

Collecting data on disability services

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Important components in developing administrative data collections

- Identify information needs: what do policy makers and stakeholders need to know?
- What data items will produce this information?
- Seek consensus and national consistency—extensive discussion and consultation with stakeholders
- Consistency with key disability concepts and other data collections (via ICF and national data dictionary)
- Field testing of data items
- Good documentation, including data guides and related materials to support those collecting the data

The Australian disability services data collection

- CSTDA National Minimum Data Set (CSTDA NMDS)
 - An agreed minimum set of nationally agreed data items and an agreed method of collection and transmission
 - Data relate to any service funded under the CSTDA, and consumers
 - Services covered: Accommodation support, Community support, Community access, Respite, and Employment services

Data items on consumers

- Demographics (7 data items)
- Living arrangements (3 items)
- Work, income and funding (4 items)
- Carer information (5 items)
- Service user's disability (5 items)
- Services received (7 items)

Data guides for administrative data collections

- Ensure data are collected consistently to maximise data quality
 - Explain overall purpose, content and structure of the collection
 - Define the scope, key concepts and counting rules of the collection
 - Provide data definitions, coding classifications, and coding guidance

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

	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					
b) Mobility					
c) Communication					
d) Interpersonal interactions and relationships					
e) Learning, applying knowledge and general tasks and demands					
f) Education					
g) Community (civic) and economic life					
h) Domestic life					
i) Working					

An example: the CSTDA NMDS support needs item (1)

- Question: How often does the service user need personal help or supervision with activities or participation in the following life areas?
- Defined as: The need for personal help or supervision in each of the areas of:
 - a. Self-care—activities such as washing oneself, dressing, eating and/or toileting;
 - ...

An example: the CSTDA NMDS support needs item (2)

- Classification: The person can undertake activities or participate in this life area with this level of personal help or supervision:
 - 1 Unable to do or always needs help or supervision in this life area.
 - 2 Sometimes needs help/supervision in this life area.
 - ...

***An example: the CSTDA
NMDS support needs item (3)***

■ Guide for use:

- This question records information about a person's need for help or supervision in their overall life to enable comparison with population data and across CSTDA-funded service types.
- This means that a need for help or supervision in a particular area may, or may not, be directly relevant to the service being provided.

...

***An example: the CSTDA
NMDS support needs item (4)***

■ Examples:

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

***An example: the CSTDA
NMDS support needs item (5)***

- When to use 'not applicable' ...
- Why is this data item collected? ...
- Example of how this data item is used
 - Data collected using this data item can be compared with population data to examine the access of various groups of people with disability to CSTDA service

***Other information to include
in a data guide***

- How the data should be transmitted to the central collection agency
- When the data should be transmitted
- How the data will be used and reported
- Who can provide advice on collecting data

Important considerations

- Data providers should be able to understand the data guide and other collection materials
- Data providers should have input into the development of the data guide
- The data guide should be field tested and reviewed to ensure it 'works'