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## 8.1 People with disability

The World Health Organization estimates that 15% of the world's population (1 billion people) have disability, which it defines as any impairment, activity limitation or participation restriction (WHO 2016). The Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) collects information on the wellbeing, functioning and social and economic participation of people with disability in Australia. The SDAC uses a broad construct of disability (Box 8.1.1) designed to align with the WHO's International Classification of Functioning, Disability and Health 2001 (ABS 2016).

#### Box 8.1.1: Australian Bureau of Statistics definition of disability

The ABS SDAC defines a person with disability as someone who has one or more specified types of limitations, restrictions or impairments that restrict everyday activities, and which has lasted (or is likely to last) for at least 6 months. The severity of disability is further defined by the degree of assistance or supervision required in core activities—self-care, mobility and communication—and grouped for mild, moderate, severe and profound limitation. People can also be identified as having a disability and schooling or employment restriction only, or disability and no restriction or limitation (ABS 2016). The concept 'people with disability' contains all of these definitions, and thus also includes 'people with severe or profound limitation'.

#### How many Australians have disability?

In 2015, an estimated 4.3 million Australians had disability—nearly 1 in 5 people (18%). While the number of people with disability has increased over time, from 4 million in 2003, the proportion of the population with disability has decreased (from 20% in 2003) (see Chapter 9.2 'Indicators of *Australia's welfare'*). Of the 4.3 million people with disability, about 1.4 million (or 5.8% of the total population) had severe or profound core activity limitation. This means that they sometimes, or always, need help with day-to-day activities related to self-care, mobility and communication. The likelihood of having disability or severe or profound core activity limitation generally increased with age (Figure 8.1.1).



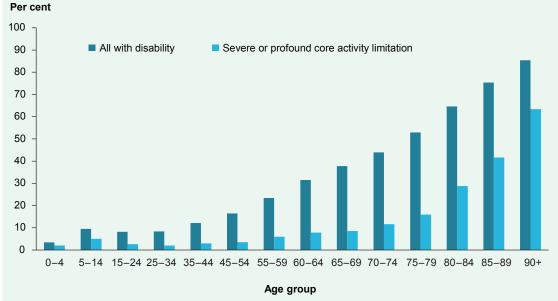




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Source: ABS 2016.

Figure 8.1.1: Proportion of the population with disability and severe or profound core activity limitation, by age group, 2015

The SDAC also found that, in 2015:

- disability prevalence was similar for males (18%) and females (19%), but females were slightly more likely to report severe or profound core activity limitation (6.4%) than males (5.3%)
- around 8% of people with disability reported having schooling or employment restrictions (see Chapter 8.2 'Participation in society by people with disability' for more information on education and employment for people with disability)
- close to 4 in 5 people (79%) with disability reported a physical condition as their main long-term health condition, with the rest reporting a mental or behavioural disorder (21%). In recent years, there has been a notable increase in people who report mental and behavioural disorders as their main long-term condition—up from 17% in 2009 and 19% in 2012
- the majority of people with disability lived in households—with 75% living with others and 21% living alone. The remaining 4.5% lived in cared accommodation
- a government pension or allowance was the main source of personal income for 42% of people with disability of working age (15–64) living in households, followed by wages or salary (37%). By comparison, wages or salary was the main source of personal income for the majority (68%) of people of working age without disability: fewer than 1 in 10 (8.5%) reported a government pension or allowance as their main source of personal income



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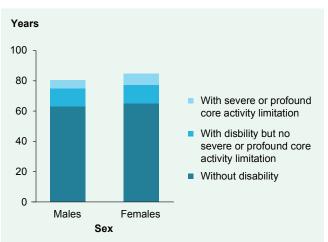
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- more than half (59%) of people with disability living in households reported needing help with at least 1 of 10 specified activities of daily living. These activities included self-care, mobility, communication, cognitive or emotional tasks, health care, reading or writing tasks, transport, household chores, property maintenance and meal preparation. The most common activity requiring assistance was health care (29%), followed by property maintenance (27%)
- of people who need help with daily activities, 62% reported their needs were fully met, 35% partly met and 2.7% not met at all. The most common activities for which a need for assistance was not fully met were property maintenance (7.7%) and cognitive or emotional tasks (7.5%)
- of people aged 15 and over living in households who received assistance from organised services in the 6 months before the survey, the majority (85%) were satisfied with the quality of service received (where the level of satisfaction could be determined).

# How long can we expect to live with and without disability?

The life expectancy of Australians has continued to increase for both males and females in recent decades. Most of these increases correspond to an increase in disability-free life expectancy, which is the expected number of years living without disability. Between 2003 and 2015, the disability-free life expectancy increased from 59.1 years to 63.0 years for males, and from 62.2 years to 65.2 years for females.

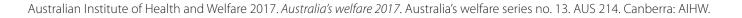


On average, boys born in 2015 could expect to live 63 years without disability and another 17 years with disability, including 5.4 years with severe or profound core activity limitation (Figure 8.1.2). Girls born in 2015 could expect to live an average of 65 years without disability and another 19 years with disability, including 7.5 years with severe or profound core activity limitation.

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### *Source:* AIHW analysis of unpublished ABS SDAC 2015 data and unpublished ABS abridged Australian life tables 2013–2015.

Figure 8.1.2: Expected number of years of life with and without disability at birth, by sex, 2015

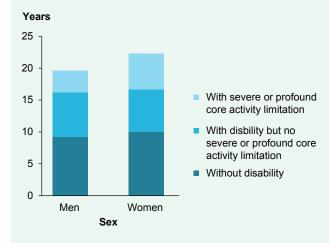




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*Source:* AIHW analysis of unpublished ABS SDAC 2015 data and unpublished ABS abridged Australian life tables 2013–2015.

Figure 8.1.3: Expected number of years of life with and without disability at age 65, by sex, 2015

Life expectancies at birth are influenced by mortality in early life. Hence, looking at life expectancies at age 65 provides an insight into healthy ageing (Figure 8.1.3). Men aged 65 in 2015 could expect to live, on average, a further 9 disability-free years, followed by 10 years with disability, including 3 years with severe or profound core activity limitation. Women aged 65 could expect to live, on average, a further 10 years without disability and another 12 years with disability, with close to half of those 12 years being with severe or profound core activity limitation.

The disability-free life expectancy estimates of people aged 65 are average estimates for the total population of that age group, including people who already have disability. As such, the number of expected years of life with disability for a person who does not have a disability at age 65 would be fewer than those presented, which average the experience of people both with and without disability at age 65.

Further information on disability-free life expectancy is presented in Chapter 9.2 'Indicators of *Australia's welfare*'.

# What support services are available to people with disability?

The disability services environment has changed a lot in recent years. Since 1991, government-funded services for people with disability have been provided under various iterations of the National Disability Agreement (NDA) (see Box 8.1.2). In 2012, the Australian Government introduced the National Disability Insurance Scheme (NDIS) (see Box 8.1.3), which is expected to largely replace the NDA over time.

Both the NDA and the NDIS reflect the intention of the Australian Government to improve the lives of people with disability, their families and carers. This intent is captured in the National Disability Strategy 2010–2020 (DSS 2016b) (see Box 8.1.4).







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## How many people receive support under the National Disability Agreement?

Under the NDA, government services are provided to people with disability to help them with aspects of daily living, such as accommodation, community involvement and employment.

#### Box 8.1.2: National Disability Agreement

Under the NDA, the Australian and state and territory governments fund a range of disability support services that aim to ensure 'people with disability and their carers have an enhanced quality of life and participate as valued members of the community' (COAG 2009). Eligibility requirements vary between jurisdictions, and the service a person can receive is largely subject to availability (for example, based on the number of available places in certain programs). Services are mainly delivered by 'block-funded' providers, with funding allocated directly to the provider.

Information on the use of services under the NDA is collected and reported by the AIHW in the Disability Services National Minimum Data Set (DS NMDS).

In 2015–16, around 332,000 people used disability support services under the NDA. (Note, however, that this is an underestimate as it excludes data from the Australian Capital Territory Government, which did not collect data in 2015–16.) The average age of service users was 35, and 5.8% were aged 65 or over. More than half (59%) were male and 6.0% were Indigenous. Intellectual disability was the most common primary disability type of service users (25%), followed by psychiatric disability (20%) and physical disability (19%).

Community support services, which support a person with disability in living in a non-institutional setting, were the most commonly used services (45%) (Figure 8.1.4). The next most commonly used services were open employment services (38%), which help people to gain and/or retain employment in the open labour market.

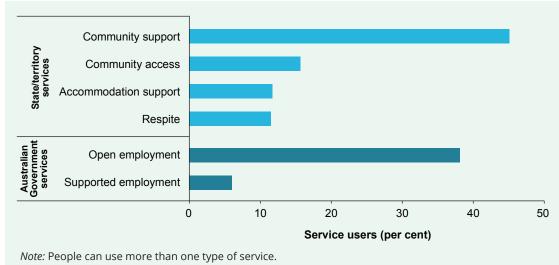






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Source: Disability Services National Minimum Data Set 2015–16.

Figure 8.1.4: Proportion of disability support service users by service group, 2015–16

### Transition of National Disability Agreement service users to the National Disability Insurance Scheme

Although most NDA service users are expected to move to the NDIS as it is rolled out, not all users will be eligible. For example, people aged 65 and over are not eligible to enter the NDIS, but those who turn 65 after becoming an NDIS participant may continue to receive support until they enter the aged care system. As well, some specialist disability support programs, such as open employment services, will not be included in the NDIS and will continue to operate separately. In 2015–16, there were 19,090 NDA service users aged 65 or older, and 126,470 who used open employment services. As not all users of services under the NDA will be supported under the NDIS, governments have set up 'continuity of support' arrangements. These will allow people who do not meet requirements for NDIS entry to continue to receive support services consistent with their current arrangements.

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. The data published by the National Disability Insurance Agency (NDIA) on people with an approved and active NDIS plan might not match the DS NMDS data on NDA service users who moved to the NDIS (see next section). There are several reasons for this. For instance, the NDIA data include data for people who have not been reported as part of the DS NMDS, such as people referred directly to the NDIS. This is especially the case for very young children and people who meet the early intervention eligibility requirements under the NDIS.



Australian Institute of Health and Welfare 2017. Australia's welfare 2017. Australia's welfare series no. 13, AUS 214. Canberra: AIHW.



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## How many people receive support under the National Disability Insurance Scheme?

According to the NDIA, 74,900 people with approved plans were participating in the NDIS (known as 'active participants') as at 31 March 2017 (NDIA 2017b). This excludes 700 people who had received an approved plan but have since exited the scheme, bringing the total number of people who have received support from the NDIS to 75,600. As well, almost 2,400 children have received a referral to the Early Childhood Education Intervention gateway. This initiative is designed to connect children aged 0–6 with early childhood providers to identify needs and provide timely access to information and support.

#### Box 8.1.3: National Disability Insurance Scheme

The NDIS aims to provide Australians with permanent and significant disability with the reasonable and necessary support needed to participate in everyday life (NDIA 2016). The NDIS is a substantial change to how services are provided to people with disability in Australia. Arrangements under the NDA largely see service providers funded for places in a set number of assistance programs. On the other hand, NDIS participants receive an individualised plan of the support needed to achieve their goals, and a funding package to purchase this support.

The NDIS was introduced through trial sites from 1 July 2013. The transition to the full scheme will occur progressively from 1 July 2016. The roll out of the NDIS varies by state and territory. In some jurisdictions, it is being rolled out geographically: people enter it at different times, according to where they live. In other jurisdictions, people enter it at different times according to their age. Full national roll out is scheduled to be completed by 1 July 2019 in all states and territories except for Western Australia, where roll out will be completed by 1 July 2020 (NDIA 2017a).

The NDIA—an independent statutory agency whose role is to implement the NDIS—collects data on the NDIS, and publishes them in quarterly reports.

NDIS active participants were younger than NDA service users, and more than half of them (52%) were aged 18 and under, as at 31 March 2017 (NDIA 2017b). The majority of participants were male (63%) and 5.1% were Indigenous. Intellectual disability was the most common primary disability group of participants (37%), followed by autism (28%) and psychosocial disability (6.5%).

Once the NDIS is fully implemented, it is estimated that it will support 475,000 people with significant and permanent disability—460,000 aged under 65; and 15,000 aged 65 and over who entered the scheme before turning 65 (Productivity Commission 2017). This represents about 11% of all people with disability in Australia (based on SDAC estimates), and 64% of people with severe or profound disability aged under 65.





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#### Box 8.1.4: The National Disability Strategy

The National Disability Strategy 2010–2020 (DSS 2016b) outlines the shared national vision for improving the lives of Australians with disability, their families and carers. It is an important mechanism to ensure the principles underpinning the United Nations Convention on the Rights of Persons with Disabilities (UN 2006) are incorporated into policies and programs across all levels of government. The Strategy embodies a national approach to inclusive public policy development and to improved access to mainstream services.

The Strategy's first implementation plan, *Laying the groundwork 2011–2014*, set the foundations to drive reform in the planning and delivery of both mainstream and disability specific programs and services. The second implementation plan, *Driving action 2015–2018*, builds on ongoing commitments to improve outcomes for people with disability.

# What financial support is available for people with disability?

As well as support services (such as those mentioned in this article that are received under the NDA or through the NDIS), people with disability may be eligible to receive financial assistance to help with activities of daily life. The Disability Support Pension and the Mobility Allowance are two such programs (DSS 2016a). Other financial support, such as to assist with study or housing, may also be available for people with disability.

In 2015–16, close to 782,900 people received the Disability Support Pension. This pension provides financial support for people with a physical, intellectual or psychiatric condition who are unable to work for 15 hours or more per week within the next 2 years because of their impairment and who have participated in a program to help prepare for, find or maintain work; or for people who are permanently blind (DHS 2017; DSS 2016a). The pension is available to people aged between 16 and the age pension age. Pension recipients represent about 18% of the total estimated number of people with disability in 2015 (according to SDAC), and about 36% of people with disability aged 15–64 (the closest comparable age group).

The Mobility Allowance was provided to about 60,000 recipients in 2015–16. This financial support helps with transport costs for people aged 16 and over who cannot use public transport without substantial assistance and who are participating in approved activities, such as work or study.



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People with disability may also be eligible for various government concession cards, which provide recipients with access to selected goods and services at a discounted rate (DSS 2017) (see also Chapter 1.3 'Understanding welfare'). People getting the Disability Support Pension will automatically be issued with a Pensioner Concession Card. People who receive the Mobility Allowance but not the Disability Support Pension will receive a Health Care Card. State and territory governments, local governments and private businesses may provide further concessions for health, household costs, education or transport.

Financial support for children with disability is available through payments made to their parents or carers, such as the Child Disability Assistance Payment, which is available to recipients of the Carer Allowance (see Chapter 8.3 'Informal carers').

#### What is missing from the picture?

It is currently not possible to provide a full picture of the experiences of people with disability in Australia and how these might be changing over time. People with disability interact with every aspect of social policy and programs in Australia. They access both specialist and mainstream services across a wide variety of areas. Although there are many data collections across different agencies that collect information on people with disability (such as the AIHW, the ABS, the Department of Social Services and the NDIA), there is currently no national process to collectively report on available data in a person-centred way, understand data quality issues, or to identify and fill data gaps.

While there is no denying that a comprehensive and consolidated picture of the experiences of, and outcomes for, people with disability is desired, there are challenges involved in doing so. Currently, specialist disability support services are provided through multiple avenues including under the NDA, NDIS, Basic Community Care, and Disability Employment Services. Hence, the total number of people receiving disability support services, and the extent of overlap of users, is difficult to determine. There are also challenges related to the varying definitions of disability used across different sources of data. Disability is generally defined depending on the type and purpose for which the data were collected. This means that definitions may differ between population surveys as well as in administrative data.

Adding to the challenge, most mainstream services (for example, health and aged care) do not include a way to identify whether a person has disability. So, comprehensive reporting on the use of these services by people with disability, and on the interactions between specialist and mainstream services, is not possible. To help address this, the AIHW has developed a disability 'flag' that can be used to identify records of people with a disability within mainstream data collections. The flag derives from a standard set of questions that assesses a person's level of functioning and need for support in everyday activities. These questions are based on the International Classification of Functioning, Disability and Health, and are broadly consistent with the short disability questions that the ABS uses in a number of its social surveys. Versions of the flag have been implemented in the AIHW's Specialist Homelessness Services Collection and the National Prisoner Health Data Collection, and are in the process of being implemented within other AIHW collections. A wider implementation of the flag would improve the ability to report more comprehensively on people with disability, and to do so in a more person-centred way.





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Data linkage is another option that could be used to more comprehensively examine the experiences of people with disability than is possible from a single source. For example, linking disability support services or payments data to national hospital data, the Medicare Benefits Schedule or the Pharmaceutical Benefits Scheme could provide an insight into how people with disability interact with mainstream health services, and how these services complement specialist disability supports. Likewise, linking disability support services data to aged care could help improve understanding of the interactions between these two sectors. Chapter 1.7 'Understanding health and welfare data' explores further the opportunities and challenges associated with using data linkage to fill data gaps, including those related to disability.

#### Where do I go for more information?

For more information relating to disability and the use of disability support services, see <u>www.aihw.gov.au/disability/</u>. The AIHW reports <u>Disability support services: services provided</u> <u>under the National Disability Agreement 2015–16</u> and <u>Life expectancy and disability in Australia:</u> <u>expected years living with and without disability</u>, and other recent publications related to disability in Australia are available for free download. Information on people with disability from the most recent ABS SDAC is available from <u>Disability</u>, ageing and carers, Australia: <u>Summary of findings, 2015</u>.

The NDIS website, <u>https://www.ndis.gov.au</u>, provides information about the scheme for people with disability, families and carers, services providers and the wider community.

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