



Australian Government
Australian Institute of
Health and Welfare

AIHW

National Disability Agreement Review
Productivity Commission Locked Bag 2, Collins St East
Melbourne VIC 8003

National Disability Agreement review—Productivity Commission Issues Paper

The AIHW welcomes the opportunity to provide a submission to the Productivity Commission's review into the National Disability Agreement. 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 ensuring that a strong evidence base is available to support policy decisions for people with disability. This requires considering the broader system of supports and payments for people with disability and their carers, and taking a strategic, connected approach to developing associated data and reporting requirements.



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. We inform policy development and public discussion through data development activities and by producing reports, datasets and other products—adding to the evidence base that is critical to good policy making and effective service delivery.

We cover nearly 50 individual health and welfare topics in addition to our compendium 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 hundreds of information products annually—including on disability, ageing and aged care, mental health, disease, injury, hospitals, homelessness, housing, child protection, and health and welfare expenditure.

We would be very pleased to meet with Commission staff to expand on the matters raised in this submission, as required. Please contact Mark Cooper-Stanbury, head of our Disability and Ageing Unit,

Yours sincerely

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6 September 2018

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AIHW submission in response to *National Disability Agreement review—Productivity Commission Issues Paper*

1. Introduction

This submission provides information to assist the Productivity Commission in preparing its report on the review of the National Disability Agreement (NDA). As a statistical agency in the Commonwealth health portfolio, it is not appropriate for the AIHW to respond directly to many of the questions in the Issues Paper. Rather, this submission is focused on the need for good data that contributes to a robust evidence base that supports policy decisions and performance monitoring. The issues and principles set out here would apply regardless of the policy architecture ultimately put forward by the Commission.

In this context, the AIHW recommends that:

- the review takes a strategic approach to considering data and reporting requirements under revised accountability arrangements, moving beyond what is needed to monitor progress and performance under the agreement itself, to also consider what is needed to form a complete picture of the broader service environment for people with disability and their carers (for example, including specialist, mainstream and other services)
- any revised agreement include a strong statement on data, based around the development, collection and reporting of nationally consistent, person-centred data
- efforts should be made to harmonise indicators and reporting activities in order to make reporting more efficient and provide clearer messages to stakeholders.

2. Issues

A strategic approach to defining data and reporting requirements is needed

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 or the community. As such, whether the NDA remains focused on specialist services or broadens to consider both specialist and other services, a strategic and connected approach to data and reporting is required that considers the totality of supports and payments available for people with disability and their carers. It should factor in how these different components fit together and what will be needed to provide a complete picture of the broader service system (for example, support provided by specialist services, mainstream services, and informal carers).

This system of interacting parts is illustrated in Figure 1 below, extracted from *Australia's welfare 2015* (AIHW 2015). The figure depicts how welfare services or payments produce outputs/outcomes, which are mostly constrained to the particular service sub-sector. Only when these services, complemented by the services from other sectors, and informal supports, are considered together, can the *wellbeing* outcomes produced by whole service system be measured, reported and understood.

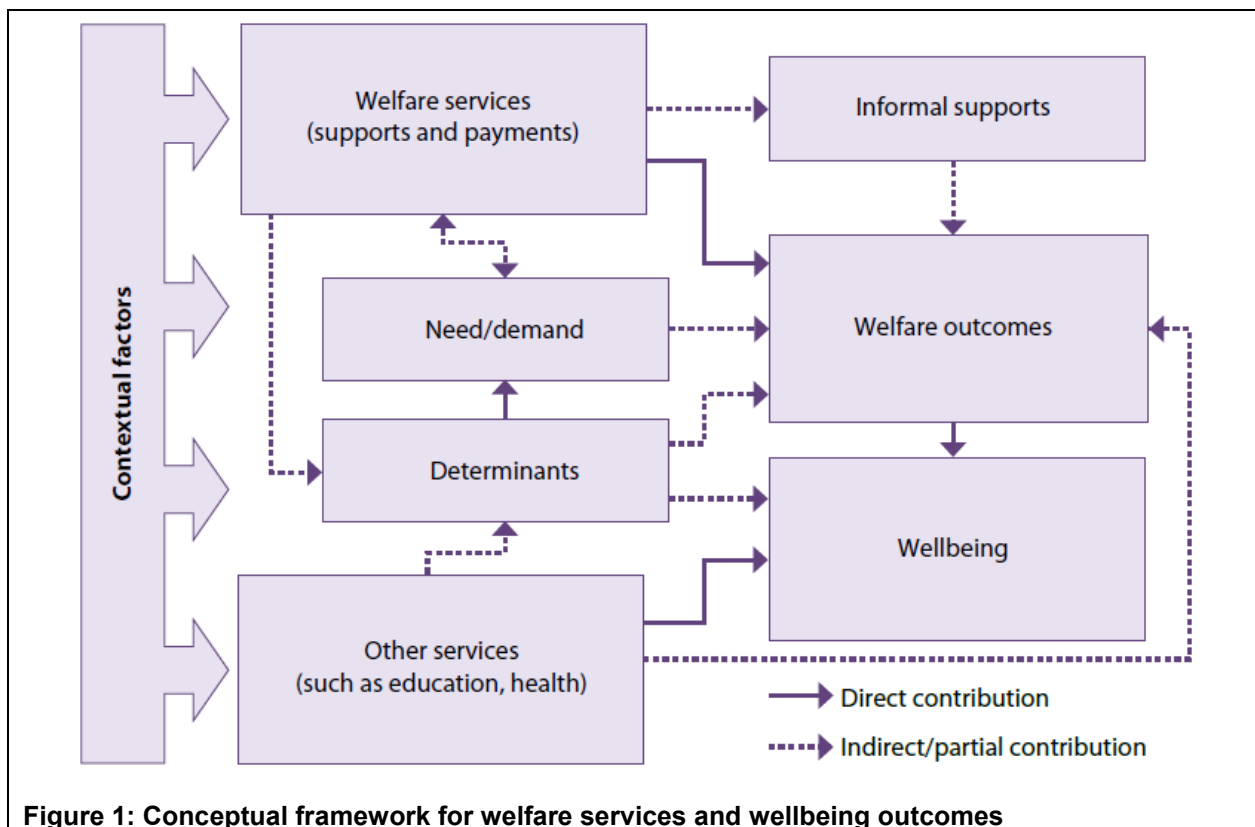


Figure 1: Conceptual framework for welfare services and wellbeing outcomes

Hence a strategic approach to data and information development, which considers how to better connect data and reporting, would allow the activities of the broader service system to be more clearly represented, impacts of changes (both positive and negative) to be assessed, and gaps in service delivery and boundary issues to be identified and quantified. It would also contribute to improved information and reporting about people with disability more generally—beyond services and payments—and help to highlight data gaps and set priorities for filling those gaps.

A strong statement on data is essential in a revised agreement

As the Issues Paper shows, the NDA is the main accountability mechanism regarding disability services. It outlines the roles and responsibilities of the Commonwealth and the States and Territories in the delivery of disability services, and defines associated objectives, outcomes and outputs, including performance benchmarks and indicators to measure these.

In order to ensure that performance and progress under the agreement can be measured, as well as to contribute to the evidence base related to people with disability more broadly, it is critical that any revised NDA include a strong statement on data. Such a statement should be based around the development, collection and reporting of reliable, nationally-consistent, person-centred data, and include the development of agreed performance measures. Contributing to the strategic approach as outlined above, it should also consider how data collection and reporting under the NDA fits in with that required to understand the broader service system for people with disability. Such data and measures underwrite the robust evidence base essential to support policy decisions for people with disability, their families and their carers.

We note that the National Housing and Homelessness Agreement finalised earlier this year exemplifies the types of statements needed, expressed in terms of:

- contributions to ongoing collection and reporting included as one of the Outputs of the agreement
- data development processes recognised in the roles and responsibilities of *all* parties

- [implicitly] the collection of data being needed to support the set of indicators and benchmarks (when agreed)
- a comprehensive Schedule on data improvement, including associated data governance arrangements.

The availability of a robust evidence base assumes even more importance in times of change, such as with the introduction of the National Disability Insurance Scheme (NDIS). At such times, good data are essential if the impact (both positive and negative) of the change on the lives of people with disability, their families and their carers is to be comprehensively assessed.

The NDIS needs to be considered in context—as one part of a broader system

As part of this, the AIHW also recommends that the NDIS continue to be considered in context. The ability to articulate a broader story—with the NDIS considered one part of a wider suite of supports and payments for people with disability (consistent with Figure 1 above)—will be critical to governments' understanding of the needs, experiences of, and outcomes for, all people with disability, including, but not limited to, those who use services provided through the NDIS.

The NDIS—widely acknowledged as a major reform—is still only one part of a broader system of supports and payments for people with disability. It was never intended to fully support all people with disability, and, once fully implemented, is estimated to 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 2015 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC)) (ABS 2016).

As the NDIS was never intended to support all people with disability, and acknowledging that people with disability, including NDIS participants, may also need and use services outside of the NDIS, it is important to ensure that data are available to enable reporting on all aspects of the service system.

Hence, in taking a strategic approach to developing data and reporting requirements, it is important to consider the broader policy and service delivery environment and place reforms such as the NDIS in that larger context.

Efforts should be made to minimise duplication and overlaps in reporting

One of the challenges presented by multiple policy documents and reporting arrangements is the degree of duplication and overlap in reporting. As Figure 4 from the Issues Paper demonstrates, there are very similar indicators reported through the Report on Government Services process and the NDA performance reporting process; there are even more when the National Disability Strategy and the AIHW's own reporting are taken into account.

Yet across these processes the indicators are slightly different in many cases, requiring multiple handling and creating confusion for stakeholders about which is the 'truth'. Even within the NDA, the indicator and benchmark relating to adequacy of support are slightly different.

Hence the AIHW recommends that efforts be made to consolidate and/or harmonise indicators, and streamline reporting activities in order to make the data collation, calculation and reporting more efficient and to provide clearer messages to stakeholders.

There is a risk that data will not be available, particularly on services delivered outside of the NDIS

The current collection of data on services provided under the NDA—the Disability Services National Minimum Data Set (DS NMDS)—is set to cease at the end of the 2018–19 collection

year. While data collection and selected reporting will occur as part of the NDIS, including some reporting on people using the Information, Linkages and Capacity Building (ILC) component of the NDIS, there needs to be consideration given to what other data will be needed. There is a risk that, if mechanisms are not in place to ensure that nationally consistent data are collected, data on the entirety of services provided (including on specialist supports and the broader service system) will not be available, especially on services provided outside of the NDIS.

Robust data on the use of services outside of the NDIS is crucial, not only to understanding the true costs, impacts and pressures on the NDIS, but also 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, all services in meeting the needs of people with disability—including specialist supports provided outside of the NDIS (such as mental health services and continuity of support), mainstream services (such as health, aged care, housing and transport), and other support (such as that provided by informal carers and the community).

The ILC will help capture some information on the use of other services. 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, it will only capture partial information; hence, more comprehensive data are needed.

A comprehensive framework for disability reporting

A strong theme in the Issues Paper is about coverage of the indicators, measures and benchmarks. However, it is hard to know whether there are coverage issues without a way of conceiving of the ‘whole picture’. One way of expressing this whole picture is through the person-centred framework used by AIHW (see Figure 2 below). This framework serves as a basis for thinking about issues related to disability more broadly and across multiple areas of interaction.



Figure 2: A framework for disability statistics

As well as the various 'sectors', there are four important considerations for fully understanding the experiences of people with disability, and the effectiveness of the wider service delivery system (including both mainstream and specialist support services). These considerations are shown in the outer ring of the Figure, and are briefly described as follows:

- Environment—environmental factors (such as physical, social and policy factors) can facilitate or hinder a person's activities and participation. As such, considering the impact of such factors is critical in understanding the lived experience of people with disabilities.
- Workforce and carers—these elements need to be considered together, as, while the 'formal' workforce represents part of the organised response to needs, carers (in the form of family, friends, neighbours) make a significant contribution to supporting people with disability, often in place of, or in addition to, formal services. Another aspect of workforce that requires attention in the context of disability is acknowledging that there is a common skill set across a number of care sectors (for example, health, disability, and aged care), and that this workforce needs to be appropriately distributed across the multiple sectors.
- Sustainability and efficiency—looks at the costs of supporting people with disability in a whole-of-system(s) way, including aspects of allocative efficiency across and within sectors, and the performance of each sector and all sectors combined.
- Integration and coordination—refers to the 'joined up' and 'people-centred' objectives of support, and covers aspects such as support planning and interactions amongst the sectors (including the relationship between specialist and mainstream disability supports).

Given the breadth of information required to fully describe the experiences and outcomes of people with disability and carers, it is unlikely that statistical reporting in the form of indicators and benchmarks will adequately cover the field. Rather, a regular national mechanism needs to be in place to collectively, and broadly, report on available data, provide context, consider data quality issues, and identify and fill data gaps in relation to people with disability and their carers and families.

Drawing these aspects together into a single source and considering the available information as a whole—in the form of a regular compendium—would improve the evidence base. Such reporting adds value to data, not only by combining sources in one place, but by adding context and meaning to the data, making connections and highlighting gaps—in short, creating 'evidence'. Such reporting moves beyond performance reporting (on services and payments, as generally associated with national agreements) to encompass information about the broader experiences of people with disability and carers (such as housing, health, pathways and outcomes) and enhances awareness of issues related to disability for governments, consumers, and the wider community.

Other data challenges, and opportunities

While there is no denying that a comprehensive and consolidated picture of the experiences of people with disability is desired—and consistent with the objectives of the current NDA—it must be acknowledged that there are challenges involved in doing so, and that critical information gaps exist. These include frequency of data, availability of important datasets, definitional variations between sources, ability to identify disability, and lack of consistent linkage information to enable data linkage.

Such challenges should not prohibit pursuing comprehensive reporting, rather these should be acknowledged and managed and ways to move forward and improve reporting considered. For example, to help address the information gap in the identification of people with disability within mainstream data collections, the AIHW has developed a standardised disability 'flag'. 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 Australian Bureau of Statistics (ABS) uses in a number of its social surveys. Versions of the flag have been implemented in the AIHW's Specialist Homelessness Services Collection and National Prisoner Health Data Collection, and are in the process of being implemented within other AIHW collections. A wider implementation of the flag would improve the ability to report more comprehensively on people with disability.

The AIHW is also 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.

Data linkage is another option that could be used to more comprehensively examine the experiences of people with disability than is possible from a single source. 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 story than is possible from individual datasets in isolation and can improve understanding of a range of issues. For example, linking disability support services or payments data to national hospital data, the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS) could provide an insight into how people with disability interact with mainstream health services, and how these services complement specialist disability supports. Likewise, linking disability support services data to aged care data could help improve understanding of the interactions between these two sectors. And linking employment services data with payments data over time could provide valuable information about the relationship between seeking employment and income support.

However, while data linkage is a powerful tool, challenges remain before its benefits can be truly realised. The lack of consistent linkage information across administrative systems in Australia, and complexities in data sharing and access arrangements, mean that linking together data from various sources is often complex, time consuming and costly. With consistent linkage identifiers, deterministic data linkage is possible and a near perfect match can be made between individuals on different datasets. Without linkage identifiers, data linkage is either not possible or, if enough other information is available, other methods, such as probabilistic linkage based on a series of weaker identifiers, can be used but accuracy varies.

It is important that strategies to improve and maximise the use of existing data sources are developed while proactively identifying those data that could be integrated through linkage. This could include considering the benefits of adding data set 'flags' to key datasets as an effective stop-gap measure, awaiting a future where consistent linkage identifiers are developed, data sharing and access arrangements become more streamlined, and data linkage becomes more straightforward.

In addition, key data sets need to be either made available or continue to be made available. For example, the National Disability Insurance Agency (NDIA) collects a wealth of longitudinal information on the NDIS but, as yet, have not established clear policies for data sharing and a dataset is not available to researchers. As noted above, there is also concern about what data will be available to look comprehensively at the provision of disability services outside of the NDIS given that the NDIS is not expected to cover all people with disability. This concern was highlighted in the recent Productivity Commission Study Report into NDIS costs. Such data are vital to examine the interactions between the NDIS and other services.

3. Responses to selected questions in the discussion paper

Does the Commission’s representation of the policy architecture supporting the NDA in figure 1 adequately capture all relevant policy areas? Is anything missing?

In addition to the policy architecture outlined in the Issues Paper, the Commission may want to note Australia’s obligations under the UN Convention on the Rights of Persons with Disabilities (UN CRPD). The purpose of the UN CRPD is to ‘promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity’ (UN 2006). As a signatory, the Convention forms part of the broader instruments by which Australia is held accountable.

To what extent should the outcomes be aspirational (worked towards but not necessarily achieved within a specified time period), versus achievable within a defined period?

We suggest that it is possible, and important, to have both sides of the coin, as it were. That is, there should indeed be aspirational statements of the long-term vision—to set the direction and level of desired achievement—and there should be measures that support practical, reportable progress in pursuit of this vision.

Are the criteria for good performance indicators listed in box 2 suitable? If not, what should be added/changed?

We note that the indicator criteria referenced were applied in the *Overcoming Indigenous Disadvantage* report, yet they would appear to be reasonably generic and suited to a review of the NDA indicators.

There would be value in expanding on the meaning or application of some of these. For example, it is not clear what ‘change in the indicator *affects* desired outcomes over time’ means. Is it possible that ‘affects’ could be replaced by ‘reflects’?

On the criterion ‘an indicator currently exists and/or ease of developing supporting datasets’, the AIHW would caution against restricting indicator selection to existing indicators unless they happen to closely match the desired measure. Too often indicators are chosen for expediency, functioning as proxies as best, and their selection often hampers data development in support of better indicators.

Two suggestions for additional criteria are:

- ‘Perform well technically (be valid, reliable, sensitive, robust, etc.)’
- ‘Lead to action’, which is complementary to the first criterion about action being reflected in the result.

The AIHW also suggests that the Commission consider criteria for assessing a whole set of indicators. Possible candidates include:

- the indicators relate to multiple objectives (that is, collect once, use often)
- the indicators should be conceptually coherent (that is, be grounded in a policy/theoretical framework)
- the set of indicators should be of an appropriate size (that is, cover the spectrum but not be unwieldy, while also allowing for disaggregation where necessary)
- the set should contain indicators that each pass the individual indicator assessment criteria.

What level of disaggregation should the indicators provide?

In general, the AIHW would advise that this is a matter of who is the intended audience. In the case of the NDA (and related accountability arrangements) there are multiple stakeholders operating at different levels. Hence, the indicators should be flexible such that high-level results

will provide a summary of performance, and then 'drill down' on those same indicators can provide results for smaller geographic areas, or particular subgroups of interest.

Is the collection and publishing of data, and funding of this, adequately dealt with in the NDA?

- ***Are existing datasets adequately resourced to provide the necessary evidence base for performance reporting under the NDA, NDS and NDIS?***
- ***Are there gaps in what data are collected?***

Much of our response to this question is covered in the substantive sections above. However, it is worth reiterating some of the concerns already addressed in the Issues Paper and in our comments above:

- Many of the survey sources are problematic in terms of scope/coverage, frequency and timeliness of data availability. For example, despite the SDAC being the principal source of many of the outcome measures, and one of the few sources of comprehensive information on carers, the survey currently only has core ABS funding for a 6-yearly cycle, with no certainty of the nature or extent of the survey outside of that cycle. It is critical that there is long-term funding commitment for regular surveys at a cycle that best complements ongoing data about support services, and information from the Census.
- While acknowledging that the NDIA produces public reports about the NDIS, the evidence base for the NDIS *could* be problematic if current, limited data release arrangements continue. It is vital that the NDIA design and produce publicly-accessible datasets suitable for performance reporting, both at a scheme level and also to contribute to monitoring at the broader disability support 'system' level, as articulated above.
- Although the disability services NMDS has been the predominant source for services data, this collection is effectively winding down as states and territories withdraw from direct service provision and/or oversight of disability support providers. There is a risk that, if mechanisms are not in place to ensure that nationally consistent data are collected, data on the entirety of services provided (including on specialist supports and the broader service system) will not be available, especially on services provided outside of the NDIS.

4. References

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