

NDIS Green Paper 1:

Data Assets, Efficiency and the NDIS

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Context:

This Green Paper is intended to contribute to the wider discussion relating to the roll out and management of the NDIS within the Australian Disability Services System. It supports the Not-for-profits UWA White Paper “Six Years and Counting: The NDIS and the Australian Disability Services System”.²

Summary:

The Australian Disability Services System requires complex, bespoke services and supports to be individualised and delivered reliably for often vulnerable people. To be effective, people with disability and care workers need to be at the very centre of the decision-making system, which means they also need to be at the centre of the data system. Through personal experiences, these people collect “Little Data” every day and use it to make daily decisions that impact their clients’ lives massively. At the same time, government agencies at the Commonwealth, state/territory and local government levels need aggregated data and analytics—that is, “Big Data”—at the appropriate levels of aggregation to support the decision-making needs of their policy makers and administrators. Developing a national data asset will substantively support the system and is overdue. However, it will not be enough to enable the provision of sound, bespoke services at the individual level. For the Australian Disability Services System to function efficiently and be integrative with mainstream government and other services, the structure of authority and control must align with those who have the best knowledge and skills regarding service users, and that can effectively utilise these skillsets. These people are not within state/territory or Commonwealth offices. Rather, they are distributed and embedded within our communities.

Of Note:

Funding cannot replace good decision making by front line workers nor government agencies, meaning increased funding in the absence of clarity about how to improve outcomes will only result in inefficiencies. As such, we need to develop data assets that encompass the Australian Disability System and involve leaders across the System, including those at the front-line, rather than just the NDIS. This can only be achieved via the development of a national, integrated and co-developed data strategy and plan using existing and new data.

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² See: <http://www.research.uwa.edu.au/not-for-profits-uwa#ndis-disability-services>

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The implementation and on-going operations of Australia’s Disability Services System³ requires many people—several hundred thousand—to make good decisions. These decisions impact the lives of millions of people including the day-to-day choices of people receiving services and supports. They also impact the work of the system’s planners and policy makers. Not only do the decisions need to be sound but they also need to be fair and applied consistently.

The quality of decisions correlates strongly with the quality of the information available to those making them. Further, unless useful data is available and able to be synthesised into information, and the facts related to that information agreed upon, group decisions are slowed or stopped entirely while stakeholders debate opinions while consistency (a major objective of the NDIS itself) suffers and inefficiency is increased. When there is consensus on the data, leaders can turn their minds to action.

Along with a robust and healthy supply of good quality services, the building and maintenance of data assets is an essential resource that directly impacts service outcomes. Australia’s data relating to disability service needs, supply, cost and use is, therefore, a critical national strategic asset to be developed.

This information must be contributed to by all, and be accessible to all, in forms that support efficient and effective decision making within the framework of the Australian Disability Services System. *Figure 1* below conceptualises the sources of data within the System schematically. Market arrangements need to support this process and will be improved by the provision of information.

“People with disabilities have identified a need for improved public reporting of NDIS review processes...Including the numbers of reviews, review timeframes, outcomes of reviews, and participant satisfaction with the review process.” (Disability Rights Now 2019, 14)

“There is no national mechanism that enables the collection of data on the health of people with disability. There is a lack of availability of administrative data on the use of mainstream health services by people with disability. Many health-related data collections do not include a way to identify if a person has disability.” (Disability Rights Now 2019, 36)

³ See the Not-for-profits UWA White Paper on the Australian Disability Services System above for a definition of this concept which is much broader than just the NDIS.

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 Australian Disability Services System Research Project
 Green Paper 1: Data Assets, Efficiency and the NDIS

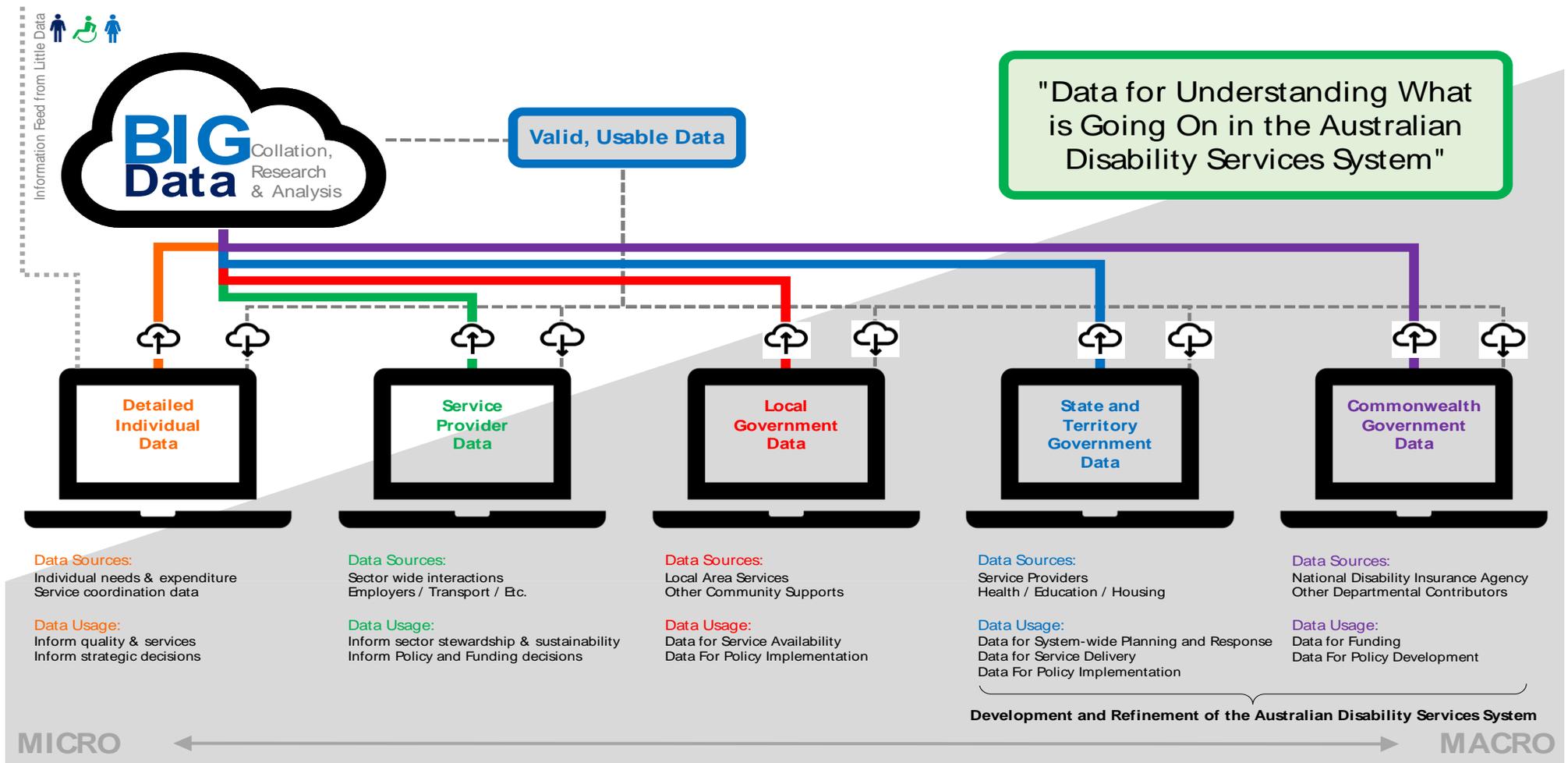


Figure 1 Schematic of disability sector data assets

Fundamental Requirements:

There is a need for a national data strategy which would have the following attributes, and which would drive the establishment and management of the National Disability Data Asset, including in relation to prioritisation of data needs.

The key attributes are:

- Data needs identified in accordance with outcomes pursued, recognising that the best data on users and suppliers will be held by front-line care support workers and local administrators.
- There should be clear, direct and observable links between the data asset and decisions made relating to all aspects of the delivery of disability services across the Australian Disability Services System.
- Data needs and prioritisation agreed between participant advocacy groups, providers and governments, including the NDIA and other government agencies providing funding and/or disability supports and services, such as departments of health or departments of education.
- Existing data sources identified and incorporated.
- Data plan, definitions and mechanisms published.
- Data is collected and aggregated via a national collection portal.
- Participants, providers, the NDIA and governments would be contributors to and users of the data asset.
- Data is made available publicly where appropriate and in accordance with a data release policy where specific needs are identified for utilisation.
- Data would not be available relating to specific individuals outside of accepted and appropriate practice, including in relation to anonymity.
- Actuarial data at local, regional, state/territory and national levels to be published.
- Forecast data/analysis related to local, state and national needs/capacity to be published.

What information is required?

Although the amount of data needed to provide and monitor the Australian Disability Services System effectively is vast, it can be classified into four main groups. Further, the data assets required cannot necessarily be created simultaneously and so priorities need to be created. Data types include:

1. Published data about user needs and demand - Demographic information

This data includes such things as counts of people with disability, types of disability, location, age, the impact of disability and predictions of future populations.

The NDIS was intended to be an insurance scheme that enabled the identification of an actuarial trajectory to determine the type, amount and timing of supports to both improve outcomes for people with disability and reduce long-term costs of support.

As such, published actuarial information, projections and data on outcomes of intervention and support are also needed.

2. Published data about services needed and supplied

This includes information on:

- The supports that are needed to achieve the outcomes for people as defined by Commonwealth and state/territory legislation and regulations. This may shift over time but must include definitional and descriptive information pertaining to the components and attributes of these services, which will support both supply capacity decisions and pricing decisions.
- The supports that are already being provided, and by whom, including by people with disabilities themselves, by family and carers and directly by local, state/territory and Commonwealth governments (e.g. education, housing, health, social).
- Mapping of comprehensive gaps between needs and supply.
- Current and future changes in supply that could result in people with disability not receiving services, including service exits by government agencies, non-government services providers or For-profit services and general market failure.
- Some of the above data are already being collected and models developed. However, this needs to be articulated as a data asset and, where work is being done to resolve the data gaps, the work needs to be recognised and articulated to all parties relevant to the Australian Disability Services System in order to avoid replication and to ensure the findings are leveraged as much as possible (e.g. see Reeders et al 2019).

3. Data to monitor the quality and impact of supply

Setting and monitoring quality standards is essential to ensure the services provided are of the expected quality while the needs and rights of recipients and their supports are respected. Data is critical to this process and helps inform regulators and others while the publication of data assists in ensuring experience—both positive and negative—is leveraged for better outcomes. Such data enables continuous improvement of the design and delivery of disability services and supports.

4. Data to ensure value for money and sustainability

Information is required to:

- Monitor all aspects of the source and application of funding for specialist and mainstream services for people with disability.
- Remember that the System is only sustainable if it actually achieves what it is established to do, this includes determining the reasonable cost of services so that the NDIA can set prices at rates that ensure sufficient supply of appropriate quality but do not result in undue profit for providers or other inefficiencies and remembering that these inefficiencies include delays in service provision, lack of provision (what we call market failure) and poor quality services designed to fit the budget rather than the need.
- Determine the cost of supports for people with disability in mainstream government services, such as specialist support for people with disability attending schools or hospitals. This is a significant task as it requires understanding the cost of provision of services by for-profit and not-for-profit providers, many of whom will provide services to people other than those with a disability and can be small-sized entities. Importantly, this should be undertaken using a national but segmented panel so that data collection and analysis can be extrapolated to the entire population of providers.
- Ensure efficiency of the NDIA and other government agencies responsible for service administration.
- Identify and deter fraud.

The real value in collecting this data is achieved when the data sets interact at a unit record level. **That is, when the needs, costs, quality and other factors of services are recorded at the individual level and for each individual service provider. With this, the utility of the data expands exponentially.**

Additional Discussion

There is a considerable amount of information held by a wide range of Commonwealth, state/territory agencies and other bodies for information types 1 to 3 above. This data consists of existing administrative data—such as health, housing and education records—and information explicitly collected concerning the population, in addition to the services needed and provided. Examples include the data collected by the Australian Institute of Health and Welfare (AIHW), the Household, Income and Labour Dynamics in Australia (HILDA) survey and the National Disability Data Network’s Disability Services National Minimum Data Set. Commonwealth and state/territory agencies also hold relevant information, including the state/territory-based disability services administrator agencies and the Australian Charities and Not-for-profits Commission (ACNC). Unfortunately, at this stage, very little of this data can be cross-matched to enable unit record level analysis.

There is even less information on the supply of services and the cost of service provision. This information had not been collected at scale prior to 2016, when National Disability Services and the University of Western Australia implemented a national collection of cost and sustainability data, which was based on a stratified sample of 180 disability organisations across Australia.⁴ While the NDIA has now commenced the collection of this data, it is not being collected in a panel structure and so its ability to be extrapolated across the population will be very limited.

To administer the Scheme, the NDIA has collected large quantities of administrative data from service users and providers since its inception and now has a substantial data asset at the unit record level. This includes data used for actuarial decisions and, if it can be combined with unit-level records of service providers, has enormous potential to be used to fine-tune service quantity, quality and cost. At this stage, much of this information is too aggregated to support a detailed understanding of demand, supply or costs. The NDIA's Data Availability Release Plan shows it intends to release further participant information. The NDIA has recently published a Public Data Sharing Policy and also provides some raw and summarised data on its website; some of this data is now available from the NDIA's website.⁵

The NDIA attempted to remedy data gaps by running early trials of the NDIS in specific regions. However, it is not clear the extent to which the data from trials influenced roll out, as the complete roll out was instigated as soon as the trials were completed (Olney & Dickson 2019). Even with these trials, the total accumulated data would not be enough to understand the difficulties of thin markets, the effect of marketisation on NFP providers, or the difficulties of provision in complex cases.

Furthermore, the results of the trial sites may have been due to more favourable ratios in participants to providers, governance and evaluators. The high amount of staff and monitoring available during these phases were not representative of the broader roll out, which was marred by issues of under-resourcing. This has led to increased costs to the Scheme's funding in the short-term, as well as an undermining capacity building for inhouse staff.

Is further information needed?

The efficient development and use of data assets is an ongoing task, made easier—yet also potentially riskier—by the speed of change in digital technology. As such, refining the data resources to enable more effective and timely responses will be an ongoing task.

⁴ See: <http://www.research.uwa.edu.au/not-for-profits-uwa#ndis-finance-reports-markets-reports>

⁵ See: <https://www.ndis.gov.au/about-us/data-and-insights>

However, the priority is not to collect more data but to more effectively use the data already available. This requires:

1. Taking stock: identifying and evaluating existing data assets, including but not limited to those held by the NDIA.
2. Taking stock: identifying and collating the current research being undertaken to collect data and aimed at resolving issues.
3. For each main stakeholder group, developing a list of key questions that need to be answered.
4. Identifying whether the data to answer these questions is available and of suitable quality
5. Determining which gaps need to be filled.
6. Determining the cost-effectiveness of further collection and analysis of further data. Data has a cost to collect and analyse, and the return on investment may not be warranted. However, a short-, medium- and long-term perspective needs to be taken to consider this issue properly.

Development of a data strategy is a high priority and needs significant investment.

One of the NDIA's key responsibilities is to monitor the scheme. In its Corporate Plan 2019-23, the NDIA states that it aspires to achieve '[a] competitive market with innovated supports' and will 'monitor and analyse data collected throughout the scheme, as well as regional intelligence and other data sources to understand and evaluate market performance and trends' (NDIA 2019). It also states that it enables the market by 'providing information, setting prices' and other activities. **The articulation of the importance of data development is a critical element but it is not only for the NDIA to develop the data asset or to use it—the Australian Disability Services System must be recruited to the collection, analysis and cultivation processes.**

However, this needs to be taken a step further with the development of a National Disability Data Strategy that identifies, collects and distributes the data assets needed to develop and monitor the sector. In September 2019, the Australian Data and Digital Council 'agreed to develop an enduring longitudinal National Disability Data Asset, incorporating datasets from multiple levels of government' (DPMC 2019). This is a welcome advancement. Additionally, Melbourne University's Disability Institute is also providing much needed leadership here in its establishment of the Democratising Disability Data initiative.⁶ However, these initiatives must be brought together at a national level.

⁶ See: <https://disability.unimelb.edu.au/research/democratising-disability-data>

The data strategy will help, but it is not enough

The quality of, and appropriate use of, data is critical to the successful implementation of the NDIS and the maturation of the Australian Disability Services System. It is critical to achieving service sustainability for the System into the long term. There is clear evidence from many sectors (e.g. education) confirming that increased funding alone does not buy better results; what is needed is better policy, and particularly, better implementation.

A national data strategy is essential to the development and monitoring of national policy. However, as for other human services, much of the information needed for proper implementation does not exist. It likely never will at the level that will support the centralised control and price setting that is at the core of the NDIA's approach. To do this requires local leaders who not only have data on individuals, families, suppliers and communities but have relationships with them. They know their history, their cultural background, and their expectations, and so are better positioned to accurately predict what they may need. Additionally, they know when demand will be high or low allowing them to shift resources to accommodate any variance, and they can respond quickly to the ever-changing needs of individuals. In essence, it is human to human data that is needed, and data sets cannot replace this.

The capacity of the Commonwealth government to effectively develop a centralised Australian Disability Services System (or indeed any service) will be determined by its capacity to collect and analyse data from all essential sources. The digital information revolution will enable immense strides to be made, but it is not and may never be detailed enough to deliver the indeed 'human' human service that has been the promise of the NDIS.

The NDIA is also tasked with price-setting and responsible for market development. Governments have taken to this role in other sectors with some success. However, realistically, a central national agency will never have enough data concerning individual markets for individual services in local areas to accurately set prices. Aggregate data will always be an inferior substitute for genuine local market knowledge. We must work toward resolving this issue and, given that technology and data scientists are already in place to undertake this work, the main missing ingredient is the agreed strategy and data asset development objectives.

Relevant references:

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