The National Disability Data Asset Charter

This Charter was created by the National Disability Data Asset Pilot Disability Advisory Council and updated in line with further consultation with Disability Representative Organisations and the National Disability Research Partnership Working Party. It has been endorsed by the National Disability Data Asset Council and Disability Reform Ministerial Council.

1. Principles for the co-governance of the National Disability Data Asset

It is intended that people with disability, including disabled people's organisations, representative organisations of children and people with intellectual disability and the wider disability community will be a part of ongoing participation to define how the National Disability Data Asset will be used, what information will be collected and the outcomes the disability data asset will seek to achieve. The wider disability community includes families of people with disability, carers, organisations that represent people with disability and allies, as per article 4.3 of the *United Nations Convention on the Rights of Persons with Disabilities and the General Comment No.7 (2018)*.

The following principles will guide community participation in the co-governance of the National Disability Data Asset. The Charter will also be supported by disability-informed ethical oversight and disability data development panels reporting to the National Disability Data Asset Council.

The principles are:

Principle 1: Including and empowering people with disability

People with disability should be able to have a voice in decisions that affect them. There should also be appropriate policies and processes to make sure people with disability and the wider disability community can express their opinion. Where relevant, researchers, peaks and service providers should be consulted. There should also be appropriate policies and processes, and accessible communications about the National Disability Data Asset including use of plain language, Auslan, Easy Read translations, and braille versions of documents to support people with disability and the wider disability community to express their opinion. All projects should commit to include participation of people with disability.

There should be appropriate processes and policies to make sure the diversity of people with disability is represented. Principle 1 also requires specific cohorts to be adequately represented and heard in processes, including First Peoples, people who may not be fluent in English, children, and young people and those who require support expressing their will and preference.

Part of participation is empowerment. Persons with disability should be supported to understand, participate in and contribute to the process. This includes support for paid co-design, education, and other avenues to make sure

people with disability are informed when part of decision-making processes that affect people with disability.

What this is intended to achieve:

- Ongoing participation in the co-governance of the National Disability Data Asset so solutions are inclusive of a wider range of people, promote equity, and will not continue to entrench social and economic inequality.

- Priorities and decision making driven by the collective needs of people with disability.

- Value defined by collaboration and shared outcomes.

- Support for the data and digital literacy and capability of the disability community.

- Enable people with disability to be included within the scope of what insights the National Disability Data Asset generates and shares.

Principle 2: Making information available and accessible

Community trust can be built on a foundation of open information sharing about the processes of governance. Governance refers to who gets to make decisions about how the National Disability Data Asset can be used and how it should evolve over time, including how people with disability are involved in these decisions. This includes who makes decisions about how the National Disability Data Asset is used to produce data insights and how they make decisions. Information on governance processes will be available to the public.

Tools will be made available to support all National Disability Data Asset users. This includes ensuring information is accessible for those with a range of disabilities, in 'plain English' (plain language in general) and understandable to the public and non-expert audiences. This information should include decisions on the uses of the National Disability Data Asset made by its governing bodies and outcomes of the governing bodies' various initiatives (for example, outcomes from analysis to produce data insights on a specific cohort of people with disability and understanding their needs).

What this is intended to achieve:

- Improved digital inclusion.

- Visibility of the ongoing use of the National Disability Data Asset for people with disability and wider disability community.

- Community engagement around the National Disability Data Asset from a position of shared knowledge.

Principle 3: Making sure the National Disability Data Asset is used properly

There should be independent assessment of whether all principles in the Charter are being followed. This may be through an independent review of system performance, direct engagement with people with disability and the wider disability community, an annual human rights audit or other means.

Before any change is made to the Charter, engagement will occur through a process agreed by the National Disability Data Asset Council. The National Disability Data Asset governance bodies should be accountable for having systems in place to make sure data is protected, and not used outside of its intended purpose.

What this is intended to achieve:

- Confidence the National Disability Data Asset is working for the benefit of people with disability.
- Risks to people with disability from the National Disability Data Asset are managed and mitigated.
- Opportunities to improve the National Disability Data Asset, its use and the Charter.
- Evidence based conversations about the National Disability Data Asset.

Principle 4: Privacy and security of data

There should be a commitment to the community of appropriate safeguards for the privacy and security of information in the asset. The safeguards will make sure that personal information such as names and addresses are only shared with government staff who are involved in linking data. This personal information will not be shared with people using the analytical data including government and non-government researchers. This will enable community trust in the asset to be built and sustained. This includes, but is not limited to, compliance with Australian privacy laws and other legal obligations. It also involves following best practice where available and applicable, as well as regular audits to make sure there is compliance with appropriate privacy and security safeguards.

This will include following the data sharing principles under the Intergovernmental Agreement on Data Sharing. Under the data sharing principles there will be processes in place for deciding who can access the data and what purposes data can be accessed for and to make sure data is shared, collected and used in an appropriately controlled environment. Appropriate protections will be applied to the data and there are rules and processes for data outputs. The data sharing principles must be applied in such a way that, when

viewed as a whole, the risks of the sharing, collection and use of data are appropriately mitigated. These safeguards should not block access to the data for legitimate uses.

What this is intended to achieve:

- Best practice safeguards e.g., the use of data sharing principles under the Intergovernmental Agreement on Data Sharing and secure data access platforms to make sure of confidentiality and respect for privacy of people with disability.

- Collective community trust in the privacy and security of the National Disability Data Asset.

- Ongoing improvement in privacy and security practices.

Principle 5: Conditions of access

This Charter is intended to guide the use of data within the National Disability Data Asset for acceptable purposes only. More information can be found in the Acceptable Uses table. Therefore, access to data will be granted under strict conditions with reference to the Charter's outline of acceptable and unacceptable uses. If these conditions are breached, access will be removed. People who use the data will need to agree to keep information private, work for an approved organisation, and carefully follow the rules. Data will also be protected under the *Privacy Act 1988* and *Data Availability and Transparency Act 2022*. Penalties apply if either of these Acts are not followed.

Access will be audited and granted in line with conditions agreed to by data custodians in Data Sharing Agreements for the National Disability Data Asset.

What this is intended to achieve:

- Safe, secure, lawful, and ethical data sharing and use within the National Disability Data Asset in accordance with established legal arrangements.

- Removal of access and penalties in accordance with the legislation where conditions of access are breached.

- Guarantees the National Disability Data Asset will not be used for purposes other than those that have been approved as acceptable uses.

Principle 6: Public sharing of findings

Anyone seeking to use the National Disability Data Asset must commit to making some insights and outputs from all approved projects available to the public in accessible formats and in line with the above principles. The benefits must be shared with people with disability and the wider disability community.

Any results and insights can be disclosed provided they align with the Charter and do not constitute Cabinet-In-Confidence materials. Only specific findings that are Cabinet-In-Confidence will be not able to be shared.

What this is intended to achieve:

- An asset that creates value to the community over time through a stronger and accessible information and evidence base.
- Analysis focused on outcomes that benefit people with disability and engage with them and the wider disability community.

Principle 7: Creating lasting benefits for all people with disability

Resources used must be directed at improving the outcomes for all people with disability. This includes using resources fairly to improve outcomes for specific cohorts of people with disability. This public benefit is critical to maintaining community trust and will be monitored through the National Disability Data Asset Council.

The development of the technical and governance infrastructure must also be done with a long-term view to make sure there is scalability, value for money and inclusivity. There must be a commitment by government to make sure the National Disability Data Asset is used and developed (including with respect to the data it includes) to build the evidence base for decisions relevant to people with disability, whether they are made by governments, by people with disability or seek to improve inclusion of and services/supports for people with disability.

To support people with disability to be actively involved in the development and representation of the National Disability Data Asset, the Council will enable disability-led research and involvement of people with disability in the development of new data methodologies and frameworks. This could include identification of gaps in existing data frameworks, including those relating to the experiences of intersectional groups.

Benchmarks on the proportion of data projects proposed by people with disability and the wider disability community will be set, monitored, reported on and reviewed by the Council. As a starting point, at least 1 in 5 projects in every given 2-year period will be sponsored by organisation/s that represent people with disability. This proportion may change over time.

What this is intended to achieve:

- Fair consideration of specific interests and fair direction of resources to improve the outcomes for specific cohorts.

- Scalable infrastructure and data to make sure expanded uses meet broader needs and future changes in needs from the disability community.

- Improved understanding of different cohorts through development of disability indicators and supporting analyses by disability types.

- Involving people with disability in research and data development fosters a new culture of disability inclusion.

- Advancing disability community leadership in data projects and the proposal of new data initiatives.

Principle 8: Access to test findings

Subject to appropriate safeguards and processes, fast access for all approved users will be required to allow for community participation in the National Disability Data Asset. For example, this will include researchers who will need to be able to review the data.

Letting researchers access and review data will allow for researchers to scrutinise findings and support better use of the data. When the National Disability Data Asset is used to provide data insights, these should be able to be tested by others to make sure they accurately reflect what the data is showing. These findings should also be made public as per Principle 6.

What this is intended to achieve:

- A commitment to improving processes for non-government users to access the asset.

- A commitment to make data available, subject to appropriate safeguards, to make sure the National Disability Data Asset can be used to review findings or insights and allow for different views in policy/research discussion.

- A commitment that no information on the National Disability Data Asset that is legally able to be made publicly available by users is hidden to prevent scrutiny of its use, subject to appropriate safeguards.

Principle 9: Data quality and improvement

This principle includes an ongoing commitment to improve the quality of data by sharing knowledge on the National Disability Data Asset. This will support more robust insights. The sharing of knowledge about methods should include enhancement of National Disability Data Asset datasets with derived indicators / flags relevant to the lives of people with disability.

By combining data from multiple sources, the National Disability Data Asset will provide a more complete picture of the programs and services used by people

with disability. The comparison of different data sources will show which information still needs to be collected by government. With this information, the government can make informed decisions about improving data collection.

What this is intended to achieve:

- A commitment to improving the quality of data to support better data use and support people in reviewing findings or insights.

- A commitment to sharing information about data quality and advisory arrangements that support escalation of significant data gaps to governance bodies.

- A commitment to ongoing improvements in the methods of developing the different cohorts for analysis, based on researcher and community input.

2. Acceptable and unacceptable uses of the National Disability Data Asset in its initial years

Acceptable uses

Acceptable Use	Description
To improve understanding of the experience of people with disability to support policy development and service provision	• Improve understanding of the experiences of people with disability, their families and carers. • Identify services/supports that people with disability are receiving (or are not receiving where needs would indicate services should be being accessed) and identify areas of improvement. • Assist with policy development, market development, service commissioning, service planning and service improvement to the benefit of people with disability as a cohort within the Australian community. • Inform decisions about equity and efficiency of services provided within a jurisdiction or service system, judged against intended outcomes. • Identify needs of people with disability, especially unmet need ("make the invisible visible"). • These uses would lead to improved policy settings for governments. • For example, early childhood and education outcomes datasets can be brought together to examine which supports help reduce developmental delay in children.
Evaluation of programs to drive improved outcomes for people with disability	• Monitor and evaluate performance of programs to drive improved outcomes for people with disability. • Provide information about outcomes to people with disability, their families and carers, to the wider community, and to governments, including link to services and formal and informal supports (where possible given the data). • Better contract management and potential outcomes-based payments for providers to improve outcomes to benefit people with disability. • For example, the outcomes for people participating in a program can be compared to those who do not participate in a program to determine effectiveness, and further funding can be tied to certain measures.
Monitoring development and implementation of international disability standards	• Promote, protect and monitor the implementation of the United Nations Convention on the Rights of Persons with Disabilities.

Acceptable Use	Description
Support people to understand the benefits of different services and help them when they deal with governments and providers	• Support choice and control for National Disability Insurance Scheme (NDIS) participants through better information for people and supporting a better evidence base on the link between supports and outcomes. • Support all people with disability to identify services they might benefit from, including learning about services in their area, and supporting a better evidence base about the link between services and outcomes. • Support people with disability to engage with governments and other entities by providing better publicly available insights about the outcomes for people with disability and drivers of those outcomes.
Support people with disability being included through sharing insights about their experience and outcomes	• Provide richer insights about the outcomes for people with disability, and drivers of those outcomes, including inclusion in communities, work, and volunteering. • Provide insights into the lived experience of people with disability.
Research that contributes to a growing evidence base for better understanding of people with disability, their families and carers	• Increasing access to standardised, linked, privacy-protected data-sharing to contribute to an evidence base to facilitate program and impact evaluation, and evidence as to what supports/inclusion measures lead to improved outcomes. In order to make sure the privacy and security of data in the National Disability Data Asset, access to the National Disability Data Asset will be granted under *the Data and Availability Transparency Act*. As a result, only accredited users under the Act i.e. Australian, state or territory governments or researchers working for Australian universities will be able to undertake research using unit level data. • Outcomes, that can further inform effective policymaking and decisions by governments, people with disability and their families and carers. • Providing access to data more rapidly for robust research. This is especially critical in times of health and (related) economic crises, when lags in data on income, unemployment, housing stability, and food security make it difficult to understand rapidly changing needs for those most impacted, including people with disability.

Unacceptable uses

Unacceptable use	Description
Identify people for any purpose	• It is not acceptable to identify people for any purpose, including compliance purposes, and other enforcement purposes. This is in alignment with the *Data Availability and Transparency Act 2022* preclusions. The data will also not be able to be used for purposes such as recruitment for research. This means no one using the National Disability Data Asset will be able to find out who people are or contact them.
Make decisions about an individual's access to government funding	• The use of National Disability Data Asset data to adjust individuals' funding will not be allowed.
Any purpose that conflicts with a human rights approach or privacy laws	• Uses of the National Disability Data Asset will comply with all relevant laws and obligations in Australia, whilst not impeding the conditions of access principle and making sure the data and findings are still able to be reviewed. • Changes to acceptable and unacceptable uses will undergo a human rights assessment, to inform any decision whether to make the change.
Use in automated decision- making tools for enforcement	• The community does not accept that use of data in automated decision-making tools for enforcement action by government is allowable. This should not block this use for trials and research, following approval processes to consider its ethical use.
Determining funding arrangements between Australian, state and territory governments without agreement	• The National Disability Data Asset will only be used to inform jurisdictional funding agreements, if it is explicitly agreed between governments for the benefit of citizens (for example, to determine where funding is required).

3. National Disability Data Asset Charter amendment process

People with disability must be able to trust the rules will not be changed by governments without an agreed, co-governed process.

For all proposed changes to the acceptable and unacceptable uses, any proposed change must go through:

1. An engagement process with people with disability, their families, carers and representative organisations,
2. A disability community committee made up of diverse people with disability, their families, representatives and carers, and
3. A consideration of human rights implications through consultation with the Australian Human Rights Commission.

If the proposed change is considered acceptable by a majority of the disability community committee, it will be recommended to the National Disability Data Asset Council by the National Disability Data Asset Operations team for the Council's consideration.

4. Ensuring the Charter is applied

To make sure that the Charter is applied, both government, people with disability and the wider disability community must be able to review the Charter's ongoing effectiveness. The National Disability Data Asset Council will receive reports on a six-monthly basis on the number of projects, the number of approved users and be provided a list of publications to monitor how the Charter is operating. This information will also be publicly available. Mechanisms to be incorporated into National Disability Data Asset operations, as far as possible to protect privacy, to enable review are:

Mechanism	Description
Making information available and accessible	• Open documentation of decision making around National Disability Data Asset uses and outcomes. • Open documentation of proposed and ongoing projects, project cohort, data sources, proposed uses and value to the community and evidence-informed decision making. • Open documentation and data on completed projects and outcomes.
Community Evaluation	• Engagement with a subset of people with disability and the wider disability community to interrogate, evaluate, question, and propose changes to, how the Charter is applied.

Mechanism	Description
Reporting	- Periodic public reporting on how the Charter is guiding use of the National Disability Data Asset
Routine Audit	- Periodic auditing by a third party against an established compliance framework.

5. Glossary

Term	Definition
Approved organisation	• An organisation approved to access data in the National Disability Data Asset. All users seeking to access the National Disability Data Asset will need to be accredited under the *Data Availability and Transparency Act 2002 (Cth) (DAT Act)*. • An organisation becomes an approved organisation when the Office of the National Data Commissioner assesses the organisation against criteria and approves their application to be an accredited user. Currently accredited users can be Australian, state and territory government bodies and accredited Australian universities.
Approved user	• A user who is given access to linked de-identified analytical data for a specific approved project. This includes accredited users from Australian, state and territory government bodies and Australian universities. This is consistent with the accredited user requirements under the DAT Act. • An approved user will be an accredited user under the DAT Act and has been approved to be provided access to the National Disability Data Asset for a specific approved project.
National Disability Data Asset Operations team	• The Operations team support the Council and provide the day-to-day operations and management of the National Disability Data Asset.
Panels	• Panels of individuals with specialist knowledge tasked with supporting the Council. • Panels will be stood up and wound down at the discretion of the Council and will provide support on priority areas for the National Disability Data Asset which could include consulting with the disability community, specific data themes, intersectionality, data improvement or areas for future development. Panels may have individual or joint responsibilities assigned by the Council.
People with disability	• As per article 1 of the United Nations Convention on the Rights of Persons with Disabilities, people with disability include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. • References to people with disability also includes disabled people's organisations and representative organisations of children and people with intellectual disability.
Wider disability community	• The wider disability community includes families of people with disability, carers, organisations that represent people with disability and allies, as per article 4.3 of the United Nations Convention on the Rights of Persons with Disabilities and the General Comment No.7 (2018).