



Mr Troy Podbury
Inquiry Manager
Productivity Commission
GPO Box 1428, Canberra ACT 2601

Dear Mr Podbury

National Disability Insurance Scheme (NDIS) Costs—Productivity Commission Position Paper

The AIHW welcomes the opportunity to provide comments on the Productivity Commission's NDIS Costs position paper. The AIHW has an active role in collecting, analysing and making publicly available information relating to people with disability. Within this context, our submission (attached) highlights the importance of comprehensive, person-centred data and a sound evidence base to support policy decisions.

The AIHW also recommends that the NDIS continue to be considered in context. The ability to articulate a broader story—with the NDIS included in the context of the wider suite of supports and payments for people with disability—will be critical to governments' understanding, not only of the costs of, and pressure on, the NDIS, but also of the broader experiences of, and outcomes for, people with disability.

About the AIHW

The AIHW is a major national agency producing independent, relevant and reliable health and welfare information and statistics to support better decisions, leading to better health and wellbeing for Australians. The AIHW informs policy development and public discussion by producing reports, datasets and other products—adding to the evidence base that is critical to good policy making and effective service delivery.

We report on nearly 50 different health and welfare topics in addition to our flagship publications *Australia's health* and *Australia's welfare*. We make our data, information and analytical products available widely, in accessible formats, and currently release over 180 reports or information products annually—including on disability, ageing and aged care, mental health, disease, injury, hospitals, homelessness, housing, child protection, and health and welfare expenditure.

Yours sincerely

Louise York
Group Head, Community Services Group
31 July 2017



AIHW submission in response to *National Disability Insurance Scheme (NDIS) Costs—Productivity Commission Position Paper*

Introduction

This submission provides information to assist the Productivity Commission in preparing its report on the review of the costs of the NDIS, with a particular focus on the need for comprehensive, person-centred data and a sound evidence base to support decision making. In this context, the AIHW recommends the final report include a stronger statement on data and continue to highlight the importance of understanding the NDIS within the context of the broader system of supports and payments for people with disability.

The NDIS in context—one part of a broader system

People with disability interact with every aspect of social policy and programs in Australia. They access both specialist and mainstream services across a wide variety of areas, and many are also supported by informal carers. In this way, the NDIS can be seen to exist as one part of a broader system of supports and payments for people with disability.

It is also important to acknowledge that the NDIS is not intended to fully support all people with disability—it is aimed primarily at supporting those aged under 65 with ‘significant and permanent disability’ in terms of ‘reasonable and necessary supports’—and that people with disability, including NDIS participants, may also use services outside of the NDIS. Once the NDIS is fully implemented, it is estimated that it will support around 475,000 people with significant and permanent disability—460,000 aged under 65; and 15,000 aged 65 and over who enter the scheme before turning 65 (PC 2017). This means that about 89% of all people with disability in Australia, and 36% of people with severe or profound disability aged under 65, won’t be supported by the NDIS (using estimates of the number of people with disability from the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC)) (ABS 2016).

As such, truly understanding the costs of, and pressure on, the NDIS, as well as the experiences of people with disability more broadly, will require understanding the wider environment in which the NDIS operates.

Robust data on the broader system is needed

Given this view of the NDIS in the context of this wider environment, a strategic approach to defining data requirements and outputs is required that looks at the totality of support and payments provided to people with disability. Consideration needs to be given not only to what data will be available as a by-product of the NDIS, but also to what other data will be needed to provide a complete picture, including on people with disability who are not covered by the NDIS. Data gaps need to be identified and consideration given to how to fill them. Such an approach would allow NDIS activities and costs, as well as those of the broader system, to be more clearly understood and measured, impacts (both positive and negative) to be assessed, and gaps in service delivery and boundary issues to be identified and quantified. It would also provide for more comprehensive, person-centred information and reporting about people with disability more generally.

To fully understand the overall disability support ‘system’, data are required not only on people with disability but also on their carers, service providers and the workforce, and the interactions with non-specialist (that is, mainstream) and other services. The following set of questions frames a comprehensive, person-centred approach to reporting on people with disability:

- the characteristics of people with disability—such as cause, type and extent of disability and associated health conditions; support needs; adaptations (changes to the environment and use of technologies); assessed support needs
- determinants of the needs for support and factors influencing outcomes—covering social, behavioural and individual determinants
- interactions with the system—for example, eligibility and access; barriers (cost, distance, etc.); unmet need; pathways through the system
- outcomes from interactions with the system—notably education, employment and social/participation outcomes; and health and general wellbeing
- aspects of the system that help/hinder intended outcomes—including policy parameters; funding models; system resources (for example, workforce levels, skills and distribution); system performance (efficiency, integration/coordination/continuity, safety/quality, responsiveness); informal carer capacity.

An ‘ecology’ view of disability support, utilising time-series data, is also critical to assessing any unintended consequences of the NDIS rollout.

Understanding the use of mainstream and other services is crucial

As implied by this set of questions, robust data on the use of services outside of the NDIS is crucial to understanding the true costs, impacts and pressures on the NDIS, as well as to form a broader, person-centred picture of the experiences of, and outcomes for, people with disability in Australia. Of particular interest to the AIHW is the interaction with, and role of, other services in meeting the needs of people with disability—including mainstream services (such as health, aged care and housing), specialist supports provided outside of the NDIS (such as mental health services), and other support (such as that provided by informal carers and the community).

While there is some information about the use of specialist services by people with disability (for example, those provided under the National Disability Agreement, now in transition to the NDIS), we know little about their access to, and use of, mainstream and other services. We also lack a strong evidence base supporting our understanding of the interactions between sectors. The NDIS Information, Linkages and Capacity Building (ILC) will help capture some of this information. However, while the ILC is available to all people with disability, its focus is on community inclusion and its scope is limited to information about, and referrals to, community and mainstream services. As such, while the AIHW agrees that the ILC will become increasingly important in this regard—especially as state and territory governments potentially cease or wind back their delivery of services—it will only capture partial information; hence, more comprehensive data are needed. Measuring the impact of the ILC on NDIS supports, as well the impact of the NDIS on mainstream and other services more broadly, cannot be achieved without understanding the wider environment, which in turn requires data.

Options for improving data on interactions between sectors include data linkage and adding ‘flags’ to existing (mainstream) data collections.

Data linkage

Data linkage (also called data matching, data integration or record matching) is a process that allows information from multiple datasets to be combined, while preserving privacy. Integrating data in this way can tell a much more powerful, person-centred story than is possible from individual datasets in isolation, and can help policy makers to improve their understanding of a range of issues (see Box 1). Linkage can also be used to assess outcomes at different ‘levels’ or for different cohorts (for example, for Indigenous Australians).

Box 1: Selected recent examples of major AIHW data linkage projects

Demonstration project to test the linkage of hospitals data with Medical Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) data

A demonstration project is underway to test the linkage of a data set based on hospitals data routinely provided to the AIHW by jurisdictions with Medical Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) data. The linked data set would be a source of patient-centred information about services provided by Australia's hospitals, medical and other services subsidised through the MBS and pharmaceuticals dispensed under the PBS. This would enhance the ability to examine patient journeys through the Australian health system.

Specialist Homelessness Services and Youth Justice

An estimated 187,500 young people aged under 18 accessed homelessness services over a 4 year period, or about 30% of all clients. The data from the homelessness services system was linked with the Juvenile Justice National Minimum Data Set. From this linkage, it was learned that more than 5,000 of these young people also had some contact with youth justice supervision. This group, compared with other specialist homeless clients of the same age, had 5 times the rate of drug and alcohol issues, double the rate of mental health issues and an overall need for more intensive support. Governments and service providers can use this analysis to design and provide more targeted responses at an individual level. For example, ensuring that mental health services are available for people exiting youth justice services and seeking homelessness support.

Human papilloma virus (HPV) vaccination program and cervical abnormalities

This study, based on Victorian HPV vaccination and Pap test data, was a world first. It showed that a population-based HPV vaccination program has produced a fall in cervical abnormalities within 5 years of its start.

Filling data gaps in relation to people with disability provides one example of the enormous potential of data linkage. For example, linking specialist disability services or payments data to national hospital, Medicare Benefits Schedule or Pharmaceutical Benefits Scheme data, could provide insights into how people with disability interact with mainstream health services, and how these services complement specialist disability supports. Likewise, linking specialist disability services data to aged care data could help improve understanding of the interactions between these two sectors, including transitions out of the scheme into permanent residential aged care. Linkages could also be explored in relation to selected mental health services, although barriers to this linkage are more significant.

Another application of data linkage (or use of the standardised disability flag, see below) relates to information on the abuse of, or by, people with disability (including domestic and sexual violence), which have been raised in multiple royal commissions and other inquiries, and are featured in government responses to these inquiries.

However, while data linkage is a powerful tool, challenges remain before its benefits can be truly realised. For example, the time taken to gain approvals to use data for linkage—largely associated with existing data access processes and protections around sharing and releasing data—is one pressing issue and affects the ability of researchers to analyse data and release results in a timely way. As such, it is important that strategies be developed to continue to improve and maximise the use of existing data sets while being proactive in identifying those that could be integrated. This could include considering the benefits of using data set 'flags' as an effective stop-gap measure, awaiting a future where data linkage becomes more straightforward.

Standardised disability flag

The AIHW has developed a disability 'flag' that can be used to identify records of people with a disability within a data collection. The flag derives from a standard set of questions that assesses a person's level of functioning and need for support in everyday activities. These questions are based on the International Classification of Functioning, Disability and Health

(ICF), and are broadly consistent with the short disability questions that the ABS uses in a number of its social surveys. The flag is intended for use in collections covering a wide range of sectors, enabling nationally consistent collection of information about the disability status of people encountering mainstream and other services.

Versions of the flag have been implemented in the AIHW's Specialist Homelessness Services Collection (SHSC) and the National Prisoner Health Data Collection (NPHDC), and are being considered for implementation in other AIHW collections. A wider implementation of the flag would enable more comprehensive reporting on people with disability and aid in better understanding the interactions between sectors.

NDIS flag

The AIHW is developing a flag for use in data collections to indicate whether a person is receiving support through the NDIS. This flag could be used to look at the use of mainstream and other services by NDIS participants. If used together with the standardised disability flag, it could potentially also be used to examine participation in the NDIS as well as to look at if there are differences in the use of mainstream services between NDIS participants and other people with disability. This flag is currently under consideration by states and territories for future implementation in the AIHW's Specialist Homelessness Services Collection (SHSC).

Improved understanding of the relationship between formal and informal care is needed

Informal care may be provided alongside formal care to either complement existing support or to fill a gap in the level of formal care provided. Often, informal carers are people close to the person in need, such as family and friends. The time and costs associated with providing care to another person can be challenging for carers, particularly for the primary carer, and may create increased financial stress, limit the carer's access to education and employment, or restrict their participation in social and community life. As such, the level of support provided to people with disability not only affects the person with disability themselves, but can also significantly affect their informal carers. It can also have impacts on the broader system if the balance of supports is not right, with people potentially needing to seek additional support for either themselves or for the person they care for.

Data leading to an improved understanding of the relationship between formal and informal care is needed if the impacts and costs of service responses, such as the NDIS, are to be fully measured and understood. The resulting evidence could also be used as a basis to target support to people with disability and their carers in more effective and potentially innovative ways.

Current data on the interaction between formal and informal care is fragmented at best, and the AIHW recommends that consideration should be given to how it can be improved. The introduction of the NDIS presents an opportunity to start this process and collect better data on informal carers of people with disability. However, such information is limited to carers of NDIS participants, meaning a gap will still remain around those who care for people who are not part of the NDIS. Also, while the National Disability Insurance Agency (NDIA) currently reports some information on families and carers of participants—including baseline outcome indicators covering financial support, workforce participation, social participation and health—detailed information on the carers of NDIS participants, such as their relationship to the participant and the extent of their caring responsibilities (for example, the number of hours spent caring per week, the type of caring activities undertaken) is either not collected or not publicly available.

A key question around cost pressures is the extent to which supports provided to people with disability has reduced or increased the pressure on informal carers, and what flow on effects this has.

The Survey of Disability, Ageing and Carers (SDAC) is a cornerstone source of information on carer arrangements for NDIS participants and non-participants alike, and the planned 2018 iteration will be well timed to capture relevant information towards the end of the NDIS roll-out period. However, the AIHW understands that the SDAC is funded by the ABS only 6-yearly, with ‘user’ funding required to keep it on a 3-year cycle. Hence there is a risk that the vital SDAC information may only be available each 6 years, which is too infrequent to inform the experiences and outcomes associated with such a major policy reform as the NDIS. Further, consideration should be given to other surveys or linkage studies to cover the broader disability population, the broader carer population (such as those that care for the aged or people with mental illness, so as to monitor the effects of disability reforms on other sectors), and on a more frequent basis.

Understanding the disability workforce and its capacity to meet demand is essential

Available data suggest that the disability workforce will need to increase substantially in coming years (ANAO 2016). This presents some challenges, such as ensuring that appropriately skilled workers are available to safely and effectively deliver services across a relatively diverse and changing market. For example, the disability services market is not a homogenous entity across Australia, especially during the transition to the NDIS, and variations exist in terms of the characteristics and needs of each local market. This means that the disability workforce responding to that need in each market may differ.

At present, comprehensive and consistent data on the disability workforce are not readily available, affecting the ability to examine key compositional factors in more detail or to identify potential issues. This includes, for example, looking at whether there are enough appropriately skilled disability workers to deliver the range of services required in various areas of Australia, without compromising quality or negatively impacting on informal carers. This may be particularly an issue in some areas of Australia where anecdotal information suggests that recruiting appropriate staff remains an issue for some providers, and one which is likely to worsen as the NDIS continues to grow.

Consideration needs to be given to measuring the effectiveness of support for various target groups

A central policy question that will be asked of the NDIS is how well it supports people with disability from different groups, particularly those at risk of poor outcomes—such as LGBTI, Indigenous, those from culturally diverse backgrounds, and those in low socioeconomic areas—and do their outcomes vary. Ideally data should be collected on such groups where possible to enable their experiences and outcomes to be measured and improvements in service delivery made as required.

NDIS data should be made available for research and reporting

The establishment of the NDIS brings with it the opportunity to capture more comprehensive data, as well as opportunities to enhance data access in line with the Australian Government’s public data agenda. Indeed, for the first time in Australia, data on scheme participants will enable a joined-up view of their disability support needs, the services provided in response to those needs, and the social and economic outcomes of those services.

To date, data on the NDIS have mainly been used to report on the financial sustainability of the scheme, but such data could, and should, be used more broadly. In light of the Australian Government’s public data agenda, the AIHW recommends that data from the NDIS be made available beyond the NDIA in accessible formats for use in research and reporting. And the data required for comprehensive monitoring of the disability system need to be more detailed than tabulations; rather, unit record files and/or data cubes for researchers should be

produced. Such outputs can be released while still maintaining privacy and data security, as evidenced by the long-standing practices of the AIHW and the ABS.

We further recommend that, while it is entirely appropriate for the NDIA to monitor the progress and sustainability of the scheme, an independent agency (such as the AIHW) should be engaged to undertake reporting more broadly, perhaps against a disability reporting framework similar to that used in the health sector.

We also support the recommendations of Madden (2017) in his initial submission to this Inquiry:

“NDIA should work with stakeholders and the AIHW and ABS to design an appropriate minimum data set for participants and supports received, which can be extracted from its data holdings.”

“A de-identified data set on participants and supports received should be provided without charge to the AIHW in a timely fashion for statistical reporting.”

We particularly note Madden’s emphasis on continuity of statistical series for key data across the old and new collections (referring to the Disability Services National Minimum Data Set).

A similar theme is raised by Bonyhady (2017) in his initial submission:

“The disability data that is being collected by the NDIA is world-leading and should be made available for research, as a matter of high priority, subject to appropriate safeguards.”

“...this Review should include recommendations on how best to ensure that the NDIA data will be made available for research to improve the lives of people with disabilities, their families and carers.”

In the context of making data available from the NDIS, it is important to consider that ‘big data’—the unprecedented volume, diversity and speed of data generation—is growing at a rapid pace. As its 2015 public data policy statement makes clear, the Australian Government is well aware of this trend, and of the pressing need to make better use of this ‘strategic national resource’ (DPM&C 2015a). There is great potential benefit in making non-sensitive data ‘open by default’ by not restricting its use or redistribution; but how to make optimal use of this huge and increasingly unstructured source of information is a major challenge. While the need to manage ‘big data’ is clearly evident, the key issue for all data users is to ensure these data are used in the most effective manner; that is, ‘smart data’. It also presents an opportunity to develop better ways to analyse and present data, and to partner with a wider range of collaborators. Ensuring that data are used as effectively as possible will require a mix of leadership, trust and openness at all levels of government and beyond.

While not entirely in scope for this submission, the establishment of the new NDIS Quality and Safeguards Commissions provides another opportunity to collect and make available key data on the experiences of people with disability, and would assist in filling an existing data gap related to the safety of people with disability and the quality of support they receive. The AIHW recommends that these data should be comprehensively collected by the new agency and made available for use in reporting more broadly.

Data standards and documentation

For data products to be accessible and useful for research and reporting, it is imperative that the data be supported by high-quality metadata, and that this metadata be developed in line with nationally recognised standards to allow comparability across data sets. The two main elements of such metadata are data standards specifying the data to be collected/captured, and documentation (including data quality information) pertaining to data products to be released. The AIHW’s metadata online registry (METeOR) would be a suitable platform for recording such data standards and data quality information.

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