Australian Government

Australian Institute of Health and Welfare

AIHW

Dr Jane Thomson
Committee Secretary
Senate Select Committee on Autism
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Dr Thomson

Senate Select Committee on Autism

The Australian Institute of Health and Welfare (AIHW) thanks you for the invitation to make a submission to the Senate Select Committee on Autism. This submission highlights data available from the AIHW that may be of relevance to this inquiry, and provides an update on the AIHW's work with key stakeholders on the National Disability Data Asset.

The AIHW is a nationally recognised independent information management agency. Our mission is to provide authoritative information and statistics to promote better health and wellbeing. The AIHW provides accessible information and statistics on a wide range of topics about Australians' health and wellbeing. We aim to inform good decisions—and improve the health and welfare of all Australians—through strong evidence that is timely, reliable, relevant and trusted.

The AIHW publishes over 180 outputs each year, ranging from comprehensive national reports to technical documents and guides to innovative web-based products. As required by the *Australian Institute of Health and Welfare Act 1987*, flagship reports, Australia's health and Australia's welfare, are published in alternate years. Further information on the roles and responsibilities of the AIHW are available at www.aihw.gov.au/about-us. We also work closely with government and non-government stakeholders to fill data gaps.

We trust you find this information useful to your inquiry. Should the Committee have any further queries about the information in this submission or seek any additional data, we are available to discuss at your convenience. Please telephone our Parliamentary section

Yours sincerely

Barry Sandison
Chief Executive Officer
16 July 2020

AIHW submission to the Senate Select Committee on Autism

Introduction

The Australian Institute of Health and Welfare (AIHW) is the national agency established to provide information and statistics on Australia's health and welfare. It is a Commonwealth corporate entity in the Health portfolio, accountable to the Australian Parliament, and is governed by the AIHW Board. AIHW's work informs debate and decisions on policy and services. We have a strong commitment to providing independent and objective information and advice in all our work. The AIHW has a long history in providing data, information and reporting on health and welfare issues and as an accredited data integrating authority has an audited ability to uphold the highest standards in the appropriate handling of sensitive and personal data. This assurance is of particular importance in the handling of health and welfare data which can be considered to be of a particularly sensitive nature.

We collect data and manage national data collections and produce over 180 information products each year. Our work is frequently referenced by the media. We also provide information to other government bodies and cross-jurisdictional councils, to external researchers and also directly back to data providers.

We also develop, maintain and promote data standards to ensure that data collected are nationally consistent. In all these activities, we enable governments and the community to make better informed decisions to improve the health and wellbeing of Australians.

Recent years have seen a rapid evolution in the ability to efficiently handle large amounts of data and produce meaningful insight through analysis of big data resources. Advances in technical opportunities to use data must continue to move in line with, and be constrained by, the ability to appropriately and ethically access available data resources.

As a Commonwealth Integrating Authority we safely link data on a range of topics, offering new insights on how Australians interact with the health and welfare systems.

Existing data and information

The AIHW 2017 publication *Autism in Australia* provides an overview of prevalence, demographics, service use and education employment outcomes for people with autism. This report is the latest piece of consolidated work undertaken by the AIHW on this subject and, while these data may be somewhat dated, it highlights the types of information available using existing data sources. This publication can be found online at: https://www.aihw.gov.au/reports/disability/autism-in-australia/contents/autism.

The report found that in 2015, an estimated 164,000 people had autism, representing about 1 in 150 Australians. In 2014–15, around 43,500 people with autism accessed disability support services under the National Disability Agreement (NDA). The report also found that:

- Autism is most commonly identified in children and young people. As such, people with autism were more likely to be younger, with 83% aged under 25. Autism was most prevalent among children aged 5 to 14 in 2009, 2012 and 2015, reflecting a general increase in diagnosis for school age children.

- Males were 4 times as likely as females to have autism, representing 81% of the population of people with autism.

- In 2015, there were an estimated 83,700 children and young people (aged 5–20) with autism and disability, living in households and attending school. The majority (85%) reported difficulty at school, with more than 1 in 4 (28%) attending a special school.

- The majority of people with autism (65%) had a disability with a profound or severe limitation in core activities.

- For NDA service users with autism aged 16 years and over, their main source of income was:

    o 74 per cent receiving a disability support pension

    o 13 per cent receiving other pensions or benefits

    o 6 per cent receiving nil income

    o 6 per cent in paid employment.

The report draws on the Australian Bureau of Statistics Survey of Disability, Ageing and Carers, and the AIHW Disability Services National Minimum Data Set. While these data sets are useful to provide a broad picture, there is no single data source that provides a comprehensive understanding of health and welfare outcomes for people with disability, including autism, in Australia. This limits our understanding of how people with disability use health and disability services, and their pathways through and across mainstream and specialist disability service delivery. It also means that there are data and knowledge gaps in the evidence base to inform the development, implementation and evaluation of appropriate and effective policies, interventions and support services.

Data linkage

Data linkage can be used to improve the utility and value of existing data sets, especially administrative data sets. Linking data from 2 or more sources could provide more detailed insights than would be possible from a single source. This methodology re-uses existing data and is non-intrusive because it avoids the need to re-contact people whose information has already been collected.

By combining information from multiple data sets, it is possible to improve our understanding of:

- how people transition between key life stages and the outcomes for different stages of life

- the types and level of service usage, and the care and support pathways people take through and across service delivery sectors and boundaries

- the relationships between risk factors, protective factors and health and wellbeing outcomes and

- how service use and health and wellbeing outcomes differ between different population and geographic groups.

As a Commonwealth Accredited Integrating Authority, the AIHW meets stringent criteria covering data governance and data management, and abides by the principles for data integration involving Australian Government data for statistical and research purposes and best practice guidelines. These include protocols to ensure secure end-to-end data management, processes to manage re-identification risks, stringent IT security and robust governance.

National Disability Data Asset

The Commonwealth and the governments of New South Wales, Queensland, South Australia, and Victoria are working together to develop a National Disability Data Asset (NDDA). The purpose of the NDDA is to improve outcomes for people with disability, their

families and carers, by sharing de-identified data to better understand the life experiences and outcomes of people with disability in Australia.

The NDDA is currently in an 18-month pilot phase, which commenced in April 2020. The pilot phase follows an agreement by the Australian Data and Digital Council in September 2019 to develop an enduring NDDA, incorporating data sets from multiple levels of government.

The pilot aims to demonstrate the value of the asset. Five government test cases are being used to demonstrate the potential of using data to support improved policy development, program design and service delivery for people with disability. The test cases focus on the following themes: early childhood; justice; education to employment; mental health; and how linked administrative data can support an outcomes framework under the new National Disability Strategy.

The pilot aims to identify the most effective ways to share, link and access data to deliver a more complete picture. This includes identifying potential barriers to data sharing and developing ways to overcome these barriers. The pilot also focuses on the best ways to protect people's privacy, including data de-identification and information security methods.

The AIHW is currently working closely with lead jurisdictions to prepare for the test cases, including establishing data governance arrangements and working through the privacy, legal and technical aspects of the supply of data and the design and build of linked data sets for the test cases.

While autism is not a specific focus of the NDDA pilot test cases, linkage with health and welfare service data sets that include potential indicators for people with autism (such as National Disability Insurance Scheme or Medicare Benefits Schedule data), will further allow identification of people with autism as a group for reporting and research purposes. The pilot test case findings will be useful to help establish a baseline of evidence and identify data gaps to support further data development work in relation to people with autism.

Further information on the NDDA is available from the Department of Social Services internet pages at:

https://www.dss.gov.au/disability-and-carers-research-and-data/the-national-disability-data-asset