

Addressing data gaps to improve evidence on AT outcomes – an update from Australia

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ABSTRACT

Australian governments are currently investing in a National Disability Data Asset (NDDA) as part of a Disability Research Strategy to inform policy and practice. This is an important opportunity to find out about the need for and use of assistive products for the first time. The NDDA is expected to address critical data gaps and help governments understand and address the needs of people with disability.

Many data collections exist across different agencies and sectors that provide assistive technology (AT) in Australia, but data gaps exist and inconsistencies in defining disability and AT limit the quality and comparability of data. There is a lack of information on what services people use (across mainstream and specialist areas), and how coordinated, timely and effective they are. There is also a lack of information on the unmet need for services and the quality and sustainability of the disability workforce. The Australian Institute of Health and Welfare (AIHW) has recommended improvements in the use of existing data sources (including surveys and administrative data), consistency of definitions across data sources, and the development of new data sources and data linkages.

The improvement and development of data sources in Australia will provide useful data for international comparison if it adopts standard terminology and concepts. Use of classification frameworks such as the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) has been recommended to improve consistency. A standardized terminology for assistive products and associated services, as proposed at the Global Research, Innovation and Education in Assistive Technology (GREAT) summit in 2019, would ensure that data collected in Australia contributes to international efforts to improve access to high quality, affordable assistive technology.

INTRODUCTION

AT providers and researchers have discussed the challenges of meeting the needs of people with disability while also demonstrating fiscal responsibility to funding bodies [1]. It is important to identify and measure what AT is and how it is acquired, and its intended outcomes for individuals and society, in order to appropriately and efficiently allocate public and private resources [2].

In Australia, a lack of conceptual clarity and terminology to describe assistive products, AT services and other rehabilitation interventions has contributed to the conspicuous absence of outcomes measurement. There is a legacy of state-government run services providing subsidized assistive products, collecting data on outputs (e.g. number, type, and cost of products) rather than functional outcomes (e.g. participation in employment, education, and recreation). The introduction of the National Disability Insurance Scheme (NDIS) that funds reasonable and necessary supports (including assistive products and AT services) across the lifetime for Australians with permanent and significant disability (approximately 10% of all Australians with disability) provides the first opportunity to collect and analyze AT outcomes data. This is dependent however, on service providers and policymakers agreeing on and using terminology to describe AT interventions, which are often embedded in rehabilitation practices and not identified as discrete variables in outcomes measures [3].

Without specific reporting on AT and concurrent interventions (e.g. environmental modification, task modification, human assistance), any reported functional outcomes may be assumed to be the result of an assistive product alone. This is despite research showing significant associations between approaches and processes used in AT provision, and demographic factors of AT users, and outcomes reported by hearing-aid and wheelchair users [4]. Use of the ICF, complemented by standardized and more granular terminology for assistive products and AT services as environmental factors, may enable internationally replicable data collection techniques that can inform national policies and international reporting to progress the goals of the WHO's Global Cooperation on Assistive Technology (GATE). The purpose of this paper is to present the proposed approach to improving data sources and evidence on people with disability in Australia, and link this to the global agenda to improve access to high quality affordable assistive technology.

METHODS

The AIHW acknowledges that, while there are many existing data sources on people with disability in Australia, the quality and usefulness of these sources varies [5]. Key challenges with the existing data include the inconsistent definitions of disability across sources, the limited availability of data that is collected but not shared

for statistical purposes, and the lack of integration of data across settings and domains of participation to understand pathways and outcomes for people with disability. The critical information gaps make impossible to report on the mainstream and specialist services that people with disability use, and their effectiveness, as well as the unmet need for services.

To improve the evidence, the AIHW have proposed work on three areas: maximizing the use of existing data sources; improving the quality and comparability of data across data sources, and; adding to data sources, including by developing new data sources in priority areas and through data linkage [5]. This will require agencies including the AIHW, the Australian Bureau of Statistics (ABS), Department of Social Services (DSS) and the National Disability Insurance Agency (NDIA) to agree on and adopt consistent definitions. The ICF has been proposed as a useful framework for improving consistency and coverage between data sources to report more comprehensively on people with disability. Consistent terminology and data rules should also reduce the complexity, timeliness and cost of data cleaning currently required prior to linking data from various sources.

RESULTS

Under the direction of the Australian Digital Council, several state governments are participating with the AIHW in a pilot of a new National Disability Data Asset (NDDA) that will help work through many of these issues. Consultation with people with disability, service providers, governments and the research community is anticipated. At the time of writing, there were no updates available since the 18 month pilot commenced in late 2019, but it is anticipated that interim findings will be reported by mid 2020 [6].

DISCUSSION

The development of the NDDA is an important project to address the data gaps on people with disability in Australia, but should also be seen in the broader context of the international agenda to improve access to AT. Any new data asset on disability that doesn't collect and report data on AT needs, provision and use is a missed opportunity, but the limited awareness of unmet need for AT in Australia, and the lack of a shared language to communicate the issues between people with disability, practitioners and policymakers risks AT being left off the policy agenda again. Key documents that are guiding policymaking in the NDIS still refer to aids and equipment rather than assistive products, including the Applied Principles and Tables of Support (APTOS), which outline the roles and responsibilities of different sectors who deliver supports to people with disability [7].

As an insurance scheme, the NDIS relies on the aggregation of data to inform actuarial decisions about funding. This necessitates descriptions of the assistive products and services provided, as well as monitoring whether consumers received interventions as intended, and functional outcomes. Several service models and instruments to measure outcomes from AT provision have been developed and validated by researchers, but are not yet promoted or mandated for use in practice by policymakers, despite the ambition of the NDIA to "capture information and build an evidence base" [8 p.3]. A focus on assistive products and lack of a systematic data collection strategy to evaluate outcomes of AT provision jeopardizes the equity and sustainability of the NDIS.

CONCLUSION

The development and pilot of an NDDA presents an opportunity to collect data on AT needs, interventions and outcomes for the first time across Australia. The AIHW's proposal to improve evidence through data linkage and improved quality and comparability should facilitate international reporting and comparison with countries providing AT in similar and different policy and practice contexts. Linking the NDDA to the WHO's global efforts to assess need and demand for AT may contribute to improved access to AT.

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