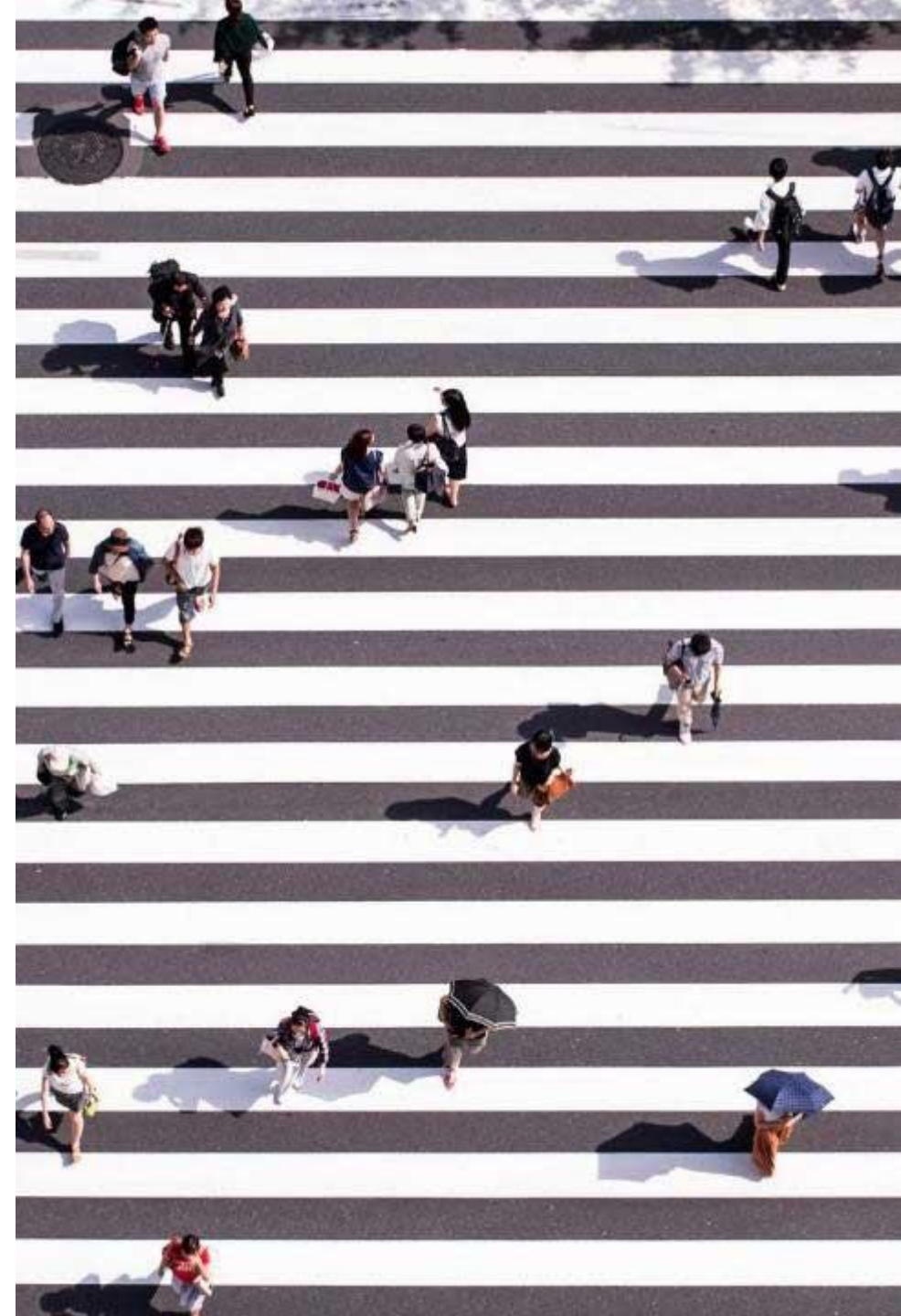


# National Disability Data Asset:

## Implementing the Pilot Phase and designing the enduring asset

Summary Report

19 December 2019



# A nation-wide, cross-domain data asset will help to better understand services delivered and outcomes for people with disability



Assist with data-driven:

- Policy development, service redesign, performance management and outcomes improvement
- Platforms and information to drive choice, control and empowerment for PwD
- Benchmarking and reporting against NDS and international standards
- Research on high-priority issues for PwD



Examples of impact:

- Observe services that people with disability are receiving and pinpoint areas of improvement
- Gain information about the pathways and services used by people with similar disabilities, and the outcomes for different services
- National-level statistics and standardisation across different levels of government
- Understanding of the needs of different cohorts of PwD

\* From the National Disability Strategy 2010-2020. The Articles outlined in the UN Convention on the Rights of Persons with Disabilities (CRPD) map to these domains. Over time, research questions could be targeted at understanding Australia's progress towards its obligations under the Convention.

# Executive Summary

## **Why pilot:** The purpose of the pilot of the National Disability Data Asset is to test and demonstrate the potential of an enduring asset

- The 18 month pilot phase will show early value through five high priority government-led test cases and invest in designing an enduring asset that will improve services for people with disability (PWD). The purpose of “piloting” is to learn, through doing, about how to best build trust and govern the asset, how to best manage privacy and legal requirements, whether data management and technology processes and systems are fit for purpose, and establish ways to drive longer-term impact for key user groups.

## **What are the demonstrations for the pilot:** The pilot will focus on demonstrating government use of the asset, and laying the foundations for use by people with disability (PWD), researchers and the wider public

- The four main purposes of the asset serve both government and community use, namely government use, platforms and information for PwD, wider public reporting, and research use. The pilot should include testing of ideas and processes across these key user groups:
- **Government use through 5 test cases:** test capacity for government to use the asset for policy development, service planning, and understanding what works through 5 test cases in different jurisdictions. Results / outputs will be shared both internally between jurisdictions as well as externally with the community where appropriate.
- **Platforms for people with disability:** deliver information to PwD as part of the government-led test cases, deliver a prototype for one platform, and agree the priority platforms and types of information to be delivered in subsequent phases.
- **Public reporting:** report metrics against the NDS Outcomes Framework from the government-led test cases, deliver select public outputs from the test cases, and measure public engagement
- **Research use:** agree research priorities, and test researcher access through test cases

## **Who will deliver:** Roles and responsibilities will be distributed across 9 key partners, including the national project team, AIHW, participating jurisdictions and the Commonwealth

- See following page for high level responsibilities

# The NDDA will be delivered and co-governed by nine key partners to implement the pilot and drive towards an enduring asset

## 2 Delivery Teams

**National Project Team**  
(NSW-hosted)

Provides high level oversight of pilot implementation through program management; drives engagement and pulls together the overall design of an enduring NDDA to present to Ministers in mid-2021

**Technical Project Team**  
**AIHW**

Builds the asset and executes data arrangements for the pilot test cases and drives designing the technical and data arrangements for the enduring NDDA

## 5 Participating Jurisdictions



**Australian Government**  
**Department of Social Services**

Ensures execution of their test case; engages with the development of the enduring NDDA design; supports co-governance of the NDDA and advocates its wider use within the jurisdiction

## Commonwealth



**Australian Government**  
**Department of the Prime Minister and Cabinet**



**Australian Government**  
**Department of Social Services**

Leads on Commonwealth-driven enablers, including ensuring delivery of long-term funding proposal to ministers and the implementation of any required changes to Commonwealth legislation or data sharing and integration approaches to enable the enduring NDDA

## NDIA

**ndia**

Supports delivery of each partner's priority test cases and engages with the development of the enduring NDDA design; supports co-governance of the NDDA and advocates its wider use within the NDIA.






The 9 partners are accountable to the **Australian Data and Digital Council** and the **Disability Reform Council**, and have reporting lines into the COAG Health and COAG Education Councils, and multiple national committees



## Background on analytics

Linked datasets in the NDDA contain individual-level records and should allow analyses of services accessed and outcomes achieved by specific cohorts of PwD

	 Cohorts of interest	 Services	 Outcomes
<b>Description</b>	<p><b>Who are the target group(s) of interest that the service / intervention is trying to help?</b></p> <p>A cohort is a group of people who share a common characteristic, experience, or needs within a defined period. To conduct downstream analyses on the services and outcomes, the cohort of interest and the cohort that it is being compared need to be clearly and consistently defined and identified in the NDDA</p>	<p><b>What services and interventions are being accessed by the target group?</b></p> <p>Services, programs and interventions are activities and benefits offered by the government to improve the outcomes of</p>	<p><b>What change should the services achieve for the target group?</b></p> <p>Outcomes are defined as the changes that occur for PwD that are attributable to an intervention. Outcomes can be short-, medium- or long-term, and based on the level of attributability to a specific government service or intervention.</p>
<b>Example</b>	e.g. Young adults (15-24 year olds) with psychosocial disability	e.g. Receipt of NDIS School Leavers Employment Supports	e.g. People are able to participate in the labour force
<b>Recommended Pilot Phase Focus</b>	<p>Participating jurisdictions to identify cohorts of interest</p> <p>AIHW to develop flags in the data asset to ensure that cohorts of interest are able to be analysed consistently</p>	<p>Each test case will have a component to analyse services accessed using individual-level dataset</p> <p>Within the scope of the Cth test case will be to further identify how service mapping methodology should be improved</p>	<p>Each test case to measure outcome indicators related to its domains using individual-level admin data available in the datasets</p>



### What is service mapping?

#### What can currently be done using data-driven approaches?

- Service mapping is an analysis that presents standardised information about services available and accessed by individual PwD and their carers. This integrated information therefore provides insights on service availability and capacity in different areas as well as individual-level information on demographic characteristics of PwD and their carers accessing the services.
- Service mapping analyses seek to resolve terminology variability (e.g. different terms used to describe similar services) and lack of common units of analysis.
- There is currently no methodology for data-driven service mapping on the scale anticipated for the NDDA. Various academics and consultancies have used different methodologies, ranging in complexity and rigour from using survey data, to provider information, government expenditure per capita data, and manually collated information about services. All approaches have their respective merits.
- Service mapping requires a provider as well as a person-centred view to be comprehensive. To extend to understanding equitable access of services is even more complicated, because it relates to the inclusiveness of a service

#### What is service mapping in the pilot phase?

- This test case is exploring the feasibility of large-scale service mapping being enabled through the NDDA. This will require work with researchers and government agencies to identify whether there is a scalable methodology, with data agencies to identify potential sources of data and sourcing of existing service directories.
- The type of service mapping that may be possible in the pilot phase is to take existing data committed to the NDDA, and other data held by AIHW (with additional permissions sought) to provide a snapshot of services accessed by PwD, including NDIS and mainstream services.

### Why is service mapping important for the NDDA?

The pilot phase will focus on understanding how broad-scale service mapping can be supported through the NDDA, as it is a crucial enabler of many potential uses of the enduring asset:

<b>NDDA Purpose:</b>	<b>Example:</b>
Government Use:	Support policy development/design and service/program planning and management
Platforms and information for PwD:	Support services directory for PwD, or information about what services are suited to 'people like me'
Public reporting:	Reporting on service delivery, particularly against UN Convention on the Rights of Persons with Disabilities and against the NDS
Research for academics and sector:	Service availability and utilisation, and evidence-informed design – which requires service mapping, are common themes in research questions

### What are the objectives of service mapping in the pilot phase of NDDA?

Service mapping provides visibility of services accessed PwD, and could therefore be used as an evidence-informed decision making and service planning tool that:

- Takes local factors and service access / utilisation / efficiency into account
- Explores potential gaps in the provision of services vs need of the population cohorts in the area
- Detects where existing funds could be spent to increase accessibility



**What is outcomes measurement?**

- Outcomes measurement refers to an analysis of the measures that indicate whether an outcome has/has not been achieved. For example, a measure of an employment outcome could include analysing changes in a person’s salary or dependence on government support.
- With unit record admin data, the NDDA allows us to measure person-centred outcomes and therefore identify the most effective services, programs and activities required to achieve said outcomes.
- Achievement of outcomes can be tracked by having clear indicators of outcomes supported in the data asset.

**Why is outcomes measurement important for the NDDA?**

Outcomes measurement is important for each of the four purposes of the NDDA:

<b>NDDA Purpose:</b>	<b>Example:</b>
Government Use:	Allow outcomes-based performance monitoring and evaluation and support whole-of-government transition towards outcomes budgeting and commissioning
Platforms and information for PwD:	Information about how to achieve best outcomes for ‘people like me’
Public reporting:	Reporting on outcomes for PwD against the National Disability Strategy and NDIS Outcomes Framework
Research for academics and sector:	How do the long-term outcomes of PwD in Australia compare to those living internationally?

**What are the objectives in the pilot phase of NDDA?**

Tracking and measuring outcomes can be used to improve the value of services and interventions by focussing on designing responses that deliver better outcomes:

- Empowers governments and service providers to be clear about the impact that they want to achieve
- Provide mechanism and opportunity for services and interventions to be better tailored to individual cohorts based on evidence of what works



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