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/combination 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.

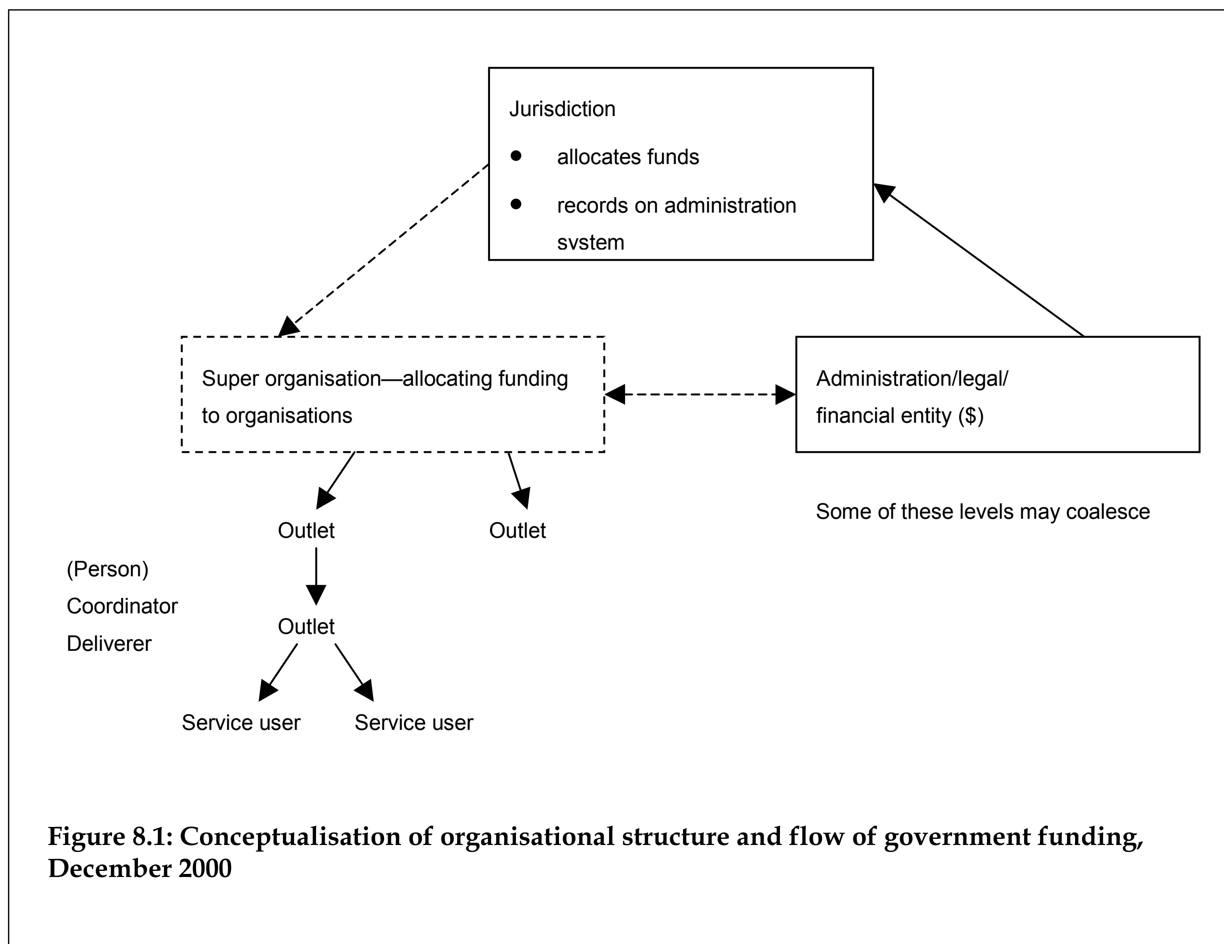


Figure 8.1: Conceptualisation of organisational structure and flow of government funding, December 2000

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.*

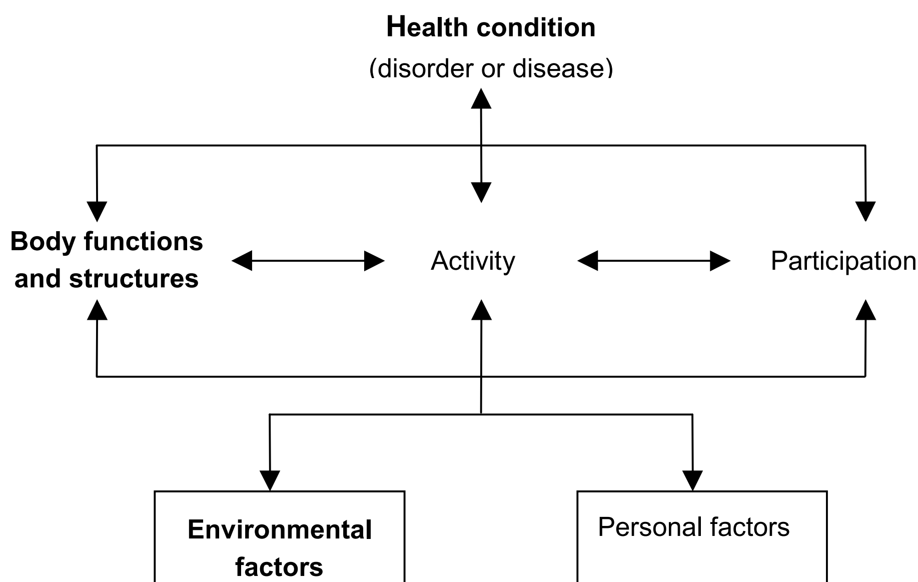
Activity *is the execution of a task or action by an individual.*

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 CSDA 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 CSDA 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 CSDA 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, relatability 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

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[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.

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[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 agued 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
	1. Full participation **2. Mild participation restriction** **3. Moderate participation restriction** **4. Severe participation restriction** **5. Complete participation restriction**	**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**
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)		
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)		
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)		
Participation in interpersonal interactions and relationships (e.g. relating with strangers, formal and information social relationships, family and intimate relationships)		
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)		
Participation in economic life (e.g. basic and complex economic transactions, economic self-sufficiency)		
Participation in community, social and civic life (e.g. community life, religion and spirituality, recreation and leisure, political life and citizenship, human rights)		

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 NCSDD[5]); 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	• 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: • 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: • group home/hostel** • residential** • other** (f) Support needs profile of people in different service types and living arrangements* (g) Reason for cessation of services***

Key for indicator availability

* 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'

(continued)

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

CSDA service type	Purpose (CSDA)	Classification	Objectives/goals	Suggested indicators
Accommodation support (continued)	*Interpretation of the purpose* 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.		'…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).	(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*

(continued)

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

CSDA service type	Purpose (CSDA)	Classification	Objectives/goals	Suggested indicators
Community support	Community support services provide the support needed for a person with a disability to live in a non-institutional setting. *Interpretation of the purpose* 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.	2.04 Early childhood intervention 2.06 Therapy (PT OT ST) 2.07 Family/individual case practice/ management 2.08 Behaviour intervention/ specialist intervention 2.09 Counselling: individual/family/ group 2.10 Brokerage/direct funding 2.11 Mutual support/self-help groups 2.13 Resource teams/ regional teams 2.05 Recreation/holiday programs	• Improve delivery early childhood intervention services • Preparation to live in the community • Access to services • Provision of information • Number of people helped For example: '…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). '…supports best practice in recreation services and reduces gaps and duplication of services' (WA annual report, 1999–2000:48).	(a) Trends over time: • living arrangements* • presence of carer and carer characteristics**** (b) Support needs profile of people in different service types* (c) Quantity of support for different service types** (d) Percentage of people with individual packages*** • service mix** • support needs** (e) Reason for cessation of services*** (f) Instances of community support—constructed using start dates***

(continued)

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

CSDA service type	Purpose (CSDA)	Classification	Objectives/goals	Suggested indicators
Community support (continued)		2.12 Print disability	'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).	
Print disability	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.			
Advocacy	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.	2.01 Advocacy 2.02 Information/referral 2.03 Combined advocacy/ information 2.14 Other community support		
Information	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.			

(continued)

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

CSDA service type	Purpose (CSDA)	Classification	Objectives/goals	Suggested indicators
Community access	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.	3.01 Continuing education/ independent living training/adult training centre 3.02 Post -school options/ social and community support/community access 3.03 Other community access and day programs	• Transition • Skills development • Support to carers • Number of people helped For example: '…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). '…support for day activities which offer people a range of options in skill development, community access, and recreation activities' (ACT annual report, 1999:29). '…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).	(a) Community access services relative to the 'potential population'* (b) Trends over time in terms of transition: • to other services* • in labour force status*** • living arrangements* • participation module*** (c) Instance of community access—constructed using start dates *** (d) Per cent of consumers with individual support packages and when they were last reviewed*** (e) Support needs profile of consumers across service types: • accommodation support, community support, transiting to other services vs those staying* (f) Carer relationship and age*** (g) Reason for cessation of services*** (h) Participation module (i) Skill development (hard area, linkage key within CSDA program but a lot may be outside CSDA—how to monitor without 'tick box' approach?)

(continued)

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

CSDA service type	Purpose (CSDA)	Classification	Objectives/goals	Suggested indicators
Respite	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	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	• Duration of respite care • Families with carers • Enhancing flexible range of options For example: '…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).	(a) Duration of respite: • hours of respite*** • days in respite*** (b) Presence of carer: • age of carer and relationship to recipient**** • age of recipient with carer**** (c) Duration of living arrangements* (d) Support needs profile of people in different service types* (e) Multiple service usage between respite and other services* • host family support, in-home and community based support (f) Per cent of respite beds being used for long term accommodation — how do we get to this? (g) Reason for cessation of services**** (h) Instances of respite — constructed by examining number of start dates over a year*** (i) Trends in respite care across years — linkage key* (j) ABS number of carers who cannot get respite care (i.e. population measure of overall success of respite program)

(continued)

Table 8.5 (contined): 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	• Duration of employment • Transition 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).	(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: • 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 testing 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 HACC MDS

CSTDA NMDS data items	Relationship to NCSDDv2.0 and HACC MDS
Service form: items provided by funding department	
A. *Funded agency ID*	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. *Service type outlet ID*	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 reference week.
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. Service type outlet ID(s)	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. Birth date estimate flag	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. Interpreter services required	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. Service user postcode (H)	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. Carer – existence of (H)	Consistent with **Carer availability** in the NCSDD and HACC MDS.
12b. Carer – primary status	No similar NCSDD data element.
12c. Carer –residency status (H)	Consistent with **Carer co-residency** in the NCSDD and HACC MDS.
12d. Carer – relationship to service user (H)	Maps to **Relationship of carer to care recipient** in the NCSDD (more categories in CSTDA NMDS) and HACC MDS.
12e Carer – age group	No similar NCSDD data element.
13. Receipt of Carer Allowance (Child)	No similar NCSDD data element.
14. Labour force status	Consistent with **Labour force status.**
15. Main source of income	Likely that this maps to **Sources of cash income.**
16. Individual funding status	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 <u>each</u> service type received in the reporting period (per service user)	
17a. Service start date	Consistent with **First service start date.**
17b. Date service last received	Is a special case of **Assistance received date.**
17c. Snapshot date flag	No similar NCSDD data element.
17d. *Service exit date*	Consistent with **Last service contact date.**
17e Main reason for cessation of services (H))	Maps with some ambiguity to NCSDD **Service cessation reason** (more categories in CSTDA NMDS). Consistent with HACC MDS.
17f. Hours received (reference week)	Relates to **Assistance received (concept)**. CSTDA item looks at the actual hours of service received in a <u>reference</u> week.
17g. Hours received (typical week)	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