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Australia's changing disability data landscape

7. Australia's changing disability data landscape

Around 1 in 6 Australians have disability – a very heterogeneous population group, with diverse characteristics, needs, aspirations and outcomes. High-quality and readily accessible information is essential to further understand the experiences of these Australians, while continuing to work with them on policies, programs and services to achieve optimal outcomes. Australia's data landscape continues to adjust in response to the demand for reliable, timely and policy-relevant statistics on people with disability, and to changes in the delivery of programs that require changes to evidence and data. The disability information base Australia has built has laid the platform for recent policy developments and improvements in the availability of information in some specific areas; however, critical data gaps remain.

This article provides a high-level overview of the disability data landscape and key factors influencing its future improvement, one of which is the keen interest in information captured on the minority of people with disability who access specialist disability supports and services. In this regard, information available on the delivery of the National Disability Insurance Scheme (NDIS) has increased in recent years. The NDIS Commission now monitors and reports on the quality and safety of NDIS supports and services for all of Australia's NDIS participants. However, there is little information on the full range of specialist support services provided to people with disability outside these arrangements, such as residual services delivered under the former National Disability Agreement (NDA).

New strategies often demand data improvement to support the measurement of targeted outcomes. The National Disability Strategy (NDS), due for renewal in 2021, will contain a detailed outcomes framework, aligned with an updated NDIS Outcomes Framework. The new strategy is expected to both require and drive data improvement to better understand outcomes for all people with disability. Similarly, recommendations from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability RC), currently in progress, will likely be a key driver for directing future data improvements.

Major data linkage initiatives in recent years include, notably, the National Disability Data Asset (NDDA) pilot, which has the potential to improve the available evidence base not only on the needs of some disability population groups, but also on their use of specialist disability and mainstream services and their outcomes. As well, the National Disability Research Partnership now provides a disability research and policy hub, which should also help to identify future data gaps that need to be resolved to better understand the experiences of people with disability in Australia.

In the light of these developments, this article discusses:

- current sources of disability statistics in Australia
- key policy developments and government reviews that are continuing to affect the ongoing development of Australia's disability data landscape
- important disability data gaps, including those highlighted in response to the Coronavirus disease 2019 (COVID-19) pandemic
- work underway to improve Australia's evidence base on people with disability, including the NDDA.

Current sources of disability-related data

Over time, national data collections have been developed to inform policy makers on the experiences of people with disability as a population group, along with their support needs and access to services. Each data source has specific advantages and disadvantages, providing information about certain aspects of the lives of people with disability or the services they receive. While available data sources are fit for purpose, they have varying degrees of accessibility, quality and usefulness for analysis of the experiences of people with disability. For example, the definition and identification of people with disability used in each collection can vary, depending on the collection type and purpose; furthermore, some data are useful only if linked to another source that allows some information about disability to be inferred.

Key national policy developments and the COVID-19 pandemic are generating a renewed focus on the timeliness and availability of data on the characteristics, service use and outcomes of all people with disability.

Specialist disability services administrative data

Several administrative datasets contain valuable information on the delivery of specialised disability supports and services. Until recently, there have been 3 national administrative data collections that are disability specific.

Disability Services National Minimum Data Set

Between 2003–04 and 2018–19, the AIHW annually compiled unit record data from jurisdictions in the Disability Services National Minimum Data Set (DS NMDS). These data related to the provision of disability support services under the NDA, such as accommodation and community support services, and open and supported employment services.

In 2018–19, the last year of data collection under the DS NMDS, a number of jurisdictions did not report these data due to their transition to the NDIS (Australian Capital Territory transitioned in 2016–17 and New South Wales in 2017–18; South Australia did not collect 2018–19 data as most clients had transitioned to the NDIS) (AIHW 2020a).

In May 2020, the AIHW released the *Disability support services: services provided under the National Disability Agreement 2018–19* bulletin, reporting on the final year of data collection for the DS NMDS (AIHW 2020a). In this bulletin, only Australian Government NDA employment services data were reported for the Australian Capital Territory, New South Wales and South Australia.

In January 2021, the Productivity Commission's Report on government services (RoGS) also reported DS NMDS data for the last time as part of the NDA's annual requirement for performance reporting (SCRGSP 2021) (see the section 'Disability Employment Services data' in this article).

There are comparability issues between DS NMDS data and the data subsequently collected under the NDIS. These data sources can still be used in tandem, however, to inform policy makers on changes that occurred in the use of disability support services over time, including during the transition period before completion of the staged roll-out of the NDIS. In *Australia's welfare 2021*, the snapshot 'Specialised supports for people with a disability' summarises the services used by people with disability who were receiving support under the NDA in the last year that data were collected under the DS NMDS (2018–19), alongside recently available NDIS data. More in depth analysis of this transition is feasible and could be explored using the National Disability Data Asset if it proceeds beyond the current pilot (see the section 'What is the National Disability Data Asset?' in this article).

National Disability Insurance Scheme data

The National Disability Insurance Agency (NDIA) is the sole administering authority of the NDIS and collects administrative data to deliver the Scheme. Section 118 of the *National Disability Insurance Scheme Act 2013* states that the NDIA has the following functions in relation to data collection:

- to manage, and to advise and report on, the financial sustainability of the NDIS

- to collect, analyse and exchange data about disabilities and the supports (including early intervention supports) for people with disability

- to undertake research relating to disabilities, the supports (including early intervention supports) for people with disability and the social contributors to disabilities (Australian Government 2013).

The collection and considered use of consistent data to inform policy development can help drive better outcomes for NDIS participants over their lifetimes. In particular, the NDIA notes that consistent data on a participant's age, functional capacity and other environmental factors are likely to influence outcomes in areas such as employment and social inclusion (NDIA 2020c).

Data released on a quarterly basis by the NDIA include:

- population demographics: numbers of NDIS participants

- plans, and support types: numbers of participant plans, access requests, 'access met' decisions and committed supports

- NDIS plan budgets: value of current participant plan budgets, historical participant plans and plan management approaches

- market supply: information on active providers and their market share

- goals and outcomes: participant plan goals in progress and key outcome indicators (for example, daily living; choice and control; lifelong learning; relationships; social, community and civic participation; and health and wellbeing)

- NDIA performance: operational performance of the NDIA (processing volumes, wait times and backlogs) (NDIA 2020b).

Disability Employment Services data

The Australian Government's Disability Employment Services (DES) program supports people with disability to prepare for, find and keep a job. Support is available for employers to implement practices that support their employees with disability. DES services were not rolled into the NDIS (unlike the Australian Government's supported employment services). DES are demand driven, meaning that places are not capped, and anyone who meets the eligibility criteria can access them.

The DES program has 2 parts:

• Disability Management Services (DMS) support job seekers with disability, injury or health condition who need assistance to find a job and occasional support in the workplace to keep a job.

• Employment Support Services (ESS) assist job seekers with permanent disability who need regular, ongoing support in the workplace to keep a job (DSS 2019a).

The Department of Social Services releases monthly DES data on its website which include information on DES caseloads, age distribution, status (for example, commenced, suspended), primary disability, and outcomes-related data (for example, job placements, period of time employed) (DSS 2021b). DES data are also reported in the annual RoGS and other national reports.

The number of people accessing the DES program (including both ESS and DMS) rose steadily from 182,000 to 313,000 between May 2016 and May 2021 (see 'Specialised supports for people with disability' at www.aihw.gov.au/reports/australias-welfare/supporting-people-with-disability for more information) (DSS 2021b).

Mainstream services administrative data

A range of mainstream systems provide services to people with disability. Administrative data from these systems can be used to report data on people with disability by using a 'flag' (or a set of questions) to identify a person with disability and the extent of their limitation or restriction.

The use of flags in mainstream collections can reduce the need to develop new disability specific data collections. In 2013, the AIHW developed a Standardised Disability Flag for potential use in mainstream service data collections that would be comparable over time and across collections. This flag is based on a standard set of questions that assess a person's level of functioning and need for support in everyday activities. The questions are based on the International Classification of Functioning and Disability and are broadly consistent with the Short Disability Module (SDM) questions that the Australian Bureau of Statistics (ABS) uses in a number of its surveys.

Versions of this flag have been implemented in 2 national collections: the Specialist Homelessness Services Collection and the National Prisoner Health Data Collection. On 1 July 2019, an NDIS indicator was also included in the Specialist Homelessness Services Collection (AIHW 2020f).

Other mainstream collections identify particular groups of people with disability through their assessments of eligibility to receive payments or support. For example, Centrelink data can be used to identify a specific group of people with disability through reference to Disability Support Pension payments and other disability-related payments received by people assessed as eligible. Similarly, state/territory education collections identify groups of children eligible to receive school-based support, with some of the information captured in the Nationally Consistent Collection of Data on School Students with Disability (which details information on the number of students with disability in schools and the adjustments they receive) (Education Services Australia 2020).

Survey data

Population surveys are the best available data source for estimates of the prevalence and level of disability in the Australian population (including changes over time) and for capturing information about people's experiences across different life areas. Survey data capture information from a broader population of people with disability than is possible with administrative data, as not all people with disability use specialist disability services.

Survey of Disability, Ageing and Carers

The ABS Survey of Disability, Ageing and Carers (SDAC) is the largest, most detailed and comprehensive source of disability prevalence data in Australia. Disability prevalence is the number or proportion of the population living with disability at a given time. The SDAC defines that a person has disability if they have at least 1 limitation, restriction or impairment that has lasted, or is likely to last, for at least 6 months and restricts everyday activities. The SDAC also measures the severity of limitations experienced by people with disability. The severity of disability is defined by whether a person needs help, has difficulty, or uses aids or equipment with 3 core activities – self-care, mobility, and communication – and is grouped into mild, moderate, severe and profound limitation.

The SDAC collects detailed information from people with disability; older people (those aged 65 and over); and carers of people with disability or a long-term health condition, or of older people. The 2018 SDAC was the ninth SDAC or equivalent survey to be run since 1981. In 2018, around 66,000 people responded to the SDAC in urban and rural areas in all states and territories. These people lived in private dwellings and self-care retirement villages or in health establishments (providing long-term care for at least 3 months). Information collected from respondents and reported by the ABS includes:

• the severity of disability

• the characteristics of people with disability

• their need for assistance

• primary carer information

• employment circumstances

• living arrangements

• overall prevalence of disability.

Disability identification and severity are established by asking more than 120 questions; progressing through a number of steps to identify, first, if a person has disability; and, second, the severity of that disability (ABS 2019b).

For detailed 2018 SDAC statistics about how many people are affected by disability and their characteristics, see 'Specialised supports for people with disability' at https://www.aihw.gov.au/reports/australias-welfare/supporting-people-with-disability.

Other survey data

A range of social surveys run by the ABS use the Short Disability Module (SDM) with its 16 questions to identify people with disability. Surveys using the SDM include the General Social Survey, the Personal Safety Survey, the National Health Survey, the Survey of Income and Housing, and the National Aboriginal and Torres Strait Islander Social Survey (which also uses a moderated version of the SDM). While the SDM is not as effective as the full suite of SDAC questions in identifying disability (comparatively overestimating the number of people with less severe forms of disability), it does provide useful information on the characteristics of people with disability as identified in each of these surveys. It also enables the characteristics of people with disability to be compared with those of their peers without disability.

The Australian Census of Population and Housing (the Census) also includes questions about the 'need for assistance with core activities' – aiming to identify people with more severe forms of disability who require personal support. These data provide information on people who need help with core activities across smaller geographic areas, and for small population groups (including those not included in the SDAC, like people living in *Very remote* areas) (ABS 2018).

What key policy developments and reviews continue to influence the disability information base?

International obligations and national policies have shaped the delivery of services for people with disability in Australia. Available data and statistics support Australia's reporting under these obligations, while also informing the ongoing review, evaluation and development of national policies over time. Further detail on the historical developments in disability services and statistics is included in Chapter 6 of *Australia's welfare 2019* at www.aihw.gov.au/reports/australias-welfare/australias-welfare-2019-data-insights/contents/summary.

A number of key government reviews are underway with the potential to reshape the provision of services – with important implications for disability data. Common themes running through recent policy changes and review recommendations include the:

• importance of accurate, reliable, timely and nationally consistent data for people with disability, and for all service sectors (specialised disability and mainstream)

• ongoing readiness of the service market and workforce to adapt to evolving requirements of the disability support sector, including inadequate service delivery in some markets where there are gaps in service delivery

• acknowledgement that specialist disability support services, such as those delivered through the NDIS, are only one part of a broader and interacting system of supports accessed by people with disability, including support by family and carers and mainstream systems

• recognition that improving the wellbeing of people with disability and their carers requires collaboration across multiple sectors and stakeholders, with responses that meet the needs of all people with disability, including (but not limited to) those accessing the NDIS

• importance of collaboration between all levels of government to resolve mainstream interface issues

- accessibility of disability-inclusive and appropriate mainstream services
- importance of quality and safety of services, and the availability of safeguards, in both specialist and mainstream service settings
- need for further training of the many varied workforces supporting people with disability across different services (for example, further workforce training in the education sector)
- need for a greater focus on the accountability of policies and programs to improve outcomes for people with disability
- need to strengthen performance frameworks and reporting to more meaningfully measure progress in key wellbeing areas (relating to issues important for both people with disability and policy makers), to identify the limitations of current data in supporting such frameworks, and to ensure reporting is accessible.

United Nations convention

The purpose of the United Nations Convention on the Rights of Persons with Disabilities (UN Convention) is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities, and to promote respect for their inherent dignity' (United Nations 2008a). Australia ratified this Convention in 2008.

Article 31 of the UN Convention requires governments to collect data to enable them to formulate and implement policies related to the UN Convention and to measure progress over time. Article 31 also stipulates that governments need to disaggregate data as appropriate, and use the information to identify and remove barriers faced by people with disability (while also disseminating these statistics and ensuring they are accessible to people with disability) (United Nations 2008b).

Australia's Attorney-General's Department is responsible for reporting under the UN Convention, and it submitted a combined second and third report to the Committee on the Rights of Persons with Disabilities on 7 September 2018 (Attorney-General's Department 2018).

The NDS 2010–2020 is the main mechanism for implementing the UN Convention in Australia (DSS 2011). Arrangements developed by Australian governments to deliver services to people with disability – such as the NDA and the NDIS – also reflect the principles of the UN Convention. Data collected under these arrangements (and others) support reporting to the UN's Committee on the Rights of Persons with Disabilities on implementing the Convention in Australia (United Nations 2021).

National Disability Insurance Scheme roll-out

In July 2013, the NDIS commenced at trial sites in some Australian states and territories. On 1 July 2020, Christmas Island and Cocos Island joined the Scheme, thus almost completing the NDIA's staged roll-out of the NDIS (it is now available nationally, although some population sub-groups are still transitioning in Western Australia and will be until 2022) (NDIA 2020a). Australian and state and territory governments jointly fund and govern the NDIS. While the provision of services under the NDIS is thought to have largely replaced what was delivered under the NDA (except for employment services), no comprehensive assessment of any service gaps between these 2 schemes has been published.

The NDIS is a fundamental change in the provision of disability support to Australians with significant disability. It provides reasonable and necessary supports to eligible Australians under the age of 65, who have permanent (or likely to be permanent) and significant disability (intellectual, physical, sensory, cognitive or psychosocial). Entry to the NDIS is restricted to participants aged under 65 but there are active participants in the NDIS aged 65 and over. Early intervention support is also provided under the NDIS to eligible children and adults. Participant choice and control are core features of the Scheme's design.

A key aim of the NDIS is to:

> … assist people with disability to live 'an ordinary life'. That is to fully realise their potential, to participate in and contribute to society, and to have a say in their own future – just as other members of Australian society do. The Scheme also involves families and carers, respecting their role whilst supporting them to achieve their goals by providing certainty of support for people with disability (NDIA 2018).

Access to disability supports and services under the NDIS is based on an insurance model, with each individual who seeks access being assessed against common criteria. Eligible individuals receive a funding package to buy the supports identified in their individualised plan. As at 30 June 2021, around 467,000 people were active NDIS participants (NDIA 2021c). The NDIA has projected that the NDIS will provide services to about 532,000 Australians (508,000 aged under 65) by June 2023 (NDIA 2020a).

The NDIA collects a comprehensive range of nationally consistent data on the characteristics, service usage and support needs of people with disability who are NDIS participants as well as on the characteristics of those services that support them (NDIA 2021a) (see the 'Current sources of disability-related data' section in this article). These data support the NDIA in making decisions that will improve the Scheme and outcomes for participants, as well as improving the NDIA's understanding of participants and markets. The NDIA's quarterly reports to Disability Reform Ministers (formerly the Disability Reform Council) contain the most up-to-date NDIS data. This is supplemented by data downloads on the NDIS website in a range of formats (NDIA 2021b).

National Disability Agreement review

The NDA has governed the provision of disability support services in Australia since 1991. Under this Agreement, Australian, state and territory governments funded a range of specialist disability services that aimed to ensure that 'people and their carers have an enhanced quality of life and participate as valued members of the community' (COAG 2011). Each year, the Productivity Commission's Steering Committee for the Review of Government Service Provision releases a report on the performance of Australian governments in delivering government services, including disability services. The Steering Committee's annual RoGS reports on available data relating to the equity, effectiveness and efficiency of service provision, along with outcomes for the disability sector (SCRGSP 2021).

In 2018, the Productivity Commission reviewed the NDA, releasing a study report in early 2019 that noted the Agreement no longer served its purpose. The Commission highlighted that:

> Improving the wellbeing of people with disability and carers across the nation requires a collaborative response from all levels of government, extending well beyond the NDIS to many other service systems, such as housing, transport, health, justice, and education (Productivity Commission 2019:2).

This study report also noted that any future data collection strategy for the NDA should include:

- data on the use of, and experiences with, mainstream services
- references to NDIA data and data sharing arrangements
- a data linkage framework (Productivity Commission 2019).

From July 2019, only the Australian Government's employment services (that is, DES) are provided under the auspices of the NDA.

National Disability Strategy renewal

The NDS 2010–2020 provides a 10-year national plan for improving the lives of Australians with disability, their families and carers (DSS 2011). The NDS relates to all people with disability, irrespective of their need or use of specialist disability services. In particular, its intent is to:

- drive improvements in access to mainstream services
- promote a more inclusive approach to the design of policies and programs
- ensure that all people with disability can participate and fulfil their potential as equal citizens.

In December 2020, Disability Reform Ministers from across Australia committed to continue efforts under the NDS to uphold the rights of people with disability between the expiry of the current strategy and the finalisation of a new NDS in 2021 (DSS 2020c).

Australian, state and territory, and local governments across Australia have worked together – in consultation with people with disability and their families, carers, advocacy organisations, peak bodies and service providers – to develop the new NDS. Findings from previous reviews – for example, the Senate Inquiry report into the delivery of outcomes under the NDS 2010–2020 (SCARC 2017) and the public consultation undertaken in 2019 – identified areas of the current NDS that have worked well and should be retained, including the current vision and 6 outcome areas. Areas for improvement were also identified, including the need for a greater focus on accountability of policies and programs to improve outcomes for people with disability (DSS 2020a).

In July 2020, a Position paper prepared jointly by the Department of Social Services and state/territory and local governments sought feedback on the proposed architecture of the new NDS. The paper proposed that the new NDS continue to be the main mechanism for meeting Australia's obligations under the UN Convention. It also recommended that the current NDS vision and 6 outcome areas be retained (DSS 2020b). As well, it noted that data collection and improvement activities under the new NDS would enable more effective monitoring and reporting, and would drive change (see the Outcomes frameworks for the NDS and NDIS section of this article).

The new NDS will be released following agreement from all levels of government.

Another key element of the new NDS will be a National Disability Employment Strategy, which the Department of Social Services is developing. This strategy aims to increase employment opportunities for people with disability by focusing on 5 priority areas:

- lifting employer engagement, capability and demand
- early intervention in transition from school to work and return to work
- driving better performance and quality from employment service providers
- making the system simpler for jobseekers with disability and employers
- changing community attitudes (DSS 2021a).

Outcomes frameworks for the NDS and the NDIS

Since 2016, the NDIS Outcomes Framework has routinely collected information on the outcomes for participants and their families and carers in different areas of their lives, thus enabling the NDIA to report on the Scheme's progress against its key aims (NDIA 2015).

Ongoing and regular measurement of the impact of the NDS and NDIS is key to ensuring improved outcomes for all Australians with disability. Currently, the NDS 2010–2020 identifies key policy areas for action under the National Disability Employment Strategy, along with a requirement for reporting and monitoring of high-level national progress against the strategy.

The Australian and state and territory governments are working together to develop a detailed NDS Outcomes Framework that will monitor outcomes achieved for all people with disability (including NDIS participants). These governments have agreed to use consistent domains and measures in both the NDS and NDIS outcomes frameworks, to more effectively track improvements over time in the lives of all people with disability (DSS 2021c). This also enables the use of NDIS data within the NDS Outcomes Framework – thus allowing the outcomes for all people with disability to be compared with the outcomes for NDIS participants.

The frameworks will aim to cover a broad range of life activities by including key sectors such as health, education and transport. This broad approach to ongoing performance monitoring is based on:

• an agreed vision for both outcomes frameworks

• shared domains – the areas in the lives of people with disability that the new NDS and NDIS seek to improve are consistent with the outcome areas of the current NDS:
  – inclusive and accessible communities
  – economic security
  – personal and community support
  – health and wellbeing
  – rights protection, justice and legislation
  – learning and skills

• national outcomes, indicators and measures – used to monitor the effectiveness of the revised NDS, and the NDIS through clear mechanisms for accountability and reporting (DSS 2021c).

Reporting and benchmarking against the new outcomes frameworks for both the NDS and the NDIS are expected to be supported by the NDDA. The NDDA is intended to be an integrated and shared data source to enable Australian governments to better understand how all people with disability are supported through services, payments and programs across multiple service systems. It is being piloted in 2020 and 2021. It aims to enable improved benchmarking and reporting against the new outcomes frameworks for both the NDS and NDIS by linking a range of data sources across specialist and mainstream service systems (see the section 'What is the National Disability Data Asset?' in this article). Key to assessing success will be the ability to measure progress over time for all people with disability, including but not limited to those accessing the NDIS.

NDIS Quality and Safeguards Commission

To support the roll-out of the NDIS, the NDIS Quality and Safeguards Commission was established in 2018 as an independent regulatory authority to monitor and enhance the quality and safety of NDIS provider supports and services. The Commission achieved full national coverage in December 2020.

The Commission replaced the different state and territory regulatory arrangements and established a single national regulator responsible for provider registration, complaints and reportable incidents (including abuse and neglect of NDIS participants). The Commission also monitors compliance with the NDIS Code of Conduct and NDIS Practice Standards, and the use of restrictive practices (NDIS Commission 2021b).

From 1 July 2020 to 31 December 2020, the Commission received around 3,700 complaints (excluding from Western Australia where it began operating only on 1 December 2020). The majority of complaints received between 1 July 2020 and 1 December 2020 were from 'Others, including guardians and advocates' (27%), or a 'Person with disability' (26%). The majority of complaints during this period related to 'Provider practice' (46%) (NDIS Commission 2021a).

The NDIS Commission is building an evidence base to perform its various functions. This includes gathering new data to support its efforts in reducing identified risks of death or serious injury for people with disability. This work is part of the Commission's function to monitor and report on deaths of people with disability who received NDIS-funded services. In recent years, it has worked with the University of New South Wales and the AIHW to analyse rates of death among people with disability and the causes of those deaths (see AIHW 2020b; NDIS Commission 2020).

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

In April 2019, the Prime Minister, the Hon. Scott Morrison MP announced the establishment of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability RC) in response to community concerns. The Disability RC covers all forms of violence against – and abuse, neglect and exploitation of – people with disability, in all settings and contexts (Morrison, the Hon. S 2019).

The Disability RC released its Interim Report in October 2020. A key theme is the lack of useful, and nationally consistent, data on the extent of violence against – or abuse, neglect and exploitation of – people with disability, especially for groups of people with disability who may be more vulnerable. These groups include children and young people; people with communication disability; Aboriginal and Torres Strait Islander people; culturally and linguistically diverse people; people experiencing homelessness; and lesbian, gay, bisexual, transgender, intersex, queer and questioning people.

The Interim Report also notes:

> There is no public data on the extent of violence, abuse, neglect or exploitation experienced by people with disability in particular settings, such as schools, residential out-of-home care, the youth and criminal justice systems, specialist disability accommodation or segregated work environments (Disability RC 2020a:295).

Other areas identified as lacking data include:

- the forms of violence specific to people with disability, such as bullying and discrimination, withholding access to medical treatments or medication, and exploiting or denying a person's control over or ownership of their body
- the nature of this violence and abuse – whether the incidents occur as part of a pattern, as in domestic and family violence, or are one-off events (Disability RC 2020a).

Given this, a key area of further inquiry for the Disability RC is how to deal with gaps in existing data collection models. In particular, it will be:

- examining the adequacy of the NDIS Quality and Safeguards Commission's data collection, monitoring and reporting systems for upholding the rights and promoting the health, safety and wellbeing of people with disability
- obtaining information about the barriers to widespread implementation of standard questions to identify people with disability in government and organisation databases
- obtaining information about how the NDDA can be used to effectively monitor violence against – and abuse, neglect and exploitation of – people with disability
- inquiring into the plans of governments, service providers and others for publishing data in a way that shows results separately for people with and without disability and, where possible, separately for Indigenous people with disability and non-Indigenous people with disability
- exploring how to collect data on experiences of violence, abuse, neglect and exploitation from groups of people who are currently not included in existing surveys
- obtaining information about why previous recommendations to improve data collection have not been implemented to better understand the barriers to implementation (Disability RC 2020a).

Data gaps highlighted by the COVID-19 pandemic

Existing data gaps on the daily life experiences of people with disability have been well documented (AIHW 2020e). Some of these gaps, such as the inability to identify people with disability outside specific settings, have been highlighted during the COVID-19 pandemic.

In March 2020, the Disability RC called on 'all Australian governments to ensure that responses to COVID-19 include dedicated strategies and take all necessary measures to protect and support people with disability' (Disability RC 2020a). The Disability RC's 'Statement of Concern' highlighted Australia's obligations under the UN Convention, noting that:

> … people with disability have the right to health without discrimination on the basis of disability, including access to population-based public health programmes (Article 25) and that governments also have a duty to take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk (Article 11) (Disability RC 2020b).

The Disability RC asserted in its 'Statement of Concern' that people with disability – especially Indigenous Australians with disability – may be disproportionally affected by the COVID-19 pandemic due to their increased risk of infection and higher number of comorbidities, along with any underlying health conditions such as chronic diseases and respiratory illness. People with disability are also disproportionally affected by the social restrictions imposed during the pandemic, and by breaks in the continuity of essential services.

The availability of detailed and timely information and statistics during the COVID-19 pandemic has been critical in guiding the responses of governments and service providers to the challenges presented by the pandemic. These circumstances have further highlighted the absence of this critical information for key risk groups, such as those people with disability.

Data gaps

Detailed reporting on the impact of the COVID-19 pandemic for people with disability has been (and continues to be) complex given the:

- fact that existing data sources for service use by people with disability are fragmented, dispersed and incomplete (specialist and mainstream)
- inconsistent definitions for disability across existing data sources
- low adoption of a disability 'flag' to identify people with disability across mainstream data sources, including for key communicable disease surveillance data
- inability to reliably report on specific population groups within the broader disability population (such as Indigenous Australians with disability, or children and young people with disability)
- relatively short time that the pandemic has been in place from a data generation perspective.

The need for high-quality, detailed data about the impact of COVID-19 will continue to be important for the foreseeable future, in order to understand the impact of the virus itself, the direct and indirect effects of isolation requirements, and the long-term economic and social impacts of shutdowns. A combination of new data collection and data linkage may assist in filling these gaps in the future.

Examples of COVID-19 pandemic information

Much of the available data specifically relating to people with disability that has been released since the start of the pandemic continue to be relevant to the provision of support for people with disability. Of particular relevance is the data highlighting the disproportionate impact of the virus on these people.

Impact on day-to-day life for people with disability

Many people with disability are at risk during the COVID-19 pandemic because of the barriers that exist to their inclusion in society and their need for ongoing support (PwDA 2020). Various studies have highlighted the day-to-day issues that affect the lives of people with disability (Box 7.1); key issues of concern identified in these studies include:

- inability to maintain social distancing: some people with disability are unable to maintain social distancing practices due to their reliance on support workers for daily personal care, including eating, drinking, toileting and dressing (Disability RC 2020b)

- disruptions to regular support services: in June 2020, around 29% of people with disability who are regular disability support service users (that is, 6% of survey participants) reported experiencing a disruption to their regular service since 1 March 2020 (for example, cancellation of services, changes in how services were delivered, and changes in the frequency of services) (ABS 2020b)

- increased likelihood of staying at home: in November 2020, people with disability (53%) were more likely than people with no disability (42%) to stay at home due to COVID-19 (ABS 2020c)

- increased expenses as a result of the pandemic: in May 2020, around 91% of people surveyed reported increased expenses. Of these, 58% had increased expenses for groceries and food, 31% for health care, 26% for the internet and telephone and 20% for hygiene/sanitising equipment (PwDA 2020).

Box 7.1: Data relating to the impact of COVID-19 on people with disability

Since August 2020, the ABS has collected information on how people are faring in response to the COVID-19 pandemic, including vulnerable people. Its Household Impacts of COVID-19 Survey began in August 2020. This telephone survey interviews around 1,500 people (aged 18 and over) per cycle in private dwellings. Each cycle (or reference period) collects information on different topics and produces weighted national estimates. The ABS notes that some proportions reported in these surveys had a margin of error of greater than 10 percentage points (reported using 'around' in this article).

The impact of the pandemic on vulnerable people or people with disability has been a topic referenced in some cycles. The ABS defines a vulnerable person 'as a person aged 65 years or over, or a person aged under 65 years with a disability or long-term health condition' (ABS 2020a). Whether a person has a disability was derived from a subset of questions from the ABS Short Disability Module.

The PwDA ran a 2-month survey during the pandemic in May 2020 (Experiences of People with Disability during COVID-19). Around 200 people responded: 88% were people with disability, and 12% were carers or family. The response rate for the survey is unknown. The majority of people were from New South Wales (29%), Western Australia (25%) and Victoria (19%). Forty-four per cent of the respondents were in the 41–50 age group (next highest age group 51–60; 19%) (PwDA 2020).

The University of Melbourne conducted an online survey of 357 disability support workers between May and June 2020 (the response rate for the survey is unknown). Respondents' ages ranged from 18–75; 83% were women and 31% were aged over 50 (Kavanagh et al. 2020).

Impact on care provided to people with disability

Many people with disability rely on unpaid and paid care on a daily basis. The COVID-19 pandemic has had an impact on this essential support. For example, the requirement for additional unpaid care to vulnerable people because of COVID-19 has increased: around 23% of adults are providing more unpaid care to a vulnerable person living in their household because of COVID-19, and 13% to a vulnerable person living outside their household. The most common activity in both cases was shopping (ABS 2020a) (see Box 7.1 for a definition of a vulnerable person).

As well, the provision of unpaid care has often been difficult. In November 2020, of those people providing unpaid care to a vulnerable person (around 16%), 25% have had difficulty providing care or assistance due to COVID–19 since 1 March 2020 (see Box 7.1 and ABS 2020c).

Importantly, disability support workers often cannot physically distance. In May and June 2020, 90% were not able to physically distance at work and 53% provided support that requires close personal contact (for example, feeding and brushing teeth). Further, disability support workers interact with an average of 6 people with disability a week in their job (Kavanagh et al. 2020).

Disability support workers have also had to cancel shifts, with 27% cancelling shifts in May and June 2020 due to concerns about COVID-19 infection, while 35% had shifts cancelled by clients or employers due to the same concerns (Kavanagh et al. 2020).

The NDIS Commission continues to support NDIS participants and providers in response to the COVID-19 pandemic. Up until 31 December 2020, it had:

• received 932 contacts from NDIS participants specifically related to COVID-19 (the Commission's contact centre is the first point of contact for NDIS participants)

• managed 188 participant complaints about how NDIS providers and workers supported participants when COVID-19 restrictions were in place

• received 1,032 provider notifications of changes to support that are related to COVID-19. The main supports and services affected were community participation, therapeutic supports and group- and centre-based activities (NDIS Commission 2021a).

The NDIA has collaborated with other governments (including the Department of Social Services, the NDIS Commission, Services Australia, and state and territory governments) to support NDIS participants during the pandemic. In December 2020, the rate of infection among participants was 2.5 times lower than among the general population. As at 31 December 2020:

• there were no known active COVID-19 cases among participants and workers

• the NDIS Commission had been notified of 183 participants and 219 workers who had returned positive tests for COVID-19

• sadly, 9 participants and 1 worker had died (NDIS Commission 2021a).

Future directions for disability data

In response to the emerging policy priorities and identified data gaps described in this article, Australian governments are undertaking a range of ongoing enhancements of the evidence base for disability policy in Australia. This includes the development of nationally agreed measures and reporting arrangements for the new NDS and NDIS outcomes frameworks (DSS 2021c) and the establishment of the National Disability Research Partnership in 2020 as a disability research and policy hub (NDRP 2021).

These initiatives will be underpinned by both existing data – such as survey data about lived experience of disability, and administrative data about service use – and new linked data, to better understand service pathways and outcomes. As well, the pilot phase of a major data linkage initiative, the NDDA (see the section 'What is the National Disability Data Asset?' in this article), has been funded to enhance information about people with disability.

Data linkage combines information about all aspects of the lives of people with disability from multiple data sources, while preserving privacy. Greater use of data linkage has the potential to dramatically enhance the range of data available to inform these emerging policy issues and help to fill existing data gaps. Data linkage studies enable the:

• identification of people with disability in mainstream collections that do not include a disability status 'flag'

• study of pathways taken by people with disability through and between specialist and mainstream service systems

• study of outcomes achieved for people with disability using various support and service types (including the study of disadvantages or inequalities experienced by people with disability in relation to their non-disabled peers).

Recent linkage studies using DS NMDS and mortality data have already provided valuable insights into the causes of death for people using disability services (AIHW 2020b) and have highlighted the potential for such approaches.

The advantages of data linkage can be leveraged by including data from many different service systems within a linked data asset, which allows these analyses to include contributions from all services and supports relevant to the outcomes of interest. Such integrated data assets have been used successfully internationally to provide in-depth analysis of people with disability. A New Zealand example of the use of linked data in relation to children and young people with disability is profiled in Box 7.2.

Box 7.2: New Zealand Integrated Data Infrastructure

The New Zealand Integrated Data Infrastructure (IDI) is a large research database that holds de-identified person-centred microdata on people and households from New Zealand. The IDI sources its data from a range of government agencies, Stats NZ surveys, and non-government organisations. They include information about life events such as:

- health: wide range of datasets like cancer registrations and chronic conditions
- education and training: early childhood through to industry training
- benefits and social services: such as benefits, youth services, student loans
- justice: corrections and police records information, for example
- people and communities: the Auckland City mission to name one, and survey data (for example, disability survey and general social survey)
- population: border movements, for example, and personal details (for example, births, deaths)
- income and work: tax and income, and household labour force, for example
- housing: tenancy and social housing information, for example.

Researchers use the IDI to gain insight into New Zealand's society and economy, often answering questions about complex issues affecting New Zealanders (Stats NZ 2020). For example, New Zealand's Ministry for Children, Oranga Tamariki (Oranga Tamariki 2020), reported on children (aged 0–17) and young people (aged 18–25) in out-of-home care or who had been involved with Oranga Tamariki, who were living with impairments as identified by administrative data in Stats NZ's IDI.

continued

Box 7.2 (continued): New Zealand Integrated Data Infrastructure

The report profiled these children and young people and explored the differences in wellbeing and service contact indicators for those with and without disability. It found that, in the 0–17 age cohort, 1 in 10 children with current or previous Oranga Tamariki involvement had at least 1 indicator of disability (such as receipt of Child Disability Allowance, Ongoing Resourcing Scheme and Disability Support Services). Of those children aged 0–17 who had been involved with Oranga Tamariki, some were even more likely to have at least 1 indicator of disability, including:

• those with higher levels of Oranga Tamariki involvement

• those in older age groups

• males

• those with non-Maori and non-Pacific backgrounds (New Zealand European, Asian and other ethnicities).

What is the National Disability Data Asset?

In September 2019, the former Council of Australian Governments Australian Data and Digital Council agreed to develop an enduring NDDA, subject to sustainable funding (Robert, the Hon. S 2019). The former Disability Reform Council (now Disability Reform Ministers) also endorsed this decision (DSS 2019b).

It is intended that the NDDA will bring together de-identified Australian Government welfare and services data, NDIS data, and service system data from the states and territories. The integrated and shared data should enable a better understanding of how people with disability are supported through services, payments and programs across multiple service systems. The data would also identify gaps and overlaps in service delivery.

If implemented, the NDDA will assist governments and researchers to understand both successful and unsuccessful pathways for achieving outcomes for people with disability. It will also include digital platforms that allow the general population, including people with disability, their families and carers, to explore the data in ways relevant to their circumstances.

The NDDA has the potential to achieve a range of long-term benefits for people with disability, disability organisations, researchers and governments. These benefits include improved:

• understanding of how different supports and services contribute to outcomes for people with disability

• understanding of how to better reach and serve vulnerable groups and groups in the community who are less often reached

• access to better, more complete data from system-wide and person-centred perspectives

• evidence about the supports and services that work, enabling disability organisations to deliver supports and services designed for the needs and situation of people with disability (NDDA 2021b).

The NDDA will be important for the successful delivery and monitoring of the NDS Outcomes Framework. It will contribute to providing a better understanding of how people with disability are supported through services, payments and programs across multiple service systems through the linkage, improvement and sharing of de-identified data.

The NDDA will also enable a shared understanding of outcomes for people with disability arising from disability policy changes, including the NDIS, and will support evaluations and policy development to inform the improvement of mainstream services and supports.

The NDDA is currently in an 18-month pilot phase that started in April 2020 (NDDA 2021a). The pilot phase includes data from the Australian Government; the NDIA; and the New South Wales, Victorian, Queensland and South Australian governments. The Australian Government agreed to provide up to $15 million to cover the costs of the pilot phase. The pilot aims to develop governance, technical and reporting models for the enduring NDDA, and to demonstrate the NDDA's value by providing insights against 5 high-priority research projects (test cases). See Table 7.1 for an overview of these 5 test cases.

The pilot test cases focus on the following themes:

• early childhood supports

• interaction of people with disability with the justice system

• pathways from education to employment

• services and supports for people with disability and mental health issues

• outcomes measurement (focusing on housing-related supports).

Table 7.1: Overview of 5 NDDA test cases

Test case	Lead jurisdiction	Research focus	Links data from
Early childhood	NSW	What are the early childhood supports accessed by young people with disability and how do these support pathways involve mainstream education and health systems?	NSW perinatal, education, child protection and hospital datasets.
Education to employment	SA	What are the pathways into employment for young adults with disabilities, through school education, senior secondary education, vocational education and training participation?	SA secondary and tertiary/VET education sector and Commonwealth income tax data.
Mental health	Victoria	What are the needs of people with disability and mental health problems, and are these needs being met to help improve outcomes?	Victorian community and hospital-based mental health service and emergency department data.
Justice	DSS & NSW	What is the interaction of people with disability with the justice system, including as victims or offenders and what services are provided?	Juvenile justice, corrections, child protection and public housing data for NSW.
Outcomes	DSS	Identification of people with disability in linked administrative data for service use and outcomes reporting.	Public housing and homelessness service data for NSW, Victoria, Queensland and SA.

DSS = Department of Social Services

It is expected that the test cases will demonstrate the potential of the linked data to inform and drive disability policy and help to shape the design and implementation of an enduring NDDA that is able to support policy and research initiatives aimed at improving outcomes for people with disability.

The NDDA is engaging the disability community throughout the pilot to understand the needs and aspirations of people living with disability. This is done through the Disability Advisory Council, which gives regular feedback on how the NDDA should be designed. It is also done through a series of discussions with individuals with disability, with family members and carers, and with organisations who advocate for people with disability, and organisations that provide services.

As Commonwealth Accredited Integrating Authorities involved in the pilot, the AIHW and the ABS meet stringent criteria covering data governance and data management, and abide by the principles for data integration involving Australian Government data for statistical and research purposes and the best practice guidelines. These include protocols to ensure secure end-to-end data management, processes to manage re-identification risks, stringent information and communications technology security and robust governance (AIHW 2019b).

Future developments

This article has set out some of the key data sources about people with disability in Australia, together with some of the key features influencing their continued improvement. While the AIHW has not undertaken a detailed comparative analysis of how data are improving over time, it looks forward to continuing to update readers in this area over future years.

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