Disability services and statistics: past, present and future

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For almost 3 decades the AIHW, alongside the Australian Bureau of Statistics (ABS), has been a key information provider for change and reform processes in the Australian disability services system. Ideas about disability itself and about the nature of appropriate supports have been driven chiefly by the efforts of people with disabilities and their advocates and families. These efforts have been strengthened by international advocacy and the work of international organisations such as the United Nations. Policymakers and service providers have engaged with people with disability to change the Australian system. With these changes and in line with new philosophies, national data collections have been developed in collaboration with those driving and implementing change. In turn, improved data and statistics have enabled policies to be reviewed, refined and improved. While there is scope for more improvement to data on disability in Australia, the cooperation among all interested parties provides a model for statistical collaboration resulting in an information base for major social reforms. This collaborative interplay of ideas, national policy development and national data is chronicled in this article. It is informative to reflect on these practices at a time of significant change in the disability services and data landscape.

The interplay of ideas, policy and national data over time

This first and major section of this article outlines the history of disability services and data in Australia. The parallel and interactive developments in ideas, policy and data are chronicled in Table 6.1, with headings indicating the major stages across the decades. The table provides details which can be read alongside this section. It is largely based on analysis of AIHW's biennial *Australia's welfare* reports from 1993. Other references are cited where relevant and a full list of sources are provided in the reference list.

Later sections look forward briefly to what might come next.

Foundations

From the 19th century through to the mid-20th century, there was a significant evolution in ideas about disability and the people involved. Exclusionary attitudes and services that failed to acknowledge people's rights began to give way to recognition of people's needs and the beginnings of rehabilitation, support services and income support provision (AIHW 1993: chapters 1 and 6). By the early 20th century, there was growing recognition in Australia of the needs of war veterans and those injured in industrial accidents, with a related querying of the previous institutional and charity models of service.

By the mid-20th century and the end of World War 2, support for people with disability was increasingly accepted as a social responsibility. There was acceptance of the need for educational, vocational and community support for people with disability. In 1948, the Commonwealth Rehabilitation Service was formally founded. A focus on community service provision continued to grow. Parents began to organise around children's needs, increasingly reluctant to leave them in poorly resourced institutions, and founding a range of disability-specific organisations. Sheltered workshops were established by voluntary organisations, often disability-specific, sometimes with nearby accommodation—a congregate model criticised and dismantled in following decades. Education for children with sensory, intellectual and physical disabilities tended to be provided by charities. Advocacy groups, including the predecessor of the National Council on Intellectual Disability, were established in the late 1950s to represent consumers, families and community members.

Human rights and the voices of people with disability

Human rights and consumer power were the catalysts for change in the 1960s and 1970s. International rights instruments were agreed and supported by Australia. Service providers began consciously to follow philosophies acknowledging the rights of people with disability to lead lives like those of all people generally and to exercise choice in doing so. Governments legislated to acknowledge their responsibilities to fund an array of services (see Table 6.1).

In 1976, the United Nations declared 1981 to be the International Year of Disabled Persons, with its themes of 'full participation' and 'equality'. Drawing on these themes, consultative mechanisms became a feature of the policy landscape, and influential representative and advocacy groups formed and participated in advisory committees. Community-based programs were developed and new Commonwealth legislation in 1986 changed the landscape for disability services. Data on services were limited at that time; however, new population survey-based data made people with disability 'visible', comparing their experiences with the rest of the population. The ABS Survey of Disability, Ageing and Carers (SDAC) has proved to be a valuable resource over all decades since its beginning in 1981.

Table 6.1: The chronology of ideas, policy and national data in Australia over recent decades

	Ideas/philosophy/focus	Australian policy, services and assistance	Data (especially on support services)
1960s–1970s	**Consumer power and human rights** 'Normalisation' principles spread from Scandinavia: providing people with disability opportunities to live a life as close to 'normal' as possible in terms of the conditions and patterns of their everyday lives (for example, Nirje 1980). 1975: United Nations Declaration on Rights of Disabled Persons. Australia a signatory to 1975 United Nations Declaration of the Rights of Disabled Persons; people with disabilities should have access to the same opportunities and rights available to all citizens. (AIHW 1993)	**Governments and NGOs together** Governments accept responsibility for community service provision. Commonwealth funds grants to voluntary organisations providing sheltered employment, accommodation and children's assistance. 1974: *Handicapped Persons Assistance Act 1974* replaces a previous array of legislation for subsidising a variety of services—training, therapy, rehabilitation, support. 1963: Australian Council for the Rehabilitation of the Disabled (later ACROD, and then National Disability Services) established to represent NGOs. 1977: Royal Commission into Human Relationships. (AIHW 1993)	

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Table 6.1 (continued): The chronology of ideas, policy and national data in Australia over recent decades

	Ideas/philosophy/focus	Australian policy, services and assistance	Data (especially on support services)
1980s	**Participation, representation, consultation** 1981: United Nations International Year of Disabled Persons—themes of 'full participation' and 'equality'. Representation and consultation more commonly used. Recognition of responsibilities of a range of government programs to achieve 'integration'. Increased role for Commonwealth in funding and policy coordination. 1983: Disabled Peoples' International established in Australia (genesis 1981 in Canada).	**New policies and structures** 1983: Disability Advisory Council of Australia established—consumers and others to advise responsible Commonwealth minister. 'Integration' and de-institutionalisation gather pace across health and community services sectors. 1985: Home and Community Care program for older people, and younger people with disability. 1986: *Disability Services Act 1986* commences—focus on consumer outcomes, community-based services (follows review of the 1974 Handicapped Persons Assistance Act). (AIHW 1993)	**Disability data beginnings** 1981: First ABS disability survey published (ABS 1981). Provides data on people's difficulties and needs for assistance with activities, with related disability prevalence estimates; data on carers and care provision. 1986: Commonwealth government figures (on persons funded under the Handicapped Persons Assistance Act) report more than: • 11,000 people in sheltered employment • 11,000 people in training centres • 7,000 people in residential accommodation (AIHW 1993:269). 1987: Australian Institute of Health established under Commonwealth legislation, providing a new collaborative model for national data development, sharing and publication.

Table 6.1 (continued): The chronology of ideas, policy and national data in Australia over recent decades

	Ideas/philosophy/focus	Australian policy, services and assistance	Data (especially on support services)
1990s	**Legislation, agreements, actions to operationalise ideals of 1980s** Governments seek to reduce role in direct community service provision, with purchaser/provider models introduced (AIHW 1997a). 1992: *Disability Discrimination Act 1992* introduced. 1996: National Disability Advisory group provides link between government, people with disability, families, carers and service providers. New international definitions for disability, removing 'handicap' and using 'participation' (AIHW 1997a:290).	**Lack of relatable data for policy** Major reports found planning and evaluation of national programs hampered by lack of relatable data sources (for example, Baume & Kay 1995; Office of Disability 1994; Senate Standing Committee on Community Affairs 1992). 1991: CSDA introduced—rationalises funding and administrative arrangements among 9 jurisdictions; Commonwealth responsible for employment services, states and territories for accommodation support and other services. Agreement to exchange data for planning purposes, national program evaluation (AIHW 1993:326). 1992: Australian Institute of Health becomes AIHW with responsibility for reporting nationally on disability services as part of 'welfare services and assistance'. AIHW establishes group to advise on national data consistency and international development work ultimately leading to ICF (Madden & Hogan 1997).	**Breadth of disability data recognised— new collaborations** AIHW recognises scope of relevant services: income support, specialist disability support, mainstream, as well as informal assistance (AIHW 1993:300). Population data and carer data included in 1993 and thereafter. Discusses concepts and challenges of designing policy-relevant data on agreed, stable, consistent definitions, while policy and terminology may change more rapidly. Data were limited in 1993: • government (state/Commonwealth) expenditure estimated as $932 million (AIHW 1993: 304) • service user data available only for Commonwealth-funded services (AIHW 1993:308–9). AIHW begins collaborative development of national minimum data set for CSDA services. Service-based 'snapshot' collection.

Table 6.1 (continued): The chronology of ideas, policy and national data in Australia over recent decades

	Ideas/philosophy/focus	Australian policy, services and assistance	Data (especially on support services)
1990s (cont.)		**Lack of relatable data for policy (continued)** AIHW commissioned to do first study of demand for disability support services (AIHW 1997c:305–8; Madden et al. 1996). 1997: COAG launches performance monitoring of government funded services; AIHW on national working group advising on and providing data and indicators. 1998: CSDA outlines new framework for service providers, acknowledges unmet demand for specialist services, specifies approach to allocation of funds (based on AIHW work on indicators—AIHW 1997a), commits to nationally consistent data collection and performance indicators. Local area coordination and tailoring services to individual needs a feature for new approaches. Funding increases. Data consistency: AIHW starts work on *National community services data dictionary* (AIHW 1997a:6) and participates in developing international disability classification with WHO.	**Breadth of disability data recognised— new collaborations (continued)** New data: pilot CSDA MDS data (incomplete) published (AIHW 1995:267–74)—numbers of services and service types and a range of consumer data. MDS data show improving completeness and data quality (AIHW 1997a, 1999). 69,198 CSDA recipients recorded as receiving services on a snapshot day in 1998 (AIHW 1999:237)—consumers and their disability 'type', need for support, age, sex, Indigenous origin. Predominance of non-government service provision (approx. 74% in 1998 (4,557 of 6,174) (AIHW 1999:237). Australian governments' expenditure on CSDA services totalled $1.868 billion in 1997–98 (AIHW 1999:236) AIHW biennial *Australia's welfare* reports provide more analysis of population data. In addition to prevalence of disability among people aged under 65 (12.5% and rates of 4% for 'severe' restriction) (AIHW 1999:216), analysis includes prevalence of major disability groups, 'outcomes' (income, time use, employment, education); also discuss Indigenous data (AIHW 1997a, 1999).

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Table 6.1 (continued): The chronology of ideas, policy and national data in Australia over recent decades

	Ideas/philosophy/focus	Australian policy, services and assistance	Data (especially on support services)
2000s	**Rights and related instruments**	**Services evolution**	**Data continue to improve and develop**
	2006: Finalisation of the UNCRPD—people with disabilities have the same rights as all others; realisation of rights and freedoms, participation in society and access to the environment and full range of services and opportunities without discrimination.

2001: WHO publishes ICF—new international model, framework and definitions. Significant for AIHW and ABS as national statistical agencies.

2003: Third Commonwealth State/Territory Disability Agreement (CSTDA) finalised, focusing on funding issues and recognising unmet need, de-institutionalisation, flexible services, contractual clarity and managing demand.

Advocacy and advice: National Disability Advisory Committee, Australian Federation of Disability Organisations, National Indigenous Disability Network established.

Work related to Disability Discrimination Act on standards for building access, education, public transport.

2009: NDA replaces CSTDA as the policy and financial agreement. Sets out Australian priorities for reform; for example, need for coordinated government efforts, person-centred approaches promoting choice, participation and inclusion, better measurement (AIHW 2009). | Focus on individual needs, efforts to link and transition between service types. De-institutionalisation gathering pace: rights to live in community.

2002–07 (third) CSTDA recognises rights of people with disability, and the valuing of families and carers. Focus includes younger people in nursing homes, attention to ageing. CSTDA features performance indicators which rely on CSTDA MDS (AIHW 2003b:337).

Workforce ageing a challenge for support services (AIHW 2007b).

Steady increases in support services expenditure, recognising unmet need. AIHW commissioned to report again on unmet need (for example, AIHW 2002, 2007c)—flags continued growth of unmet need because of ageing and other factors (AIHW 2007b:193). | Trends in snapshot day data published: for example, proportion in community or group home 60% in 1995 to 70% in 2000; more community living (non-institutionalisation for younger people) (AIHW 2001:292, 310).

2001: Collaborative work starts on new MDS collection, to include all 'consumers' for most service types (AIHW 2003a).

AIHW collaboratively develops ICF-related data standards for inclusion in *National community services data dictionary* (AIHW 2004)

Indigenous data available—show 'severe' disability rate at least 2.1 times that of other Australians (ABS & AIHW 2005).

AIHW 2005: New 'full-year' CSTDA NMDS data included 'outcomes' data based on analysis of ABS population data (SDAC and other surveys with the disability module) using ICF framework for participation. Carers and the duration of informal care. Special box on Indigenous data and disability rates in population.

Environmental factors included in ABS survey and disability identification in mainstream service collections.

AIHW 2009: includes new 2006 census data showing geographical spread of disability (uneven distribution, more common in disadvantaged areas). |

Table 6.1 (continued): The chronology of ideas, policy and national data in Australia over recent decades

	Ideas/philosophy/focus	Australian policy, services and assistance	Data (especially on support services)
2010s	**Policies reflecting the UNCRPD—and a new era begins** Array of national policies in place, linked to UNCRPD: National Disability Strategy 2010, National Disability Agreement, NDIS. Era of NDIS begins. Insurance based scheme, uncapped expenditure. Provides packages of funding for individual 'plans'. Choice and control are key objectives.	**Policy development informed by data** 2011: Productivity Commission report recommends NDIS; 400, 000 participants estimated (Productivity Commission 2011) based on ABS SDAC data. This figure can be compared (loosely) to 295,000 under NDA in 2009–10 (AIHW 2011a:143). NDIS becomes national policy, 'launched' at trial sites in July 2013. Emphasis on also directing people to mainstream services. Transfer of funding support from states/territories to Commonwealth (NDIA). Disrupts data collection arrangements, with no transition data arrangements planned. Collaborations in existing and new forms proceed (see Box 6.6)	**New data challenges** NDIS participant numbers rising. Hard to relate NDA recipient numbers (apart from transitions from NDA to NDIS); no common data standards. Proposed redevelopment of MDS continues: emphasis on individualised funding, description of service interventions and measuring unmet need. 2013 AIHW biennial report notes 317,600 NDA users and provides some 5-year trends (AIHW 2013a). Analysis of participation in education and employment. Notes need for ongoing data on service provision (AIHW 2013a:232). In 2015, format of biennial report changed to follow 'life course'; that is, data split by age groups. 321,500 using disability support service, including 4,200 transitioning to NDIS. Data on type of service, brief data on population. 13,610 people with approved NDIS plans (AIHW 2015). 332,000 using NDA services in 2015–16 (Australian Capital Territory did not collect data) (AIHW 2017a:305). Service type data presented. 'During 2015–16, 3,500 NDA service users were reported in the DS NMDS as having moved to the NDIS, adding to the 9,600 reported to have made the transition since the start of the NDIS' (AIHW 2017a:306). 'According to the NDIA, 74,900 people with approved plans were participating in the NDIS (known as 'active participants') as at 31 March 2017 (AIHW 2017a:307).

Collaborations and the first Commonwealth/State Disability Agreement

The 1990s saw continuing development of legislative, policy, administrative and, increasingly, statistical infrastructure to operationalise the ideals that were now well articulated nationally and internationally; for example, in the *Disability Discrimination Act 1992*. National collaboration on service provision and policy was formalised, with the Commonwealth/State Disability Agreement (CSDA) setting out shared responsibilities for service provision and funding. Under the 1998 CSDA all governments committed to collaboration on nationally consistent data collection and performance indicators.

In 1992, the AIHW was given responsibility for statistics on a range of community services, including disability services. Major reports had called for greater consistency among the various disability data to inform policy development and program evaluation (Baume & Kay 1995; Office of Disability 1994; Senate Standing Committee on Community Affairs 1992). The AIHW responded with work on definitions, classifications and national data standards. Advisory arrangements were established to enable the AIHW to collaborate on disability data, definitions and consistency, including with representatives of governments, disability groups and non-government organisations (NGOs) (Box 6.1).

Box 6.1: Collaboration—promoting quality in data design and use

Collaboration and consultation have been hallmarks of the disability field in Australia for decades. Advisory and consultative mechanisms have broadened the input into policy development processes and data design. National agreements among governments have ensured collaboration on policy, service delivery and the design of nationally consistent data. The best results in all these areas are achieved when all stakeholders are informed and enabled to contribute to design and improvement (AIHW 2007a).

The ABS and the AIHW have advisory groups that include subject matter experts and representatives from the relevant fields and enable a wide range of those with interests—including those with lived experience of disability, advocacy groups, those with policy and program responsibilities and others—to help define the main questions the data must answer.

The AIHW's biennial welfare reports have always included information on a broad scope of services—including disability income support, specialist disability support, mainstream (for example, AIHW 1993:300)—and reported on relevant data on these services, as well as on informal care provision. In 1993, the AIHW began development of a minimum data set (MDS) for CSDA services in collaboration with disability administrators from all jurisdictions. Initially the collection was a service-based 'snapshot' collection based on 1 day, with pilot data published in 1995. Collaboration and consistent data definitions became twin themes underpinning the framing and collection of data of importance to policymakers and the many other stakeholders in the disability field. The MDS data were immediately used in indicators of service provision by a national working group established under the Council of Australian Governments (COAG) to assist the Productivity Commission prepare its reports on government services (for example, SCRCSSP 1997 and annually thereafter). The AIHW concept of, and data for, 'potential population'—factoring in the greater needs of people of Indigenous origin—were used in the denominator of these indicators (Box 6.2). The AIHW was commissioned to do a first study of demand for disability support services (Madden et al. 1996; AIHW 1997a, 305-307). Following the publication of the 1996 report, disability services funding was increased and unmet demand was recognised as requiring attention in the 1998 CSDA, which specified the approach to allocation of funds (also based on the indicators work of the AIHW).

Box 6.2: Performance indicators and resource allocation require the right denominators

COAG has been a driver of the use of indicators to monitor the outcomes of policies and services. For 20 years, the reports on government services have made extensive use of ABS and AIHW data as key ingredients for the indicators (for example, SCRCSSP 1997 and annually). The working group collaborating on disability services included membership of the 2 statistical agencies. The AIHW provided data for numerators (for example, on provision of different service types) while population data for the denominators made use of ABS SDAC data.

Denominators should reflect the size of the potential target population, and also make visible population groups with higher rates of disability. One such group is Aboriginal and Torres Strait Islander Australians. The AIHW initially used sub-national data to estimate that Indigenous disability rates could be approximately twice those of other Australians. These estimates were used as weights in denominators for indicators describing the rates of need and supply (AIHW 1997b, 2006). In 2005, it became possible to refine (and to a large extent confirm) these early estimates, when the results of a new survey, using similar disability concepts to the SDAC, enabled a comparison of national rates among Indigenous and non-Indigenous Australians (ABS & AIHW 2005; AIHW 2005:221).

International developments and their influence in Australia

In the following decade, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was finalised in 2006, with many countries proceeding to ratify it, including Australia in 2008. Australia developed a National Disability Strategy by the end of the decade (2010) to ensure the UNCRPD principles were integrated into policies and programs in Australia; services were to focus on individual needs rather than the service types available. The National Disability Agreement (NDA) 2009 replaced previous Commonwealth–State/Territory agreements as the national policy and financial agreement, focusing on social and economic participation outcomes, inclusion and choice.

The World Health Organization (WHO) framework and statistical classification—the International Classification of Functioning, Disability and Health (ICF)—was published in 2001 (WHO 2001), a few years before the UNCRPD. With its inclusion of key concepts such as participation in all spheres of life and environmental factors affecting functioning and disability, it is well aligned with the ideas of the UNCRPD and able to provide the definitions and infrastructure for statistics relevant to the UNCRPD. Also of importance to the ABS and the AIHW, as the national statistical organisations bound to follow international statistical standards, it proved capable of underpinning common national data standards for disability, to promote consistency across the various collections relevant to disability (Box 6.3).

More data available and used

The efforts of the previous decade were bearing fruit and data were able to be used to understand the experiences of people with disability, as a population group, their needs and access to services, consistent with current philosophies and policies (for example, AIHW 2005:202–69). The use of common definitions and ideas in both population data and disability support services data and the resulting relatability of collections were critical to this analysis (Box 6.4).

In 2006, disability questions were included in the Census of Population and Housing for the first time, providing a data source for small population groups and geographical areas. Again, the use of common data standards was essential to enable meaningful comparisons across data sets. Analysis of the Census data illustrated the uneven distribution of disability across Australia, with disability more common in disadvantaged areas (AIHW 2009:147–54).

Box 6.3: Data standards—for consistent, joined-up national data on disability

Common national data standards, in line with international statistical standards, promote consistency and efficiency in statistical design and collection. National disability data standards based on the ICF were developed by the AIHW, in collaboration with its multi-perspective advisory group, and then approved for publication and use by high-level national data committees (AIHW 2004).

The ABS also uses available international statistical standards such as the ICF and its predecessor. This clarity and stability has been one of the underlying strengths of the disability collections since 1981. Data standards underpin cross-sectoral policy-relevant data which are not dictated by any particular policy of the day. Population data can then be analysed from different perspectives, in different sectors, and meaningful trends across time compiled. The ABS includes a 'disability module' in many of its population surveys, enabling the comparison of people with disability and other Australians; for example, in terms of health, time use, income and expenditure (AIHW 1997a:336–8; AIHW 2010).

Common national data standards can also ensure that administrative data relate to population data (users of services being targeted subgroups of the population), and also that 'joined-up' data can be related across sectors to help build a coherent national picture. For example, a 'disability flag' based on these standards is used in the AIHW's Specialist Homelessness Services Collection (AIHW 2013b). Identifiers can also be included in mainstream service collections to describe the accessibility of these services to people with disability.

With the increasing reliance on the CSDA MDS collection to describe services provided through the NDA (boxes 6.2, 6.4 and 6.5), it was decided to enhance it significantly by collecting data on all users of most service types. Collaborative redevelopment was carried out during 2000–2002 (AIHW 2003a). Many data items from the original snapshot collection were retained, and new items introduced. The validity of the 'support needs' data item for national data capture was confirmed; this was based on the ICF activities/participation domains to which many of the assessment instruments in use across the country could be mapped. The new collection was then able to provide 'full-year' (rather than a single snapshot day) data on, for example:

• service users—age, sex, Indigenous status, country of birth, disability group, support needs, presence of informal carer and carer arrangements; services received; whether received individualised funding

• services—location and service group/type, hours and weeks of operation.

Box 6.4: When population data and services data can be related, more informative analysis is possible—illustrations over time

The national disability services data collections included data items that were consistent and comparable, both across years and with those collected in national population surveys. Some insights thus made possible include:

- *The consistency of Indigenous and disability concepts across collections* enabled **access** to services to be compared. For example, of people receiving disability support services in 2003–04, 3.5% were Aboriginal or Torres Strait Islander people (AIHW 2005:239). This compared with 2.4% in the Australian population— higher, but not double as could be expected from the higher disability rates for the overall population (see Box 6.2). Rates of Indigenous use rose in later years, to around 6% (AIHW 2019).

- *Consistency of concepts of support needs and life domains across population and services data collections* enabled **targeting** of support services to be examined. For example, in 2009, 3.6% of the Australian population aged under 65 always or sometimes needed assistance with self-care, mobility or communication (AIHW 2011a:135-6). In 2009–10, 58% of disability support services users had such needs for assistance in these life domains, with even higher percentages needing assistance in other areas of life (AIHW 2011c:28). This comparison indicates effective targeting of these support services. (For more information on data and targeting support services see also Box 6.2 on potential population and AIHW 2002 on unmet need.)

- *Consistency of disability and carer concepts across collections* enabled the picture to be filled-out to include the significance of **carers** to the service sector. For example, in 2015, SDAC data showed that primary carers who were parents generally cared for their son or daughter for longer than other carers; 20% of parent carers had been caring for 20 or more years compared with 12% for spouse carers (ABS 2016). Services data from that year (2015–16) showed that most service users had a carer (66%) and that most (80%) of them were cared for by a parent (compared with 9.3% by their spouse or partner) (AIHW 2017b).

- *Consistency of ideas about disability across collections* enabled an overall picture to be assembled. The complexity of disability was recognised in AIHW's biennial *Australia's welfare* reports from the first, in 1993. These reports have some information on participation in all areas of life, access to support services and to mainstream services, and on the paramount importance of informal assistance provided by family and friends (for example, AIHW 2005:202–69).

The CSDA MDS became the Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS), and the first full financial year of data collection took place between 1 July 2003 and 30 June 2004.

A major innovation tested late in the life of the previous MDS collection was continued: the 'statistical linkage key' enabling the linkage of de-identified data across data collections without the need to identify individuals. This enabled the compilation of more reliable data on numbers of service users (avoiding double counting) and new service users, the improvement of data checking and quality, the analysis of multiple service use and the tracking of patterns from year to year (for example, AIHW 2011b, 2012). Importantly, the introduction of a statistical linkage key across multiple community service collections made it possible, for the first time, to explore the interface between disability support and other key services for people with disability, such as the then Home and Community Care program (AIHW 2014).

Since 2000, meaningful trend data were able to be assembled from both the snapshot MDS and full year NMDS collections. Combined with population data from the ABS and the expenditure data published in the COAG reports on government services (Box 6.2), the vision of a coherent national picture began to be realised. Trends in de-institutionalisation were visible in both population data and services data. Trends in service provision, use and funding could be tracked (Box 6.5).

Data gaps remained. For example, there was little or no information about people's experience with disability services, although a consumer satisfaction survey was conducted as part of the report on government services in 2000 (Productivity Commission 2000). 'Disability flags' were seldom adopted in mainstream service collections, meaning that access by people with disability to these services remained largely invisible. Data about outcomes for people with disability (for example, successful post-school transition, appropriate housing), and how these related to both their goals and the services received, were available only through research and evaluation, rather than as a by-product of the service system. And, while limited data linkage had been undertaken, data about services used by people with disability remained generally limited to use of services funded under the CSTDA.

Box 6.5: Trends and tracking change—illustrations over time

Collecting comparable data over time allows meaningful trend data to be gathered. Some examples include:

- **De-institutionalisation trends**—population data revealed a strong trend towards living in the community, especially among younger people (aged 5–29) with 'severe disability' (from 1 in 7 living in institutional settings in 1981 to 1 in 100 by 2003) (AIHW 2008). Data on services revealed the complementary picture, with fewer service users in institutional settings (snapshot and full year data to 2005–06) (AIHW 2008).

- **Increases in numbers of services users and government expenditure**—the numbers of service users across all service groups increased by nearly 50% between 2003–04 and 2008–09 (to 279,000 individuals) (AIHW 2011b:viii). Meanwhile, total government expenditure on disability support services increased by 22% in real terms (in 2008–09 dollars), from $4.1 billion in 2003–04 to $5.2 billion in 2008–09 (AIHW 2011b:11). In 2016–17, there were an estimated 331,000 people using services provided under the NDA. The Australian and state and territory governments spent $7.8 billion on disability support services under the NDA (AIHW 2018:1, 9).

- **Changes in disability group**—the pattern of some primary disabilities has shifted over time. For example, the proportion of service users with an intellectual disability has decreased, and the proportion with psychiatric disability has generally increased (AIHW 2012:26).

- **Changes in support needs**—the support needs of service users have increased over time. For example, in 2017–18, 61% of disability service users always or sometimes needed assistance with self-care, mobility or communication compared with 58% in 2009–10 (see also Box 6.4) (AIHW 2011c, 2019).

- **Transition of NDA service users to the National Disability Insurance Scheme (NDIS)**—about 83,000 NDA service users are recorded as having transitioned to the NDIS since 2013–14 (AIHW 2019). These service users generally have a higher level of support need than other service users, and are more likely to need at least some assistance in 1 or more broad life areas. They are also more likely to have an intellectual or learning disability, live with their family, receive the Disability Support Pension and not be in the labour force.

A new era

The culmination of years of advocacy, adoption of the UNCRPD principles, and policy consultation and development resulted in significant and widely welcomed change in the most recent decade. The NDIS replaced a system that had been framed around service 'types' and service providers as grant recipients. It introduced a system that considers individual needs and provides a budget and package based on these needs directly to people with disability so they can purchase supports and services of their choice. Significant new funding was to be made available; according to Productivity Commission estimates in 2011, numbers of recipients were expected to increase from approximately 300,000 (as reported under the previous system) to over 400,000 (under the NDIS) (AIHW 2011a:143; Productivity Commission 2011).

The new administrative arrangements were dramatically different from the previous Commonwealth–state/territory arrangements. The new National Disability Insurance Agency (NDIA) became the sole administering authority, with responsibility for nationwide assessment and planning (and associated data) of individual packages and budgets. State and territory governments generally withdrew from administration, although remaining as major funders of the new scheme in partnership with the Australian Government. Collaboration with respect to disability statistics and related performance indicators continued, sometimes in new forms (Box 6.6).

In the process of administering the NDIS, the NDIA works with people with disability to understand their support needs, define a package of supports and monitor improvement in individual outcomes. The data captured as part of this process potentially provide an unprecedented opportunity to improve understanding of how supports improve the lives of people with disability and their families and carers.

With the massive challenges of launching such a large new scheme, the focus was on delivery and the launch at trial sites from July 2013. While new data on client satisfaction were collected—consistent with the focus on people with disability being able to shape the services they receive—less focus was put on national statistical reporting. Importantly, data continuity with previous systems was not prioritised. While there are flags in both the NDA and NDIS data systems to record people transitioning between these systems, they produce different estimates of the numbers transitioning over time. And the lack of consistency between the collections has limited (at least to date) the ability to publicly monitor whether service access has improved for people in the NDIS compared with those in the previous system.

Box 6.6: Statistical collaboration post introduction of the NDIS

Collaboration on statistical data and reporting continued, albeit via processes less visible to the community.

Collaborative arrangements included:

• The NDIA worked with State/Territory and Commonwealth governments through the COAG Disability Reform Council to develop a new performance framework for reporting about the NDIS in their quarterly reports; announced new data insights forums commencing in July 2019.

• The ABS continued to collaborate widely with government and non-government stakeholders on the content of its Survey of Disability, Ageing and Carers (SDAC) and other statistical products, through its SDAC Steering Committee and Reference Group.

• The AIHW created a new Disability Analysis and Research Advisory Group in 2018, with government, non-government and disability representative stakeholders, to guide its disability statistics reporting program, including a recently released report *People with disability in Australia* www.aihw.gov.au/reports/disability people-with-disability-in-australia funded by the Department of Social Services (DSS).

• The Productivity Commission consulted widely on its Review of the National Disability Agreement and, in its role as secretariat for the Steering Committee on the Review of Government Service Provision, commenced work with NDIA, ABS, AIHW, DSS and states/territories to develop new indicators for inclusion in the Report on Government Services and a revised definition of the 'potential population' for specialist disability support services, still in development.

• DSS commenced community consultation in 2019 on a new national disability strategy for beyond 2020, including its potential data requirements.

• Under the auspices of the Australian Digital Council, several states and DSS are leading work with the NDIA and AIHW on a proposal to develop a new National Disability Data Asset (see below).

In its role as system administrator, the NDIA began publishing data on participant numbers, plan take-up and participant satisfaction. Other statistical reporting continued to provide information about non-NDIS disability services (for example, AIHW 2019) and a range of disability indicators under the NDA (for example, SCRGSP 2018). In 2019, the NDIA contributed some data to the annual report on government services, which notes that 'performance information on the National Disability Insurance Scheme (NDIS) is currently under development' (SCRGSP 2019:15.1).

Specifically on data, the Productivity Commission observed

> *"Performance reporting is not possible without access to adequate data. An absence of adequate data undermines the basis for performance reporting, and can adversely affect policy making. Currently, performance data for the NDA is (almost exclusively) based on the ABS' Survey of Disability, Ageing and Carers (SDAC) and the Australian Institute of Health and Welfare's Disability Services National Minimum Data Set. The ongoing availability of data from these sources is uncertain, and there is a risk that some data may not be available—particularly data on use of services provided outside the NDIS..."*

(Productivity Commission 2019:20)

The future of disability statistics

By the early 2000s, the development of reliable and stable statistics on the need for and supply of disability supports, based on common information standards and classifications, had set up Australia well for exciting policy developments in disability support (culminating in the NDIS). Already, the AIHW had reported on unmet demand for disability supports, and the Australian Government had increased funding, following a campaign by disability organisations which used the AIHW results as a base. Numbers of recipients of support services had risen considerably (Box 6.5).

The development and enactment of the NDIS has been a dramatic response to unmet need. The ABS SDAC provided the data base for the NDIS cost estimates by the Productivity Commission in 2011, which were generally confirmed by the Australian Government Actuary (2012) and have formed the base for funding the NDIS up to the present.

The NDIS process provides considerable potential to learn more about disability in Australia and the related support needs, how they are met and with what outcomes. First a person must apply and provide a range of data required to be accepted as an NDIS participant. Then the person's support needs are described in a support plan proposal and assessed by the NDIA. Once a support package is in place, supports are bought by participants, and the majority are paid for by the NDIS.

The result of this process is that the NDIA is amassing a large amount of information on a wide range of people with disability who have support needs, including those who apply but are not accepted as participants. At the same time, the state/territory-based funding of organisations to provide support services is ending, closing down the source of the previously published disability support statistics.

The NDIA publishes a range of material, including quarterly reports (see www.ndis.gov.au/about-us/publications/quarterly-reports) and, since July 2019, a new website, which improves data accessibility (www.ndis.gov.au/about-us/data-and-insights). Together these sources provide data on NDIS performance indicators, some statistical information on applicants, including their type of disability and the NDIS calculation of level of functioning, participant outcome reports, family and carer outcome reports, thematic analyses on special topics, and information on participant satisfaction. Quarterly reports are made available to the public, within approximately 6 weeks of the end of the quarter, in the form of reports and dashboards. It is understood that the NDIA is working with other agencies to consider the potential to link NDIS data with other sources (see also below).

The potential for improved statistics has not yet been fully realised. The performance indicators published each quarter by NDIA relate mostly to NDIS performance and sustainability, not to what participants receive. For example, at the participant level, there is no information on the size of, or supports included in, packages. The NDIA also does not supply de-identified unit record data on participants, applicants, supports provided or any information on outcomes to statistical agencies. In addition, the NDIS data standards do not completely align with those developed for the Disability Services National Minimum Data Set (DS NMDS) collection and followed by each state/territory and service providers, and the data dictionaries in use by the NDIA are not freely available. Not having access to metadata creates difficulties in interpreting and understanding the data produced by the NDIA, including how it relates to data produced under the previous system.

There is therefore a challenge and an opportunity to ensure that the community is fully informed about the provision and recipients of disability supports. At the time when the funding of disability supports by the community is rapidly increasing, it is vital that the NDIA and the statistical agencies report statistics and performance information that contribute to a broad picture of people with disability and their supports from not only the NDIS, but also from other services such as health, education and aged care.

These recognised challenges to ongoing national statistics come about as an unintended consequence of dramatic improvements in national arrangements for support of people with disability. It is timely to recall the importance of national statistics for policymakers, affected individuals and the broader community (see Box 6.7).

> **Box 6.7: National statistics—why, what and how**
>
> Australian statistical practice follows the United Nations fundamental principles of official statistics. These principles recognise that official statistics 'provide an indispensable element in the information system of a democratic society, serving the Government, the economy and the public with data about the economic, demographic, social and environmental situation' (Principle 1, United Nations 2014). The necessary data may be drawn from all types of sources, including administrative records. Statistical agencies must observe scientific principles and ethical standards, and use international concepts and classifications to promote consistency and efficiency. Methods and processes should be made public. Individual data must be kept confidential, with data being released as statistics.
>
> The AIHW and the ABS follow these principles in producing national statistics. In addition, the AIHW presents a biennial welfare report to the Minister for Health containing information and statistics about: the provision of welfare services to the Australian people; and an outline of the development of welfare-related information and statistics.
>
> There are accepted methodologies for the design of official statistical collections and large national databases. These methods are sometimes set out in guides explaining the principles and processes for statistical collections (for example AIHW 2007b; WHO & UNESCAP 2008). Such resources expand on design themes including: the importance of collaborative planning and being clear about purpose and the key questions to be answered; the importance of stakeholder consultation, collaboration and field testing; and using data standards to promote quality and consistency. The full cycle of design, collection and publication is completed when useful and respectful statistics that satisfy the user purposes and needs originally agreed are publicly released.

There are opportunities to improve national statistics about the experience of people with disability. For example, the development of data integration agencies by the Australian Government—alongside the now well-established data linkage capacity of the AIHW, the ABS and many states and territories—provides far more capacity to bring data together, under well-established data protection and ethics arrangements, to describe and understand the situation of people with disability. Building on this, in late 2018, the Australian Digital Council agreed to progress a pilot to build a longitudinal and enduring cross-jurisdictional data asset to improve services for people with disability (ADC 2018). The pilot development is being led by several state governments, the Australian Government and the AIHW, in collaboration with the NDIA.

If progressed, such a data asset has the potential to solve a problem common to both previous and existing data about disability; namely the need for improved understanding of the extent to which people with disability access services provided outside of the specialist disability system, such as mental health, housing and education services. Depending on its shape, it may also improve understanding of the pathways and outcomes of people with disability over time, including pre- and post-NDIS implementation.

There may also be opportunities for improving disability data via development of a new national disability strategy for beyond 2020. The recent review of the NDA highlights some of the data challenges in understanding outcomes for people with disability, recommending it be revitalised and better integrated with the National Disability Strategy to:

• 'improve cohesion in intergovernmental arrangements for disability policy …
• clarify the roles and responsibilities of governments in the NDA …
• improve accountability mechanisms under the NDA' (Productivity Commission 2019:5).

This review highlights that developing an overall plan for disability data is important because not all people with disability will be NDIS participants. A new national disability strategy for beyond 2020 can hopefully include such a plan. The combination of continued support for regular conduct of the ABS SDAC (with SDAC 2018 due for release in late 2019), improved access to NDIA data, considering how to capture information about specialist disability services offered outside the NDIA, and data linkage all have great potential to provide a more complete picture of people with disability in Australia.

At the same time, there is an urgent need for improved data collection on the rapidly growing disability support industry and workforce. The industry and occupation classifications used by the ABS are not able to distinguish employees of the aged care and disability support sectors. The ability to separately identify these occupations has been identified as a much needed improvement.

The information vision that has driven disability data development and analysis in recent decades has served the community well—to ensure data are talking the same language as people and policy, and are consistent across sectors. This vision requires ongoing effort to develop and use national data standards across sectors, including attention to the common concepts and language in international classifications such as the ICF. Administrative data derive from operational management systems and these also should be designed in awareness of these standards; there is a general absence of sound ICF-based assessment tools for functioning and disability. 'Joined-up' analysis is further aided by technical processes such as statistical linkage keys and identifiers in mainstream services, used appropriately with full respect for individual confidentiality and privacy. The vision requires that data are available in various forms to the diversity of stakeholders, to inform the public, foster research and to hold up a mirror to public policy.

The interplay of philosophy, advocacy, reform, policy and statistics created this information vision. It is built on communication: ongoing awareness, collaboration and consultation across sectors. Ideas and advocacy have driven policy reform, and advocates have been involved in policy consultations and development. Statisticians have participated and generated consultation about data, and have designed data collections and analyses to monitor policy, so as to answer questions asked by advocates and policymakers, and inform Australian society generally.

The NDIS is a historic policy and service shift—the realisation of ideas, goals and work over many years. This article has described how national statistics were an agent of these changes. Now national statistical reporting must keep pace with change, based on collaboration among all those involved in the fruitful interplay of ideas, policy and national data.

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