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Inquiry into the funding and operation of the Commonwealth State/Territory Disability Agreement—AIHW response to questions on notice

On 13 October 2006, members of the AIHW, including myself, attended the above inquiry.

Please find attached the AIHW responses to two questions on notice, namely:

1. AIHW advice on how disability services data could be structured to better inform policy (Senator Patterson)
2. AIHW advice on the most appropriate research program that should be undertaken in relation to disability in Australia, particularly on the issue of unmet need for services (Senator McLucas).

For further information on this information, please contact Louise York, Acting Head, Functioning and Disability Unit on louise.york@aihw.gov.au or 6244 1271.

Yours sincerely

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Issue 1: Improving the policy-relevance of disability services data

1. Purpose

The Senate Community Affairs Committee has asked the AIHW to produce a paper indicating how disability services data could be structured to provide more policy-relevant information.

2. Background

The AIHW has been the national coordinator for the Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS) collection since it commenced in 1994. The CSTDA NMDS collection produces information about services provided or funded by State, Territory and Australian governments under the CSTDA and the people accessing these services.

The AIHW has a long-standing commitment to pursuing high quality disability services data and completely funded its work on the CSTDA NMDS from 1994 to 2003 from its core appropriation funding. In light of the lack of growth in this funding, the increasing complexity of the disability services field, and the increasing information needs of disability administrators, the AIHW successfully negotiated an agreement with the disability administrators to fund part of the Institute's role in the CSTDA NMDS. From 2003–04, the AIHW and the Disability Policy and Research Working Group (DPRWG) have jointly funded the coordination of the CSTDA NMDS collection under a Memorandum of Understanding with FACSIA.

From 1994 to 2002, national disability services data were collected on one 'snapshot day' each year. Following a substantial redevelopment exercise between 1999 and 2002, a new CSTDA NMDS was implemented in 2002. Full-year data, including expanded information in specific areas, has been available from 2003–04. The latest AIHW publication on the collection, *Disability support services 2004–05*, was published on 31 August 2006.

3. AIHW recommendations

The policy relevance of information collected under the CSTDA NMDS could be improved in seven key areas—grouped into two clusters:

(A) Adding new data items (on funding, outputs and outcomes)

(B) Improving the quality of data already available.

The following pages provide details of these seven key areas of data improvement (section 4) along with current or planned activities to make such improvements (section 5).

Many of the Institute's recommended areas of data improvement are already on the agenda of the DPRWG and AIHW involvement in progressing them appears likely. However, while the AIHW is keen to work with the DPRWG to improve the quality of existing data and assist in specifying the types of additional data that could inform the new CSTDA4 performance reporting framework, there are limits in the extent to which these efforts will lead to improved data. The impact of these efforts will be limited unless there is a significant injection of funds to support both jurisdictions and funded agencies to meet their obligations to provide quality data which informs the objectives of the CSTDA. Clear provisions in the new CSTDA4 around funding for data improvement and enhancement to support its new performance reporting framework are required.

4. Improving the policy-relevance of the CSTDA NMDS

(A) Adding new data items

1. Improved CSTDA expenditure data

Figure 1 provides a simple conceptualisation of the flow of funding and information between jurisdictions, agencies, service type outlets and service users. In some cases, the levels are one and the same (e.g. the jurisdiction funds service type outlets directly, the funding is provided directly by jurisdictions to service users). Information provided at the service type outlet level includes staff hours, weeks of operation per year, and hours of operation per day. Information provided at the service user level includes disability group, support needs, carer arrangements and quantity of service received (for selected service types only). The CSTDA NMDS includes identifiers at both the agency and service type outlet level so that the relationship between agencies and service type outlets can be established.

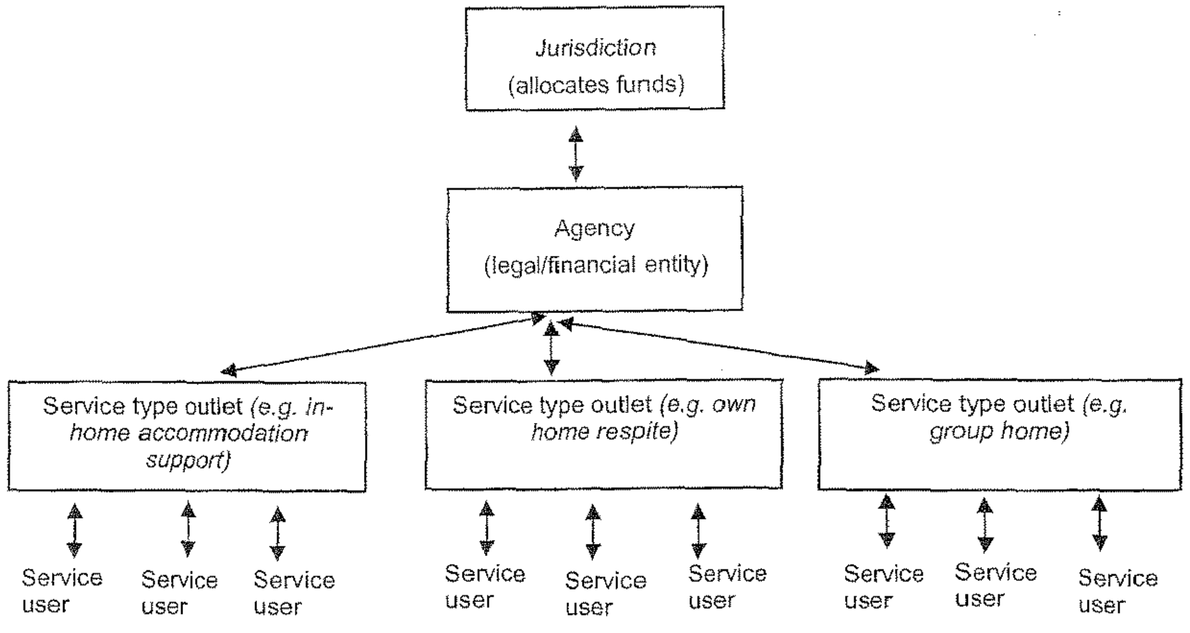

Figure 1: CSTDA NMDS conceptualisation of organisational structure and flow of government funding

Source: Adapted from AIHW 2002 Australia's national disability services data collection: redeveloping the CSTDA NMDS

There is wide variation in the level of detail jurisdictions are able to provide about how they spend CSTDA funding. A small number of jurisdictions are able to supply CSTDA funding data at the service type outlet level (i.e. funding is attributed to the level at which the service is provided); some jurisdictions at the higher agency level (the overarching organisation which provides one or more CSTDA service types); while others are not currently able to report data at either level.

There are many potential uses of expenditure data if it were available at the service type outlet level, including:

- Expenditure per service user and per outlet could be calculated for each service type (e.g. in-home respite, centre-based respite, group homes, in-home accommodation support, early childhood intervention).
- Comparisons between service user data and expenditure data could be based on actual data received – meaning that there would be no need to account for response rates.
- A range of data items could then be cross-tabulated to produce information on efficiency and performance. For example, expenditure could be related to any of the service type outlet items such as staff hours, operation times, agency sector; or could even be directly compared with measures of service quantity such as hours of service received.
- Costs could also be compared to various client profiles, for example, funding in relation to particular disability groups or level of support needed.

2. Improved information about the quantity of services received by CSTDA service users

It is not currently possible to accurately compare hours received by service users across all service types and jurisdictions. While the current CSTDA NMDS includes a number of measures of hours of service received by service users (i.e. hours received in a typical week, hours received in the reference week), such information is only available for selected service types and both pieces of information are not provided by all jurisdictions. These quantity measures were selected for inclusion in the redeveloped CSTDA NMDS in 2002 following extensive consultation with jurisdictions and service providers and reflect a compromise to suit their varying business processes and information requirements.

Improved information about quantity of services received would enable the following types of questions to be answered for the first time:

- What was the average quantity of service received from community access programs? How did this vary for therapy services, early childhood intervention services and counselling services? What proportion of service users living in the community received less than 5 hours of support per week? Does this quantity appear to vary in relation to the person's support needs, carer availability, disability group or geographic location within Australia?

3. Improved information about outcomes for CSTDA service users

The current CSTDA NMDS does not include measures or indicators of individual 'outcomes' or quality of life. Methods for collecting such information were developed and tested during the redevelopment of the collection in 1999–2002. The proposed 'participation module' was designed to enable jurisdictions to collate information collected from service providers and service users in various ways into a common framework, for national comparison. Agreement could not be obtained from all jurisdictions to incorporate this information in the redeveloped CSTDA NMDS and it was therefore excluded from the national collection. Such information, collected directly from service users via appropriately tested mechanisms such as consumer ratings surveys and quality of life measures (in the presence of advocates where necessary) and/or through individual planning processes with service providers, could look both at an individual's 'extent of participation' in various life areas and their 'satisfaction with participation'.

Improved information about outcomes for services users would inform the objectives of the CSTDA itself. For example, it would be possible to explore the extent to which CSTDA service users participate in a broad range of life areas such as recreation, communication with family and friends, employment or education and how they (and their carers and advocates) rate their satisfaction with this level of participation.

(B) Improve the quality of the information we already have

4. Improved coverage of CSTDA-funded services reporting under the CSTDA NMDS

The CSTDA NMDS is designed to collect administrative data on *all* CSTDA-funded services throughout Australia and all people who access these services over a financial year (that is, coverage similar to a census). In practice, however, response rates are not 100%. In the two most recent collections, service type outlet response rates were reported to be 93–94%, with marked variation across jurisdictions. Improved coverage of CSTDA-funded services would increase the accuracy of information about the number and types of services available to people with disabilities throughout Australia. This would also contribute to a more accurate estimate of the number of services users accessing CSTDA-funded services and, therefore, a more accurate indictor of met demand for people with disabilities (although not accounting for under-met demand).

Improvement in the coverage of CSTDA-funded services would enable the following types of questions to be answered more accurately:

- How many organisations were funded in Australia in the last financial year and which service types did they provide? How did this vary within and across jurisdictions? How does this profile of service provision compare with previous years?

5. Improved coverage of service users receiving CSTDA-funded services

It is very difficult (if not impossible) under the current CSTDA NMDS collection to accurately estimate the number of service users that are missing from the collection. Service users can be excluded from the national data either because they receive services from a non-responding outlet or because their outlet does not provide data in relation to all service users. A current question designed to double check for missing service users is not well completed by outlets. Missing or incomplete information about people receiving CSTDA-funded services clearly limits the accuracy of annual estimates of the number of service users as well as information about their profile (e.g. in terms of demographic information, support needs, disability group and service type(s) received).

An accurate estimate of service user numbers is also currently affected wherever service type outlets do not supply valid statistical linkage key information for service users (i.e. selected letters of name, sex and date of birth). This reduces the capacity for the state/territory or AIHW to account for duplicate records for the service user and can lead to an overestimate of the number of service users in some outlets, and potentially jurisdictions.

Improvement in the coverage of CSTDA NMDS service users would enable the following types of questions to be answered more accurately:

- How many CSTDA services users were there in New South Wales last year and how did this compare to Victoria and Queensland? How many service users accessed therapy or early intervention services funded under the CSTDA during the financial year and how did these numbers compare across jurisdictions?

6. Reduction in missing data for individual items

The full-year CSTDA NMDS collection is still experiencing higher levels of 'not stated' and 'not known' responses for individual data items, compared with the former 'snapshot day' collection. For example, some data items had very high 'not stated' rates for the 2004–05 data collection (Indigenous status 21%, primary disability 16%, existence of informal carer 20%), affecting the interpretability of these items within the reporting year and the comparability of these items across different collection years.

A reduction in the level of missing data provided under the CSTDA NMDS would enable the following types of questions to be answered more accurately:

- What was the profile of service users accessing counselling funded under the CSTDA (e.g. disability group, support needs, carer availability) and how did this differ across jurisdictions?) How many people with intellectual disability accessed CSTDA-funded services this financial year and how does this compare with previous years? Are CSTDA service users more or less likely to have an informal carer living with them this year compared to last year?

7. Increase comparability of collection scope across states and territories

Comparability of CSTDA NMDS data across states and territories is complicated by variation in the service types funded under the CSTDA (and therefore included in the CSTDA NMDS). For example:

- Three jurisdictions include users of psychiatric-specific services in the CSTDA NMDS while the other jurisdictions do not. The bulk of mental health services are funded and provided under the health portfolio, but in some cases these services do receive some CSTDA funding.
- Most but not all jurisdictions include early intervention services under the CSTDA.
- Jurisdictions appear to vary in the extent to which they fund therapy services from within the CSTDA or elsewhere.

Improved understanding of where these differences lie and how they affect the CSTDA NMDS data, would improve its interpretability and enable clearer cross-jurisdiction comparisons.

5. Current and planned activities to improve information from the CSTDA NMDS

Efforts to improve the quality of existing CSTDA NMDS data are already on the DPRWG agenda. The DPRWG has asked the CSTDA NMDS Data Network (a sub-committee of the DPRWG, of which the AIHW is secretariat) to develop and implement a data quality framework during 2006–07. The goal of this activity is to improve CSTDA NMDS data quality and the new data quality framework will include strategies for improving and monitoring progress against areas 4–6 above. A report on this work will be provided to the DPRWG in May 2007.

Area 7 will be addressed to some extent in the CSTDA NMDS Data Network data quality activities during 2006–07. However, the lack of comparability in some areas of the CSTDA NMDS largely relates to the scope of which service types are funded in each jurisdiction under the CSTDA. This lack of comparability across jurisdictions is most evident in service types that are closer to the 'interface' between specialist disability services and the broader generic health system. For example, variation across jurisdictions in the types of services funded under the CSTDA (and reported under the CSTDA NMDS) is particularly likely in service types such as early childhood intervention, therapy services and services for people with psychiatric disability.

Improvements in funding, output and outcome data may also be driven to some extent by the development of a new CSTDA performance reporting framework to support CSTDA4. The DPRWG has indicated its interest in the AIHW being involved in the revision of the performance reporting framework and the AIHW welcomes this opportunity. Funding, output and outcome data items were all the subject of extensive work, including consultation with jurisdictions and service providers, during the redevelopment of the CSTDA NMDS (1999–2002). While such information was not eventually included in the redeveloped collection, much of the data development work has been done. This past work could now be revisited and built on with new consultation, data development and field testing to improve data in these areas in the future. Such consultation would need to focus on the needs of policy makers as well as the information needs, current practices and possible respondent burden placed on service outlets and service users.

Issue 2: Research program to inform CSTDA

Purpose

The Senate Community Affairs Committee has asked the AIHW to produce a paper about the most appropriate research program that should be undertaken in relation to disability in Australia, particularly on the issue of unmet need for services.

Background

Under the CSTDA:

> 'people with disabilities' means people with disabilities 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 significant ongoing and/or long-term episodic support and which manifests itself before the age of 65' (2003 CSTDA).

'The following objective underpins the national framework for services for people with disabilities:

> The Commonwealth and States/Territories strive to enhance the quality of life experienced by people with disabilities through assisting them to live as valued and participating members of the community' (2003 CSTDA).

Beyond these high level statements of the target group and objective of the Agreement, CSTDA-funded services are currently delivered across states and territories in the absence of nationally comparable eligibility requirements, assessment methods or waiting list systems.

In this environment, the AIHW has conducted various studies into unmet demand for CSTDA services, published in 1995, 1997 and 2002. In the 2002 study, the extent of *demand* was estimated using detailed analysis of the ABS Survey of Disability, Ageing and Carers. These population estimates of demand were cross-checked with available information from jurisdiction waiting lists (where in existence) and views from peak bodies and other stakeholders. Information about the *supply* of services under the CSTDA has been obtained from the CSTDA NMDS. These basic elements of the methodology have been used in each study.

Under the terms of the current CSTDA, the Australian government matches contributions by state and territory governments to a Research and Development Trust Fund. The annual research and development budget throughout CSTDA3 (2002–07) has been $400,000 per annum. The AIHW role as CSTDA Data Agency is funded from this budget (at a cost of approximately $150,000 per annum). During the period 2002–07, no funds from this budget have been directed to data quality improvement.

Priority areas for research

Priority areas for research and analysis that could inform the CSTDA and related policies are:

- Improve disability services data collected under the CSTDA NMDS in the seven key areas identified by the AIHW (see Issue 1 on improving the policy-relevance of the CSTDA NMDS).
- Improve the availability of information about met and unmet demand for disability services. Any data improvements in the CSTDA NMDS will only improve the quality and relevance of information about the supply of disability services under the CSTDA. Research into met demand, unmet demand and under-met demand, as published by the AIHW in 1995, 1997 and 2002, will periodically provide information about the extent to which this supply of service is meeting the needs of the CSTDA target group. Such specialised research will continue to be required in the absence of routine, coordinated and nationally comparable data about the demand for these services. Work in this area is on the current Disability Policy and Research Working Group agenda but has been suspended until the new CSTDA is signed.
- Ensure that future work on met and unmet demand for disability services extends to analysis of community support services. This is a particularly complex service area, requiring special research, data analysis and consultation. Given the recent increase in the provision of community support services under the CSTDA, it appears necessary to conduct a study on demand and unmet demand for these particular support services.
- Conduct analysis of multiple data sources, both administrative data and population survey data, to research the interfaces between disability, aged care, mental health and other health and community service programs. Data linkage of existing services data such as the CSTDA NMDS and the HACC NMDS is an important component of this work. Such data linkage work is feasible although resource intensive both technically and in terms of the negotiation and liaison required with data custodians and ethics committees. Such analysis would provide information about the extent to which people (across different ages, living arrangements, locations etc.) use CSTDA, HACC or a combination of CSTDA and HACC services. Such analysis could therefore inform future policy and planning around these programs.
- Increased research effort into the health of people with disabilities. This would include continued efforts by the AIHW and others to promote the inclusion of disability data items in relevant ABS surveys, particularly the National Health Survey and other appropriate administrative data collections.
- Work on interfaces between CSTDA-funded services and other services could be extended to include a systematic review of national equipment services, focusing on the improvement of nationally comparable information available on these services. While equipment services are currently funded outside the CSTDA, such a study could explore the impact of unmet demand for equipment services on CSTDA-funded services and their clients.