Potentially avoidable deaths of people with disability in Australia in 2013-2018:

Contributing causes and risk factors

Final Report December 2023

# Executive Summary

This report summarises the findings of an NDIS Quality and Safeguards Commission (NDIS Commission) led analysis of 9,062 deaths among 526,515 people accessing disability services under the National Disability Agreement (NDA) from 2013 to 2018. The primary aim of the current study was to identify all contributing health risksfor potentially avoidable deaths (PADs). This study builds on a previous analysis undertaken by the [Australian Institute of Health and Welfare (AIHW 2020)](https://www.aihw.gov.au/reports/disability-services/mortality-patterns-of-people-using-disability-serv/contents/summary) to identify causes and risk factors for deaths in people with disability, particularly where the death was attributed to their disability also known as “overshadowing”.

### Key findings

|  |  |
| --- | --- |
| **High prevalence contributing causes**  | When considering all contributing causes in people with disability, the most common causes were: ‘Injuries to multiple body regions, crushing, asphyxiation, poisoning by drugs’ (16% of deaths)**;** ‘Lung diseases due to external agents’ (primarily aspiration pneumonia) (11%), ‘Influenza and pneumonia’ (11%), ‘Coronary heart disease’ (10%), and ‘Mental and behavioural disorders due to psychoactive substance use’ (9%). |
| **“Overshadowing”** | Conditions affecting respiration were frequently recorded as a contributing cause of death for people whose death was attributed to their disability i.e. “*overshadowing”*. Aspiration pneumonia was the most common contributing cause of death for people whose deaths were primarily attributed to Cerebral palsy (48% with aspiration pneumonia), Multiple sclerosis (22%) and Huntington’s disease (22%). |
| **Differences to general population** | Large differences existed in contributing causes between people using NDA services and the general population. ‘Epilepsy and status epilepticus’ were 37x more likely to be a contributing cause in people with disability, while ‘Lung diseases due to external agents’ were 30x more likely, ‘Influenza and pneumonia’ 10x, and ‘Septicaemia’ 7x. |
| **Which are potentially avoidable** | The most frequent contributing causes categorised as potentially avoidable were Influenza and pneumonia**,** Coronary heart disease**,** Diabetes**,** Epilepsy and status epilepticus,Kidney failure, andSepticaemia. However, other contributing causes such as ‘Injuries to multiple body regions, crushing, asphyxiation, poisoning by drugs’ or ‘Lung diseases due to external agents may also be avoidable. |
| **Risks** | Men with disability, people with physical or psychosocial disability, people with disability living in residential aged care or supported living, or living in more disadvantaged or remote areas were at a greater risk of death across a number of contributing causes. |

### Background

Two previous reports commissioned by the NDIS Commission provided evidence on deaths of people with disability. In 2019, the University of New South Wales (UNSW) Department of Development Disability, Neuropsychiatry undertook a Scoping Review on the causes and contributors to deaths of people with disability (Salomon & Trollor, 2019). The Scoping Review used publicly accessible reports to examine the deaths of 901 people primarily with intellectual disability living in residential care settings in Victoria, QLD and NSW. The most common underlying causes of death were: Respiratory diseases; Nervous system diseases; Circulatory diseases; and Cancer.

A second report by AIHW used linked Disability Services-and Mortality data to identify the most prevalent primary causes of death among Australian people receiving specialist disability support services between 2013 and 2018 (AIHW 2020a). The study population included 526,515 individuals and 9,062 deaths. This report identified that people using specialist disability services in Australia had mortality rate 4.7 times as high as the general population, even when adjusting for differences in age and sex. However, the most frequent causes of death varied by type of disability, age, sex and service type.

#### Figure 1: The most frequent primary causes of death identified in the AIHW report (AIHW 2020a)

**Most frequent primary causes of death**

Other keys findings of the AIHW report included that the leading potentially avoidable cause of death in the study population was coronary heart disease followed by suicide.

### Objectives of the current study

Although both previous reports (Salomon & Trollor, 2019; AIHW 2020a) identified a primary (underlying) cause of death of people with disability. As deaths may not be due to one single cause, the decision-making about what to consider the primary cause can be unclear (Gorina & Lentzner 2008). In addition, a particular limitation of relying on one cause of death is that the deaths are frequently attributed to a person’s disability. This can result in “overshadowing” other potentially avoidable factors that may have led to their death (Heslop 2015; Trollor 2017). Therefore, we undertook a re-analysis of the linked datasets used in AIHW 2020a to identify whether there were other causes that contributed to the deaths of people with disability and whether they were potentially avoidable. We particularly wanted to identify other contributing factors that could potentially be avoided when the primary cause of death was attributed to the person’s disability.

### Research questions

The aim of this research was to answer the following questions:

1. What are the mostfrequentcontributing causes of death for people with disability?
2. Does this change when the person’s death is attributed to their disability i.e. “overshadowing”
3. Which of these contributing causes are considered ‘potentially avoidable’?
4. Which specific causes of death are more likely to occur in people with disability compared to the general population?
5. What risk factors are associated with the most frequent contributing causes of death?

# Methods

### Ethical approval

This study was approved by the AIHW Ethics Committee (Ref. E02019/4/1103). The methods and results section of this report are reported in accordance with the REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) recommendations (Benchimol et al 2015).

### Study design

This study was a dynamic (open) cohort study utilising retrospective data that were routinely collected for purposes other than research. A dynamic cohort means that study participants can leave or be added over the study period. Data on some participants will also have been collected both before and after the study period, however these data are not included in this study.

### Setting and participants

The study participants were Australians under 65 years of age who used disability support services funded under the NDA between 1 July 2013 and 30 June 2018. This resulted in astudy population of 526,515 people with disability, of whom 9,062 died in a year they were receiving NDA services (1.7%).

This study populationincluded around 23% of the estimated 2.4 million Australians aged under 65 with disability in 2018. People who transitioned from using NDA services to the National Disability Insurance Scheme (NDIS) are only included in the disability service data until they transitioned to the NDIS.

Data from the study population were also compared to the general population of Australians aged under 65 years to identify whether there were differences in the rates of contributing causes between people with disability and the general population. The number of people in the general population per year was calculated from the Australian Bureau of Statistics (2020) minus the number using NDA services. Individual-level data were available on deaths among the general population that occurred between 1 July 2013 and 30 June 2018.

### Data linkage

This study primarily used AIHW Disability Services National Minimum Data Set (NMDS) data which was linked with the AIHW National Death Index (NDI) via the Medicare Consumer Directory (MCD).

#### Table 1: Datasets used for this study

| Dataset  | Description | Number |
| --- | --- | --- |
| Disability service data | Service use data for all people using NDA services and information relating to their service providers | 595,585 |
| Person data | Sociodemographic (e.g. age, gender), disability and support needs data for people using NDA services whose details matched with the Medicare Consumer Directory | 555,866 |
| Disability death data | Individual-level data on contributing causes of deaths for people who died between 1 July 2013 and 30 June 2018 and were using NDA services at the time of their death. | 9062 |
| General population death data | Individual-level data on contributing causes of deaths among general population who died between 1 July 2013 and 30 June 2018.  | 129,755 |

#### [Figure 2:](#_Figure_3:_Description) Key variables used in study analyses

### Defining causes of death

The Australian death certification process allows for up to 20 diseases to be reported as causing or contributing to a death (AIHW 2019). Cause of death data was available as International Classification of Diseases – 10th revision codes (ICD-10 codes). ICD-10 codes are assigned to all conditions on a medical certificate cause of death (Australian Bureau of Statistics 2008).

|  |
| --- |
| **Underlying cause of death (UCoD)**: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 one underlying cause is selected from among all the conditions reported on the death certificate. AIHW 2020a**Associated Cause of Death (ACoD)**: 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. AIHW 2020a**Contributing causes of death (CCoD):** For the purpose of this report, the UCoD plus all ACoDs are collectively referred to as contributing causes. For example, if a person had cardiovascular disease listed as either an underlying or associated cause of death, this was counted as a death with cardiovascular disease as a contributing cause. |

#### Figure 3: Example of Cause of Death form completed by a medical practitioner

|  | **Part I** | **Cause of death** | **Interval between onset and death** |
| --- | --- | --- | --- |
| Underlying cause of death |  | **Disease or condition directly leading to death**The disease, injury or condition which led directly to the death *not only* the mode of dying such as heart or respiratory failure. | 1. Pneumonia due to K. pneumoniae
 | 1 week |
| Associated causes of death |  | **Antecedent causes**Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last. | 1. Cerebral infarction with hemiplegia
 | 2 months |
| **Part II** | **Cause of death** | **Interval between onset and death** |
| **Other significant conditions**Any other significant condition(s) contributing to the death but not related to the disease, injury or condition causing it. | Ischaemic heart disease |  |

### Grouping of ICD-10 codes

Over 12,000 specific causes of illness, injury and death are represented in ICD-10 codes (Becker et al 2006). To undertake analyses and categorisation of ICD-10 codes, the AIHW follows the recommendations of the World Health Organization (WHO) (Becker et al 2006) with minor modifications to suit the Australian context for grouping and categorising causes of death, illness and injury. We used this Australian-modified version of the groupings ICD- 10 codes for this study (AIHW 2023).

### Defining PADs

A PAD is a death among people aged under 75 that may be avoidable in the context of the present health-care system (AIHW 2020b). They include deaths from conditions that are potentially preventable through individualised care and/or treatable through existing primary or hospital care (AIHW 2020b). However, this does not mean that the deaths of individual people had been assessed as avoidable (AIHW 2020a).

# Results

### Demographic profile of study population

The study population consisted of 526,515 people aged less than 65 years who used NDA services at some point between July 2013 and June 2018. People using NDA services had a similar age distribution to the general population, but were more likely to be male (59% vs 50% in general population), living in a regional or remote area (35% vs 28%), born in Australia (83% vs 67%) and living in a more disadvantaged area (49% vs 40%) (See [Table 2](#_Table_2:_Characteristics)).

#### Table 2: Characteristics of people using NDA services compared to general population

|  | **People using NDA services (2013-2018), n (%)** | **General population n (%)** |
| --- | --- | --- |
| Total n (%) | 526,515 (100.0) | 20,224,053 (100.0) |
| Sex |  |  |
| Male | 309,790 (58.8) | 10,112,352 (50.0) |
| Female | 215,827 (41.0) | 10,111,701 (50.0) |
| Not stated | 898 (0.2) | - |
| Age in years\* |  |  |
| Median age (IQR) | 31 (17-49) | 30-34 |
| <20 | 166,413 (31.6) | 5,967,400 (29.5) |
| 20-34 | 119,058 (22.6) | 5,223,173 (25.8) |
| 35-49 | 114,464 (21.7) | 4,774,538 (23.6) |
| 50-64 | 126,580 (24.0) | 4,258,942 (21.1) |
| Remoteness of residence\*\* |  |  |
| Major city | 344,350 (65.4) | 14,480,422 (71.6) |
| Inner regional | 125,395 (23.8) | 3,640,329 (18.0) |
| Outer regional | 47,659 (9.1) | 1,698,820 (8.4) |
| Remote | 4,438 (0.8) | 242,690 (1.2) |
| Very remote | 1,731 (0.3) | 161,792 (0.8) |
| Missing | 2,942 (0.6) | - |
| Socioeconomic status\*\* |  | 20,224,053 |
| 1 (most disadvantaged) | 130,425 (24.8) | (~20.0) |
| 2 | 128,638 (24.4) | (~20.0) |
| 3 | 108,323 (20.6) | (~20.0) |
| 4 | 85,303 (16.2) | (~20.0) |
| 5 (most advantaged) | 70,871 (13.5) | (~20.0) |
| Missing | 2,955 (0.6) | - |
| Country of birth |  |  |
| Australia | 436,443 (82.9) | 13,489,443 (66.7) |
| Other primarily English speaking country | 22,620 (4.3) | 1,698,820 (8.4) |
| Other country (English proficiency group 2-4) | 51,897 (9.9) | 3,620,104 (17.9) |
| Unknown/not stated | 15,555 (3.0) | 1,415,684 (7.0) |

\*\* Percentages were calculated based on Australian Statistical Geography Standard 2016 Statistical Area Level 2 (SA2).

### Type of disability

Among people using NDA services, the most common primary disabilities were psychosocial (24%), physical (21%) and intellectual disability (17%) (See [Table 3](#_Table_3:_Disability)).

The majority of people in the study populationhad one disability type recorded (57%) or two disability types recorded (26%). When two disability types were recorded, the most common was 11% of people with a primary psychosocial disability, also having a physical disablility.

### Disability supports

The most frequent support services were in the areas of relationships (52%), working (50%), and learning (48%) (See [Table 3](#_Table_3:_Disability)).

The majority of people in the study populationreceived only one type of service (71-79% across different years of the study). Between 10% and 13% received three or more service types, with some people receiving up to 12 different service types within a year.

#### Table 3: Disability and support needs of study population

|  | **People using NDA services, n (%)** |
| --- | --- |
| Total n (%) | 526,515 (100.0) |
| Primary disability type |  |
| Psychosocial | 124,487 (23.6) |
| Physical | 108,379 (20.6) |
| Intellectual | 89,223 (16.9) |
| Autism | 51,132 (9.7) |
| Neurological | 29,735 (5.6) |
| Developmental delays | 22,097 (4.2) |
| Specific learning/ADD | 18,338 (3.5) |
| Acquired brain injury | 15,161 (2.9) |
| Vision | 13,935 (2.6) |
| Hearing | 13,104 (2.5) |
| Speech | 8,415 (1.6) |
| Deafblind | 851 (0.2) |
| Not stated | 31,658 (6.0) |
| Support needs |  |
| Median n needs per person | 5 (2-8) |
| Relationships | 274,802 (52.2) |
| Working | 262,025 (49.8) |
| Learning | 251,664 (47.8) |
| Education | 240,938 (45.8) |
| Communication | 219,635 (41.7) |
| Civic/economic | 210,065 (39.9) |
| Mobility | 189,704 (36.0) |
| Domestic life | 175,901 (33.4) |
| Self-care | 159,540 (30.3) |
| No support needs recorded | 82,667 (15.7) |

Note: more than one support type is usually accessed therefore the total number of supports is more than 100%.

### Contributing causes of death for people using disability services

Only 20.6% of people who died while using NDA services had a single cause of death while over a quarter of people (27.0%) had four or more causes of death.

#### Figure 4: Number of causes of death per person in study population



*\*causes of death = 1 includes n=109 (1.2%) with cause of death coded as missing*

[Table 4](#_Table_4:_Most) ranks the most frequent CCoD for the study population. These rankings are markedly different to the UCoD only method where the values in **bold** are the five most prevalent causes using the UCoD method only.

These most frequent categories of contributing causes were: ‘Other ill-defined causes’, ‘Injuries to multiple body regions, crushing, asphyxiation, poisoning by drugs, other’, ‘Lung diseases due to external agents’, ‘Influenza and pneumonia’ and ‘Coronary heart disease’. Of these, only ‘Influenza and pneumonia’ and ‘Coronary heart disease’ were considered PADs using standardised criteria (AIHW 2022).

The inclusion of associated causes of death as a contributing cause had a large impact on what were the most frequent causes of death for people with disability. For example, ‘Injuries to multiple body regions, crushing, asphyxiation, poisoning by drugs, other’ was recorded as a contributing cause of death for nearly 16% of people with disability, but was recorded as the underlying cause of death for less than five people.

#### Table 4: Most prevalent contributing causes of death

| Rank\* | AIHW PAD? | Becker grouping of ICD10 codes | CCoD\*\*\* | UCoD only | CCoD\*\*\* | UCoD only |
| --- | --- | --- | --- | --- | --- | --- |
|  |  |  | People using NDA,n (%) of deaths | General population, n (%) of deaths |
| 1 | No | Other ill-defined causes | 2,554 (28.2) | 168 (1.9) | 27,449 (21.2) | 1,927 (1.5) |
| 2 | No | Injuries to multiple body regions, crushing, asphyxiation, poisoning by drugs, other | 1,434 (15.8) | <5 | 24,433 (18.8) | <5 |
| 3 | No | Lung diseases due to external agents | 975 (10.8) | 59 (0.7) | 2,135 (1.6) | 106 (0.1) |
| 4 | Yes | Influenza and pneumonia | 952 (10.5) | 157 (1.7) | 6,306 (4.9) | 1,106 (0.9) |
| 5 | Yes | Coronary heart disease | 915 (10.1) | ***519 (5.7)3*** | 17,570 (13.5) | 11,261 (8.7) |
| 6 | Some ICD10 codes | Certain conditions originating in the perinatal period, congenital malformations, deformations and chromosomal abnormalities | 896 (9.9) | ***574 (6.3)1*** | 2,311 (1.8) | 1,638 (1.3) |
| 7 | No | Mental and behavioural disorders due to psychoactive substance use | 844 (9.3) | 48 (0.5) | 15,763 (12.1) | 733 (0.6) |
| 8 | Yes | Diabetes | 761 (8.4) | 260 (2.9) | 9,212 (7.1) | 2,877 (2.2) |
| 9 | No | Epilepsy and status epilepticus | 746 (8.2) | 261 (2.9) | 1,365 (1.1) | 556 (0.4) |
| 10 | No | Cerebral palsy and other paralytic syndromes | 709 (7.8) | ***393 (4.3)5*** | 400 (0.3) | 109 (0.1) |
| 11 | Yes | Kidney failure | 600 (6.6) | 58 (0.6) | 6,911 (5.3) | 524 (0.4) |
| 12 | Yes | Septicaemia | 585 (6.5) | 89 (1.0) | 5,920 (4.6) | 729 (0.6) |
| 13 | No | Spinal muscular atrophy and related syndromes | 562 (6.2) | ***537 (5.9)2*** | 506 (0.4) | 456 (0.4) |
| 14 | No | Liver disease | 527 (5.8) | 247 (2.7) | 10,985 (8.5) | 4,625 (3.6) |
| 15 | No | Mood (affective) disorders | 522 (5.8) | <5 | 7,878 (6.1) | 13 (0.0) |
| 16 | Yes | Cerebrovascular disease | 516 (5.7) | 248 (2.7) | 6,379 (4.9) | 3,312 (2.6) |
| 17 | Some ICD10 codes | Heart failure and complications and ill-defined heart disease | 493 (5.4) | 79 (0.9) | 6,177 (4.8) | 867 (0.7) |
| 18 | Yes | Suicide | 471 (5.2) | ***470 (5.2)4*** | 11,575 (8.9) | 11,561 (8.9) |
|  |  |  | People using NDA,n (%) of deaths | General population, n (%) of deaths |
| 19 | No | Other disorders of the nervous system | 470 (5.2) | 109 (1.2) | 3,526 (2.7) | 534 (0.4) |
| 20 | Yes | Accidental poisoning | 395 (4.4) | 373 (4.1) | 5,969 (4.6) | 5,542 (4.3) |
|  |  | Total deaths | 9,062 (100) | 129,755 (100) |

**Note:** Because people can have multiple causes of death recorded, the totals across causes of death are greater than the number of people who died when using this method.

[Table 5](#_Table_5:_ICD-10) below further examines the individual ICD-10 subgroups within each of the three high frequency categories of contributing causes identified in [Table 4](#_Table_4:_Most) above.

#### Table 5: ICD-10 codes that make up Becker groupings for three most frequent causes of death\*

|  |  |  | **People using NDA Services** |
| --- | --- | --- | --- |
| **Rank** | **AIHW PAD?** | **AIHW Grouping and ICD10 codes** | **CCoD (number deaths)** | **CCoD (% deaths)** | **UCoD only (number deaths)** | **UCoD only (% deaths)** |
| **1** | **No\*\*** | **Other ill-defined causes. This includes ICD10 codes:** | **2,554** | **28.2%** | **168** | **1.9%** |
|   |   | Respiratory failure, unspecified | 635 | **7.0%** |  |  |
|   |   | Cardiac arrest, cause unspecified | 434 | **4.8%** |  |  |
|   |   | Other general symptoms and signs  | 233 | **2.6%** |  |  |
|   |   | Other and unspecified convulsions  | 210 | **2.3%** |  |  |
|   |   | Respiratory arrest  | 169 | **1.9%** |  |  |
| **2** | **No** | **Injuries to multiple body regions, crushing, asphyxiation, poisoning by drugs, other. This includes ICD10 codes:** | **1,434** | **15.8%** | **<5** | **<0.1%** |
|   |   | Poisoning by, adverse effect of and underdosing of benzodiazepines | 270 | **3.0%** |  |  |
|   |   | Asphyxiation | 250 | **2.8%** |  |  |
|   |   | Foreign body in respiratory tract, part unspecified | 219 | **2.4%** |  |  |
|   |   | Poisoning by, adverse effect of and under dosing of other opioids | 164 | **1.8%** |  |  |
|   |   | Poisoning by, adverse effect of and underdosing of other and unspecified antidepressants | 140 | **1.5%** |  |  |
| **3** | **No** | **Lung diseases due to external agents including: This includes ICD10 codes:** | **975** | **10.8%** | **59** | **0.7%** |
|   |   | Pneumonitis due to inhalation of food and vomit | 972 | **10.7%** |  |  |

### Contributing causes of death for people whose deaths were primarily attributed to disability – “overshadowing”

The underlying cause of death in people with disability is frequently attributed to the person’s disability. In the report of deaths undertaken by the AIHW (AIHW 2020a), three of the five most frequent underlying causes of death were related to disability i.e. Perinatal and congenital diseases, Spinal muscular atrophy and related syndromes, and Cerebral Palsy and other paralytic syndromes. For people whose underlying cause of death was motor neuron disease, cerebral palsy, Down syndrome, and multiple sclerosis, we report other contributing causes in [Table 6](#_Table_6:_Most).

Conditions affecting respiration are often recorded as a contributing cause of death for people who have their disability recorded as their underlying cause of death (“overshadowing”). In particular, *Pneumonitis due to inhalation of food and vomit* (commonly known as aspiration pneumonia) was frequently an associated cause of death for people with their disability recorded as their underlying cause of death.

Pneumonitis due to inhalation of food and vomit’ (primarily aspiration pneumonia) was the most common associated cause of death for people who had their underlying cause of death listed as their disability. The rates for people whose death was attributed primarily to their disability was:

* Cerebral palsy - 48%
* Multiple sclerosis - 22%
* Huntington’s disease - 22%

Unspecified dementia was an associated cause of death for over 40% of people with an underlying cause of death recorded as Down syndrome.

#### Table 6: Most common associated causes of death for high prevalence potentially overshadowed deaths

| **Underlying cause of death (UCoD)** | **Most common associated causes of death \*** | **Number** | **%** |
| --- | --- | --- | --- |
| Motor neuron disease (G122) | Respiratory failure, unspecified | 120 | 23.2 |
| Pneumonitis due to inhalation of food and vomit | 54 | 10.4 |
| Pneumonia, unspecified organism | 25 | 4.8 |
| Respiratory arrest | 19 | 3.7 |
| ***Total with UCoD*** | ***518*** | ***100*** |
| Cerebral palsy, unspecified (G809) | Pneumonitis due to inhalation of food and vomit | 134 | 47.7 |
| Epilepsy, unspecified | 75 | 26.7 |
| Pneumonia, unspecified organism | 32 | 11.4 |
| Respiratory failure, unspecified | 30 | 10.7 |
| Foreign body in respiratory tract, part unspecified | 23 | 8.2 |
| Other and unspecified convulsions | 21 | 7.5 |
| Cardiac arrest, cause unspecified | 18 | 6.4 |
| Inhalation and ingestion of other objects causing obstruction of respiratory tract | 18 | 6.4 |
| Sepsis, unspecified organism | 15 | 5.3 |
| Aphagia and dysphagia | 12 | 4.3 |
| Unspecified acute lower respiratory infection | 10 | 3.6 |
| Gastro-esophageal reflux disease without esophagitis | 10 | 3.6 |
| ***Total with UCoD*** | ***281*** | ***100*** |
| Down syndrome, unspecified (Q909) | Unspecified dementia | 96 | 40.3 |
| Pneumonitis due to inhalation of food and vomit | 86 | 36.1 |
| Pneumonia, unspecified organism | 47 | 19.7 |
| Epilepsy, unspecified | 39 | 16.4 |
| Alzheimer’s disease, unspecified | 31 | 13 |
| Other and unspecified convulsions | 14 | 5.9 |
| Bronchopneumonia, unspecified organism | 13 | 5.5 |
| Respiratory failure, unspecified | 12 | 5 |
| Sepsis, unspecified organism | 11 | 4.6 |
| ***Total with UCoD*** | ***238*** | ***100*** |
| Multiple sclerosis (G35) | Pneumonitis due to inhalation of food and vomit | 50 | 22.3 |
| Sepsis, unspecified organism | 32 | 14.3 |
| Pneumonia, unspecified organism | 31 | 13.8 |
| Urinary tract infection, site not specified | 24 | 10.7 |
| Respiratory failure, unspecified | 17 | 7.6 |
| Pulmonary embolism without acute cor pulmonale | 10 | 4.5 |
| ***Total with UCoD*** | ***224*** | ***100*** |
| Huntington's disease (G10) | Pneumonitis due to inhalation of food and vomit | 25 | 21.6 |
| Pneumonia, unspecified organism | 19 | 16.4 |
| ***Total with UCoD*** | ***116*** | ***100*** |
| Muscular dystrophy (G710) | *Respiratory failure, unspecified* | 23 | 26.7 |
| Pneumonia, unspecified organism | 14 | 16.3 |
| Pneumonitis due to inhalation of food and vomit | 14 | 16.3 |
| ***Total with UCoD*** | ***86*** | ***100*** |

\*not mutually exclusive i.e. a person may have more than one associated cause of death

### **Differences** in **contributing causes between people using disability services and the general population**

There were large disparities between people using disability services and the general population in the rates of contributing causes, even after adjusting for age, sex, state and year. [Table 7](#_Table_7:_Rates) below reports adjusted risk ratios for specific contributing causes of deaths for people using disability services. Large differences existed between people with disability and the general population in the 15 most frequent contributing causes of death. The greatest differences were for deaths due to *Epilepsy and status epilepticus*, *Lung diseases due to external agents*, *Influenza and pneumonia*, and *Septicaemia*.

#### Table 7: Rates of death for people using NDA services compared to the general population

|  |  |  |
| --- | --- | --- |
| **Contributing cause of death** | **Adjusted risk ratio** | **95% CI** |
| Epilepsy and status epilepticus | 37 | 34 to 41 |
| Lung diseases due to external agents (primarily aspiration pneumonia) | 30 | 28 to 33 |
| Influenza and pneumonia | 10 | 9.4 to 10.8 |
| Septicaemia | 6.6 | 6.0 to 7.2 |
| Other ill-defined causes | 6.4 | 6.1 to 6.6 |
| Kidney failure | 5.8 | 5.3 to 6.3 |
| Diabetes | 5.4 | 5.0 to 5.8 |
| Cerebrovascular disease | 5.3 | 4.8 to 5.9 |
| Mood disorders | 4.5 | 4.1 to 4.9 |
| Injuries to multiple regions, poisoning | 4.0 | 3.8 to 4.2 |
| Mental & behavioural disorders due to psychoactive substance use | 3.6 | 3.4 to 3.8 |
| Coronary heart disease | 3.4 | 3.2 to 3.6 |
| Liver disease | 3.2 | 2.9 to 3.5 |

### Risk factors associated with contributing causes of death

Regression methods were used to examine the association between participant characteristics and risk of death for the five most prevalent potentially preventable contributing causes of death among people using NDA services:

* Injuries to multiple body regions, poisoning by drugs, other;
* Lung diseases due to external agents;
* Influenza and pneumonia;
* Coronary heart disease; and
* Mental and behavioural disorders due to psychoactive substance use.

[Table 8](#_Table_8:_Risk) outlines the predictors of risk for each of the high frequency contributing causes of death. The key risk factors for these contributing causes of death were:

* Being male and living in residential aged care or supported living was a common risk factor across the most frequent contributing causes of death.
* People with physical or psychosocial disability also had a higher risk across a number of contributing causes.
* For deaths due to ‘Influenza and pneumonia’ and ‘Coronary heart disease’, living in a lower socioeconomic status area was a risk factor. The remoteness of a person’s residence was also a risk for people who died of ‘Mental and behavioural disorders due to psychoactive substance use’.
* There was a clear social gradient for coronary heart disease as a contributing cause, with people living in more disadvantaged areas and in outer regional and remote/very remote areas having the highest risk.

#### Table 8: Risk factors for high frequency contributing causes

|  | **Injuries to multiple body regions, crushing, asphyxiation, poisoning by drugs, other** | **Lung diseases due to external agents** | **Influenza and pneumonia** | **Coronary heart disease** | **Mental and behavioural disorders due to psychoactive substance use** |
| --- | --- | --- | --- | --- | --- |
|  | **Hazard ratio** | **95% CI** | **Hazard ratio** | **95% CI** | **Hazard ratio** | **95% CI** | **Hazard ratio** | **95% CI** | **Hazard ratio** | **95% CI** |
| **Sex** | p<0.001 |  | p=0.005 |  | p=0.25 |  | p<0.001 |  | p<0.001 |  |
| **Male** | 1.0 |  | 1.0 |  | 1.0 |  | 1.0 |  | 1.0 |  |
| **Female** | 0.6 | 0.5-0.7 | 0.8 | 0.7-0.9 | 1.0 | 0.9-1.1 | 0.4 | 0.4-0.5 | 0.4 | 0.4-0.5 |
| **Residential setting** | p<0.001 |  | p<0.001 |  | p<0.001 |  | p<0.001 |  | p<0.001 |  |
| **Private residence** | 1.0 |  | 1.0 |  | 1.0 |  | 1.0 |  | 1.0 |  |
| **Supported living/ accommodation** | 1.7 | 1.4-2.0 | 1.9 | 1.6-2.3 | 1.3 | 1.1-1.6 | 1.2 | 0.9-1.5 | 1.3 | 0.9-1.7 |
| **Boarding house/ private hotel** | 1.3 | 1.0-1.6 | 0.3 | 0.1-1.1 | 0.7 | 0.4-1.3 | 1.3 | 1.0-1.8 | 1.3 | 1.0-1.7 |
| **Residential aged care** | 2.0 | 1.3-3.3 | 4.0 | 3.1-5.2 | 3.9 | 3.0-5.2 | 1.4 | 0.9-2.3 | 2.9 | 1.7-4.8 |
| **Other** | 1.4 | 1.2-1.7 | 1.1 | 0.9-1.4 | 1.1 | 0.9-1.4 | 1.7 | 1.3-2.1 | 2.0 | 1.5-2.6 |
| **Not stated** | 2.6 | 2.2-3.2 | 1.7 | 1.3-2.4 | 1.6 | 1.2-2.1 | 1.6 | 1.2-2.2 | 2.8 | 2.2-3.6 |
| **Primary disability** | p<0.001 |  | p<0.001 |  | p<0.001 |  | p<0.001 |  | p<0.001 |  |
| **Intellectual or learning** | 1.0 |  | 1.0 |  | 1.0 |  | 1.0 |  | 1.0 |  |
| **Physical or diverse** | 3.5 | 3.0-4.2 | 2.1 | 1.8-2.5 | 2.2 | 1.9-2.6 | 2.3 | 1.8-2.8 | 7.1 | 5.3-9.6 |
| **Sensory or speech** | 0.8 | 0.6-1.2 | 0.4 | 0.2-0.7 | 0.5 | 0.3-0.9 | 1.9 | 1.4-2.7 | 2.8 | 1.7-4.4 |
| **Psychosocial** | 6.4 | 5.4-7.6 | 0.4 | 0.3-0.6 | 1.0 | 0.8-1.3 | 2.1 | 1.6-2.7 | 12.0 | 8.8-16.2 |
| **Not stated** | 1.9 | 1.4-2.8 | 0.9 | 0.5-1.5 | 1.4 | 0.9-2.1 | 2.1 | 1.3-3.4 | 5.8 | 3.6-9.4 |
| **Country of birth** | p<0.001 |  | p=0.06 |  | p=0.003 |  | p<0.001 |  | p<0.001 |  |
| **Australia** | 1.0 |  | 1.00 |  | 1.0 |  | 1.0 |  | 1.0 |  |
| **Primarily English speaking**  | 1.1 | 0.9-1.4 | 0.8 | 0.5-1.1 | 1.0 | 0.7-1.3 | 0.9 | 0.7-1.2 | 1.1 | 0.9-1.5 |
| **Other country** | 0.5 | 0.4-0.6 | 0.7 | 0.6-1.0 | 0.6 | 0.4-0.8 | 0.4 | 0.3-0.6 | 0.3 | 0.2-0.4 |
| **Socioeconomic status** | p=0.10 |  | p=0.15 |  | p<0.01 |  | p=0.03 |  | p=0.06 |  |
| **1 (most disadvantaged)** | 1.0 |  | 1.0 |  | 1.0 |  | 1.0 |  | 1.0 |  |
| **2** | 0.9 | 0.8-1.1 | 1.2 | 1.0-1.4 | 1.1 | 0.9-1.3 | 0.9 | 0.7-1.1 | 1.1 | 0.9-1.3 |
| **3** | 1.0 | 0.9-1.2 | 1.2 | 1.0-1.5 | 0.9 | 0.8-1.1 | 0.8 | 0.6-0.9 | 1.2 | 0.9-1.4 |
| **4** | 1.0 | 0.8-1.2 | 1.3 | 1.0-1.6 | 0.8 | 0.7-1.0 | 0.8 | 0.6-1.0 | 0.8 | 0.6-1.1 |
| **5 (most advantaged)** | 1.2 | 1.0-1.4 | 1.1 | 0.9-1.4 | 0.7 | 0.5-0.9 | 0.7 | 0.6-0.9 | 1.2 | 0.9-1.5 |
| **Remoteness** | p=0.25 |  | p=0.05 |  | p=0.93 |  | p<0.001 |  | p=0.01 |  |
| **Major city** | 1.0 |  | 1.0 |  | 1.0 |  | 1.0 |  | 1.0 |  |
| **Inner regional** | 0.9 | 0.8-1.1 | 0.9 | 0.7-1.0 | 1.0 | 0.8-1.2 | 0.7 | 0.6-0.8 | 0.9 | 0.7-1.0 |
| **Outer regional** | 0.8 | 0.7-1.0 | 0.8 | 0.6-1.0 | 1.0 | 0.8-1.3 | 1.3 | 1.0-1.6 | 1.0 | 0.8-1.3 |
| **Remote/Very remote** | 1.2 | 0.8-1.8 | 0.6 | 0.3-1.0 | 0.9 | 0.5-1.4 | 2.2 | 1.5-3.1 | 1.8 | 1.1-2.8 |

\* Adjusted hazard ratios also controlling for age, number of support needs, and use of employment services only.

Significantly different Hazard ratios are shown in red. In general this effect is significant when the 95% CI does not include 1.

**Interpreting this table**

For each category, the first subcategory is compared to all other subcategories. For example, data from people with disabilities categorised as Physical or diverse, Sensory or speech, Psychosocial are compared to Intellectual or learning disabilities.

A Hazard ratio (HR) of greater than 1 indicates risk is higher compared to the comparison group population and reduced where the HR is less than 1. As an example, people with psychosocial disability were more than 6 times as likely to have *‘Injuries to multiple body regions, crushing, asphyxiation, poisoning by drugs, other’*, as a contributing cause compared to people with intellectual or learning disability (HR = 6.4). In general this effect is significant when the 95% CI does not include 1.

### Do rates of PADs vary between services outlets?

Funnel plots were used to examine whether the variation in rates of PADs was related to the size of service outlets in 2018. The data used for this analysis were based on *UCoDs only in 2018*. There was variation between service outlets in rates of PADs. There were 6 service outlets (3.1%) with rates much higher than expected (above 99.8% control limits) and 17 outlets (8.8%) with rates above 95% control limits.

High than expected PAD rates were found in smaller service outlets (provider size < 500).

#### Figure 5: Variation in rates of PADs compared to size of services outlets\*



\* Excludes people using employment services only and outlets with <100 participants. Adjusted model for age, sex. UCoD only method. High volume providers have been grouped at n=1,250 and n=1,500 people to preserve anonymity.

# Summary of findings

The current study shows that including all contributing causes make considerable differences in what are the most frequent risks in the deaths of people with disability. Taking all contributing causes into account can also limit potential “overshadowing” by uncovering additional causes in deaths that were attributed to a person’s disability. We were also able to identify a range of risk factors that were associated with the most frequent contributing causes.

### Aspiration pneumonia was frequently identified as a contributing cause in the deaths of people with disability

Of the 9,062 people using disability services who died during 2013-2018, 11% had aspiration pneumonia as one of the contributing causes to their death. This is consistent with other smaller studies that have found that aspiration pneumonia and choking were among the most common respiratory causes of death for people with disability in NSW, Queensland and Victoria. (Trollor 2017; Salomon &Trollor 2019).

### “Overshadowing” of the deaths of people with disability

This current study has identified that attributing a person’s death to their disability may prevent other contributing factors from being identified. The most common factors associated with deaths of people with disability were respiratory and cardiac arrest, effects of medicines including opioids, benzodiazepines and antidepressants, lung diseases, influenza and pneumonia, and coronary heart disease.

### PADs

The top three most frequent causes of death in the study population, are generally not categorised as potentially avoidable using standardised criteria (AIHW 2022). These were: Other ill-defined causes, ‘Injuries to multiple body regions, crushing, asphyxiation, poisoning by drugs, other’ and ‘Lung diseases due to external agents’. However, these larger categories of contributing causes by ICD-10 codes included:

* Injuries to multiple body regions, crushing
* Asphyxiation
* Poisoning by drugs, that includes poisoning by, adverse effect of and underdosing of antidepressants benzodiazepines or opioids
* Lung diseases due to external agents including pneumonitis due to inhalation of food and vomit.

Although these contributing causes are not coded as PADs using standardised criteria (AIHW 2022), some of these contributing causes may still be considered potentially preventable or treatable.

### Risk factors

This study has demonstrated a number of risk factors associated with frequent contributing causes of deaths that could be potential flags for further investigation. In addition, people with these identified risks may be key populations with whom to identify and implement effective preventative strategies that can reduce potentially avoidable risks. For example, living in residential aged care or supported living was a common risk factor across several high prevalence contributing causes of death. This indicates that targeted interventions in these settings, may be priority areas to reduce the risk of PADs.

## Study limitations

This study utilises retrospective data on NDA services users, as National Death Index registry data for NDIS participants were not available to be linked for this project.

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