



Australian Government

Australian Institute of  
Health and Welfare

# Mortality patterns among people using disability support services: 1 July 2013 to 30 June 2018

Summary



# **Mortality patterns among people using disability support services: 1 July 2013 to 30 June 2018**

**Summary report prepared by the AIHW for the National Disability Insurance  
Scheme Quality and Safeguards Commission (September 2020)**

**The Australian Institute of Health and Welfare is a major national agency whose purpose is to create authoritative and accessible information and statistics that inform decisions and improve the health and welfare of all Australians.**

© Australian Institute of Health and Welfare 2020



This product, excluding the AIHW logo, Commonwealth Coat of Arms and any material owned by a third party or protected by a trademark, has been released under a Creative Commons BY 3.0 (CC-BY 3.0) licence. Excluded material owned by third parties may include, for example, design and layout, images obtained under licence from third parties and signatures. We have made all reasonable efforts to identify and label material owned by third parties.

You may distribute, remix and build upon this work. However, you must attribute the AIHW as the copyright holder of the work in compliance with our attribution policy available at [www.aihw.gov.au/copyright/](http://www.aihw.gov.au/copyright/). The full terms and conditions of this licence are available at <http://creativecommons.org/licenses/by/3.0/au/>.

A complete list of the Institute's publications is available from the Institute's website [www.aihw.gov.au](http://www.aihw.gov.au).

ISBN 978-1-76054-747-9 (PDF)

ISBN 978-1-76054-748-6 (Print)

#### **Suggested citation**

Australian Institute of Health and Welfare 2020. Mortality patterns among people using disability support services: 1 July 2013 to 30 June 2018 (Summary report). Cat. no. DIS 76. Canberra: AIHW.

#### **Australian Institute of Health and Welfare**

Board Chair  
Mrs Louise Markus

Chief Executive Officer  
Mr Barry Sandison

Any enquiries relating to copyright or comments on this publication should be directed to:

Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601

Tel: (02) 6244 1000

Email: [info@aihw.gov.au](mailto:info@aihw.gov.au)

Published by the Australian Institute of Health and Welfare

**Please note that there is the potential for minor revisions of data in this report.  
Please check the online version at [www.aihw.gov.au](http://www.aihw.gov.au) for any amendments.**

# Contents

- Preface .....iv
- 1 Introduction .....1
- 2 Key findings.....4
- 3 Findings by disability type.....8
- 4 Findings by disability support service types .....12
- 5 Conclusion.....16
- 6 Glossary .....17

# Preface

The Australian Institute of Health and Welfare was engaged by the National Disability Insurance Scheme Quality and Safeguards Commission to undertake a data linkage study to explore mortality patterns among people who accessed disability support services from 1 July 2013 to 30 June 2018.

This summary report, and the accompanying technical report, are Australia's first national reports on mortality for this population.

These reports provide an important but high-level overview of mortality patterns among people who accessed disability support services. This preliminary work aims to support more sophisticated analysis of these data, and more detailed breakdowns of the results, including refined disability type groupings. This work will also be extended to assemble and investigate evidence for both excess mortality and morbidity to inform evidence based advice, education and regulation aimed at reducing both.

Each and every person described in these reports deserves to be treated with respect, in recognition of the value of the lives they lived. More broadly, the experience of people with disability of being devalued and discriminated against within various systems, including the health system, is acknowledged. All people with disability should be provided services with dignity acknowledging their contribution to society, community and the economy and the unique individual worth of all lives.

These reports complement a review undertaken in 2019 on reported deaths among people with disability who were in receipt of specialist disability supports and services in Victoria, New South Wales and Queensland (Salomon & Trollor 2019). The review suggested that this group of people with disability died about 20 to 35 years earlier than the general population.

# 1 Introduction

About 1 in 6 (18%, or 4.3 million) people in Australia have disability. Like all Australians, people with disability should have the opportunity to reach their potential and participate equally in Australian society. To achieve this, people with disability can seek access to, and pursue positive outcomes across all areas of everyday life, such as education, employment, health, housing and justice. People with disability who need support to participate in everyday life can use specialist disability services, mainstream services, and/or be supported by informal carers. They may also receive financial assistance to help with daily activities.

Good health is often understood as a primary foundation for any individual to achieve their goals. The relationship between disability and health is complex. Long-term health conditions might lead to disability, and disability can contribute to health problems. In general, people with disability report poorer general health and higher levels of psychological distress than people without disability.

Valuable insight on the health of a population can be gained by measuring the number of deaths, and the health conditions or injuries that led to those deaths. Causes of death are documented on a death certificate and can be classified into disease groups. The coding of death certificates produces an underlying cause of death.

This information can be used to guide and evaluate health policy and interventions. For those with disability, creating a comprehensive picture of deaths could help to inform and improve care and outcomes for all people with disability.

To this end, this report examines deaths among people with disability who used disability support services under the National Disability Agreement (NDA) for the 5 years from 1 July 2013 to 30 June 2018. It looks only at people aged under 65 (*Note: The NDA has been largely replaced by a National Disability Insurance Scheme (NDIS) that was introduced in 2016 and is expected to support about 478,000 people with disability aged under 65 by the time it is fully rolled out.*)

## About the study

The study included 526,515 people aged under 65 who accessed disability support services (Box 1) from 1 July 2013 to 30 June 2018, or about 22% of the 2.4 million Australians under age 65 with disability in 2018. Due to eligibility criteria for access to disability support services funded under the NDA, this report is not representative of the broader disability population in Australia. That is, unless otherwise stated, results presented within this report relate to this selected group of people with disability (i.e. those who were eligible for, and accessed disability support services); referred to as the 'study population'.

### **Box 1: What are disability support services?**

Specialist disability support services help people with disability participate fully in daily life. They may supplement other support a person receives, such as that provided by mainstream services, the community and/or informal carers.

Specialist disability support services are primarily aimed at people aged under 65, but support is also available to eligible people aged 65 and over. Disability support services may include:

*(Continued)*

### **Box 1 (continued): What are disability support services?**

- assistive technology (for example, wheelchairs, hearing aids, voice-recognition computer software)
- case management
- early childhood intervention services
- life skills development
- specialist accommodation
- support to live in the community (for example, personal care and domestic assistance)
- support to participate in community activities
- respite care.

The AIHW Disability Services National Minimum Data Set (DS NMDS) was the source of information on people using disability services funded under the NDA. The DS NMDS was linked to the AIHW National Death Index using the Medicare Consumer Directory. Details on the data sources, population inclusion and limitations of this study can be found in the *Mortality patterns among people using disability support services: 1 July 2013 to 30 June 2018: technical report* that accompanies this summary report.

Results are also provided for a general population of all Australians aged under 65 who are not using disability services. This group comprised about 20 million people—about 36 times as many people as in the study population. For each measure (except crude rates), age and sex standardisation has been conducted to take into account any differences between these two populations.

Key factors to note when interpreting results are presented in Box 2 and a glossary of frequently used statistical terms is included at the end of this summary (Box 3) with further terms and detail provided in the glossary.

### **Box 2: Factors to note when interpreting results**

People using disability services may have complex needs related to ongoing health conditions. These conditions may be present before the use of disability services and may coexist with disability; therefore, care must be taken when examining rates and ratios between the different disability groups, service types and the general population.

While the general population had nearly equal numbers of males and females, close to 60% of the study population were male.

Those aged 65 and over were removed from the study and general populations for analyses. In addition, results were age-standardised to take into account any remaining differences between the age structures (except when reporting crude rates). The median age for the general population in this study was 32 for males and females. In the study population, the median age for males was 29, and the median age for females was 37.

It should be noted that the age and sex structure can vary substantially across the disability and service types. As such, age and sex-specific rates may be more informative than

*(Continued)*



### **Box 2 (continued): Factors to note when interpreting results**

examining the overall rates for the population.

The concept of 'potentially avoidable deaths' is used in this report. This refers to deaths among people aged under 75 that are avoidable in the context of the present health-care system. The rate of PADs in Australia is used as an indicator of the health system's effectiveness—they are classified using nationally agreed definitions. They do not indicate that these deaths have individually been assessed as avoidable.

### **Box 3: Key statistical terms used in this report**

**age-standardised rate:** A method of removing the influence of age when comparing populations with different age structures. There are 2 methods commonly used to adjust for age—direct and indirect standardisation (see below). In this report, direct age-standardisation was used to compare mortality rates over time, with age-standardised mortality rates generally expressed as the rate per 100,000 population.

**crude rate:** The number of events in a given period divided by the size of the population at risk in the specified time period. In this report, crude mortality rates are generally expressed as the rate per 100,000 population.

**potentially avoidable deaths (PADs):** Deaths among people aged under 75 that are avoidable in the context of the present health-care system. They include deaths from conditions that are potentially preventable through individualised care and/or treatable through existing primary or hospital care. They do not indicate that these deaths have individually been assessed as avoidable.

**potential years of life lost (PYLL):** Measures the impact of premature or untimely death by counting the number of years between the age at death and a defined cut-off age for premature death. In this report, dying before age 75 is considered premature. Therefore, a person dying at age 45 has potentially lost 30 years of life, while a person dying at age 80 is deemed to have lost no years of life prematurely. This measure gives greater weight to deaths at younger ages, compared with measures that count only numbers of deaths, which tend to be dominated by deaths of the elderly.

# 2 Key findings

The **mortality rate** is the number of deaths in a population during a given time period, divided by the population of interest over that same period.

After adjusting for differences in the age and sex structure of the populations, the people with disability in the study population had a mortality rate 4.7 times as high as the rate for the general population (Table S3.1).

The 3 most common underlying causes of death among people with disability in the study population were perinatal and congenital conditions (6.3% of deaths), spinal muscular atrophy (5.9%) and coronary heart disease (5.7%). For people aged under 20, the 3 most commonly occurring underlying causes of death were perinatal and congenital (21%), cerebral palsy and other paralytic syndromes (14%) and selected metabolic disorders (9.8%) (Figure 1).

**Figure 1: Leading 5 causes of death for study and general populations based on underlying causes of death, percentage of deaths in age group, by age at death, people aged under 65 only, 2013–14 to 2017–18**

Age	1st	2nd	Rank		
			3rd	4th	5th
Study population					
< 20	Perinatal & congenital 20.8%	Cerebral palsy & related 13.8%	Selected metabolic disorders 9.8%	Epilepsy 5.4%	Diseases of myoneural junction 4.0%
20–34	Suicide 15.6%	Accidental poisoning 9.3%	Cerebral palsy & related 7.9%	Perinatal & congenital 7.1%	Epilepsy 5.1%
35–49	Accidental poisoning 7.6%	Suicide 7.2%	Coronary heart disease 5.0%	Cerebral palsy & related 4.6%	Spinal muscular atrophy 4.6%
50–64	Spinal muscular atrophy 8.1%	Coronary heart disease 7.9%	Perinatal & congenital 5.1%	Brain cancer 4.4%	Lung cancer 3.6%
Total	Perinatal & congenital 6.3%	Spinal muscular atrophy 5.9%	Coronary heart disease 5.7%	Suicide 5.2%	Cerebral palsy & related 4.3%
General population					
< 20	Perinatal & congenital 20.2%	Suicide 14.1%	Land transport accidents 13.4%	Ill-defined causes 5.7%	Brain cancer 3.4%
20–34	Suicide 31.4%	Land transport accidents 13.8%	Accidental poisoning 11.3%	Assault 2.6%	Colorectal cancer 2.1%
35–49	Suicide 14.0%	Accidental poisoning 9.3%	Coronary heart disease 7.8%	Breast cancer 4.6%	Land transport accidents 4.5%
50–64	Coronary heart disease 10.5%	Lung cancer 9.8%	Colorectal cancer 5.2%	Breast cancer 4.5%	Liver disease 4.0%
Total	Suicide 8.9%	Coronary heart disease 8.7%	Lung cancer 7.1%	Colorectal cancer 4.3%	Accidental poisoning 4.3%

Source: Table S4.1.

Leading causes of death varied by the primary disability type of the service users (Figure 2).

**Figure 2: Leading 5 causes of death for study population based on underlying causes of death, by primary disability type, people aged under 65 only, 2013–14 to 2017–18**

Primary disability type	1st	2nd	Rank 3rd	4th	5th
Intellectual	Perinatal & congenital 17.7%	Cerebral palsy & related 9.4%	Epilepsy 6.5%	Coronary heart disease 4.1%	Influenza & pneumonia 3.2%
Specific learning/ADD <sup>(a)</sup>	Suicide	Land transport accidents	Accidental poisoning	Diabetes	Accidental falls
Autism	Epilepsy 10.0%	Influenza & pneumonia 7.0%	Cerebral palsy & related 6.0%	Suicide 6.0%	Cerebrovascular disease 5.0%
Developmental delay <sup>(a)</sup>	Perinatal & congenital	Selected metabolic disorders	Other nervous system	Other degenerative diseases of nervous system	Epilepsy
Physical	Coronary heart disease 8.1%	Cerebral palsy & related 6.9%	Diabetes 5.0%	Diseases of myoneural junction 4.0%	Liver disease 3.9%
Acquired brain injury	Brain cancer 12.0%	Cerebrovascular disease 7.5%	Coronary heart disease 6.5%	Liver disease 4.8%	Accidental poisoning 4.8%
Neurological	Spinal muscular atrophy 29.0%	Demyelinating diseases 11.9%	Brain cancer 7.3%	Huntington disease 6.6%	Diseases of myoneural junction 3.3%
Vision	Diabetes 13.4%	Coronary heart disease 9.6%	Brain cancer 8.6%	Lung cancer 4.5%	Cerebrovascular disease 3.4%
Hearing <sup>(a)</sup>	Coronary heart disease	Suicide	Cerebrovascular disease	Liver cancer	Lip, oral and pharynx neoplasms
Psychosocial	Suicide 20.7%	Accidental poisoning 14.2%	Coronary heart disease 8.4%	Liver disease 4.8%	Ill-defined causes 4.2%

(a) Percentages for deaths in these groups are not presented due to small counts.  
 Note: Due to small counts, leading causes of death for people with deafblind and speech primary disabilities cannot reliably be determined. See Table S4.2 for more information on causes of death.  
 Source: Table S4.2.

The leading causes of death differ by primary disability group and age (Figure 3).

**Figure 3: Leading 5 causes of death for study population based on underlying causes of death, by primary disability group and age at death, people aged under 65 only, 2013–14 to 2017–18**

Age	1st	2nd	Rank 3rd	4th	5th
Intellectual/learning					
20–34	Cerebral palsy & related 14.1%	Perinatal & congenital 13.1%	Epilepsy 9.2%	Influenza & pneumonia 3.9%	Suicide 3.9%
35–49	Cerebral palsy & related 11.6%	Perinatal & congenital 11.6%	Epilepsy 7.7%	Coronary heart disease 3.9%	Cerebrovascular disease 3.0%
50–64	Perinatal & congenital 21.1%	Coronary heart disease 5.9%	Cerebral palsy & related 4.9%	Epilepsy 4.8%	Influenza & pneumonia 3.8%
Physical/diverse					
20–34	Diseases of myoneural junction 11.1%	Cerebral palsy & related 8.5%	Suicide 7.9%	Brain cancer 6.9%	Perinatal & congenital 6.4%
35–49	Spinal muscular atrophy 9.4%	Brain cancer 6.2%	Accidental poisoning 5.9%	Demyelinating diseases 5.1%	Huntington disease 4.7%
50–64	Spinal muscular atrophy 14.4%	Coronary heart disease 7.5%	Demyelinating diseases 5.8%	Brain cancer 5.5%	Cerebrovascular disease 3.9%
Sensory/speech					
20–34 <sup>(a)</sup>	Suicide	Brain cancer	Diabetes	Benign neoplasms	Neoplasms of mesothelial and soft tissue
35–49 <sup>(a)</sup>	Diabetes	Coronary heart disease	Cerebrovascular disease	Suicide	Accidental poisoning
50–64	Coronary heart disease 12.2%	Diabetes 11.4%	Brain cancer 7.5%	Lung cancer 4.7%	Breast cancer 3.9%
Psychosocial					
20–34	Suicide 41.9%	Accidental poisoning 25.7%	Ill-defined causes 3.2%	Land transport accidents 2.8%	Event of undetermined intent 2.8%
35–49	Suicide 21.8%	Accidental poisoning 18.6%	Coronary heart disease 6.9%	Ill-defined causes 5.5%	Liver disease 5.1%
50–64	Coronary heart disease 12.2%	Suicide 10.4%	Lung cancer 6.8%	Liver disease 6.3%	Accidental poisoning 6.3%

Source: Table S4.3.

The leading causes of death also differ by the services used (Figure 4).

**Figure 4: Leading 10 causes of death for study population based on underlying causes of death, by service type, people aged under 65 only, 2013–14 to 2017–18**

Rank	Residential accommodation	Other accommodation	Respite services	Community support	Community access	Employment
1	Perinatal & congenital 16%	Spinal muscular atrophy 9.6%	Spinal muscular atrophy 10.0%	Perinatal & congenital 8.1%	Perinatal & congenital 11.0%	Suicide 13.0%
2	Cerebral palsy & related 12.0%	Cerebral palsy & related 6.0%	Cerebral palsy & related 9.3%	Spinal muscular atrophy 7.7%	Cerebral palsy & related 9.5%	Coronary heart disease 10.0%
3	Epilepsy 5.7%	Coronary heart disease 4.6%	Perinatal & congenital 8.3%	Cerebral palsy & related 5.9%	Epilepsy 5.5%	Accidental poisoning 9.9%
4	Coronary heart disease 3.7%	Perinatal & congenital 4.3%	Diseases of myoneural junction 4.6%	Brain cancer 5.3%	Coronary heart disease 4.6%	Liver disease 4.8%
5	Cerebrovascular disease 2.8%	Demyelinating diseases 4.3%	Demyelinating diseases 3.8%	Coronary heart disease 4.0%	Cerebrovascular disease 3.9%	Lung cancer 3.0%
6	Huntington disease 2.8%	Suicide 4.2%	Brain cancer 3.6%	Demyelinating diseases 3.5%	Influenza & pneumonia 2.6%	Diabetes 3.0%
7	Demyelinating diseases 2.8%	Diabetes 3.0%	Selected metabolic disorders 3.2%	Epilepsy 3.3%	Diseases of myoneural junction 2.5%	Ill-defined causes 2.8%
8	Lung diseases, external agents 2.5%	Cerebrovascular disease 3.0%	Epilepsy 3.2%	Diabetes 3.0%	Huntington disease 2.3%	Cerebrovascular disease 2.7%
9	Influenza & pneumonia 2.4%	Brain cancer 2.9%	Coronary heart disease 3.2%	Diseases of myoneural junction 2.7%	Ill-defined causes 2.3%	Land transport accidents 2.4%
10	Appendicitis, hernia and intestinal obstruction 2.1%	Accidental poisoning 2.9%	Influenza & pneumonia 2.3%	Cerebrovascular disease 2.7%	Suicide 2.3%	Cardiomyopathy 2.0%

Source: Table S4.4.

In this report, potentially avoidable deaths (PADs) are deaths below the age of 75 from conditions that are potentially preventable through primary or hospital care.

People in the study population had a crude rate of 240 potentially avoidable deaths (PADs) per 100,000 people. Once adjusted for the age differences between populations, this rate was 3.6 times as high as the general population.

Although the leading causes of death in the study population were perinatal and congenital conditions and spinal muscular atrophy, the leading causes of potentially avoidable deaths were coronary heart disease and suicide (Figure 1). These 2 potentially avoidable deaths were the top 2 leading causes of death in the general population. Further detail of PADs are provided throughout this summary report under each disability and service type groups.

### 3 Findings by disability type

The concept of primary disability type used in this report comes from the DS NMDS and refers to the disability that most clearly reflects the person's experience of disability, and causes them the most difficulty in everyday life (not just within the context of the support offered). Based on the DS NMDS classification, broad disability groupings have been used in this report to summarise and present high-level information, before further detail is provided on more specific disability types.

The broad disability groupings may include conditions which are not clinically aligned, but have been grouped to allow reliable age-specific breakdowns to be presented in the resulting tables (i.e. tables and results that are not impacted by small cell sizes). Where possible, the disability groupings include individuals with similarities in one or more of the following; experiences of disability and patterns of impairments, activity limitations, participation restrictions, support needs and/or related health conditions. 'Disability group' is not a diagnostic or clinical grouping, and there is not a one-to-one correspondence between a health condition and a disability group. For more information, see the [data guide](#) for the Disability Services National Minimum Data Set.

#### People with intellectual or learning disability

For the purposes of this report, this diverse, broad group comprised people with an intellectual disability (58%), specific learning disability or attention deficit disorder (8.1%), autism (27%) or developmental delay (7.0%). This group was largely made up of younger people, with 3 in 4 (75%) aged under 35 and a median age of 22 (Table S2.2).

People with intellectual or learning disability accounted for 1 in 4 (26%) of deaths in the study. Among those with intellectual or learning disability, around 31% of deaths were considered potentially avoidable (Table S5.2).

Among those with an intellectual or learning primary disability:

- The crude mortality rate was 410 deaths per 100,000 people—the lowest of any primary disability group (Table S3.5). The mortality rate for females was about 1.5 times as high as that for males, though females tended to be slightly older than males (the rate ratio equates to 1.1 once age is taken into account) (Table S3.4). Within this group, the mortality rate varied by type of disability:
  - People with intellectual primary disability had the highest crude mortality rate (640 deaths per 100,000 people). The median age of these service users was 29 and median age at death was 50.
  - Children with developmental delays had the second highest crude mortality rate (250). The median age of these service users was 4 and median age at death was 2.
  - The third highest rate was for people with specific learning disability or attention deficit disorder (80). The median age of these service users was 22 and median age at death was 30.
  - People with autism had the lowest crude mortality rate of all disability types (70). The median age of service users was 16 and median age at death was 24.
- The rate of PYLL was 130 per 1,000 people.
- Overall the rate of PADs was 130 per 100,000 people—the lowest crude rate by disability group. Within this group, people with intellectual disability (190 PADs per 100,000

people) had the highest crude rate followed by specific learning or attention deficit disorder (54), developmental delay (33) and autism (28) (see Table S5.3).

- People aged 50–64 had the highest rate of mortality and PADs compared with the other age groups.
- The leading causes of death for this group were perinatal and congenital conditions (17% of deaths), cerebral palsy and other paralytic syndromes (8.7%) and epilepsy (6.4%) (Table S4.3). The leading causes of death for people with:
  - intellectual disability were perinatal and congenital conditions (18%), cerebral palsy (9.4%) and epilepsy (6.5%).
  - specific learning or attention deficit disorder were suicide, land transport accidents and accidental poisoning. However, these results should be interpreted with caution due to small cell sizes.
  - autism were epilepsy (10%), influenza and pneumonia (7.0%), suicide (6.0%) and cerebral palsy (6.0%).
  - developmental delay were perinatal and congenital conditions, selected metabolic disorders and other nervous system conditions.

*Note proportions are not presented when the numerator is less than 5 or the denominator is less than 100, due to statistical reliability.*

## People with physical or diverse disability

For the purposes of this report, this group comprised people with physical disability (68%), acquired brain injury (11%) or neurological disability (21%). This group was generally older than the other groups—2 in 5 (44%) were aged 50–64 (compared with 27% for the next highest group, psychosocial).

Nearly half of the deaths (49%) over the 5 years were of people with physical or diverse disability.

Among those with physical and diverse disability:

- The crude mortality rate was 1,100 deaths per 100,000 people—the highest of any disability group (Table S3.5). Within the physical or diverse disability group people with:
  - neurological primary disability had the highest crude mortality rate (1,900 deaths per 100,000 people). This was the highest mortality rate of any disability in the data. The median age of these service users was 41 and median age at death was 54.
  - acquired brain injury had the second highest crude mortality rate (nearly 1,900). The median age of these service users was 46 and median age at death was 53.
  - physical primary disability had the lowest overall crude mortality rate in this group (800). The median age of these service users was 48 and median age at death was 53.
- The rate of PYLL was 300 PYLL per 1,000 people—the highest of any disability group.
- The crude rate of PADs was 360 per 100,000 people—the highest of any disability group. Within this grouping people with acquired brain injury (820 PADs per 100,000 people) had the highest crude rate followed by physical disability (310) and neurological disability (270) (see Table S5.3).

- The leading causes of death for this group were spinal muscular atrophy (11% of deaths), coronary heart disease (5.7%) and brain cancer (5.6%) (Table S4.3). The leading causes of death for people with:
  - physical disability were coronary heart disease (8.1%), cerebral palsy and other paralytic syndromes (6.9%) and diabetes (5.0%).
  - acquired brain injury were brain cancer (12%), cerebrovascular disease (7.5%) and coronary heart disease (6.5%).
  - neurological disability were spinal muscular atrophy (29%), demyelinating diseases of the central nervous system (12%) and brain cancer (7.3%).

Although the high mortality rate among this group is partly due to the higher proportion of older people in the group, the physical or diverse group also had the highest mortality and PAD rate for people aged under 50.

## People with sensory or speech disability

For the purposes of this report, this group comprised people with deafblind (3%), vision (37%), hearing (42%) or speech disability (18%). One in 15 (6.4%) people in the study had a sensory and speech disability.

About 1 in 23 deaths (4.3%) of deaths were of people with sensory or speech disability.

Among those with a sensory and speech disability:

- The crude mortality rate was 430 deaths per 100,000 people (see Table S3.5). The rate was slightly higher for females (450) than males (425). Within the sensory or speech disability group, people with:
  - vision primary disability had the highest crude mortality rate (870 deaths per 100,000 people). The median age of these service users was 40 and median age at death was 55.
  - deafblind primary disability had the second highest crude mortality rate (660). The median age of these service users was 39 and median age at death was 54.
  - hearing disability had the third highest rate (160). The median age of these service users was 38 and median age at death was 52.
  - speech disability had the lowest crude mortality rate in the group (110). The median age of these service users was 5 and median age at death was 56.
- The overall rate of PADs was 210 per 100,000 people—the second lowest crude rate by disability group. Within this group, people with vision disability (430 PADs per 100,000 people) had the highest crude rate followed by deafblind (300), hearing disability (88) and speech (44)(see Table S5.3).
- The leading causes of death were diabetes (10.3% of deaths), coronary heart disease (9.8%) and brain cancer (7.2%) (Table S4.3).
  - There were no leading causes of death for people with deafblind disability due to small counts, however several deaths were due to cancers. See Table S4.2 for the complete list of observed causes of death.
  - The leading causes of death for people with vision disability were diabetes (13%), coronary heart disease (9.6%) and brain cancer (8.6%).
  - The leading causes of death for people with hearing disability were coronary heart disease, suicide and cerebrovascular disease.



- There were no leading causes of death for people with speech disability due to small counts, however several deaths were due to cancers. See Table S4.2 for the complete list of observed causes of death.

*Note proportions are not presented when the numerator is less than 5 or the denominator is less than 100 due to statistical reliability.*

## **People with psychosocial disability**

One in 5 (21%) people in the study population had a psychosocial disability. People in this group were generally younger adults—69% were aged between 20 and 49, higher than other groups (the next highest was intellectual or learning disability at 49%).

About 1 in 6 (1,400, or 16%) deaths were of people with psychosocial disability. The median age of these service users was 40, while the median age of death was 48.

Among those with a psychosocial disability:

- the crude mortality rate was 490 deaths per 100,000 people (Table S3.5). The rate for males was 600 deaths per 100,000 people, or 1.6 times as high as that for females.
- the crude rate of PADs was 320 per 100,000 people, the second highest among the disability groups (see Table S5.3).
- the rate of PADs for people aged 20–34 was 240 per 100,000 people—the highest in the study population.
- suicide was the leading cause of death across different age groups and accounted for about 1 in 5 (21%) of deaths. The suicide rate was highest among those aged 20–34 (118 deaths per 100,000 people) (Table S4.3).
- the second and third most common causes of death were accidental poisoning (14% of deaths) and coronary heart disease (8.4%).

## 4 Findings by disability support service types

This report looks at disability support services provided in 6 broad service type categories: residential accommodation, other accommodation, respite, community support, community access, and employment. The NDA also funded two other service types that are not included in this report: advocacy, information, other forms of communication; and other support. A person may use multiple service types, and more than 1 service within each service type.

On average, people who used at least 1 disability support service used 1.3 service types each year.

Note that the profile of people using different service types varies substantially in terms of their age, sex and disability type/group. Therefore, patterns of mortality should be interpreted with this in mind.

### Residential accommodation services

Residential accommodation services provide accommodation to people with disability and includes large and small residential and institutions with 24-hour care, hostels (generally not 24-hour care), group homes, centre-based respite and respite homes. In any year, around 1 in 11 (9.4%) service users used residential accommodation services.

Around 4 in 5 (81%) of people using residential accommodation disability support services had an intellectual or learning disability. The median age of these service users was 37.

People using these services accounted for 1 in 6 (18%) deaths in the study population.

Among residential accommodation service users:

- There was a crude mortality rate of 1,300 deaths per 100,000 people. People with neurological primary disability using these services had the highest crude mortality rate of 3,000 deaths per 100,000 people, followed by people with acquired brain injury (2,500). The median age of these service users was 43 for people with neurological disability and 49 for people with an acquired brain injury.
- The crude rate of PYLL was 350 per 1,000 people.
- The crude rate of PADs was 310 per 100,000 people, 4.9 times as high as for the general population.
- The leading causes of death were perinatal and congenital conditions (16% of deaths), cerebral palsy and other paralytic syndromes (12%) and epilepsy (5.7%). The leading cause of death for people with neurological disability using residential accommodation disability support services were Huntington disease (23% of deaths), demyelinating diseases of the central nervous system (23%) and spinal muscular atrophy (6.8 %).

### Other accommodation services

Other accommodation support disability services include attendant care, personal care, in-home accommodation support, alternative family placement, and accommodation support services that provide short-term, one-off instances of accommodation. Each year, about 1 in 15 (6.5%) of the study population used these services, and they were generally older than

other service users—about 60% were aged over 35 with a median age of 40. People using other accommodation support services accounted for 15% of deaths in the study population.

This group had the lowest proportion of recipients with primary disability in the intellectual or learning (45%) and the highest proportion of people with physical and diverse (31%) and psychosocial (20%) disability.

Among those who received other accommodation services:

- The crude mortality rate was 1,500 deaths per 100,000 people—the highest of any service type. People with neurological primary disability using these services had the highest crude mortality rate of 4,300 deaths per 100,000 followed by people with physical disability (2,400). Of these, the median ages for these service users was 50 for people with neurological disability and 45 for people with physical disability).
- The crude overall rate of PYLL was 420 per 1,000 people—the highest of any service type.
- The crude rate of PADs was 540 per 100,000 people—the highest of any service type.
- The leading causes of death included spinal muscular atrophy (9.6% of deaths), cerebral palsy and other paralytic syndromes (6.0%) and coronary heart disease (4.6%). The leading cause of death for people with neurological disability using other accommodation disability support services were spinal muscular atrophy (35% of deaths), demyelinating diseases of the central nervous system (14%) and Huntington disease (6.0%).

## Respite services

Respite support services provide short-term and time-limited break for families and other voluntary care givers of people with disability, to assist in supporting and maintaining the primary care giving relationship.

About 1 in 11 (8.8%) of the study population used disability respite services each year on average. More than 4 in 10 (44%) people using respite services were aged under 20, and 7 in 10 (72%) were aged under 35. Overall, about 2 in 3 (67%) of these service users had an intellectual or learning disability as their primary disability, and a further 1 in 5 (18%) had a physical or diverse disability. The median age of respite service users was 21.

People using respite services accounted for less than 1 in 10 (9.3%) deaths of people with disability in the study, lower than all other service types. This group also had the lowest rate of PADs and second lowest crude rates of mortality (after those who only used employment services).

Among those who received respite services:

- The crude mortality rate was 680 per 100,000 people, the lowest of any service type (excluding those who used only employment services).
- The crude rate of PYLL was 240 per 1,000 people.
- The crude rate of PADs was 160 per 100,000 people.
- The leading causes of death included spinal muscular atrophy (10% of deaths), cerebral palsy and other paralytic syndromes (9.3%) and perinatal and congenital conditions (8.3%).

## Community support services

Community support services provide the support needed for a person with disability to live in a non-institutional setting—includes therapy support for individuals, early childhood intervention, behaviour and specialist intervention, counselling, regional resource and support teams, case management, local coordination and development and other community support.

Community support services was the second most commonly used service, with close to half (43%) people with disability accessing these services. Service users were generally younger, with half (50%) aged under 20. The median age of community support services was 19. Over half (55%) of these services users had an intellectual or learning primary disability, and 1 in 4 (23%) had a physical or diverse disability. People using community support services accounted for 62% of deaths in the study population.

Among those that received community support services:

- The crude mortality rate was 940 per 100,000 people, below that of residential or other accommodation services.
- The crude rate of PYLL was 280 per 1,000 people.
- The crude rate of PADs was 350 per 100,000 people. Those aged 50–64 had the highest mortality and PADs rates compared with other service types.
- The leading causes of death for this group were perinatal and congenital conditions (8.1% of deaths), spinal muscular atrophy (7.7%) and cerebral palsy and other paralytic syndromes (5.9%).

## Community access services

Community access services are designed to provide opportunities for people with disability to gain and use their abilities to enjoy their full potential for social independence. They were used by 1 in 7 (15%) people in the study population, and were mostly used by those who did not attend school or were not employed full time. Nearly 2 in 5 (39%) service users were aged between 20 and 34.

Around 3 in 5 (63%) of service users had intellectual or learning primary disability. A further 1 in 9 (11%) people had sensory or speech primary disability, the highest level of representation for sensory or speech across service types. The median age of community access service users was 32.

Around 1 in 6 (18%) deaths were for people using community access services.

Among those using community access services:

- The crude mortality rate was 790 per 100,000 people.
- The crude rate of PYLL was 230 per 1,000 people.
- The crude rate of PADs was 250 per 100,000 people.
- The leading causes of death were perinatal and congenital conditions (11% of deaths), cerebral palsy and other paralytic syndromes (9.5%) and epilepsy (5.5%).

Overall the users of community access services had the lowest rates of mortality and PYLL within each age group, compared with all other service types, except those using employment services only.

## Employment services

Disability employment services provide opportunities and assistance to help people obtain and/or retain employment in the open labour market, or work in specialised and supported work environments. These services are designed for people of working age; the median age of these service users was 40.

Employment services were used by half (50%) of people with disability in the study, and many used other services. For people using only employment services, male service users tended to be younger than females (about 2 in 5 (38%) males were aged 20–34 compared with 3 in 10 (29%) females) while about 2 in 5 (37%) female service users were aged 50–64 (compared with 28% of males). People using only employment services accounted for 22% of deaths in the study population.

More than one-third (36%) of service users only using employment services had physical or diverse primary disability and nearly 2 in 5 (38%) had psychosocial disability.

- More than 1 in 5 (22%) deaths were people who had used only employment services.
- People using only employment services had a crude mortality rate of 320 deaths per 100,000 people and 86 PYLL per 1,000 people. These were lower than all other service types.
- The crude rate of PADs was 190 per 100,000 people.
- The leading causes of death were suicide (14% of deaths), coronary heart disease (11%) and accidental poisoning (11%).

The crude mortality and PYLL rates were the lowest among any service type for every age and sex category.

## 5 Conclusion

This summary report, and the accompanying technical report, are the first national reports on mortality among people with disability who use disability support services in Australia. They show that people with disability who accessed disability support services over a 5-year period had a higher mortality rate than the comparable general population. They show there was variation in the leading causes of death, the overall rates of death, and the number of potentially avoidable deaths, by primary disability type and disability service types. This highlights the varying support needs among disability service users, and can highlight potential areas of targeted support and health interventions (particular among those groups with high rates of potentially avoidable deaths). To this end, future work could focus on enhancing the understanding of the complex interrelationship between disability, service use, and age and sex.

# 6 Glossary

## 6.1 General terms

**age structure:** The relative number of people in each age group in a population.

**cause(s) of death:** All diseases, morbid conditions or injuries that either resulted in or contributed to death—and the circumstances of the accident or violence that produced any such injuries—that are entered on the Medical Certificate of Cause of Death. Causes of death are commonly reported by the **underlying cause of death**.

**community access:** Services designed to provide opportunities for people with disability to gain and use their abilities to enjoy their full potential for social independence. Includes learning and life skills development, recreation/holiday programs and other community access.

**community support:** Services that provide the support needed for a person with disability to live in a non-institutional setting. Includes therapy support for individuals, early childhood intervention, behaviour/specialist intervention, counselling, regional resource and support teams, case management, local coordination and development and other community support.

**coronary heart disease:** A disease due to blockages in the heart's own (coronary) arteries, expressed as angina or a heart attack. Also known as **ischaemic heart disease**.

**disease:** A physical or mental disturbance involving symptoms (such as pain or feeling unwell), dysfunction or tissue damage, especially if these symptoms and signs form a recognisable clinical pattern.

**influenza (flu):** An acute contagious viral respiratory infection marked by fever, fatigue, muscle aches, headache, cough and sore throat.

**mortality:** Number or rate of deaths in a population during a given time period.

**other accommodation support:** Services that provide support needed to enable a person with disability to remain in their existing accommodation or to move to more suitable or appropriate accommodation. Includes attendant care/personal care, in-home accommodation support, alternative family placement, other accommodation support.

**pneumonia:** Inflammation of the lungs as a response to infection by bacteria or viruses. The air sacs become flooded with fluid, and inflammatory cells and affected areas of the lung become solid. Pneumonia is often quite rapid in onset and marked by a high fever, headache, cough, chest pain and shortness of breath.

**residential accommodation services:** Services that provide accommodation to people with disability. Includes large residential/institution, small residential/institution, hostels, group homes, centre-based respite/respite homes.

**respite services:** Services that provide a short-term and time-limited break for families and other voluntary caregivers of people with disability, to assist in supporting and maintaining the primary caregiving relationship, while providing a positive experience for the person with disability.

**underlying cause of death:** The disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence that produced the fatal injury. See also **cause(s) of death** and **associated cause(s) of death**.

## 6.2 Statistical terms

**age-standardisation:** A way to remove the influence of age when comparing populations with different **age structures**. This is usually necessary because the **rates** of many diseases vary strongly (usually increasing) with age. The age structures of the different populations are converted to the same 'standard' structure, and then the disease rates that would have occurred with that structure are calculated and compared.

**age-standardised rate:** A method of removing the influence of age when comparing populations with different age structures. There are 2 methods commonly used. to adjust for age—direct and indirect standardisation (see below). In this report, direct age-standardisation was used to compare mortality rates over time, with age-standardised mortality rates generally expressed as the rate per 100,000 population.

Unless specified, age-standardised rates used the direct method.

**crude rate:** The number of events in a given period divided by the size of the population at risk in the specified time period. In this report, crude mortality rates are generally expressed as the rate per 100,000 population.

**direct age-standardisation:** A directly age-standardised rate is derived by applying the age-specific rates in the study population to a single standard population. To calculate directly age-standardised rates in this report, the Australian Estimated Resident Population as at 30 June 2001 was used as the standard population.

**indirect age-standardisation:** An indirectly age-standardised rate is calculated by applying the age-specific rates from a standard population to the age distribution of the study population. Therefore, the indirect method calculates how many events would be expected in each group in the study population if the age-specific rates of the standard population were applied.

Indirect age-standardisation was used when examining rates for the study and general populations together.

**mortality rate difference:** A measure of the absolute gap in age-specific, crude and age-standardised rates between 2 populations. In this report, mortality rate differences were calculated as the mortality rate per 100,000 for the study population minus the mortality rate per 100,000 for the general population.

**mortality rate ratio:** A measure of the relative gap in age-specific, crude and age-standardised rates between 2 populations. In this report, mortality rate ratios were calculated as the mortality rate per 100,000 for the study population divided by the mortality rate per 100,000 for the general population.

**potentially avoidable deaths (PADs):** Deaths among people aged under 75 that are avoidable in the context of the present health-care system. They include deaths from conditions that are potentially preventable through individualised care and/or treatable through existing primary or hospital care. They do not indicate that these deaths have individually been assessed as avoidable.

Potentially avoidable deaths are classified using nationally agreed definitions.

The rate of PADs in Australia is used as an indicator of the health system's effectiveness—they are classified using nationally agreed definitions. For example:

- land transport accidents, ischaemic heart disease, suicide and selected infections are considered potentially avoidable



- congenital conditions, cerebral palsy, epilepsy and muscular atrophy are considered not potentially avoidable.

Some conditions listed as the underlying cause of death, including potentially avoidable deaths, may be present before a person begins to use disability support services. Care should be taken when interpreting rates for causes of death and potentially avoidable deaths to not incorrectly attribute these outcomes to the people or type of care provided.

The definition of potentially avoidable deaths is outlined in the METeOR specification: [National Healthcare Agreement: PI 16-Potentially avoidable deaths, 2019](#).

**potential years of life lost (PYLL):** Measures the impact of premature or untimely death by counting the number of years between the age at death and a defined cut-off age for premature death. In this report, dying before age 75 is considered premature. Therefore, a person dying at age 45 has potentially lost 30 years of life, while a person dying at age 80 is deemed to have lost no years of life prematurely. This measure gives greater weight to deaths at younger ages, compared with measures that count only numbers of deaths, which tend to be dominated by deaths of the elderly.

**PYLL rate:** A rate calculated by summing the individual PYLL for a population group and dividing by the number of people in the group. In this report, PYLL rates are expressed per 1,000 population rather than 100,000 population which is used to express mortality rates.

**PYLL rate difference:** A measure of the absolute gap in PYLL rates between 2 populations. In this report, PYLL rate differences were calculated as the PYLL rate per 1,000 for the study population minus the PYLL rate per 1,000 for the general population.

**PYLL rate ratio:** A measure of the relative gap in PYLL rates between 2 populations. In this report, PYLL rate ratios were calculated as the PYLL rate per 1,000 for the study population divided by the PYLL rate per 1,000 for the general population.

**rate:** A rate is one number (the numerator) divided by another number (the denominator). The numerator is commonly the number of events in a specified time. The denominator is the population 'at risk' of the event. Rates (crude, age-specific and age-standardised) are generally multiplied by a number such as 100,000 to create whole numbers.



[aihw.gov.au](http://aihw.gov.au)



Stronger evidence,  
better decisions,  
improved health and welfare

