



Faculty of Medicine, The Department of
Developmental Disability Neuropsychiatry 3DN

A scoping review of causes and contributors to deaths of people with disability in Australia

SUMMARY OF KEY FINDINGS

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Executive Summary

The establishment of the National Disability Insurance Scheme's Quality and Safeguards Commission presents a unique opportunity to develop Australia's first nationally consistent arrangement for reviewing deaths of people with disability. In preparation for this national death review process the Commission requested the Department of Developmental Disability Neuropsychiatry at UNSW Sydney to conduct an Australia-wide scoping review focused on mortality trends and factors relating to the deaths of people with disability.

This report summarises key findings from the scoping review. It is the first of its kind to provide a national baseline picture of death trends and related factors by drawing on published state and territory level disability death review data. The report details findings from the death reviews of 901 people with disability providing across the states of Vic, QLD and NSW. Deaths span a time period of 2007-2018. Along with insight into mortality rates and causes, the report highlights areas of problematic practice across jurisdictions that potentially contributed to some deaths.

ABOUT THE SOURCES

Only 3 states, New South Wales (NSW), Queensland (QLD) and Victoria (VIC) had published in- scope death reviews to draw on for this report

VIC:

Disability Services Commissioner (DSC). A review of disability service provision to people who have died 2017-18. Melbourne: Disability Services Commissioner **VIC 17-18**

Parliament of Victoria, Family and Community Development Committee 2016, Inquiry into abuse in disability services: final report, State Government of Victoria, Melbourne **VIC 07-16**

N=95

NSW

NSW Ombudsman (2015). Report of reviewable deaths in 2012 and 2013.

Volume 2: Deaths of people with disability in residential care **NSW 12-13**

Ombudsman NSW (2018). Report of reviewable deaths in: 2014 and 2015 & 2016 and 2017: Deaths of people with disability in residential care **NSW 14-17**

N=733

QLD

Office of the Public Advocate (QLD). 2016. Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland.

A systematic advocacy report **QLD 09-14**

N=73

For the remainder of the report these sources are referenced as:
VIC 17-18; VIC 07-16; QLD 09-14; NSW 12-13; NSW 14-17

Which deaths were In-scope for this review?

In-scope deaths varied widely across reports and jurisdictions. Variance was due to a number of factors:

Differences in the methodology	Heterogeneity in terms of reference
The investigative powers of each team and the investigative process used to identify and analyse in-scope deaths varied across reports. There was no consistent method across reports for analysing cause of death based on demographic or disability related data. The type of demographic and disability related data collected across reports also varied	<ul style="list-style-type: none"> Types of disabilities that were in-scope (i.e. intellectual disability only versus all disabilities) Types of deaths (i.e. expected or unexpected or both) Differences in how 'disability service providers' are defined under each jurisdiction's Disability Act also impacted which populations were included
Differences across Coroner's Acts	Different data collection periods
Each Australian state and territory has its own Coroners Act. The wording of each act has implications for which deaths of people with disability were considered 'reportable' across jurisdictions	Length and time range of in-scope deaths varied across reports from 7 months to 9 years. Time period variously spanned 2007 to 2018

Implications for analysing and understanding death trends

Different terms of reference and methodological approaches across included reports mean that while we can comment on some key issues and causes of death among people with disability at the ICD Chapter and Sub-Chapter level, **we cannot**:

- Directly compare differences in causes of death for people with different types of disability
- Directly compare types of deaths across jurisdiction based on the person's living arrangement or other types of demographic data
- Comment on comparative rates of deaths or causes of death across jurisdictions Identify patterns in death data over time

Only three states (VIC, NSW and QLD) had any published data related to deaths of people with disabilities available for analysis. Deaths trends in all other jurisdictions may vary considerably from those reported here

These gaps in knowledge underscore the importance of the work the Commission will undertake to develop a truly national insight into factors relating to the deaths of people with disability

About the people who died

The deaths of 901 people with disability are covered in this report

Median age at death was substantially (20-36 years) lower than that of the general Australian population

Deaths of men were overrepresented across jurisdictions

The overwhelming majority of in-scope deaths involved people with **intellectual disability**

RISKS AND VULNERABILITIES

Mental Health Concerns

Were such data was collected, high levels of co-occurring mental health concerns were common. These included depression, self-harming behaviours and anxiety.

Physical health problems

The vast majority of people who died experienced multiple physical health problems in addition to their disability. These included dental problems (51%- 83% of people) and epilepsy (28%- 49% of people). Constipation, urinary incontinence and Gastro Oesophageal Reflux Disease (GORD) were also common.

Swallowing & mealtime support

Where such data was collected, it was noted that a considerable proportion of people who died experienced issues that may have impacted how and/or what they ate. For example:

- missing teeth and other dental problems
- swallowing problems related to GORD, medications and disease processes

Mobility & communication

A high number of in-scope deaths involved people who required communication and/or mobility support. The number of people requiring a communication plan who actually had one in place was either unknown or not reported in most samples.

Prescriptions	Vaccinations
<p>High Rates of polypharmacy were noted</p> <p>Psychotropic medications were commonly prescribed to people with disability who had died, often in the absence of a diagnosed mental illness</p>	<p>Across jurisdictional samples, 14% to 48% of people had not received an influenza vaccination in the 12 months before their death</p> <p>Where reported, it appeared that between 25% and 83% had not received a pneumococcal vaccination in the last 12 months</p>
Comprehensive health assessments	Weight, exercise & other lifestyle risks
<p>Date of last comprehensive health assessment was unknown for a significant minority</p> <p>In some cases there was a lack of documented referral and follow-up for people with identified health risks such as diabetes, obesity and hypertension</p>	<p>Where reported, it appeared that over a half of people who died were outside of a healthy weight range</p> <p>Weight and exercise status was unknown for a significant minority, suggesting that regular monitoring may not have been occurring</p>

Language and cultural status of the people who died

The proportion of deaths that involved people of **Aboriginal or Torres Strait Islander** origin (ATSI) varied across reports from 0% in the VIC 17-18 sample, to 11% in the QLD 09-14 sample

The proportion of deaths of people with **Culturally and Linguistically Diverse backgrounds** varied from 5% (in the 2016-2017 disability Services sample within the NSW 14-17 report) to 20% (in the 2016-2017 assisted boarding house sample within the NSW 14-17 report)

Causes of death

Across jurisdictions, **the majority of deaths (59%-71%) were 'unexpected'**

The vast majority of deaths across samples (88%-93%) were attributed to **'natural' causes** (i.e. illness and disease)

QLD was the only state to analyse cause of deaths based on whether they were potentially 'avoidable', 'treatable' or 'preventable': They found that **over half of all deaths reviewed (53%) were due to potentially treatable or avoidable causes**

Underlying cause of death at ICD chapter level	Underlying cause of death at ICD sub-chapter level
<p>The four most common underlying causes of death at Chapter level were:</p> <ul style="list-style-type: none">• Respiratory diseases (19%)• Nervous system diseases (14%)• Circulatory diseases (13%)• Neoplasms (13%)	<p>Leading underlying causes of death at ICD sub-chapter level were:</p> <ul style="list-style-type: none">• Respiratory deaths: pneumonitis due to solids and liquids, and pneumonia• Circulatory system deaths: Ischaemic heart disease• Nervous system deaths: epilepsy• Congenital and chromosomal deaths: Down syndrome Neoplasms:• Malignant neoplasms of the digestive organs and malignant neoplasms of the trachea, bronchus and lungs

EXTERNAL CAUSES OF DEATH

Unnatural or external causes of death accounted for 5% to 8% of all deaths investigated

The vast majority of these deaths related to accidental choking

ASSOCIATED CAUSES OF DEATH

NSW was the only state that systematically and quantifiably accounted for contributing and direct causes of death in addition to underlying causes. They found that for people receiving disability services *respiratory disease* was the largest contributory cause of death. For their boarding house sample, *circulatory diseases, neoplasms, mental and behavioural disorders and respiratory diseases* were the leading contributory causes

Key issues identified through the review

RESPIRATORY DEATHS

Respiratory disease was the major underlying cause of death for people with disability across reviewed reports (19% of deaths). In comparison, respiratory disease accounts for only approximately 9% of deaths in the general Australian population

Across death reviews, aspiration pneumonia was highlighted as the most common underlying cause of respiratory death for people with disability, accounting for just under half of all respiratory deaths, and 8% of all in-scope deaths

High rates of psychotropic prescriptions and polypharmacy, increasing risk of impaired swallowing function, sedation and hypersalivation

Lack of proactive and appropriate treatment of known risks such as dental problems, GORD, epilepsy, dysphagia, PICA

Delays in diagnosis and treatment of respiratory related illness

Lack of timely access to influenza and pneumococcal vaccines

Identified areas of concern



Lack of comprehensive nutrition and swallowing assessments for at risk groups

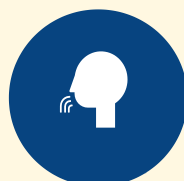
Safe mealtime guidelines not consistently being adhered to due to lack of staff knowledge and/or understaffing

Poor management of respiratory infection risk following surgery for falls and fractures

Poor access to respiratory specialists and other chronic disease management and other out-of-hospital programs

Risk factors and areas of problematic practice were noted to be similar to those for respiratory deaths

Deaths relating to choking



Across reports, accidental choking was highlighted as the leading external cause of death for people with disabilities

Choking was associated with 34 of the 901 in-scope deaths for this review

Of the 29 deaths where cause of choking was reported:

- The vast majority, (83%) were related to choking on food
- 4 people (14%) choked on vomit
- 1 person (3%) choked on a foreign object (latex glove)

DEATHS RELATED TO EPILEPSY

Diseases of the nervous system accounted for 14% of all deaths

Epilepsy was the cause of 37% of nervous system deaths

Epilepsy accounted for 5% of the total 901 deaths included in this review.

Some people who died appeared to have been administered sub-therapeutic dosages of anticonvulsant medication

Identified areas of concern



Some cases of sub-optimal recording and charting of seizure activity were noted

It was not always clear whether people had access to a specialist neurologist for management and oversight of their epilepsy, including regular medication reviews, prior to death

DEATHS DUE TO NEOPLASMS AND CIRCULATORY DISEASE: Poorly managed lifestyle risks

Neoplasms were the underlying cause of death for 13% of in-scope deaths. Malignant neoplasms of the digestive organs and malignant neoplasms of the trachea, bronchus and lungs were the most frequently reported neoplasm types

Circulatory disease was listed as the underlying cause of death of 121 of the 901 cases included in this scoping review (13%). Ischaemic heart disease featured as the leading underlying cause of circulatory deaths at the ICD Sub-Chapter level

High prevalence of known risk factors including obesity, hypertension, diabetes, low physical activity levels, hypertension

Lack of care co-ordination between services to address identified risk factors

Identified areas of concern



High rates of psychotropic prescriptions and polypharmacy and insufficient specialist review of medications

Poor management of lifestyle related risks including insufficient referral and contact with specialists to manage known risks

Lack of staff awareness of, or compliance with healthy lifestyle policies

Overarching issues spanning jurisdictions and types of death

Accessing preventative health care measures

Across reports, a lack of proactive support for preventative health care measures including recommended vaccinations, dental check-ups, comprehensive health examinations and allied health referrals, was noted

Managing emerging and chronic health risks

Findings across jurisdictions raise concerns about service providers failing to proactively manage emerging and chronic health risks. For example, identifying obesity but failing to refer the person for weight loss support

Supporting client communication

Limited use of communication plans and other communication accommodations may have curtailed some clients' ability to express emerging health concerns to staff. The one report that examined this issue in detail found 38% of those who required a communication plan did not have one in place

Responding to medical emergencies

Staff were not always confident, or aware of best practice standards for responding to a medical emergency such as an epileptic seizure or a choking event. In some cases, staff had difficulty distinguishing between an urgent and a non-urgent health situation, thus leading to delays in treatment



SUPPORTING END OF LIFE CARE FOR PEOPLE WITH DISABILITIES

Case studies in several of the in-scope death reviews revealed a lack of clarity, and potentially poor practice, around end of life care for people with disabilities

Of particular concern, are cases where the decision to withhold treatment may have been made in relation to the clinician's perception of the person's quality of life rather than to best practice as indicated by the persons presenting conditions and treatment options