

Australia's national disability services data collection

**Redeveloping the Commonwealth–State/Territory
Disability Agreement National Minimum Data Set
(CSTDA NMDS)**

The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is to improve the health and well-being of Australians by informing community discussion and decision making through national leadership in developing and providing health and welfare statistics and information.

DISABILITY SERIES

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**Redeveloping the Commonwealth–State/Territory
Disability Agreement National Minimum Data Set
(CSTDA NMDS)**

February 2003

Australian Institute of Health and Welfare
Canberra

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Disability field

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Abbreviations

ABS	Australian Bureau of Statistics
ACDC	Annual Client and Disability Services Collection
ACROD	National Industry Association for Disability Services
AIHW	Australian Institute of Health and Welfare
CSDA	Commonwealth/State Disability Agreement
CSTDA	Commonwealth–State/Territory Disability Agreement
DSSC	Disability Services Sub-Committee
DTS	Data Transmission Strategy
FIG	Facilitation and Implementation Group
HACC	Home and Community Care
ICF	International Classification of Functioning, Disability and Health
MDS	Minimum Data Set
NCSDdv2.0	National Community Services Data Dictionary Version 2.0
NDA	National Disability Administrators
NHDD	National Health Data Dictionary
NGO	Non-government Organisation
NMDS	National Minimum Data Set
SLA	Statistical Local Area

Glossary

The term '**jurisdictions**' is used throughout this report to refer to the State, Territory and Commonwealth agencies responsible for funding and administering disability support services under the CSTDA.

'**CSDA MDS**' refers to the snapshot collection established in 1994 after the signing of the first Commonwealth/State Disability Agreement in 1991. The CSDA MDS was conducted on a snapshot day each year from 1994 to 2002.

'**CSTDA NMDS**' refers to the redeveloped ongoing collection, which was fully implemented nationally in October 2002. The change in the collection's name stems from the negotiations of the third Commonwealth–State/Territory Disability Agreement.

Summary

This report describes the process of redeveloping the existing Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS) and the information that will be available from the new Commonwealth-State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS).

Background

(See Chapter 1)

The Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS) collection was set up in 1994, to monitor and report publicly on the CSDA which in 2000-01 was a \$2.5 billion program. Its establishment enabled complete, nationally comparable data on disability services funded under the CSDA to be collected in Australia for the first time. The CSDA places responsibility for planning, policy setting and management of employment services with the Commonwealth, whilst the States and Territories are responsible for all other disability services. Advocacy, print disability and information services are considered shared responsibilities under this agreement.

The process of review and redevelopment began in 1999 during the life of the second CSDA, when it was acknowledged that there was a significant change in the nature of service provision, information needs and availability of technology in use across the disability field. As a result of the redevelopment, full-year data about CSDA-funded agencies and service users will be available for 2002-03, in turn increasing the power of information collected and providing better outcomes for all major stakeholders. The new data set is known as the CSTDA NMDS in anticipation of a third agreement being finalised.

Process

(See Chapters 2-4)

The redevelopment project was managed by a process reflecting the existing relationships between the Australian Institute of Health and Welfare, the National Disability Administrators, and the State, Territory and Commonwealth government departments responsible for disability services and the ongoing management of the existing CSDA MDS snapshot collections. A Facilitation and Implementation Group (comprising representatives from all jurisdictions responsible for CSTDA-funded services, non-government and consumers representatives, and members of the AIHW) was established at the outset of the project to provide advice and assistance to the project management team.

The project focused strongly on consultation with government and non-government stakeholders, including CSTDA-funded agencies, service users, carers and peak organisations. Throughout the project the CSTDA NMDS underwent three rounds of field testing, as well as numerous consumer discussion sessions, which aided significantly in the finalisation of the data items and collection materials.

The redeveloped CSTDA NMDS has moved from a 'snapshot' day collection to a full-year collection, which significantly improves the power of information collected.

Data development

(See Chapters 5 and 8)

The CSTDA NMDS redevelopment project plan included a 'short list' of data items that were investigated for the redeveloped CSTDA NMDS. The 'short list' reflected the information needs of the Disability Administrators across the country. Through the various rounds of field testing, the original 'short list' of data items was revised in line with the findings of the field testing, and developed in accordance with national data standards, to produce a final data collection.

Key products

(See Chapter 6)

A range of collection materials and products have been developed to support the new CSTDA NMDS:

- Data Guide
- Service Type Outlet and Service User paper forms
- Data Transmission and Technical Guide
- Data Dictionary
- Network Guide
- Training materials

All materials were developed through consultation with various stakeholders and are publicly available from the AIHW web site (www.aihw.gov.au/disability).

Privacy and data principles

(See Chapter 7)

In the planning stages of the 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.

The Privacy and Data Principles developed are based on the *Privacy Act 1988*, *Privacy (Private Sector) Amendment Act 2000*, the Disability Service Standards and AIHW policies concerning data collection, storage and transmission.

The new data

(See Chapters 2, 8 and 9)

The redeveloped collection will satisfy a far wider range of information needs relating to this major national program.

1 Introduction

A new Commonwealth–State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS) was launched nationally in October 2002. This report describes the process of redeveloping the existing Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS) and the information that will be available from the new CSTDA NMDS collection.

The CSTDA NMDS redevelopment project was jointly funded by National Disability Administrators and the Australian Institute of Health and Welfare. Considerable resources were committed to the project over a number of years. This enabled an extensive and iterative consultation process to be undertaken, involving the specification of information needs by stakeholders, careful development of suitable data items, definitions and collection materials, and field testing. As a result, the final CSTDA NMDS is a policy relevant collection that will provide a wide range of stakeholders with essential information about disability services and the people they support in the coming years.

1.1 Time for a new CSDA MDS

Before the first CSDA MDS there were no nationally comparable data on disability services. From 1994, the Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS) comprised both:

- a set of data items, together with their definitions, agreed by Disability Administrators to be of significance for national collation and reporting purposes under the CSDA; and
- an agreed method of collection and collation.

Many uses of the data have been detailed in various reports (e.g. AIHW 2002a; AIHW 2002b). The data have been essential in order to report on services provided under the CSDA, a \$2.5 billion program in 2000–01. Without such data it would not have been possible to estimate the extent of unmet need existing in the disability services sector (AIHW 1997; 2002b). Nor would it have been possible for the field to contribute in a timely manner to the *Report on Government Services*, an annual publication designed to report on the performance of services across a broad range of areas, including education, health, justice, community services and housing (e.g. SCRCSSP 2002).

The disability services field in Australia is a scene of ambitious policy goals and change. This dynamic environment has seen significant developments in recent years in the:

- nature of services and service delivery methods, in particular the trend towards more flexible services focusing on individual needs;
- information needs and capabilities of the field, including the need for greater accountability and the development of performance indicators and performance based contractual agreements; and
- available technology and the greater sophistication in its use across the disability services field.

These goals and changes are represented in the second Commonwealth/State Disability Agreement (CSDA 1998) and the third Commonwealth-State/Territory Disability Agreement (CSTDA 2002) still under negotiation in February 2003.

In 1999, in view of these changes, the National Disability Administrators (NDA), comprising senior administrators responsible for the CSDA, in cooperation with the Australian Institute of Health and Welfare (AIHW) began a process, to review and redevelop the CSDA MDS and related data collections.

A vision

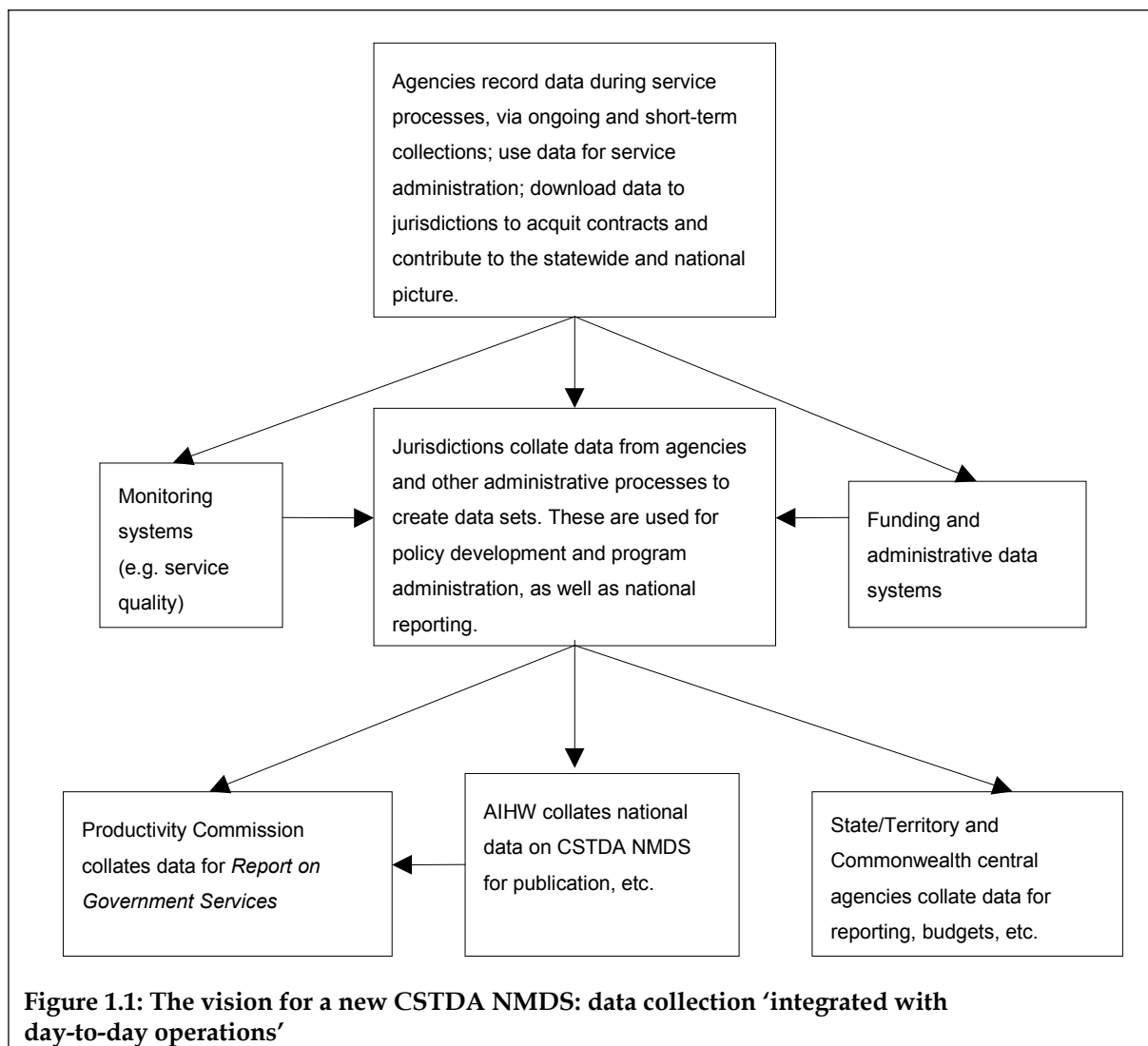
The vision for a new CSTDA NMDS was agreed to encompass:

- a CSTDA NMDS 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 (see Figure 1.1); and
- the continued use of statistical linkage keys to enable data from various sources to be related and collated without duplication of effort.

There would still be two key components of the new NMDS—agreement on nationally significant data items, and agreement on a framework for collection and national collation.

The vision for the new collection is to provide better information and outcomes to all major stakeholders:

- For people with disabilities: data that permit an evaluation of services received, in terms of accessibility and appropriateness, efficiency and effectiveness, and ultimately lead to improved services and service outcomes;
- For service delivery agencies: data that are more relevant to their own information needs and easier to record and collate, with the assistance of better software tools and support;
- For governments: data that better inform planning, service development and service delivery as well as meet other critical information needs.



Redeveloping the CSDA MDS

The process of redeveloping the CSDA MDS into the CSTDA NMDS was conducted in two stages:

- Stage 1: Preliminary CSDA MDS redevelopment project 1999; and
- Stage 2: CSTDA NMDS redevelopment and implementation project 2000–02.

Both stages were collaborative efforts involving the AIHW and the NDA.

Stage 1

The AIHW first began working with the NDA to redevelop the CSDA MDS in 1999. Broadly, this first phase of redevelopment involved an examination of recent and emerging changes to policies, funding arrangements and service structures, and their implications for administrators' data needs, as well as an examination of the main methodological issues facing each jurisdiction, including sampling and enumeration issues, and technological change. Information for Stage 1 was obtained via questionnaire, ongoing liaison and a number of consultative workshops with all jurisdictions. Administrators were asked to articulate what they required from a redeveloped disability services data collection. A closely related body of work to develop key indicators (of costs, outputs and outcomes) in the disability services sector was also a crucial part of the preliminary redevelopment work (AIHW 2000a).

Stage 2

In March 2000, the AIHW presented the results of Stage 1 and resulting proposals for redeveloping the collection to the NDA for consideration. A workshop involving all major stakeholders was subsequently held in April 2000. This workshop further developed the AIHW redevelopment plans into a detailed redevelopment project plan, agreed by stakeholders and the NDA. This project plan formed the basis of the CSTDA NMDS redevelopment project.

Chapter 3 contains more detail on the processes involved in redeveloping the CSTDA NMDS.

1.2 Report outline

This report focuses on the redevelopment work undertaken during 2000–02, while drawing where relevant on the earlier data development and conceptual work undertaken.

The report:

- showcases the key information available from the new CSTDA NMDS (Chapter 2);
- outlines the stages and phases of the redevelopment, in relation to the project plan (Chapter 3);
- summarises the purpose, methodology and main outcomes for each round of field testing (Chapter 4);
- provides an overview of the data items selected for the final CSTDA NMDS, including a discussion of every data item originally on the table for inclusion (Chapter 5);
- describes the key products available relating to the CSTDA NMDS – the Data Guide (including Privacy and Data Principles), Service Type Outlet and Service User forms, Data Transmission and Technical Guide, Data Dictionary, Network Guide and training materials (Chapter 6);
- discusses the process of developing the CSTDA NMDS Privacy and Data Principles and includes a copy of the principles (Chapter 7); and

- discusses some of the specialised data development areas, namely: service type, organisational units, agency identifiers and CSTDA funding; disability and functioning; support needs; and the development of indicators of outputs and outcomes, including a trial individual participation module (Chapter 8).

The report aims to be a document of record, of interest to the disability field and to future users and managers of the resulting data set.

2 Data available from the CSTDA NMDS

This chapter details the scope and nature of the redeveloped collection together with the final data items included within the CSTDA NMDS. The chapter also discusses some of the key uses of CSTDA NMDS data and provides a range of examples to illustrate the type of information now available from the new collection.

2.1 The scope and nature of the CSTDA NMDS

The most significant change in the new CSTDA NMDS (compared with the snapshot CSDA MDS collection) is that, for most service types, funded agencies are required to provide information about all service users during the year (rather than just those who receive a service on a snapshot day). This means that funded agencies are asked to collect and store information on an ongoing basis, for transmission to their funding department at specified points in time (quarterly in some jurisdictions and annually in others). Funding departments transmit annual data to the AIHW for national collation at the end of each financial year.

Box 2.1 summarises the key concepts of the CSTDA NMDS collection. Briefly, most agencies funded under the CSTDA are requested 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 the financial year; and
- the CSTDA 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 8.1 for further details).

2.2 The data items included in the CSTDA NMDS

As detailed in later chapters of this report, the CSTDA NMDS data items were developed following extensive consultation with administrators, jurisdiction staff, funded agencies and service users. The final data items agreed for inclusion in the CSTDA NMDS are designed to:

- meet the information needs of stakeholders, including national disability administrators, funding departments, funded agencies and service users;
- align and integrate with data collection methods used by funded agencies and jurisdictions;
- be a *minimum* data set, seeking only information that is considered useful at a national level and feasible to collect (i.e. responder burden was considered throughout the redevelopment project);

- conform to national data collection standards (i.e. the *National Community Services Data Dictionary* where appropriate data elements are available, and to other developments in the field such as the Home and Community Care Minimum Data Set), and thereby reduce the likelihood of duplication by funded agencies; and
- provide some continuity with the previous CSDA MDS.

The data items included in the CSTDA NMDS at implementation are listed in Table 2.1 and also presented in the format of a simplified information model (Figure 2.1).

Box 2.1: Key definitions for the CSTDA NMDS collection

Service

A service is a support activity delivered to a service user, in accord with the CSTDA. 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 CSTDA.

Service user

A service user is a person with a disability who receives a CSTDA-funded service.

A service user may receive more than one service over a period of time or on a single day.

Service type

Service type is the support activity which the service type outlet has been funded to provide under the CSTDA.

The NMDS classifies services according to 'service type'. The 'service type' classification groups services into seven categories: accommodation support; community support; community access; respite; employment; advocacy, information and print disability; and other support services. Within each of these categories there are subcategories.

Service type outlet

A service type outlet is the unit of the funded agency that delivers a particular CSTDA service type at or from a discrete location.

If a funded agency provides, say, 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.

Funded agency

A funded agency is an organisation that delivers one or more CSTDA service types (service type outlets). Funded agencies are usually legal entities. They are generally responsible for providing CSTDA 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.

Scope of the CSTDA NMDS collection

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 CSTDA. 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. CSTDA or other), it is asked to provide details of all service users and staff (for each service type).

Source: AIHW 2002c.

2.3 Key uses of CSTDA NMDS data

In the past, CSDA MDS snapshot data had been used for a wide range of purposes, such as to:

- support budget submissions for increased funding or changing funding emphasis;
- support planning for future service delivery;
- resist proposals to increase the level of service user contributions by demonstrating the high proportion of CSDA service users who have benefits or pensions as their main income source;
- provide national comparisons of numbers of service users living in institutional vs community-based settings; and
- indicate that certain groups of people (e.g. people of Aboriginal and Torres Strait Islander origin) are not accessing services as much as should be expected.

The new CSTDA NMDS is a full-year data collection, which introduces a number of new data items. These changes significantly improve the power of the information collected. For example, for the first time:

- a profile of all people receiving a CSDA-funded service in a financial year will be available;
- new data on carer arrangements will enable the issue of ageing carers to be monitored and planned for; and
- information will be available about the quantity of service provided to service users and this can be examined in relation to various characteristics of these service users, such as their support needs, disability group and carer arrangements, and whether they live in metropolitan or rural locations.

Table 2.1: Data items for the redeveloped CSTDA NMDS

Service type outlet items	Service user items	Information required for each service type received in the reporting period (per service user)
<p>A. Funded agency ID (J)</p> <p>B. Service type outlet ID (J)</p> <p>C. Service type (J)</p> <p>D. Service type outlet postcode (J)</p> <p>E. Service type outlet SLA (J)</p> <p>F. Funding jurisdiction (J)</p> <p>G. Agency sector (J)</p> <p>H. CSTDA funding*</p> <p>1. Full financial year operation</p> <p>2. Weeks per year of operation</p> <p>3. Days per week of operation</p> <p>4. Hours per day of operation</p> <p>5. Staff hours (reference week)</p> <p>6. Staff hours (typical week)</p> <p>7. Number of service users</p>	<p>B. Service type outlet ID(s) (J)</p> <p>1. Record ID</p> <p>2a. Letters of surname (H)</p> <p>2b. Letters of given name (H)</p> <p>2c. Date of birth (H)</p> <p>2d. Birth date estimate flag</p> <p>2e. Sex (H)</p> <p>3. Indigenous origin (H)</p> <p>4. Country of birth (H)</p> <p>5. Interpreter services required</p> <p>6. Communication method</p> <p>7. Living arrangements (H)</p> <p>8. Service user postcode (H)</p> <p>9. Residential setting (H)</p> <p>10. Disability group (primary, other significant)</p> <p>11. Support needs (9 areas)</p> <p><i>Carer arrangements (informal):</i></p> <p>12a. Carer—existence of (H)</p> <p>12b. Carer—primary status</p> <p>12c. Carer—residency status (H)</p> <p>12d. Carer—relationship to service user (H)</p> <p>12e. Carer—age group</p> <p>13. Receipt of Carer Allowance (Child)</p> <p>14. Labour force status</p> <p>15. Main source of income</p> <p>16. Individual funding status</p>	<p>17a. Service start date</p> <p>17b. Date service last received</p> <p>17c. Snapshot date flag (snapshot date previously assumed)</p> <p>17d. Service exit date</p> <p>17e. Main reason for cessation of services (H)</p> <p>17f. Hours received (reference week)</p> <p>17g. Hours received (typical week)</p>

* Jurisdictions have agreed to provide CSTDA funding at the funded agency or service type outlet level, depending on the nature of funding agreements with agencies. Therefore, funding data may or may not appear on Service Type Outlet forms, depending on jurisdiction practice.

(J) Item provided by jurisdiction rather than funded agency.

(H) Related HACC data item.

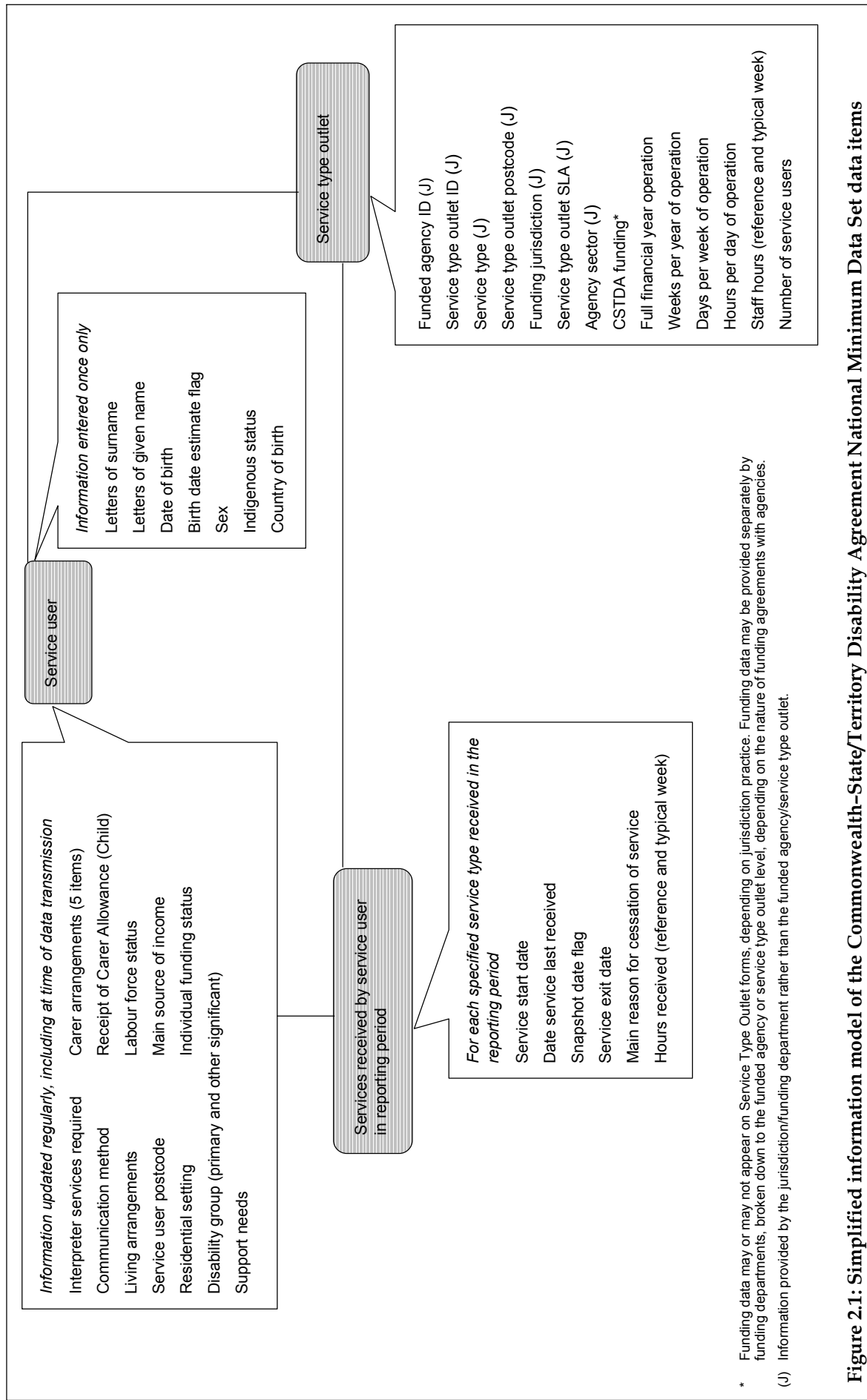
Italics New item in the CSTDA NMDS.

Notes

1. Some new items replace deleted items (e.g. 'interpreter services required' replaces 'main language spoken at home').

2. Not all service type outlets report on all data items; please refer to Table 8.1 for further details.

Source: AIHW 2002c.



* Funding data may or may not appear on Service Type Outlet forms, depending on jurisdiction practice. Funding data may be provided separately by funding departments, broken down to the funded agency or service type outlet level, depending on the nature of funding agreements with agencies.
 (J) Information provided by the jurisdiction/funding department rather than the funded agency/service type outlet.

Figure 2.1: Simplified information model of the Commonwealth-State/Territory Disability Agreement National Minimum Data Set data items

2.4 Resourcing the project

The CSTDA MDS ongoing collections are resourced by the participants. Non-government organisation (NGO) data providers supply data to the funding jurisdiction, which may support NGO costs, or aspects of the collection, particularly during change periods. Each jurisdiction processes these and its own data and sends a data file to the AIHW for annual national collation and reporting. The AIHW has supported its work on national data development, collation, analysis and reporting from its own resources; this has increased some fourfold since 1993–94. The redevelopment project was also funded and supported by all participants, but with the AIHW receiving significant resources from the NDA, who contributed support for some 70% of the AIHW work on the project.

2.5 What information will the CSTDA NMDS give us?

For the first time, the new CSTDA NMDS collection provides information about all service users receiving CSTDA-funded support during a financial year (for most service types). The redeveloped collection also increases the range of information about each service user, by including extra data items on important characteristics such as carer arrangements and quantity of support received.

In summary, the new collection will provide information about:

- service users, in terms of age, sex, Indigenous status, country of birth, disability group, support needs and more;
- the characteristics of carers of service users such as their age group, relationship to the service user and whether they live with the service user;
- profiles of service type outlets, in terms of service type delivered, staffing hours and patterns of operation;
- funding provided under the CSTDA, related to the service unit which receives the funding, either the actual service type outlet or the higher level funded agency, thus enabling calculation or estimation of government funding per CSTDA service type (e.g. in-home support, centre-based respite, learning and life skills development); and
- indicators of the amount of service provided, varying with service type (e.g. hours for in-home accommodation support, people for residential accommodation support) and duration of support received.

Table 2.2 summarises the information the NDA wanted from the new data set, as stated during the preliminary stage of the redevelopment project, and details the relevant information that will be available from the redeveloped CSTDA NMDS collection.

Box 2.2 provides some examples of the types of questions that can now be answered using the CSTDA NMDS.

Table 2.2: Information to be available from the CSTDA NMDS collection, compared to the stated information needs of NDA

Information needs of NDA as reported to AIHW in 1999–00	Information available from the CSTDA NMDS
How many people were supported—and what were their characteristics and support needs?	The profile of all service users supported in a financial year (for most service types): age, sex, Indigenous status, country of birth, interpreter services required, communication method, living arrangements, service user postcode, residential setting, disability (primary and other significant), support needs, carer arrangements and details, income support, labour force status and individual funding arrangements—and the inter-relationships of these characteristics.
What was received—not just type of service, but some measure of 'quantity' of service provided by service type, e.g. staff hours, funding per service user?	<p>For each service user:</p> <ul style="list-style-type: none"> • the service type(s) received and patterns of service they used during the year (e.g. use of multiple service types); • whether they were 'active' service users at the end of the CSTDA NMDS reporting period; • the duration of service received; • the quantity (hours) of service received (for some jurisdictions estimates based on actual hours in a week); • transition into and out of CSTDA-funded services over time (e.g. transition to mainstream services); • reason for service user transition out of CSTDA-funded service type outlets; for example, factors relating to the service type outlet's operations (e.g. budgetary issues) or changes in service user needs and circumstances (e.g. increased support needs, moving to a new area); • whether or not the service user received support on the 'snapshot day', which enables comparability with data from previous snapshot day collections (i.e. continued trends) and an evaluation of the success of the new CSTDA NMDS collection. <p>All of the above information on service type received, quantity of service type received, transition, etc., can be described according to service user characteristics such as age, sex, Indigenous status, disability, individual funding status, etc.</p> <p>For each service type outlet:</p> <ul style="list-style-type: none"> • the number of service users receiving support in a year (for many service types); • the staff hours (both paid and volunteer), which enables analysis of staff hours allocated to each CSTDA service type, average staff hours per service user, etc. (for some jurisdictions estimates based on actual hours in a week).

(continued)

Table 2.2 (continued): Information to be available from the CSTDA NMDS collection, compared to the stated information needs of NDA

Information needs of NDA as reported to AIHW in 1999–00	Information available from the CSTDA NMDS
<p>From whom was it received—details of the funded agency, e.g. size in terms of caseload, staff profile and hours; the agency’s role in the system, e.g. case coordinator or ‘secondary’ provider?</p>	<p>For each service type outlet:</p> <ul style="list-style-type: none"> • service type funded; • total CSTDA funding*; • size—in terms of total service users per year, service users receiving support on a ‘snapshot’ date (i.e. an ‘as at’ count), and in terms of staff levels (both paid and volunteer); • operation patterns (e.g. days per week, weeks per year); • location (postcode and Statistical Local Area); • agency sector (e.g. government or non-government); • indications of service user turnover. <p>Service type outlets can be related to funded agencies (i.e. a funded agency is an organisation that delivers one or more CSTDA service types).</p>
<p>For how much (in terms of cost to government)?</p>	<p>How government funding is distributed across CSTDA service types.</p> <p>Average CSTDA funding (i.e. government funding contribution) per: service type outlet*, staff hour (for some jurisdictions estimates based on actual hours in a week), service user (most service types), service quantity (many service types).</p> <p>How much government funding was directed to the government vs non-government sector.</p>
<p>With what outcome?</p>	<p>Outcome indicators are available for Commonwealth employment services (e.g. duration of employment, hours per week of employment, etc.).</p> <p>A ‘Participation module’ is included in jurisdiction materials for use by interested jurisdictions (by a variety of means during normal agency processes). Individual service user outcomes, such as those available by asking people about their extent of and satisfaction with participation in a variety of life areas, are not, however, available from the CSTDA NMDS.</p> <p>Service-specific outcomes, such as percentage of accommodation support clients living in community settings, were not endorsed for inclusion as part of the CSTDA NMDS. The process of developing such draft indicators was, however, useful in defining the scope of essential data items for inclusion in the final CSTDA NMDS collection.</p> <p>(See Section 8.4, Chapter 8 for further details)</p>

* Jurisdictions have agreed to provide CSTDA funding at the funded agency or service type outlet level, depending on the nature of funding agreements with agencies.

Box 2.2: Types of questions that can now be answered using the CSTDA NMDS

Service users

- *How many people were supported by CSTDA-funded agencies in the last financial year?*
- *How many of these people were reported to have an intellectual or psychiatric primary disability?*
- *How many of these people were reported to have both an intellectual and a psychiatric disability?*
- *How do the people supported by CSTDA-funded agencies in the last financial year compare with those identified as having a disability in the ABS Survey of Disability, Ageing and Carers?*
- *What proportion of service users moved out of CSTDA services in the last financial year? What were the main reasons service users left CSTDA-funded agencies? How does this compare with previous years? How many people left to take up mainstream services?*
- *What CSTDA service types were accessed by people with individual funding packages in the last financial year? What were the demographic characteristics of people with individual funding packages accessing services in the last financial year? How do these personal and service access characteristics compare with people who were not receiving individual funding packages?*
- *What proportion of service users accessed multiple CSTDA service types in the last financial year? What were the most common patterns of multiple service type use?*
- *How many CSTDA service users were living in institutional/residential accommodation this year compared with last year?*
- *How many CSTDA service users have an ageing carer (over 65 years) or one under 15 years? How does this compare with previous years? Does this differ across States and Territories?*
- *How many people received respite care under the CSTDA in the last financial year? What proportion of this support was in-home support vs out of home?*
- *What was the average number of hours of support received by people accessing in-home respite in the last financial year? How does this compare with the previous financial year?*
- *What was the support needs profile of people receiving in-home accommodation support compared with people receiving residential accommodation support? Employment support compared with learning and life skills development (i.e. day activities)?*

Service type outlets

- *What was the average CSTDA funding per service type outlet offering in-home accommodation support? How does this compare with the average CSTDA funding per service type outlet offering residential accommodation support?*
- *What was the average CSTDA funding per service user receiving centre-based respite support? How does this compare with CSTDA funding per service receiving in-home respite support or residential accommodation support?*
- *On average, what were the operating hours, days and weeks of respite services in the last financial year? How does this compare with learning and life skills development (i.e. day activities)?*
- *What were the average staff hours per week for service type outlets offering therapy support in the last financial year? How does this compare with the previous financial year? How does this compare with service type outlets offering early childhood intervention?*

3 CSTDA NMDS redevelopment project

3.1 Redeveloping the CSTDA NMDS

The process of redeveloping the CSDA MDS into the CSTDA NMDS was conducted in two stages of collaborative work involving the AIHW and the NDA:

- Stage 1: Preliminary CSDA MDS redevelopment project 1999; and
- Stage 2: CSTDA NMDS redevelopment and implementation project 2000–02.

This chapter provides some brief background to Stage 1 (Section 3.2), before focusing in more detail on Stage 2, the CSTDA NMDS redevelopment and implementation project, commencing in October 2000 (Section 3.3). The remaining sections provide details of the key activities and milestones under each of the redevelopment project plan components: project management (Section 3.4); data development and policy (Section 3.5); data transmission strategy (Section 3.6); and communication and training (Section 3.7).

3.2 Preliminary CSDA MDS redevelopment project 1999

In 1999, the AIHW was commissioned by the NDA to carry out the following work in relation to the CSDA MDS:

- a) An examination of recent and emerging changes to policies, funding arrangements and service structures, and their implications for administrators' data needs.
- b) A review of measures of 'support needed' and the development of nationally 'mappable' data items on client support needs.
- c) An examination of the main methodological issues facing each jurisdiction, including sampling and enumeration issues, and technological change.

In view of the Institute's charter and its role in the CSDA MDS collection since its inception, significant AIHW resources were also contributed to this 1999 phase of the redevelopment project.

The first step in establishing the information needs of national administrators was to distribute a comprehensive survey, developed by the AIHW in conjunction with a reference group, and completed by all jurisdictions, on behalf of the NDA. This was followed by six months of extensive consultation, analysis and an AIHW workshop attended by a range of NDA and other nominees. Following the November 1999 workshop, the key information needs of disability administrators were summarised by the AIHW as being:

- how many people were supported – and what were their characteristics and support needs;

- what was received – not just type of service, but some measure of ‘quantity’ of service provided by service type, e.g. staff hours, funding per consumer;
- from whom was it received – details of the service provider, e.g. size in terms of caseload, staff profile and hours; the agency’s role in the system, e.g. case coordinator or ‘secondary’ provider;
- for how much (in terms of cost to government, although there was also interest in the notion of ‘total cost’ to the service provider); and
- with what outcome. (March 2000 report to NDA, page 5-2) (See also Table 2.2.)

By March 2000, the AIHW produced a major report to the NDA, which included four main technical outputs:

- a list of potential data items for possible inclusion in the new CSDA MDS;
- a disability services information model;
- proposals for additional data development work, including specifying ‘outputs’ and counting rules, which would affect the collection methods; and
- suggestions for progressing the redevelopment, via refinement, field testing and implementation.

In the report, the AIHW presented two options for the timing of the CSTDA NMDS redevelopment. The options drew on input received at the AIHW–NDA workshop held in November 1999 and considered the need for data development (including indicators work), testing, communication and implementation, alongside the development of possible software tools.

- Option 1 presented a timetable providing for phased implementation over a two-year period. Full-year data from all agencies would have been available in late 2003. This was the preferred option of AIHW based on its past experience in project planning and implementation of data collections, managing and participating in data development and collection, communication with the field, and in the design and implementation of supporting software and systems.
- Option 2 presented a fast-tracked timetable for implementation, within just over 12 months from commencement. Full-year data would have been available in late 2002.

3.3 CSTDA NMDS redevelopment project 2000–02

Establishing the project plan and agreeing on timing

In response to the AIHW suggestions for progressing the redevelopment (in the March 2000 report to the NDA), administrators decided on a brief planning phase, involving all major stakeholders, to plan the detailed design, testing and implementation phases of the proposed redevelopment. A planning workshop, attended by major stakeholders, was held in April 2000. The goal of the workshop was to develop a project plan to turn the vision for a new CSDA MDS – the data set and the enhanced collation framework – into a reality for stakeholders. The workshop laid out the groundwork for a plan that ultimately comprised:

- details of the work needed and how it would be carried out: data development, including refining and testing data specifications and collection methods in the field; the

development of information technology tools; communication with and support and training in the field;

- recommended roles and a management structure for carrying out the work;
- estimates of resources for all aspects of the work;
- recognition of current or very recent work in jurisdictions and the AIHW which might assist speedy implementation; and
- a considered view on a feasible implementation timetable, considering the tasks to be done and the views of all stakeholders.

In terms of timing, the agreed project plan was a hybrid of Options 1 and 2. The plan aimed for ongoing collection by all agencies from April 2002, within 18 months of project commencement. National data, based on data entry over a quarter, would be available by September 2002. It was hoped that the data entered in one financial year quarter would provide details about all service users accessing CSTDA services in the 2001–02 financial year. Thus, depending on the success of implementation, the April–June 2002 quarterly data were to provide full-year client data. Full-year client data, based on a full year of data entry, would be available in late 2003.

Following the preliminary CSDA MDS redevelopment work and establishment of an agreed project plan, the NDA commissioned the AIHW to redevelop the CSDA MDS collection. The redevelopment project began in October 2000. As with Stage 1, the AIHW contributed considerable additional resources to the redevelopment project between 2000 and 2002.

In summary, in light of the strong demand for more comprehensive data on disability services and their clients, National Disability Administrators and the AIHW agreed to pursue an ambitious redevelopment timetable. The agreed project timetable meant that interrelated project components would need to be pursued simultaneously. For example, it was agreed that the development of a data transmission strategy (and possible software development) would need to commence prior to the completion of data development processes (such as the finalisation of data items and data collection guides and forms). Careful communication would be required with the field to provide satisfactory forewarning of proposed changes to data items. In practice, some of these interrelated activities created serious challenges for the jurisdictional departments responsible for implementing the redeveloped collection and for the field. In particular, jurisdictions found it difficult to commence software development prior to the availability of final data collection materials. By December 2001, the NDA therefore agreed to extend the project timetable, to commence ongoing collection from October 2002 (six months later than originally agreed).

The components of the CSTDA NMDS redevelopment project plan

The redevelopment process for the CSTDA NMDS was designed around four core interrelated components:

- project management;
- data development and policy;
- data transmission strategy; and
- communication and training.

Each of these components was to be progressed over time, in four main phases:

- Phase 1 – establishment and development;

- Phase 2 – field testing, communication and ongoing development;
- Phase 3 – ‘wrapping up’; and
- Phase 4 – implementation.

The exact timing of these phases changed during the course of the project, following the NDA decision in December 2001 to extend the overall timetable for redevelopment.

Work completed under each of the project components during the redevelopment is outlined in Table 3.1 and further details are included in Sections 3.4 to 3.7.

Table 3.1: Key milestones in the CSTDA NMDS redevelopment and implementation project, 1999–2002

	Project management	Data development and policy	Data transmission strategy (DTS)	Communication and training
March–May 1999	All jurisdictions surveyed about information needs and preferred collection methods			
March–October 1999		Detailed data development carried out		
November 1999		AIHW holds workshop with NDA nominees to assist in finalising preliminary work on redevelopment		
March 2000	AIHW reports to NDA on preliminary work for CSDA MDS redevelopment			
April 2000	Planning workshop (Melbourne) to develop an agreed project plan to redevelop the CSDA MDS			
April–September 2000		Decision and contracting processes		
October 2000	AIHW begins redeveloping the CSDA MDS			
December 2000	Facilitation and Implementation Group (FIG) nominated, and first meeting held (Canberra) AIHW develop draft privacy and data principles for FIG comment	Papers prepared for FIG meeting—data definition, management, communication, etc.	AIHW and NDA Liaison Group engage external consultants to research and advise on an appropriate DTS First DTS workshop held (Canberra) with all FIG members	Communication strategy developed
January 2001		AIHW complete Round 1 field testing in WA, NT, NSW, QLD and the ACT		First national communication newsletter released: 'CSDA MDS collection to be redeveloped' AIHW public and private web sites 'live'
February 2001		Indicator Development Workshop (Canberra)		
March–April 2001	2 FIG teleconferences held AIHW progress report to NDA (including report from external consultants on the appropriate DTS for the new collection)		Data transmission strategy report available (SMS)	Second national communication newsletter release: 'CSDA MDS redevelopment: field testing about to begin'

Table 3.1 (continued): Key milestones in the CSTDA NMDS redevelopment and implementation project, 1999–2002

	Project management	Data development and Policy	Data transmission strategy (DTS)	Communication and training
May 2001		AIHW and Disability Services Queensland (DSQ) conduct consumer discussion group for Round 2 field testing (Brisbane) AIHW trains NSW staff in Round 2 field testing procedures	Data transmission advisory group established to provide advice regarding software development	
May–June 2001	AIHW progress report to NDA—data development and policy, data transmission, and communication and training		Data Transmission Strategy (DTS) Workshop 1 (Adelaide)—to develop functional, environmental and implementation requirements DTS Workshop 2 (Adelaide)—to assess the merits of existing software tools, namely HACCC e-form and Western Australia’s ACDC	
July–August 2001	FIG meeting (Canberra) AIHW progress report to NDA—progress report, key features of field testing and software testing, live pilot, etc.	Round 2 field testing complete (AIHW testing with jurisdictions, jurisdiction testing with funded agencies, AIHW – jurisdiction testing with service users)	NDA liaison group teleconference—discuss the strategy for implementing the recommendations in the DTS report All jurisdictions agree to commence developing and testing optional software for use in April 2002 live pilot and beyond AIHW release the draft national Data Transmission and Technical Guide	
September 2001		AIHW complete draft national collection materials for Round 3 field testing		
October 2001		AIHW Ethics Committee approval obtained for draft Privacy and Data Principles AIHW attend, present and provide advice at Round 3 field testing workshop in the NT (Darwin)		Third national communication newsletter released: ‘CSDA MDS redevelopment: final testing starting soon’ (including all data items potentially in the new collection)
November 2001				Training strategy developed by AIHW in consultation with the NDA Liaison Group

Table 3.1 (continued): Key milestones in the CSTDA NMDS redevelopment and implementation project, 1999–2002

	Project management	Data development and Policy	Data transmission strategy (DTS)	Communication and training
November–December 2001	Series of FIG teleconferences—field testing, April live pilot, communication, data principles, timing, etc. AIHW progress report to NDA—project update, final proposed data items, implementation issues and risks NDA requests AIHW to provide a revised timetable following field testing. Timetable developed and agreed by all.	AIHW conduct Round 3 field testing workshop in ACT (Canberra) Round 3 field testing complete (jurisdiction testing with funded agencies and service users)		AIHW engage external training contractors (in consultation with NDA Liaison Group)
February 2002	FIG/Network teleconference—revised timetable, communication, 2002 snapshot collection AIHW progress report to NDA—suggested data items for inclusion in the 2002 snapshot collection	'Final' national materials available (i.e. from this point onwards, no changes are made to data items or codes in the Data Guide, forms, Data Transmission and Technical Guide, etc.)		Fourth national communication newsletter released: 'CSTDA NMDS redevelopment: Project timetable extended after completion of field testing' (included new timetable and final data items included in the CSTDA NMDS)
May 2002	FIG/Network teleconference—communication and training Final 'snapshot' collection for NSW, VIC QLD, SA, TAS, ACT and NT AIHW progress report to NDA			External training consultants complete training in each jurisdiction (for jurisdiction staff)
June 2002	Redeveloped CSTDA NMDS used in full-year collections by Commonwealth and Western Australia			Fifth national communication newsletter released: 'Redeveloped CSTDA NMDS now being introduced'
July 2002	FIG/Network teleconference			
August 2002		Final national materials available for jurisdictions and on AIHW web site		
September 2002	FIG/Network teleconference AIHW and jurisdictions finalise implementation plans and procedures			
October 2002	Implementation			

3.4 Project management

The redevelopment project was managed by a process reflecting the existing relationships between the Australian Institute of Health and Welfare, the National Disability Administrators, and the State, Territory and Commonwealth government departments responsible for disability services and the ongoing management of the CSDA MDS snapshot collections. The AIHW was the project manager for the redevelopment project, and its role, together with the other 'key players', is described in Box 3.1.

Throughout the redevelopment project FIG members attended two face-to-face meetings and eight teleconferences. In addition, most FIG members attended the face-to-face workshop on indicators and a number participated in two additional workshops to develop the national technical specifications following discussions on the data transmission strategy. The AIHW also visited all jurisdictions at least once during the redevelopment project to field test and/or to participate in jurisdiction training. The redevelopment project demonstrated clearly that, while teleconferences are a useful and efficient way to exchange information, they work best if complemented by periodic face-to-face meetings allowing multilateral discussions.

Box 3.1: The role of 'key players' in the CSTDA NMDS redevelopment project

National Disability Administrators (NDA)

NDA comprise the heads of government disability services throughout Australia. Having commissioned the redevelopment of the CSDA MDS, the NDA were responsible for making key decisions during the course of the project, including sign-off at key points during the project.

Australian Institute of Health and Welfare (AIHW)

The AIHW was responsible for project management, data development and the coordination of information technology development, communication and training. The Institute had ultimate responsibility for formulating recommendations, based on the input and advice of Facilitation and Implementation Group (FIG) members, for decision by the NDA.

Facilitation and Implementation Group (FIG)

A Facilitation and Implementation Group was established at the outset of the redevelopment project to provide advice and assistance to the AIHW. The membership of FIG comprised:

- *representatives from all jurisdictions with responsibility for advice, liaison, and a range of operational responsibilities for the redevelopment;*
- *three non-government and consumer representatives: one nominee each from ACROD and the National Caucus of Disability Consumer Organisations, and one non-government member of the National Community Services Data Committee, invited to join the FIG on the basis of individual expertise; and*
- *the core members of the AIHW project management team.*

The FIG was not a decision making body. Rather, the overall role of FIG members was to support the project in a range of ways ensuring that:

- *the right information was efficiently made available for use on the project;*
- *communication was effective; and*
- *the most appropriate people and organisations were involved in and informed about the redevelopment.*

The method of achieving these overall goals varied according to the membership role, as follows.

Members representing jurisdictions – these members were effectively jurisdictional coordinators or 'key facilitators', with responsibility for a range of operational tasks, including:

- *communication within their own jurisdictional administration and also with service providers in their jurisdiction;*
- *field testing in their jurisdiction, including facilitating appropriate NGO involvement;*
- *ensuring the timely development of new data processing systems;*
- *providing advice and information to project management – including locating the right people in each jurisdiction to respond to or undertake different tasks, and getting responses to AIHW back on time;*
- *ensuring jurisdictional input to the data transmission strategy; and*
- *acting as the conduit for communication within their own jurisdiction, including arranging mailouts to the field.*

Non-government organisation and consumer representatives – these members were to participate in FIG meetings, providing advice on all aspects of the redevelopment, including:

- *data needs of the sector;*
- *field testing (including suitable sites);*
- *data transmission strategies; and*
- *communication products and methods (for instance strategic use of existing channels of communication).*

Throughout the redevelopment project, the AIHW, as project manager, worked with:

- the FIG, in the first instance, developing a policy document detailing its roles and responsibilities (for NDA endorsement);
- the NDA Liaison Group, with representatives from Victoria, the Commonwealth and Tasmania. This group had the role of facilitating communication between the AIHW and the NDA, providing high level advice to the AIHW, and representing the NDA in the various sub-contracting arrangements required of the AIHW throughout the redevelopment (i.e. elements of the data transmission strategy and training were sub-contracted by the AIHW to specialist organisations);
- a Data Transmission Advisory Group, comprising FIG representatives from Western Australia, Queensland, Victoria and South Australia (in the middle stages of the project); and
- contracted trainers in the later stages of the project.

The AIHW role was overall project management, including to:

- organise, facilitate and document continuing communication and meetings with key stakeholders (FIG, NDA Liaison Group and the NDA);
- prepare a series of progress reports for the NDA;
- coordinate the preparation of national communication newsletters to the field;
- contract and manage two external consultancies, namely:
 - SMS Consulting to work with the AIHW and FIG to develop the CSTDA NMDS data transmission strategy and conduct a number of workshops to establish the key requirements of possible CSTDA NMDS software; and
 - Age Communications to develop training materials (based on AIHW technical collection materials) and deliver training to every jurisdiction.
- obtain AIHW Ethics Committee approval for the proposed privacy and data principles and procedures for the redeveloped CSTDA NMDS and coordinate the agreement of all jurisdictions to the proposed policies and practices;
- coordinate and participate in three rounds of field testing (see Chapter 4 for further details);
- coordinate comments in relation to various rounds of draft data collection materials for the redeveloped CSTDA NMDS; and
- monitor and encourage adherence to agreed timelines.

As indicated earlier, the redevelopment project timetable was extended in December 2001 following Round 3 field testing. In doing so, the planned April live pilot was dropped and the implementation of the redeveloped CSTDA NMDS was rescheduled to October 2002 instead of July 2002. This also meant that agencies funded by New South Wales, Victoria, Queensland, South Australia, Tasmania, the Australian Capital Territory and the Northern Territory were asked to participate in a final snapshot collection in May 2002. As in previous collections, agencies funded by Western Australia and the Commonwealth identified service users who were seen on a selected snapshot day in June 2002, as part of their full-year collections.

Table 3.1 (column 2) provides a timeline of the major project management milestones throughout the redevelopment project.

3.5 Data development and policy

The redevelopment project plan identified a number of key areas of data development work essential to the project. The main areas of work undertaken throughout the project are listed below together with references within this report for further information:

- developing data items and their definitions (Chapter 5);
- developing output and outcome indicators (Chapter 8);
- field testing (Chapter 4);
- developing privacy and data principles (Chapter 7); and
- preparing national materials for the CSTDA NMDS collection (Chapter 6).

A number of key data development and policy tasks were undertaken early in the redevelopment and implementation project. These included:

- the development of policy documents detailing FIG roles and responsibilities, data principles, the communication strategy and the field testing strategy;
- an indicators development workshop, with representation from all jurisdictions, as well as consumer and non-government representatives and a representative from the Productivity Commission (see Chapter 8 for further details relating to the indicators workshop);
- a draft CSTDA NMDS data dictionary prepared by the AIHW, with further work continuing on refining the data definitions contained within it; and
- the completion of Round 1 field testing by the AIHW (see Chapter 4 for further details).

From mid-2001, data items and key products were further developed, refined and tested, together with the associated concepts and collection methodology. Two rounds of field testing were conducted (Rounds 2 and 3) with funded agencies, consumers and jurisdictions (see Chapter 4 for further details). In December 2001, following Round 3 field testing, the NDA approved the recommended data items for inclusion in the CSTDA NMDS, service types, output quantity measures and the layout of all collection materials.

AIHW Ethics Committee approval was obtained in October 2001 for the draft Privacy and Data Principles for the CSTDA NMDS. These principles were placed in the public domain for comment and included in Round 3 field testing documentation (see Chapter 7 for further details).

Data development work in December 2001 to March 2002 focused on finalising the key CSTDA NMDS materials for use in the national training. The collection forms and Data Guide were finalised, and forwarded to the training contractors to incorporate into the training strategy.

Following the amendment of the redevelopment project timetable in December 2001, some extra data development work was undertaken to strategically use the final 2002 snapshot collection. Data items that appeared in previous snapshot collections and were modified in the redeveloped collection were included in the 2002 snapshot collection, as they did not require training, for example the reclassification of 'service types'. Introducing these revised data items enabled funded agencies to move forward towards the new collection. Strategic use of the 2002 snapshot collection also enabled 'staged' implementation of the redeveloped CSTDA NMDS collection while maintaining national consistency.

By April 2002 the majority of data development work was completed. All key materials and documents were in final draft and were 'frozen' during the national training sessions. The national training served as a 'reality check' on all CSTDA NMDS materials, and following the training a number of minor clarifications were made to the materials. The AIHW made a commitment to all jurisdictions that no data items, codes or specifications would change as a result of the national training. All collection materials were finalised and placed in the public domain in August 2002.

During this last phase all jurisdictions confirmed their commitment to the Privacy and Data Principles, by signing an undertaking of endorsement of the CSTDA NMDS privacy arrangements.

Table 3.1, column 3, provides a timeline of the major data development milestones throughout the redevelopment and implementation project.

3.6 Data transmission strategy

The area of data transmission was probably the most fluid at the outset of the redevelopment project:

- While it was clear that CSTDA NMDS data would be transmitted from agencies to jurisdictions, and from jurisdictions to the AIHW, the actual methodology for achieving this data transmission (including the possible development of a software tool and associated products and support tools) was still to be investigated.
- It was clear that the data transmission and data development components of the redevelopment project were intricately linked. That is, the data transmission strategy would need to align with the disability services information model and other data development work, particularly on organisational units and linkage keys. This would enable data to be collected from different (but specified) 'levels' within organisations and related (via linkage keys) to administrative data on agency funding, as well as the client and service profile of the related outlets. However, the work on organisational units and linkage keys had yet to be completed.
- The April 2000 planning workshop considered that the investigation and development of a data transmission software product was an intrinsic part of the CSTDA MDS redevelopment. However, there were varied views as to how nationally uniform it could be. Some jurisdictions indicated they would want to use their own specific software, while others argued the benefit to the non-government sector if there were a nationally uniform product (especially for large organisations working across a number of jurisdictions). Firming up on the parameters of a possible software product was therefore to be an early task of the project.

The work on data transmission was designed around eight major tasks, possibly to be revised pending an early NDA decision on the development of a software product or products. It was agreed that a consultant would be engaged by the AIHW to develop a data transmission strategy and present options for NDA consideration. Pending NDA decision, the remaining proposed tasks may need to be revised (i.e. some were only to be implemented if the NDA agreed that development of a software tool was required).

The eight key tasks for the data transmission component of the project were:

1. Develop data transmission strategy
2. Prepare tender specification for software
3. Select software developer
4. Develop and alpha test IT product
5. Refine and beta test IT product
6. Prepare documentation and learning products
7. Design and test central databases in each jurisdiction and in the AIHW
8. Implementation

In December 2000, the project management team, in conjunction with the NDA Liaison Group, engaged external consultants (SMS Consulting) to investigate and report on options for an appropriate data transmission strategy (DTS) for the CSTDA NMDS. An initial workshop was conducted and attended by all FIG members and the consultants to first define the term 'data transmission strategy' and then to discuss possible elements of such a strategy. Following the workshop the project consultants visited each jurisdiction to:

- gain an understanding of the jurisdiction's view of the 'organisational unit' level that will transmit data to jurisdictions;
- obtain an overall profile of the funded agencies and service type outlets, in terms of their use of information technology and information systems;
- gain an understanding of how jurisdictions currently operate, in terms of collecting and collating data from funded agencies, and in transmitting the annual data to the AIHW;
- identify any candidates for software systems that could meet with jurisdiction and/or funded agency/service type outlet needs nationally or across a number of jurisdictions; and
- discuss with jurisdictions any weaknesses, threats or risks in the data transmission strategy approach.

Following discussions with each jurisdiction and the AIHW, the consultants produced a Data Transmission Strategy Report. This report highlighted recommendations at each of the three possible 'levels' of data transmission involved in the CSTDA NMDS collection:

1. Data transmission between agencies and jurisdictions should be:
 - supported by the development of nationally consistent transmission software, based either on the Western Australian ACDC software, or on the HACC e-form. Advantages and disadvantages of both options were discussed and further exploration and costing of both options was recommended in the course of specifying national system and technical requirements;
 - further supported by information, training and other initiatives to enhance data quality; and
 - flexible and allow agencies to use other existing data collection and transmission methods, including paper forms, local IT and commercial IT solutions.
2. Data transmission between jurisdictions and the AIHW is 'best practice' but could be improved by:

- jurisdictions enhancing efforts to provide the AIHW with data conforming to agreed formats and edit checks; and
 - the AIHW providing jurisdictions with more formalised feedback about data quality.
3. Software support for information management and data transmission within and among agencies was also investigated but was not recommended for national development at this stage. It was, however, recommended that liaison with commercial software vendors be undertaken in addition to the general publication of technical specifications, so as to actively promote the development of suitable software.

In May 2001 SMS Consulting were re-contracted to work with FIG to:

- (a) develop a technical specification for data transmission of the redeveloped CSTDA NMDS between funded agencies and jurisdictions; and
- (b) assess the relative merits of existing software tools, namely the Home and Community Care (HACC) e-form and Western Australia's ACDC.

To assist the consultants with these tasks the Data Transmission Advisory Group, together with a number of funded agencies from Victoria and South Australia, AIHW project staff and software experts for HACC e-forms and ACDC, attended and participated in two data transmission workshops. Following these workshops the consultants produced a 'Technical specification and evaluation of data transmission tool' report. The report recommended that the NDA proceed with the development of a data transmission tool (or tools) and included advice about the appropriate steps required to progress successfully.

Guided by this report, each jurisdiction made decisions regarding the development of software for optional use by agencies when transmitting data to jurisdictions. At this time all jurisdictions reconfirmed their commitment to accept paper transmission and align forms with the national specifications.

To test software tools, it was proposed that for all jurisdictions, except the Commonwealth and Western Australia, a full live pilot would be conducted in April 2002 and run for at least four weeks. A primary aim of the live pilot was to test data transmission tools and thereby enable refinements to the software and other materials to be made prior to full implementation in July 2002.

The development and testing of data transmission tools was the responsibility of each jurisdiction. A number of jurisdictions expressed interest in pursuing the Western Australian software tool (ACDC) for use within their State/Territory, while the remaining jurisdictions either modified existing tools or tendered to develop new tools.

During July 2001 the AIHW developed a draft national Technical and Data Transmission Guide. This guide was made available to all jurisdictions and placed in the public domain, so that any software development would be in line with the national CSTDA NMDS specifications.

Towards the end of 2001 the availability of data transmission software for the planned April live pilot became an issue. The AIHW, as project manager, proposed a shorter live pilot in April to reduce the burden on funded agencies that were adopting the software tools. It was however eventually agreed by the NDA to revise the project timeline and drop the April live pilot, allowing jurisdictions extra time to develop and test software products.

In the final phase of the project, jurisdictions (except for Western Australia and the Commonwealth, where updated software had already been introduced in June 2002) continued to develop and test data transmission software, develop technical help desk

arrangements, finalise supporting technical documentation and amend jurisdiction databases. A number of jurisdictions indicated that they would participate in a November test transmission, designed to test both software and the data transmission processes (i.e. between funded agencies and jurisdictions, and jurisdictions and the AIHW).

The major data transmission milestones throughout the redevelopment and implementation project are highlighted in Table 3.1, column 4.

3.7 Communication and training

The development of and commitment to a communication strategy throughout the redevelopment project was designed to facilitate consistent and effective communication with and support of the field during the redevelopment process. Ongoing communication with the field was considered essential to the project and was achieved primarily through the use of national newsletters and a central web site dedicated to the redevelopment project. Plans to deliver training to jurisdictions were also an important component of this area of work. They involved developing and carrying out a strategy and timetable that fitted with the other components of the redevelopment project (that is, data development, data transmission and project management).

In January 2001 a portal was established on the AIHW web site for the CSTDA NMDS redevelopment project (www.aihw.gov.au). This site contained a public area where up-to-date and project-specific information and materials were posted. A public discussion list was also developed, enabling funded agencies, consumers and carers who were unable to participate in field testing to provide feedback or comments on the redevelopment project at any stage. A private password-protected site was also created for project management purposes and was accessible to all FIG members. This site contained all meeting papers, their agendas and minutes, key project documents, project materials and an up-to-date contact list of all FIG members and the project management team.

Also in January 2001, the first national communication (i.e. 'newsletter') was agreed and distributed to the field by all jurisdictions, ACROD and the National Caucus for Disability Consumer Organisations, as well as being placed on the AIHW web site. This newsletter outlined why the redevelopment was happening, how it was going to happen and when.

The key communication and training tasks achieved during Phase 2 (October 2000 to December 2001) included:

- The release of a further three national communication newsletters. These newsletters were distributed by all jurisdictions, as well as ACROD and the National Caucus for Disability Consumer Organisations, and informed the field on topics such as: progress of the field testing and how funded agencies could become involved; the redevelopment timetable; details about the planned April live pilot; availability of training and resources; and contact details for the FIG. The newsletters kept the field advised of the data items for possible inclusion in the CSTDA NMDS and the final data items.
- Updating the public area of the AIHW CSTDA NMDS redevelopment web site to include all national communications, draft data principles and field testing materials. The FIG area of the web site was also updated to include copies of all meeting agendas, minutes, policy documents, etc.

- Developing and agreeing on a national training strategy, which involved engaging external training contractors, through a tender process, to develop appropriate training materials and methods for the CSTDA NMDS redevelopment.

There was an increased effort in the area of communication in December 2001. A fifth national communication was released advising funded agencies and the field of the new timetable, the revised dates of implementation and the need to conduct a final snapshot collection in mid-2002. As with previous communications, this newsletter was distributed by all jurisdictions and placed on the AIHW web site. The maintenance and updating of the web site continued throughout Phase 3 of the project, although the CSTDA NMDS discussion list was shut down following the completion of Round 3 field testing.

Following a tender process, the AIHW sub-contracted Age Communications to:

- develop, trial and refine data training and 'train-the-trainer' materials to be used in the implementation of the redeveloped CSTDA NMDS;
- design, trial and refine a two-day workshop process incorporating both training for data providers or the requirements of the redeveloped CSTDA NMDS (data training) and a 'train-the-trainer' component; and
- deliver data and 'train-the-trainer' training in each jurisdiction.

The bulk of this work was carried out between March and June 2002. Age Communications completed training in each jurisdiction in June 2002, having undertaken one-day training sessions for Western Australia and the Commonwealth, and two-day training sessions for all remaining jurisdictions. A range of jurisdiction staff, trainers and funded agencies attended these sessions, together with one or more representatives from the AIHW to respond to technical queries. All jurisdictions achieved the appropriate mix and level of attendance to meet their particular needs.

Following the national training sessions, each jurisdiction delivered training to their funded agencies. Training in some jurisdictions involved a 'road show' and workshop sessions, and in others, one-on-one training. It was envisaged that by October 2002 all funded agencies would have received some form of training in the redeveloped CSTDA NMDS collection.

The AIHW continued to update the AIHW public and private redevelopment web site. For example, all key collection materials (the Data Guide, forms, Data Transmission and Technical Guide, national training materials and Data Dictionary) were placed on the public web site. The Network Guide was placed on the private web site.

It was agreed in August 2002 that national newsletters were no longer needed and jurisdictions took responsibility for further detailed communication with funded agencies.

The major communication and training milestones throughout the redevelopment project are highlighted in Table 3.1, column 5.

4 Field testing

4.1 The purpose of field testing

Three rounds of field testing were undertaken during the redevelopment project, including testing with jurisdictions, funded agencies and service users. The overall aim of the field testing was to test:

- the meaning and relevance of the proposed data items in the field; and
- the feasibility of their collection.

For example, field testing with funded agencies enabled the project team and funding departments to gain an understanding of the business rules and practices of agencies, their data collection methods, current business and information technology systems, and the potential impact of the new data collection proposals. Testing with service users focused on the meaning and relevance of the proposed data items as well as seeking advice on the feasibility and acceptability of collecting proposed data items.

Field testing performed a vital role in each of the highly interrelated project components by, for example:

- informing data development (both data items and data principles for the redeveloped collection);
- facilitating communication between the major stakeholders in the project;
- enabling further information to be gathered about appropriate methods of data transmission; and
- enabling the AIHW and FIG to provide sound advice to the NDA about the redeveloped collection.

Field testing materials were developed by the AIHW in consultation with the FIG.

4.2 Round 1—preliminary field testing

Purpose of Round 1 field testing

The purpose of the Round 1 field testing was to:

- refine the list of data items developed in the preliminary stages of the CSDA MDS redevelopment project;
- obtain an understanding of agency systems and what ongoing collection and full-year service user numbers would mean to them; and
- obtain an understanding of the context in which any data transmission products would operate.

It was anticipated that the results from Round 1 field testing would refine the data items and collection materials before more extensive testing in Round 2, which would involve a wider range of CSTDA-funded agencies and jurisdictional staff.

Methodology of Round 1 field testing

Round 1 field testing began in September 2000 and was completed in February 2001. The field testing involved AIHW project staff visiting a small selection of funded agencies within a number of jurisdictions (in total, 22 funded agencies across five jurisdictions). The jurisdictions involved in the field testing were responsible for identifying funded agencies for participation. Jurisdictions sampled across:

- metropolitan, regional, rural and remote locations;
- agencies with different service types and sizes;
- government and non-government funded agencies; and
- funded agencies with specific issues affecting service users of diverse cultural and linguistic backgrounds and Indigenous origin.

For the purpose of Round 1 field testing the AIHW developed a short questionnaire in order to obtain a general understanding of:

- what information funded agencies need and use;
- how funded agencies handle information (i.e. obtain, record, store, update and retrieve it); and
- whether there are new service delivery models in use within the field and how they relate to funding arrangements.

The responses obtained from each visit were collated into an overall report on Round 1 field testing which informed the direction of data development and Round 2 field testing.

Main outcomes of Round 1 field testing

The first round of field testing provided valuable information, not only giving AIHW project staff a better understanding of agency systems and issues, but also in gathering ideas for the content and methodology of the redeveloped CSTDA NMDS collection. For instance, it became clear that throughout the project it would be possible to:

- build up a picture of agency practice, including in paper systems, to indicate how full-year client data can be produced without massive agency systems redesign; and
- develop ways of encouraging funded agencies to use the CSTDA NMDS data items on their administrative forms – to promote data quality and consistency throughout the process.

It also became clear that collection of certain data items, such as health condition/ diagnosis of service users, was unlikely to be feasible. All agencies visited in Round 1 felt that it was too difficult to collect accurate medical diagnoses from clients. This was either because a medical diagnosis had not been given to the agency or because agencies believed that asking clients about their diagnosis may be too intrusive. (For more information on the progress of specific data items following Round 1 field testing, see Chapter 5.)

4.3 Round 2—first pilot field test

Purpose of Round 2 field testing

The key objectives of Round 2 field testing were to:

- examine data collection methodology in each jurisdiction and in a range of funded agency environments within each jurisdiction; and
- discuss issues surrounding a range of key data elements via ‘reality testing’ with funded agencies and service user discussion groups.

During this round of field testing, beginning in July 2001, new data items were thoroughly tested nationally using standard materials developed by the AIHW. Information was also gathered about the current state of agency information systems and ways of minimising the impact of the redevelopment on administrative systems. Round 2 field testing also investigated the likely impact of planned changes on jurisdictional systems.

Methodology of Round 2 field testing

Three types of field testing were conducted in Round 2, along with an additional strand of data development, relating to outcome indicators:

- Jurisdiction field testing with funded agencies
- AIHW field testing with jurisdictions
- AIHW and jurisdiction field testing with service users
- Outcome indicators development (service-specific and service user outcomes)

All Round 2 field testing materials were developed by the AIHW, with input from the FIG.

Jurisdiction field testing with funded agencies

Each jurisdiction was responsible for identifying funded agencies to participate in field testing, sampling agencies with a wide range of characteristics, including service type. The majority of jurisdictions conducted face-to-face interviews with funded agencies using a standard questionnaire developed by the AIHW. Issues discussed included:

- funded agency details and information management practices, such as:
 - definitions of outlet/service provider/organisation;
 - ability to provide information according to CSTDA NMDS service types;
 - current information management practices;
 - preferred data transmission methods; and
 - technology use and experience.
- a wide range of data items and concepts, such as:
 - numbers of service users over time and at points in time;
 - quantity of service for all service types;
 - indicators of support need for service users;
 - residential setting and living arrangements;
 - informal carer arrangements; and

- unmet needs of service users.

Two jurisdictions that did not conduct face-to-face interviews for Round 2 field testing, instead opted to gather feedback through information sessions involving groups of funded agencies.

AIHW field testing with jurisdictions

AIHW project staff conducted interviews with each jurisdiction using a standard questionnaire. The interview was designed to obtain a more comprehensive understanding of the processes involved in preparing and running CSTDA MDS collections in each jurisdiction, as well as exploring specific data development issues such as:

- service-related questions, including:
 - service type classification (and related output measures);
 - organisational unit level;
 - unique agency identifier;
 - CSTDA funding; and
 - agency role and sector.
- service user-related questions, including:
 - labour force status;
 - location of outlet (i.e. postcode and Statistical Local Area (SLA));
 - location of service user (i.e. postcode and SLA); and
 - main reason for cessation of services.

AIHW and jurisdiction field testing with service users

The AIHW, in conjunction with Disability Services Queensland and the consumer representative on the FIG, organised and conducted a service user discussion session as part of Round 2 field testing. Two other jurisdictions held similar discussion sessions, each discussing the following data item issues:

- residential setting and living arrangements;
- informal carer arrangements;
- individual funding identifier;
- equipment and environmental modifications identifier;
- indicators of service user support needs; and
- service user participation.

Outcome indicators (service-specific and consumer indicators)

As part of Round 2 field testing, all jurisdictions provided input on suitable outcome indicators for the CSTDA program and commented on the associated data items and methods required in order to generate these outcome indicators. This input contributed to the subsequent development by the AIHW of proposed service-specific outcome indicators for all CSTDA NMDS service types and individual service user outcome indicators.

Main outcomes of Round 2 field testing

The results of Round 2 field testing enabled the AIHW and FIG to make recommendations to the NDA about data items for inclusion in Round 3 field testing (see Chapter 5 for further details) and to progress work on outcome indicators (see Section 8.4).

Following Round 2 field testing it was agreed that the following items should *not* proceed to Round 3:

- main language spoken at home;
- unmet needs;
- need for equipment or environmental modifications;
- agency role; and
- outcomes: consumer participation.

It was agreed that the following data items be included in Round 3 field testing:

- date estimate flag (to indicate that date of birth has been estimated and to assist in the accuracy of the linkage key);
- whether or not interpreter services are required for a language other than English (instead of main language spoken at home); and
- snapshot date flag (at least for the first collection, to provide a method for comparing previous data with the one-month data being provided in the planned April 2002 live pilot and full-year data to be provided from July 2002).

A range of clarifications were also incorporated into the Data Guide and other collection materials following Round 2 field testing.

Round 2 field testing confirmed that a flexible approach to the collection of national CSTDA funding data would be required. It was proposed from the outset that this information would be provided by jurisdictions, drawing from administrative or contract databases, rather than directly from funded agencies or service type outlets. Round 2 field testing revealed that relating CSTDA funding to service type outlets would be easy for some jurisdictions (e.g. Western Australia and the Commonwealth) where contracts are specifically designed in terms of CSTDA NMDS service types and harder for others (e.g. Victoria, where contracts are generally written in terms of service activities, which do not relate clearly to CSTDA NMDS service types). The continued use of block grants for some large organisations was a complicating issue for a number of jurisdictions.

Some more general issues were also raised following Round 2 field testing.

First was a twofold general reaction of funded agencies to the redeveloped CSTDA NMDS collection:

- on the one hand, funded agencies did not really seem to have absorbed the fact that the collection was to become ongoing, essentially from April 2002 when the live pilot was planned to commence. This identified the need for jurisdictions to ensure that communication newsletters were getting through to the appropriate people within funded agencies;
- on the other hand, there were also consistent comments about the need for funded agencies to be adequately supported and resourced for any new collection (for instance in terms of computers and training). This resulted in a recommendation to the NDA representatives to explore options in their jurisdiction for supporting funded agencies in the transition to the new collection.

Second, there was a keen interest in and awareness of issues surrounding consumer consent and the collection principles for the new collection. Both service users and funded agencies regularly raised the issue of consumer consent and the comments received were useful in refining the data principles for the CSTDA NMDS collection.

Third, a greater understanding was obtained of the information management methods currently in place as well as the preferred information management methods for funded agencies:

- the dominant information management method in all jurisdictions except Western Australia and the Commonwealth was paper based, sometimes in conjunction with local databases, usually in Microsoft Excel and less often in Microsoft Access. This reinforced the earlier findings in relation to the data transmission strategy, namely that the new collection would need to continue to support a variety of data transmission methods;
- the preferred method of transmission for agencies in most jurisdictions was data entry and transmission software, as long as the costs of such software (e.g. software, training and possibly hardware) were met by the funding department.

Finally, an indication was obtained of the proportion of CSDA-funded agencies that complete the HACC and the CSTDA minimum data set collections. The proportion of funded agencies sampled in Round 2 who also received HACC funding (and therefore participate in the HACC MDS collection) varied from 14% in New South Wales to 50% in the Australian Capital Territory and Queensland.

4.4 Round 3—second pilot field test

Purpose of Round 3 field testing

The goals of Round 3 field testing were to:

- confirm and refine the proposed data items in the new CSTDA NMDS;
- confirm their feasibility of collection; and
- refine their definitions and the wording of associated questions.

Methodology of Round 3 field testing

During Round 3 field testing (November 2001), funded agencies were asked to test the new CSTDA NMDS collection documentation by completing paper forms in relation to a small number of service users. Service user input was also sought during the testing.

Testing with funded agencies

Each jurisdiction was asked to sample CSTDA-funded agencies to ensure that those with varied service types, location, service user characteristics, etc, were included in Round 3 field testing. AIHW analysis of jurisdictions' sampling plans indicated that all service types were represented and a number of service types not adequately represented in Round 2 had been picked up in this field test.

The AIHW developed special field testing forms to enable funded agencies to complete forms, using the associated Data Guide. The field testing forms encouraged agencies to identify issues relating to questions, definitions, and response options, and whether or not

the information requested was routinely recorded and retrievable by funded agencies. Jurisdictions then reported to the AIHW using a specified reporting template.

Methods for undertaking Round 3 field testing varied nationally and included:

- inviting funded agencies to attend workshops based around Round 3 field testing materials;
- mailing out the field testing materials to funded agencies, asking them to complete the forms and mail them back; and
- conducting one-on-one interviews between the funding department and the funded agency, working through the field testing materials.

To maximise agency input, particularly in regional areas, jurisdictions were encouraged to use freecall telephone numbers and/or other accessible feedback methods.

Service user involvement

Three methods for obtaining service user input for Round 3 field testing were proposed:

- jurisdictions could ask agencies to fill out the service user forms in partnership with at least one service user and/or advocate during the field test (a question was included on collection forms to reflect whether or not this was done);
- jurisdictions could conduct service user groups to discuss the collection and forms; and/or
- jurisdictions could ask service user groups to field test with funded agencies and/or service users.

All States and Territories encouraged agencies to complete at least some test forms along with a service user and/or their advocate (i.e. Method 1).

Main outcomes of Round 3 field testing

The main outcomes resulting from Round 3 field testing revolved around two key areas:

- suggestions for improving the collection materials (i.e. Data Guide and collection forms); and
- timing and resources.

Collection materials

While no data items were deleted as a result of Round 3 field testing, the testing did result in a number of other recommendations to clarify data items and simplify and re-order questions on the forms and in the Data Guide.

For example, Round 3 field testing forms enabled funded agencies to record multiple service types for an individual service user on a single service user form. This method was designed to reduce responder burden and essentially mimicked the way a simple database enables a single service user record to be 'attached' to various service types received by the service user. On paper forms, this method in fact proved too complex to be helpful to agencies and was therefore not incorporated into the final collection materials.

Round 3 field testing also resulted in some modification to the range of data items requested for each service type. For instance, a range of service types such as therapy services for individuals, early childhood intervention and counselling would not be asked questions about the hours of service received by service users.

Following Round 3 field testing there were still some items or issues that were problematic where FIG consensus remained difficult. For the problematic data items or issues the AIHW proposed solutions based not only on jurisdiction input from Round 3 field testing but also on technical considerations. The AIHW followed the broad principle of national minimum data sets that a solution be found that is reasonable to all jurisdictions, rather than offering a 'state of the art' solution that is only possible for implementation in one or two jurisdictions. One motivation of the proposed solutions was to avoid the risk of overloading agencies and creating a situation where the entire collection is jeopardised by a small number of controversial data items. At the same time, the solutions represented progress in terms of the information available from the CSTDA NMDS.

The problematic data items or issues were:

- staff hours;
- quantity of service received by service users for each service type (i.e. service quantity measure);
- how to collect information about brokerage and individual funding (relates to questions on service type and individual funding flag); and
- total CSTDA funds.

The agreed solutions to these items are detailed in Sections 5.2 to 5.4 of Chapter 5 (staff hours and total CSTDA funds) and Section 8.4 (quantity of service received and how to collect information about brokerage and individual funding). Solutions were agreed with the possibility that they could be developed further or implemented across a broader range of service types over time.

Sections 5.2 to 5.4 detail changes and amendments made to the final data items as a result of Round 3 field testing. These changes, together with clarifications to the Data Guide, were made to the collection materials prior to national training.

Timing and resources

Following Round 3 field testing a number of jurisdictions expressed the concerns of their funded agencies about the proposed live pilot scheduled for April 2002. Through Round 3 field testing many funded agencies stated that they needed more time to amend collection procedures and prepare for the new CSTDA NMDS. In addition, a number of jurisdictions had experienced delays in developing appropriate optional CSTDA NMDS software for use by funded agencies. In light of these issues the National Disability Administrators asked the AIHW to revise the redevelopment project timetable, the proposed April 2002 live pilot was abandoned, and a new implementation date of 1 October 2002 was set.

4.5 Post field testing—national training

Between April and June 2002, each jurisdiction received training in the new CSTDA NMDS—both data item training and train-the-trainer training, which would enable them to train their funded agencies. In nearly all jurisdictions, a range of service providers and jurisdiction staff attended these training sessions. Training involved participants progressing through a data workbook of exercises, including case scenarios, using the Data Guide. Thus, the training sessions provided a final opportunity to test the clarity of data item definitions and explanatory text. Key collection materials were reviewed and explanatory text refined in light of this training experience.

5 Data item history and development

5.1 Possible data items for the redeveloped CSTDA NMDS

The CSTDA NMDS redevelopment project plan included a 'short list' of data items to be investigated for the redeveloped CSTDA NMDS. This 'short list' had been prepared by the AIHW following the preliminary redevelopment work in 1999, including the work on indicators for costs, outputs and outcomes. The 'short list' thus reflected the articulation by Disability Administrators across the country of what their key information needs were.

This chapter presents each of these initially proposed data items and details:

- whether they were included in the final CSTDA NMDS;
- for those that were excluded, when and why they were excluded from the final CSTDA NMDS; and
- any variations or major issues that arose for each data item during their testing and refinement.

The following sections present the final CSTDA NMDS data items according to whether they are 'service type outlet' data items (Section 5.2), 'service user' data items (Section 5.3), or 'services received' data items (Section 5.4). The final data items are presented in the same order as they appear in Table 2.1.

Further detail on a number of special data development areas is included in Chapter 8 (e.g. organisational units, support needs, and individual participation).

From August 2001 it was agreed by Disability Administrators that the terms 'client' and 'consumer' should be replaced with the more generic term 'service user' in all CSTDA NMDS documentation. The terms 'service type outlet' and 'funded agency' were agreed in late 2001.

5.2 Service type outlet data items

CSTDA NMDS data item	Shortlist data item	Data item history
Funded agency ID	Unique agency identifier	Concept included from Round 1 field testing onwards. Early discussion focused on the purpose of unique agency identifiers (i.e. whether the identifiers would be unique at a national level, unique within jurisdictions, or unique to the CSTDA funding sector). Development benefited from the work conducted for the Data Transmission Strategy. See Chapter 8 on organisational units for further details.
Service type outlet ID*	–	Concept included from Round 1 field testing onwards. Early discussion focused on the purpose of unique service type outlet identifiers (i.e. whether the identifiers would be unique at an agency level, a national level, unique within jurisdictions, or simply unique to the CSTDA funding sector). Development benefited from the work conducted for the Data Transmission Strategy. See Chapter 8 on organisational units for further details.
Service type*	Service provided	Included from Round 1 field testing. The definition and classification of ‘Service type’ also relate to work on indicators (i.e. in relation to outputs and outcomes). Initially there was discussion about classifying each service type delivered rather than each funded service type. See Chapter 8 on service type for further details.
Service type outlet postcode*	Location of agency/outlet	Included from Round 1 field testing onwards.
Service type outlet SLA		Included from Round 1 field testing onwards. This item is provided by jurisdictions, based on address details of service type outlets. It was agreed that all jurisdictions would aim to provide this data item over time.

CSTDA NMDS data item	Shortlist data item	Data item history
Funding jurisdiction*	Funding source category	<p>Funding source category was excluded from Round 1 field testing onwards. Funding source category would have collected information about whether funding was from CSTDA, HACC or other sources. However, it was considered that the funding source category may vary for service users for different service events. As the new collection would not be designed to support reporting of service events, funding source category was excluded.</p> <p>Funding jurisdiction was included from Round 1 field testing onwards.</p>
Agency sector*	Agency sector	Included from Round 1 field testing onwards.
CSTDA funding*	Provision of funding	Included from Round 1 field testing. This item is generally provided by jurisdictions rather than service type outlets. The goal is for funding to be provided for every funded service type (i.e. service type outlet).
Full financial year operation*	Whether operated for full financial year	Included from Round 1 field testing onwards.
Weeks per year of operation*	–	Included from Round 1 field testing onwards.
Days per week of operation*	–	Included from Round 1 field testing onwards.
Hours per day of operation*	–	Included from Round 1 field testing onwards.
Staff hours (reference week)*	Staff profile	A measure of staff hours was included from Round 1 field testing onwards (and has been included in the CSTDA MDS snapshot collection since its inception). Following Round 3 field testing it was agreed to include the two data items ‘Staff hours (reference week)’ and ‘Staff hours (typical week)’.

CSTDA NMDS data item	Shortlist data item	Data item history
Staff hours (typical week)	–	A measure of staff hours was included from Round 1 field testing onwards (and has been included in the CSTDA MDS snapshot collection since its inception). There was discussion of the most appropriate counting methods (e.g the interest of some jurisdictions in information about total hours over the reporting period, the difficulty experienced by agencies in estimating staff hours per CSTDA service type, the issue of direct vs indirect staff hours). Following Round 3 field testing it was agreed to include the two data items ‘Staff hours (reference week)’ and ‘Staff hours (typical week)’. ‘Staff hours (typical week)’ enables agencies to indicate that the reference week staffing profile may not be typical. This method also follows accepted survey principles. That is, more accurate data will be provided by asking agencies about an immediate period than by asking agencies to calculate an average over a whole reporting period. Even though the week preceding data collection may not be typical for all agencies, over the CSTDA agency population better averages will be available.
Number of service users*	–	Included from Round 3 field testing onwards. A key purpose of collecting this data item is to enable an estimation of the number of service users who ‘opt out’ of the CSTDA NMDS.
–	Agency role (funder, provider, purchaser, broker)	Refer to ‘Individual funding status’ and ‘Service type outlet ID’, ‘Funded agency ID’.
–	Care coordinator	Initially listed for consideration but dropped following the November 1999 AIHW –DSSC workshop.
–	Receipt of funding	Excluded following Indicators Workshop, where it was suggested that individual service event information would not be required in the redeveloped collection.
–	Capacity (of service type outlets/funded agencies, e.g. places)	This item was excluded following the Indicators Workshop as it was agreed that capacity was not an appropriate output indicator. The Victorian and Queensland 2000 snapshots also trialed this data item with little success.

CSTDA NMDS data item	Shortlist data item	Data item history
–	Location of service event	Excluded from Round 1 field testing onwards. This information is considered too onerous to collect. In addition, following the Indicators Workshop it was agreed that service event information would not be required from the redeveloped data collection (i.e. the collection would not be event-based).
–	Organisational level	The organisational level is identifiable at the service type outlet and funded agency level by using 'Service type outlet ID' and 'Funded agency ID'. Organisational levels are reflected in the data model that underpins all collection materials, particularly the Data Transmission and Technical Guide. See Chapter 8 on organisational units for further details.

* Data item included in the existing CSDA MDS.

5.3 Service user data items

CSTDA NMDS data item	Shortlist data item	Data item history
Record ID*	–	Included from Round 1 field testing onwards.
Letters of surname *	Statistical linkage key	Second, third and fifth 'Letters of surname' for statistical linkage key. Placed before 'Letters of given name' to align with the HACC MDS.
Letters of given name*	Statistical linkage key	Second and third 'Letters of given name' for statistical linkage key. Placed after 'Letters of surname' to align with the HACC MDS.
Date of birth*	Age (date of birth)	Included from Round 1 field testing onwards.
Birth date estimate flag	–	Included from Round 2 field testing onwards to resolve issues around missing parts of 'Date of birth'. The flag enables an estimation of age and enables analysts to distinguish actual from estimated dates of birth.
Sex*	Sex	Included from Round 1 field testing onwards.
Indigenous origin*	Indigenous status	Amended from Round 3 field testing onwards to adhere to ABS and NCSDDv2.0 standards for collection. These standards state that the response option for 'Not stated' should not appear on any primary data collection material.
Country of birth*	Country of birth	Included from Round 1 field testing onwards.
Interpreter services required		Introduced from Round 3 field testing onwards.
Communication method*	Method of communication	Included from Round 1 field testing onwards.
Living arrangements*	Living arrangements	Included from Round 1 field testing onwards. Proposals by some FIG members to include additional information on whether or not service users were able to choose their own house mates, and whether or not they live with other people with a disability, were not supported by the NDA.

CSTDA NMDS data item	Shortlist data item	Data item history
Service user postcode	Location of client	Included from Round 3 field testing onwards. Collection of further geographic detail (e.g. suburb, town, etc.) was considered for Round 2 field testing but excluded due to its sensitive nature.
Residential setting*	Type of accommodation	Included from Round 1 field testing onwards. The data response options relating to tenure (i.e. owner, renter, etc.) were removed following Round 3 field testing. There was considerable discussion about the definition of domestic scale dwelling. It was agreed that a maximum of six people indicated a domestic scale dwelling such as a group home.
Primary disability group*	Disability grouping	Included from Round 1 field testing onwards.
Other significant disability group*		Included from Round 1 field testing onwards.
Support needs*	Activity limitation (support needs)	Included from Round 1 field testing onwards. See Chapter 8 on support needs for further details.
Carer – existence of	Carer – existence of	Included from Round 1 field testing onwards.
Carer – residency status	Carer – co-resident status	Included from Round 1 field testing onwards.
Carer – primary status	–	Included from Round 2 field testing onwards. This data item enables information collected about informal carers to be related to population data collected by the ABS.
Carer – relationship to service user	–	Included from Round 2 field testing onwards as a result of AIHW work on service level outcome indicators. Although there was resistance from some service providers there was considerable interest in this data item from service users and administrators (e.g. funding directed to ageing carers) and it was agreed that the inclusion of this item would significantly enhance the outcome information available from the collection.

CSTDA NMDS data item	Shortlist data item	Data item history
Carer – age group	–	Included from Round 2 field testing onwards as a result of AIHW work on service level outcome indicators. Although there was resistance from some service providers there was considerable interest in this data item from service users and administrators (e.g. funding directed to ageing carers) and it was agreed that the inclusion of this item would significantly enhance the outcome information available from the collection.
Receipt of Carer Allowance (Child)*	Main income source	Following Round 3 field testing, the data item ‘Main income source’ was more clearly split into two separate data items (compared to existing CSDA MDS question). ‘Receipt of Carer Allowance (Child)’ is asked of service users aged under 16 years. ‘Main source of income’ is asked of service users aged 16 years and over.
Labour force status	Labour force status	Included from Round 1 field testing onwards.
Main source of income*	Main income source	Following Round 3 field testing, the data item ‘Main income source’ was more clearly split into two separate data items (compared to existing CSDA MDS question). ‘Main source of income’ is asked of service users aged 16 years and over. ‘Receipt of Carer Allowance (Child)’ is asked of service users aged under 16 years.
Individual funding status	–	Included from Round 2 field testing onwards. This item was initially included partly as individual outcome indicator. Following Round 2 field testing it was agreed that this data item should not be used for this purpose. It is included to enable an examination of, for example: what types of services individualised funding is 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.); and trends in the use of individualised funding over time.
–	Status in employment	Excluded from Round 2 field testing onwards as this data item was only considered relevant to Commonwealth employment services.
–	Full-time/part-time employment status	Excluded from Round 2 field testing onwards as this data item was only considered relevant to Commonwealth employment services.

CSTDA NMDS data item	Shortlist data item	Data item history
—	Main language spoken at home	<p>Excluded from Round 3 field testing onwards. In 2001, the Commonwealth Interdepartmental Committee on Multicultural Affairs (a committee managed by the Department of Immigration and Multicultural Affairs) produced <i>The Guide: Implementing the Standards for Statistics on Cultural and Language Diversity</i>. This Guide notes that there are four Minimum Core Set variables recommended by the ABS in order to collect consistent, comparable and accurate information on cultural and language diversity in Australia (Country of Birth of Person, Main Language Other Than English Spoken At Home, Proficiency in Spoken English, Indigenous Status). Not every variable is relevant to every data collection system. The Guide noted that one practical means of generating aggregate information about users and potential users of government services is to use the English Proficiency (EP) Country Groups, developed by DIMA (1996). EP Country Groups were developed based on two of the four Minimum Core Set variables (Country of Birth of Person and Proficiency in Spoken English). People can be assigned to an EP Country Group on the basis of the variable Country of Birth of Person. NDA therefore agreed to exclude the variables Main Language Other Than English Spoken At Home and Proficiency in Spoken English. It was also agreed to include a question to reflect whether or not a service user requires interpreter services.</p>
—	Proficiency in spoken English	<p>Excluded from all field testing, see 'Main language spoken at home'.</p>
—	Who assessed support needs	<p>Excluded from Round 2 field testing onwards. There was inadequate demand for national data given the extra burden on data providers and the current assessment framework in which they operate, agency record management practices and data development in this area. A data item to record assessment type was also considered but excluded from testing for the above reasons.</p>
—	Date of last assessment	<p>Excluded from Round 2 field testing onwards. There was inadequate demand for national data given the extra burden on data providers and the current assessment framework in which they operate, agency record management practices and data development in this area.</p>

CSTDA NMDS data item	Shortlist data item	Data item history
–	Participation restriction	Excluded from Round 3 field testing onwards. It was agreed that further development should be undertaken (outside the redevelopment project timeline) to develop and introduce the concept of a participation module for use by service providers and jurisdictions at various stages of normal service administration. See Chapter 8 on indicators for further details.
–	Impairment/condition /diagnosis	Excluded from Round 2 field testing onwards. Data items ‘body structure’, ‘body functions’ and ‘impairment extent’ were considered for inclusion. However, there was inadequate demand for national data given the extra burden on data providers and the current assessment framework in which they operate, agency record management practices and data development in this area. A data item for ‘Health condition/diagnosis’ was also considered but did not proceed to Round 2 field testing. ‘Health condition/diagnosis’ was considered too complex, unreliable and irrelevant in the CSTDA NMDS context. The concept for ‘health condition’ is also reflected in the data element for ‘disability group’.
–	Unmet needs	Excluded from Round 3 field testing onwards. It was agreed following Round 2 field testing that the CSTDA NMDS did not appear to be an appropriate vehicle for collecting this information, particularly given the lack of shared assessment and eligibility procedures across and within jurisdictions. There was scepticism about the value of the data that would result from the proposed unmet need question. The NDA acknowledged the value in improving understanding of unmet need for disability services.
–	Critical needs	Initially listed for consideration but dropped following the November 1999 AIHW-DSSC workshop.
–	Household structure	Initially listed for consideration but dropped following the November 1999 AIHW-DSSC workshop.
–	Family	Initially listed for consideration but dropped following the November 1999 AIHW-DSSC workshop.

CSTDA NMDS data item	Shortlist data item	Data item history
-	-	<p>Environmental/equipment modification flag</p> <p>Following the Indicators Workshop it was agreed to trial an 'environmental/equipment modification flag' in Round 2 field testing. The basis for its inclusion was that equipment is often provided as a part of services such as early childhood intervention, therapy, etc. It was suggested that there could be a 'flag' to indicate whether the consumer received equipment or environmental modifications that cost more than a specified amount (e.g. \$100), paid for by CSDA funding allocated to that provider. This could be included as a 'tick box' on the consumer form and would apply to all service types. The information provided by such a 'flag' might help explain why some consumers receive very few hours of service (i.e. assistance for some is mainly in the form of equipment/modifications).</p> <p>Excluded following Round 2 field testing because the complexities of asking for this information were considered to outweigh the benefits of having national information of this nature. This is considered an important area for further data development and jurisdictions should be encouraged to collect useful information on equipment and environmental modifications.</p>
-	-	<p>Service level outcomes</p> <p>As part of its data development work, the AIHW developed a set of service level outcome indicators. It was agreed that the development of the proposed service level outcome indicators had been a useful exercise in terms of highlighting a number of important data items for inclusion in Round 3 (e.g. reason for cessation of services, carer data items were subsequently included in the CSTDA NMDS). However, official endorsement of the service level outcome indicators was not seen as appropriate or necessary. It was agreed that the service level outcome indicators (e.g. trends over time in community vs other living arrangements, reasons for transition out of CSTDA-funded services) would not be included in any collection documentation. See Chapter 8 on indicators for further details.</p>

* Data item included in the existing CSDA MDS.

5.4 Services received data items

CSTDA NMDS data item	Shortlist data item	Data item history
Service start date	Client entry and exit	Included from Round 1 field testing onwards. Prior to Round 3 field testing it was agreed that agencies would not be required to provide historical data for this item (i.e. all existing clients could be recorded as having the new collection's start date as their service start date). Final collection materials provide agencies with a number of options for recording 'Service start date'.
Date service last received	–	<p>During Round 2 field testing agencies were asked whether they could identify clients who had been 'active' or 'on the books' during a given reporting period. This concept was designed to support the reporting of information about the number of active clients over time (i.e. given that jurisdictions have varying reporting periods, and the national collection is annual). This concept was excluded from Round 3 field testing.</p> <p>'Date service last received' was included from Round 3 field testing onwards. This data item allows 'active' status to be generated according to rules set by jurisdictions and/or nationally. It therefore avoids rigidly defining active status for all service types and reliance on artificial end dates (i.e. requiring service providers to enter a stop date if a service user has not received a service for three months).</p>
Snapshot date flag*	–	Included from Round 3 field testing onwards. This data item is essential to ensure continuity of data interpretation in years 2001, 2002 and 2003, despite the fact that each year's data will be collected on a different basis. It also enables comparability with (trends) data for previous snapshot day collections and an evaluation of the success of the redeveloped collection by, for example, allowing the extent of improvement in data to be documented.
Service exit date	–	Included from Round 1 field testing onwards.
Main reason for cessation of services	–	Included from Round 3 field testing onwards as a result of AIHW work on service level outcome indicators. That is, it was agreed that the inclusion of this item would significantly enhance the outcome information available from the collection.

CSTDA NMDS data item	Shortlist data item	Data item history
Hours received (reference week)	–	Service quantity measures were included from Round 1 field testing and discussed extensively at forums such as the Indicators Workshop. Round 2 field testing explored the possibility of collecting CSDA-funded hours per outlet for a service type or CSDA-funded hours per service user for a service type. It was subsequently agreed to test varied output quantity measures in Round 3 field testing. The proposed output quantity measures varied according to service type (e.g. number of people and duration of support for residential/institution, hours of service per service user for in-home accommodation support, and number of outlets funded for advocacy services). Following Round 3 field testing it was agreed to retain service quantity measures for a restricted set of service types. These service types would be asked about 'Hours received (reference week)' and 'Hours received (typical week)'. See Chapter 8 on indicators for further details.
Hours received (typical week)	–	As above for 'Hours received (reference week)'. This data item was included to enable agencies to indicate that the hours received by a service user in a reference week may not be typical. See Chapter 8 on indicators for further details.
–	Service purchase by client	Initially listed for consideration but dropped following the November 1999 AIHW-DSSC workshop.

* Data item included in the previous CSDA MDS.

6 Key products for the CSTDA NMDS

A range of collection materials or products has been developed to support the new CSTDA NMDS. The AIHW produces national versions of these collection materials, to which jurisdictions sometimes make minor variations or additions to meet local needs. It is agreed by all jurisdictions that any such changes or additions should always be consistent with, and should not jeopardise the collection of, the national CSTDA NMDS agreed by all jurisdictions and endorsed by the National Disability Administrators.

Each of the key products for the CSTDA NMDS is outlined in this section, along with details of their main purpose and audience. Copies of national materials can be obtained from the AIHW web site (www.aihw.gov.au/disability).

6.1 Data Guide

The Data Guide is for use by all funded agencies preparing data for transmission to jurisdictions. It can be used as a hard copy reference document for people filling out paper forms or entering data into data transmission software. Software developers are encouraged to include the contents of the Data Guide in software, to enable a funded agency entering data on a specific item to click onto information about the data item's definition and justification.

The Data Guide aims to provide adequate information in an accessible and relevant format without burdening the user with detail that is not needed. It includes sections which:

- explain the data collection methods and transmission requirements;
- outline the CSTDA NMDS Privacy and Data Principles and associated procedures (see also Chapter 7);
- present all data items in a simplified information model; and
- provide details of all data items, including question format, response options, guide for use, justification for each data item and examples of use in statistical reports.

6.2 Service Type Outlet and Service User paper forms

Paper forms, developed by the AIHW and updated each year, are made available to all jurisdictions for distribution to interested funded agencies. The forms are designed for use by agencies that do not wish or are unable to adopt software for the purposes of transmitting data to jurisdictions.

6.3 Data Transmission and Technical Guide

The Data Transmission and Technical Guide was developed to assist CSTDA-funded agencies to transmit data for the redeveloped CSTDA NMDS collection to the funding jurisdiction. It sets out technical requirements for data structure, essential for amalgamation of the data at a jurisdictional and national level. It is envisaged that this document will be used 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 CSTDA NMDS collections. The Data Transmission and Technical Guide is also a useful reference tool for people and jurisdictions developing software for agency systems. The Data Transmission and Technical Guide should always be read in conjunction with documentation for the redeveloped CSTDA NMDS collection, particularly the CSTDA NMDS Data Guide. It is recommended that agencies using this document contact their funding jurisdiction as local variations may be added to the national MDS.

6.4 Data Dictionary

The CSTDA NMDS Data Dictionary is a new feature of the collection. The Data Dictionary is a technical resource available to all contributors and users of the CSTDA NMDS collection (via the AIHW web site or on request from jurisdictions). The Data Dictionary is essentially a technical companion to the Data Guide and provides detailed data definitions for every data element in the new collection. The Data Dictionary has been prepared in accordance with international standards and is in the same format as the National Community Services Data Dictionary and the Home and Community Care (HACC) National MDS Data Dictionary.

The Disability Services Information Model, included in the CSTDA NMDS Data Dictionary, provides a high-level representation of the interrelationships between data items and concepts in the redeveloped CSTDA NMDS. The model is an important tool in understanding and retaining the logic of the data structures underlying the redeveloped CSTDA NMDS collection.

6.5 Network Guide

The Network Guide is intended for use by staff in Commonwealth, State and Territory Governments and at the Australian Institute of Health and Welfare who are directly involved with the coordination and running of the CSTDA NMDS collection (the 'Network'). The Network Guide includes sections on how to coordinate the data collection in each jurisdiction according to the agreed timetable, how to provide data for the national collation (e.g. file structures, cleaning procedures and transmission protocols within jurisdictions and nationally). As with other collection materials, the Network Guide aims to promote national consistency in the way CSTDA NMDS data are collected and to improve the quality of the data obtained from the collection. The Network Guide will be updated each year. (Note: this is the only one of the national materials that is not on the public web site.)

6.6 Training materials

National training materials were developed, based on the collection's technical materials, particularly the Data Guide and paper forms. The national training materials were developed to support the delivery of two workshops:

- Familiarisation Workshop – a 1.5 hour introductory session to the CSTDA NMDS collection.
- Data Item Workshop – a one-day workshop covering the technical application of the Data Guide to all of the redeveloped CSTDA NMDS data items.

The training materials comprise:

- Familiarisation Workshop slides;
- Briefing paper (outlining the background to the CSTDA NMDS and its redevelopment);
- Data Item Workshop slides;
- Data Item Workbook;
- Workbook Activities;
- Data Item Workbook Answers;
- Familiarisation and Data Item Workshops evaluation sheets; and
- Trainer's Guide.

These materials can be used by jurisdiction staff when training funded agencies and also by funded agencies wishing to train their own staff.

7 Privacy and data principles

7.1 Introduction

Preliminary work on the CSDA MDS redevelopment in 1999 established the importance of developing and refining data principles for the CSDA MDS collections in the course of the redevelopment. Final CSTDA NMDS Privacy and Data Principles are included in the CSTDA NMDS Data Guide, along with practical guidance for agencies about the ethical collection and transmission of service user data. Further privacy procedures are also included in the Network Guide, for use by jurisdiction and AIHW staff.

This chapter outlines the methodology for developing the collection's privacy and data principles, before presenting the principles themselves. The chapter closes with a brief summary of the additional procedural guidelines for funded agencies, jurisdictions and the AIHW.

7.2 Developing the privacy and data principles

The April 2000 planning workshop identified a number of issues that were likely to arise in the course of the CSTDA NMDS redevelopment project. For instance, the disability standards require that information not be sought from clients unless it is necessary for service delivery purposes. The workshop asked: Does the information have to be directly relevant to the immediate service? Or could it also be primarily of policy relevance to the funding body, which cannot justify its expenditure without being able to report on the information? Country of birth is an example of a data item where these questions could arise.

As a result, the project plan stated that issues such as these should be addressed by establishing operational data principles early in the life of the project. These principles could be expanded or revised in the course of the project. They would address:

- privacy and confidentiality principles;
- relevance;
- responder burden and the 'minimum' data set;
- consistency with jurisdictional reporting;
- national consistency, its benefits and the costs of changes to national standards;
- linkage keys and identifiers; and
- data ownership, transmission, storage and release.

These principles might influence what data items are required for different service types.

Relevant source material was identified and included:

- privacy legislation, including the *Privacy Act 1988* (and associated Information Privacy Principles) and *Privacy Amendment (Private Sector) Act 2000* (and associated National Privacy Principles);¹
- the Disability Service Standards; and
- relevant AIHW data policies.

Draft privacy and data principles, based on the above documents, were prepared for FIG comment in December 2000. Jurisdiction FIG representatives were asked to provide both general comment and to investigate the principles in relation to local legislation and procedures (e.g. departmental guidelines in relation to privacy). Following a number of rounds of comment, draft principles were placed on the public AIHW redevelopment web site for public comment in mid-2001. The draft principles were also included in the draft Data Guide, used in Round 3 field testing in late 2001.

7.3 The CSTDA NMDS Privacy and Data Principles

The CSTDA NMDS Privacy and Data Principles, as they appear in the final Data Guide, are included below. Further background detail, including extracts from source documents, is included in the Data Guide.

The privacy and data principles are drafted under three main headings: ethos; purpose and 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 CSTDA 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.

¹ During the course of the project, the *Privacy (Private Sector) Amendment Act 2000* was passed, with legislation effective from December 2001. This legislation extended the *Privacy Act 1988* (covering most government service providers) to non-government or private service providers. The CSTDA NMDS collection draws on data supplied by government and non-government disability service providers and is therefore subject to the eleven Information Privacy Principles (IPPs) for Commonwealth and Australian Capital Territory agencies and the ten National Privacy Principles (NPPs) for private (including non-government) providers. According to the privacy legislation, data collected under the CSTDA NMDS are health information and therefore personal information that is also sensitive in nature.

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.²
- 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 for 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 CSTDA 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.

² In accordance with AIHW Ethics Committee guidelines, each jurisdiction has provided written confirmation that:

1. Agencies participating in the CSTDA 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 them 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 <CSTDA 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 CSTDA-funded services you have the right to access your own files and to update or correct information included in the CSTDA NMDS 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. Any deviations from the standards are detailed below, including how alternative arrangements accord with relevant privacy legislation.

However this information is regarded as crucial to the effective delivery of the CSTDA 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 below.

Purpose and content

P1. CSTDA 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 CSTDA NMDS should contribute to the goals and objectives of the CSTDA.

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 CSTDA NMDS should be: based on national and international standards where appropriate; defined clearly, concisely and comprehensively; in accord 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 to the CSTDA NMDS items, especially where these 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 CSTDA 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 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; and
 - 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, i.e. securely stored and released in a non-identifiable form (see also previous footnote).

Q4. Dissemination and use

- Dissemination and use of the data should be in accord with these CSTDA 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 CSTDA 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. CSTDA service users).

7.4 Statistical linkage key

The statistical linkage key is made up of a number of components collected in the CSTDA NMDS:

- selected letters of surname;
- selected letters of given name;
- date of birth; and
- sex.

These components are combined into a 14-character key that is used in analysis to statistically reduce the incidence of multiple counting of service users across CSTDA-funded service types, and to enable an estimate of the actual number of service users at a point in time to be obtained. (Further information on the use of the statistical linkage key can be found in AIHW 2002a, Appendix 4). The statistical linkage key used in the CSTDA NMDS was initially developed for the Home and Community Care (HACC) Minimum Data Set.

The DSSC first discussed the statistical linkage key in relation to the CSDA MDS collection in June 1998. From these discussions it was decided to pilot test the linkage key in selected jurisdictions in the 1998–99 CSDA MDS snapshot collection

For the original pilot of the statistical linkage key in 1998–99, the AIHW prepared a submission to the Institute’s Ethics Committee for consideration. The Ethics Committee approved the submission subject to each participating jurisdiction providing written conformation that:

- the ‘information subjects’ (people with a disability who are the service users) will be informed about the information being recorded and its purpose.
- 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.
- 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.
- the information will be used only for statistical purposes and will not be used as a basis for any legal, administrative or other.

Following a successful pilot, the linkage key became an ongoing feature of the collection, and these conditions remained in place for all participating departments. All departments confirmed their conformity with these conditions, with variations depending on jurisdictional arrangements, particularly concerning client information and ‘opt out’ arrangements.

The linkage key has been an invaluable tool with the collection, not only for its original purpose of removing double counting and enabling more precise estimates of client numbers to be made – an essential capacity for analysis of the extensive new data in the redeveloped collections. It has also enabled analysis of patterns of multiple service use to be carried out (see AIHW 2002a). Moreover, the linkage key has identified some data inconsistencies in near-matching records, thereby enabling data quality to be enhanced.

The statistical linkage key is a probabilistic linkage mechanism, with a small but non-zero error rate. It is not a unique personal identifier.

7.5 Privacy procedures

The CSTDA NMDS Privacy and Data Principles were developed by the AIHW, in consultation with the FIG, to ensure that privacy issues are adequately addressed in the redeveloped CSTDA NMDS collection. This section provides a basic outline of the responsibilities of funded agencies, jurisdictions and the AIHW.

It is important to note that the people and organisations involved in the CSTDA NMDS collection are custodians of data provided by individuals and funded agencies. Thus, funded agencies, jurisdictions and the AIHW do not 'own' data. They are, however, responsible for the protection, storage, analysis and dissemination of the data in accord with the purposes for which they were collected as well as the principles of respect and fairness and the quality standards outlined in the CSTDA NMDS Privacy and Data Principles.

Responsibilities of funded agencies

It is the responsibility of each CSTDA-funded agency to inform every service user that data about them will be sent to the CSTDA funding department, and from there to the AIHW to become part of a national data set. 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 be used to affect entitlements.

Funded agencies are thus responsible for ensuring that all service users included in the collection are informed of their rights and shown the client rights statement (see footnote on page 58).

Responsibilities of jurisdictions

All jurisdictions have signed an undertaking agreeing to the privacy arrangements established for the CSTDA NMDS (see footnote on page 58 for an example undertaking).

Jurisdictions are also responsible for ensuring that:

- all jurisdiction staff involved in the CSTDA NMDS collection are familiar with the collection's Privacy and Data Principles, including the client rights statement and the jurisdiction undertaking;
- the CSTDA NMDS Privacy and Data Principles are included in the Data Guide sent to each funded agency;
- information about the principles and procedures is included in training for funded agencies;
- relevant State/Territory or Commonwealth legislation as well as local policies and procedures are referred to when responding to queries in relation to privacy and confidentiality; and
- data dissemination is carried out without compromising confidentiality.

Responsibilities of the AIHW

All AIHW staff with access to CSTDA NMDS data have signed a confidentiality undertaking, which is consistent with the *AIHW Act 1987* and the *Privacy Act 1988*. In addition to adhering to the CSTDA NMDS Privacy and Data Principles, the AIHW has its

own policy and procedures on information security and privacy. Excerpts from this document are provided in Section 6 of the Data Guide.

For jurisdictions as well as the AIHW, data dissemination must be carried out without compromising confidentiality. Cell sizes of less than 2 or 3 should be thoroughly vetted to see if they compromise confidentiality – at a national level they may not, but with small groups (e.g. disability groups or with jurisdictions) they may.

The AIHW may release national data, in response to special requests. The following protocols are observed in relation to requests for specific tables from the national database:

- Where national tables are requested from the AIHW, they are vetted to ensure that there are no small cell sizes and copies of the requested tables are sent to all jurisdictions.
- Where tables are requested that require a national breakdown by State/Territory, tables are sent to jurisdictions before going to the requestor.
- Where State/Territory-only tables are requested (i.e. jurisdiction-specific data), people are referred to the relevant jurisdiction for provision of the data.

Access to the national database is only provided under strict conditions. A potential researcher must make a formal request for access to CSTDA NMDS. This 'request for access' form is then forwarded to all contributing jurisdictions for approval. If approved by all jurisdictions the researcher will be able to access the data after signing the AIHW confidentiality undertaking signed by all AIHW staff.

8 Specialised data development areas

This chapter details some areas of data development that were particularly complex, interesting or fundamental to the final CSTDA NMDS.

First, the development and conceptual processes involved in the following data items or areas are discussed:

- service type, organisational units, agency identifiers and CSTDA funding (Section 8.1);
- disability and functioning (Section 8.2);
- support needs (Section 8.3);
- indicators of outputs and outcomes, including a trial participation module in which to record service user outcomes (Section 8.4);
- informal carer arrangements (Section 8.5); and
- feeding back into National Data Standards (Section 8.6).

Throughout the redevelopment project, the refinement of data items and concepts drew from a range of sources and processes. These included: the expressed information needs of Disability Administrators; extensive consultation with the FIG (including non-government representatives of service users and funded agencies); field testing (with funding departments, funded agencies and service users); and the development of an appropriate data transmission strategy and framework. The work undertaken in each of these areas was highly interrelated, with developments in one area feeding back to others.

8.1 Service type, organisational units, agency identifiers and CSTDA funding

Following the preliminary redevelopment work in 1999, the AIHW noted a range of agency characteristics for possible inclusion in the redeveloped CSDA MDS. The April 2000 'shortlist' included:

- service type – to indicate either the main funded service type or the service type actually provided by CSTDA-funded entities;
- organisational level – to show where in its own organisational structure an agency or outlet fits;
- unique agency identifier – to identify the agency in which provision of the service event occurred; and
- CSTDA funding.

Accurate classification of service types is fundamental to the redeveloped CSTDA NMDS, which has as its basic counting unit a 'service type outlet' (which, by definition, delivers one CSTDA service type from a discrete location). A realistic understanding of organisational levels existing in the field, in conjunction with agency identifiers to describe and locate these levels, is also essential to the redeveloped CSTDA NMDS, as it enables the collection to

incorporate maximum flexibility in the way funded agencies and jurisdictions collect, transmit and collate data. Such reporting flexibility is especially necessary in the case of funding data, which is available at various levels within jurisdictions.

This section outlines the conceptual work undertaken during the redevelopment project to develop these four interrelated data items.

Service type

A service type classification has been included in the CSDA MDS since its inception, to reflect the main service type each outlet was funded to provide under the CSDA. The CSDA MDS service type classification had evolved over time in an effort to reflect changes in funding methods and service delivery models. However, at the time of the preliminary redevelopment project in 1999, it appeared that the service type classification needed some revision to bring it into line with modern reality in the field. In addition, administrators expressed interest in exploring a service type classification that described *services actually provided or delivered*, rather than *main service type funded*.

The development of a robust new service type classification was critical to the new CSTDA NMDS for a number of reasons:

- It was always planned that the CSTDA NMDS would be a tiered information system, with varied information requirements for different service types. Thus, the classification of each service type outlet would have ramifications for the type of data collected.
- It was apparent from early on in the redevelopment that service types were likely to be intricately related to the data transmission unit and the work on organisational units. That is, it was hoped that organisations would be able to record information in relation to each service type they provide but be offered flexibility in terms of the organisational level that would transmit the data to the funding department.
- Work conducted in relation to service type was closely interrelated with work done in relation to outputs, outcomes and costs. For example, output measures were expected to vary according to CSTDA NMDS service type (e.g. while hours of service might be appropriate for some service types, it would not be for others). Administrators were also interested in improving information about cost per output.
- It was clear that the redeveloped collection needed to better reflect funding mechanisms such as brokerage and individual funding packages. It was not yet clear whether these funding mechanisms should be considered service types or funding characteristics or both.

In late 2000, jurisdictions were asked to provide information to assist the AIHW to review the existing CSDA MDS service type classification to incorporate changes in each jurisdiction and to explore its use as a *service provided* data item rather than as a way of categorising funding (i.e. *main service type funded*). The AIHW also explored the topic of service type (both funded and provided) with funded agencies in Round 1 field testing.

By early 2001, the AIHW had developed a draft revised 'service activity' classification – actually a revision of the sub-classifications of the eight main service types recognised in the Commonwealth/State Disability Agreement itself. The draft revised classification was prepared for discussion at an intensive two-day indicator development workshop held at the AIHW in February 2001. The indicators workshop aimed to make progress on the agreed priority of ensuring that the new CSTDA NMDS collection provide the NDA with national

indicators of output, cost and outcome. The draft revised 'service activity' classification was central to discussions of outputs and costs. The revised classification was designed to:

- allow jurisdictions to map the service types they fund to a national framework;
- be the framework for output indicators – client counts and possible service quantity measures – which could be related to data on government funding by service category; and
- allow CSTDA funding information to be obtained as an administrative by-product of jurisdictions' normal financial operations.

That is, the concept of service activity was intended to reflect *service provided* and to work in association with a separate classification for *main service type funded*.

Discussions at the indicators workshop provided important guidance on specific changes that could be made to the draft 'service activity' classification. It became clear at this time that separate classifications of *service provided* and *funded service type* would not be practical or useful. Future drafts of the service type classification therefore aimed to group like with like in a functional sense, to better reflect *funded service types*.

Jurisdictions advised that most funding agreements were in fact framed according to the service types or activities an agency was funded to provide. Where this was not the case (e.g. block grants), jurisdictions were generally aiming to modernise funding arrangements to clarify the purpose of CSTDA funding (in terms of outputs and outcomes per service type).

After incorporating comments from the indicators workshop the AIHW further revised the classification for funded service type, mapped it to each jurisdiction's local service type names (e.g. program names) and suggested output measures for each service type. In the Round 2 interviews conducted by the AIHW with each jurisdiction, staff were asked:

- to confirm whether the mapping of jurisdictions' local terminology to the national draft service type classification was correct;
- a series of generic questions. For example: 'Can the two categories "Family/individual case practice/management" and "Brokerage/direct funding/individual support packages" be combined or are there brokerage services that offer no case coordination? If an "individual funding package" flag is included in the redeveloped CSDA MDS, should direct funding and individual support packages still be collected as service types?'
- a series of specific questions which related to the way service types were funded and provided in their jurisdiction. For example, 'Does the NSW service type "Community Support Team – School Therapy" which focuses on school aged children, with the aim to link consumers with a wider range of supports, belong under the national service type "Therapy support for individuals" or "Early childhood intervention"?''
- to confirm the appropriateness of the suggested output measures for each service type (e.g. 'contracted hours' for therapy and early childhood intervention, number of funded places in a group home at a specified date).

Particular data development effort was focused in the service type areas of:

- family/individual case practice/management services and brokerage/direct funding/individual support packages. This was an effort to reflect services provided via Local Area Coordination and seek an appropriate method for recording the services delivered as a result of individual and flexible funding packages. For example, a range of

individual packages had emerged that included various combinations of coordination, brokerage and direct service delivery;

- information and referral services and how they relate to the provision of other services (e.g. respite, resources for parents and carers);
- the possible need for a new category for provision of 'financial and material assistance'. This would include, for example:
 - aids and equipment;
 - one-off payments;
 - assistive devices;
 - home modifications;
 - education fees; and
 - taxi subsidy schemes.

The service type classification and associated definitions were then revised, with FIG input, prior to commencement of Round 3 field testing.

The redeveloped CSTDA NMDS service type classification

The key definitions and collection methods of the CSTDA NMDS collection are outlined in Chapter 2 (see Box 2.1). Briefly, funded agencies are requested to provide funding departments with information about each service type they are funded to provide. Service type is defined as the 'support activity which the service type outlet has been funded to provide under the CSTDA' and a service type outlet is defined as 'the unit of a funded agency that delivers a particular CSTDA service type at or from a discrete location'. The new service type classification is critical to the new CSTDA NMDS collection which:

- has varied information requirements, depending on the service type funded (see Table 8.1);
- seeks separate information about every service type funded and the service users accessing each service type outlet. There is some flexibility in terms of whether organisations transmit information to the funding department directly from service type outlets or from funded agencies (on behalf of the service type outlets they operate);
- has varied output measures, depending on the service type (see Table 8.4, Section 8.4).

Table 8.1: CSTDA NMDS service type classification and information requested according to each CSTDA NMDS service type

Draft 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	All	All	All (except for data items on hours received—items 17f–g)*
1.02 Small residential/institution	All	All	All (except for data items on hours received—items 17f–g)
1.03 Hostels	All	All	All (except for data items on hours received—items 17f–g)
1.04 Group homes	All	All	All (except for data items on hours received—items 17f–g)
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 17f–g)
Community support			
2.01 Therapy services for individuals	All	All	All (except for data items on hours received—items 17f–g)
2.02 Early childhood intervention	All	All	All (except for data items on hours received—items 17f–g)
2.03 Behaviour/specialist intervention	All	All	All (except for data items on hours received—items 17f–g)
2.04 Counselling (individual/family/group)	All	All	All (except for data items on hours received—items 17f–g)
2.05 Regional resource and support teams	All	All	All (except for data items on hours received—items 17f–g)
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	All (except for data items on hours received—items 17f–g)
Community access			
3.01 Learning and life skills development	All	All	All
3.02 Recreation/holiday programs	All	Linkage key elements only (items 2a–2e)	None
3.03 Other community access	All	All	All

(continued)

Table 8.1 (continued): CSTDA NMDS service type classification and information requested according to each CSTDA NMDS service type

Draft 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/respite homes	All	All	All
4.03 Host family respite/peer support respite	All	All	All
4.04 Flexible/combo 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 17f-g)
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 17f-g)
5.03 Open and 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 17f-g)
Advocacy, information and print disability			
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 Print disability	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	All (except number of service users—item 7)	None	None

* The data item numbers (e.g. 17f) refer to the question numbers on the Service Type Outlet and Service User forms, the CSTDA NMDS Data Guide and the CSTDA NMDS Data Transmission and Technical Guide. See Appendix 1 for a copy of the collection forms and www.aihw.gov.au/disability for copies of the remaining CSTDA NMDS collection materials.

The special case of brokerage and individual funding

A key aim of redeveloping the service type classification was to facilitate improved collection of information about services provided via brokerage or individual funding. By December 2001, following Round 3 field testing, this remained one of the most complex issues for the project team. The issue was eventually solved using three mechanisms, as follows.

Individual funding status as a service user characteristic

In December 2001 it was agreed that a data item would be included to identify the 'individual funding status' of each service user. Collecting this information will enable an examination of, for example:

- what types of services individualised funding is 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.); and
- trends in the use of individualised funding over time.

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

Individual funding and brokerage as service type outlet characteristics

However, by December 2001 there had been no agreement across jurisdictions on how to specify service types relating to individual funding packages, brokerage, Local Area Coordination, individual case management, etc. Because of this lack of consensus, a very broad service type category, '2.06 Case management, local coordination and development', was trialed in Round 3. This broad service type category 'includes elements of individual or family focussed case management and brokerage as well as coordination and development activity within a specified geographical area... Brokerage is one method of purchasing appropriate supports for an individual and should be included in this category' (AIHW 2002c: 22).

The broad category appeared to have been confusing in some jurisdictions, due to the particular way they funded in this area. It was therefore agreed that the broad service type category '2.06 Case management, local coordination and development' be retained for national collation purposes, allowing jurisdictions who wish to split the category into sub-components to do so at a jurisdictional level (while supplying national data to the AIHW according to the agreed classification).

Counting rules for brokerage to avoid double counting

In addition, counting rules were agreed in order to avoid or limit double counting of services provided via brokerage (either service type 2.06 or other service types, where 'sub-contracting' arrangements were sometimes used). The following rules are included in the *CSTDA NMDS Data Guide: Data Items and Definitions 2002-03* (Box 8.1).

Box 8.1: Counting rules for individual funding and brokerage

Where agencies are funded separately and clearly to provide service type 2.06 'Case management, local coordination and development', service type outlets:

- *are required to record all service user details, including the hours received by the service user of **this** funded service type (i.e. number of hours it took for case coordination/ management, arranging purchase of appropriate services, etc.); and*
- *are not required to report on the services purchased/brokered/arranged on behalf of the service user for national MDS purposes (i.e. do not report the number of respite, therapy hours purchased or received etc.); and*
- *are required to record all service type outlet information, including staff hours relating to the case coordination/management/brokerage activities; and*
- *are not required to report on the staff hours needed by the agencies who provide the purchased/ brokered services (e.g. respite, therapy, etc.).*

The linkage key will enable analysis of the range of services provided within the CSTDA service system to any service user. Services purchased outside the CSTDA service system are not captured.

Sub-contracting within other CSTDA NMDS service types

Sub-contracting (sometimes and confusingly also called 'brokerage') can also exist within service types (e.g. in-home accommodation support provider sub-contracting provision of some in-home accommodation support to another agency, which may or may not be CSTDA-funded). In this case:

- *the funded agency/service type outlet that receives funding under the CSTDA is responsible for providing details about the service user and the service of this type that they receive. That is, it is up to the funded agency/service type outlet to gather service user information from the sub-contractor. The sub-contractor should be asked not to provide details of the hours received for this service user (of this service type), in their own CSTDA MDS data return, if also included in the CSTDA MDS.*
- *the funded agency/service type outlet would include the staff hours sub-contracted in their own staff hours allocation (and the sub-contractor outlet should not include these hours in their service type outlet return, if also included in the CSTDA MDS).*

Similar counting rules apply to recording staff hours relating to service type 2.06 'Case management, local coordination and development' or brokerage in a more general sense.

Organisational units, agency identifiers and CSTDA funding

It was envisaged that specifying an organisational level of an agency (e.g. overarching management level, funding management or accountability level, service delivery level, etc.) might allow the CSTDA NMDS collection to begin to deal with the structural complexity in the disability field. Funding data could be collected 'naturally', in respect of the entity receiving funding, whether a service type outlet or an agency higher up the chain, (i.e. increased flexibility in reporting). Many jurisdictions had expressed interest in collecting information on cost efficiency (cost per unit of output), which required answers to the questions:

- where do the funding dollars go? and
- what services are delivered for these dollars?

Specifying organisational unit level, in conjunction with suitable agency identifiers, would support the collection of such funding information. For example, if an agency identifier was constructed that included information on organisational level then, following linkage, the

fact that different organisations 'hook' their funding to different levels, could be accommodated in the model. This might also assist if there are any differences in the way jurisdictions define 'outlets', 'agencies', 'organisations', etc.

At the first FIG meeting in December 2000, the AIHW presented a draft classification of 'organisational units', recently developed by a national working group (the Organisational Units Working Group) for the health field. The draft classification defined organisational units at six levels: Enterprise Group, Enterprise, Management Unit, Establishment, Location and Units/Wards. The classification had been designed to be consistent with the definitions of business unit levels used by the ABS, and scheduled for revision in 2003. FIG members were asked to consider whether it could be adapted for the disability services field.

The AIHW also undertook a modelling exercise with the FIG to tease out the possible avenues through which funding dollars can travel before services are actually delivered. This included a discussion of the way in which outlets, sites, locations, organisations, agencies, etc, are defined in each jurisdiction. Jurisdictions were also asked to consider exactly what it is that they would like to know in relation to cost efficiency, and what they thought would be feasible to collect. This modelling exercise confirmed the AIHW understanding that:

- the predominant funding model within the CSTDA sector is for an administrative/financial entity to receive government funds and then (a) use them to deliver services or (b) distribute them among a number of outlets that deliver services; but
- there is a range of other models, some of which mean the jurisdiction has access to detailed service delivery information and some which mean the jurisdiction has only higher level funding information (i.e. the dollars cannot be explicitly related to service types or outputs) (see Figure 8.1 for examples).

This exploratory work was progressed at the first FIG meeting and then pursued further at the indicators workshop in February 2001.

In Round 2 field testing, the AIHW asked each jurisdiction to comment on draft organisational unit definitions (Box 8.2) and how closely they related to administrative reality in their jurisdiction. Staff were asked to comment on whether they could provide information in this way (e.g. service types for each outlet, outputs for each outlet, funding dollars allocated to organisations and how this relates to outputs at an outlet level). They were also asked about the value in developing a unique agency identifier.

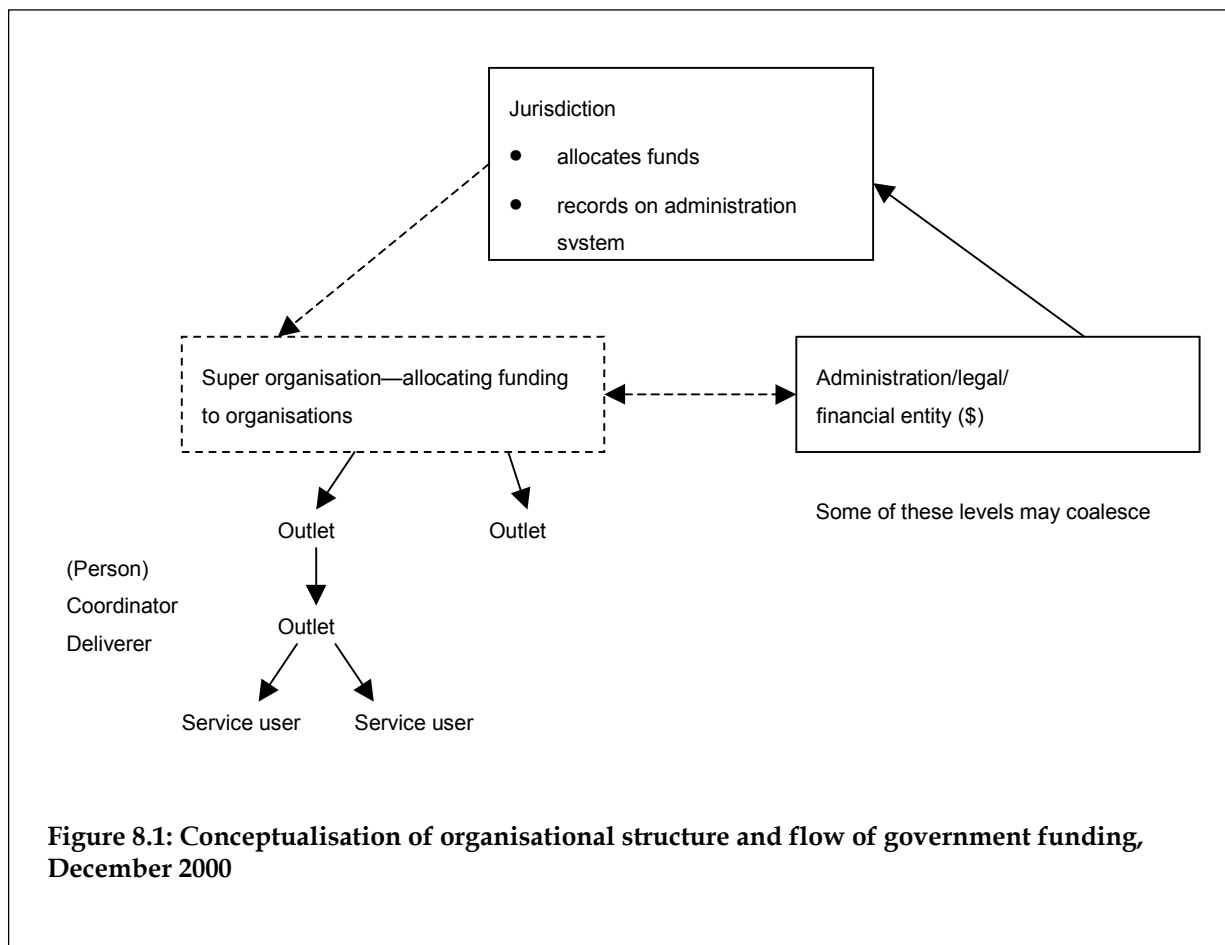


Figure 8.1: Conceptualisation of organisational structure and flow of government funding, December 2000

Box 8.2: Organisational unit definitions trialed in Round 2 field testing

Service outlet

A service outlet is a service provider providing a particular CSDA service type.

Service provider

A service provider is an agency that delivers one or more CSDA service types.

Auspicing organisation

Some service providers are part of a wider auspicing organisation – either non-government or government – that has some management control over the provider. Frequently this is the legal entity that receives government funding. The funding may come as a block grant, as output-based funding or as outcome-based funding (AIHW 2000a). In practice, the framework in which outputs are defined appears to be the CSDA ‘service type’ (AIHW 2000b) framework – that is, the auspicing organisation can relate the funding to a service type (outlet). There is a possible issue for some organisations receiving block grants where funding may not be clearly allocated according to service types.

Government funder (CSDA)

Government organisations that administer CSDA funds, and allocate them to NGOs, governmental entities (sometimes part of the funding department) to provide CSDA services, and to individuals to purchase services (AIHW 2000a).

It was pointed out at this stage that unique agency identification, including identification of whether the agency is an outlet, service provider (combination of outlets) or organisation (combination of service providers) may:

- assist jurisdictions to model interrelationships between agencies they fund;
- provide a method for increasing flexibility of data transmission; and
- enable easier mapping of CSTDA funding data (collected by the jurisdiction at one level, e.g. organisation) to related CSTDA service type and output information.

During this period, the AIHW and some jurisdictions also participated in a series of workshops to develop specifications for a possible CSTDA NMDS data collection and transmission tool. It was agreed by the NDA that developing unique agency identification within jurisdictions, relating to various organisational unit or agency levels, was essential in terms of supporting not only data transmission software, but also the collection methodology overall.

The August 2001 report to the NDA stated that there appeared to be three possible organisational unit levels:

- organisation (or sponsoring organisation);
- service provider (or management body); and
- service outlet.

These were similar to the organisational levels previously defined.

The new collection would require a set of related ID numbers so that these organisational relationships are recognised. This would enable the funding amounts to be collected in a way that relates simply to administrative reality, but still allows funding to be related to groups of clients. The ID for an outlet, for instance, would comprise (organisation ID) (management body ID) (outlet ID), with outlet ID defining both the service type and location of the outlet.

It was noted:

1. All three levels are not always present in any organisational structure. In any one structure either one or both of the top two levels may be redundant. Thus, it is possible to have one, two or three levels of management, for example:
 - an outlet is its own management body and there is no higher organisation involved, i.e. outlet = management body and there is only one entity (outlet);
 - there is no higher organisation, i.e. management body = organisation and there are only two entities (outlet and management body).
2. Funding can go to any level in the hierarchy, depending on jurisdictional arrangements. Agencies receiving funding are not asked to split funding to organisational levels lower than at which the funding is given by the funding department.

For instance:

- funding may go to an organisation/sponsor as a block grant; the new system will record this; the sponsoring organisation organises client data collection at outlet level and the funding is related to the whole client group 'under' that organisation; or
- funding may be given to a management body/service provider that provides a number of service types (e.g. accommodation and respite). If the funding body does not split the funds, the MDS system will not; the system will record the level and ID

of the body to whom the funds went, and the client data (at outlet/service type level) can be related (via layered agency IDs) to that package of funding. The same applies where one service type is provided at a number of different locations.

If funding systems become more refined (e.g. funding is provided closer to outlet or 'cost centre' level), the system can adapt immediately, as the funding is simply recorded at a new (presumably lower) level in the system.

The NDA agreed that each jurisdiction would establish an identifier structure to relate to their own administrative practice, within this national framework [ID structure being (organisation ID) (management body ID) (outlet ID)].

Funding data would then be transferred to the national collation from jurisdictions (rather than agencies). Jurisdictions could specify the IDs of recipient agencies in a way that includes the agency level and relationship to outlets. If a jurisdiction is funding outlets directly, this is straightforward and is reflected in the data.

Following further data development work and Round 3 field testing it was agreed to compress the organisational unit levels down to only two organisational units, as these better reflected reality in the field. The names of the organisational units were also amended to:

- service type outlet; and
- funded agency.

The names were amended to make it clearer that a service type outlet is an organisational unit that delivers one and only one CSTDA NMDS service type, and a funded agency is the organisational unit that receives the government funding.

The final definitions of service type outlet and funded agency are in Box 2.1 (Chapter 2). Data items for Service type outlet ID, Funded agency ID and CSTDA funding are all included in the CSTDA NMDS.

8.2 Disability and functioning

The April 2000 'shortlist' of data items for the redeveloped CSTDA NMDS reflected jurisdiction interest in exploring a range of data items to describe the functioning and disability profile of CSTDA service users. The 'shortlist' suggested that existing data items for 'disability group', 'method of communication' and 'support needs' be retained as well as exploring additional items such as 'health condition/diagnosis', 'impairment' (as defined in the International Classification of Functioning, Disability and Health (ICF)), 'who assessed support needs', 'what was the date of last assessment' and 'participation restriction'. As a set, these data items are relevant to information on support needs, service user outcomes, and to providing basic information about the person's disability – all stated information requirements of administrators.

The data items 'who assessed support needs' and 'what was the date of last assessment' were not included in the final CSTDA NMDS (see Chapter 5). The concept of 'participation restriction' was operationalised in both the support needs data item (see Section 8.3) and the participation module (see Figure 8.4). This section focuses on the development of the revised disability group data item (included in the final CSTDA NMDS) and the reasons why the data items 'health condition' and 'impairment' were not included in the final CSTDA NMDS.

Using the International Classification of Functioning, Disability and Health (ICF)

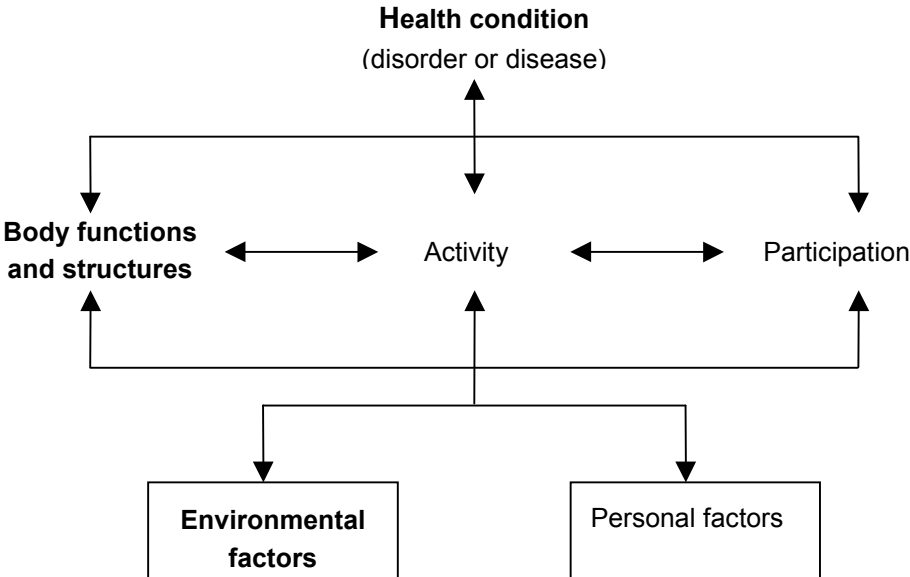
Throughout the redevelopment project, the ICF provided a useful framework for data development. In the ICF a person’s functioning or disability is conceived as a dynamic interaction between health conditions and environmental and personal factors (WHO 2001:6; and see Figure 8.2). Functioning and disability 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, or a restriction in participation.

In the case of developing possible new data items to describe the disability and functioning of CSTDA service users, the conceptualisation of disability and functioning in the ICF (Box 8.3 and Figure 8.2) provided a useful framework for illustrating areas where information was currently missing from the CSTDA NMDS.

Box 8.3: Overview of ICF components

- In the context of health:*
- Body functions** are the physiological functions of body systems (including psychological functions).
- Body structures** are anatomical parts of the body such as organs, limbs and their components.
- Impairments** are problems in body function or structure such as a significant deviation or loss.
- Activity** is the execution of a task or action by an individual.
- Participation** is involvement in a life situation.
- Activity limitations** are difficulties an individual may have in executing activities.
- Participation restrictions** are problems an individual may experience.

Source: WHO 2001.



Source: WHO 2001.

Figure 8.2: Interactions between components of the ICF

Disability group

'Disability group' is the name given to the common terminology used in the field to group people. The grouping is a broad categorisation of disabilities in terms of the underlying health condition, impairment, activity limitations, participation restrictions and environmental factors. Thus, 'disability group' is a one-dimensional representation of a multidimensional concept, 'disability'. The National Community Services Data Dictionary Version 2.0 (NCSDDv2.0) refers to it as 'the grouping that most clearly expresses the experience of disability by a person'. This alludes to the fact that many of these group names are self-identified.

Disability groups (e.g. intellectual, physical, psychiatric disability, etc.) have been included in the CSTDA MDS since its inception (as two data items, 'primary disability group' and 'other significant disability groups'). Along with information on 'support needs' and 'method of communication', 'disability group' has been used to describe the functioning and disability profile of the client population. Information on disability group is considered to have been useful to service users, service providers, administrators and researchers. In particular, this information enables an answer to be given to common questions such as 'how many people with physical disability (for example) access CSTDA services?' and 'how does this compare with the presence of people with physical disability (for example) in the general population?'

Considerable consultation and data development work was undertaken in 1999 and 2000 to refine the disability groups currently in use and ensure that they met the needs of key stakeholders. This work resulted in the inclusion of two new disability group data elements in the National Community Services Data Dictionary Version 2.0 (NCSDDv2.0) as well as a range of other data items to describe disability and functioning, and a comprehensive Disability Information Annex to the NCSDD (AIHW 2000c).

The consultation process re-confirmed that support groups for people with disabilities are often organised according to disability groupings. Common experience as well as a particular cluster of health conditions, impairments, activity limitations, participation restrictions and support needs is the key to the existence of these groups; people want and frequently request data relating to members of the group (AIHW 2000a). Further, the disability groupings have also been useful for providers of services to particular client groups with similar clusters of health conditions, impairments, activity limitations, participation restrictions and support needs. A service can employ people with a particular range of skills that matches the needs of the people with disabilities being supported (AIHW 2000a).

In the NCSDD two separate approaches are taken to grouping similar clusters of disabilities:

- Disability grouping – Australian national.
- Disability grouping – International.

The CSTDA NMDS 'disability group' is based on the updated NCSDD Disability grouping – Australian national (which, in turn, was based on the original CSTDA MDS disability grouping). 'Disability group' was tested in each of the three rounds of field testing and also benefited from considerable input during national training conducted in each jurisdiction. The final CSTDA NMDS Data Guide and Data Dictionary include additional explanatory text to assist service users and funded agencies to identify the appropriate disability group. For further detail about disability groups, also see the NCSDDv2.0, including the Disability Information Annex 4.3 (AIHW 2000c).

Health condition

Health condition or diagnosis was considered for the CSTDA NMDS, as it is relevant to people with disabilities and service providers and because diagnostic information and less 'broad' information than that provided by the current 'disability groups' was requested by administrators. The main reasons for considering the collection of 'health condition' were:

- it is collected in population surveys by the Australian Bureau of Statistics (ABS);
- it is often provided by funded agencies (i.e. at least some funded agencies appear to think in terms of 'health condition' rather than 'primary disability group' even though the primary focus of disability services is to provide support for daily living – for the outcomes of health conditions and environmental factors – rather than to focus on or simply treat the health condition); and
- it would enable more consistent mapping of health condition to various different groupings used in Australia (e.g. using health condition plus body function impairment to map to disability groupings used to assess eligibility for specific government benefits and pensions).

The AIHW investigated possible options for a data element on 'health condition' and an associated code list for use in the disability services sector. At the outset of the redevelopment project, it appeared possible that data developments in the Home and Community Care (HACC) program might be useful in relation to health condition. However, this did not prove to be the case.

At the beginning of the redevelopment project, a 'health condition' data element had recently been developed by the AIHW for the Aged Care Assessment Program (ACAP). The associated 'health condition' code list grouped International Classification of Diseases (ICD) codes in a way which would produce data comparable to the 'disabling condition' categories used in the ABS Survey of Disability, Ageing and Carers. The AIHW offered to adapt the draft ACAP health condition code list so that it elevated ICD codes of particular interest to the disability field. For example, the AIHW would include the conditions and syndromes that are currently forwarded to the AIHW through the CSDA MDS collections. Using an ACAP-like code list would result in a health condition code list relating to ICD groups, rather than disability groups (as per the AIHW grouping described above). Prior to commencing this considerable body of work, FIG members were asked to consider:

- *Why collect information on health condition?*
What questions does the collection of 'health condition' answer? How useful or important is this information at the national level? What are the costs and benefits?
- *The quality of data collected*
In the CSDA MDS snapshot collection, the option exists to provide health condition in addition to information on primary disability group. The following question appeared on the 2000 CSDA MDS service user form: 'If you had difficulty choosing the group for Primary Disability Group, please also write your (the consumer's) condition(s) here'. Bearing in mind that health condition was therefore not compulsory, the following data quality problems arose in the data provided:
 - health condition was provided but primary disability was not provided;
 - health conditions were misspelled in a wide variety of ways;
 - primary disability groups were listed under health condition (i.e. non-health conditions were included);

- where only health condition was provided, the AIHW experienced great difficulty in allocating CSTDA disability group codes, as these codes are a mixture of impairments and disability groupings, and can not be directly inferred from health condition alone.
- *The logistics of collecting health condition information*
As part of the development of the 'health condition' data element for the ACAP, extensive pilot testing was undertaken in the field. The reviewers found that there was concern about non-clinical staff coding health conditions, especially mental health conditions. In order to generate quality data on health condition, the reviewers made a series of suggestions about, for example:
 - the need to use a relatively detailed code list from ICD-10-AM (probably computerised), along with regular updating of that list;
 - the need for assessors to have knowledge of what is included in the coding lists so that they have the expertise to record the relevant information for coding;
 - the need for relevant clinical expertise and experience with relevant classifications; and
 - considerable training and implementation support.
- *The sensitivity of collecting health condition information*
Sensitivity may be a particular issue in relation to mental health and certain types of service provision.
- *Specific information issues relating to health condition*
Are we interested in pathology or manifestation, as there will be confusion unless specified? If manifestation, would Body function impairment be easier? How would the collection deal with multiple health conditions?

Following discussion with FIG it was agreed by the NDA that attempting to collect information about health condition was too complex, potentially unreliable and possibly irrelevant in the CSTDA NMDS context. The concept of health condition is reflected in the data element for disability group but not included as a data element in its own right. Health condition is no longer requested as supplementary information to primary disability group where the person completing the service user details has difficulty in allocating to a primary disability group.

Impairment

At the outset of the redevelopment project there was interest in collecting information about 'body function impairment'. Impairments are defined in the ICF as 'problems in body function or structure such as a significant deviation or loss' (WHO 2001:10). The NCSDDv2.0 offers specific data elements for Body functions and Impairment extent. The draft ACAP Data Dictionary V.10 also included a draft data element called 'body function impairment', which seeks to operationalise the NCSDD data elements.

It was considered possible that ICF impairment coding may be more useful than ICD-10 coding (i.e. health condition) for the purposes of the CSTDA NMDS because:

- agencies are more likely to be providing support on the basis of body function impairments, activity limitations and participation restrictions than health condition; and

- it might be easier for a funded agency (in conjunction with the service user) to identify functional impairments than the underlying pathology relating to a person's functional impairment.

As with 'health condition' the AIHW offered to undertake further work, based on the NCSDD and the ACAP data elements, to develop a suitable 'body function impairment' data element and associated codes list, for field testing. However, administrators agreed that there was inadequate demand for national data of this nature given the extra burden on data providers and current assessment framework and agency record management systems in place in the disability services sector. The concept of impairment is therefore reflected in the 'disability group' data item in the final CSTDA NMDS but not included as a data item in its own right.

8.3 Support needs

A national indicator of disability support needs has been included in the CSDA MDS since its inception in 1994.

In 1999, as part of an initial review of the CSDA MDS, the AIHW undertook a project aiming to produce:

- a review of measures of 'support needs', the findings being related to policies, practices and developments in Australia in the disability field and in other closely related fields, including the Home and Community Care (HACC) program;
- a presentation of options for data items which would encapsulate the main data needs and developments in Australia; and
- a discussion of each option in relation to its relevance, quality, reliability to other developments including HACC, and comparability to national and international developments in population measures of disability.

The 1999 'support needs' project was approached with the understanding that National Disability Administrators were interested in relatively high-level support needs indicators, to which the data items currently collected in 'local language' in each jurisdiction could be mapped. The project was not concerned with standardising the assessment of individuals at a local level but rather about clarifying the concepts used to describe people's support needs so that information gathered during assessment could be mapped up to a national indicator or indicators and used for national comparison.

The ultimate objective was therefore to develop options for a summary rating or indicator of support needs:

- which was comparable with population data, specifically data collected on individual support needs via the ABS Survey of Disability, Ageing and Carers;
- to which current State, Territory and Commonwealth practices, in as wide a range of services as possible, could be mapped;³ and

³ The goal was to reflect enough of the language used in each jurisdiction to ensure that jurisdictions could translate the scales they use into an overarching scale (i.e. that the various types of language could be meaningfully calibrated into an overall scale to which their input could be mapped).

- which would be consistent with current national data dictionaries and collections, to increase the potential for national comparability and reduce the potential for duplication in collection.

There were a number of constraints or factors to consider in the search for a 'support needs' framework.

Firstly, it was essential that any support needs framework relate to the definition of 'people with disabilities' in the 1998 CSDA:

people with a disability attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to be permanent and results in substantially reduced capacity in at least one of the following:

- self care/management
- mobility
- communication

requiring ongoing or episodic support. (CSDA 1998)

Secondly, as noted above, it was also critical that the support needs framework be comparable with population data. This constraint implied that the framework would probably need to be a general support needs indicator, rather than a service-specific support needs indicator. That is, the framework would aim to indicate an individual's overall support needs, rather than their support in terms of services required.

Finally, it was critical that the support needs framework relate as closely as possible to existing data standards and practice in the area of disability and related support services.

The AIHW therefore aimed for consistency with (and an ability to map to):

- the CSTDA definition of 'people with disabilities';
- the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (1998);
- the National Community Services Data Dictionary Version 2.0 (then in draft);
- the existing CSTDA NMDS (to a slightly lesser extent);
- tools currently in use in jurisdictions; and
- other major data collections, assessment tools, data development activities and concepts of relevance, wherever possible.

The methodology for the 1999 'support needs' project was a two-stage process. In stage one, the issues surrounding 'support needs' were explored by:

- reviewing relevant literature, including national and international data dictionaries and classifications;
- examining a range of relevant Australian data collections;
- investigating a number of well-known tools for assessing support need;
- analysing information provided by jurisdictions, detailing policy directions and the assessment tools and frameworks currently in operation or under development; and
- synthesising this information to elucidate the major issues for discussion at an AIHW-NDA workshop in November 1999.

As part of the work undertaken in stage one (1999–2000), a draft support needs data item was developed based on the life areas from the International Classification of Functioning, Disability and Health (ICF).⁴ In determining how to rate support needs within these life areas, the project team looked at the ABS Survey of Disability, Ageing and Carers as well as 21 assessment tools identified by jurisdictions as in common use to the field. In doing so the concepts ‘difficulty with activity’ and ‘assistance with activity’ were explored.

This work led to the recommendation that only ‘Assistance with activity’ be collected for the following reasons:

- the disability services involved in the CSTDA and its NMDS collection provide *assistance* to people with disabilities;
- there was a large information gap in assessment tools used in the field, in terms of the level of information collected about ‘Difficulty with activity’ (see Table 8.2); and
- the ABS survey assumes that difficulty is experienced if a respondent identified needing assistance with an activity. The ABS then only asks the subset of those respondents who did not need assistance whether they experienced any difficulty in completing the activity.

Using these findings, development of the support needs question progressed using the ICF life areas and the concept ‘Assistance with activity’.

Table 8.2: Relationship of tools currently in use to proposed data elements

Concept	Percentage of instruments and assessment tools using concept
Difficulty with activity	19
Assistance with activity—non-personal assistance (e.g. presence of aids/equipment/devices)	67
Assistance with activity—existence of or requirement for personal assistance (any scale, e.g. none/minimal/some/substantial, occasional/frequent/continual, independent/with assistance/dependent)	79
Personal assistance—hours per week (i.e. how much assistance in hours per week?)	10
Personal assistance—frequency of support (as per ABS, i.e. how many times per day, week, month?)	10
Personal assistance—intensity (staff ratio)	10
‘Intensity’ (as per ABS—always needs assistance, sometimes needs assistance)	52
Presence of carer	29

In stage two, the AIHW:

- undertook further research and analysis in accordance with the direction provided by the workshop; and
- developed a number of support needs data options for NDA consideration.

⁴ During the CSTDA NMDS redevelopment the ICF was endorsed by the World Health Assembly in May 2001; prior to this, an earlier draft of the classification was used (the International Classification of Functioning and Disability (ICIDH-2 Beta-2 Draft)).

The ICF was an essential tool during the process of developing the support needs framework (and the participation module discussed in Section 8.4). The redevelopment exercise demonstrated three general ways the ICF can be used:

- *as a framework* to organise thoughts and ensure that major factors of interest are not omitted from the final data item or minimum data set;
- as a set of classifications that can be used as a 'smorgasbord' from which to select the *domains* of most interest to stakeholders in the data that will be collected via the final data item or minimum data set; and
- to provide *qualifiers* that assist the researcher to select a measurement scale that is either directly related to an ICF qualifier or that ensures that the data collected will map to an ICF qualifier.

Further details of the way the ICF was used in developing the support needs framework can be found in the ICF Australian User Guide (forthcoming).

The work undertaken in the preliminary redevelopment project was subsequently advanced during the redevelopment of the CSTDA NMDS in 2000-02. The support needs framework was included in each of the three rounds of field testing and included in the final CSTDA NMDS (see Figure 8.3 below for a copy of the item as it appears in the CSTDA NMDS Data Guide).

A number of common themes emerged during field testing and were addressed in the final collection materials. For example:

- There was usually discussion about the appropriate level of detail in each of the selected life areas against which support needs are recorded. Often funded agencies and consumers would express a desire to describe support needs in relation to each component of a life area. That is, instead of being asked to record how often a person needs help or supervision in communication generally, some would prefer that this item separately ask about expressive and receptive communication. This desire possibly related to a continued misunderstanding that the support needs data item is an assessment tool (which it is not), rather than a framework into which the results of a range of assessments used in the field can be transcribed.
- There was also discussion about the breadth of information collected in the support needs question. That is, some jurisdiction staff and funded agencies felt that the number of life areas in which support needs information was requested was too broad. For example, some employment services reported that it was inappropriate for them to be recording information about life areas such as self-care or domestic life. Again, this probably relates to difficulties in promoting the function of the support needs data item, as a tool to relate the needs of CSTDA service users to those of the general population. Historically, the support needs question has been a critical item in terms of answering very important questions about the needs of people currently accessing CSTDA services, particularly in relation to the rest of the population. (This has apparently become less of an issue as case-based funding tools for employment services now cover the majority of these areas.)

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

The person can undertake activities or participate in this life area with this level of personal help or supervision (or would require this level of help or supervision if the person currently helping were not available)	1) Unable to do or always needs help/ supervision in this life area	2) Sometimes needs help/ supervision in this life area	3) Does not need help/ supervision in this life area but uses aids or equipment	4) Does not need help/ supervision in this life area and does not use aids or equipment	5) Not applicable
a) Self-care , e.g. washing oneself, dressing, eating, toileting					
b) Mobility , e.g. moving around the home and/or moving around away from home (including using public transport or driving a motor vehicle), getting in or out of bed or a chair					
c) Communication , e.g. making self understood, in own native language or preferred method of communication if applicable, and understanding others					
d) Interpersonal interactions and relationships , e.g. actions and behaviours that an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions					
In the following questions 'not applicable' is a valid response only if the person is 0–4 years old.					
e) Learning, applying knowledge and general tasks and demand , e.g. understanding new ideas, remembering, problem solving, decision making, paying attention, undertaking single or multiple tasks, carrying out daily routine					
f) Education , e.g. the actions, behaviours and tasks an individual performs at school, college, or any educational setting					
g) Community (civic) and economic life , e.g. recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money					
In the following questions 'not applicable' is a valid response only if the person is 0–14 years old.					
h) Domestic life , e.g. organising meals, cleaning, disposing of garbage, housekeeping, shopping, cooking, home maintenance					
i) Working , e.g. actions, behaviours and tasks to obtain and retain paid employment					

Source: CSTDA NMDS Service User Form, 2002.

Figure 8.3: Support needs framework or 'information matrix'

8.4 Indicators of outputs and outcomes

Administrators reported in 1999–2000 that they wished to improve output, cost and outcome data and to move forward on the basis of the AIHW *Integrating Indicators* report in 2000 (AIHW 2000a). A two-day indicator development workshop was therefore held at the AIHW on 7–8 February 2001. Its purpose was to develop indicators of outcome, output and cost for inclusion in the redeveloped CSTDA NMDS. Representatives of all jurisdictions and of disability service and consumer organisations and the Productivity Commission attended the workshop.

The workshop represented a key component of 'Phase One' of the indicator development work suggested in the *Integrating Indicators* report (AIHW 2000a:81), which states:

An appropriate approach [to indicator development] may be to convene a working group that would undertake intensive development of data items over one or two workshops. Members of the group should, collectively, have the expertise to put theory, policy, administration and data collection on the table together.

The data items developed should have a strong grounding in current practice 'on the ground', to ensure that data collection is feasible and that the resultant measures or indicators are relevant, not only in the context of high-level policy, but also at program and service level, for planning and management purposes.

The development of indicators of output, cost and outcome was a central component of the redevelopment of the NMDS, and relates to the key information needs of disability administrators, summarised as follows in the March 2000 report to the NDA on the NMDS redevelopment scoping study:

- how many people were supported – and what were their characteristics and support needs;
- what was received – not just type of service, but some measure of 'quantity' of service provided by service type, e.g. staff hours, funding per consumer;
- from whom was it received – details of the service provider, e.g. size in terms of caseload, staff profile and hours; the agency's role in the system, e.g. case coordinator or 'secondary' provider;
- for how much (in terms of cost to government, although there was also interest in the notion of 'total cost' to the service provider); and
- with what outcome. (March 2000 report to NDA, page 5-2)

It should be noted that two important areas of data development were considered out of scope for the redevelopment project: quality and demand. The reasons for their exclusion are discussed in the *Integrating Indicators* report (AIHW 2000a). A question relating to the concept of unmet demand or unmet need was subsequently included in Round 2 field testing but excluded from the final NMDS for similar reasons to those outlined in the *Integrating Indicators* report (see Section 5.3 on 'unmet needs').

The indicators workshop noted that the establishment of national indicators was a challenging area. For example, workshop participants voiced doubts that there was currently an 'agreed enough' policy and funding framework as a solid foundation for collecting and relating funding and output data, despite considerable consistency of practice among jurisdictions. Issues were also raised about the feasibility of developing outcome indicators, both for individual service users and at a service level. The successful development of a set

of service-level outcomes was seen to hinge on whether national outcome goals could be specified for different service types. However, early in the project the NDA agreed that the AIHW should continue to pursue data development in all these areas.

The development of suitable indicators continued throughout the redevelopment project, drawing on field testing, reviewing annual reports and policy statements about service goals, and extensive consultation with the FIG. This section includes a brief summary describing the way the final indicators evolved. A separate discussion is included for each of the three areas in which indicator development was undertaken:

- outputs;
- costs; and
- outcomes.

It was recognised from very early on in the development process that a revised classification of CSTDA service types was needed in order to support indicators of both outputs and costs (and to some extent outcomes). This revised classification would:

- allow jurisdictions to map the service types they fund to a national framework;
- be the framework for output indicators and enable output indicators to be related to data on government funding by service type; and
- allow service funding information to be obtained as an administrative by-product to jurisdictions' normal financial operations.

Further information on the development of the service type classification is provided in Section 8.1.

Outputs

From the beginning of the redevelopment project, discussion focused on two types of output indicator:

- consumer counts; and
- measures of quantity of service received.

For each service type there was discussion about counts and measures that would be meaningful and feasible to collect, given the type of data that are currently collected by funded agencies and/or required by administrators.

Discussion of outputs (and costs) also provided important guidance on changes that could be made to the existing CSDA service type classification. From early on in the redevelopment, it was agreed that the revised service classification should aim to group 'like with like' in a functional sense, to better reflect funded service activities.

Consumer 'counts'

Following the indicators workshop, the NDA agreed that Round 2 field testing should explore the following consumer 'counts':

- consumers over the financial year; and
- an 'as at 30 June' count of 'active' consumers (with workable definitions to be explored during field testing); and/or
- a count of consumers who received a service on 30 June.

These types of consumer 'counts' would provide:

- service user characteristics (i.e. demographics, disability type, support needs, etc.) for all consumers who received services in the year and, with the linkage key, a complete picture of patterns of CSTDA service use (i.e. the characteristics of all consumers who received each service type over the year, rather than just those who accessed services on the snapshot day);
- an indication of service user turnover during the year;
- comparability of service user data with other data collections that provide 'as at' counts;
- continuity with previous 'snapshot day' MDS data so that time series could be constructed; and
- average government funding per service user receiving a service during the year (in conjunction with suitable cost information).

Consumers over the financial year

The need for this information was not disputed throughout the redevelopment project. This information is available in the final CSTDA NMDS by asking funded agencies to record details of all service users accessing each CSTDA NMDS service type, in conjunction with information about when a service user last received support.

Consumers 'active' in the reporting period

Originally, it was suggested that this type of information could be collected by asking agencies to identify the number of consumers considered 'active' during a reporting period. This would be achieved by a 'tick box' approach for each service user.

This approach was partly adopted because, early in the redevelopment project, the FIG did not recommend the inclusion of start and end dates for each service user (i.e. date support commenced and date support ceased) either over a reporting period or in terms of episodes of care. However, following the indicators workshop and report to the NDA, a number of jurisdictions expressed their belief that start and stop dates were critical to the new NMDS. Round 2 field testing therefore included questions to establish the feasibility of collecting either 'active' status or 'date support started' and 'date support ended'. In Round 2 field testing, a service user was deemed to have ended support if: they had ended the support relationship with the agency; the agency had ended the support relationship with the service user; or three months had elapsed since support was last received. The third criterion was included to support quarterly data collection (proposed in some jurisdictions), but field testing revealed that the methodology was too complex. It was also agreed that the NMDS collection would not be a service episode-based collection.

In August 2001 the NDA agreed that all existing service users should be migrated to the new collection with a uniform start date (e.g. 1 October 2002). This was proposed to avoid asking service providers to examine historical files to establish the date a service user first received service. (This was consistent with the experience of the HACC MDS collection, where 'Date of entry into HACC service episode', was eventually dropped from the collection following the difficulty providers experienced in going back through historical records to find when the person first entered the program.) This rule was slightly relaxed in the final collection materials to enable interested agencies to enter a true start date, if desired.

'Date service last received' was included in the collection from Round 3 onwards. By asking service providers to specify the last date on which a service user received a service, this data item:

- avoids rigidly defining 'active' status for all service types;
- avoids relying on artificial end dates (i.e. requiring service providers to enter a stop date if a service user has not received a service for three months); and
- solves some of the collation difficulties arising from the varied reporting periods proposed in different jurisdictions (i.e. this question can be asked in relation to the relevant reporting period – e.g. when did the consumer last receive a service in this quarter, financial year? – depending on jurisdiction).

Information on the 'active' status of service users is available in the final CSTDA NMDS through the data items, 'service start date', 'date service last received' and 'service exit date'.

Consumers who received a service on 30 June

By August 2001 (i.e. before Round 3 field testing) there was renewed discussion about the value of retaining a question on whether a client received a service on a given snapshot day (during the transition to the new collection). It was, however, considered essential by the AIHW that a tick box response be retained in the collection for 2002 and 2003 for this purpose in order to ensure continuity of data interpretation in the years 2001, 2002 and 2003. It was also argued that the data item would enable an evaluation of the success of the redevelopment by, for example, allowing the extent of improvement in data to be documented.

The data item 'snapshot date flag' is included in the final CSTDA NMDS.

Service quantity measures

Following the indicators workshop the NDA also agreed that, in addition to a count of consumers over the financial year, measures of output quantity should continue to be explored. It was understood that output quantity measures would vary by service type. The development of consensus around the issue of output quantity measures was one of the most challenging areas of the redevelopment project.

The indicators workshop recommended that the appropriate output quantity measures to explore were:

- total quantity of service contracted/funded at outlet level – to give average quantity per service user over the year; and
- quantity of service planned/contracted for each service user – to provide information on the quantity and distribution of service outputs among service users in relation to service user characteristics (e.g. demographics, disability type, support needs, carer status).

Both options would allow calculation of average government funding per output (either at jurisdiction or outlet level, depending on how funding data were collected).

The indicators workshop did not recommend the collection of hours actually received by service users over the financial year, advising that collection of this type of information was unrealistic from a funded agency perspective. However, as the project progressed it became clear that administrators were interested in information about hours actually received by service users, at least for some key service types, for which this information was often required in funding agreements.

Prior to Round 3 field testing, preferred output quantity measures were proposed for each CSTDA NMDS service type. For many service types, the proposed output quantity measure was hours of service per service user. However, agreement had not been possible across jurisdictions about the preferred method of specifying or collecting this information. It was therefore agreed that the following hierarchy should be tested in Round 3 for those service types where 'hours of service per service user' was the proposed output measure.

Hierarchy for hours of service per service user

- (1) Hours delivered per service user (best practice output measure)
- (2) Average hours allocated per service user (i.e. where outlets receive funding for total hours of service delivery, their weekly allocation of hours to each service user) (acceptable output measure)
- (3) Average hours allocated per service user (based on full-time equivalent staff hours) (fall back output measure)

Data providers would need to specify whether measure (1), (2) or (3) was used. (Round 3 field testing materials)

It was proposed that all of the measures would be accepted, with (1) being the most preferred and (3) the least preferred. Round 3 field testing documentation was developed to determine whether this flexibility could be incorporated into forms and guides in a way that was not too confusing for data providers.

In summary, the following output quantity measures were tested in Round 3 (Table 8.3).

Table 8.3: Output quantity measures proposed for Round 3 field testing

Service types	Proposed output quantity measures
Accommodation support (large and small residential/institutions, hostels, group homes, other accommodation support)	Number of people receiving the service type over the reporting period AND Duration (calculated using start date and date service last received in the reporting period)
Accommodation support (attendant care/personal care, in-home accommodation support, alternative family placement)	Hours of service per service user over the reporting period (determined according to the hierarchy above) AND Duration (calculated using start date and date service last received in the reporting period)
Community support, community access (except recreation/holiday programs) and respite	Hours of service per service user over the reporting period (determined according to the hierarchy above)
Recreation/holiday programs	Average hours allocated per service user (based on full-time equivalent staff hours and total service users estimated using linkage key)
Employment	Durable employment outcome as defined by the Commonwealth Department of Family and Community Services (FaCS).
Advocacy, information and print (including mutual support/self-help groups)	Number of outlets funded AND Equivalent full time staff hours plus days of operation per week/year
Other support	Number of outlets funded AND Equivalent full time staff hours plus days of operation per week/year

Following Round 3 field testing, most jurisdictions still acknowledged that collecting information about quantity of service received by service users is important in order to describe what people with disabilities are actually getting from the CSTDA service system. However, varied views remained about the feasibility of collecting this information from agencies and disagreement about which service types should be required to provide this level of information.

It was then agreed that the final CSTDA NMDS would ask agencies to provide 'hours received' from the following service types: attendant care/personal care; in-home accommodation support; alternative family placement; case management, local coordination and development; learning and life skills development; other community access; and all forms of respite support. In relation to these service types, it was agreed that agencies be asked to provide:

- total actual hours received by the service user in the week prior to data transmission; and
- average/typical hours received per week by the service user from the service type outlet over the reporting period (included to enable agencies to indicate that the week prior to transmission was not an average/typical week).

Agencies would not be asked to record contracted hours in lieu of 'hours received' information (as trialed in Round 3).

All jurisdictions agreed that quantity of service information should be expanded to remaining service types over time.

The collection of information about hours received had been particularly complicated in the case of one service type: case management, local coordination and development. Special efforts were therefore made to clarify the collection method for this service type, in order to avoid double counting. These are included in the CSTDA NMDS Data Guide for 'hours received' and 'staff hours'.

Examples of output measures available from the redeveloped CSTDA NMDS (following the changes made after Round 3 field testing) are summarised in Table 8.4.

Table 8.4: Examples of output quantity measures for the redeveloped CSTDA NMDS

Service types	Proposed output quantity measures
Accommodation support (large and small residential/institutions, hostels, group homes, other accommodation support) Community support (therapy services for individuals, early childhood intervention, behaviour/specialist intervention, counselling (individual/family/group), regional resource and support teams, other community support)	Number of service users receiving the service type over the reporting period Average hours allocated per service user, (based on staff hours (reference week and typical week))
Accommodation support (attendant care/personal care, in-home accommodation support, alternative family placement) Community support (case management, local coordination and development) (except for community development activity within this service type) Community access (except recreation/holiday programs) Respite	Number of service users receiving the service type over the reporting period Hours of support received per service user in (in a reference week and a typical week) over the reporting period
Recreation/holiday programs	Number of service users receiving the service type over the reporting period (estimated using linkage key and the data item 'number of service users') Average hours allocated per service user, based on staff hours (reference week and typical week)
Employment	Durable employment outcome as defined by the Commonwealth Department of Family and Community Services (FaCS).
Advocacy, information and print (including mutual support/self-help groups)	Number of service users (estimated using the data item 'number of service users') Number of service type outlets funded Hours of operation per day, days of operation per week, weeks of operation per year Staff hours (reference week and typical week)
Other support	Number of service type outlets funded Hours of operation per day, days of operation per week, weeks of operation per year Staff hours (reference week and typical week)

Duration (calculated using start date and date service last received in the reporting period) can also be recorded for most service types. This is most likely to be used as an output measure in the case of accommodation support services.

Additional features that could be included

Discussion at the indicators workshop also led to the testing of two additional data items: an Individual funding 'flag' and an Equipment and modifications 'flag'.

The concept of an Individual funding flag was to be included as a 'tick-box' attached to consumer-level information, to identify service users who are purchasing services via individual funding packages. This would provide information on:

- numbers of service users with individual funding packages;
- types of services purchased with individual funding packages; and

- characteristics of service users receiving individual funding packages in comparison with other service users.

Together with measures of output quantity it would provide information on:

- amount and type of service outputs purchased using individual funding packages; and
- a more accurate indication of government funding dollars per output for different service types.

An Individual funding 'flag' was tested in Rounds 2 and 3 of field testing and is included in the final CSTDA NMDS. Following Round 2 field testing, particularly with consumers, there was a suggestion that this 'flag' be used as an indicator of consumer outcomes (i.e. with the use of individual funding packages seen as a positive outcome for consumers). However, it was eventually agreed by all that this data item should not be used as an outcome indicator.

The indicators workshop also suggested that an Equipment and modifications 'flag' should be tested in Round 2 field testing. This item would be included as a 'tick-box' attached to consumer-level information, to indicate whether the service user received equipment or environmental modifications that cost more than a specified amount (e.g. \$100). This would provide information on:

- numbers and characteristics of service users who receive equipment/modifications; and
- service types for which the provision of equipment forms a substantial component of services provided.

This item was excluded following Round 2 field testing because the complexities of asking for this information were considered to outweigh the benefits of having national information of this nature (see Section 5.3 for further detail).

Costs

Following the indicators workshop, the NDA agreed that the redevelopment project should continue to explore specific mechanisms for improving cost and related data, for instance by relating government funding dollars (as recorded in jurisdictional financial systems) to the service type outlet level. In relation to both outputs and costs it was agreed that a revised service type classification should be tested. Field testing would include efforts to improve the harmonisation of the service type classification with jurisdiction service funding frameworks, to enable collection of nationally consistent data on funding dollars by service type.

The indicators workshop suggested that gathering information about total costs (to a funded agency) of delivering a CSTDA service was not feasible, and overly intrusive. The workshop therefore recommended that a question about what proportion of a funded agency's total funds was accounted for by CSTDA funding should not proceed for field testing. Instead it was suggested that the NDA could consider how an occasional survey of annual reports might be conducted in order to obtain information on the average contribution of non-CSTDA funding sources to the provision of CSTDA services.

Each round of field testing included questions about CSTDA costs to government, and this issue was explored in depth when the AIHW conducted Round 2 field testing with jurisdictions. In December 2001 the NDA agreed that jurisdictions would be responsible for supplying funding information, for national collation, to the AIHW at whatever level they currently specify or provide funding (i.e. at the funded agency or service type outlet level). That is, as discussed throughout the redevelopment, jurisdictions will generally obtain

funding information from administrative or funding systems, in the format available (i.e. at the level at which they fund) and relate to appropriate service type outlet IDs.

The data item 'Total CSTDA funds' is included in the CSTDA NMDS. The method of collecting this information varies across jurisdictions; for example, some jurisdictions plan to collect it directly from funded agencies, while other jurisdictions will extract the data from their existing administrative databases. Because of this variation, the data item is not included in the national collection materials for funded agencies, but rather in the Network Guide, for jurisdiction use.

Outcomes

The ultimate goal of disability services is to deliver positive outcomes for service users, and the concepts of participation and quality of life are central to the notion of outcome. This is reflected in Clause 4(1) of the 1998 CSDA, which states:

The Commonwealth and the States strive to enhance the quality of life experienced by people with a disability through assisting them to live as valued and participating members of the community.

Two types of outcome are defined in the *Integrating Indicators* report (AIHW 2000a:xv, 40):

- **Individual outcomes.** These relate to the individual consumer, and may be narrow (e.g. getting a job) or broad (e.g. improved quality of life).
- **Service-level outcomes.** These are based on aggregations of individual outcomes, and thus reflect how well a service is achieving outcomes for its consumers.

From the outset, outcome indicators were therefore pursued in these two areas.

Individual outcomes

Information collected during the preliminary CSTDA NMDS redevelopment work (i.e. the scoping study) established that there was general agreement among administrators that it is important to collect information on outcomes for consumers of disability services. Discussion at the indicators workshop recognised that the kind of consumer outcomes that disability services are aimed at achieving are long term, and approaches to measuring or monitoring outcomes need to recognise this.

At the workshop, a question on consumer participation was put forward by the AIHW for discussion and consideration for inclusion in the CSTDA NMDS. It was similar in form to the question trialed by Victoria in the 2000 CSDA MDS collection. The AIHW offered to further develop this question into an individual outcome data 'module'. It was proposed that questions in the module should be framed around the ICF (International Classification of Functioning, Disability and Health) Participation domains and underlying concepts, and development work should benefit from the experience provided by Victoria's trial of a question on consumer participation in the 2000 CSDA MDS collection. There would be scope to investigate questions on a range of outcome-related issues, including participation, quality of life, service quality, consumer satisfaction and consumer expectations. Questions on services received and support needs could also be included.

From the outset it was envisaged that such a module could be used in all jurisdictions to collect information directly from CSTDA service users. The information would not be collected at the same time as the service-oriented collection, but could be used at convenient points in the administrative cycle, possibly in association with other information collection

activities (e.g. Western Australia's Local Area Coordination reviews, jurisdiction consumer satisfaction surveys, or individual case planning).

The module was therefore recommended as an 'adjunct' CSTDA MDS resource, and not for inclusion in the CSTDA NMDS itself. Nationally consistent data on outcomes could then be available with the data from the redeveloped CSDA MDS if each jurisdiction ran the module at some point in the administrative cycle.

The individual outcome data 'module', known as the 'Participation module', was included in Round 2 field testing with consumers. The module was not generally supported for inclusion in Round 3 field testing nor for implementation in 2002. A key reason for its exclusion from the CSTDA NMDS itself was concern about the validity of asking consumer participation questions via service providers and the appropriateness of the CSTDA NMDS as a vehicle for collection such information (of particular concern to the consumers consulted).

However, such a module was generally considered to be worth including in the CSTDA NMDS materials to provide a resource to facilitate the collection, if deemed desirable by jurisdictions, of comparable information on extent of participation and satisfaction of participation. It was agreed that further development should be undertaken (outside the redevelopment project timeline) to develop a participation module for use by funded agencies and jurisdictions at various stages of normal service administration. Such a module could be used, for example, when conducting 'satisfaction surveys', discussing people's overall goals, developing individual service plans and in assessing overall quality of life. The trial Participation module, as it appears in the CSTDA NMDS Network Guide, is provided in Figure 8.4.

Life domain	Extent of participation (judged by service provider or assessment process)	Satisfaction with participation (judged by consumer, with advocate if necessary) in relation to duration, frequency, manner or outcome
	<ol style="list-style-type: none"> 1. Full participation 2. Mild participation restriction 3. Moderate participation restriction 4. Severe participation restriction 5. Complete participation restriction 	<ol style="list-style-type: none"> 1. High satisfaction with participation 2. Moderate satisfaction with participation 3. Moderate dissatisfaction with participation 4. Extreme dissatisfaction with participation 5. No participation 6. No participation and none desired
<p>Participation in communication and conversation (e.g. producing and receiving spoken, non-verbal, formal sign or written messages, involvement in conversation, discussion with or without use of communication devices and techniques)</p>		
<p>Participation in mobility within the home and community environment (e.g. changing and maintaining body position; carrying, moving and handling objects; walking and moving; moving around using transportation)</p>		
<p>Participation in domestic life (e.g. acquiring necessities such as a place to live and goods and services; household tasks such as preparing meals; caring for household objects and assisting others)</p>		
<p>Participation in interpersonal interactions and relationships (e.g. relating with strangers, formal and information social relationships, family and intimate relationships)</p>		
<p>Participation in education, work and employment (e.g. informal education, preschool, school, vocational and higher education; work preparation such as apprenticeships; acquiring, keeping and terminating a job, remunerative or non-remunerative employment)</p>		
<p>Participation in economic life (e.g. basic and complex economic transactions, economic self-sufficiency)</p>		
<p>Participation in community, social and civic life (e.g. community life, religion and spirituality, recreation and leisure, political life and citizenship, human rights)</p>		

Figure 8.4: Trial 'participation module' or framework

Service-specific outcomes

Following the indicators workshop it was agreed that the AIHW, in consultation with FIG, would draft service-specific outcome indicators (for a small number of service types) and related data items for field testing. These would then be tested and submitted to NDA for approval, to ensure that they reflect the national policy framework. If approved they would become part of the CSTDA NMDS collection and work would proceed to other service types.

Employment services provided a good example of the process of developing service-specific outcome indicators. Over a number of years the Commonwealth had developed measures of participation outcome specifically related to the program goals of employment services – work of 8 or more hours per week for 13 or more weeks (although the term output is used rather than outcome by the Commonwealth). The Commonwealth now routinely collects data on achievement of these outcomes.

The AIHW explored annual reports and policy documents from all jurisdictions in search of policy statements about the outcome goals of each CSTDA service type. By June 2001, the AIHW had developed a draft set of service-level outcome indicators for NDA consideration (Table 8.5). In a report to the NDA, it was recommended that:

1. The NDA note the mapping undertaken in relation to service-specific outcomes and the related draft suggested indicators.
2. The NDA note that, with the addition of just three data items to the data set now being tested, the scope of indicators is significantly enhanced. These three items are: carer age (developed item already in the NCSDD⁵); carer relationship (developed item already in the NCSDD); reason for leaving service (developed item in HACC MDS). (June 2001 report to NDA, page 2)

These three further items were then included for Round 3 field testing.

By August 2001, the FIG stated that the development of the proposed outcomes had been a useful exercise in terms of highlighting a number of important data items for inclusion in Round 3. However, the FIG considered that official endorsement of the proposed outcome indicators was not appropriate or necessary in this forum and that the indicators should not be included in collection documentation. The NDA endorsed this view.

⁵ National Community Services Data Dictionary.

Table 8.5: Service-level outcomes and suggested indicators (June 2001) – draft

CSDA service type	Purpose (CSDA)	Classification	Objectives/goals	Suggested indicators
Accommodation support	Accommodation support services provide accommodation to people with a disability, and services which provide the support needed to enable a person with a disability to remain in their existing accommodation.	1.01 Institution/large residential 1.02 Hostels 1.03 Group homes 1.04 Attendant care 1.05 Outreach support/other 'in-home' support/drop-in support 1.06 Alternative family placement 1.07 Other accommodation support	<ul style="list-style-type: none"> • Devolution/de-institutionalisation (including hostels) • Ageing parents • Increase in community support • Remaining in accommodation with support For example: '...planning for a staged approach towards devolution of people with disabilities form large residential facilities' (NSW annual report 1999–2000:15). '...priorities for disability services include... increasing supported accommodation, especially for the sons and daughters of ageing parents and people in greatest need' (WA annual report, 1999–2000:12).	(a) Accommodation support services relative to the 'potential population' (b) Living arrangement of all consumers – percent in own home/private setting* (c) Carer relationship and age of carer: <ul style="list-style-type: none"> • per cent of all consumers with carer >65**** (carer age) • per cent of all consumers with parent carer >65**** (carer relationship to consumer) (d) Average hours of support to non-institutional/non-group home/hostel consumers*** (depending on agreed output measures) (e) Duration of service type: <ul style="list-style-type: none"> • group home/hostel** • residential** • other** (f) Support needs profile of people in different service types and living arrangements* (g) Reason for cessation of services***
<div style="border: 1px solid black; padding: 5px;"> <p>Key for indicator availability</p> <ul style="list-style-type: none"> * currently available from existing CSDA MDS ** available with minor re-classification of existing data item *** needing new data items (already on redeveloped CSDA MDS 'short list') **** needing new data items or collection methods (not currently on the redeveloped CSDA MDS 'short list') </div>				

(continued)

Table 8.5 (continued): Service-level outcomes and suggested indicators (June 2001) – draft

CSDA service type	Purpose (CSDA)	Classification	Objectives/goals	Suggested indicators
<p>Accommodation support (continued)</p>	<p><i>Interpretation of the purpose</i> Accommodation support provided in non-residential settings (i.e. 1.04 and 1.05) is distinguished from Community support services because services provided in the accommodation support category relate generally to personal care and basic home living assistance to remain in current accommodation.</p>		<p>‘...ongoing efforts to reduce reliance on institutional support for clients of Disability Services’ (Tas annual report 1999–2000:52). ‘ [Increase funding in] Attendant care and personal care services for people who are at risk of premature placement [in accommodation] or are inappropriately placed in residential care’ (NT strategic plan, 1999–2000:10).</p>	<p>(h) Trends over year in living arrangements and shift from institution to non-institution (reason for ceasing support)**** (i) Accommodation support – ‘severity’ of core activity restriction* (j) Consumers of CSDA-funded accommodation services, Indigenous status, by State/Territory* (k) Consumers of CSDA-funded accommodation services, non-English-speaking origin, by State/Territory* (l) Consumers of CSDA-funded community-based or ‘in-home’ accommodation support services by State/Territory*</p>

(continued)

Table 8.5 (continued): Service-level outcomes and suggested indicators (June 2001) – draft

CSDA service type	Purpose (CSDA)	Classification	Objectives/goals	Suggested indicators
<p>Community support</p>	<p>Community support services provide the support needed for a person with a disability to live in a non-institutional setting.</p> <p><i>Interpretation of the purpose</i></p> <p>In contrast to accommodation support provided in the community, community support services focus on broader needs of the person with a disability, in terms of participation, therapy, access to information, and also on the needs of carers and families.</p>	<p>2.04 Early childhood intervention</p> <p>2.06 Therapy (PT OT ST)</p> <p>2.07 Family/individual case practice/management</p> <p>2.08 Behaviour intervention/specialist intervention</p> <p>2.09 Counselling: individual/family/group</p> <p>2.10 Brokerage/direct funding</p> <p>2.11 Mutual support/self-help groups</p> <p>2.13 Resource teams/regional teams</p> <p>2.05 Recreation/holiday programs</p>	<ul style="list-style-type: none"> • Improve delivery early childhood intervention services • Preparation to live in the community • Access to services • Provision of information • Number of people helped <p>For example:</p> <p>‘...objective is to ensure that specialist services are available to government and non-government funded services and families to support people with disabilities to live in the community’ (NSW annual report, 1999–2000:28).</p> <p>‘...supports best practice in recreation services and reduces gaps and duplication of services’ (WA annual report, 1999–2000:48).</p>	<p>(a) Trends over time:</p> <ul style="list-style-type: none"> • living arrangements* • presence of carer and carer characteristics**** <p>(b) Support needs profile of people in different service types*</p> <p>(c) Quantity of support for different service types**</p> <p>(d) Percentage of people with individual packages***</p> <ul style="list-style-type: none"> • service mix** • support needs** <p>(e) Reason for cessation of services***</p> <p>(f) Instances of community support – constructed using start dates***</p>

(continued)

Table 8.5 (continued): Service-level outcomes and suggested indicators (June 2001) – draft

CSDA service type	Purpose (CSDA)	Classification	Objectives/goals	Suggested indicators
<p>Community support (continued) Print disability</p>	<p>Print disability services produce alternative formats of communication for people who by reason of their disabilities are unable to access information provided in a print medium.</p>	<p>2.12 Print disability</p>	<p>'Increasing safeguards and advocacy [so that]...people with a disability and their families have the knowledge and skills they require to protect the rights, welfare and safety from vulnerability' (Qld strategic plan, 1999–2000).</p>	
<p>Advocacy</p>	<p>Advocacy services are 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.</p>	<p>2.01 Advocacy 2.02 Information/referral 2.03 Combined advocacy/information 2.14 Other community support</p>		
<p>Information</p>	<p>Information services provide accessible information to people with disabilities, their carers, families and related professionals. This service type provides specific information about disabilities, specific and generic services, and equipment, and promotes the development of community awareness.</p>			

(continued)

Table 8.5 (continued): Service-level outcomes and suggested indicators (June 2001) – draft

CSDA service type	Purpose (CSDA)	Classification	Objectives/goals	Suggested indicators
<p>Community access</p>	<p>Community access services and programs are designed to provide opportunities for people with a disability to gain and use their abilities to enjoy their full potential for social independence.</p>	<p>3.01 Continuing education/ independent living training/ adult training centre</p> <p>3.02 Post -school options/ social and community support/ community access</p> <p>3.03 Other community access and day programs</p>	<ul style="list-style-type: none"> • Transition • Skills development • Support to carers • Number of people helped <p>For example:</p> <p>‘...develop a more effective and integrated approach to adult training, learning and support...One of the key measures of success will be greater access to employment opportunities’ (NSW annual report, 1999–2000:23).</p> <p>‘...support for day activities which offer people a range of options in skill development, community access, and recreation activities’ (ACT annual report, 1999:29).</p> <p>‘...address areas of unmet need such as day options and in home services that support the development of a person with a disability and can give support to family and carers’ (SA planning framework, 1999:23).</p>	<p>(a) Community access services relative to the ‘potential population’*</p> <p>(b) Trends over time in terms of transition:</p> <ul style="list-style-type: none"> • to other services* • in labour force status*** • living arrangements* • participation module*** <p>(c) Instance of community access – constructed using start dates ***</p> <p>(d) Per cent of consumers with individual support packages and when they were last reviewed***</p> <p>(e) Support needs profile of consumers across service types:</p> <ul style="list-style-type: none"> • accommodation support, community support, transitioning to other services vs those staying* <p>(f) Carer relationship and age***</p> <p>(g) Reason for cessation of services***</p> <p>(h) Participation module</p> <p>(i) Skill development (hard area, linkage key within CSDA program but a lot may be outside CSDA – how to monitor without ‘tick box’ approach?)</p>

(continued)

Table 8.5 (continued): Service-level outcomes and suggested indicators (June 2001) – draft

CSDA service type	Purpose (CSDA)	Classification	Objectives/goals	Suggested indicators
<p>Respite</p>	<p>Respite services specifically 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, whilst providing a positive experience for the person with a disability</p>	<p>4.01 Own-home respite 4.02 Centre-based respite/respite homes 4.03 Host family respite/peer support respite 4.04 Other respite/flexible respite/combination</p>	<ul style="list-style-type: none"> • Duration of respite care • Families with carers • Enhancing flexible range of options <p>For example:</p> <ul style="list-style-type: none"> • ...encourage service providers to develop a range of flexible respite options responsive to individual consumer and family needs' (NT strategic plan, 1999:9). • ...over the next two years our target is to provide support to 780 families under a respite and family care strategy' (WA annual report, 1999-2000:59). • ...particular emphasis on freeing up many respite beds that are currently being used for long term accommodation, with those individuals being affected being supported into more appropriate accommodation, and encouraging a broader and more flexible range of options... (NSW annual report 1999-2000:15). 	<p>(a) Duration of respite:</p> <ul style="list-style-type: none"> • hours of respite**** • days in respite*** <p>(b) Presence of carer:</p> <ul style="list-style-type: none"> • age of carer and relationship to recipient**** • age of recipient with carer**** <p>(c) Duration of living arrangements*</p> <p>(d) Support needs profile of people in different service types*</p> <p>(e) Multiple service usage between respite and other services*</p> <ul style="list-style-type: none"> • host family support, in-home and community based support <p>(f) Per cent of respite beds being used for long term accommodation – how do we get to this?</p> <p>(g) Reason for cessation of services****</p> <p>(h) Instances of respite – constructed by examining number of start dates over a year***</p> <p>(i) Trends in respite care across years – linkage key*</p> <p>(j) ABS number of carers who cannot get respite care (i.e. population measure of overall success of respite program)</p>

(continued)

Table 8.5 (continued): Service-level outcomes and suggested indicators (June 2001) – draft

CSDA service type	Purpose (CSDA)	Classification	Objectives/goals	Suggested indicators
Employment	Employment services means services which provide employment assistance to people with a disability to assist them obtain and/or retain employment	5.01 Open employment 5.02 Supported employment 5.03 Open and supported employment 5.04 Other employment	<ul style="list-style-type: none"> Duration of employment Transition <p>For example: ‘...raise awareness of disability services, employment assistance programs and relevant income support payments among target groups through a range of marketing activities’ (FaCS annual report, 1999–2000). ‘...pursue equitable access to disability support services on the basis of support needs, Aboriginal and Torres Strait Islander origin, ethnicity, gender and geographic location’ (FaCS annual report, 1999–2000). ‘...new practices and policies to reduce the barriers for all people with disabilities seeking to access work or other community participation opportunities...’ (NSW annual report, 1999–2000:34).</p>	(a) Consumers of CSDA-funded employment services relative to ‘potential population’* (b) Consumers of CSDA-funded employment services – severity of core activity restrictions* (c) Consumers of CSDA-funded employment services, Indigenous status by State/Territory* (d) Consumers of CSDA-funded employment services, non-English-speaking origin by State/Territory* (e) Consumers of CSDA-funded employment services, auspicing organisation by State/Territory* (f) Number of consumers receiving employment support* (g) Number of jobs – counted using start dates*** (h) Duration of employment*** (i) Per cent workforce age population on disability income support* (j) Trends over time in terms of transition: <ul style="list-style-type: none"> from community access support services*

Note: Table 8.5 uses the terminology and classifications in place at June 2001, for example: CSDA (not CSTDA); consumer (not service user). The service type classification used is the one available at the time.

8.5 Informal carer data items

Recent years have witnessed a growing recognition of the critical role that informal support networks play in assisting people with disabilities within the community. Not only do informal carers help people to live in the community, but the absence of an informal carer can be a significant risk factor contributing to institutionalisation. Concern about the needs of ageing carers has placed them on the policy agenda nationally.

The February 2001 indicator development workshop acknowledged the importance of informal carers, and 'short listed' a number of carer data items to be tested for inclusion in the CSTDA NMDS, including 'carer arrangements – informal', 'carer – primary status', 'carer – residency status', 'carer – relationship to service user' and 'carer – age group'.

Considerable consultation and data development work was undertaken throughout the course of the project to refine these data items to make them applicable to the disability services field. Early data development work revealed that there was a different concept of 'carer' between the CSTDA and HACC programs regarding respite services. The HACC program and its associated collection considers a carer to be the primary service user of respite services, and that the person receiving the respite was the secondary user. The CSTDA program explicitly defines a service user – for all service types – as 'a person with a disability who receives a CSTDA-funded service' (AIHW 2002c). This meant that a person considered a carer in the CSTDA collection was a service user in the HACC collection.

The carer data items were tested during the three rounds of field testing using the CSTDA NMDS definition of a service user. Results from the testing indicated that the definition of service user and concept of 'carer' were applicable and feasible for collection in the CSTDA NMDS.

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 services. Information about the primary status, residency status, relationship to the service user and age group of the informal carer, all contribute to an overall profile of informal carers.

8.6 Feeding back into national data standards

From the outset of the redevelopment project, the NDA stated that the data items in the CSTDA NMDS should conform to national data standards. The main vehicle in Australia for national data consistency and standards in the community services field is the National Community Services Data Dictionary, most recently version 2. The NDA also wanted data development to conform, where appropriate, to other developments in the field such as the Home and Community Care Minimum Data Set (HACC MDS). It was envisaged that the resulting increased consistency of data definitions would create efficiencies for community service organisations, which would then be collecting common data elements in national data collections for related programs (e.g. programs providing services for younger people with disabilities and programs of aged care services).

Data development work conducted during the project to incorporate such national standards and developments included:

- targeting funded agencies (via field testing) which provide both CSTDA and HACC service, and obtaining feedback and comments from them on how to best align the two data collections;
- conducting mapping exercises between CSTDA NMDS, HACC MDS and NCSDDv2 data elements and their definitions; and
- focusing on the statistical linkage key in the CSTDA and HACC collection and ensuring they are an exact match across collections.

Table 8.6 outlines the final CSTDA NMDS data items and relates them to the NCSDDv2 data elements. Data items appearing in both the CSTDA and HACC collections are flagged with '(H)' after the data item name.

Table 8.6: Consistency between data items in the redeveloped CSTDA NMDS and those in the NCSDDv2 and HACCC MDS

CSTDA NMDS data items	Relationship to NCSDDv2.0 and HACCC MDS
Service form: items provided by funding department	
A. <i>Funded agency ID</i>	Relates to but is not completely consistent with Agency identifier because it does not include State/Territory identifier or Establishment sector. However it does enable unique identification of funded agencies and their service type outlets (via the inter-relationship of the Service type outlet ID and funded agency ID).
B. <i>Service type outlet ID</i>	Relates to but is not completely consistent with Agency identifier because it does not include State/Territory identifier or Establishment sector. However it does enable unique identification of service type outlets and, where applicable, their parent funded agency (via the inter-relationship of the Service type outlet ID and funded agency ID).
C. Service type	Maps to Service types available . Work has been to ensure alignment with the new National Classification of Community Services.
D. Service type outlet postcode	Consistent with Postcode .
E. Service type outlet SLA	Consistent with Geographic location .
F. Funding jurisdiction	No similar NCSDD data element. This is a combination of State/Territory identifier and whether the funding source is Commonwealth or State/Territory. The data item can be used to produce output data as per State/Territory identifier .
G. Agency sector	No similar NCSDD data element. Is not the same as the NHDD Establishment sector.
Service form: items provided by service	
1. Full financial year operation	No similar NCSDD data element.
2. Weeks per year of operation	Consistent with Service operation weeks .
3. Days per week of operation	Consistent with Service operation days except that the NCSDD data element asks for days of operation during a reference week, while the CSTDA NMDS asks for usual days of operation. Suggest that the term 'reference week' be removed from the NCSDD so that this item can apply to reference week or usual week (as per other service operation data elements).

Table 8.6 (continued): Consistency between data items in the redeveloped CSTDA NMDS and those in the NCSDDv2 and HACC MDS

CSTDA NMDS data items	Relationship to NCSDDv2.0 and HACC MDS
4. Hours per day of operation	Consistent with Service operation hours .
5. Staff hours (reference week)	Relates to Hours per week – paid staff and Hours per week – volunteer/unpaid staff . CSTDA NMDS item looks at the actual number of hours worked by staff in a <u>reference week</u> .
6. Staff hours (typical week)	Relates to Hours per week – paid staff and Hours per week – volunteer/unpaid staff . CSTDA NMDS item looks at hours worked in a typical week. Enables the outlet to reflect that the staff hours in the reference week may not be typical. (Average for those jurisdictions that collect all.)
7. Number of service users	Relates to Client (concept) .
Service user form	
B. <i>Service type outlet ID(s)</i>	See above in service type outlet items.
1. Record ID	No similar NCSDD data element.
2a. Letters of surname (H)	Consistent with HACC data item Letters of surname . No similar NCSDD data element although relates to Family name .
2b. Letters of given name (H)	Consistent with HACC data item Letters of given name . No similar NCSDD data element although relates to Given name .
2c. Date of birth (H)	Consistent with Date of birth in the NCSDD and HACC MDS.
2d. <i>Birth date estimate flag</i>	No similar NCSDD data element. Consistent with NHDD Estimated date flag although the CSTDA NMDS data item only allows the respondent to select a year and indicate that the day and month are estimates. In contrast, the NHDD data element suggests that the respondent should be able to indicate whether any component of the date is an estimate.
2e. Sex (H)	Consistent with Sex in the NCSDD and HACC MDS.
3. Indigenous status (H)	Consistent with Indigenous status in the NCSDD and HACC MDS.
4. Country of birth (H)	Consistent with Country of birth in the NCSDD and HACC MDS.

Table 8.6 (continued): Consistency between data items in the redeveloped CSTDA NMDS and those in the NCSDDv2 and HACC MDS

CSTDA NMDS data items	Relationship to NCSDDv2.0 and HACC MDS
5. <i>Interpreter services required</i>	This item maps to Interpreter services required . Increased clarity is needed in the NCSDD about whether Interpreter services required relates to interpreters for non-English verbal speech only or also for non-verbal language such as sign language.
6. Communication method	Nearly consistent with Communication method (CSTDA NMDS no longer retained an 'other' category, code order has changed and code for sign language now specified as being effective, i.e. 'sign language (effective)').
7. Living arrangements (H)	Maps to Living arrangements in the NCSDD (more categories in NCSDD) and consistent with HACC MDS.
8. <i>Service user postcode (H)</i>	Consistent with Postcode in the NCSDD and HACC MDS.
9. Residential setting (H)	Maps to Residential setting in the NCSDD (more categories in CSTDA NMDS) and maps to Accommodation setting in the HACC MDS.
10. Disability group (primary, other significant)	No similar NCSDD data element. Relates to trial data element ' Assistance with activity' in NSCDD V2.0 but updates to align with ICF and ABS national population survey.
11. Support needs (9 areas)	Relates to Activity areas, Assistance with activity
12a. <i>Carer – existence of (H)</i>	Consistent with Carer availability in the NCSDD and HACC MDS.
12b. <i>Carer – primary status</i>	No similar NCSDD data element.
12c. <i>Carer – residency status (H)</i>	Consistent with Carer co-residency in the NCSDD and HACC MDS.
12d. <i>Carer – relationship to service user (H)</i>	Maps to Relationship of carer to care recipient in the NCSDD (more categories in CSTDA NMDS) and HACC MDS.
12e. <i>Carer – age group</i>	No similar NCSDD data element.
13. Receipt of Carer Allowance (Child)	No similar NCSDD data element.
14. <i>Labour force status</i>	Consistent with Labour force status .
15. Main source of income	Likely that this maps to Sources of cash income .
16. <i>Individual funding status</i>	No similar NCSDD data element.

Table 8.6 (continued): Consistency between data items in the redeveloped CSTDA NMDS and those in the NCSDDv2 and HACC MDS

CSTDA NMDS data items	Relationship to NCSDDv2.0 and HACC MDS
Information required for each service type received in the reporting period (per service user)	
17a. <i>Service start date</i>	Consistent with First service start date .
17b. <i>Date service last received</i>	Is a special case of Assistance received date .
17c. <i>Snapshot date flag</i>	No similar NCSDD data element.
17d. <i>Service exit date</i>	Consistent with Last service contact date .
17e. <i>Main reason for cessation of services (H)</i>	Maps with some ambiguity to NCSDD Service cessation reason (more categories in CSTDA NMDS). Consistent with HACC MDS.
17f. <i>Hours received (reference week)</i>	Relates to Assistance received (concept) . CSTDA item looks at the actual hours of service received in a <u>reference week</u> .
17g. <i>Hours received (typical week)</i>	Relates to Assistance received (concept) . CSTDA item looks at hours of service received in a typical week. Enables the service user to reflect that the hours received in the reference week may not be typical. (Average for those jurisdictions that collect all).

Key:

Italics New item in the CSTDA NMDS

Bold NCSDDv2.0 data element.

(H) Related HACC data item

‘Consistent with’ means that the items in each classification (both conceptually and in terms of codes) are consistent.

‘Maps to’ means that the items are conceptually consistent across the two classifications but all of the codes are not necessarily present so some mapping is required.

‘Related to’ means that there may be some conceptual difference or different level of detail in one classification vs the other (e.g. the NSCDD concept of **Client (concept)** is referred to in the CSTDA NMDS data item ‘number of service users’)

‘No similar’ means that there is no equivalent data element in the NCSDDv2.0

9 Conclusion

The Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS) collection was set up in 1994, and in 2000–01 was a \$2.5 billion program. Its establishment enabled complete, nationally comparable data on disability services funded under the CSDA to be collected in Australia for the first time. Since its inception the data have been used extensively for planning and reporting purposes and to:

- monitor trends in services and service user profiles;
- respond to public enquiries about services or service users;
- respond to ad hoc data requests from specific services or areas; and
- substantiate budget submissions relating to disability funding.

The process of review and redevelopment began in 1999 during the life of the second CSDA, when it was acknowledged that there was a significant change in the nature of service provision, information needs and availability of technology in use across the disability field.

The process focused strongly on asking policy makers and other stakeholders about their main information needs, as well as government departments responsible for CSTDA-funded services, CSTDA-funded agencies, service users, non-government organisations, carers, peak organisations and anyone else interested in the disability service field. The methodology employed throughout the project gave them the opportunity to comment, participate in and test the redeveloped collection. This process of extensive consultation and field testing ensured that the CSTDA NMDS reflected the information needs of the field and was a valuable process in strengthening relations with all stakeholders.

It was also necessary to consider:

- the feasibility of collecting meaningful information in this was – that is, from service providers in a national administrative data collection;
- the workload of service providers; and
- the extent to which the data could be considered as a genuine by-product or administrative necessity in the service delivery process.

The balancing of information needs and these practical considerations was essential to achieving the ‘vision’ outlined in Chapter 1.

Although the redevelopment process sought the information needs of policy makers and stakeholders, it was not possible to meet all of these fully in the redeveloped collection. A notable example of information needs not met by the collection is the issue of unmet needs for services, which was raised by a number of stakeholders. Various options were considered, but rejected on the grounds that this data collection vehicle might well yield unreliable data – for instance, double counting (if waiting list data are not well managed) or under-counting (because of undue focus on the needs of people known to existing services). There is further discussion of the processes of estimating unmet need in a recent AIHW study on this topic, including a discussion on the possible further development of registers and waiting lists producing unmet needs data aligned to the CSTDA NMDS service data (AIHW 2002b).

In the future, full-year data about service users and a number of new data items from the CSTDA NMDS collections will increase the power of the information collected and provide better outcomes for all major stakeholders. For people with disabilities, the data will be useful for evaluating the accessibility, appropriateness, efficiency and effectiveness of CSTDA-funded services. This should lead to improved services and outcomes. The data will also be more relevant to the needs of funded agencies, and will better inform government planning, service development and service delivery.

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Appendix 1: CSTDA NMDS 2002–03 Service Type Outlet and Service User forms

CSTDANMDS

Commonwealth-State/Territory Disability Agreement
National Minimum Data Set Collection

Name and Address (please correct any errors)

Service type outlet form 2002-2003

A separate Service type outlet form should be filled in for each CSTDA-funded service type outlet (i.e. for each CSTDA-funded service type provided at or from a given location). Your CSTDA funding department should have filled in items A-G before your agency received this form. Please check the responses using the Data Guide - pages 16-29, initially for any queries you may have.

A. Funded agency ID

B. Service type outlet ID

C. Service type .

D. Service type outlet postcode

E. Service type outlet SLA

F. Funding jurisdiction

G. Agency sector

Service type outlet name: _____

Funded service type: _____

Please verify the information provided above.

Please name a person in your service type outlet/funded agency who is involved in completing the forms and can be contacted about any queries. Please print.

Contact Name _____

Title or position _____

Email _____

Phone number

Fax number

Please turn over >

1. Has this service type outlet operated for the full 2002-03 financial year? Yes 1 No 2 See Data Guide page 30

2. How many weeks per year does this service type outlet usually operate? See Data Guide page 31

'No regular pattern of operation through a year' includes seasonal services such as Christmas holiday programs.

No regular pattern 90 OR

3. How many days per week does this service type outlet usually operate? See Data Guide page 32

'No regular pattern of operation through a week' includes school holiday programs.

No regular pattern 90 OR

4. How many hours per day does this service type outlet usually operate? See Data Guide page 33

'No regular daily pattern of operation' includes flexible hours, on call, 24 hour sleepover etc. Please do not provide the number of hours per week.

No regular pattern 90 OR

Staff hours: What were the total hours worked by staff (including those worked by contracted staff) and volunteers working on behalf of this service type outlet:

5. In the 7-day reference preceding the end of the reporting period?	Paid staff – paid hours worked by staff including contracted staff.	Unpaid staff – unpaid hours worked by staff and volunteers.	See Data Guide page 34
	a) <input type="text"/>	b) <input type="text"/>	

6. In a typical 7-day week?	Paid staff – paid hours worked by staff including contracted staff.	Unpaid staff – unpaid hours worked by staff and volunteers.	See Data Guide page 36
	a) <input type="text"/>	b) <input type="text"/>	

Please enter a dash (-) in the right hand box for any category where the value is 'nil'. Please round hours up to the nearest whole hour.

If the service type of this service outlet is 'Other support' (7.01–7.04) please do not complete question 7 and do not fill out any Service user forms.

7. How many service users received this service type from this service type outlet during the reporting period? See Data Guide page 37

Please do not provide numbers of 'beds' or 'places' or 'instances of service'.

Thank you for your time and effort.

Service user form 2002-2003

Service types 1.05-1.07, 2.06, 3.01, 3.03, 4.01-4.05 should complete *all* questions on this form for each service user who received a service within the reporting period. Service types 1.01-1.04, 1.08, 2.01-2.05 and 2.07 should complete all questions except 17f and 17g; service type 3.02 should fill out questions B, 1 and 2- Linkage key elements only; and service types 5.01 - 5.03 should fill out all questions except 12b-c and 12e (some carer questions).

B. Service type outlet ID

--	--	--	--	--	--	--	--

See Data Guide page 40

Please copy the Service type outlet ID from the related Service type outlet form.

1. Record ID

--	--	--	--	--	--

See Data Guide page 41

2. Statistical Linkage Key

2a. Letters of surname

1st	2nd	3rd	4th	5th	6th

See Data Guide page 42

2b. Letters of given name

--	--	--	--	--	--

See Data Guide page 43

2c. Date of birth

d	d	m	m	y	y	y	y

If not known, estimate year, enter 01/01 for day and month and tick 2d.

2d. Is the service user's date of birth an estimate?

Yes 1

See Data Guide page 46

2e. What is the service user's sex?

Male 1 Female 2

Service type 3.02 - Recreation/holiday program services, please stop here.

3. Is the service user of Aboriginal or Torres Strait Islander origin?

See Data Guide page 47

Aboriginal but not Torres Strait Islander origin 1

Torres Strait Islander but not Aboriginal origin 2

Both Aboriginal and Torres Strait Islander origin 3

Neither Aboriginal nor Torres Strait Islander origin 4

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 origin.

4. In which **country** was the service user **born**?

See Data Guide page 49

- | | |
|---|---|
| Australia <input type="checkbox"/> 1101 | Scotland <input type="checkbox"/> 2105 |
| England <input type="checkbox"/> 2102 | Greece <input type="checkbox"/> 3207 |
| New Zealand <input type="checkbox"/> 1201 | Germany <input type="checkbox"/> 2304 |
| Italy <input type="checkbox"/> 3104 | Philippines <input type="checkbox"/> 5204 |
| Viet Nam <input type="checkbox"/> 5105 | Netherlands <input type="checkbox"/> 2308 |

If other country please specify _____

Where the country of birth is known but is not specified in the classification, please specify it in the space provided.

5. Does the service user require **interpreter services**?

See Data Guide page 50

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

6. What is the service user's most effective **method of communication**?

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

See Data Guide page 51

This item is considered 'not applicable' to young children. Hence children aged 0-4 years should be coded as 'Child aged under 5 years'.

7. Does the service user usually **live alone** or **with others**?

See Data Guide page 52

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

'Usually' means 4 or more days per week on average.

The service user's living arrangements must relate to the same place described in residential setting (see question 9).

8. What is the **postcode** of the service user's usual residence?

See Data Guide page 53

The service user's postcode must relate to their residential setting (see question 9).

9. What is the service users usual residential setting?

See Data Guide page 54

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

The type of physical accommodation the person usually resides in ('usually' means four or more days per week on average).

10. What are the service user's primary and other significant disability group(s)?

a. Primary disability group

b. Other significant disability group(s)

<i>Tick 1 box only</i>	<input type="checkbox"/> 1	Intellectual	<input type="checkbox"/>
	<input type="checkbox"/> 2	Specific learning/ADD - other than Intellectual	<input type="checkbox"/>
	<input type="checkbox"/> 3	Autism - including Asperger's syndrome	<input type="checkbox"/>
	<input type="checkbox"/> 4	Physical	<input type="checkbox"/>
	<input type="checkbox"/> 5	Aquired brain injury	<input type="checkbox"/>
	<input type="checkbox"/> 6	Neurological - including epilepsy & Alzheimer's Disease	<input type="checkbox"/>
	<input type="checkbox"/> 7	Deafblind - dual sensory	<input type="checkbox"/>
	<input type="checkbox"/> 8	Vision	<input type="checkbox"/>
	<input type="checkbox"/> 9	Hearing	<input type="checkbox"/>
	<input type="checkbox"/> 10	Speech	<input type="checkbox"/>
	<input type="checkbox"/> 11	Psychiatric	<input type="checkbox"/>
	<input type="checkbox"/> 12	Developmental Delay - only valid for a child aged 0 – 5 years	<input type="checkbox"/>

Disability group(s) (other than that indicated as being 'primary') that also cause difficulty for the person.

See Data Guide pages 56-59

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

See Data Guide page 60

Please indicate the level of help or supervision required for each life area (rows a – i) by ticking only one level of help or supervision (columns 1 – 5).

<i>The person can undertake activities or participate in this life area with this level of personal help or supervision (or would require this level of help or supervision if the person currently helping were not available)</i>	1) Unable to do or always needs help/ supervision in this life area	2) Sometimes needs help/ supervision in this life area	3) Does not need help/ supervision in this life area but uses aids or equipment	4) Does not need help/ supervision in this life area and does not use aids or equipment	5) Not applicable
LIFE AREA a) Self-care e.g. washing oneself, dressing, eating, toileting	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	
b) Mobility e.g. moving around the home and/or moving around away from home (including using public transport or driving a motor vehicle), getting in or out of bed or a chair	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	
c) Communication e.g. making self understood, in own native language or preferred method of communication if applicable, and understanding others	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	
d) Interpersonal interactions and relationships e.g. actions and behaviours that an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	

In the following questions 'not applicable' is a valid response **only if the person is 0-4 years old.**

e) Learning, applying knowledge and general tasks and demands e.g. understanding new ideas, remembering, problem solving, decision making, paying attention, undertaking single or multiple tasks, carrying out daily routine	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
f) Education e.g. the actions, behaviours and tasks an individual performs at school, college, or any educational setting	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
g) Community (civic) and economic life e.g. recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

In the following questions 'not applicable' is a valid response **only if the person is 0-14 years old.**

h) Domestic life e.g. organising meals, cleaning, disposing of garbage, housekeeping, shopping, cooking, home maintenance	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
i) Working e.g. actions, behaviours and tasks to obtain and retain paid employment	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

12. Carer arrangements (informal)

See Data Guide page 63

The following questions are asking about the presence of an **informal carer** who provides support to the service user (i.e. these questions are **not about paid carers**)

12a. 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?

Yes 1 >Go to 12b No 2 >Go to 13

'Regular' and 'sustained' in this instance means that care or assistance has been ongoing, or likely to be ongoing for at least six months.

12b. Does the carer assist the service user in the area(s) of **self-care, mobility** or **communication**?

Yes 1 No 2

Questions 12b-e relate the informal carer identified in 12a

See Data Guide page 65

12c. Does the carer live in the **same household** as the service user?

Yes, Co-resident carer 1 No, Non-resident carer 2

See Data Guide page 66

12d. What is the **relationship** of the carer to the service user?

See Data Guide page 67

- | | |
|---|---|
| Wife/female partner <input type="checkbox"/> 1 | Daughter-in-law <input type="checkbox"/> 7 |
| Husband/male partner <input type="checkbox"/> 2 | Son-in-law <input type="checkbox"/> 8 |
| Mother <input type="checkbox"/> 3 | Other female relative <input type="checkbox"/> 9 |
| Father <input type="checkbox"/> 4 | Other male relative <input type="checkbox"/> 10 |
| Daughter <input type="checkbox"/> 5 | Friend/neighbour – female <input type="checkbox"/> 11 |
| Son <input type="checkbox"/> 6 | Friend/neighbour – male <input type="checkbox"/> 12 |

When answering this question complete the sentence **The carer is the service user's...**

This question relates to the informal carer identified in 12a

12e. What is the **age group** of the **carer**?

See Data Guide page 69

- | | |
|---|--|
| Less than 15 years <input type="checkbox"/> 1 | 45 - 64 years <input type="checkbox"/> 4 |
| 15 - 24 years <input type="checkbox"/> 2 | 65 years and over <input type="checkbox"/> 5 |
| 25 - 44 years <input type="checkbox"/> 3 | |

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.

Only complete question 13 if the service user is aged under 16 years.

13. If aged under 16 years: do the service user's parents or guardians receive the **Carer Allowance (Child)**?

See Data Guide page 70

Yes ₁ No ₂ Not known ₃

This question is not asking about Carer Payment even though some parents of children aged less than 16 years receive it in addition to Carer Allowance (Child).

Only complete question 14 if the service user is aged 15 years or more.

14. If aged 15 years or more:

See Data Guide page 71

What is the service user's **labour force status**?

Employed ₁ Unemployed ₂ Not in the labour force ₃

Only complete question 15 if the service user is aged 16 years or more.

15. If aged 16 years or more:

See Data Guide page 73

What is the service user's **main source of income**?

Disability Support Pension ₁ Other income ₅
Other pension or benefit ₂ Nil income ₆
Paid employment ₃ Not known ₇
Compensation payments ₄

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.

Continue questions for service users of all ages.

16. Is the service user currently receiving individualised funding under the CSTDA?

Yes ₁ No ₂ Not known ₃

See Data Guide page 74

17. Services received 2002-2003

For service types 1.05–1.07, 2.06, 3.01, 3.03 and 4.01–4.05 complete all sections (a) to (g).
For all remaining service types (except 3.02, 6.01-6.05, 7.01-7.04), please complete sections (a) to (e) only.

Responses to the remaining questions must relate to the service type outlet ID indicated in data item B of the Service user form.

Note: if the service user received more than 1 service type from your agency you will need to complete a separate Service user form (see Data Guide page 15).

17a. When did the service user commence using this service type?

d	d	m	m	y	y	y	y

See Data Guide page 77

A service is a support activity delivered to a person, in accord with the CSTDA. 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 CSTDA.

17b. When did the service user last receive this service type?

d	d	m	m	y	y	y	y

See Data Guide page 78

17c. Did the service user receive this service type on the snapshot day?

Yes 1

No 2

See Data Guide page 79

17d. When did the service user leave this service type?

See Data Guide page 80

d	d	m	m	y	y	y	y

*If the service user is still with the service leave blank and
>Go to question 17f*

A service user is considered to leave a service when either:

- 1. the service user ends the support relationship with the service outlet;*
- 2. the service outlet ends the support relationship with the service user; or*
- 3. twelve months have elapsed since the service user last received support.*

**Only answer this item, if Item 17d has been coded
(i.e. the service user is no longer receiving the service).**

17e. What reason did the service user report for leaving this service?

Service user no longer needs assistance from service type outlet – moved to mainstream services 1

See Data Guide page 81

Service user no longer needs assistance from service type outlet – other 2

Service user moved to residential, institutional or supported accommodation setting 3

Service user's needs have increased – other service type required 4

Services terminated due to budget/staffing constraints 5

Services terminated due to Occupational Health and Safety reasons 6

Service user moved out of area 7

Service user died 8

Service user terminated service 9

Other 10

Questions 17f and 17g only need to be completed by service types 1.05–1.07, 2.06, 3.01, 3.03 and 4.01–4.05.

Hours received – please indicate the **number of hours** of support received by to the service user for this CSTDA service type:

The amount of CSDA-funded support received by a person for this CSDA service type during the reporting period.

17f. In the 7-day reference week preceding the end of the reporting period?

See Data Guide page 83

17g. In a typical 7-day week?

See Data Guide page 85

Thank you for your time and effort.

Appendix 2: Facilitation and Implementation Group representatives on the CSTDA NMDS

Chair	Ching Choi (AIHW) (December 2000 – February 2002) Diane Gibson (AIHW) (March 2002 – October 2002)
Australian Institute of Health and Welfare – Project team	Ros Madden (December 2000 – October 2002) Louise York (December 2000 – October 2002) Chrysanthe Psychogios (December 2000 – October 2002)
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South Australia – Department of Human Services	Mike Griffiths (December 2000 – October 2002)
Tasmania – Department of Health and Human Services	John Nehrmann (December 2000 – October 2002) Annie Curtis (April 2002– October 2002)

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Commonwealth – Department of Family and Community Services	Celia Poole (December 2000 – August 2001) Michael Cooper (August 2001 – October 2002)
ACROD	Helen McAuley (December 2000 – August 2001) Sean Regan (August 2001 – August 2002)
National Caucus of Disability Consumer Organisations	Julie Simpson (December 2000 – August 2002)
Non-government Organisation (Mission Australia)	Peter Sandeman (December 2000 – August 2001)