Australian Government
Australian Institute of
Health and Welfare

Better information and statistics
for better health and wellbeing

Inquiry into Disability Care and Support
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

RE: *Disability Care and Support* **draft report**

Introduction

The Australian Institute of Health and Welfare (AIHW) welcomes the opportunity to make a submission in response to the *Disability Care and Support* draft report.

The AIHW is a major national agency set up by the Australian Government under the Australian Institute of Health and Welfare Act to provide reliable, regular and relevant information and statistics on Australia's health and welfare. We are an independent statutory authority established in 1987, governed by a Management Board, and accountable to the Australian Parliament through the Health and Ageing portfolio.

Our aim is to improve the health and wellbeing of Australians through better health and welfare information and statistics. We collect and report information on a wide range of topics and issues, ranging from health and welfare expenditure, hospitals, disease and injury, and mental health, to ageing, homelessness, child protection and of course, disability.

Relevant AIHW capability

AIHW has the following capabilities that are relevant to the PC inquiry and its recommendations and provide context to subsequent AIHW feedback:

1) **Well established data collection and management infrastructure and expertise**

Over time the AIHW has acquired considerable expertise and infrastructure allowing for the ongoing collection of administrative data across a range of related human services sectors including health, community services, housing and disability. Key elements of this capability include technical infrastructure, staff expertise and well-developed and longstanding internal processes for data processing and database management.

2) Legislated authority to collect, manage and disseminate information.

As mentioned, the activities of AIHW are guided by the Australian Institute of Health and Welfare Act 1987 (AIHW Act). This act gives the AIHW legislated authority to perform the following functions as they related to health and welfare-related information: data standards development and maintenance, data collection and management, production of information and statistics, reporting to the Minister and the public, and dissemination of information and statistics to third parties.

3) A well-established and multi-faceted data supply chain.

AIHW has the experience of receiving and managing information from governments and NGOs, and has the flexibility to deal with a range of information collection types and processes, including both administrative and survey data. In order to efficiently gather the data we require in a timely and usable (i.e. standardised) manner, we collaborate closely and have effective data partnerships with many experts from around Australia, including the Australian Bureau of Statistics, governments at all levels, universities, research centres, and non-government organisations. For example, a current development activity will lead to improved and more timely data on people who use homelessness services drawing on information from over 1,500 largely NGO service providers after 1 July this year.

4) Leadership in data standards development and maintenance

The AIHW plays a significant leadership role in developing and maintaining national metadata standards that are essential to the development of robust statistical collections. This is achieved through active participation and leadership in national committees and our maintenance of METeOR (Metadata electronic Online Repository), Australia's repository for national metadata standards for health, community services and housing assistance information. The Institute works closely with governments and non-government organisations to achieve greater adherence to these standards in administrative data collections to promote national consistency and comparability of data and reporting.

5) Major supplier of information to a range of stakeholders, in multiple formats

AIHW plays a significant role in the dissemination of data and information for public policy, public reporting, research and to inform community debate. The Institute produces around 150 reports each year, and provides information that is made available to agencies for their own purposes, such as the COAG Reform Council (CRC) and the Report on Government Services (ROGS), as well as for broader research purposes.

Virtually everything that the Institute produces is publicly available and all our publications are available as free downloads from our website (www.aihw.gov.au), which had more than 1.3 million visits in 2009-10. We have developed a more innovative presentation of hospitals information, the MyHospitals website (www.myhospitals.gov.au), and we have plans to release more of our products in an online format in the future.

6) Expertise in disability care and services

AIHW has developed a solid understanding of the issues facing people with disability in Australia, particularly those receiving specialist disability services. AIHW has, for example, administered the National Minimum Data Set for disability services since 1994 and undertakes a range of research projects and information publications each year (some of AIHW's work is the disability field has been referenced in the draft report**).**

7) Expertise in data linkage

The Institute possesses significant expertise and has extensive experience in undertaking data linkage for research into a wide range of health and welfare policy and research work, including in the disability area.

In the context of the new Commonwealth data linkage framework, AIHW is looking to expand its capabilities in data linkage by becoming one of the first organisations accredited to undertake complex data linkage projects involving Commonwealth data. Accreditation will give assurance to data custodians and the public that high levels of security and strong governance processes are in place to protect the privacy of individuals, while maximizing the potential of available data sets held by the Institute to provide new insights into complex policy issues, thereby supporting better policy decisions.

8) Robust governance and oversight of information

AIHW has a long history of providing high quality information and data within an environment that protects the privacy of individuals. The AIHW is bound by the Privacy Act of 1988, which incorporates a series of Information Privacy Principles (IPPs) that regulate how the AIHW obtains, stores, uses and discloses personal information. The AIHW Act also contains stringent provisions for the protection of personal information, including criminal penalties for unauthorised disclosure. In addition, the AIHW Ethics Committee, provides oversight to the provision of data for research purposes, as well as to our internal activities including data linkage. Finally, in producing our reports and other information products the Institute employs numerous quality control checks to ensure the accuracy and the appropriate application of statistical approaches in the reporting of information.

9) **Experience developing performance measures**
One of our more recent key roles has been to develop, build and improve performance indicators and targets for national agreements between the Commonwealth and State and Territory governments; particularly in the areas of health care and hospitals, housing and homelessness, disability services and Indigenous health, welfare reform and disability. In this work, the aim is to provide more outcome-based and “actionable” measures of impact and performance. This is taking place not only at the level of COAG and ROGS reporting, but also within individual sectors and programs the National Disability Agreement auspices, where providers and policymakers alike, along with service recipients, are increasingly interested in this type of information.

More information about the Institute, in terms of its activities, capabilities and performance can be found on our website (www.aihw.gov.au/about) or in our 2009-10 Annual Report.

Some specific comments on the report

As an information agency, AIHW’s comments concentrate on the data matters, particularly those canvassed in Chapter 10.

Section 10.1 Introduction to collecting and using data under the NDIS: AIHW agrees that comprehensive data collections and systems will be needed for both the NDIS and NIIS. However, and not withstanding the critical requirement for actuarial data to drive the financial functioning of the schemes, information is needed about services, providers and clients in order to understand the effectiveness aspects of the schemes and assess whether intended outcomes are being met. It is worth noting that AIHW has well established capabilities in establishing data collections, managing standards and reporting and evaluating disability and related services.

Section 10.2 Deficiencies in the existing evidence base: Having an independent research capacity will enable a more complete and credible use of any administrative data generated by the NDIS, as well as allow for less quantitative research. However, the proposal to establish a special capability in a new body may be more problematic. Any new body may find it difficult to obtain and retain the necessary analytical capacity. Second, there is the real issue of duplication of infrastructure and expertise that is already held in existing institutions, including the AIHW, that could drive greater costs to governments and the community than would otherwise be necessary. Collaborative arrangements with existing agencies, including the AIHW, may be more cost effective.

10.3 Why an effective evidence base under the NDIS is needed: AIHW agrees that, within confidentiality constraints, the NDIA should make data and analysis publically available. In this regard it is worth noting that AIHW is experiencing rapidly increasing demand for access to data linked unit record across and within health and welfare domains. In future, such access can only be provided by accredited Commonwealth Integrating Authorities which are able to operate with the highest levels of security and probity in order to maintain confidentiality. AIHW intends to seek accreditation early, enabling it to provide researchers with linked data.

10.4 Data systems: AIHW welcomes the recommendation advocating consultation with relevant stakeholders in the design and implementation of data systems for the NDIS and NIIS. We strongly recommend that AIHW be one of the stakeholders that the NDIA consults with in the establishment of information requirements, data standards and rules for accessing data. In this regard we alert the Commission to the potential roles AIHW might play.

Potential future roles for the AIHW

The development and establishment of the NDIS would be aided by firstly using information from the current DS NMDS data collections and drawing on AIHW's expertise in the areas of disability and data management.

AIHW is currently investigating the redevelopment of the Disability Services National Minimum Data Set (DS NMDS), to make it more relevant to emerging needs, including any transitional requirements. The timing of this provides an excellent opportunity to further refine the usefulness of such statistical resources to planning and transitional requirements. The redevelopment could also consider the early collection of indicative new service type data that will be included in the NDIS but not currently included in the DS NMDS.

It is also worth noting that AIHW is well placed to assist with data needs for (young) 'people who have been inappropriately placed in nursing homes'. The paper proposes the early inclusion of these people in the NDIS, that is, from 2015. AIHW currently is contracted on a year-by-year base to collate and report the Younger People with Disability in Residential Aged Care (YPIRAC) data collection. The YPIRAC collection has been required for inclusion in the DS NMDS as soon as possible. The relationship between YPIRAC and this early implementation group of NDIS will need to be clarified (for instance, YPIRAC currently includes younger people at risk of entering residential aged care). AIHW may contribute to the work on an appropriate transition pathway for the data collection.

The AIHW could also contribute to the development of data standards, data dictionaries and data collection guides for the NDIS and provide ongoing data management, processing and reporting services using the wealth of data from the new administrative sources of the NDIS and NIIS.

We would be pleased to discuss the other matters raised in our submission in further detail, at your convenience.

Yours sincerely

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Director
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