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

Technical report

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

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

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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 technical report, and the accompanying summary 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.

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Summary

This report used linked data to examine deaths among people with disability who used disability support services funded under the National Disability Agreement (NDA) for the 5 years from 1 July 2013 to 30 June 2018. The study included 526,515 people aged under 65 who accessed disability support services, or about 23% of the 2.4 million Australians under age 65 with disability in 2018.

Compared with the general population, people using disability support services had higher rates of mortality

People with disability in the study had a mortality rate 4.7 times as high as the rate for the general population, after adjusting for differences in the age and sex structure of the populations.

The 3 most common underlying causes of death among people with disability in the study 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 conditions (21%), cerebral palsy and other paralytic syndromes (14%) and selected metabolic disorders (9.8%).

People using disability support services had higher rates of potentially avoidable deaths

People with disability had a crude rate of 240 potentially avoidable deaths (PADs) per 100,000 people. After adjusting for age, the rate for the study population was 3.6 times as high as the general population. The leading causes of PADs in the study population were coronary heart disease followed by suicide. These were also the 2 leading causes of PADs (and overall leading causes of death) in the general population.

The rate of PADs in Australia is used as an indicator of the health system's effectiveness, with deaths considered potentially avoidable in the context of the current health system classified using nationally agreed definitions. They do not indicate that these deaths have individually been assessed as avoidable.

The rate of death varied by type of disability

People with acquired brain injury and neurological primary disabilities had the highest crude rate of death (1,900 per 100,000 people) while people with specific learning/attention deficit disorder and autism had the lowest (76 and 66 per 100,000 people, respectively). This difference in rates is in part due to age differences between these groups, with those who had acquired brain injury and neurological disorders being typically older (median ages of 46 and 41 respectively), while those with specific learning/attention deficit disorder and autism were generally younger (median ages of 22 and 16, respectively).

The rate of potentially avoidable deaths varied by type of disability

People with acquired brain injury had the highest rate of PADs (820 per 100,000), followed by those with vision (430 per 100,000) and psychosocial (320 per 100,000) primary disability.

The rate of death varied by type of disability service used

Although the rate of death varied by type of disability service, this is likely due to the differing characteristics of individuals, including age, sex and underlying disability, that are related to an individual using each type of service. However, it is still important to understand mortality patterns across service types in order to consider where interventions and services can be best applied.

Crude mortality rates were highest among people with disability receiving residential accommodation support (1,300 deaths per 100,000 people) or other accommodation support (1,500). Lower rates of death occurred among those receiving community support (940) and community access (790) services, followed by respite (680) and employment services (320).

Cause of death patterns varied by disability and service type

Leading causes of death varied across different disability and service type groupings, closely related to the markedly different age and sex characteristics of service users in these groups. Age- and sex-specific rates are presented throughout the report wherever possible to illuminate these differences. Future work will further explore these interrelationships.

1 Introduction

1.1 Aims of this report

The National Disability Insurance Scheme Quality and Safeguards Commission (the Commission) engaged the Australian Institute of Health and Welfare (AIHW) to provide a national-level report and data tables (that is, numbers, rates and trends) on the mortality of people with disability who have used disability support services funded under the National Disability Agreement (NDA).

This technical report and supplementary tables provide the first national picture in Australia on the deaths of people using NDA disability support services, using linked data. The report provides nationally consistent information on overall mortality, premature death, causes of death and potentially avoidable deaths (PADs) for people using disability support services funded under the NDA between 2013–14 and 2017–18. It accompanies a summary report that provides a brief overview of the study and key findings (see *Mortality patterns among people using disability support services: 1 July 2013 to 30 June 2018: summary report*).

This report was developed to assist the Commission consider areas of risk, and measures to reduce potentially preventable deaths. It also aimed to inform planning on future data requirements to inform policy and improve outcomes for people with disability.

1.2 Scoping review

At the request of the Commission, Professor Julian Trollor (Head, Department of Developmental Disability Neuropsychiatry, University of NSW Medicine) had previously conducted a scoping review to provide a national baseline picture of trends, issues and current monitoring practices for deaths of people with disability across Australia, based on findings from existing state and territory reports (Salomon & Trollor, 2019). This report is a complementary piece of work to be considered in the context of that scoping review.

The scoping review focused on reports by Victoria, New South Wales and Queensland on deaths of people using disability support services (Salomon & Trollor 2019). The review suggested that this group of people with disability died approximately 20 to 35 years earlier than the general population. Deaths from respiratory causes (mainly aspiration pneumonia and pneumonia) appeared to be over-represented, as did nervous system deaths (especially epilepsy-related deaths) for people with disability compared with the general Australian population. Deaths from particular types of external causes (specifically, choking on food) were also over-represented. However, it was not possible to quantify the exact number of in-scope deaths across reports that were potentially treatable or preventable within the context of the current health system (the prevailing definition of 'avoidable deaths').

It was noted that several limitations were to be kept in mind when interpreting the results of the scoping review. In particular, there was substantial variance in the data reported (such as different time periods, scope of data and methodological differences) and the legislative frameworks that underpinned collection of the information. For example, there were marked definitional differences as to what constituted a 'reportable' death of a person with disability under each jurisdiction's *Coroner's Act*.

1.3 Overview of the project and scope

Not all deaths of Australians with disability are included in this report. In-scope deaths are those where the person received disability support services funded under the NDA between 1 July 2013 and 30 June 2018. The AIHW Disability Services National Minimum Data Set (DS NMDS) is the source of information on people using disability services funded under the NDA. The DS NMDS was linked to the AIHW National Death Index (NDI) using the Medicare Consumer Directory (MCD). Details on the data sources, population inclusion and limitations of this study can be found in appendices A, C and D.

The linked data set was created for the period 1 July 2013 to 30 June 2018. This period aligns with the launch of the National Disability Insurance Scheme (NDIS) on 1 July 2013 and its introduction across Australia in July 2016.

The study population in this report is defined as all persons who were:

- a user of disability services (state/territory or Australian Government) as recorded in the DS NMDS between 1 July 2013 and 30 June 2018 (526,515 individuals), and
- linked to the MCD, and
- aged under 65, and
- recorded as a death between 1 July 2013 and 30 June 2018.

The study population comprised 526,515 individuals and 9,062 deaths.

The AIHW Ethics Committee approved this linkage study. Further information on the data linkage process used for this project, including validation and data quality checks, can be found in Appendix B.

1.4 Interpreting this report

This report provides the first national picture on the deaths of people aged under 65 using disability support services provided under the NDA (between 1 July 2013 and 30 June 2018). It complements the scoping review conducted by Salomon & Troller (2019).

The Australian Bureau of Statistics (ABS) publication *Causes of death, Australia, 2018* (ABS 2018) and the AIHW report *Deaths in Australia* (AIHW 2019a) also provide information on Australian mortality, however these reports do not provide information specifically relating to those with disability.

Due to differences in project scope and source data, the following points should be considered when comparing this report with the above-mentioned sources:

- This report includes information on broader groups of people with disability, disability services and deaths than reports focusing on notifiable deaths (which contribute to only a portion of the deaths in this report).
- This report produces slightly different Australian mortality figures by year for people aged under 65 than the above-mentioned ABS and AIHW reports, as the year of occurrence is used, not the year of registration of death. Further, there are differences in processing for the NDI that lead to a small change in total counts.
- This report also varies from others in the scoping review as the studied population is restricted to those aged under 65 to align it with the age criteria for participation in the NDIS. Therefore, the rate of potential years of life lost (PYLL), the rate of PADs and the proportion of deaths that are avoidable will be higher in this report than reports that include data for those aged 75 and over. This is because deaths that occur over age 75

do not contribute towards counts of PYLL and PADs but are included in the denominator in reports including data for those aged 75 and over. This affects the rates for the general population more than the study population due a higher proportion of deaths over age 75.

- This report also includes people aged under 20, who were not included in all reports identified in the scoping review. Taken together, this age group has a lower mortality rate than people over the age of 20 and may result in a lower crude mortality rate for the study population in this report compared to other reports.
- 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. Age and sex standardisation are used throughout the report alongside age-specific rates (and total crude rates) to account for this variation when comparing mortality outcomes for the study population and the general population, or comparing mortality outcomes across disability types.
- 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 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.

1.5 Mortality analysis

Representation of rates

Rates in this report are presented as counts of the event per 1,000 or 100,000 people. These rates are calculated from the data across the 5 years and can be considered as the average rate in a financial year.

Cause of death

Cause of death data provide important information on leading causes of death in a given population, as well as the extent and nature of premature mortality, including PADs.

Generally, cause-specific mortality data are reported based on the 'underlying cause of death'; that is, the specific disease or injury that initiated the train of events leading directly to death. This analysis therefore does not focus on the other multiple causes that may have contributed to death. The death certification process in Australia allows for up to 20 diseases to be reported as causing or contributing to a death (AIHW 2019a).

Box 1.1 outlines the definitions used to describe causes of death in this report.

Box 1.1: Describing causes of death

Death certificates document the diseases considered to be instrumental in causing a death. These are usually completed by a medical practitioner or coroner.

Key definitions used to describe causes of death include:

- **underlying cause of death:** The condition, disease or injury listed on the Medical Certificate of Cause of Death that initiated the sequence of events leading directly to death; that is, the primary or main cause of death. For each death, only 1 underlying cause is selected from among all the conditions reported on the death certificate.
- **associated cause(s) of death:** A cause(s) listed on the Medical Certificate of Cause of Death, other than the **underlying cause of death**. They include the immediate cause, any intervening causes, and conditions that contributed to the death but were not related to the disease or condition causing death.
- **multiple causes of death:** All the causes listed on the Medical Certificate of Cause of Death. These include the **underlying cause of death** and all **associated cause(s) of death**.

A summary of the statistical methods used in this report are provided in Box 1.2.

Box 1.2: 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.

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.

Continued)

Box 1.2 (continued): Key statistical terms used in this report

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.

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.

2 Disability service recipients

This section describes the characteristics of the study population in terms of their age, sex, disability type and service use. The aim of the section is to provide context for the subsequent mortality analysis.

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 <<https://www.aihw.gov.au/getmedia/1026f60a-cc97-40fb-a6ef-46c25ec006a6/ds-nmds-data-guide-2016-17.pdf.aspx>>.

2.1 Disability types and groups in the DS NMDS

In the DS NMDS, a person's disability is defined as the primary disability if it is the one 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). It is not a diagnostic grouping, nor is there a one-to-one correspondence between a health condition and a disability group.

There are 12 different types of disability in the DS NMDS classification that are grouped into 4 broad categories throughout this report:

- The intellectual or learning group comprised people with an intellectual disability (58%), specific learning disability or attention deficit disorder (8.1%), autism (27%) or developmental delay (7.0%). Overall, 2 in 5 (40%) people in the study had an intellectual or learning primary disability.
- The physical or diverse group comprised people with physical disability (68%), acquired brain injury (11%) or neurological disability (21%). Around 3 in 10 (28%) people in the study had a physical or diverse primary disability.
- The sensory or speech group comprised people with deafblind (3.0%), vision (37%), hearing (42%) or speech disability (18%). One in 16 (6.4%) people in the study had a sensory or speech primary disability.
- People with psychosocial disability comprise the final group. One in 5 (21%) people in the study population had a psychosocial primary disability.

Where possible, detail on specific disability types is presented, however this is not always possible due to statistical reliability issues.

A person may also experience another disability at the same time as the primary disability that causes them difficulty, which is referred to as 'other significant disability group' in the DS NMDS. Analysis of other significant disability groups is not presented in this report and all references to disability in this report are to primary disability.

As shown in Figure 2.1, people with primary disability in the intellectual or learning and sensory or speech groups were generally younger than people with primary disability in the physical or diverse and psychosocial groups. Over 2 in 5 (44%) of people with primary disability in the physical or diverse group were aged 50–64.

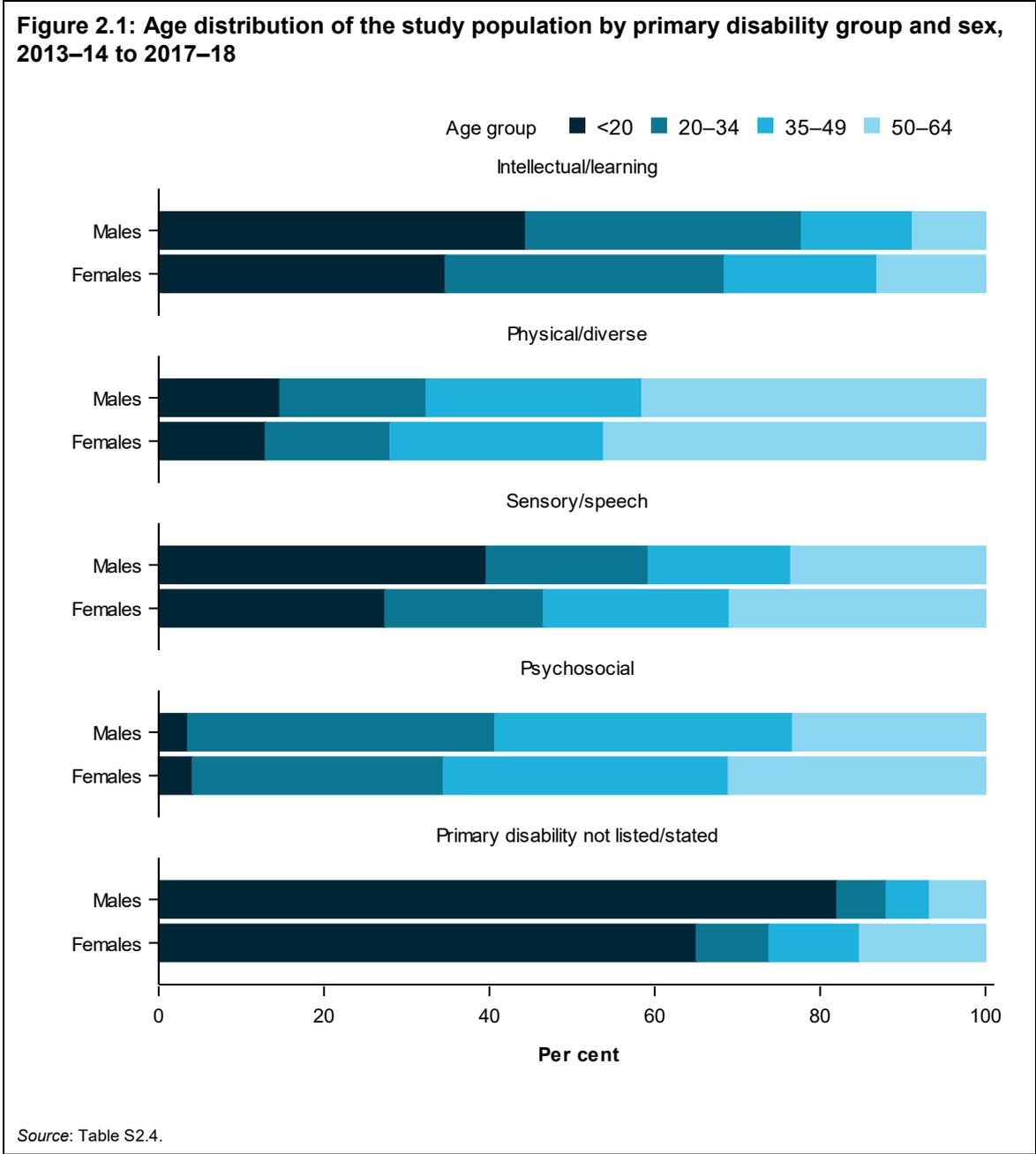
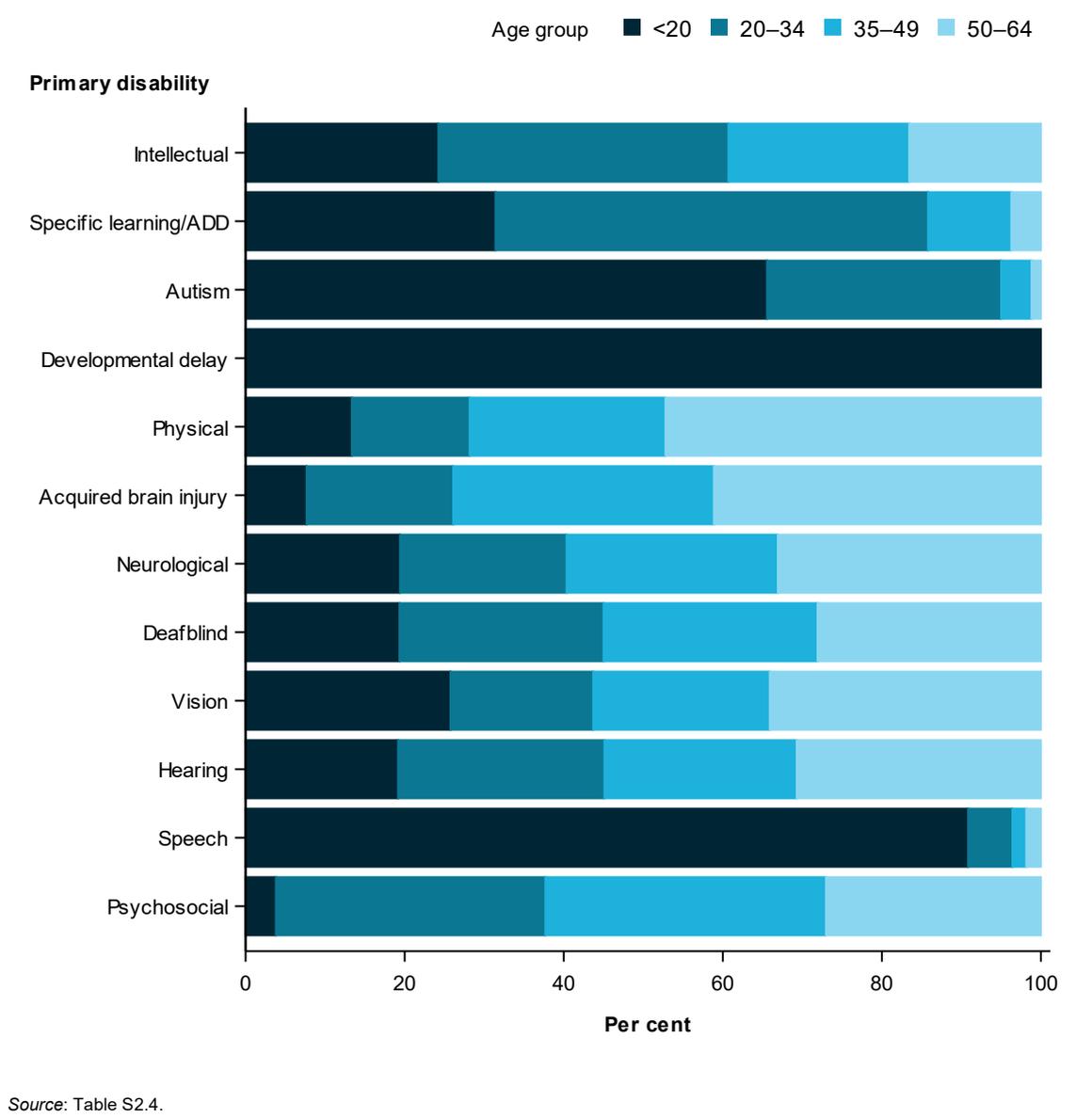


Figure 2.2 shows how the age profile of disability service users varies across the disability types within these broad disability groups, highlighting the need to look carefully at the interplay of disability type, age and service use when examining mortality measures throughout this report.

Figure 2.2: Age distribution of the study population by primary disability, 2013–14 to 2017–18



2.2 Service types and groups in the DS NMDS

Specialist disability services delivered under the NDA formed one part of a broader system of supports and payments for people with disability. Data on these services were collected as per the DS NMDS between July 2009 and June 2019. For the purposes of this report, temporal coverage of the DS NMDS data was from 1 July 2013 to 30 June 2018.

Under the NDA, a service type was the support activity accessed by the person with disability. These service types were grouped into 7 broad groups: accommodation support, community support, community access, respite, open employment, supported employment, and advocacy and other support. For the services covered in this report, See Box 2.1. A service user may use more than 1 type of service and more than 1 type of service within

each of these groups of services. On average, each service user used 1.3 services each year.

In this report, the service type group described as 'accommodation support' in the DS NMDS is split into 2 further sub-groups, defined as 'residential accommodation support' or 'other accommodation support' (see Box 2.1). This report focuses on residential accommodation support, other accommodation support, respite care, community support and community access services, as these are services that can transition to the NDIS. Data for employment services (that do not transition to the NDIS are also presented in parts of the report, with further detail available in the supplementary tables.

Box 2.1: Service types presented in this report

- Residential accommodation support services provide accommodation to people with disability—includes the following DS NMDS service types: large or small residential/institutions with 24-hour care, hostels (generally not 24-hour care), group homes, and centre-based respite/respite homes. These services account for 10% of service use.
- Other accommodation support services 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 the following DS NMDS service types: attendant care/personal care, in-home accommodation support, alternative family placement, and other accommodation support. These services account for 7% of service use.
- Respite support services provide a 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, while providing a positive experience for the person with disability. These services account for 9% of service use.
- 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/specialist intervention, counselling, regional resource and support teams, case management, local coordination and development and other community support. These services account for 10% of service use.
- 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—includes learning and life skills development, recreation/holiday programs and other community access.
- Employment services provide employment opportunities and assistance to people with disability to obtain and/or retain paid employment in the open labour market (open employment services), or to work in specialised and supported work environments (supported employment services).

The different service types are not used at equal volumes or intensity and some may only be used for small parts of the year. The approximate proportion of service users for each service type in a year was:

- 1 in 11 (9.4%) for residential accommodation support services
- 1 in 15 (6.5%) for other accommodation support services
- 1 in 11 (8.8%) for respite support services
- 1 in 2 (43%) for community support services

- 1 in 7 (15%) for community access services
- 1 in 2 (50%) for employment services (Table S2.3).

These proportions do not sum to 100%, demonstrating the level of overlapping service users. The age, sex and primary disability structure of the study population should be considered when assessing results for the service types. Figure 2.3 shows the proportion by age for male and female service users, which shows that:

- females tend to be older than males for every service type
- recipients of other accommodation services or employment services are generally older than other service type users—around 60% were aged 35 and over in both groups compared with 54% for residential accommodation support. Less than half of service users were aged 35 and over in the other service types
- most people receiving respite (72%) and community support services (68%) were aged under 35
- community access services had the highest proportion (39%) of people aged 20–34 compared with other service types.

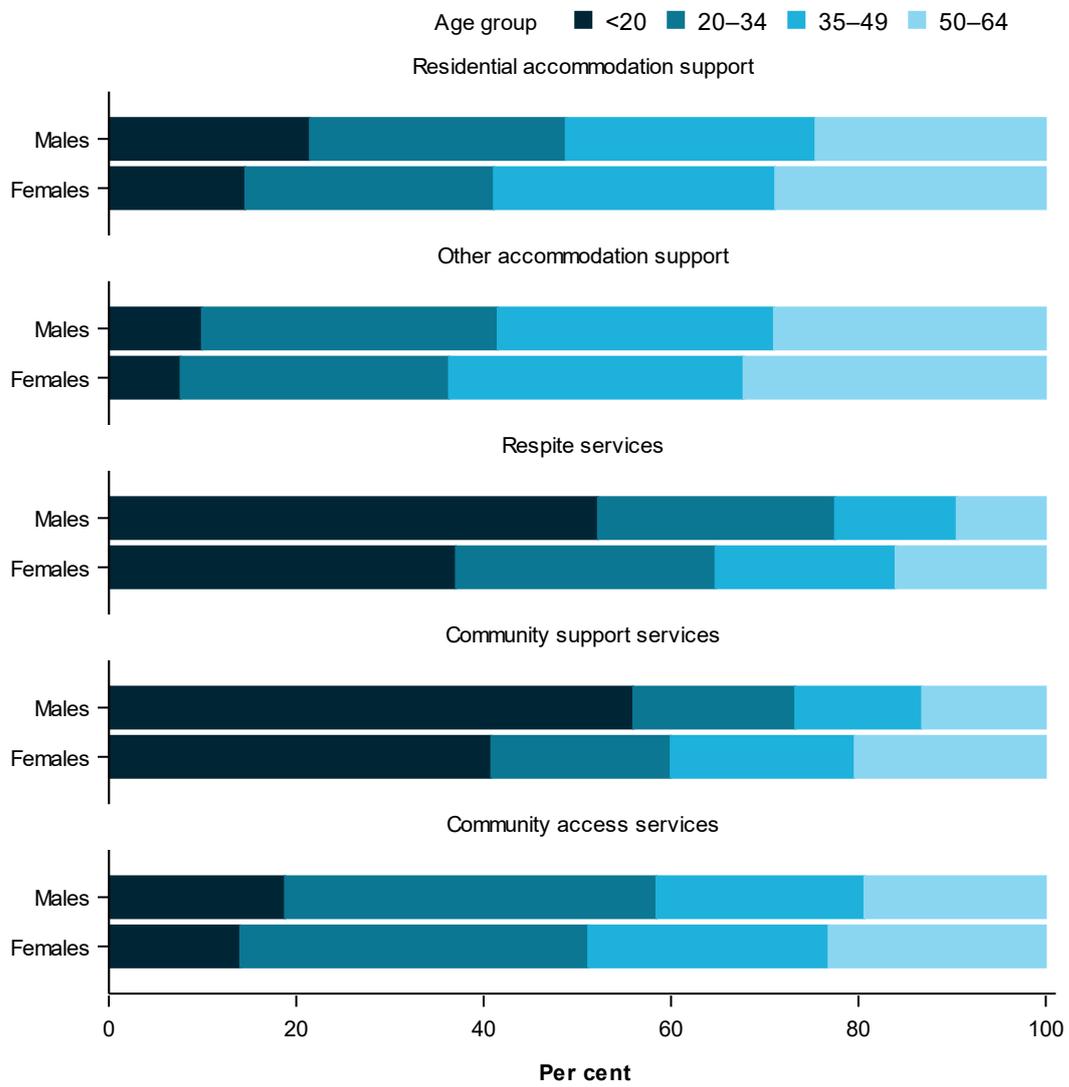
2.3 Service use by disability group

People with intellectual or learning primary disability represented 2 in 5 (40%) users in the study population (see Table S2.2), however, there was some variation by service type (see Figure 2.4):

- Eight in 10 users of residential accommodation had an intellectual or learning (81%) disability. The next most common primary disability group was physical or diverse (15%). The median age for these services users was 37.
- Other accommodation support services had the second lowest proportion of users with primary disability in the intellectual or learning group (45%) and the second highest proportion of people with physical or diverse (31%) and psychosocial (20%) primary disability. The median age for these services users was 40.
- Overall, approximately 2 in 3 (67%) people using respite services had intellectual or learning disability as their primary disability, with physical or diverse primary disability accounting for an additional 18% of this group. The median age for these services users was 21.
- Over half (55%) of people using community support services had an intellectual or learning disability, and 1 in 4 (23%) had a physical or diverse disability. The median age for these services users was 19.
- People with sensory or speech primary disability comprised around 1 in 8 (12%) of community access service users, the highest level of representation across the different services. Around 3 in 5 (63%) people using community access services had intellectual or learning disability. The median age for these services users was 32.
- Roughly 2 in 5 (38%) people using only employment services had a psychosocial disability. Over 1 in 3 (36%) people had physical or diverse primary disability. This group had the lowest proportion of people with intellectual or learning disability (22%). The median age was 39 for anyone using employment services and 40 if they used only employment services.

For further detail on the disability type profiles for each service type, see Table S2.6.

Figure 2.3 : Age distribution of the study population by service type and sex, 2013–14 to 2017–18



Note: A service user can use multiple services within a financial year and may contribute to multiple bars.

Source: Table S2.5.

Figure 2.4: Leading 5 primary disability types for the study population by service type, 2013–14 to 2017–18

Service type	1st	2nd	3rd	4th	5th	Remaining
Residential accommodation support	Intellectual 69.7%	Autism 10.9%	Physical 6.8%	Neurological 4.4%	Acquired brain injury 4.0%	4.2%
Other accommodation support	Intellectual 37.7%	Psychosocial 20.1%	Physical 16.0%	Neurological 7.5%	Acquired brain injury 7.2%	11.6%
Respite services	Intellectual 45.1%	Autism 20.5%	Physical 9.5%	Psychosocial 6.7%	Not stated/listed 5.9%	12.2%
Community support services	Intellectual 31.9%	Autism 15.8%	Physical 10.8%	Neurological 8.1%	Not stated/listed 8.0%	25.4%
Community access services	Intellectual 50.5%	Autism 11.5%	Hearing 8.1%	Psychosocial 7.6%	Physical 7.4%	15%
Employment services	Psychosocial 34.6%	Physical 27.1%	Intellectual 16.4%	Autism 6.4%	Specific learning/ADD 5.3%	10.2%

Note: A service user can use multiple services within a financial year and may contribute to multiple rows.

Source: Table S2.6.

3 Mortality

This section examines the mortality statistics (number and rates of deaths that occurred from 1 July 2013 to 30 June 2018) among the 526,515 people aged under 65 who were receiving disability support services, analysed alongside deaths among the general population of the same age.

The aim of this section is to provide a greater understanding of the number and rate of deaths for the study population.

Between 1 July 2013 and 30 June 2018, among people aged under 65, there were 9,062 deaths in the study population, compared with 129,755 in the general population (see Table S3.2). As shown in Figure 3.1, for both the study and general populations, there was an increasing rate of death with increasing age; however, the rate of death was higher among the study population in each age group. The mortality rate also increased more rapidly with age for the study population.

The observed crude mortality rate for the study population was 650 deaths per 100,000 people. After adjusting for age and sex, the mortality rate of the study population was 4.7 times as high as expected, based on the mortality rate of the general population (using indirect standardisation, see Table S3.1).

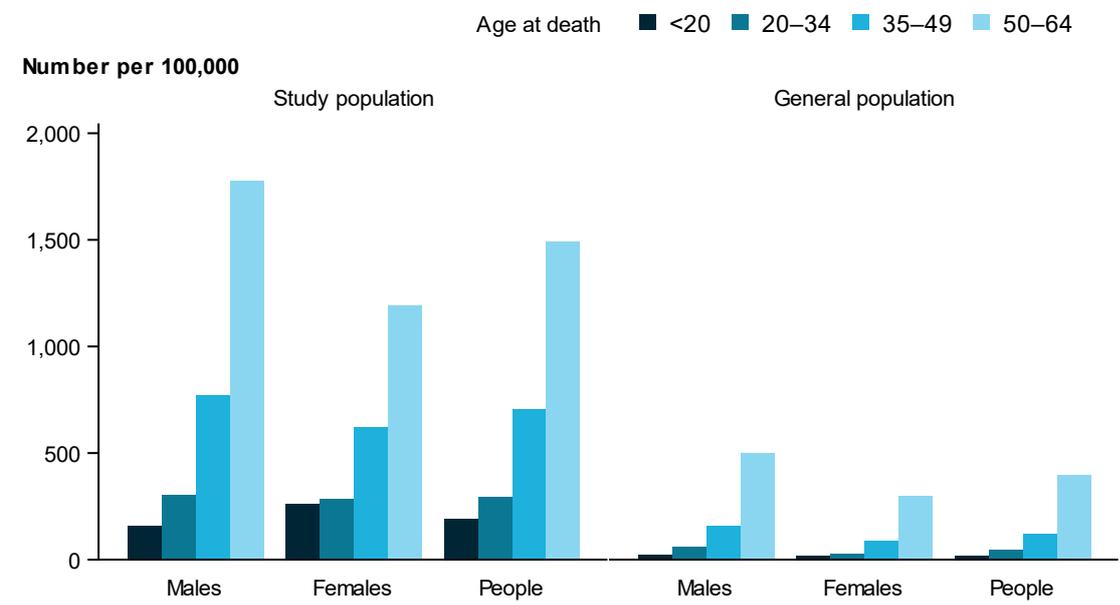
The median age of death for the study population was 52 for both males and females, slightly lower than that for the general population (54 for males and 55 for females) (see Table S3.3).

3.1 Age and sex

Males are over-represented among the study population, accounting for nearly 3 in 5 (59%) people (Table S2.1). In comparison, in the general population the numbers of males and females are similar (each around 50%). Examining mortality data shows that:

- around 3 in 5 (61%) of deaths in the study population were for males, in line with the sex distribution of the study population
- around 3 in 5 (63%) of deaths in the general population were for males, despite an equal distribution of males and females in the population
- crude mortality rates in the study population were slightly higher for males (660 deaths per 100,000 people) than females (630) (see Table S3.2)
- crude mortality rates for males in the general population were 1.7 times that of females (160 deaths per 100,000 people compared with 95)
- the mortality rates for the study population were higher than the general population in each age group (see Figure 3.1)
- the mortality rate ratio between the study and general population decreases with age, largely due to the elevated mortality rate for younger age groups in the study population (with the study populations' mortality rates ranging from 10 times as high for those aged under 20, decreasing to 4 times as high for those aged 50–64).

Figure 3.1: Age-specific mortality rates for the study and general population, by sex, 2013–14 to 2017–18



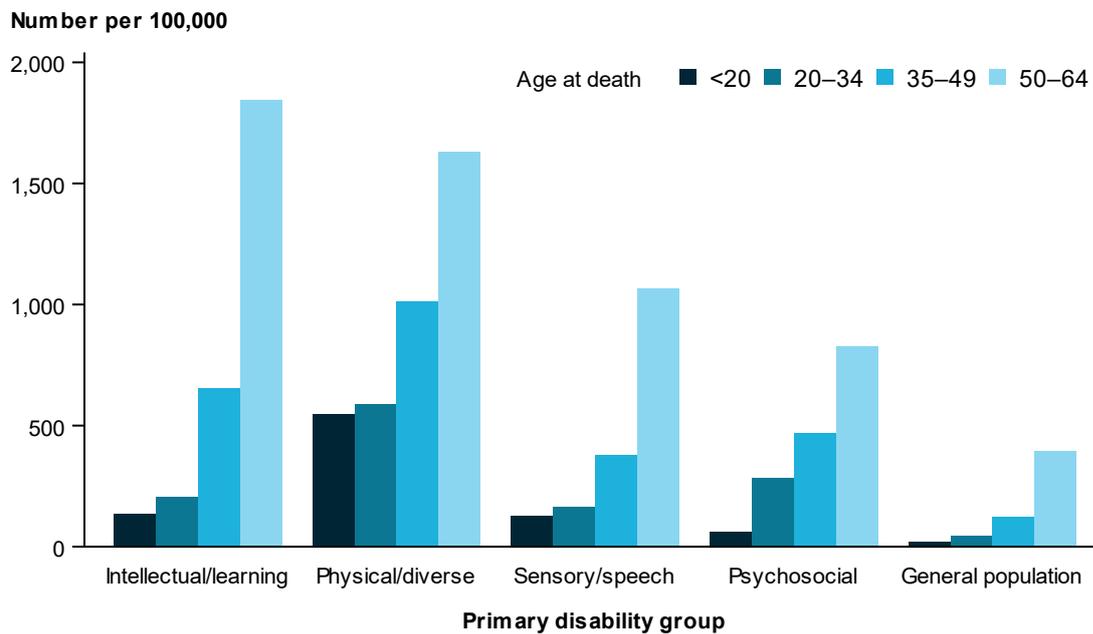
Source: Table S3.2.

Mortality generally increases with age and is highest in the 50–64 age group in both the study and general population. Just under one-quarter (24%) of the study population were aged 50–64, with this age group accounting for over half the deaths (56%) in this group (see tables S2.4 and S3.2). The 50–64 age group accounts for a relatively lower proportion of all deaths in the study population compared to the general population, in part due to the relatively higher proportion of deaths under 20 in this population.

For those aged 50–64 in the study population:

- the mortality rate was 1,500 deaths per 100,000 people
- the highest mortality rate was among people with intellectual or learning disability (1,800 deaths per 100,000 people), followed by those with physical or diverse disability (1,600) (see Figure 3.2).

Figure 3.2: Age-specific mortality rates for the study population by primary disability, and for the general population, 2013–14 to 2017–18



Source: Tables S3.3 and S3.6.

3.2 Type of disability

People with intellectual or learning disability

People with intellectual or learning primary disability accounted for around one-quarter (26%) of the observed deaths (2,333 deaths; see Table S3.4). While comprising the largest group within the study population (about 40%; see Table S2.2), people with intellectual or learning primary disability were generally younger than people in other primary disability groups, leading to the relatively lower proportion of deaths (see Figure 2.1).

The crude mortality rate for people with intellectual or learning disability was 410 deaths per 100,000 people. When broken down by specific disability types, the crude mortality rate for people with:

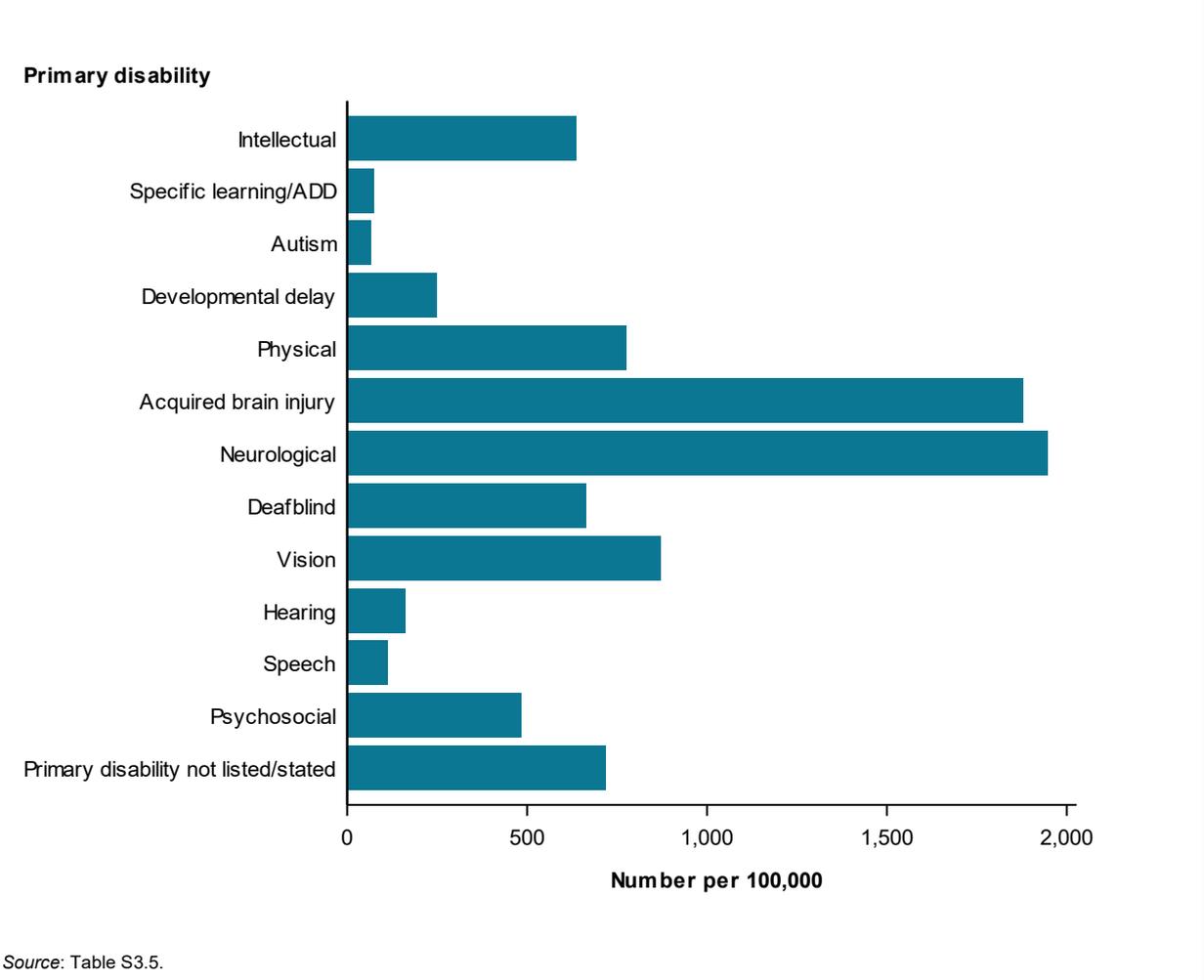
- intellectual disability was 640 per 100,000 (age-standardised rate of 700)
- specific learning or attention deficit disorder was 76 per 100,000
- autism was 66 per 100,000 (age-standardised rate of 230)
- developmental delay was 250 per 100,000 (see Figure 3.3 and Table S3.5).

Note age-standardised rates are not calculated where the number of deaths is not sufficient to meet reliability requirements.

Although males in the overall study population had a higher crude mortality rate than females, among those with an intellectual or learning disability, the rate was higher for females (520 deaths per 100,000 people) than males (360) (see Table S3.4). This equates

to a rate ratio of about 1.5, which is partially due to females with intellectual or learning primary disability being older, on average, than their male counterparts. After controlling for age structure, the rate for females was 1.1 times as high as the rate for males.

Figure 3.3: Crude mortality rates for the study population, by disability type, 2013–14 to 2017–18



People with physical or diverse disability

People with primary disability in the physical or diverse disability group made up about one quarter (28%) of the study population, however, they accounted for half of the observed deaths (4,457 of 9,062 deaths over the 5-year period to 2017–18, see tables S2.2 and S3.4). Of these deaths, 62% were male and 38% were female (males accounted for 55% of the people with physical or diverse disability in the study).

People with physical or diverse primary disability also had the highest mortality rate, with a crude rate of 1,100 deaths per 100,000 people.

When broken down by specific disability types, the crude mortality rate for people with:

- physical disability was 780 per 100,000 people (age-standardised rate of 630)
- acquired brain injury was 1,900 per 100,000 people (age-standardised rate of 1,300)
- neurological was 1,900 per 100,000 people (age-standardised rate of 1,460) (Table S3.5).

People with sensory or speech disability

People with sensory or speech disability accounted for the smallest proportion of deaths in the study population (388, or 4.3% of study population deaths) with a crude mortality rate of 430 deaths per 100,000 people. The rate was slightly higher for females (450) than males (425; see Table S3.4).

When broken down by specific disability types, the crude mortality rates for people with a primary disability of:

- deafblind was 660 per 100,000 people
- vision was 870 per 100,000 people (age-standardised rate of 640)
- hearing was 160 per 100,000 people
- speech was 110 per 100,000 people (Table S3.5).

Note age-standardised rates are not calculated where the number of deaths is not sufficient to meet reliability requirements.

People with psychosocial disability

Around 1 in 6 (1,447 deaths; 16%) of deaths in the study population were for people with a psychosocial disability, with a crude rate of 490 deaths per 100,000 people (see Table S3.4). The crude rate for males was 1.7 times as high as the rate for females (600 deaths per 100,000 people, compared with 360) (see Table S3.4).

3.3 Deaths by service type

Within the study population, 62% of people who died were receiving community support services (see Table S3.8)—the most utilised service after employment services (see Table S2.3). In comparison (noting that a person may use multiple services):

- 18% of people who died received residential accommodation support services
- 15% of people who died used other accommodation support services
- 9% of people who died received respite care support services
- 18% of people who died used community access services
- 22% of people who died used employment services only.

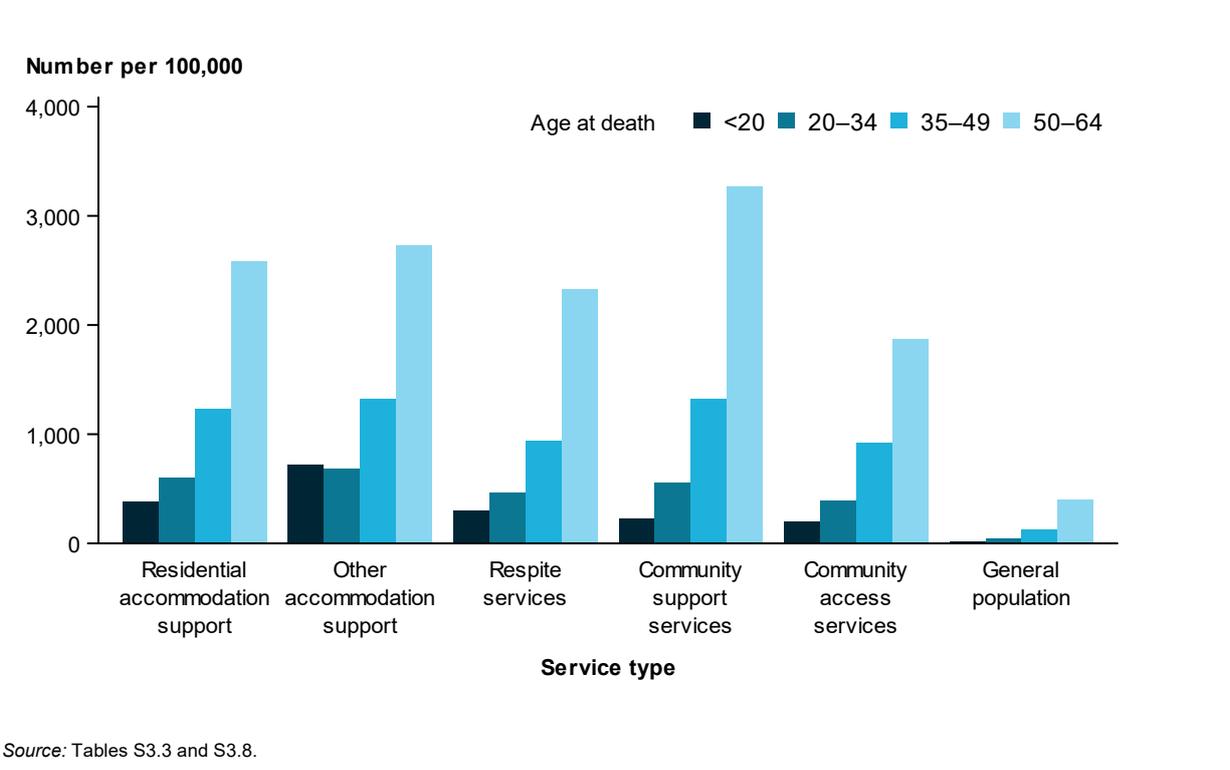
Crude mortality rates were higher for people with disability receiving residential accommodation support (1,300 deaths per 100,000 people) or other accommodation support (1,500) than for those receiving community support (940) and community access (790) services (see Table S3.7). Crude mortality rates were lower for people using respite services (680) and lowest for people using open employment services only (320).

Although males had a higher crude mortality rate overall when compared with females (660 per 100,000, compared with 630), there was some variation by service type. Within residential accommodation, respite care and community support services, the crude mortality rates were higher for females than males. Among those using other accommodation services, community access services and employment only services, the rates were higher for males (see Table S3.7).

Across all service types, people aged 50–64 had the highest mortality rates (see Figure 3.4). Among those aged 50–64, recipients of community support services had the highest mortality rate at 3,000 deaths per 100,000 people.

For people aged under 20, those who received other accommodation support services (720 deaths per 100,000 people) had the highest mortality rate, which was nearly twice as high as the next highest category—recipients of residential accommodation support services (380 deaths per 100,000 people).

Figure 3.4: Age-specific mortality rates for the study and general population, by service type, 2013–14 to 2017–18



3.4 Premature deaths

Premature deaths are deaths that occur at a younger age than a selected cut-off. This report uses potential years of life lost (PYLL) as a measure of the impact of premature death (see Box 1.2). PYLL are determined by the difference between age at death and an arbitrary cut-off (with the age of 75 generally used as a cut-off). In this study, this measure reflects the number of PYLL for people aged under 65, assuming that their potential life expectancy is 75 years.

The overall rate of PYLL from the 9,062 deaths observed in the study population was 180 PYLL per 1,000 persons, while the rate was 32 for the general population.

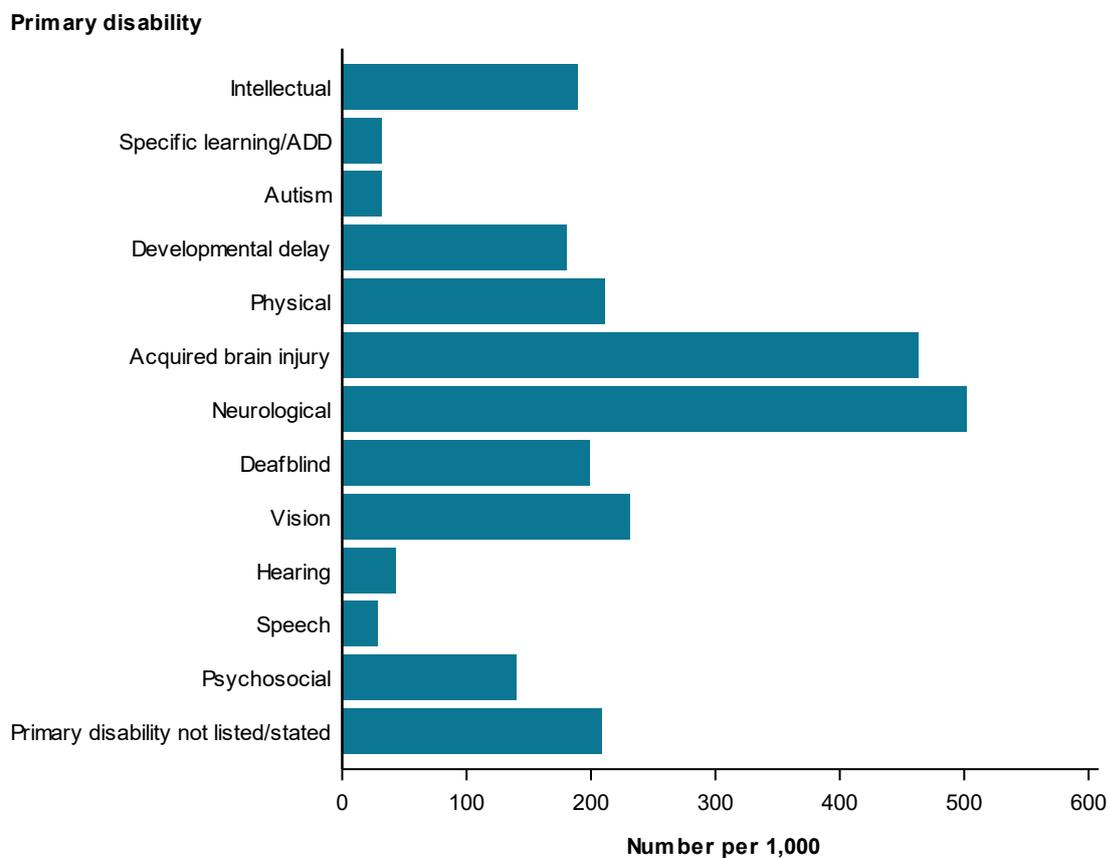
The rate of PYLL was slightly higher for males (190 PYLL per 1,000 population) than females (180) in the study population. These rates were higher than the equivalent rates for the general population (40 for males, 23 for females). Due to the higher rate of mortality and PYLL for males in the general population than for females, the mortality gap between the study and general populations was greater for females (155) than for males (145). When examining specific age groups in the study population, only females under age of 20 had a higher rate of PYLLs compared with males (see Table S3.3).

Premature deaths by primary disability

Service users with neurological disability had the highest crude rate of PYLL (at 500 PYLL per 1,000 people), followed by acquired brain injury (460). The next highest categories were vision (230), physical (210), deafblind (200) and intellectual (190), developmental delay (180) and psychosocial (140) disabilities. Rates of PYLLs were lowest for people with speech disability (28), specific learning disability or attention deficit disorders (32), autism (32), and hearing disability (44) (see Figure 3.5).

Although males had higher crude PYLL rates than females, the crude PYLL rates for people with intellectual, learning, sensory or speech primary disability were higher for females than males (see Figure 3.6).

Figure 3.5: Crude rate of PYLL for the study population, by disability type, 2013–14 to 2017–18



Source: Table S3.5.

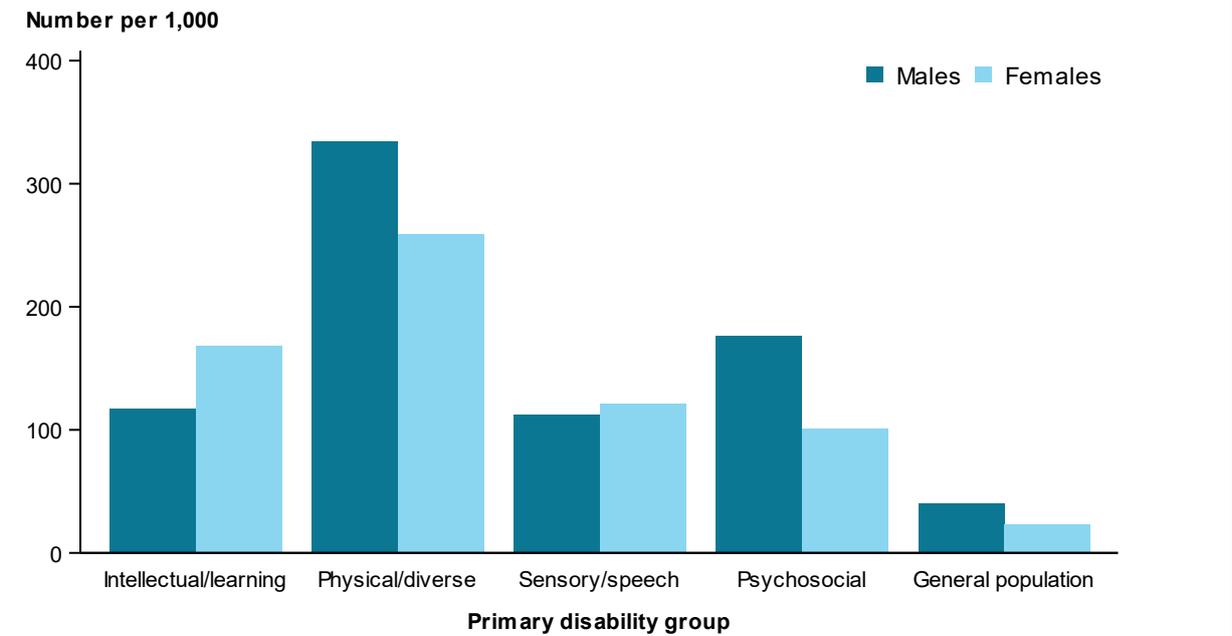
Premature deaths by service type

Recipients of other accommodation support services had the highest PYLL crude rate (420 PYLL per 1,000 people, see Table S3.7), with recipients of residential accommodation support services having the second highest (350).

Rates of PYLL were similar for respite service users (240 PYLL per 1,000 people), community support (280) and community access (230). The rate of PYLLs was lowest for people using only employment services at 86 PYLL per 1,000 people overall.

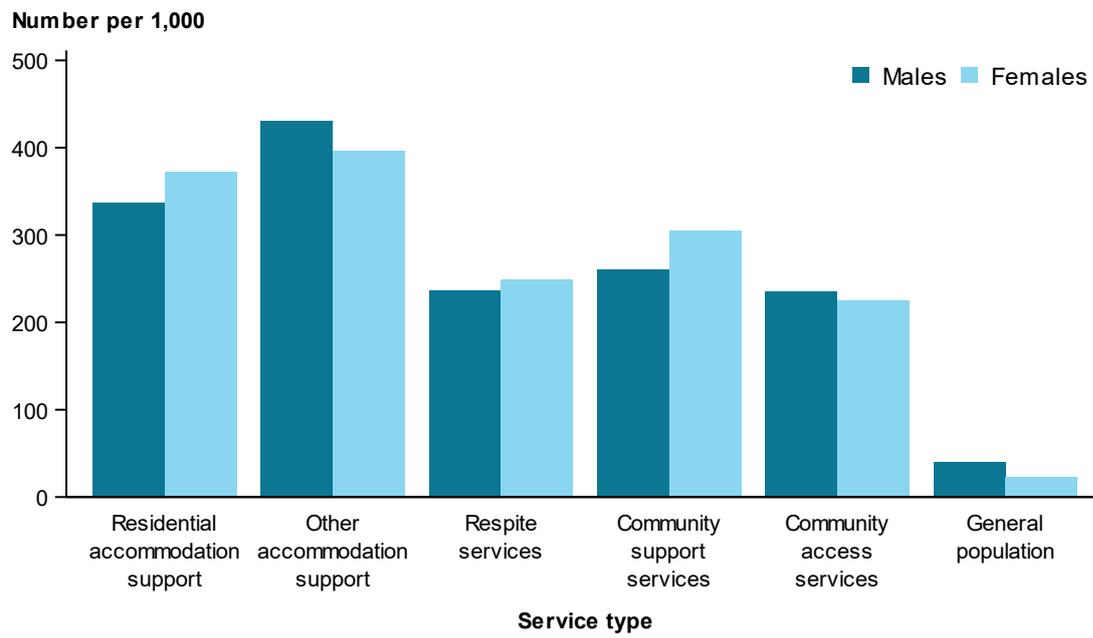
Similar to the mortality rates by service types, the PYLL crude rate was higher for males overall (190 PYLL per 1,000 people) than females (180, see Table S3.7), however females using residential accommodation support, respite and community support services had a higher crude rate of PYLL than males (see Figure 3.7).

Figure 3.6: Crude rate of PYLL for the study and general population, by primary disability group and sex, 2013–14 to 2017–18



Source: Tables S3.4 and S3.5.

Figure 3.7: Crude rate of PYLL for the study and general population, by sex and service type, 2013–14 to 2017–18



Source: Tables S3.3 and S3.7.

4 Leading causes of death

This chapter examines the leading causes of death for the study population. The term leading cause of death refers to the most commonly recorded cause of death for a population group, and is presented as a ranking from most common, to least common.

Between 2013–14 and 2017–18, the 3 most common ‘underlying causes of death’ among the study population were perinatal and congenital conditions (6.3% of deaths), spinal muscular atrophy (5.9%) and coronary heart disease (5.7%) (see Figure 4.1). These conditions in particular are commonly seen among the intellectual or learning and physical or diverse primary disability groups, explored in greater detail in this chapter.

A limitation of this study is that a health condition relating to a person’s disability can be coded as the underlying cause of death if it potentially led to another condition or event that caused the death. This can mask other causes of death that might be potentially avoidable, as well as reducing comparability with the general population. See Appendix D for further detail.

4.1 Commonalities between study and general populations

When broken down by age, the top 2 leading causes of death were similar for the study and general populations; perinatal and congenital conditions (most common among <20), suicide (most common among 20–34) and coronary heart disease (1st and 2nd leading cause of death among 50–64). For each of these causes of death, the study population had a higher rate of occurrence than the general population.

Certain causes of death for the study population—cerebral palsy, selected metabolic disorders and epilepsy—appeared in the leading 5 causes in several age and sex groups in the study population (they were a leading cause for people below age 50. See Table S4.1) but were not in the leading 10 causes in the general population.

Figure 4.1: Leading 5 causes of death for the study and general population, based on underlying causes of death, by age at death 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%	Spinal muscular atrophy 4.6%	Cerebral palsy & related 4.6%
50–64	Spinal muscular atrophy 8.1%	Coronary heart disease 7.9%	Perinatal & congenital 5.1%	Brain cancer 4.5%	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

4.2 Age and sex

For those aged under 20, the 3 leading causes of death in the study population were the same for males and females (perinatal and congenital, cerebral palsy, metabolic disorders) (see Table S4.1).

For those aged below 35, there were more similarities in the most commonly occurring causes of death between males and females.

The top leading causes accounted for a lower proportion of observed deaths in the older age groups of the study population—for people aged under 20, the 10 leading causes of death accounted for 67% of all deaths, while the 10 leading causes accounted for 46% of deaths for those aged 50–64 (see Table S4.1).

4.3 Type of disability

People with intellectual or learning disability

For people with intellectual or learning primary disability, the leading underlying causes of death were consistent across age groups; they included perinatal and congenital conditions (17%), cerebral palsy (8.7%), epilepsy (6.4%), coronary heart disease (3.9%), influenza and pneumonia (3.4%) (see Figure 4.2 and Table S4.3).

When broken down by specific disability types, the leading cause of death for people with:

- intellectual disability was perinatal and congenital conditions (18%), followed by cerebral palsy (9.4%) and epilepsy (6.5%)
- specific learning or attention deficit disorder was suicide, followed by land transport accidents and accidental poisoning. However, these data should be interpreted with caution due to small cell sizes
- autism was epilepsy (10%), followed by influenza and pneumonia (7.0%), suicide (6.0%) and cerebral palsy (6.0%)
- developmental delay was perinatal and congenital conditions, followed by selected metabolic disorders and other nervous system conditions (see Figure 4.3).

People with physical or diverse disability

For people with physical or diverse primary disability, spinal muscular atrophy (12% of deaths), coronary heart disease (5.7%), brain cancer (5.6%), demyelinating diseases of the central nervous system (4.9%) and cerebral palsy and other paralytic syndromes (4.0%) were leading underlying causes overall (see Figure 4.2 and Table S4.3). These were more commonly seen in older age groups.

When broken down by specific disability type, 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%) (see Figure 4.3).

For people with physical or diverse primary disability under age 20, the 3 most common causes of death were perinatal and congenital conditions (20% of deaths), cerebral palsy and other paralytic syndromes (20%) and metabolic disorders (11%) (see Table S4.2). These were the same 3 leading causes for people under age 20 with an intellectual or learning primary disability.

People with sensory or speech or psychosocial disability

In contrast to the intellectual or learning and physical or diverse disability groups, there were fewer health conditions relating to disability among the leading causes of death for people with sensory or speech, or psychosocial primary disability.

For people with sensory or speech primary disability, the leading causes of death were diabetes (10% of deaths), coronary heart disease (9.8%), brain cancer (7.2%), cerebrovascular disease (4.1%) and lung cancer (3.6%) (see Table S4.3).

When broken down by specific disability type, the leading causes of death for people with:

- vision disability were diabetes (13%), coronary heart disease (9.6%) and brain cancer (8.6%)
- hearing disability were coronary heart disease, suicide and cerebrovascular disease (see Figure 4.3).

There were no leading causes of death for people with deafblind or speech disability due to small counts. See Table S4.2 for the list of deaths for each disability type.

Figure 4.2: 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 ^(a)	Suicide	Brain cancer	Diabetes	Benign neoplasms	Neoplasms of mesothelial and soft tissue
35–49 ^(a)	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.

Figure 4.3: Leading 5 causes of death for the study population based on underlying causes of death, by primary disability type, 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 ^(a)	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 ^(a)	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 ^(a)	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 reliable 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.

Suicide was a leading cause of death for people with psychosocial primary disability for all adult age groups, though the rate decreased with age—there were 118 deaths to suicide per 100,000 people for those aged 20–34 compared with 86 for those aged 50–64 (see Table S4.3).

Overall, among the study population suicide accounted for 21% of deaths under age 65. Accidental poisoning (14% of deaths), coronary heart disease (8.4%) and liver disease (4.8%) were the next leading causes of death (see Figure 4.3).

4.4 Leading causes by service types

The top leading causes of death were consistent among the services types except for employment services, appearing as a combination of perinatal and congenital conditions;

cerebral palsy, epilepsy, spinal muscular atrophy, coronary heart disease and cerebrovascular disease. The leading causes for people using employment services were suicide (13%), coronary heart disease (10%) and accidental poisoning (9.9%) (see Figure 4.4).

For people aged under 20, the leading 2 causes of death in each service type (except employment only) were perinatal and congenital conditions, and cerebral palsy. The leading cause of death for people aged 50–64 using other accommodation support, respite care support and/or community support services was spinal muscular atrophy.

For people using residential accommodation support services, the leading causes of death were congenital and perinatal conditions (16% of deaths), cerebral palsy (12%) and epilepsy (5.7%). Congenital and perinatal conditions, alongside cerebral palsy, were among the top 3 conditions in all 4 age groups in Table S4.4.

Figure 4.4: Leading 10 causes of death for the study population based on underlying causes of death, by service type, 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.

5 Potentially avoidable deaths

PADs are defined as deaths among people younger than 75 that are considered to be potentially avoidable within the present health-care system. The PADs measure was designed, and is used, to measure the effectiveness of the overall health system in Australia. It includes deaths from conditions and events that are recognised to be potentially preventable through individualised care and/or treatable through existing primary or hospital care. It does not indicate that these deaths have individually been assessed as avoidable.

Examples of causes of deaths considered to be potentially avoidable include perinatal conditions, accidental poisoning and ischaemic heart disease (listed as coronary heart disease in leading cause figures and tables), whereas congenital abnormalities, epilepsy and brain cancer are not. In this study, excluding people aged over 65 means that all deaths for the defined conditions and events will contribute to the potentially avoidable counts and rates in this report. This may result in higher rates of PADs when compared with studies that include deaths after age 75.

A range of factors can affect the risk of mortality for causes of death considered to be potentially avoidable. Thus, rates of PADs are affected by factors outside of the overall health system and available care.

This section looks at the rate of PADs for people aged under 65 (crude, age-standardised and age-specific).

The crude rate of PADs for the study population was 240 PADs per 100,000 people (see Table S5.1), compared with 64 for the general population (age-standardised rates of 220 and 64, respectively).

The study population had a higher age-specific rate of PADs in each sex and age category relative to the same group in general population (around 3 times as high for males, and between 4 and 6-times as high for females; see Table S5.1).

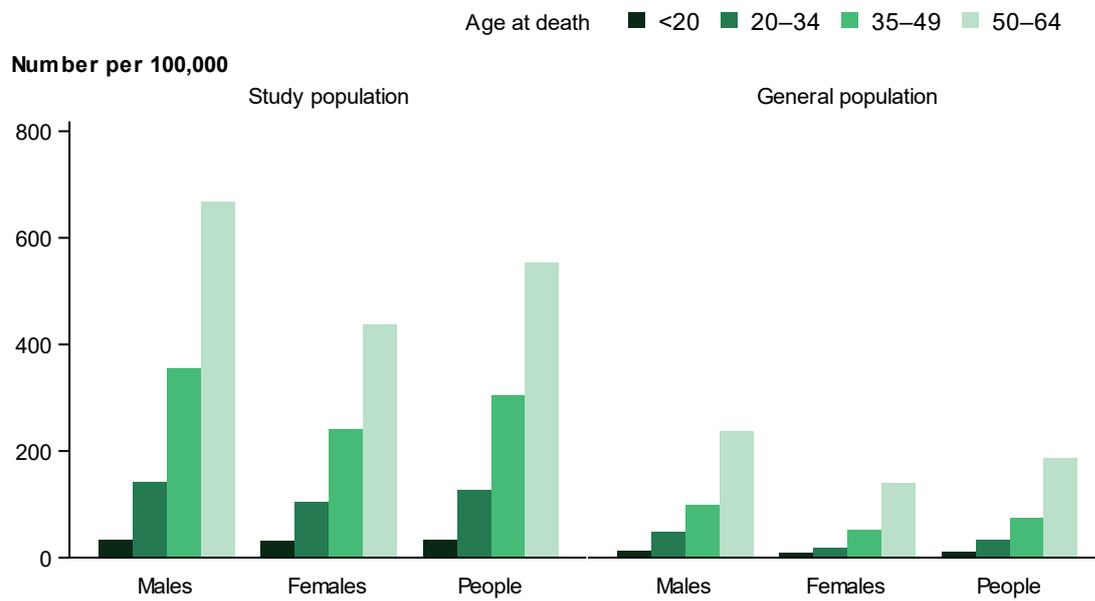
The leading potentially avoidable cause of death in the study population was coronary heart disease, followed by suicide. These 2 PADs were also the top 2 PADs among the general population.

5.1 Age and sex

The crude rates of PADs were higher for males than females. Among males in the study population there were 260 PADs per 100,000 people, compared with 220 for females. Once the difference in age structures are considered, males had a rate 1.5 times that of females. In the general population, there were 88 PADs per 100,000 people for males, compared with 39 for females (see Table S5.1). Once the difference in age structures is considered, males in the general population had a rate 1.9 times that of females.

However, there was variation among the sexes by age. For those in the study aged under 20, the rate of PADs was similar for males and females. After this age, the rate of PADs increased at a greater rate for males than females (see Figure 5.1).

Figure 5.1: Crude rates of PADs for the study and general population, by sex and age group, 2013–14 to 2017–18

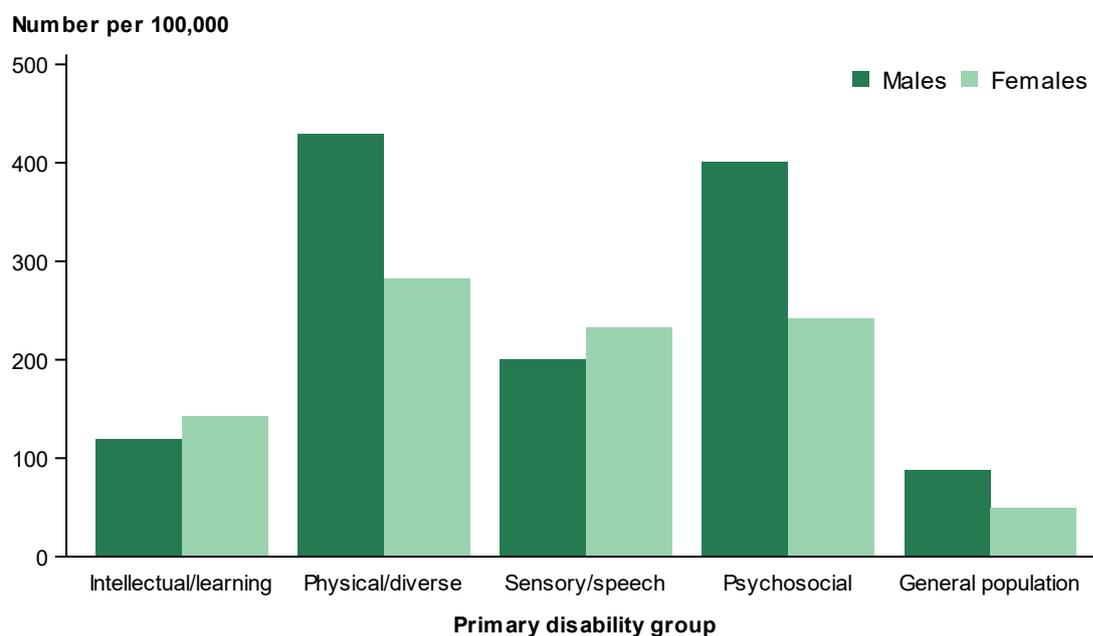


Source: Table S5.1.

5.2 Type of disability

The crude rate of PADs was highest for the people with physical or diverse (360 per 100,000 people) and psychosocial (320) primary disability; by comparison, the crude rate was 210 for people with sensory or speech primary disability and 130 for people with intellectual or learning primary disability (see Table S5.3). Within each of these groups, there were variations in the crude rates by sex (see Figure 5.2) and disability type (see Figure 5.3).

Figure 5.2: Crude rate of PADs for the study and general population, by primary disability group and sex, 2013–14 to 2017–18



Source: Table S5.1 and S5.2.

People with intellectual or learning disability

The crude rate of PADs was 130 per 100,000 people with intellectual or learning primary disability in the study population, with an age-standardised rate of 200 per 100,000. The crude rates of PADs for people with intellectual or learning disability were higher for females (140 PADs per 100,000 people) than males (120), however after adjusting for differences in age rate was higher for males (200) than females (180).

There was variation in the rate of PADs by specific primary disability types. The crude PADs rate for people with:

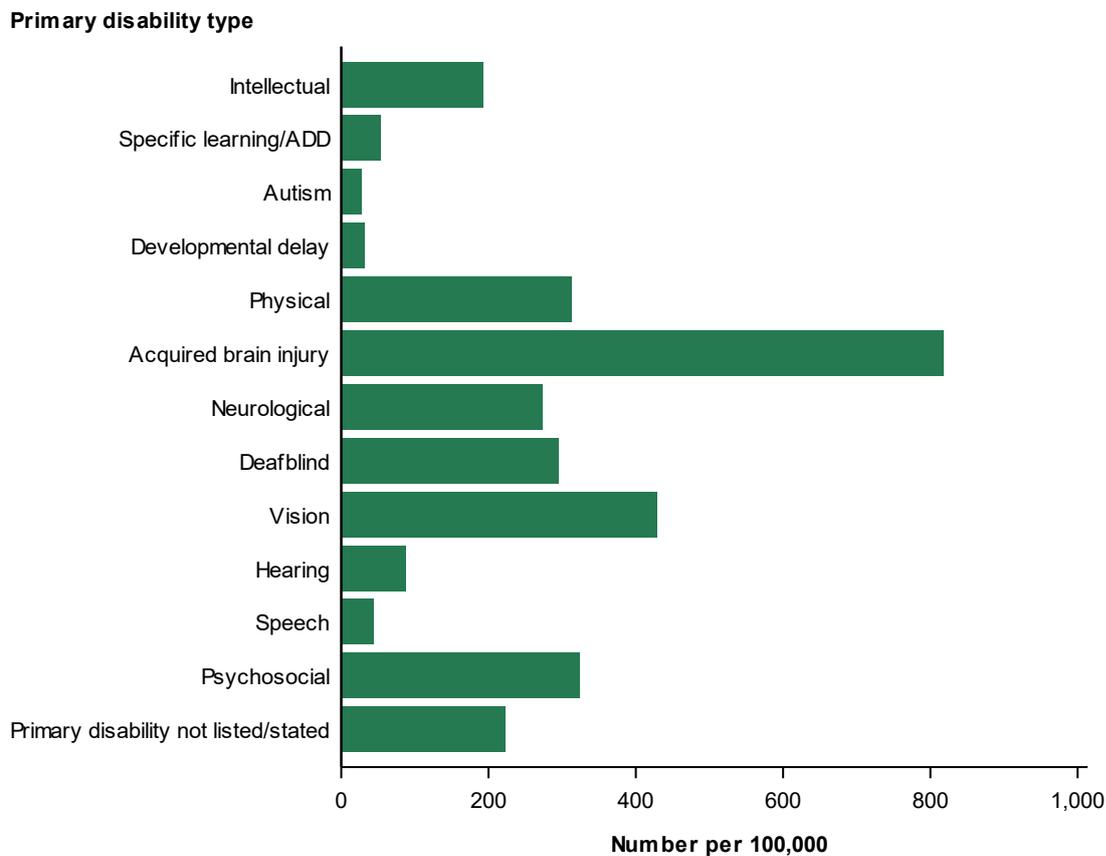
- intellectual disability was 190 per 100,000 people (age-standardised rate of 210)
- specific learning or attention deficit disorder was 54 per 100,000
- developmental delay was 33 per 100,000
- autism was 28 per 100,000 (age-standardised rate of 93) (Figure 5.3 and Table S5.3).

Note age-standardised rates are not calculated where the number of deaths is not sufficient to meet reliability requirements.

People with physical or diverse disability

The crude rate of PADs for people with a physical or diverse disability was 360 per 100,000 people, with an age-standardised rate of 240 per 100,000. The crude rates of PADs for people with physical or diverse disability were higher for males (430 PADs per 100,000 people) than females (280) and remained so after age standardisation (290 vs 190).

Figure 5.3: Crude rate of PADs for the study population, by primary disability type, 2013–14 to 2017–18



Source: Table S5.3.

When broken down by specific disability type, the crude rate of PADs for people with:

- acquired brain injury was 820 per 100,000 people (age-standardised rate of 520)
- physical disability was 310 per 100,000 people (age-standardised rate of 210)
- neurological was 270 per 100,000 people (age-standardised rate of 200) (Figure 5.3 and Table S5.3).

People with sensory or speech disability

The crude rate of PADs for people with a sensory or speech disability was 210 per 100,000 people, with an age-standardised rate of 180 per 100,000. The crude rates of PADs for people with sensory or speech disability were higher for females (230 PADs per 100,000 people) than males (200), however once age-standardised the rates were higher for males (180) than females (170).

When broken down by specific disability type, the crude rate of PADs for people with a primary disability of:

- vision was 430 per 100,000 people (age-standardised rate of 300)
- deafblind was 300 per 100,000 people

- hearing was 88 per 100,000 people
- speech was 44 per 100,000 people (Figure 5.3 and Table S5.3).

Note age-standardised rates are not calculated where the number of deaths is not sufficient to meet reliability requirements.

People with psychosocial disability

The crude rate of PADs for people with psychosocial disability was 320 per 100,000 people, with an age-standardised rate of 230 per 100,000 (Figure 5.3 and Table S5.3).

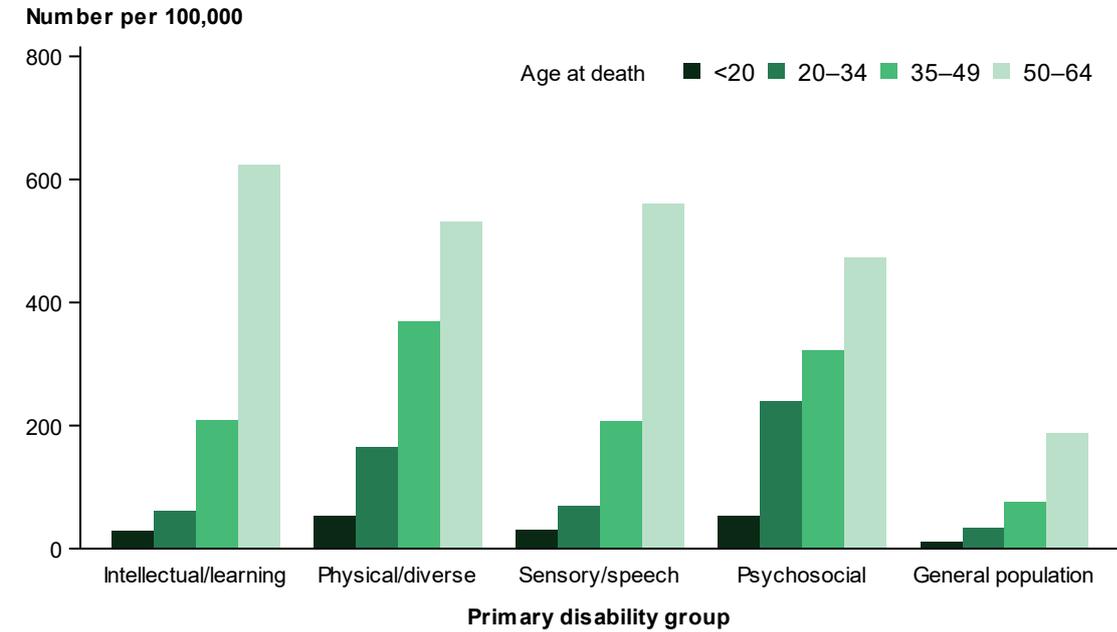
The crude rates of PADs for people with psychosocial disability were higher for males (400 PADs per 100,000 people) than females (240). After age was taken into account, the rate remained higher for males (290) than females (170).

Disability group and age

The relationship between age and PADs was not the same for all people with disability—as shown in Figure 5.4:

- People with physical or diverse, or psychosocial disability had higher rates of PADs below the age of 50 compared with the intellectual or learning and sensory speech groups.
- The rate of PADs increased the most for the intellectual or learning and sensory or speech groups when comparing 50–64 with 35–49 year old groups.
- For people aged 20–34, those with psychosocial disability had the highest rate of PADs (240 PAD per 100,000 people) despite having a lower mortality rate than people with physical or diverse disability.
- For people aged 50–64, those with intellectual or learning (620 PADs per 100,000 people) or sensory or speech (560) primary disability had the highest rate of PADs.

Figure 5.4: Age-specific rate of PADs for the study and general population, by primary disability group and age at death, 2013–14 to 2017–18



Source: Tables S5.1 and S5.4.

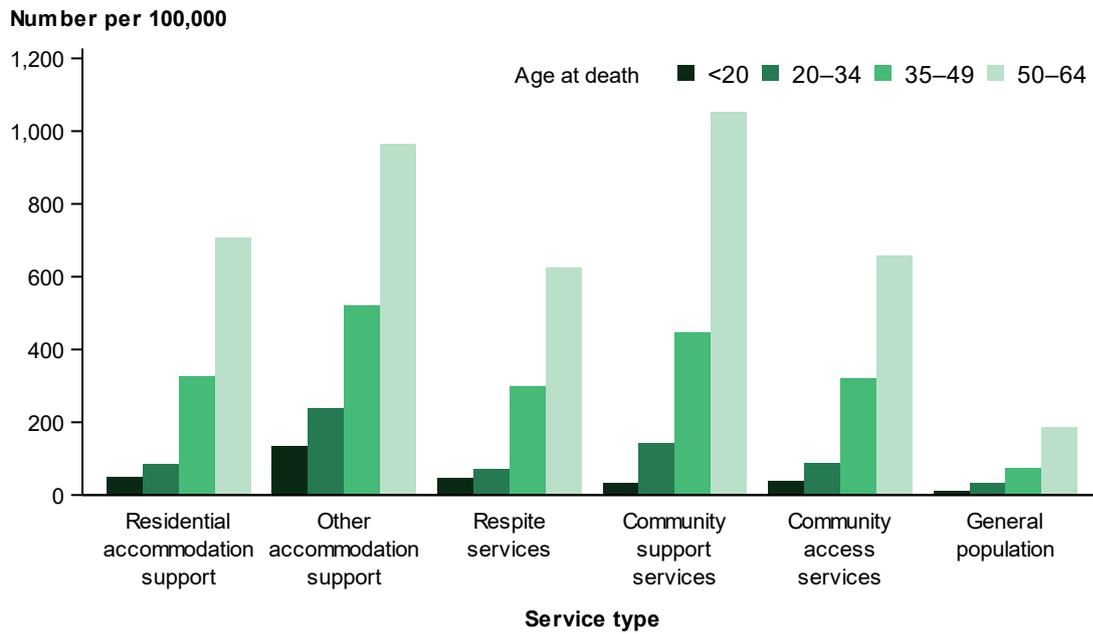
5.3 Potentially avoidable deaths by service types

People who received other accommodation support services had the highest crude rate of PADs (540 per 100,000 people), followed by people receiving residential accommodation services (310). Respite care support had the lowest rate at 160 PADs per 100,000 people, with community support (280) and community access (250) close to the study population average (240) (see Table S5.5). As seen in Figure 5.5, the groups with highest overall rate of PADs did not always have the highest age-specific mortality rates—age-specific rates of PADs were highest for the other accommodation support and community support services.

Males had higher crude rates of PADs than females for residential accommodation support (330 and 290 PADs per 100,000 people, respectively), other accommodation support (570 and 490, respectively) or community access services (260 and 240, respectively), but the rate of PADs was higher for females than males for respite care (180 and 150, respectively) or community support services (290 and 280, respectively) (see Figure 5.6). However, once age is taken into account, the rate of PADs are higher for males in both respite care and community support services (270 compared with 200, and 400 compared with 290, respectively for each service type).

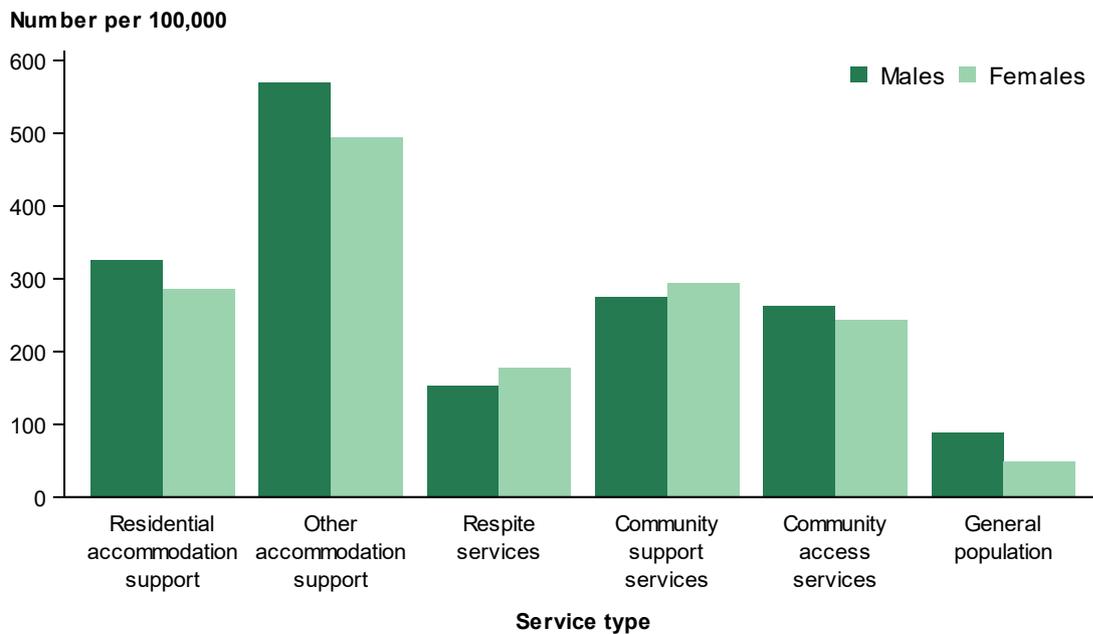
Across all categories, the highest rate of PADs was seen in people aged 50–64 (see Figure 5.5). Of those aged 50–64, community support users had the highest rate of PADs at 1,000 per 100,000 people. For those under age 50, other accommodation support users had the highest age-specific rate of PADs.

Figure 5.5: Age-specific rate of PADs for the study and general population, by service type and age at death, 2013–14 to 2017–18



Source: Tables S5.1 and S5.6.

Figure 5.6: Crude rate of PADs for the study and general populations, by service type and sex, 2013–14 to 2017–18



Source: Tables S5.5 and S5.1.

6 Conclusion

The technical report, and the accompanying summary report, are the first Australian national reports on mortality among people who use disability support services. 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 for 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.

Appendix A: Data sources

Disability Services National Minimum Data Set

Up until 30 June 2019, the AIHW's Disability Services National Minimum Data Set (DS NMDS) was a source of information about people who used National Disability Agreement (NDA) funded disability services. The last financial year for which data were collected under the DS NMDS was 2018–19. Under the NDA, the Australian Government was responsible for providing employment services for people with disability, and the states and territories for providing all other services.

The DS NMDS included information on more than 30 individual service types, which could be grouped into broad service types. A service user may use more than 1 type of service within each of these groups. Please refer to [Disability support services: services provided under the National Disability Agreement 2017–18](#) for more information on services provided under the NDA. See Table S2.3 for the counts of service types used by the study population (see Appendix C for inclusion criteria of the study population).

The AIHW's DS NMDS was an annual collection of a standard set of data items. Analysis of this data set involved grouping all records pertaining to an individual and then determining that individual's service use for each financial year. Grouping multiple records for an individual relied on statistical linkage (see Appendix B for details). These grouped data could then be used to estimate counts of service users.

Between 1 July 2013 and 30 June 2018, about 595,585 people used disability support services funded under the NDA. Of these, 567,245 people were aged under 65.

Most, but not all, people using NDA-funded services captured under the DS NMDS are expected to join the National Disability Insurance Scheme (NDIS), depending on their need and eligibility to receive disability services through the NDIS. The NDIS provides support services for people with a 'permanent and significant' disability under the age of 65 on entry. Therefore, service users aged 65 and over in the DS NMDS are unlikely to move to the NDIS and may instead be supported by the aged care system. Statistical outputs in this analysis are restricted to data for people aged under 65 unless noted in this report.

Open employment services (Disability Employment Services)—namely Australian Government services provided under the NDA and collected as part of the DS NMDS—will not be rolled into the NDIS (unlike the Australian Government's supported employment services, which will be).

See [Disability Services National Minimum Data Set 2018-19; Quality Statement](#) for further details.

Medicare Consumer Directory

In administering Medicare, Services Australia collects personal information from customers at the time of their enrolment and amends this information to reflect changes in their circumstances. This database is referred to as the Medicare Consumer Directory (MCD). Records must link to the MCD for inclusion in this project. The MCD also supplied information on sex and age for all records recorded as a death in the National Death Index (NDI) between 1 July 2013 and 30 June 2018.

National Death Index

The NDI, a database held at the AIHW, is a register of all deaths that have occurred in Australia since 1980. It contains cause of death, classified according to the International Statistical Classification of Diseases and Related Health Problems (ICD) (since 1997, this has been using the 10th Revision, ICD-10), and identifying information (date of birth, name, sex, date of death and postcode).

The AIHW obtains the data from the Registrars of Births, Deaths and Marriages in each state and territory, together with cause of death data coded by the ABS and provided annually. See [National Death Index \(NDI\)](#), [Data Quality Statement](#) for further details.

Appendix B: Linkage methodology

Maintaining privacy

The Data Integration Service Centre at the AIHW carried out all data linking—one of a handful of accredited Commonwealth Integrating Authorities. This accreditation requires the AIHW to adhere to stringent criteria and abide by the National Statistical Service High Level Principles for Data Integration involving Commonwealth data for Statistical and Research Purposes, and best practice guidelines. As well as operating within these guidelines, data linkage at the AIHW is carried out under the protections of the *Privacy Act 1988*, and the *Australian Institute of Health and Welfare Act 1987* (which carries additional privacy protections for companies and deceased people).

Strict separation of identifiable information and content data is maintained within the Data Integration Service Centre in accordance with the AIHW linkage protocols, so that no one person will ever have access to both. Summary results from the linked data set are presented in aggregate format. Personal identifying information was not used, and no individual can be identified in any reporting. The linked data set created for this study will be stored securely on site at the AIHW for 7 years in keeping with the *Commonwealth Archives Act 1983*.

Data linkage

Data linkage, also known as data integration, is a process that brings together information relating to an individual from more than 1 source. This report used linkage between 3 data sets:

- Disability Service National Minimum Dataset (DS NMDS)
- Medicare Consumer Directory (MCD)
- National Death Index (NDI)

Full-name data were available for both the MCD and the NDI; however, only statistical linkage key (SLK) data were available for the DS NMDS. The data sets were linked to the MCD using a name-based linkage map for the NDI and SLK for the DS NMDS. The MCD was used as an intermediate linkage file, providing pointers for the linkage between the DS NMDS and the NDI. Use of the MCD enabled improved match rates given that it contains changes in names and address information for a person over time.

An SLK is an alphanumeric code that attempts to identify people for linkage purposes. It consists of a concatenation of 5 letters of name, date of birth (represented as 8 digits) and sex. This combination of components results in a high level of uniqueness for an individual's records; therefore, it is possible to count people without the individual's identity being disclosed. In the small number of cases, where different people have the same SLK, the postcode of the client was used as an additional match variable.

An SLK is generally derived at the source of the data and therefore can be provided with a data set without the individual's identity being disclosed. This method is often used where 1 or more of the linked data sets do not contain directly identifiable information, such as names and addresses, to allow record matching. In this case, directly identifiable information was not available for records in the DS NMDS. Due to the information recorded for individuals potentially being different in the different data sets, derived SLKs may result in record match rates that are lower than those using directly identifying information.

A total of 2,162,191 records were received for linkage from the DS NMDS. There was no person level identifier on the data set. Therefore, every record was treated independently and linked to the MCD.

Overall, a total of 2,073,140 DS NMDS records (95.9%) linked to the MCD using the multi-step key-based linkage (KBL) approach. A project–person number (PPN) was generated for each set of records that linked to an MCD record, or for each unique SLK combination for records that did not link.

A total of 89,051 records (approximately 4%) remained unlinked to the MCD. Of the 4% unlinked, over half were either records with a 1 January date of birth (often recorded when date of birth is unknown) or had missing SLK name information. Therefore, of the unlinked records, there was a skew towards poorer quality data, and hence why these records remained unlinked to the MCD.

The use of the MCD in linkage gave a greater certainty of the uniqueness of individuals compared with the estimates for individuals presented in the Disability support services report (AIHW 2019b) (see Appendix A for notes on grouping records for an individual). The use of the MCD resulted in a lower estimate of the number of service users (276,963 service users in 2017–18) compared to the Disability support services report (280,274), which did not use the MCD (AIHW 2019b).

Of the 276,963 service users, 12,684 records could not be linked to the MCD due to incorrect or incomplete data.

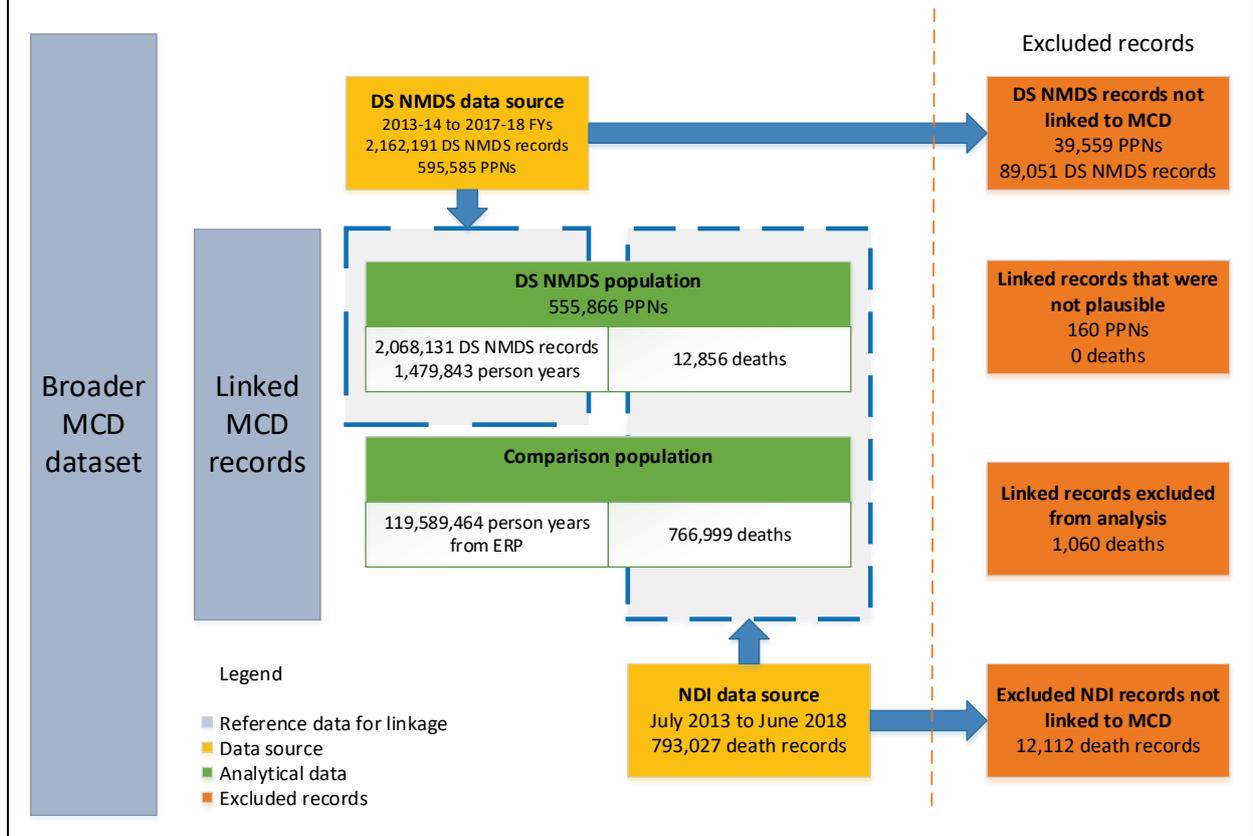
Figure B.1 outlines the data linkage flow and counts for the project.

Data quality checks

Before analysis, the AIHW undertook data validation and data quality checks with the DS NMDS–NDI linked data set. Data cleaning tasks included:

- de-duplicating data sets into single-row-per-person-year tables
- applying the original processing rules for both disability services and cause of deaths data. Where modifications were required, the code was checked for consistency with original data reporting
- cross-comparing the 2 data sets to exclude records and data that were not compatible
- conducting sensitivity and specificity checks on the linkage results. Results showed good results for sources known to have accurate and complete information. Review of linkage for records without accurate or complete information suggests sufficient counts were included to not bias results
- comparing with external data sources to examine the integrity of data, including unlinked source data sets and comparable projects.

Figure B.1: Results of data linkage of the DS NMDS with the MCD and NDI and data quality checks. Person counts reflect all individuals in the source data sets.



Appendix C: Identification of populations

Study population

The study population included all disability service users under the age of 65 who are recorded in the Disability Service National Minimum Dataset (DS NMDS) and linked to the Medicare Consumer Directory (MCD). This population is used as the denominator to calculate death rates. Disability service users recorded as a death in the National Death Index (NDI) between 1 July 2013 and 30 June 2018 are the focus of mortality outcome measurements presented throughout this report. There were 555,866 disability service users between 1 July 2013 and 30 June 2018 who were linked to the MCD. Of these, 526,515 were under the age of 65, of whom 9,062 (1.7%) died during the time they were receiving disability support services.

Death records linked to the study population are analysed according to the service user's characteristics (such as primary disability and service use) in the financial year of service to keep it aligned with reporting from the DS NMDS. For people who died after their end date of service in the DS NMDS, an inclusion criterion of 30 days was used so that deaths following short-term hospitalisation are analysed with other users of the same services. A total of 136 additional records were included using this criterion. Except for users transitioning to National Disability Insurance Scheme (NDIS) services, deaths of former service users are included in analysis for the general population.

Around 150 users were excluded from the study population because the service was recorded as having been provided for the first time after the date of death. As well, 1,060 deaths for users were excluded because the service provision had transitioned to the NDIS.

Some services provided under the National Disability Agreement (NDA) are short term and/or not dependent on the disability classification, or are provided before a person's disability type can be determined. Service providers and recipients are not required to submit information relating to disability in some of these circumstances. Between 11,000 and 14,000 service users only used these services and/or did not have a primary disability listed in each year of analysis (see Table S2.2) and thus account for around 4% of the study population. This includes service users who use only recreation/holiday programs (service type 3.02), a service type that is not required to complete this data item. A high proportion of the remaining people with missing disability information are children (below age of 6) who used early childhood intervention services (service type 2.02), which are specific for children with developmental delay.

Additionally, service users that use only open employment services will not transition to the NDIS (see Section 5 for more information). Both people without a listed disability and recipients of disability employment services are included in the analysis.

General population (comparison population)

In this report, the general population is the Australian population under age 65, less disability service users who were included/counted within the DS NMDS. Death rates between 2013 and 2018 were calculated using data from the NDI.

The population used as the denominator to calculate death rates was the Australian Bureau of Statistics (ABS) estimated resident population estimates as at 30 June for each year from 2013 to 2018, less all disability service users who were recorded within the DS NMDS for each year within the study period. The ABS derives these estimated resident population estimates from its Census of Population and Housing, and adjusts them for deaths, births and net migration.

Appendix D: Technical notes

Caveats of this analysis

In interpreting the results of this study, it is important to bear in mind the following factors that limited the degree of analysis that could be undertaken, while recognising that this is a 'ground-breaking piece of analysis'.

Transition to the National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) was launched in trial sites from 1 July 2013, with progressive roll-out to the full scheme from 1 July 2016. Most National Disability Agreement (NDA) service users are expected to transition to the NDIS (depending on their need and eligibility) and hence exit the Disability Service National Minimum Dataset (DS NMDS) collection over time. This affects data from 2013–14 onwards. Some service type outlets may also be less responsive because of complexities associated with the changeover to the NDIS. See [Disability Services National Minimum Data Set 2017–18; Quality Statement](#) for further details.

Due to the gradual transition of service provision from the NDA to the NDIS, the profile of the NDA service population varied over the years of the study. Some changes in the population from 2013–14 to 2017–18 were:

- a higher proportion of older service users in later years, with a median age of 30 in the 2013–14 data and 35 in 2017–18.
- a small decrease in proportion of males, from 60% of service recipients being male in 2013–14 to 58% in 2017–18.
- a decrease in the proportion of people with intellectual or learning primary disabilities: from 42% in 2013–14 to 35% in 2017–18.
- an increase in the proportion of people with physical or diverse disability, from 26% to 30%.
- an increase in the proportion of people with psychosocial disability, from 19% to 24%.

In comparison, the median age group for the general population was approximately 32 years of age and the population was 50% male across each year of analysis.

Variance across years and jurisdictions

Service type outlet and service user participation rates, as well as the response rates to various data items, vary across years and jurisdictions. See [Disability Services National Minimum Data Set 2017–18; Quality Statement](#) for further details.

Statistical linkage keys

As with all collections that use a statistical linkage key (SLK) to identify service users, a small degree of misidentification is expected. There is a small possibility that some of the linked records do not belong to the same individual, and, conversely, that some matching records do not belong to the same individual.

DS NMDS records that did not link to the Medicare Consumer Directory (MCD) were excluded from the analysis as it is unknown if there were National Death Index (NDI) records

for these. As half of these DS NMDS records had name or date of birth information for the SLK, it is likely that some belong to individuals that linked for other records. It is also possible that a small number of NDI records that should have matched to DS NMDS records will therefore contribute towards mortality counts for the general population.

Using the MCD as the basis for estimating counts of distinct users within the DS NMDS improves accuracy compared with the method used for the Disability support services report (AIHW 2019b). The Disability support services report is expected to be an over count of service users, while this report is more likely to be a slight undercount.

In interpreting the results of this study, it is important to bear in mind the following limitations in relation to the NDI.

Revisions of the cause of death information

The NDI is updated monthly except for cause of death information, which is usually updated annually, with new information supplied by the Australian Coordinating Registry (for the Registrars of Births, Deaths and Marriages) and the National Coronial Information System, after coding by the ABS.

The first release of the coded causes of death is referred to as the 'preliminary' version. In this version, deaths that were reported to the coroner but remain as an open case usually have a non-specific cause (unknown) cause of death.

Following the release of the preliminary cause of death data, the cause of death for coroner-certified deaths is revised to ascertain a more specific cause of death for any subsequently closed coroner cases. This revision results in a 'revised' version of the cause of death data. The same process occurs again to produce a 'final' version of cause of death data.

Aspects of these processes that can influence the accuracy and timeliness of data are that only coroner-certified deaths are subject to revision. Deaths are reported to a coroner under the following circumstances (which varies by jurisdiction):

- the death is unexpected, and the cause is unknown
- the person died in an unnatural or violent manner
- the death occurred during or as a result of an anaesthetic
- the death occurred to a person being 'held in care' or custody immediately before they died
- the identity of the person is unknown.

Overshadowing of the true underlying cause of death for people with disability

Previous research has identified concerns in cases where deaths are attributed to the aetiology or the cause of the intellectual disability, and therefore the true underlying cause of death could be overshadowed (Trollor et al. 2016).

This report uses the underlying cause of death listed on Medical Certificate of Cause of Death and the death codes were not revised to take into account the aetiology of the service user's disability condition.

Potentially avoidable death calculation

The AIHW calculates potentially avoidable deaths using the definition set by the National Healthcare Agreement. For more information, see the [METeOR specification](#). The indicator definition may not help identify specific 'potentially avoidable deaths' in the context of disability services.

Information about other factors that may place service users at greater risk of death

Salomon & Trollor's (2019) scoping review examined risk factors such as intensity of service provision, service user's level of functioning (particularly with respect to mobility and communication), co-occurring physical and mental health conditions, weight, body mass index, smoking status, levels of physical activity, nutrition, swallowing and mealtime support, vaccination status and other preventative health actions (for example, health checks). Except for basic information on a service user's level of functioning, this information was not available from the administrative data used for this report.

Abbreviations

ABS	Australian Bureau of Statistics
ADD	Attention deficit disorder
AIHW	Australian Institute of Health and Welfare
DS NMDS	Disability Services National Minimum Data Set
KBL	Key Based Linkage
MCD	Medicare Consumer Directory
NDA	National Disability Agreement
NDI	National Death Index
NDIS	National Disability Insurance Scheme
PAD	potentially avoidable death
PPN	project–person number
PYLL	potential years of life lost
SLK	statistical linkage key

Glossary

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

associated cause(s) of death: A cause(s) listed on the Medical Certificate of Cause of Death, other than the **underlying cause of death**. They include the immediate cause, any intervening causes, and conditions that contributed to the death but were not related to the disease or condition causing death. See also **cause(s) of death**.

cancer (malignant neoplasm): A large range of diseases where some of the body's cells become defective, begin to multiply out of control, invade and damage the area around them, and can then spread to other parts of the body to cause further damage.

cardiovascular disease/condition: Any disease of the circulatory system, namely the heart (cardio) or blood vessels (vascular). Includes angina, heart attack, **stroke** and peripheral vascular disease. Also known as **circulatory disease**.

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**. See also **associated cause(s) of death** and **multiple causes of death**.

cerebrovascular disease: Any disorder of the blood vessels supplying the brain or its covering membranes. A notable and major form of cerebrovascular disease is stroke.

chronic: A term describing something that is persistent and long lasting.

chronic diseases/conditions: A diverse group of diseases/conditions, such as heart disease, cancer and arthritis, which tend to be long lasting and persistent in their symptoms or development. Although these features also apply to some communicable diseases (infectious diseases), the term is usually confined to non-communicable diseases.

circulatory disease: Alternative name for cardiovascular disease.

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**.

diabetes (diabetes mellitus): A chronic condition where the body cannot properly use its main energy source—the sugar glucose. This is due to a relative or absolute deficiency in

insulin, a hormone produced by the pancreas that helps glucose enter the body's cells from the bloodstream and be processed by them. Diabetes is marked by an abnormal build-up of glucose in the blood; it can have serious short- and long-term effects. The three main types of diabetes are type 1 diabetes, type 2 diabetes and gestational diabetes.

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.

International Statistical Classification of Diseases and Related Health Problems (ICD): The World Health Organization's internationally accepted classification of death and disease. The Tenth Revision (ICD-10) is currently in use.

ischaemia: A reduced or blocked blood supply. See also **ischaemic heart disease**.

ischaemic heart disease: Also known as **coronary heart disease**. See also **ischaemia**.

life expectancy: An indication of how long a person can expect to live, depending on the age they have already reached. Technically, it is the number of years of life left to a person at a particular age if death rates do not change. The most commonly used measure is life expectancy at birth.

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

multiple causes of death: All the causes listed on the Medical Certificate of Cause of Death. These include the **underlying cause of death** and all **associated cause(s) of death**. See also **cause(s) of death**.

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.

potentially avoidable deaths: Deaths among people younger than age 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 are a subset of premature deaths. The **rate** of potentially avoidable deaths in Australia is used as an indicator of the health system's effectiveness. Potentially avoidable deaths are classified using nationally agreed definitions.

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.

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

respite support: 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.

stroke: An event that occurs when an artery supplying blood to the brain suddenly becomes blocked or bleeds. A stroke often causes paralysis of parts of the body normally controlled by that area of the brain, or speech problems and other symptoms. It is a major form of **cerebrovascular disease**.

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**.

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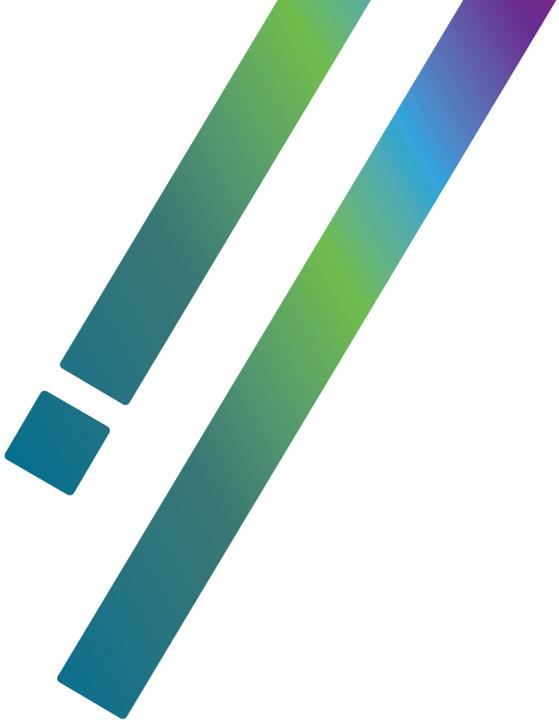
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