities (the tasks a person does), or a restriction in participation (the involvement of a person in life situations). The International Classification of Functioning, Disability and Health (ICF) recognises two main components of functioning and disability: a body component comprising classifications of Body Function and Body Structure; and an Activities and Participation component providing a complete set of domains for aspects of functioning from both an individual and societal perspective. Environmental factors represent an important new component of the ICF in recognition of their influence on functioning and disability. Personal factors are also recognised but are not classified.
- **The disability groupings** are a broad description of similar experiences of disability and patterns of impairments, activity limitations, participation restrictions, support needs

and related health conditions. 'Disability group' is not a diagnostic grouping, and there is not a one-to-one correspondence between a health condition and a disability group.

- Disability groupings have been used in the CSTDA NMDS and will continue to be used in DS NMDS. Disability groupings are included in *the National Community Services Data Dictionary* (see NCSDC 2004). They have been developed and modified over a period of years in cooperation with government and non-government organisations, including service user representative organisations. The disability groupings used in the NMDS can be related to the broad groupings that are used in the ABS Survey of Disability, Ageing and Carers and internationally in such documents as the UN Convention on the Rights of Persons with Disabilities (UN 2006) and the UN Standard Rules on the Equalization of Opportunity for Persons with Disability (UN 1993).
- This data item should ideally reflect the views of both the person and the funded agency. If there is a difference, the funded agency's assessment should be recorded. (*If the primary disability group cannot easily be chosen, then define primary disability as the person's disability to which the service caters.*)
- The examples provided below have been subject to discussion and are intended to be a helpful guide. As per the guide for use, the examples below are based on an impairment of functioning approach. As such, these examples are not intended to be definitions of disability but associative functional descriptors.

Disability group	Examples
Intellectual	Effects appearing in the developmental period (age 0–18 years) associated with impairments of mental functions, difficulties in learning and performing certain daily life skills and limitations of adaptive skills in the context of community environments compared to others of the same age. Includes for example, syndromes arising from chromosomal abnormalities and developmental processes.
Specific learning/ Attention Deficit Disorders (ADD)	A general term referring to a group of disabilities, presumed due to central nervous system dysfunction rather than an intellectual disability, covering significant difficulties in the acquisition and use of organisational skills, listening, speaking, reading, writing, reasoning or mathematical skills.
Autism	A pervasive developmental disorder involving disturbances in cognition, interpersonal communication, social interactions and behaviour (in particular obsessive, ritualistic, stereotyped and rigid behaviours).
Physical	Conditions that are attributable to a physical cause or impact on the ability to perform physical activities, such as mobility. Physical disability often includes impairments of the neuromusculoskeletal systems including, for example, the effects of paraplegia, quadriplegia, muscular dystrophy, motor neurone disease, neuromuscular disorders, cerebral palsy, absence or deformities of limbs, spina bifida, arthritis, back disorders, ataxia, bone formation or degeneration, scoliosis.
Acquired brain injury	Characteristically, multiple disabilities arising from damage to the brain acquired after birth. Results in deterioration in cognitive, physical, emotional or independent functioning. May be as a result of accidents, stroke, brain tumours, infection, poisoning, lack of oxygen or degenerative neurological disease.
Neurological	Applies to impairments of the nervous system occurring after birth, includes epilepsy and organic dementias (e.g. Alzheimer's disease) as well as such conditions as multiple sclerosis and Parkinson's disease.
Sensory and speech	Deafblind refers to dual sensory impairments associated with severe restrictions in communication, and participation in community life. Vision disability encompasses blindness and vision impairment (<i>not corrected by glasses or contact lenses</i>). Hearing disability encompasses deafness, hearing impairment, hearing loss. Speech disability encompasses speech loss, impairment and/or difficulty in being understood.

Psychiatric	Includes recognisable symptoms and behaviour patterns, frequently associated with distress, which may impair personal functioning in normal social activity. Includes the typical effects of conditions such as schizophrenia, affective disorders, anxiety disorders, addictive behaviours, personality disorders, stress, psychosis, depression and adjustment disorders.
Developmental delay	Only a valid response for children aged 0–5 where conditions have appeared in the early developmental period, but no specific diagnosis has been made and the specific disability group is not yet known.

- Please note for psychiatric disability one would normally expect there to be a diagnosis. General issues with behaviour (where there is no specific diagnosis) should be reflected in the support needs data item 11 (e.g. 11(d) support needs in relation to ‘interpersonal interactions and relationships’) rather than here in ‘disability group’.
- Note that deafblindness is not just vision impairment with a hearing loss, or a hearing loss with a vision impairment. Deafblindness is a unique disability of its own requiring distinct communication and teaching practices.

Why is this data item collected?

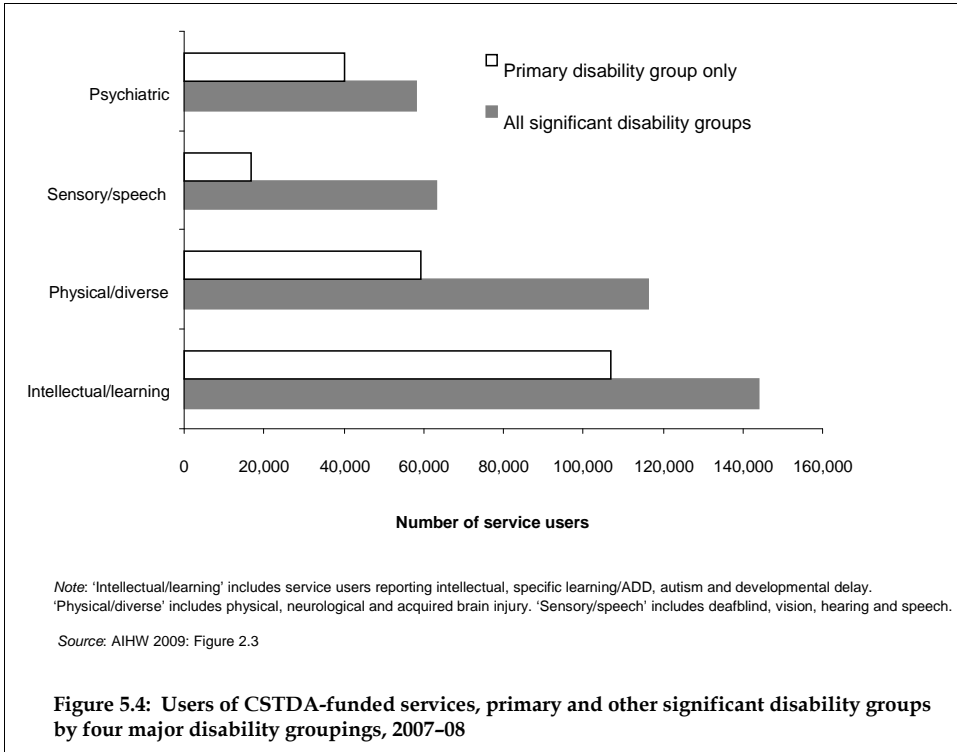
One of the most common requests for information relates to the question: ‘How many people with a specific type of disability are there in Australia and how many are accessing government-funded services?’ The purpose of this classification is to ensure that data are collected in a consistent way across the country, reflecting current usage of terminology in the field, so that such questions can be answered.

Many different definitions of disability are used in Australia, both in administrative data collections and in Acts of Parliament. The consistent identification of disability in national data collections has been recommended in a number of reports, so as to enable:

- the collection of more consistent data on disability support and related services, including data on service use by different groups
- the monitoring of access to generic services by people with a disability
- population data and service data to be related, thereby improving the nation’s analytical capacity in relation to the need for and supply of services.

For further information on disability groupings see the National Community Services Data Dictionary V4.0 (NCSDC 2006; available from <http://meteor.aihw.gov.au/content/index.phtml/itemId/347342>).

Example of how this data item is used



10b Other significant disability group(s)

Question: What are the service user's other significant disability groups? (tick all other significant disabilities)

Defined as: Disability group(s) (*other than that indicated as being 'primary'*) that also clearly express the experience of disability by a person and/or cause difficulty for the person.

Classification:

- 1 Intellectual (*including Down syndrome*)
- 2 Specific learning/ Attention Deficit Disorder (*other than Intellectual*)
- 3 Autism (*including Asperger's syndrome and Pervasive Developmental Delay*)
- 4 Physical
- 5 Acquired brain injury
- 6 Neurological (*including epilepsy and Alzheimer's disease*)
- 7 Deafblind (*dual sensory*)
- 8 Vision (*sensory*)
- 9 Hearing (*sensory*)
- 10 Speech
- 11 Psychiatric
- 12 Developmental delay (*apply to 0–5 year olds only, where no other category is appropriate*)

Guide for use

- All appropriate disability groups should be ticked (except the disability group that is the same as was given in Item 10a). For example, a person with a **primary** disability group of acquired brain injury (code 5), who **also** experiences difficulty in aspects of their life due to a speech disability and a psychiatric disability, should tick codes 10 and 11 for item 10b. Code 5 should not be ticked in this example, since acquired brain injury would already have been reported in Item 10a, 'primary disability group'.
- Using the two items 'primary disability group' and 'other significant disability group(s)', avoids the need to use 'multiple disability' as a response. Use of 'multiple disability' does not provide as much information about the specific disability groups relevant to the person.

Why is this data item collected?

To enable a more complete picture of the number of people, within the major disability groupings, than would otherwise be available with 'primary disability group' only. In conjunction with information from Item 10a it enables a more detailed description of the person's disability, both in terms of identifying additional specific disability groups and identifying disability groups that are associated with the primary disability group specified in Item 10a.

Example of how this data item is used

The average number of disability groups reported per service user was 1.7 – this ranged from 1.2 for service users reporting a speech disability, to 2.2 for those reporting deafblind as a disability (AIHW 2009: Table 2.5).

11 Support needs

Question: How often does the service user need personal help or supervision with activities or participation in the following life areas?

Defined as: The need for personal help or supervision in each of the areas of:

- a. Self-care—activities such as washing oneself, dressing, eating and/or toileting
- b. Mobility—moving around the home and/or moving around away from home (for instance, using public transport), getting in or out of bed or a chair
- c. Communication—making self understood by strangers/family/friends/staff, in own native language or most effective method of communication if applicable, and understanding others
- d. Interpersonal interactions and relationships—including, for example, actions and behaviours that an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions
- e. Learning, applying knowledge and general tasks and demands—understanding new ideas, remembering, solving problems, making decisions, paying attention, undertaking single or multiple tasks, carrying out daily routines
- f. Education—for example, the actions, behaviours and tasks an individual needs to perform at school, college or any educational setting
- g. Community (civic) and economic life—for example, participating in recreation and leisure, religion and spirituality, human rights, political life and citizenship, and economic life such as handling money
- h. Domestic life—undertaking activities such as shopping, organising meals, cleaning, disposing of garbage, housekeeping, cooking and home maintenance. (This does **not** include care of household members, animals and/or plants)
- i. Working—for example, undertaking the actions, behaviours and tasks needed to obtain and retain paid employment.

Classification: The person can undertake activities or participate in this life area with this level of personal help or supervision

- 1 **Unable to do** or always needs help or supervision in this life area.
- 2 **Sometimes** needs help/supervision in this life area.
- 3 **Does not need** help or supervision in this life area but **uses** aids and/or equipment.
- 4 **Does not need** help or supervision in this life area and **does not use** aids and/or equipment.

A response to the item is:

- 5 **Not applicable**—only use where the need for support or assistance is due to the person's age, not their disability.

Guide for use

- This question records information about a person's **need for help or supervision in their overall life** to enable comparison with population data and across NDA-funded service types.
- This means that a need for help or supervision in a particular life area may, or may not, be directly relevant to the service being provided. As well as this a particular life area may not be relevant to a service user aged 15 years and over but would be an estimated assessment of what level of support the service user would need to participate in that particular life area.
- This also means that some areas may appear less appropriate for an individual person than other areas, since they are intended to cover people within any of the disability groups.
- The need must be due to the person's disability, and should be ongoing (*have lasted or be expected to last for 6 months or more*). It must relate to the extent of need **over and above** that which would usually be expected due to their age, i.e. it should be evaluated in relation to a **person of the same age without a disability**.
- Where a life area includes a range of examples, e.g. domestic life includes cooking, cleaning and shopping, if a person requires support in any of the areas then the **highest** level of support should be recorded.
- Where support needs vary markedly over time e.g. episodic psychiatric disability please record the level of support needed during the reference week.
- **The support needs data item is not an assessment tool.** The data item is designed as a framework into which the results of assessment information already collected by your agency can be mapped. Agencies across the country use a range of different assessment tools and methods. Agencies who participated in field testing the 2002 redevelopment of the CSTDA NMDS reported that much of the information included in assessment tools could be mapped to the above framework. This is consistent with earlier work done by AIHW where common assessment tools used in jurisdictions were examined to identify common life domains and measurement scales.
- Interpreters for language are considered to provide personal assistance, and are not considered aids and/or equipment.
- Animals used for personal mobility (i.e. guide dogs and companion animals) are generally considered to fall into the category of aids and/or equipment. Also included within this category are prosthetic and orthotic devices, wheelchairs, transfer devices etc.
- 'Not applicable' (code 5) should only be used where an individual's support needs cannot be ascertained due to the age of the service user. For example, a service user aged 4 years old would be expected to respond 'not applicable' for the life area of 'working'. A service user who will never be able to study due to disability, old age, or other permanent reasons **should not** record 'not applicable' as a response, but should indicate the level of support needs that **would be required** in order to study.

Examples

- A person, aged between 16 and 64 years, with a severe intellectual disability with associated physical disability and challenging behaviour might be coded as 1 in all areas.
- Some psychiatric conditions may result in code 2 for interpersonal interactions and relationships (e.g. behaving within accepted limits) and working, and code 4 for other areas.

- A person with no speech might be coded as 1 or 2 for communication and code 3 or 4 for all other items. Note that in this example, data item 6, Communication method, may indicate that the person has effective non-spoken communication.

When to use ‘not applicable’

Only use ‘not applicable’ where the need for help or supervision is **due to the person’s age**. For the purposes of this collection use ‘not applicable’ only when the person is in the following age ranges:

- Learning, applying knowledge and general tasks and demands: less than 5 years
- Education: less than 5 years
- Community (civic) and economic life: less than 5 years
- Domestic life: less than 15 years
- Working: less than 15 years.

For example:

- The need for help or supervision would be ‘not applicable’ in the area of ‘working’ for a child (i.e. less than 15 years of age) for whom employment is not yet a consideration, regardless of their disability.
- The need for help or supervision would be ‘not applicable’ in the area of ‘education’ for a child (i.e. less than 5 years of age) who would not be expected to be attending school regardless of their disability.

Why is this data item collected?

To aid in analysing access to and service usage patterns of service users with varying levels of support need. This is possible because the data item relates to Australian Bureau of Statistics population data.

Comparisons with other service types, such as between open and supported employment types, could demonstrate differences in access patterns for people with specific support needs.

Analysis based on this data item and others, such as communication method, living arrangements, residential setting and disability group(s) (that is, items 6, 7, 9 and 10), could provide indicators or other relationships relevant to service provision. For instance, about people:

- with a psychiatric disability who need support with interpersonal interactions and relationships
- who need continual support with self-care and have little or no effective communication
- who live alone and need support with domestic life
- who receive an employment service, need support with community (civic) and economic life and live with family members.

This data item is also designed to be consistent with the International Classification of Functioning, Disability and Health (WHO 2001). This classification is endorsed by the World Health Assembly and all participating countries are encouraged to use the classifications and thereby increase comparability of data across countries and – perhaps more importantly – comparability of a wide range of disability data sets within Australia.

Example of how this data item is used

Data collected using this data item can be compared with population data (collected by the Australian Bureau of Statistics) to examine the access of various groups of people with disability to NDA-funded services.

In 2007–08, the life areas with the largest proportion of service users always needing support (or unable to undertake that activity) were working (25%), community (civic) and economic life (24%) and education (22%). Life areas with the smallest proportion of service users always needing support were mobility (13%), communication (15%), and domestic life (17%) (AIHW 2009: Table 3.8).

12 Carer arrangements (informal)

12a Carer – existence of

Question: Does the service user have an informal carer, such as a family member, friend or neighbour, who provides care and assistance on a regular and sustained basis?

Defined as: Whether someone, such as a family member, friend or neighbour, has been identified as providing regular and sustained care and assistance to the person requiring support.

Classification: 1 Yes
2 No

Guide for use

Do not complete data items 12b–12e, if this data item (12a) is coded 2 ('No'). Instead move on to data item 13 'Receipt of Carer Allowance (Child)'.

- All carer items (12a–e) are about the presence and characteristics of an informal carer. Informal carers include those people who receive a pension or benefit for their caring role but do not include paid or volunteer carers organised by formal services. This includes a host family or foster care situation where the family is paid to care for a service user.
- A carer is someone who provides a significant amount of care and/or assistance to the person on a regular and sustained basis. 'Regular' and 'sustained' in this instance means that care or assistance has to be ongoing, or likely to be ongoing for at least 6 months.
- Excluded from the definition of carers are paid workers or volunteers organised by formal services (including paid staff in funded group homes).
- Items 12b–12e are asking about the person's main informal carer – the person who provides the most significant care and assistance related to the service user's capacity to remain living in their current environment.
- It is recognised that two or more people may equally share the caring role (e.g. mother and father) however, for the purposes of this collection, characteristics are only requested for one of these carers.
- It is also recognised that the roles of parent and carer, particularly in the case of children, are difficult to distinguish. Carers of children may consider they are a carer (as well as a parent) if they provide more care to their child than would be typical of the care provided to a child of the same age without a disability.
- This data item is purely descriptive of a service user's circumstances. It is not intended to reflect whether the carer is considered by the funded agency capable of undertaking the caring role.
- In line with this, the expressed views of the service user and/or their carer should be used as the basis of determining whether the service user is recorded as having a carer or not.
- When asking a service user about the availability of a carer, it is important for agencies to recognise that a carer does not always live with the person for whom they care. That

is, a person providing significant care and assistance to the person may not live with the person in order to be called a carer.

Why is this data item collected?

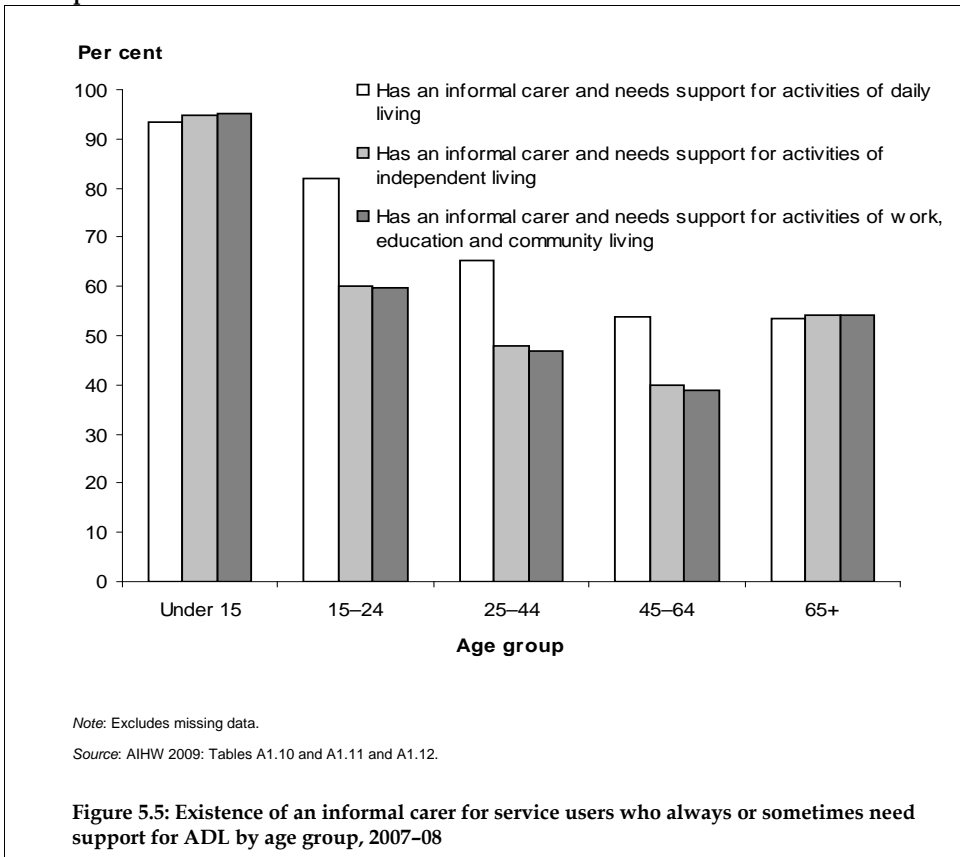
Recent years have witnessed a growing recognition of the critical role that informal support networks play in caring for people with disabilities within the community. Not only are informal carers responsible for helping people to remain within the community, but the absence of an informal carer is a significant risk factor contributing to institutionalisation.

The caring role is particularly supported by the provision of respite services.

Increasing interest in the needs of carers and the role they play has promoted greater interest in collecting more reliable and detailed information about carers and the relationship between informal care and the provision of and need for formal services.

There are a number of policy initiatives across Australia that recognise the needs of ageing carers and specifically target services to relieve them.

Example of how this data item is used



12b Carer – primary status

Question: Does the carer assist the service user in the area(s) of self-care, mobility or communication?

Defined as: Whether the carer assists the person requiring support, in one or more of the following activities of daily living: self-care, mobility or communication.

Classification: 1 Yes
2 No

Guide for use

Do not complete this data item if 12a was coded 2 'No'. Instead **leave the item blank** and move on to data item 13 'Receipt of Carer Allowance (Child)'.

- Items 12b–12e are about the person's main informal carer – the person who provides the most significant care and assistance related to the service user's capacity to remain living in their current environment. It is recognised that two or more people may equally share the caring role (e.g. mother and father) however, for the purposes of this collection, characteristics are only requested for one of these carers.
- Self-care, mobility and communication are considered to be 'activities of daily living' defined in data item 11 'Support needs' (11a–c). (Self-care – activities such as bathing, dressing, eating and/or toileting; Mobility – moving around the home and/or moving around away from home (including using public transport), getting in or out of bed or a chair; and Communication – making self understood by strangers/family/friends/staff, in own native language if applicable, and understanding others).
- If the only support provided to a service user is in the area of public transport or driving a motor vehicle and this support is not required every time the service user uses these modes of transport, then a person is not generally considered to be a primary carer. For example, if a person drives the service user to the shops every second Wednesday to go shopping, and the service user can normally move/get around on their own using public transport or a motor vehicle, then the person would not be considered a 'primary carer'.

Why is this data item collected?

To further identify the role of a carer, this data element asks whether the carer provides care or assistance in the areas of self-care, mobility or communication. Information gathered from this part of the data element can be used to identify whether the carer is a primary carer (as per the Australian Bureau of Statistics Survey of Disability, Ageing and Carers) and thereby relate to population estimates of the numbers of informal carers (12a) who are also primary carers (12b). This is important in being able to estimate unmet need for services.

Example of how this data item is used

In 2007–08, 67% of service users who reported having an informal carer indicated that their carer was a primary carer (AIHW 2007).

12c Carer – residency status

Question: Does the carer live in the same household as the service user?

Defined as: Whether or not a carer lives with the person for whom they provide care and support.

Classification:

- 1 Yes, co-resident carer
- 2 No, non-resident carer

Guide for use:

Do not complete this data item if 12a was coded 2 'no'. Instead **leave the item blank** and move on to data item 13 'Receipt of Carer Allowance (Child)'.

- Items 12b–12e are asking about the person's main informal carer – the person who provides the most significant care and assistance related to the service user's capacity to remain living in their current environment. It is recognised that two or more people may equally share the caring role (e.g. mother and father) however, for the purposes of this collection, characteristics are only requested for one of these carers.
- A co-resident carer is a person who provides care and assistance on a regular and sustained basis to a person who lives in the same household. A non-resident or visiting carer is a person who provides care and assistance on a regular and sustained basis to someone who lives in a different household.
- A carer is considered to be co-resident if they usually live in the same household: 'usually' being 4 or more days per week on average.
- If a service user has both a co-resident (e.g. a spouse) and a visiting carer (e.g. a daughter or son), the coding response should be related to the carer who provides the most significant care and assistance related to the service user's capacity to remain living in their current environment (i.e. the main carer). The expressed views of the service user and/or their carer(s) or significant other should be used as the basis for determining this.

Why is this data item collected?

Carer co-residency information helps to establish a profile of the characteristics of informal carers and as such increase knowledge about the dynamics and patterning of the provision of informal care. In particular, whether the carer lives with the person for whom they care or not is an indication of the level of informal support available to people with a disability and of the intensity of care provided by the carer.

Example of how this data item is used

In 2007–08, over half of service users with an informal carer (72,047 of 112,293, or 64%) reported that their carer was co-resident. Informal carers who were reported to be the primary carer were more likely to be co-resident than non-primary carers (87% compared with 59%) (AIHW 2009: Table 3.7).

12d Carer – relationship to service user

Question: What relationship is the carer to the service user?

Defined as: The relationship of the carer to the person for whom they care.

- Classification:**
- 1 Wife/female partner
 - 2 Husband/male partner
 - 3 Mother
 - 4 Father
 - 5 Daughter
 - 6 Son
 - 7 Daughter-in-law
 - 8 Son-in-law
 - 9 Other female relative
 - 10 Other male relative
 - 11 Friend/neighbour – female
 - 12 Friend/neighbour – male

Guide for use

Do not complete this data item if 12a was coded 2 'No'. Instead **leave the item blank** and move on to data item 13 'Receipt of Carer Allowance (Child)'.

- Items 12b–12e are asking about the person's main informal carer – the person who provides the most significant care and assistance related to the service user's capacity to remain living in their current environment. It is recognised that two or more people may equally share the caring role (e.g. mother and father) however, for the purposes of this collection, characteristics are only requested for one of these carers.
- If a person has more than one carer (e.g. a spouse and a son), the coding response to carer relationship should relate to the carer who provides the most significant care and assistance related to the person's capacity to remain living in their current environment (i.e. the main carer). The expressed views of the service user and/or their carer or significant other should be considered to be the primary or principal carer in this regard.
- Codes 1 and 2 (wife/female partner and husband/male partner) both include married, de facto and same sex partners who are carers.
- Codes 3 and 4 (mother/father) include foster parents.
- Code 9 (other female relative), allows for the wide range of family members who may be involved in a caring role with the service user. This code therefore includes the female family members not listed in the codes elsewhere (e.g. aunts, nieces, female cousins, grandmothers, step mother, step daughters and so on).
- Similarly, code 10 (other male relative) covers the range of male family members who may act as carers. This code includes the male family members not listed in the codes elsewhere (e.g. uncles, nephews, male cousins, grandfathers, male grandchildren, step father, step sons and so on).

Why is this data item collected?

Information about this relationship assists in the establishment of a profile of informal caring relationships and the assistance provided to maintain and support those relationships. As such it increases knowledge about the dynamics of caring and provides an insight into the gender and inter-generational patterns of informal care giving in the community.

This item enables DS NMDS data to be compared with Australian Bureau of Statistics population data and facilitates the estimation of unmet need, particularly among ageing parents and very young carers (sons and daughters).

Example of how this data item is used

Table 5.2: CSTDA-funded service users with an informal carer, relationship of carer to service user by service user age, 2007–08

Relationship of carer to service user	Age group of service user (years)						Total
	0–14	15–24	25–44	45–64	65+	Not stated	
	Number						
Spouse	—	168	2,165	4,103	1,788	5	8,229
Mother	29,909	16,083	15,322	4,119	96	33	65,562
Father	1,439	1,419	1,891	650	15	4	5,418
Child	—	26	172	677	810	2	1,687
Other family	1,220	1,032	1,554	2,450	464	5	6,725
Friend/neighbour	132	256	493	625	179	—	1,685
Not stated	2,882	3,462	7,991	7,129	1,505	18	22,987
Total	35,582	22,446	29,588	19,753	4,857	67	112,293
	Per cent						
Spouse	—	0.7	7.3	20.8	36.8	7.5	7.3
Mother	84.1	71.7	51.8	20.9	2.0	49.3	58.4
Father	4.0	6.3	6.4	3.3	0.3	6.0	4.8
Child	—	0.1	0.6	3.4	16.7	3.0	1.5
Other family	3.4	4.6	5.3	12.4	9.6	7.5	6.0
Friend/neighbour	0.4	1.1	1.7	3.2	3.7	—	1.5
Not stated	8.1	15.4	27.0	36.1	31.0	26.9	20.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

12e Carer – age group

Question: What is the age group of the carer?

Defined as: The age group of the carer.

Classification:

- 1 Under 15 years
- 2 15–24 years
- 3 25–44 years
- 4 45–64 years
- 5 65 years and over

Guide for use:

Do not complete this data item if 12a was coded 2 'No'. Instead **leave the item blank** and move on to data item 13 'Receipt of Carer Allowance (Child)'.

- Items 12b–12e are asking about the person's main informal carer – the person who provides the most significant care and assistance related to the service user's capacity to remain living in their current environment. It is recognised that two or more people may equally share the caring role (e.g. mother and father) however, for the purposes of this collection, characteristics are only requested for one of these carers.
- When asking the service user about the age of their carer it is considered more appropriate to ask about broad age groups rather than actual age.
- It is important that this item is regularly updated (once a year) to ensure the carer is recorded in the correct age group. Failure to update this item may result in the carer incorrectly remaining in the age group they were originally recorded in. This may lead to apparent inconsistencies with other data items such as the service user's age (especially where a parent-child relationship exists between the carer and service user).

Why is this data item collected?

Information about the age group of the carer assists in the establishment of a profile of informal caring relationships and the assistance provided to maintain and support those relationships. In particular, knowledge of the age distribution of service users' carers enables forward planning with respect to carers of certain ages (e.g. less than 15 years, over 65 years).

This item enables DS NMDS data to be compared with Australian Bureau of Statistics population data and facilitates the estimation of unmet need, particularly among ageing parents and very young carers (sons and daughters).

Example of how this data item is used

In 2007–08, 37,541 (33%) of 112,293 informal carers whose age was reported were aged between 25 and 44 years. A further 31,541 (28%) were aged between 45 and 64 years, and 10,538 (9%) were 65 years and over (AIHW 2009: Table 3.5).

13 Receipt of Carer Allowance (Child)

Question: If aged under 16 years: does the service user's parents or guardian receive the Carer Allowance (Child)?

Defined as: Receipt of the Carer Allowance (Child) by a parent or guardian of a person, if the service user is aged less than 16 years.

Classification:

- 1 Yes
- 2 No
- 3 Not known

Guide for use

Do not complete this data item if the service user is **aged 16 years or more**. Instead **leave the item blank** and move onto data item 14 'Labour force status'.

- This question is not asking about Carer Payment (formerly Carer Pension), even though some parents of children aged less than 16 may receive it in addition to Carer Allowance (Child) (formerly the Child Disability Allowance).
- Code 3 'Not known' should only be recorded when it has not been possible for the service user or their carer/family/advocate to provide the information (i.e. they have been asked but do not know).

Why is this data item collected?

To assess the relationship between receipt of Carer Allowance (Child) and receipt of NDA-funded services, in terms of a range of items, including frequency of support needed.

Example of how this data item is used

There were 52,966 'child' consumers (under the age of 16) receiving CSTDA-funded services during 2007-08. Of these, 33% had a parent or guardian who was known to receive Carer Allowance (Child) (AIHW 2009: Table 2.13).

14 Labour Force Status

Question: If aged 15 years or more, what is the service user's labour force status?

Defined as: The self-reported status the person currently has in being either in the labour force (employed/unemployed) or not in the labour force.

Classification:

- 1 Employed
- 2 Unemployed
- 3 Not in the labour force

Guide for use

Do not complete this data item if the service user is aged under 15 years, instead **leave the item blank** and move onto data item 16 'Individual funding status'.

- Note that the definition of 'employed' used in this data item includes all people who work for 1 hour or more in the week preceding the end of the reporting period. The definition of 'employed' is the one used by the Australian Bureau of Statistics and the information you provide will thereby enable the employment status of NDA service users to be compared with the employment status of the general population. The definition of 'employed' used here is not the same as the definition of a 'durable employment outcome' used by Australian Government-funded disability employment services (which relates to employment for at least 8 hours per week).
- Employed: employed persons comprise all those aged 15 years and over who, during the week preceding the end of the reporting period:
 - (a) worked for 1 hour or more for pay, profit, commission or payment in kind in a job or business, or on a farm (comprising 'Employees', 'Employers' and 'Own Account Workers') (includes 1 hour or more worked in supported employment or under the Community Development Employment Program (CDEP))
 - (b) worked for 1 hour or more without pay in a family business or on a farm (i.e. 'Contributing Family Worker')
 - (c) were 'Employees' who had a job but were not at work and were:
 - on paid leave
 - on leave without pay, for less than 4 weeks, up to the end of the reporting period
 - Stood down without pay because of bad weather or plant breakdown at their place of employment, for less than 4 weeks up to the end of the reporting period
 - on strike or locked out
 - on workers' compensation and expected to be returning to their job
 - receiving wages or salary while undertaking full-time study
 - (d) were 'Employers', 'Own Account Workers' or 'Contributing Family Workers' who had a job, business or farm, but were not at work.
- Unemployed: unemployed persons are those aged 15 years and over who were not employed during the week preceding the end of the reporting period, and:

- (a) had actively looked for full-time or part-time work at any time in the 4 weeks up to the date of data transmission; were available for work in the reporting period, or would have been available except for temporary illness (i.e. lasting for less than 4 weeks to the end of the reporting period); or were waiting to start a new job within 4 weeks from the end of the reporting period and would have started in the week of data transmission if the job had been available then
- (b) were waiting to be called back to a full-time or part-time job from which they had been stood down without pay for less than 4 weeks up to the end of the reporting period (including the whole of the reporting week) for reasons other than bad weather or plant breakdown.

Note: Actively looking for work includes writing, telephoning or applying in person to an employer for work, as well as answering a newspaper advertisement for a job; checking factory or job agency notice boards; being registered with a job placement agency; checking or registering with any other employment agency; advertising or tendering for work; contacting friends or relatives; attending pre-employment training or labour market programs such as 'Work For The Dole'.

- Not in the labour force: persons not in the labour force are those persons who, during the reporting period, were not in the categories employed or unemployed, as defined. They include persons who were keeping house (unpaid), retired, voluntarily inactive, permanently unable to work, persons in institutions (hospitals, gaols, sanatoriums, etc.), students, trainee teachers, members of contemplative religious orders, and persons whose only activity during the reporting period was jury duty.

Why is this data item collected?

Labour force status is an indicator of the socio economic status (economic activity) of a person and is a key element in assessing the circumstances and needs of individuals and families, as well as their participation in society.

Example of how this data item is used

Of the 192,631 services users of working age during 2007–08, 64,935 (34%) reported not being in the labour force. A further 64,718 (34%) were employed, and 46,294 (24%) unemployed (AIHW 2009: Table 2.12).

15 Main source of income

Question: If aged 16 years or more: what is the service user's main source of income?

Defined as: The main source of income of the person, if they are aged 16 years or more.

- Classification:**
- 1 Disability Support Pension
 - 2 Other pension or benefit (*not superannuation*)
 - 3 Paid employment
 - 4 Compensation payments
 - 5 Other (*e.g. superannuation, investments etc.*)
 - 6 Nil income
 - 7 Not known

Guide for use

Do not complete this data item if the service user is **aged under 16 years**. Instead **leave the item blank** and move onto data item 16 'Individual funding status'.

Do not complete data item 13 'Receipt of Carer Allowance (Child)' if data item 15 has been answered (i.e. because the service user is aged 16 years or more).

- This item refers to the source by which a person derives most (equal to or greater than 50%) of his/her income. If the person has multiple sources of income and none are equal to or greater than 50%, the one which contributes the largest percentage should be counted.
- This item refers to a person's own main source of income, not that of a partner or of other household members.
- If it is difficult to determine a 'main source of income' over the reporting period (i.e. it may vary over time) please report the main source of income during the reference week.
- Code 7 'Not known' should only be recorded when it has not been possible for the service user or their carer/family/advocate to provide the information (i.e. they have been asked but do not know).

Why is this data item collected?

To provide an indication of income.

Example of how this data item is used

For the 192,631 service users aged 16 years or more in 2007–08, Disability Support Pension (DSP) was the most widely reported main income source (56%), followed by other pension or benefit (16%) and paid employment (3.4%) (AIHW 2009: Table 2.12).

16 Individual funding status

Question: Is the service user currently receiving individualised funding under the NDA?

Defined as: Whether or not a person is currently receiving individualised funding under the NDA.

Classification:

- 1 Yes
- 2 No
- 3 Not known

Guide for use

- Individualised funding should have all of the following characteristics:
 - the funding dollars are provided from within the NDA program
 - funding dollars are allocated to an individual on the basis of needs assessment, funding application or similar process
 - these funding dollars may be directly under the control of the individual or their carer/advocate; or may be managed by, or in consultation with, a NDA-funded agency to access a range of services for the individual; or may be given directly to the NDA-funded agency who provides the service to the individual
 - the funding is transportable and able to move with the individual if they choose to use another service
 - the individual funding package is generally related to a policy ethos of fostering individual choice and autonomy.
- If your service type outlet manages a program or package that does not meet one or more of these criteria then the service user does not receive individualised funding under the NDA and you should record code 2 'No' (i.e. the program or package must meet all criteria to be classified as individualised funding for the purposes of the DS NMDS).
- If a service user receives multiple NDA-funded services through an individual funding package, then all services received must be reported through the DS NMDS.
- For the purposes of the DS NMDS, all employment services provided by the Australian Government through 'case-based funding' are considered to be provided on an individualised funding basis. Code 1 'Yes' for this data item if your service type outlet is providing service type '5.01 – Open employment' or '5.02 – Supported employment'.
- If a service user receives multiple services from a funded agency, and is funded to receive these services from an individual funding package as well as another funding mechanism (e.g. block funding) then record code 1 'Yes' for this data item.
- Examples of individualised funding include:
 - Western Australia – Intensive Family Support funding
 - Queensland – Adult Lifestyle Support Packages, family support programs and post-school programs

- Australian Government-funded programs – Case Based Funding (CBF) and Futures for Young Adults (FFYA)
- Australian Capital Territory – Individual Support Packages
- Victoria – Futures for Young Adults (FFYA), flexible care packages (Making a Difference (MaD), HomeFirst, Family Choice Program and Continuity of Care State-wide Fund)
- Tasmania – Individual Support Program (ISP) and Supporting Individual Pathways
- Northern Territory – Client Focussed Funding (CFF).
- Code 3 ‘Not known’ should only be recorded when it has not been possible for the service user or their carer/family/advocate to provide the information (i.e. they have been asked but do not know).

Why is this data item collected?

Collecting this information will enable an examination of, for example:

- what types of services individualised funding are being used to purchase
- how service users with individualised funding differ from other service users (e.g. in terms of disability group, support needs, age etc.)
- trends in the use of individualised funding over time.

Consumer representatives involved in the 2002 CSTDA NMDS redevelopment strongly advocated the collection of this information.

Example of how this data item is used

Table 5.3: Service users, individual funding status by service group, 2005–06

Service group	Has individualised funding		Does not have individualised funding		Not known		Not stated/ not collected		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
Accommodation support	13,094	36.8	21,324	60.0	589	1.7	559	1.6	35,566	100.0
Community support	19,648	20.3	60,227	62.3	4,684	4.8	12,105	12.5	96,664	100.0
Community access	14,017	29.4	29,598	62.0	1,203	2.5	2,920	6.1	47,738	100.0
Respite	7,590	27.8	17,998	65.9	1,069	3.9	662	2.4	27,319	100.0
Employment	73,157	100.0	0	0.0	0	0.0	0	0.0	73,157	100.0
Total	93,476	43.0	100,668	46.4	6,916	3.2	16,083	7.4	217,143	100.0

Source: AIHW 2007: Table 2.20.

17 Service user's receipt of services

For every NDA-funded service type received by a service user in the reporting period complete the following questions (i.e. you may need to photocopy forms if you are using paper forms – see Section 3.5 of this Data Guide for further details).

It is important to note that your responses to this section depend on the service type(s) you are funded to provide.

- Service type outlets providing service types 1.05–1.07, 2.06, 3.01, 3.03 and 4.01–4.05 are to complete all sections 17a to 17f.
- Service type outlets providing 1.01–1.04, 1.08, 2.01–2.05, 2.07, 5.01 and 5.02 are to complete sections 17a to 17d only.
- Service type outlets providing service type 3.02 are only required to complete items 2a–e for each service user; and items 17a–17b.

Service type outlets providing service types 6.01–6.05 and 7.01–7.04 are not required to provide service user/services received information and should not complete these questions.

Example of how these data items (17a–f) are used

Almost one quarter of service users exited from one or more services during 2007–08 (Table 6.7). One quarter (25%) of employment users and 23% of community support users exited, compared with 8% of respite, 9% of community access and 10% of accommodation support users. The most common reason for leaving a service was that a person no longer needed assistance (34%) – evenly split between those who moved to mainstream services (17%) and 'other' reasons (17%). A further 14% of users exited because they moved to new or different accommodation settings, 9% opted to terminate the service themselves, and 29% cited some other reason. Users of employment services were most likely to report exiting due to increased support needs (8% compared to 4% of all users). Service exit rates have seen a small increase since 2003–04, from 20% to 23% (AIHW 2005). The largest increase over that time was for community support users (from 19% to 23%).

Average hours of support received by all service users per outlet varied between service types (Figure 6.1). Respite outlets provided the highest number of hours of support on average during 2007–08 (500 hours per outlet in total).

On average, service users received 12 hours of support in the reference week (Table 6.5). Average hours of support received per service user varied across service types.

- In the reference week, users of non-residential accommodation services received the most hours of support (17 hours on average per user), followed by users of community access services (12 hours).
- Case management, local coordination and development services delivered substantially fewer hours on average than other types (1–2), indicating significantly lower direct contact hours involved with this service type.

Service users of residential accommodation support services (1.01 to 1.04) had a mean duration of service of 306 days during 2005–06. The median duration was 365 days across the four service types, equaling the total number of days in 2005–06. This indicates that more than half of the total service users accessing these accommodation services were supported for the full 12-month period (AIHW 2007).

17a Service start date

Question: When did the service user commence using this service type?

Defined as: The date on which a person began to receive support from a NDA-funded service type outlet.

Classification: ddmmyyyy

Guide for use

- **Service users who commence services after 1 October 2002**, should have their actual commencement date recorded (i.e. the date this service type was first received by the service user).
- **Existing service users (i.e. those receiving services prior to October 2002)**, should either be recorded as commencing:
 - on their **known** service start date, for example, a service user starting on 2 September 2002 may be recorded as 02092002
 - on an **estimate** of their service start date; by recording '0101' for the day and month and estimating the year.
 - on 1 October 2002, that is 01102002. Use this option if the start date is unknown or cannot be recorded for some other reason.
- The service start date must relate to the service type outlet ID (and associated service type) indicated in data item B of the Service User Form.
- The service start date does not have to be updated each reporting period unless the service user formally exits the service (see data item 17c).
- This item should always be recorded as an 8-digit valid date comprising day, month, and year. Year should always be recorded in its full 4-digit format.
- A service is a support activity delivered to a person, in accord with the NDA. Services within the scope of the collection are those for which funding has been provided, during the specified period, by a government organisation operating under the NDA.
- A service user is considered to have started receiving a NDA-funded service type once they have been judged as eligible for the service type and have actually received support within that service type. Support may include assessment processes once the service user has been accepted as eligible for the service type. However it does not include assessment where assessment is for eligibility or to a place on a waiting list.
- Support does not generally include requests for information or phone queries.
- At times, an outlet may provide the service user with one-off assistance. For example, a service user may only require respite care on one occasion. Where this assistance is NDA-funded the general rule is that all service users details should be recorded as required for that service type. If the service user is not expected to use the service type outlet again, a service exit date and appropriate reason for cessation should be entered.

Why is this data item collected?

Service start date (in conjunction with service exit date) gives some indication of length of stay (duration of service) of service users in the NDA program and of the intensity of service provision. In conjunction with the data item 17c – service exit date, it can be used to identify the number of NDA-funded service users as at the end of the DS NMDS reporting period, and at any time.

17b Date service last received

Question: When did the service user last receive this service type?

Defined as: The date the person last received a service of this service type during the reporting period.

Classification: ddmmyyyy

Guide for use

- The 'Date service last received' must relate to the service type outlet ID (and associated service type) indicated in data item B of the Service User Form.
- This data item **is** asking about the most recent date on which this service user received support from this service type outlet.
- This data item **is not** asking about the date the service user permanently stopped receiving support from this service type outlet (see instead data item 17c – service exit date).
- This data item **is not** asking about the date on which the service user's form was completed.
- This item should always be recorded as an 8-digit valid date comprising day, month, and year. Year should always be recorded in its full 4-digit format
- A service is a support activity delivered to a person, in accord with the NDA. Services within the scope of the collection are those for which funding has been provided, during the specified period, by a government organisation operating under the NDA.
- Support does not generally include requests for information or phone queries.

Why is this data item collected?

Used to determine the number of active service users in any specified reporting period.

17c Service exit date

Question: When did the service user leave this service type outlet?

Defined as: The date on which the person ceases to be a service user of the NDA-funded service type outlet.

Classification: ddmmyyyy

Guide for use

- The service exit date must relate to the service type outlet ID (and associated service type) indicated in data item B of the Service User Form.
- This item should always be recorded as an 8-digit valid date comprising day, month, and year. Year should always be recorded in its full 4-digit format.
- A service user is considered to leave a service when either:
 - the service user ends the support relationship with the service type outlet
 - the service type outlet ends the support relationship with the service user.
- Where a service user has not left the service type outlet please leave blank and go to data item 17e – Hours received (reference week).

NOTE: Where no services have been provided within the financial year, the record should be excluded from the DS NMDS.

Why is this data item collected?

Service exit date (in conjunction with service start date) gives some indication of length of stay of service users in the NDA program and of the intensity of service provision. In conjunction with the Item 17a – Service start date, it can also be used to identify the number of current NDA service users as at the end of the DS NMDS reporting period.

Example of how this data item is used

There were 55,966 service users (23% of the total 245,746) who were recorded as exiting a service during 2007–08. Respite services had the lowest proportion (7.6%) of service users exiting a service. Employment and community support had the highest proportions (25% and 23% respectively) (AIHW 2009).

17d Main reason for cessation of services

Question: What reason did the service user report for leaving this service type outlet?

Defined as: The reason that the person stopped receiving services from the service type outlet.

- Classification:**
- 1 Service user no longer needs assistance from service type outlet – moved to mainstream services
 - 2 Service user no longer needs assistance from service type outlet – other
 - 3 Service user moved to residential, institutional or supported accommodation setting
 - 4 Service user's needs have increased – other service type required
 - 5 Services terminated due to budget/staffing constraints
 - 6 Services terminated due to Occupational Health and Safety (OHS) reasons
 - 7 Service user moved out of area
 - 8 Service user died
 - 9 Service user terminated service
 - 10 Other

Guide for use

Do not complete this data item if item 17c 'Service exit date' has been left blank (i.e. the service user has not left the service. Instead, **leave the item blank** and move onto data item 17e – 'Hours received (reference week)').

- The main reason for cessation of services must relate to the service type outlet ID (and associated service type) indicated in data item B of the Service User Form.
- **Service user no longer needs assistance – moved to mainstream services:** the service user has moved on to mainstream services (e.g. to TAFE or further education, from employment service to paid open labour market).
- **Service user no longer needs assistance – other:** the service user needs have **decreased**, may be managing on their own, or making use of other assistance, or the original problem has been resolved or no longer exists (e.g. a service user's needs have decreased and they move from a high intensity respite service to a recreation program).
- **Service user moved to residential, institutional or supported accommodation setting:** the service user no longer needs assistance from the service type outlet as they have moved to a residential or institutional care setting (e.g. hospital, residential aged care facility) or to supported accommodation/living facility (e.g. group home).
- **Service user's needs have increased – other service type required:** the service user's needs have **increased** to the point where the service type outlet is no longer the most appropriate service type outlet.

- **Services terminated due to budget/staffing constraints:** the service user's needs have not changed but the service type outlet can no longer provide assistance due to budget or staff constraints.
- **Services terminated due to Occupational Health and Safety (OHS) reasons:** service type outlet terminated service to service user for worker (or volunteer) occupational health and safety reasons.
- **Service user moved out of area:** the service user ceased to receive assistance from the service type outlet because the service user moved out of the geographic area of coverage of the service type outlet. That is, the reason the service type outlet ceased to assist the service user is primarily because of a change in the service user's residential location and not because of any change in their need for assistance.
- **Service user terminated service:** the decision to cease receiving assistance from the service type outlet is made by the service user. That is, it was the service user's choice and not the result of any agency assessment of need or change in the service user's external circumstances. If the service user had not made this choice they would have continued to receive assistance from the agency.
- **Other:** the reason for the service user ceasing to receive assistance from the service type outlet is not listed above or is unknown. Includes the situation where a service user is no longer eligible for services due to age. **'Other' should only be indicated where other responses do not represent the user's reasons for cessation of service.**

Why is this data item collected?

Reason for cessation of service provides information about the circumstances surrounding the ending of a service user's receipt of services from a service type outlet. This data item contributes to a general understanding of the patterns of transition and service user movements into and out of the support services. Reason for cessation of services also gives some indication of the relationship between service user turnover, factors relating to the service type outlet's operations and changes in service user needs and circumstances. It can also provide important information on aspects of ageing of NDA clients.

Example of how this data item is used

The reasons most commonly reported for exiting a service was 'other' reason (29%), followed by service users no longer needing assistance because they moved to mainstream services (17%). Around 9% of exiting service users terminated the service themselves and 3% moved out of the geographic area (AIHW 2009).

17e Hours received (reference week)

Question: Indicate the number of hours of support received by the service user for this NDA service type in the 7-day reference week preceding the end of the reporting period.

Defined as: The number of hours of support received by a person for this NDA service type in the 7-day reference week preceding the end of the reporting period.

Classification: 0-168 Number of hours
900 Less than 1 hour

Guide for use

Do not complete this data item if your service type outlet code is: 1.01-1.04, 1.08, 2.01-2.05, 2.07, 3.02, 5.01, 5.02, 6.01-6.05, 7.01-7.04. Instead, **leave the item blank**.

Only complete this data item if your service type outlet code is: 1.05-1.07, 2.06, 3.01, 3.03, 4.01-4.05.

- 'Hours received' must relate to the service type outlet ID (and associated service type) indicated in data item B of the Service User Form.
- This item is asking about **hours actually received** by service users (for each NDA service type they receive from your funded agency).
- Code '900' ('less than 1 hour') has been added in response to queries raised by agencies wishing to more accurately report receipt of services lasting less than 1 hour. This is a supplementary, optional code.
- Hours should be rounded up to the nearest whole hour (where less than one hour was received, agencies may alternatively record '900').
- This item is **not** asking about administration, transport or other similar hours that the service user directly or indirectly benefits from. For example, time taken travelling to visit a service user should not be included, nor should time spent by staff preparing for the arrival of service users. These hours are captured in your response to service type outlet data items 5 and 6 on staff hours.
- Where service users receive support in a group setting please record the hours received in this setting for **all** attending service users (i.e. do not apportion group hours across the number of service users attending). For example, where one worker is supplying services to 3 service users for 4 hours, please count each service user as receiving 4 hours of service.
- Include the hours received during sleepover duties in the total hours received by the service user.
- If your **service type outlet is funded to provide service type 2.06 Case management, local coordination and development**, please note the following rules for calculating hours:
 - record hours spent for the service user to coordinate, manage or arrange brokerage of other services. This includes phone calls and paperwork related to that service

user. If hours spent on such tasks are related to a number of service users, please split hours accordingly.

- **do not** record the hours the service user receives from the agencies who provide any services arranged, purchased or brokered by your service type outlet as part of providing service type 2.06.
- If your service type outlet sub contracts the provision of part or all of a service type (other than 2.06) you are funded to provide to another agency:
 - you are responsible for providing relevant details about the sub-contracted activity (e.g. in-home accommodation support provider sub contracting the provision of some in-home accommodation support to another agency, which may or may not be NDA-funded), and
 - please include hours received by the service user that you have sub contracted in this way in the total hours received by the service user.

Why is this data item collected?

This information is needed to indicate the quantity of service received by service users. A measure of service quantity per service user and service type enables stakeholders to examine patterns of service delivery for service users with various characteristics (e.g. disability group, support needs) across service type outlets with various characteristics such as service type, geographic location, jurisdiction etc.

17f Hours received (typical week)

Question: Indicate the number of hours of support received by the service user for this NDA service type in a typical (or average) 7-day week (over the reporting period).

Defined as: The number of hours of support received by a person for this NDA service type in a typical or average 7-day week (over the reporting period).

Classification: 0-168 Number of hours
900 Less than 1 hour

Guide for use

Do not complete this data item if your service type outlet code is: 1.01-1.04, 1.08, 2.01-2.05, 2.07, 3.02, 5.01, 5.02, 6.01-6.05, 7.01-7.04. Instead, **leave the item blank**.

Only complete this data item if your service type outlet code is: 1.05-1.07, 2.06, 3.01, 3.03, 4.01-4.05.

- Hours received must relate to the service type outlet ID (and associated service type) indicated in data item B of the Service User Form.
- This data item is designed to enable service type outlets to reflect that the hours received by the service user in the reference week (indicated in data item 17f) may not be reflective of a typical or average week. Where the response for 17f is typical for a usual week, please repeat it for 17g.

[Jurisdictions to select only one of the following two definitions of typical week and promote in your jurisdiction. It is recommended that the collection of average actual hours (option 1 below) be implemented where possible.]

1. This item is calculated as an average of the actual hours received by this service user in a typical week (over the reporting period). That is, this item is derived from the 'total hours received during the reporting period'.

OR

2. Please record the service user's usual or typical weekly pattern of support while receiving your service in the reporting period. This enables service type outlets to indicate whether or not the reference week was typical.
- Code '900' ('less than 1 hour') has been added in response to queries raised by agencies wishing to more accurately report receipt of services lasting less than one hour. This is a supplementary, optional code.
 - Hours should be rounded up to the nearest whole hour (where less than 1 hour was received, agencies may alternatively record '900').

Why is this data item collected?

This information is needed to indicate the quantity of service received by service users. A measure of service quantity per service user and service type enables stakeholders to examine patterns of service delivery for service users with various characteristics (e.g. disability group, support needs) and across service type outlets with various characteristics such as service type, geographic location, jurisdiction etc.

6 Disability Services NMDS privacy and data principles

6.1 Introduction

In the planning stages of the 2002 CSTDA NMDS redevelopment it was agreed that it would be important to develop and refine privacy and data principles for the CSTDA NMDS collection in the course of the redevelopment. These principles continue to apply for the DS NMDS. Section 6.2 sets out these principles.

Everyone participating in the DS NMDS collection is urged to read the privacy and data principles and undertake their role in the collection in accord with these principles. The principles draw heavily on legislation and standards designed to protect the rights of all involved.

The privacy and data principles are designed to apply to data collected for the DS NMDS collection, from disability support agencies, transmitted to jurisdictions and the AIHW for national collations and analysis. Similar principles could be used, however, in data collections more generally.

Under National Privacy Principle 5.1 of the *Privacy Amendment (Private Sector) Act 2000* relevant agencies must set out in a document clearly expressed policies on their management of personal information. For agencies that have not developed such a privacy policy, the DS NMDS privacy and data principles may be a useful basis or starting point for your policy on managing personal information. Additionally, the Australian Law Reform Commission website contains useful information relating the recent review of the privacy act. Please see <http://www.alrc.gov.au> for details.

Section 6.2 first presents relevant background material and Section 6.3 draws on this material to outline privacy and data principles for the DS NMDS collection under three main headings: ethos; content; and quality, methods and procedures.

For more information on privacy and non-consent in the DS NMDS, refer to Section 3.3.

6.2 Relevant background material

The Privacy Act and Information Privacy Principles

The *Privacy Act 1988* contains 11 Information Privacy Principles (IPPs) which govern the conduct of Commonwealth and Australian Capital Territory Government agencies in the collection, management, use and disclosure of records containing personal information. These principles have stood the test of time in a decade of rapid technical development (see Appendix A).

The *Privacy Amendment (Private Sector) Act 2000* came into effect on 21 December 2001. This Act extends the coverage of the Privacy Act to protect personal information in the private sector. The Amendment Act includes 10 National Privacy Principles (NPPs) which set the baseline standards for privacy protection by private sector (and non-government) organisations. The Act provides for the development and approval, by the Federal Privacy Commissioner, of sector-specific codes. All jurisdictions and the AIHW are working closely together to investigate options for a National Health Information Regulatory Framework (NHIRF) to provide nationally consistent privacy arrangements for health information and complaints procedures. In addition, the Australian Law Reform Commission has completed a review of the Privacy Act (May 2008) and will be making a series of recommendations to government on changes to the Australia's privacy regime.

The Privacy Commissioner has issued guidelines to explain in a clear and simple way how the NPPs work in practice. Acknowledging that personal health information is generally considered to be amongst the most sensitive and intimate of personal information, the Office of the Federal Privacy Commissioner has issued health privacy guidelines which complement the general NPP guidelines and provide specific guidance on how the NPPs operate in the private health sector. The Act defines health information as including information or an opinion about the health or a disability (at any time) of an individual.

The AIHW will keep this document up to date as new information becomes available. An information sheet developed by the Office of the Federal Privacy Commissioner about the new private sector privacy law is attached (Appendix B). Further information on privacy can be obtained from the Federal Privacy Commissioner's web site at www.privacy.gov.au.

Disability service standards

Standard 4 of the Disability Service Standards (FaCS 2005) states that:

Each service user's right to privacy, dignity and confidentiality in all aspects of his or her life is recognised and respected.

Agencies must have written policies and procedures designed to achieve the standard, preferably developed in consultation with service users. Related considerations include:

- Information held by an agency will often include pertinent personal details.
- Access to this personal information is privileged, and needs to be limited to protect the privacy of each person with a disability. Service users should know by whom, when and why personal information is being accessed.

Standards on personal information and activities include:

- 4.3 The agency only collects service user information that is directly relevant to effective service delivery.
- 4.4 Each service user is informed of the types of personal information that the agency holds and the reason for holding this information.
- 4.5 Each service user's consent is to be obtained before any information about him or her is sought or released by the agency.

Related considerations are:

- Policies and procedures exist to ensure that personal and employment records are securely stored and are accessible only to staff who need to use them. In addition, records should only contain information which is necessary for the purposes of providing the service.
- Service user access (with support if necessary) to personal and employment details can assist in ensuring information is kept up-to-date and accurate.
- Staff are aware of their privileged access to information: this is communicated in staff recruitment, selection, training and supervision procedures.

Relevant AIHW data policies

The AIHW operates under the *AIHW Act 1987*, which has strong confidentiality provisions. These confidentiality principles are expanded through AIHW policy and procedures relating to security and privacy information. They are approved by the Institute's Board, and take into consideration related data custodianship procedures. These policies and procedures seek to put into effect the principles set out in the Institute's legislation and other relevant legislation, and also the principles set out in Appendix A. The Institute's Ethics Committee approves access to databases under certain conditions.

Some of the AIHW principles relating to data custodianship complement the other material quoted in this paper. A brief excerpt is at Appendix C.

Principles and standards for Indigenous data

The National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID) has developed a set of 11 data principles. These data principles are a set of recommendations for jurisdictions, rather than mandatory principles, which have been endorsed by the Australian Health Ministers' Advisory Council (AHMAC) and aim to improve the protective rights of health data for Aboriginal and Torres Strait Islander Australians. The principles were subject to review in 2008, where issues regarding collection, storage and use of Aboriginal and Torres Strait Islander health data can be identified.

National Aboriginal and Torres Strait Islander Health Data Principles

All organisations with significant responsibilities in Aboriginal and Torres Strait Islander health data should encourage the application of these principles and establish meaningful partnerships with Aboriginal and Torres Strait Islander Australians.

Mindful of Aboriginal and Torres Strait Islander peoples understanding of ownership, including ownership of personal and community information, and any relevant agreements

with various parties, including governments, these principles set out a culturally respectful foundation for the collection, storage and use of their health and health related information.

Principle 1: The management of health-related information about Aboriginal and Torres Strait Islander persons must be ethical, meaningful, and support improved health and better planning and delivery of services.

Principle 2: The analysis, interpretation and reporting of Aboriginal and Torres Strait Islander health and health-related information should, where feasible, occur collaboratively with Aboriginal and Torres Strait Islander peoples.

Principle 3: The privacy and confidentiality of Aboriginal and Torres Strait Islander people will be protected in accordance with any relevant legislation and privacy codes.

Principle 4: Aboriginal and Torres Strait Islander peoples should be informed at the point of service that attendance/participation may contribute to administrative or mandatory data collections and that such data will be used to improve the quality, coverage and scope of health services and protect the public health. Data collection agencies and data custodians should have a policy that provides this information to people at the point of data collection and appropriate governance arrangements to review its implementation.

Principle 5: In general, free and informed consent should be obtained from Aboriginal and Torres Strait Islander peoples prior to any information management activities, except where mandatory reporting or legislative provisions apply. Otherwise, where there is a proposal to initiate an information management activity without the consent of Aboriginal and Torres Strait Islander peoples, it must be clearly demonstrated both that the activity will advance the interests of Aboriginal and Torres Strait Islander peoples and that it is impractical and infeasible to obtain further specific consent.

Principle 6: The value of the resources required to collect and use information should be assessed in the light of the potential benefit to Aboriginal and Torres Strait Islander peoples' health.

Principle 7: The collection, collation and utilisation of information should be conducted in the most efficient and effective manner possible and minimise the burden on Aboriginal and Torres Strait Islander people.

Principle 8: Systematic and ethical processes for sharing information should be encouraged to assist in policy, planning, management and delivery of health services to Aboriginal and Torres Strait Islander people.

Principle 9: Aboriginal and Torres Strait Islander communities should be provided with feedback about the results and possible implications arising from data analysis.

Principle 10: Information collections require regular review and refinement in order to ensure ongoing relevance to service delivery and the potential for improved health outcomes.

Principle 11: Cultural respect and security of data practices must be promoted across all collections. Aboriginal and Torres Strait Islander individuals and communities should be afforded the same ethical and legal standards of protection as are enjoyed by other Australians. This may require the development and application of methods that are different to or in addition to those in mainstream data collections.

6.3 Privacy and data principles for the Disability Services NMDS

The following privacy and data principles are based on the material outlined in Section 6.2. These privacy and data principles draw together the material into a concise and holistic document.

The privacy and data principles are drafted under three main headings: ethos, content, and quality, methods and procedures.

Ethos

E1. Respect: privacy, dignity and confidentiality

The national minimum data set should be defined and collected in a climate of mutual respect:

- All participants in the DS NMDS collection should respect the rights to privacy, dignity and confidentiality of the service user.
- Funded agencies should be respected for their role in providing a valued service and for their need to operate cost-effectively and competitively in a mixed economy.
- Service funders should be respected for their role in policy, administration and high-level advocacy in the sector, and their associated need to monitor the activities and outcomes of services and the profile and needs of service users.

E2. Fairness and transparency

Data should be collected in accordance with the privacy principles attached:

- Funded agencies should ensure that service users are aware of the data being recorded, the purpose of recording, and which data will be transmitted to other bodies, including funders and national statistical agencies, and for what purpose (see Box 2).
NDA-funded services have the right to access your own files and to update or correct information included in the DS NMDS collection.
- Service users should be made aware of their right to seek access to their records and to correct or update information about them, if it is incomplete, inaccurate or out-of-date.
- Funding departments should ensure that, similarly, funded agencies are aware of the data being recorded, the purpose of recording them, and which data will be transmitted to other bodies including national statistical agencies.
- Fairness and openness concerning purposes, data, procedures and release. Jurisdictions and the AIHW should publish clear statements about the purpose of each data item in the DS NMDS, and the purpose of data collection and jurisdictional and national collation, analysis and dissemination. The purpose of data may legitimately extend to the collection of information that, while not immediately related to the service a person receives at a point in time, relates to the continued availability of that service. (For example, the collection of information on ethnicity or Indigenous origin may or may not be directly relevant to the provision of a service to a service user on a particular day. However this information is regarded as crucial to the effective delivery of the NDA

program, by establishing the accessibility and equity of the program, and hence ensuring its continuing financial support by governments.)

E3. Custodianship as a principle

- Funded agencies, jurisdictions and the AIHW are the custodians of information collected from service users and funded agencies. They do not 'own' data, but are responsible for the protection, storage, analysis and dissemination of the data in accord with: the purposes for which they were collected; the principles of respect and fairness outlined above; and the quality standards outlined in the following sections.

Purpose and content

P1. Disability Services National Minimum Data Set principles

- The data items included in a national minimum data set should be nationally relevant and important, and able to be collected consistently and interpreted meaningfully.
- The DS NMDS should contribute to the goals and objectives of the NDA.

P2. Cost-effectiveness

Including or changing data items imposes costs on all participants in a national collection.

- Data items should, as far as possible, be: consistent with agency and jurisdictional administrative reporting procedures; and able to be efficiently collected and transmitted.
- The costs of change to data items or collection methods should be weighed up against the desire for continued improvement in content.

Quality, methods and procedures

Q1. Quality of data items

Data items in the DS NMDS should be: based on national and international standards where appropriate; defined clearly, concisely and comprehensively; in accordance with national information priorities; tested for meaning and feasible collection in the field; and collected and maintained accurately, with opportunities for correction by the service user, the funded agency, the jurisdictional administration and the AIHW.

Q2. Quality of data capture and collection methods

- Funded agencies should attempt to align data items on their administrative forms (e.g. age, sex and Indigenous origin) as closely as possible with the DS NMDS items, especially where they conform to national standards for community service data definitions.
- Jurisdictions should attempt to ensure related new policy and service developments (e.g. service definitions and assessment methods) can be mapped to the information framework of the DS NMDS data concepts, to promote quality, consistency and continuity of national data.

Q3. Custodianship standards: security of storage and access procedures

'Identifiable information' is defined here to be: individual records containing age, sex and statistical linkage key components that could be related back to an individual (or could enable an individual's identity to be reasonably ascertained); and agency records that could be used to identify an individual funded agency. 'Identifiable information' is different from 'identifying information' where individual names and other identifiers are included (i.e. the individual is identified uniquely and with certainty.)

Data custodians are responsible for ensuring their data holdings are protected from unauthorised access, alteration or loss.

- Paper-based identifiable information should be kept securely locked away when not in use. The minimum requirements are that information must be accessible only to those who are authorised, and that outside normal working hours, the information must be stored in locked drawers or cabinets.
- Particular care must be taken regarding the printout and photocopying of paper-based information. Users should stand by printers, photocopiers and fax machines while this material is being printed, copied, sent or received.
- Information users should follow normal practice for the use of Information Technology systems to ensure the security and privacy of in-confidence information stored on computer systems including, but not limited to:
 - user account and password protection, use and management
 - automatic screen shutdown or automatic log-off in place on all PCs.
- Identifiable information should not be copied to or held on workstation hard disks, or copied and removed from the data holding without permission of the data custodian.
- Funded agencies must take reasonable steps to destroy or permanently de-identify personal information if it is no longer needed for any purpose for which the information was collected.
- In relation to the collection of the statistical linkage key components, the AIHW Ethics Committee has recommended protocols which are in place by agreement between all jurisdictions and the AIHW. These protocols include advising the service user that information about them will be released to the relevant funding body and the AIHW. However this information will not identify the service user by full name or address and will be kept confidential; that is, securely stored and released in a non-identifiable form (see also Box 2).

(See also Appendix C for excerpt from AIHW information security procedures.)

Q4. Dissemination and use

- Dissemination and use of the data should be in accordance with these DS NMDS privacy and data principles and those relating to the purpose of the collection.
- Data should be carefully interpreted, and any conclusions drawn based on rigorous and balanced analysis of the DS NMDS data and other relevant information.
- In published tables, the amount of personal information in small cells should be reduced to decrease the potential for identification.
- Published data should be made available, in suitable formats to data providers (e.g. funded agencies) and data subjects (e.g. NDA service users).

Box 2: AIHW Ethics Committee guidelines for the DS NMDS

In accordance with AIHW Ethics Committee guidelines, each jurisdiction has provided written confirmation that:

1. *Agencies participating in the DS NMDS collection will be informed of the collection's Privacy and Data Principles, which outline their legal obligations under the Privacy Act 1988 and the Privacy (Private Sector) Amendment Act 2000, and refer agencies to the Acts themselves.*
2. *The 'information subjects' (people with a disability who are the service consumers) will be informed about the information being recorded and its purpose, as well as their right to access the information and update or correct it. The following paragraph has been approved for this purpose:
Please note that <agency name> is required to release information about service users (without identifying you by full name, or address) to <NDA funding dept name>, and to the Australian Institute of Health and Welfare, to enable statistics about disability services and their clients to be compiled. The information will be kept confidential. This information is used for statistical purposes only and will not be used to affect your entitlements or your access to services. As a user of National Disability Agreement-funded services you have the right to access your own files and to update or correct information included in the Disability Services National Minimum Data Set collection.*
3. *The unit record file will not be matched, in whole or in part, with any other information for the purposes of attempting to identify individuals, nor will any other attempt be made to identify an individual.*
4. *The person/organisation will not disclose, release or grant access to the information to any other person or organisation, except as statistical information that does not identify an individual.*
5. *The information will be used only for statistical purposes and will not be used as a basis for any legal, administrative or other purpose.*
6. *Details relating to any deviations from the standards are provided, including how alternative arrangements accord with relevant privacy legislation.*

Appendix A: Summary of information privacy principles

Appendix A provides a summary of the Information Privacy Principles contained in the *Privacy Act 1988*. The Information Privacy Principles regulate the information-handling practices of Australian Government agencies and their contractors.

The Information Privacy Principles in plain English

(Graham Greenleaf - July 1989)

Principle 1: Restricting collection of information to lawful purposes and by fair means

Agencies must not collect personal information unless:

- (i) it is collected for a lawful purpose directly related to a function or activity of the agency
- (ii) the means of collection are lawful and fair.

Principle 2: Informing people why information is collected

Agencies must ensure that people from whom they solicit personal information are generally aware, before collection or as soon as practical thereafter, of:

- (i) the purpose of collection
- (ii) any legal authority for the collection
- (iii) any third parties to which the collecting agency discloses such information as a usual practice.

Principle 3: Ensuring personal information collected is of good quality and not too intrusive

Where an agency solicits personal information (whether from the person that the information is about or otherwise), it must take reasonable steps to ensure

- (i) that the information is relevant to the purpose of collection, up-to-date and complete
- (ii) that its collection does not unreasonably intrude upon the person's personal affairs.

Principle 4: Ensuring proper security of personal information

An agency must protect personal information against misuse by reasonable security safeguards including doing everything within its power to ensure that authorised recipients of the information do not misuse it.

Principle 5: Allowing people to know what personal information is collected and why

Any person has a right to know whether an agency holds any personal information (whether on him or her or not), and if so:

- (a) its nature
- (b) the main purposes for which it is used
- (c) the classes of persons about whom it is kept
- (d) the period for which each type of record is kept
- (e) the persons who are entitled to have access to it, and under what conditions
- (f) how to obtain access to it.

Each agency must maintain an inspectable register of this information, and must inform the Privacy Commissioner annually of its contents.

Principle 6: Allowing people access to their own records

A person has a right of access to personal information held by an agency, subject to exceptions provided in the *Freedom of Information Act 1982* or any other law.

Principle 7: Ensuring that personal information stored is of good quality, including allowing people to obtain corrections where it is not

Agencies must make corrections, deletions and additions to personal information to ensure that it is:

- (i) accurate
- (ii) relevant, up-to-date, complete and not misleading (given the purpose of collection and related purposes), subject to exceptions provided in the *Freedom of Information Act 1982* or any other law.

Agencies are also required to add a reasonable statement by a person to that person's record, on request.

Principle 8: Ensuring that personal information is of good quality before using it

Agencies must take reasonable steps to ensure that personal information is accurate, up-to-date and complete (given the purpose of collection and related purposes) before using it.

Principle 9: Ensuring that personal information is relevant before using it

Agencies may only use personal information for purposes to which it is relevant.

Principle 10: Limiting the use of personal information to the purposes for which it was collected

Agencies may not use personal information for purposes other than for which it was collected, except:

- (a) with the consent of the person
- (b) to prevent a serious and imminent threat to a person's life or health

- (c) as required or authorised by law
- (d) where reasonably necessary for the enforcement of criminal or revenue laws
- (e) for a directly related purpose.

In the case of exception (d), but not otherwise, the use must be logged.

Principle 11: Preventing the disclosure of personal information outside the agency

Agencies may not disclose to anyone else personal information, with the same exceptions as apply as to Principle 10(a)–(d), plus an additional exception where the subject of the information is reasonably likely to be aware of the practice of disclosure (or reasonably likely to have been made aware under Principle 2). The recipient of information under one of these exceptions may only use it for the purpose for which it was disclosed.

Appendix B: Private sector privacy law

Appendix B is extracted from Information Sheets, developed by the Office of the Federal Privacy Commissioner (2001) about the new private sector privacy law (see office of the Privacy Commissioner 2001). Further information on privacy can be obtained from the Federal Privacy Commissioner's web site (see Office of the Privacy Commissioner 2001).

An overview of the *Privacy Amendment (Private Sector) Act 2000*

The *Privacy Amendment (Private Sector) Act 2000* regulates the way the private sector organisations can collect, use, keep secure and disclose personal information. For the first time, it gives individuals the right to know what information an organisation holds about them and a right to correct that information if it is wrong.

What does the Act mean to service users?

The Act means service users now have the right to know why a private sector organisation is collecting their personal information, what information it holds about them, how it will use the information and who else will get the information. Except for some special circumstances, service users can ask to see this information and for the information to be corrected if it is wrong. Service users can also make a complaint if they think their information is not being handled properly. A service user could also apply to the Federal Court or the Federal Magistrate's Court for an order to stop an organisation from engaging in conduct that breaches the National Privacy Principles (NPPs).

What is 'personal information'?

The Act covers personal information. It has special protection for personal information that is sensitive information. The Privacy Act only applies to information that is recorded in some form, which can include in an electronic record.

Personal information is information or an opinion that can identify a person.

Sensitive information is information about an individual's racial or ethnic origin, political opinions, membership of a political association, religious beliefs or affiliations, philosophical beliefs, membership of a professional or trade association, membership of a trade union, sexual preferences or practices, criminal record, or health information.

Who will the new private sector provisions apply to?

The Act will apply to 'organisations' in the private sector. An organisation can be an individual, a body corporate, a partnership, an unincorporated association or a trust. It will cover:

- businesses, including not-for-profit organisations such as charitable organisations, sports clubs and unions, with a turnover of more than \$3 million
- federal government contractors
- health funded agencies that hold health information (even if their turnover is less than \$3 million)

- organisations that carry on a business that collects or discloses personal information for a benefit, service or advantage (even if their turnover is less than \$3 million)
- small businesses with a turnover of less than \$3 million that choose to opt-in
- incorporated state government business enterprises
- any organisation that regulations say are covered.

The new provisions will not apply to:

- state or territory authorities, e.g. Ministers, departments, courts and local government councils
- political parties and acts of political representatives in relation to electoral matters
- most small businesses with an annual turnover of less than \$3 million
- acts or practices in relation to employee records of an individual if the act or practice directly relates to a current or former employment relationship between the employer and the individual
- acts or practices of media organisations in the practice of journalism.

When does the Act come into operation?

Most organisations, including all health services holding health information, will have 12 months to get ready for the new scheme. The new provisions will apply from 21 December 2001. Small businesses (except health services) covered by the new provisions have an additional 12 months meaning full coverage of the new provisions effective from December 2002.

What are the National Privacy Principles (NPPs)?

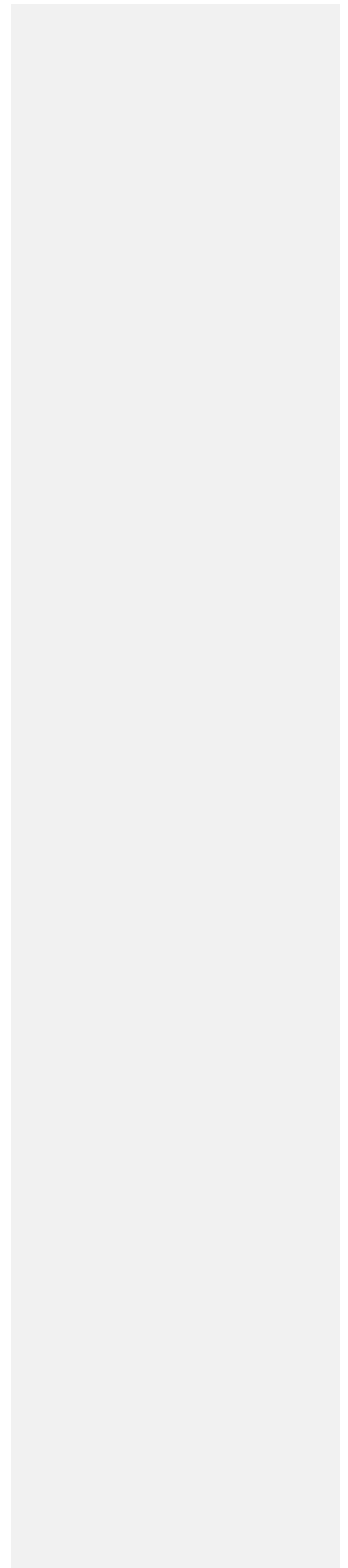
The NPPs set the base line standards for privacy protection. Organisations may have and enforce their own privacy codes. These codes must be approved by the Privacy Commissioner as having obligations at least equivalent to the NPPs and meet other requirements. The code must have an independent code adjudicator to handle complaints. If the code does not provide for a complaints handling mechanism the Privacy Commissioner is the code adjudicator.

Organisations that do not have their own code must comply with the NPPs set out in the *Privacy Amendment (Private Sector) Act*. The Privacy Commissioner handles complaints in these circumstances.

The NPPs are 10 principles or rules in the Act about how organisations should handle personal information. They cover collection (NPP1), use and disclosure (NPP 2), data quality (NPP3), data security (NPP 4) openness (NPP 5), access and correction (NPP6), identifiers (NPP7), anonymity (NPP 8), transborder flow of data (NPP 9) and sensitive information (NPP 10).

Only some of the NPPs will apply to information that organisations already hold when the new provisions come into effect. The NPPs relating to data security, data quality when information is used and disclosed, identifiers and transborder flow will apply regardless of when the information was collected. The principle relating to access and correction will apply to all information collected after the new provisions apply, and any already existing information that is used. Those principles relating to collection, use and disclosure, data

quality when it is collected, and sensitive information will not apply to information collected before the new provisions come into effect.



Appendix C: AIHW security and privacy

AIHW policy and procedures on information security and privacy: excerpts

The AIHW has documented procedures, approved by its Board, covering information security and privacy. These policies and procedures seek to put into effect the requirements of the Institute's legislation and other relevant legislation (i.e. *The Privacy Act 1988*). The AIHW has particularly strong attributes as a data custodian as we are bound by our own legislation in addition to privacy legislation and have a strong culture of ensuring data security.

The principles relating to data custodianship complement the Information Privacy Principles in Appendix A, and are worth considering in the context of the DS NMDS redevelopment. A brief excerpt follows.

Selected principles on information storage, retention and retrieval

1. Data custodians are responsible for ensuring their data holdings are protected from unauthorised access, alteration or loss.
2. Paper-based identifiable information must be kept securely locked away when not in use. The minimum requirement is that, outside normal working hours, the information must be stored in locked drawers or cabinets.
3. Particular care must be taken regarding the printout and photocopying of paper-based information. Users must stand by printers, photocopiers and fax machines while this material is being printed, copied, sent or received.
4. Information users must follow normal practice for the use of Information Technology (IT) systems to ensure the security and privacy of in-confidence information stored on computer systems including, but not limited to:
 - user account and password protection, use and management
 - automatic screen shutdown or automatic log-off in place on all PCs.
5. Identifiable information must not be copied or removed from Institute premises without specific approval from the relevant data custodian (where the release has been approved by the AIHW Ethics Committee).
6. Identifiable information must not be copied to or held on work station hard disks.
7. In published tables, the amount of information in small cells should be reduced to decrease the potential for identification.

Note: Copies of all relevant source documents are available from the AIHW on request.

Appendix D: Summary of brokerage and subcontracting

Summary of brokerage and subcontracting—concepts, key principles and examples

Concept	Key principle	Example
Service details recorded by brokerage service types (2.06)	ONLY services received by service user for 2.06 are to be recorded. That is, do NOT record the hours of actual service that was brokered and provided by another service type outlet. This also applies where NDA funding comes from the broker, but the broker does not control the service delivery.	A brokerage service type outlet (A) provides a referral to a therapy service type outlet (B). Service type outlet A records only the hours they spent referring the service user to B, and NOT the hours that B spent providing therapy. It is up to service type outlet B to record these hours (if they are NDA-funded). Note: if service type outlet B is not NDA-funded, the information about hours of support provided will not be captured under the national data set where this support has been brokered (however, as explained in the Data Guide, jurisdictions may collect this information for their own purposes).
Hours recorded by service type outlets that pay the subcontractor	The service type outlet that pays a subcontractor is responsible for recording details of services received. To avoid double counting, it is important that the subcontractor does not also report details of the service provided.	A service type outlet (C) pays another service type outlet (D) to provide services, and a contract is involved. That is, service type outlet C is taking responsibility for service provision, and service type outlet D is an agent of C. It is the responsibility of C to record all details of services received, that is, C must obtain this information from D.
NDA-funded brokerage provided to arrange services that are not NDA-funded.	Service details arranged by a broker for non-NDA services only have brokerage (2.06) details recorded (as above). Jurisdictions are welcome to collect details of non-NDA services separately (for own records), however they will not be included in the national data set. The national data set is trying to report on NDA-funded services, and the picture should not be artificially inflated by brokerage activities.	An accommodation service type outlet (E) brokers a non-NDA service type outlet (F) to mow a service user's lawn. The hours spent brokering by E are counted, but the details of F are not (for the purposes of the national data set), due to the fact that no NDA funding is involved.

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