



The Australian Institute of Health and Welfare (AIHW) first submission to Inquiry into Disability Care and Support (16 August 2010)

This AIHW submission informs the Inquiry into Disability Care and Support. It describes some broad data issues that may have an impact on establishing and monitoring a new national disability care and support system. It also provides a list of recent AIHW reports on disability prevalence, disability services and assistance in Australia. These are available from the AIHW website and may be of use to those undertaking the enquiry.

AIHW notes that a comprehensive data collection, analysis and reporting system will be necessary to monitor costs, service delivery and outcomes. Such a data system should be developed at the time any new disability care and support system is put into place – not retrofitted. Development of a high quality data system requires early involvement of the relevant data agencies.

National data development and collaboration

To ensure effective collection, sharing and reporting of Disability Care and Support information, jurisdictions and providers will need to adopt a cooperative approach so that essential, accurate, reliable, timely and nationally consistent information is available nationwide about the Disability Care and Support system. This approach will need to be facilitated through agreed rules regarding collection, compilation, interpretation, reporting and sharing of national information. This includes agreed data standards, definitions, classifications and protocols for data collected for the purposes of national information.

Principles include

- Minimise duplication of data collections through a focus on collaborative development of data sources suitable for reuse for a range of information requirements.
- Consider data standardisation to promote consistent reporting and facilitate linking of data from multiple sources and /or sectors.
- Consider and recognise that each jurisdiction has own objectives service, standards, data, performance indicators and reporting goals when creating national reporting requirements.

Need for improving and redeveloping disability data collections

The shift towards person-centred service delivery has the potential to change the way that services are arranged and provided in a new system. This requires redeveloping the

disability service data collections that can report the process of new approaches to service delivery. Substantial resources and a strategic approach are needed to redevelop the existing disability data collections and improve the scope, quality and consistency of data for measuring and benchmarking need and unmet demand for disability services and assistance.

Data on outcomes of person-centred services

There is a growing need for person-centred rather than service program-centred information. The focuses of existing disability services data collections are on service types and outputs, that is, the number of and amount of different types of services received and the number of people who receive them. Little information is being collected about individualised funding specifically and individual support arrangement in general. The current data collections contains no information about whether services offered or accessed are those needed or chosen by people with disability. Capturing this type of information requires significant systems and data redevelopment effort.

Data linkage and use of common disability identifiers across community services collections

People with disability, like the general population, rely on a range of government-funded services to meet their various care and support needs. Disability specialist services alone cannot meet all the needs of people with disability. There are recognised strong links between specialist disability services and community services and other generic mainstream services. Therefore, there is a need for cross-sectoral data that crosses service program boundaries.

Possible options for data linkage and cross-sectoral disability data collections include:

- To adopt a standard disability identifier and require common disability data elements to be collected across community services and other mainstream services data collections
- To foster and develop data linkages between collections of specialist disability services, community services and other mainstream services.
- To investigate the possibility of data linkage between the ABS population disability survey and Census and other administrative data collections on services

Improvement in measures and data collections on need and unmet demand for disability services

While the existing Disability Services National Minimum Data Set is a valuable source of nationally consistent data on the supply of disability specialist services, currently it does not collect information on need and unmet demand for disability services. The ABS Survey of Disability, Ageing and Carers does not directly provide information on need and unmet demand for specific types of disability services. The existing jurisdiction data on unmet demand are incomplete, inconsistent and subject to various data issues. These data gaps highlight the importance of the development work on consistent definitions and improved measures and data collections of need, demand and unmet demand for disability related services and assistance.

Improvement in the coverage, quality and consistency of data on informal carers

The contribution of, and impact on, informal care arrangements are important issues in considering the new service system. While a number of different data collections on informal carers are available, the data are inconsistent and fragmentary and the coverage of the data is

limited. It is important to develop an integrated national approach to improve and redevelop the existing data collection in carers for information about needs of informal carers and how to support them.

Other potentially useful data sources

Medical Indemnity National Collection (MINC)

The AIHW is the national data custodian of public sector medical indemnity data. In this role, it is responsible for the collection, quality control, management and reporting of the data. AIHW also presents combined public and private sector medical indemnity data to give a national picture of medical indemnity claims in Australia. The Medical Indemnity National Collection (MINC) assist policy makers in developing measures to minimise the incidence of medical indemnity claims and the associated costs.

Australian Spinal Cord Injury Register (ASCIR)

The Australian Spinal Cord Injury Register (ASCIR) is a national register of incident cases of spinal cord injury which occur in Australia and overseas to Australian residents. The ASCIR operates as a collective venture of the Directors of all six spinal units (SUs) in Australia and the National Injury Surveillance Unit (NISU), a Collaborating Unit of the Australian Institute of Health and Welfare (AIHW). The data include clinical information on the type of neurological damage (paraplegia, quadriplegia) that would be useful for consideration of disability.

AIHW recent reports on disability, disability services and assistance in Australia

Recent publications (Available online at www.aihw.gov.au/publications)

AIHW 2001. Australia's welfare 2001. AIHW cat no. AUS 41. Canberra: AIHW.

AIHW 2002. Unmet need for disability services: effectiveness of funding and remaining shortfalls. AIHW cat. no. DIS 26. Canberra: AIHW.

AIHW 2003a. Australia's welfare 2003. AIHW cat. no. AUS 41. Canberra: AIHW.

AIHW 2003b. Disability prevalence and trends. Disability series cat. no. DIS 34. Canberra: AIHW.

AIHW 2003c. Disability: the use of aids and the role of the environment. Disability series. AIHW cat. no. DIS 32. Canberra: AIHW.

AIHW 2004a. Disability and its relationship to health conditions and other factors. AIHW cat. no. DIS 37. Canberra: AIHW.

AIHW 2004b. Carers in Australia: assisting frail older people and people with a disability. Aged care series no. 8. AIHW cat. no. AGE 41. Canberra: AIHW.

AIHW 2004c. Children with disabilities in Australia. AIHW cat. no. DIS 38. Canberra: AIHW.

AIHW 2005. Australia's welfare 2005. AIHW cat no. AUS 65. Canberra: AIHW.
cat. no. DIS 50. Canberra: AIHW.

AIHW 2006a. Life expectancy and disability in Australia 1988 to 2003. Disability series cat. no. DIS 47. Canberra: AIHW.

AIHW 2006b. Disability updates: children with disabilities. Bulletin no. 42. AIHW cat. no. AUS 19. Canberra: AIHW.

AIHW 2006c. Therapy and equipment needs of people with cerebral palsy and like disabilities in Australia: Disability Series. Cat. no. DIS 49. Canberra: AIHW.

AIHW 2006d. Australian incontinence data analysis and development. AIHW cat. no. DIS 44. Canberra: AIHW.

AIHW 2007a. Australia's welfare 2007. AIHW cat no. AUS 93. Canberra: AIHW.

AIHW 2007b. Current and future demand for specialist disability services. Disability series. Cat. no. DIS 50. Canberra: AIHW.

AIHW 2007c. Disability in Australia: acquired brain injury. Bulletin no. 55. Cat. no. AUS 96. Canberra: AIHW.

AIHW 2008a. Disability in Australia: trends in prevalence, education, employment and community living. Bulletin no. 61. Cat. No. AUS 103. Canberra: AIHW.

AIHW 2008b. Disability in Australia: intellectual disability. Bulletin no. 67. Cat. No. AUS 110. Canberra: AIHW.

AIHW 2009a. Disability in Australia: multiple disabilities and need for assistance. Disability series. Cat. no. DIS 55. Canberra: AIHW.

AIHW 2009b. The geography of disability and economic disadvantage in Australian capital cities. Cat. no. DIS 54. Canberra: AIHW.

AIHW 2009c. Younger people with disability in residential aged care program: final report on the 2007–2008 minimum data set. AIHW cat. no. DIS 53. Canberra: AIHW.

AIHW 2009d. Disability support services 2007–08: national data on services provided under the Commonwealth State/Territory Disability Agreement. Disability series. Cat. no. DIS 56. Canberra: AIHW (This is a most recently published annual report of the collection).

AIHW 2009e. Carers National Data Repository scoping study: final report. Cat. no. AGE 59. Canberra: AIHW.

AIHW submission to the 2008 Inquiry into Better Support for Carers

Available online at:

<http://www.aph.gov.au/house/committee/fchy/carers/subs/sub1033.pdf>

The AIHW submission addresses the following terms of reference of the inquiry:

- The role and contribution of carers in society and how this should be recognised
- Practical measures required to better support carers
- Specific needs of particular groups of carers

AIHW technical advice report to the Treasury (August 2009 unpublished report)

Projected life expectancy and disability in Australia 2010 to 2040: AIHW technical advice report to the Treasury (August 2009)

The Treasury requested the AIHW to prepare projected disability and disability-free life expectancies between 2010 and 2040 along similar lines to the 2006 AIHW report on life expectancy and disability in Australia 1998 and 2003 (AIHW 2006a). The report provided Treasury with a better understanding of future health expectancies and the results was relevant to Treasury modelling for the intergenerational report.

The AIHW agreed to undertake this work as technical advice to the Treasury, that is, the work is not for publication by the AIHW.