The National Disability Data Asset

The Commonwealth and state and territory governments are working together to develop a National Disability Data Asset (NDDA).

The purpose of the NDDA is to improve outcomes for people with disability, their families and carers, by sharing de-identified data to better understand the life experiences and outcomes of people with disability in Australia.

The NDDA is currently in an 18-month pilot phase, which commenced in April 2020. The pilot phase follows an agreement by the Australian Data and Digital Council in September 2019 to develop an enduring NDDA, incorporating datasets from multiple levels of government.

The pilot aims to demonstrate the value of the asset. Five government test cases are being used to demonstrate the potential of using data to support improved policy development, program design and service delivery for people with disability.

The test cases focus on the following themes: early childhood; justice; education to employment; mental health; and how linked administrative data can support an outcomes framework under the new National Disability Strategy.

The pilot will undertake targeted user research, co-design and consultations with people with disability and the broader disability community. These engagements will support explorations of digital experiences the NDDA may be able to support, as well as possible designs for the enduring asset.

Why is a data asset important?

Currently, the ability to measure and improve outcomes for people with disability is limited. This is because much of the data collected by agencies is not linked and some of the data does not identify if people have disability. This means that no one has a complete picture of the life experiences and life outcomes of people with disability.

The pilot aims to identify the most effective ways to share, link and access data to deliver a more complete picture. This includes identifying potential barriers to data-sharing and developing ways to overcome these. The pilot will also focus on the best ways to protect people's privacy, including data de-identification and information security methods.

Who is involved in the NDDA pilot?

The pilot is being delivered and co-governed by nine partners:

- the Commonwealth of Australia, represented by the Department of the Prime Minister and Cabinet and the Department of Social Services;
- the Governments of New South Wales, Queensland, South Australia, and Victoria;
- the National Disability Insurance Agency;
- the National Project Team (based in the NSW Department of Premier and Cabinet); and
- the Technical Project Team (based in the Australian Institute of Health and Welfare).

The pilot is being guided by a Disability Advisory Council, which is Chaired by Dr Ben Gauntlett, Disability Discrimination Commissioner (see list of members below). The Council will engage the disability community and provide guidance to the project team throughout the pilot phase.

Council members bring expertise in disability policy, advocacy, social investment, research, service provision, business, economics and law. Members also bring experience working with a wide range of people with disability, including people with complex needs, Indigenous Australians, people from culturally and linguistically diverse backgrounds, and people living in regional and remote communities.

Disability Advisory Council members

- Dr Ben Gauntlett, Disability Discrimination Commissioner and Chair of the Disability Advisory Council

- Dr Scott Avery, Senior Lecturer, School of Social Sciences, UWS

- Professor Bruce Bonyhady, Professor of Enterprise (Disability Economics), Executive Director & Chair, Melbourne Disability Institute, NDIS Architect

- Belinda Drew, CEO, Community Services Industry Australia, Chair, Social Enterprise Finance Australia

- Damian Griffis, CEO, First Peoples Disability Network (Australia) Ltd

- Professor Anne Kavanagh, Chair of Disability and Health, Head of the Disability and Health Unit in the Centre for Health Equity, Co-Director, NHMRC Centre of Research Excellence in Disability and Health

- Professor Gwynnyth Llewellyn, Director of Family and Disability Studies, USYD, Head, WHO Collaborating Centre for Strengthening Rehabilitation Capacity in Health Systems, Co-Director, NHMRC Centre of Research Excellence Disability and Health, Disability and Inequity Stream Leader, Centre for Disability Research and Policy

- Dr Steven McEachern, Director, Australian Data Archive, ANU

- Kevin Stone, CEO, Victorian Advocacy League for Individuals with Disability (VALID), Chair, Inclusion Australia (National Council on Intellectual Disability)

- Professor Julian Trollor, Head of Development Disability Department, UNSW

- Leah Van Poppel, CEO, Women with Disabilities Victoria (WDV)

- John Walsh AM, NDIS Architect