NDIS Public Data Sharing Policy

Summary

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Overview

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Data critical to success of NDIS

Public sharing of NDIS data will enable people with disability to become informed consumers, resulting in increased market innovation, and a more sustainable NDIS.

The participant is at the centre of everything we do

All data sharing must be underpinned by principles that put people with disability at the centre of decisions, and are compliant with relevant legislation.

Equal access to data to promote fair markets

Market data will be made publicly available as open source. Sharing for commercial purposes, beyond data publicly available, will not be considered.

Whole of government mandate for transparency

The Australian Government is committed to increasing transparency and availability of government data. The NDIA has developed this policy in line with the Australian Government's approach to accountability and transparency.

Data sharing decisions are underpinned by ethical use, responsible and lawful release.

Decisions to share data must align with community expectations and standards. The NDIA must consider ways to mitigate the risk of data misuse and all decisions must meet the legal requirements of relevant legislation, such as the NDIS Act and the Privacy Act.

Why is data sharing important?

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Empowers people with a disability

At the centre of the NDIS are participants who are informed consumers, exercising choice and control about the supports and services they access.

Creates competitive, innovative markets

Access to data can assist providers in streamlining their services, and find geographies and niches with unmet demand.

Informs policy development and research

With greater access to information, academics can undertake valuable research, and governments can develop informed policy. This enables evidence-based policy decisions.

Reports on the performance of the NDIS

Data sharing allows key stakeholders, including government and the public, to understand performance of the NDIA, and progress against the NDIS strategic intent.

Builds community confidence in the NDIA

Transparency makes the NDIA more accountable. It promotes visibility of government activity while motivating the NDIA to continue meeting community expectations.

Collecting, using and sharing data is a critical part in creating an environment that supports participant outcomes and establishing a financially sustainable NDIS.

As recognised in the Productivity *Commission's Disability Care and Support Inquiry* (2011), decision making informed by data will result in better outcomes for individuals, businesses and governments.

Through data sharing, it is anticipated that people with disability will:

- Be better informed consumers
- Drive market innovation and quality of supports
- Ensure the financial sustainability of the NDIS

The *NDIA Corporate Plan 2019-2023* outlines the NDIA Board's commitment to data sharing, and its importance to improving social and employment outcomes for people with disability and their families. The NDIA is committed to creating a growing and competitive market with innovative supports.

Principles underpinning this policy

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NDIS Public Data Sharing Policy

Ethical use

There is an expectation that data is released only when in the public interest.

Data sharing arrangements must consider the purpose, or intended use, of NDIS data – this purpose must align to community expectations.

The participant is at the centre of everything we do

Any decision to share data must be made with participants best interest in mind, and respects the origins of NDIS data.

This includes the rights of people with a disability to have the same right as other members of Australian society, and to respect their worth and dignity to live free from abuse, neglect and exploitation.

Lawful Release

The NDIA database contains sensitive data. All disclosures of NDIS data must be compliant with relevant legal obligations.

Any data release must be compliant with the NDIA's Privacy Policy and operational guidelines covering the handling of protected agency information.

Responsible release

While the NDIS matures, data quality and interpretability will be variable.

Data being considered for release must consider the maturity of the processes and systems that generate that data.

NDIA is the custodian of NDIS data

It is critical the NDIA maintain trust of all persons about whom it holds and owns data, including participants and providers.

The way custodians deal with data must be legal, with consent and align with reasonable expectations of participants and providers.

What data does this policy cover?

The NDIS Public Data Sharing Policy considers:

Which data?

The data that the NDIA will consider for release is expanded upon in Appendix A: Data Available for Release in the full NDIS Public Data Sharing Policy document.

Subject areas include:

- Population demographics
- Plans, support types and plan budgets
- Market supply
- Goals & outcomes
- NDIA performance

The policy details the minimum quality / maturity standards for subject areas to be considered 'safe'. 'Safe' data:

- Requires limited subject-matter expertise to interpret
- Is accurate
- Can be appropriately de-identified or identifiable dependent on the nature of the agreement (such as integrated government datasets)

For what purpose?

The NDIS Public Data Sharing Policy defines the allowable use of data held by NDIA. Purposes allowable under the policy include:

- To inform participants of availability (and effectiveness) of support models
- To inform policy development
- To enable academic research into disability, support models and outcomes.
- To inform markets of supply and demand
- To build public confidence in the administration and sustainability of the NDIS

To whom?

The NDIS Public Data Sharing Policy considers the entities with whom data held by the NDIA may be shared. The policy considers sharing with:

- The general public
- Participants
- Service Providers (via open data)
- Academic researchers
- Governments

By which mechanism?

The NDIS Public Data Sharing Policy defines the processes and platforms through which the NDIA may share data it holds. These mechanisms include:

- Published, synthesised reports
- Interactive data visualisations
- Downloadable data cubes
- Contribution to multi-organisation data assets

- Direct exchange with external entities
- Enduring authorised datasets
- Tailored data release
- Multi-organisational linked data assets

How does the NDIA make a decision to share data?

In making decisions around sharing data externally, the NDIA CEO or their delegate must consider:

Whether the data can be shared

How it should be released to minimise risk

An assessment is conducted against the Five Safe Framework:

The framework considers risks across 5 different domains to provide direction on the conditions and format of data release.

- Projects – data is shared for an appropriate purpose;
- People – The user has the appropriate skills and authority to access data;
- Settings – The way data is shared minimises risks of unauthorised use or disclosure;
- Data – Appropriate and proportionate protections are applied to the data; and
- Outputs – Reports and analyses have appropriate safeguards prior to release.

For more information on the Five Safe Framework please refer to section 2.5 of the NDIS Public Data Sharing Policy

Who does this policy affect?

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NDIS Participants

The NDIS Public Data Sharing Policy covers:

- The inclusion of all participant data in aggregated and synthesised data.
- Participant consideration in setting boundaries of acceptable use of NDIS data in research.

NDIA Staff

Release of protected NDIS data is a delegated role of the NDIA CEO. The NDIS Public Data Sharing Policy outlines the situations where release of data is permissible, and the process for consideration outside of the policy.

All NDIA staff (incl. Partners in the Community) must abide to the NDIS Act 2013. The NDIS Public Data Sharing Policy reinforces the need for NDIA staff to lawfully handle protected NDIS information.

Providers

The NDIS Public Data Sharing Policy covers:

- The allowable use of open, publicly released information for commercial purposes.
- The restriction on tailored data exchanges for commercial purposes.

Governments

Commonwealth and State/Territory governments require access to information to plan and manage services within host jurisdictions. The NDIS Public Data Sharing Policy covers the sharing of de-identified and identified data directly with host jurisdictions.

Researchers

Data will be available to academic researchers in standardised, downloadable formats. Additionally, the NDIS Public Data Sharing Policy covers:

- The partnering of NDIA with research organisations.
- The sharing of unreleased data for specific research projects.

Not all arrangements are covered by the policy.

The NDIS Public Data Sharing Policy does not cover:

- APIs and other commercial arrangements.
- Data access as a part of contracted NDIA work.
- Data sharing or release required for the purposes of the NDIS carrying out its legislated purposes and operations.
- Specific queries in response to enquiries from Ministers.
- Data sharing in response to concerns for safety and/or natural disaster.
- Requests made under the Freedom of Information legislation.

How will data be released?

Open access via NDIS website

Synthesised reports

Where data interpretability is complex, there are public interest sensitivities and/or data quality prohibits public data sharing, the NDIA will conduct data analyses and release those reports publicly.

These reports will provide an alternative way to access information without the need to access visualisations and/or data cubes.

Interactive visualisations

Data will be presented visually, either as maps, charts or infographics. These visualisations will be able to be filtered to display populations or characteristics of interest.

Data Cubes

Aggregated data will be available in downloadable formats for self-directed exploration and/or integration into external parties' systems and analyses.

Metadata

Data dictionaries and 'how to use' guides will be published to support interactive visualisations and data cubes.

Tailored Data Release

Multi-organisation data assets

Integrated data assets managed by third parties, where data from multiple organisations are combined for the purpose of supporting academic and policy research. Data of this kind will be authorised via an MOU/Public Disclosure Certificate and transferred via secure file transfer protocol.

Enduring authorised datasets

Sharing arrangements involving a periodic refresh of data (including real time). These arrangements typically are exchanges between government departments. This data is released via a MOU/Public Disclosure Certificate or a Data Sharing Agreement.

Tailored data release

Data that is tailored to the needs of academics, research organisations, government departments and agencies. Exchange will occur directly between the NDIA and the other party. This data is released as per the method prescribed in the Five Safe risk assessment.

Definitions of data to be released

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The section summarises the data to be released in data visualisations and data cubes. Detailed metadata will be made available concurrent to the public release of NDIS data.

1. Population demographics

Data on:
- Current participant volumes
- Projected participant numbers at full scheme

Able to be analysed by -
- Geographic region
- Age group
- Disability group

4. Goals & outcomes

Data on:
- Goals and progress against goals
- Key outcomes indicators

Able to be analysed by -
- Geographic region
- Age group
- Disability group
- Type of goal

2. Plans, support types and plan budgets

Data on:
- Access requests
- Access met
- Current participant plans
- Historical participant plans
- Plan management approaches

Able to be analysed by -
- Geographic region
- Age group
- Disability group
- Type of support

5. NDIA performance

Data on:
- Operational performance of the NDIA
- Processing volumes
- Wait times

Able to be analysed by -
- Geographic region
- Age group
- Disability group

3. Market supply

Data on:
- Providers
- Market share

Able to be analysed by -
- Geographic region
- Participant characteristics
- Type of support

Further information and how to request NDIS data

For more information please refer to the full NDIS Public Data Sharing Policy

For further information on the *Five Safes Framework*, how to gain access to NDIS data, how to provide feedback to the NDIA and what data is available to access please refer to the full NDIS Public Data Sharing Policy.

If you want to request NDIS data, you must complete a tailored data request form:

- This form is available from the website

- The NDIA will typically assess applications within 28 days of receiving a complete form

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Delivered by the
National Disability
Insurance Agency