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

Findings

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Background

Why monitoring deaths matters

Mortality data can provide crucial insight into population specific patterns and support the development of targeted preventative and public health initiatives (Lauer & McCallion, 2015). Mortality data are helpful in identifying gaps in care pathways, directing future health care and social service spending, and providing focus to research initiatives (Rogers & Crimmins, 2011). Changes in mortality data over-time can support governments to assess the impact of policy shifts and other changes in the health and social care landscape on populations and specific sub-groups (Lauer & McCallion, 2015). Effective monitoring of mortality data is particularly critical for vulnerable populations that have experienced persistently negative health outcomes.

Mortality among people with disability: an overview

Compared to the general population, people with disabilities are more likely to experience multiple health disadvantages including an elevated mortality rate and lower age of death. A recent systematic review of mortality among people with intellectual disability, for example, found that this group dies, on average, 20 years earlier than the general population (O'Leary et al., 2018). Systematic reviews of mortality data for people with autism spectrum disorder paint a similar picture, with age of death for this group being notably lower than that of the general population (Hirvikoski et al., 2015) and mortality rates being two to three times higher (Woolfenden et al., 2012). These rates are consistent with findings from a recent data linkage project conducted by our department that found that people on the autism spectrum in NSW have a mortality rate 2.06 times that of the general population (Hwang et al., 2019). People with serious mental illness have also been found, in a recent meta-analysis (Walker et al., 2015), to have a significantly higher mortality rate than comparison populations, with a median of 10 potential life-years lost and a pooled relative mortality risk of 2.22.

People with disabilities appear not only to be at increased risk of premature mortality, but also at increased risk of dying from potentially preventable causes. The United Kingdom's confidential inquiry into premature deaths of people with learning disabilities (Heslop et al., 2013), for example, found that 42% of the deaths of people with intellectual disability that occurred during the study period were 'premature'. People with intellectual disability were far more likely, compared to matched non-intellectually disabled controls, to have died from causes related to the quality of the health care they received. Care provision, treatment planning and co-ordination across and between different disease pathways and service providers, and documentation of treatment were all significantly poorer for the group with intellectual disability.

Deaths from potentially preventable causes also appear to be over-represented among Australians with disabilities. For example, a recent analysis of deaths of people with intellectual disability in NSW conducted by our department (Trollor et al., 2017) found that 38% of these deaths were classified as 'potentially avoidable', including mortality from some diseases of the circulatory system, respiratory system, infections and cancers. A disproportionate number of people on the autism spectrum have also been found to die from potentially preventable causes such as poisoning and injury (Hirvikoski et al., 2015; Hwang et al., 2019). An earlier analysis of excess deaths among psychiatric patients in Western Australia found that approximately 80% were due to physical health conditions, many of which were potentially preventable (Lawrence et al., 2013).

Despite documented risk of premature mortality, including from preventable causes, mortality data for people with disabilities are not tracked or integrated in a consistent manner. National and international efforts to track causes and contributors to death for people with disabilities have been hindered by definitional and methodological inconsistencies between jurisdictions. Representative national or state-level mortality data for people with disabilities are not always identifiable, or are grouped in varying or inconsistent categories within existing surveillance systems (Lauer & McCallion, 2015).

Inconsistencies in the quality and robustness of reporting systems used between jurisdictions can present challenges when conducting national or international comparisons (Lauer & McCallion, 2015).

In Australia, some state or territory bodies have historically had their own system for tracking mortality data. Reports on deaths of people with disabilities in Australia have therefore differed widely between jurisdictions, both in terms of scope and timeframe. For example, the Victorian Disability Services Commissioner recently released their first review of deaths of people receiving disability services in Victoria, which covered part of the 2017/2018 time period. In NSW, the NSW Ombudsman is responsible for biannual reporting. The NSW Ombudsman has published nine reports into the deaths of people with disability residing in residential care have been conducted in NSW to date. In Queensland, there has been no specific process for systemically reviewing deaths of people with disability apart from the coronial process for deaths in care. The Queensland Office of the Public Advocate recently published a one-off review of deaths of people with disability in care in Queensland during the period of 2009 to 2014. They supplemented information provided by the State Coroner with information provided by a number of government and non-government agencies to generate insight into mortality trends. To date, state and territory data have not been aggregated to provide national insights into trends relating to deaths of people with disability.

The introduction of the NDIS Quality and Safeguards Commission: an opportunity for change

The National Disability Insurance Scheme (NDIS) Quality and Safeguards Commission (referred to as ‘the Commission’ for the remainder of this review) will be operationalised across all Australian states and territories by 2020. The establishment of the Commission provides an exciting opportunity to develop Australia’s first nationally consistent arrangement for reporting deaths of people with disability who receive NDIS funding. The National Disability Insurance Scheme *(Provider Registration and Practice Standards) Rules 2018* mandate that all registered NDIS providers across Australia must notify the NDIS Commission of reportable incidents, including deaths of people that occurred in connection with their services. Thus, the NDIS Commission will have responsibility for investigating and developing insight into the causes of and contributors to such deaths. This scoping review has been developed in response to the need for the Commission to obtain an Australia-wide insight into deaths and factors relating to the deaths of people with disability.

Aim

The aim of this scoping review is to provide, at the request of the Commission, a national baseline picture of trends, issues and current monitoring practices relating to deaths of people with disability across Australia, based on findings from existing state and territory reports.

Objectives

1. Identify key themes and findings relating to deaths of people with disability across jurisdictions, including broad and underlying causes deaths, risk factors, and risk reduction strategies.
2. Summarise and comment on methodological approaches to monitoring and data analysis used across jurisdictions including: inclusion and exclusion criteria for reportable deaths; definitions for avoidable, expected and unexpected deaths; and investigative methods used to explore causes of and contributors to deaths.

Methodology

Review Type

A scoping review was conducted to identify and interrogate relevant data from different state and territory jurisdictions. A scoping review was considered the most appropriate methodology in light of the heterogeneity of existing state and territory reports. Scoping reviews are particularly useful when operational definitions and conceptual boundaries require clarification (Khalil et al., 2016), no comprehensive review of the body of work has been conducted, or there is sufficient heterogeneity in source scope and methods to make a meta-analysis or other systematic form of data aggregation impractical (Tricco et al., 2018). Scoping reviews are appropriate when, as is the case for this study, insight is sought into general trends about the nature of a problem, rather than seeking a singular specific answer to a research question (Tricco et al., 2018).

Inclusion criteria

All Australian state and territory government publications pertaining to deaths of people with intellectual disability, who were in receipt of specialist disability supports and services during the period of the NDIS rollout, were in-scope. For the purposes of this review, the period of NDIS rollout was defined as 1st January, 2013 until 1st April, 2019. Reports covering a broader time-span, which overlapped with this period, were considered in- scope.

Identification of sources

Published reviews meeting inclusion criteria were identified by searching each state and territory's website and other topical grey literature. The study authors also contacted all relevant state and territory departments and coroners' courts, as well as the National Coronial Inquest System (NCIS) administrators, to confirm that no other reports meeting selection criteria were available. Table 1 identifies jurisdictions where electronic responses were received confirming that their jurisdictions had no consolidated or publicly accessible reports or collections of topical data pertaining to deaths of people with disability that they were aware of. Additionally, electronic communication with the NCIS administrators confirmed that they had no publicly available summary reports, fact sheets or other recommendations aggregating findings related to deaths of people with disability referred to the coroners' courts. Table 2 lists jurisdictions where one or more reports meeting inclusion criteria were identified.

Table 1: Jurisdictions where no in-scope reports were identified

Jurisdiction	Departments responding to request for reports/information concerning deaths of people with disability	Reports identified
ACT	ACT Office for Disability ACT Human Rights Commission ACT Courts and Tribunal	No

NT	NTG Office of Disability	No
SA	SA Coroner’s Court	No
TAS	Office of the Health Complaints Commissioner Ombudsman Tasmania	No
WA	Ombudsman Western Australia Office of the State Coroner	No

Table 2: Jurisdictions where one or more in-scope reports were identified

Jurisdiction	Title of identified report
NSW	NSW Ombudsman (2018). Report of reviewable deaths in 2014 and 2015, 2016-2017. Deaths of people with disability in residential care. NSW Ombudsman (2015). Report of reviewable deaths in 2012 and 2013. Volume 2: Deaths of people with disability in residential care.
VIC	Disability Services Commissioner (DSC). A review of disability service provision to people who have died 2017-18. Melbourne: Disability Services Commissioner Parliament of Victoria, Family and Community Development Committee 2016, Inquiry into abuse in disability services: final report, State Government of Victoria, Melbourne
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.

Data extraction

Five identified reports met the inclusion criteria. The principal investigator extracted the following information, where available, from each report:

- Inclusion and exclusion criteria, time period and terms of reference
- Operational definitions of key mortality reporting terminology
- Investigative methods and the processes used to identify and examine causes or contributors to deaths
- Cohort demographics
- Primary and additional disability types
- Other identified mental health and physical health issues
- Underlying cause of death and other contributing causes
- Any differences in risk factors or causes of death between cohorts
- Any methodological limitations identified by study authors
- Key themes, findings and recommendations made by study authors

Where possible, we also reached out to study authors to provide clarification or additional detail where necessary.

Data analysis

Extracted data were compared and aggregated thematically across all reports in order to:

- Identify national trends and issues pertaining to deaths of people with disabilities
- Make recommendations for resolving methodological inconsistencies in data monitoring, investigation and analysis and provide the Commission with guidance for developing a uniform best practice data collection and analysis framework.

This report describes findings from the scoping review. A separate report will be prepared for the Commission outlining recommendations stemming from these findings.

Findings

This section of the review provides an overview of the five in-scope reports, summarises inclusion/exclusion criteria, and outlines the investigative processes undertaken to examine deaths across jurisdictions.

Overview of reports

Only three Australian States (VIC, NSW and QLD) had publicly available reports pertaining to deaths of people with disability within their jurisdiction (see Table 3). Of these, NSW was the only state with a well-established, systematic and ongoing system for tracking such data. Mandatory biennial reporting of deaths of people with disability in residential care commenced in NSW in 2002. The NSW Ombudsman's 2012-13 and 2014-17 reports are in-scope for this review. In VIC, the Victorian Disability Services Commissioner released one report covering part of 2017-18 (included in this review) and plans to release one final topical report later in 2019 before handing over its death reporting functions to the Committee. The Victorian Inquiry into abuse in disability services was a one-off report, covering in-scope deaths from 2007-2016. The only in-scope report from QLD included deaths from 2009-2014 and was a one-off report produced by the Office of the Public Advocate.

Table 3: In-scope reports

Jurisdiction	Report title	Report frequency
VIC	Disability Services Commissioner (DSC). A review of disability service provision to people who have died 2017-18. Melbourne: Disability Services Commissioner ** For remainder of report will be referenced as 'VIC 17-18'*	First report of its kind: One final report will be published later in 2019 then the NDIS commission will take over death reporting functions
VIC	Parliament of Victoria, Family and Community Development Committee 2016, Inquiry into abuse in disability services: final report, State Government of Victoria, Melbourne ** For remainder of report will be referenced as 'VIC 07-16'*	First of its kind
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. *For remainder of report will be referenced as 'QLD 09-14'*	First of its kind

Jurisdiction	Report title	Report frequency
NSW	NSW Ombudsman (2015). Report of reviewable deaths in 2012 and 2013. Volume 2: Deaths of people with disability in residential care. **For remainder of report will be referenced as 'NSW 12-13'*	8th report of its kind Mandatory biannual reporting commenced in 2002
NSW	Ombudsman NSW (2018). Report of reviewable deaths in: 2014 and 2015 & 2016 and 2017: Deaths of people with disability in residential care **For remainder of report will be referenced as 'NSW 14-17'*	9th report of its kind Covers two biannual reporting periods

In-scope deaths

Table 4 summarises key inclusion and exclusion criteria for each report. In-scope deaths varied widely across reports. In summary, variance was due to a number of factors including:

Different data collection periods: Length and time range of in-scope deaths varied from 7 months (VIC 17-18) to 9 years (VIC 07-16).

Differences in terms of reference: Significant heterogeneity in terms of reference was also noted across reviews. For example, the VIC 07-16 report was restricted to deaths of people with disability in residential care whose deaths could be potentially related to abuse and neglect in care provided by a disability service provider. In contrast, the VIC 17-18 report had much broader terms of reference, including both expected and unexpected deaths of all Victorians in receipt of disability services. In QLD, the Office of the Public Advocate (QLD 09-14) examined both expected and unexpected deaths across a range of settings, but only where the person had an intellectual disability. In NSW (NSW 12-13 & 14-17), only deaths of people with disabilities in residential care were in-scope.

Differences in how 'disability service providers' are defined under each jurisdiction's Disability Act also impacted which populations were included.

Reviewing exclusion criteria across reports, it appears that the deaths of certain types of people with disability are under-represented in this scoping review, including:

- Deaths of people with disability who live at home and/or do not access disability services
- Deaths of people with disability who reside in residential aged care facilities
- Deaths of people with disabilities who are in custody or in a mental health facility.

The great variance in terms of reference and inclusion criteria between reports means that the deaths examined in this scoping review are highly unlikely to be representative of the broader population of people with disabilities residing in Australia.

Definitional differences as to what constitutes a ‘reportable’ death of a person with disability under each jurisdiction’s Coroner’s Act: Table 5 summarises what constitutes a ‘reportable death’ across in-scope jurisdictions. Each Australian state and territory has its own Coroners Act, the wording of which has different implications for which deaths are considered ‘reportable’ (Middleton & Buist, 2014). For example, deaths of people with disability receiving non-government funded disability care in Victoria are not considered ‘reportable’ under the Victorian Coroner’s Act. Of note, not all deaths that were reportable to the state coroner were automatically in-scope for the death review in that jurisdiction. For example, deaths of people detained in a secure mental health facility and deaths of people in custody are reportable to the coroner but are not in-scope for the NSW Ombudsman review of deaths of people with disability in residential care, even when the person was known to have a disability.

Table 4: Inclusion and exclusion criteria for in-scope reports

Report ID	Time period	In-scope deaths	Deaths of people with disabilities that were out-of-scope
VIC 17-18	24/07/2017-2018 *Report noted to cover a 7 month time	Both expected and unexpected deaths of people who were in receipt of disability services as defined by the *Disability Act 2006 (The Act)*, whose deaths were subsequently reported to the investigating team by DHHS* through its client incident reporting system *or* by notification from the State Coroner. Included people with disability who accessed:	Deaths where the person's service provider was not a disability service provider or a regulated disability service as defined by the Act.

	period but no exact end date was specified	• Individual support services (day services, flexible support packages, individual support packages, outreach support, respite) • Information, planning and capacity building services (case management, access) • Targeted services (behaviour intervention services, independent living training) • Residential services (residential institutions, shared supported accommodation) • Victorian approved National Disability Insurance Scheme (NDIS) disability and psychosocial supports.	Deaths of people not receiving any disability services and whose deaths were not mandated to be reported to the state coroner for some other reason
VIC **07-16**	2007 until 2016 *Exact start and end dates not specified	• Deaths of people with disability that occurred in a residential facility in Victoria; and • Were reportable to the State coroner; and • Included mention of the *Disability Act 2006* as part of their entry to the National Coronial Information System; and • Were included by the committee in the 200 deaths it reviewed out of the total of 570 deaths identified using above method, and • Were deaths potentially related to abuse and neglect in care provided by a disability service provider.	Deaths where abuse or neglect were not suspected Deaths not selected for the subsample case review (370 of the 570 deaths identified by coroner) Deaths occurring at home or hospital Deaths not reportable to the coroner
QLD **09-14**	2009-2014 *exact start and end dates not specified	A person was included in the sample if: • They had an intellectual disability or cognitive impairment; and • They were aged 18 years or over at time of death; and • Their death was a death in care as defined in the Coroners Act 2003; and • They resided in accommodation support service funded or provided by the Department of Communities, Child Safety and Disability Services or in a level 3 residential service; and • Their death was reported to the State Coroner with at least a Police Report, or Medical Practitioner's Report and Coroner's Findings, or Cause of Death certificate available.	Deaths of people under 18 years of age Deaths of people who were not cognitively impaired Deaths of residents in other health facility (such as an aged care facility). Deaths with insufficient details contained in the file received from the Coroner

NSW **12-13**	1 Jan 2012-31st Dec 2013	- A person with disability was included in the sample if the person was living in, or temporarily absent from, residential care provided by a service provider or an assisted boarding house in NSW. - 'Service provider' is defined as: "The Department of Family and Community Services; an implementation company under the *National Disability Insurance Scheme (NSW Enabling) Act 2013*; a person or organisation funded, authorised or licensed by the Minister for Family and Community Services, the Minister for Ageing or the Minister for Disability Services to provide a service; the Home Care Service of NSW or a person or organisation funded by the Home Care Service to provide a service; a	Deaths of people living at home Deaths of aged care facility residents (including younger adults with disabilities who live in this setting) Deaths in custody Deaths of detainees in a

		person or organisation that is covered by an arrangement made after 7 April 1994 between a Minister of NSW and a State or Commonwealth Minister, under which arrangement that State or Commonwealth Minister agrees to the person or organisation being a service provider for the purposes of this Act; an authorised carer or designated agency within the meaning of the *Children and Young Persons (Care and Protection) Act 1998*; or the proprietor or occupier of premises that consist of an assisted boarding house”. • “Residential care” includes group homes, residential centres, assisted boarding houses, and other accommodation for people with disability, such as centre-based respite.” Until 30 June 2018 residential care provided by persons or organisations that are funded under the National Disability Insurance Scheme (NDIS) are also included.	mental health facilities
NSW **14-17**	1st Jan 2014-31st Dec 2017	As above	As Above

Table 5: ‘Reportable’ deaths

Report ID	What deaths are reportable in this jurisdiction?
VIC **17-18**	**Definition of ‘reportable death’ to state coroner:** Relies on definition of ‘reportable death’ in the Victoria Coroners Act 2008 “Under the *Coroners Act 2008* (Coroners Act), the death of a person in receipt of disability services is a ‘reportable death’, and must be reported to the Coroner if the body is in Victoria, or the death occurred in Victoria, or the cause of death occurred in Victoria, or the person ordinarily resided in Victoria at the time of death, and it meets one of the following criteria: • the death appeared unexpected, unnatural or violent or to have resulted directly or indirectly from an accident or injury • the death occurred during a medical procedure or following a medical procedure where the death is or may be causally related to the medical procedure and a registered medical practitioner would not, immediately before the procedure was undertaken, have reasonably expected the death • the deceased person was immediately before their death, placed in custody or care. A person placed in custody or care includes a person who was under the control, care or custody of the Secretary of DHHS. This includes people in receipt of disability accommodation services administered by DHHS under the Act. In these cases, the death must be reported to the Coroner, regardless of the circumstances of the death • the deceased person who immediately before their death was a patient within the meaning of the *Mental Health Act 2014* 59 • the deceased person was under the control, care or custody of the Secretary of the Department of Justice or a police officer 60 • the deceased person was subject to a non-custodial supervision order under ss. 26 or 38ZH of the *Crimes (Mental Impairment and Unfitness to be Tried) Act 1997* 61 • the identity of the deceased person is unknown 62 • if the death occurs in Victoria and a death notice under s. 37(1) of the *Births, Deaths and Marriages Registration Act 1996* has not been signed or is not likely to be signed by a doctor who was responsible for the person’s medical care immediately before their death, or who examined the body of the person after their death • the death occurs outside Victoria and the cause of death is not certified by a person who is authorised to

	certify the death and the cause of death - the death is of a prescribed class of person - the death occurs in prescribed circumstances" **Of note, deaths of people with disability receiving non-government funded disability care are not included under this definition of 'reportable' deaths** **Definition of reportable death to the VIC Disability Services Commissioner:** In September 2017, the *"Disability Amendment Bill 2017"* was passed, making it mandatory for the state coroner and DHHS to report both expected and unexpected deaths of people receiving disability services at the time of death to the Disability Services Commissioner
VIC **07-16**	As Above (minus the *Disability Amendment Bill 2017* that was enacted after this report's publication).
QLD **09-15**	*The Coroner's Act 2003 (Qld)* provides the legislative framework for reporting, recording, investigating, and for inquiries into deaths in care in Queensland: - A 'death in care' includes the death of people with disability, mental illness, or children who are in certain types of care facilities/arrangements. - Deaths in care must be reported to a Coroner or a police officer by the relevant service provider, even if the service provider may believe that someone else (for example, a doctor or an ambulance officer) has reported the death. For the death of a person with disability to be considered a death in care, the person must have had a disability as defined in the *Disability Services Act 2006* and have been: - living in a level 3 accredited residential service; or in receipt of disability accommodation services by an agency funded by DCCSDS. These include ASRS and private homes or rental homes where one or more people with a disability live with support from a non-government organisation funded by DCCSDS; - living in a residential service (other than a private dwelling or aged care facility) wholly or partly funded by the Department of Health (such as long-stay health care facilities including Halwyn Centre or the Jacana Centre); - a forensic disability client detained to the Forensic Disability Service; - was detained in an authorised mental health service or certain other criteria under the Mental Health Act 2000 (Qld); or was a person under guardianship under certain provisions of the Adoption Act 2009 (Qld) or Child Protection Act 1999 (Qld). A person's death is still a death in care if the person died somewhere other than the care facility in which they ordinarily lived."

NSW **12-13**	In NSW, all deaths of people with disability in residential care are coronial deaths, and are required to be reported to NSW Police and the State Coroner. They are also required to be notified to the NDIS Quality and Safeguards Commission or FACS: • The deaths of people with disability who were living in residential care provided by a registered NDIS provider are required to be notified to the NDIS Quality and Safeguards Commission. • The deaths of people with disability who were living in residential care provided by FACS or an assisted boarding house are required to be reported to FACS. The definition of a death in residential care includes, "Persons with disability who, at the time of their death, were living in or temporarily absent from, residential care provided by a service provider or an assisted boarding house." Ref: https://www.ombo.nsw.gov.au/what-we-do/our-work/community-services/reviewable-deaths On 1 July 2013, the NDIS began in the Hunter region of NSW. For the purposes of this report, all of the functions of the Ombudsman's office in NSW – including reviewable deaths functions – apply to the NDIS launch sites.

	According to the NSW Coroners Act deaths are 'reportable' in the following circumstances: • "The death was violent or unnatural (for example, homicide, suicide, drug, alcohol and poison related deaths) • The death was sudden and the cause of it unknown • the death resulted, directly or indirectly, from an accident or injury, even if there is a prolonged interval between the incident and death (for example, drownings; deaths caused by a traumatic event such as a motor vehicle accident) • the death occurred during or following a health-related procedure where the death is or may be causally related to the procedure and a registered medical practitioner would not, immediately before the procedure was undertaken, have reasonably expected the death • a Medical Certificate of Cause of Death has not been signed and is not likely to be signed (for example, where an opinion about the probable cause of death cannot be formed) • the deceased had not been attended by a doctor in the last six months • the deceased was in, temporarily absent from or residing at a declared mental health facility within the meaning of the Mental Health Act 2007 for the purpose of receiving care, treatment or assistance • the identity of the deceased in not known • the death occurred in custody • the death occurred as a result of, or in the course of, a police operation • the deceased was a child in care to whom a report has been made about them or a sibling in the 3 years preceding their death to the Department of Family and Community Services; • the deceased was living in, or temporarily absent from, an authorised residential centre for persons with a disability." Reference: http://www.coroners.justice.nsw.gov.au/Pages/coroner_role/coroners_role.aspx
NSW 14-17	As Above

Investigative methodology

Table 6 summarises the investigative powers of each team, and the investigative process used to identify and analyse in-scope deaths.

Table 6: Investigative methodologies used

Report ID	**Investigative powers held**	**Methodology used to investigate deaths**
VIC 17-18	2017 Amendments to the *Disability Act 2006* gave the Disability Services Commissioner power to:	The Disability Services Commissioner established a systematic Death Review Team comprised of experts with a range of backgrounds including disability, government investigations, social work, legal, academic, medical and data analysis.

	- Initiate investigations into allegations of abuse or neglect in the provision of disability services - Undertake investigations into	The team received death notifications of in-scope deaths from both DHHS and the State Coroner. If deaths were reported to state coroner, the state coroner sent the systematic review team records and information such as medical examiners reports, police reports, medical records, and coronial findings. A phase-based investigation was then conducted:

	matters referred by the Minister or the Secretary of DHHS • Appoint authorised officers and undertake visits and inspections of premises on which a disability service provider is providing a service that is being investigated • Issue a Notice to Take Action to a service provider where it has been identified that there are opportunities to improve the disability services, or to prevent abuse or neglect • Receive reports from a service provider on actions it has taken to comply with a Notice to Take Action • Undertake follow-up investigations.	1) written notice provided to the relevant service provider/s to advise of the establishment of investigation under s. 1281 of the Act. An information sheet is provided at this time to explain the process and approach to undertaking the investigation. 2) A questionnaire is also sent to the service provider to complete about the person who died: includes questions about demographics, health, wellbeing, disability service provision. 3) Documents for 3-12 months before person's death are also requested from service provider. These documents include: o palliative care or treatment plans for expected deaths o non-critical client event logs o communication, shift handover, staff meeting and daily case notes o staff rosters o plans including behaviour support, health and general person-centred plans o client file notes o previous reviews or investigations as relevant o current health assessments at the time of the person's death o hospital discharge summaries as relevant o incident reports. 4) Once all these documents are received by review team, they begin a 'desktop review' of all these documents: o If issues are identified that may place other people with disability at risk, such matters are quickly escalated with the service provider to rectify immediately. In cases where potential criminal conduct may have occurred, matters are referred to Victoria Police. o Where it is determined the investigation would benefit from additional enquiries, we use other methodologies. These include site visits, either through exercising Authorised Officer powers or by pre-arrangement with the service provider, and conducting interviews with family members, next of kin and staff from disability service providers. o Investigative report provided to secretary of DHHS. • If necessary, Notice to Take Action issued to service provider. • As needed, recommendations of a systemic nature provided to the secretary of DHHS • If relevant, general advice provided to disability service providers to prevent abuse or neglect within these services.
VIC 07-16	Parliament of Victoria Family and Community Development Committee had powers to make enquiries and view case reports pertaining to potentially in-scope deaths.	The committee requested the VIC state coroner's office to retrospectively extract in-scope cases from the 'National Coronial Information System' (NCIS). All cases in the specified time period that occurred within a residential care facility that contained mention of the Victorian Disability Act were extracted. For the purposes of the Inquiry, the committee then manually reviewed 200 of the 570 deaths extracted via review of case reports to determine cases of potential abuse or neglect.

QLD **09-14**	The Public Advocate is empowered by section 210A of the Guardianship and Administration Act 2000 to: “request all information necessary to monitor and review the delivery of services and facilities to	An advisory panel was established. The panel included heads of agencies holding statutory roles with functions relevant to monitoring the provision of supports and services including health services to adults with disability as well as medical practitioners with specific expertise in the health care of people with disability, including intellectual disability In-scope death information was requested from the following government and non-government agencies:

	adults with impaired capacity for a matter, and about the policies and procedures in relation to the provision of services and facilities to the adults." With these powers they were able to request information from both government and non-government agencies.	• The State Coroner: documents requested included coronial documents, police documents, other investigative documents related to the death • The Department of Communities, Child Safety and Disability Services (DCCSDS): Once the review of the Coroner's findings and investigation documents commenced, DCCSDS also provided the Public Advocate with more specific details about those people identified through the Coroner's documentation as having been in receipt of DCCSDS funded or provided services, including details about their primary diagnosis, the disability service in which they resided, and any critical incident reports associated with their death. • Queensland Health: documents requested included patient discharge summaries from six months prior to death, client files from 12 months before death, and any clinical incident report, root cause analysis or SAC1 reportable event review for the person. • Department of Housing and Public Works: Data requested included the number of deaths of people with disability in care in level three residential services between 2010 to 2013 as well as any reports or documents recording the thematic analysis of deaths in care or critical incidents with respect to people with disability in level 3 accredited residential services. • Non-government service providers were requested to provide copies of client files, usually restricted the 12 months before their death. • Office of the public guardian: Data were requested on the number and nature of deaths of people with disability in care that were brought to the attention of Community Visitors. Investigative steps: 1) Standard demographic data extracted from each file 2) Review panel examines demographic information, plus coroner's investigative documents and any critical incident reports available 3) Review panel analyses the sequence of events leading up to the death to: ○ Determine if the death was an unexpected death; or either potentially treatable or potentially preventable and so potentially avoidable. ○ Identify issues in the provision of health care or support provided to the person; and ○ Identify whether the person had any risk factors or other characteristics that may have placed them at a greater likelihood of developing the conditions that led to death. The panel then analysed demographic patterns and trends across deaths; identified issues in the provision of support and health care for people in the sample that may also impact people with disability more broadly; identified risk factors for people with disability whose deaths were considered avoidable; and made recommendations to improve the delivery of health care and support to people with disability to address the risk of avoidable deaths.

NSW 12-13	Under Part 6 of the Community Services (Complaints, Reviews and Monitoring) Act 1993 (CS CRAMA), the NSW Ombudsman has power to review the deaths of any person living in, or temporarily absent from, residential care provided by a service provider or an	A reviewable disability deaths expert advisory panel has been established. Where necessary, consultation is undertaken with this advisory panel. For example, in the 2012-13 calendar years, expert advice was sought in relation to the deaths of 55 people. The NSW Ombudsman commences investigation once being notified of in-scope deaths by the following bodies: 1) The Registrar of Births, Deaths and Marriages must provide the Ombudsman with a copy of death registration information relating to a child's death not later than 30 days after receiving the information

	assisted boarding house.	2) The Chief Executive of Ageing, Disability and Home Care (ADHC) must provide the Ombudsman with copies of any notification received by the Chief Executive relating to a reviewable death not later than 30 days after receiving the notification, and 3) The State Coroner must notify the Ombudsman of any reviewable death notified to the State Coroner not later than 30 days after receiving the notification. **Investigative process typically involves:** 1) Analysis of the initial information provided by the disability accommodation service (Client Death Notification form, key support plans) and our internal information holdings (including previous deaths at that location/service; current and recent complaints and/or reportable incidents at that location/service; previous matters involving that person, etc.) to determine the level of review that will be undertaken. For example, if the person was 85 years of age, their death was due to causes that are consistent with the general population at that age, and there are no evident concerns, a 'data only' review will generally be conducted. Data only reviews involve capturing all relevant information for biennial reporting purposes, but not undertaking a further review. The majority of matters have a more detailed review. 2) For deaths requiring a more detailed review- relevant written records are obtained and reviewed– typically includes all records held by the disability accommodation provider about the person for at least the previous 12 months (as well as any internal review conducted by the provider following the person's death); all records held by involved health services (LHDs) for the same time period or as relevant; all records held by the GP; Ambulance records for key events; and other services as needed (e.g.: the day program provider; FACS' Boarding Houses Team; particular specialists, etc.). The Coroner's office provides us with key records (as required under CS CRAMA), including the COD, PM report, etc. 3) Where issues are identified or clarifying information is needed, the investigative team writes to the relevant agency (typically the disability accommodation provider and/or LHD) seeking further information from them/ providing them with an opportunity to respond. Depending on the matter, there may be additional actions, including meetings with the agency; monitoring of agreed actions, etc. 4) All of the key data and other information go into the Death Review System (Resolve database), which is used for reporting and other purposes.
NSW 14-17		As above

Overview of deaths and characteristics of those who died

Across the five reports, the deaths of 901 people with disability were examined (see Table 7). The NSW Ombudsman report covering two biannual periods (2014-15 and 2016-17) had the largest sample size (n=494), while the VIC 07-16 report examined the deaths of seven individuals only. This section of the review summarises the characteristics of the people who died, including age, gender, cultural status, accommodation type, time and place of death, causes of disability, other mental and physical health problems, medication status, communication and mobility needs, capacity to consent, smoking, weight and physical activity status, date of last annual health exam, and vaccination status. No demographics were systematically provided for the in-scope deaths in the VIC 07-16 inquiry so this section is left blank. Table 7 summarises key demographic across reports.

Gender

Deaths of men were overrepresented across all reports.

Median age at death

Across all samples, reported median age at death was substantially (20-36 years) lower than that of the general Australian population. A younger age at death was noted for people receiving disability services, compared to assisted boarding house residents, in the NSW samples (NSW 12-13 & 14-17).

Median age at death by gender

Of the two reports that discussed median age at death by gender, findings were inconsistent: The VIC 17-18 report found that women in their sample lived, on average, 2 years longer than men (54 years versus 52 years). However, this pattern was reversed in the QLD 09-14 report, where women in the sample lived, on average, 4 years less than men (49 versus 53 years). In both cases, the gender gap in median age of death appears somewhat less substantial than the five years reported in the general population (ABS, 2016).

Cultural status

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). Unfortunately, no report analysed cause of death, disability type or any other factor by cultural status, so we are unable to comment on any death trends or risk factors specific to these populations.

Table 7: Cohort demographics

Report ID	N	Gender	Age at death	Cultural Status	Comparisons provided to state or national statistics where provided
VIC 17-18	88	Male: 59% Female: 40% Trans-gender: 1%	*Range:* 10-78 yrs *Median age* (whole sample): not stated *Median age* (by gender): 52 years for men 54 years for women	ATSI: 0% CALD: 14%	In 2016, the median age of death for whole Victorian population was 80.3 years for males; 85.5 years for females. *"Our data indicates that people receiving disability services in Victoria die younger compared with the general Australian population; Based on median age, about 29 years younger."*
VIC 07-16	7	-	-	-	-
QLD 09-14	73	Male: 70% Female: 30%	*Range:* 21-81yrs *Median age* (whole sample): 51yrs Median age (by gender): 53yrs for men 49yrs for women	ATSI: 11% Pacific Islander: 1%	Men in the sample noted to live approximately 25 years less than the general population. Women in the sample noted to live approximately 36 years less than the general population

NSW **12-13**	239	**Disability services:** Male: 56% Female: 44% **Assisted boarding**	**Disability services** • *Range:* 18-87yrs • *Median age* (whole sample): 55yrs • Median age (by gender): not stated **Assisted boarding**	**Disability services** ATSI: <1% CALD: 6% **Assisted boarding houses:** ATSI:0%	The average age at death of people with disability in residential care was approximately 25 years younger than the average of the general Australian population

		houses: Male: 79% Female: 21%	**houses:** - *Range:* 46-87yrs - *Median age* (whole sample): 59yrs - Median age (by gender): not stated	CALD: 14%	
NSW 14-17	494	**Disability services:** Male: 59% Female: 41% **Assisted boarding houses:** Male: 83% Female: 17%	**Disability services:** - *Range:* not stated - *Median age* (whole sample): 55yrs - Median age (by gender): not stated **Assisted boarding houses:** - *Range:* not stated - *Median age* (whole sample): 60yrs - Median age (by gender): not stated	**Disability services** **2014-2015** ATSI: 1% CALD: 7% **Disability services** **2016-2017** ATSI: 2% CALD: 5% **Assisted boarding houses** **2014-2015** ATSI: 13% CALD: 13% **Assisted boarding houses** **2016-2017** ATSI: 10% CALD: 20%	Life expectancy gap, compared to the general population noted to be: - 25 years for people in disability services - 20 years for people in assisted boarding houses

Where did people usually reside at the time of their death?

Table 8 summarises the accommodation status and disability service arrangements of people whose deaths were in-scope for this review (where such data were available to us). NSW was the only state to provide a stratified analysis of demographics, health status, and causes of and contributors to death based on the person's accommodation type. The NSW Ombudsman reports divide the sample into two groups; 'disability services' residents (recipients of ADHC or NGO services) and 'assisted boarding house' residents. This division was made based on the significantly differing legislative and service provision requirements across settings. We note that findings vary substantially in the NSW samples based on accommodation type and that such a stratified analysis has allowed the NSW Ombudsman to develop a more nuanced picture of different types of deaths as a result. We commend such an approach to the Commission and note that more targeted intervention strategies may be developed as a result.

Table 8: Accommodation status

Report ID	Accommodation type and disability service provision
VIC **17-18**	*Government or private:* • 50% (44 people) in receipt of government funded disability services at time of death • 50% (44 people) in receipt of non-government funded disability services at time of death *Service type breakdown:* • Shared supported accommodation (83%; 73 people) • Individual support package (8%; 6 people)
VIC **07-16**	-
QLD **09-14**	• 89%: Usually resided in disability provided or funded services at time of death (89%): This was comprised of 53% in supported accommodation provided by non-government organisations and 36% supported by government run AS&R • 11%: Usually resided in level 3 residential service accommodation at time of death
NSW **12-13**	• 121 people (51%) lived in Department of Family and Community Services: Ageing, Disability and Home Care (ADHC) accommodation • 101 people (42%) lived in non-government (ADHC-funded) accommodation • 14 people (6%) lived in assisted boarding houses, and • 3 people (1%) were living in private or community housing with ADHC or NGO support.

NSW 14-17	• 234 people (47%) lived in FACS accommodation • 238 people (48%) lived in non-government organisation (NGO) accommodation – FACS or NDIS funded • 18 people (4%) lived in assisted boarding houses • 3 people (0.6%) were living in private or community housing with FACS or NGO support.

The health status of people who died

Primary and additional disabilities

Primary and additional disabilities are outlined in Table 9. The way in which a person's disabilities were recorded and accounted for varied from state to state. In Victoria (VIC 17- 18), the person's 'primary' disability type was recorded in the death review. This was defined as, 'the primary disability type requiring most support'. Information about 'additional' disabilities was also collected, however, no working definition for this term was provided. In QLD (09-14), the 'primary' disability type was defined as the disability recorded on the person's coronial documentation. In NSW (12-13 & 14-17), the Ombudsman listed all disabilities as part of their analysis without distinguishing between primary or additional disability status for reporting purposes.

Despite these differences in reporting methods, it is clear that the overwhelming majority of in-scope deaths across samples involved people with intellectual disability. In samples that ranked frequency of primary disabilities, intellectual disability was consistently highest ranked (impacting between 40%- 54% of people). Where intellectual disability was considered as *either* a primary or secondary cause of disability, it was listed as a cause of disability for between 74% and 89% of people whose deaths were in-scope. In the Victorian sample (VIC 17-18), people were more likely to have mild or moderate intellectual disability (60%), compared to severe or profound intellectual disability (37%). In the 2012-13 NSW sample, however, people were reported as being more likely to have moderate or severe intellectual disability (99%), compared to mild intellectual disability (1%). Level of intellectual disability was not provided in any of the other reports.

Table 9: Type of disability

Report ID	Type of disabilities
VIC **17-18**	**Primary disability type requiring most support:** • **Intellectual disability: 40%** *Detailed breakdown:* Mild (11%)*;* Moderate (14%)*;* Profound (4%)*;* Severe (9%)*;* Unknown (2%) • **Physical disability: 19%** *Detailed breakdown:* Cerebral palsy (inc spastic quadriplegia) (14%)*;* Other (5%) • **Neurological: 19%** *Detailed breakdown:* Acquired brain injury (7%)*;* Huntington's disease (4%)*;* Multiple Sclerosis (4%)*;* Muscular dystrophy (2%)*;* Other (2%)

	• **Syndrome-related: 16%** *Detailed breakdown:* Down syndrome (7%)**;** Fragile X (4%)**;** Tourette (1%)**;** Other (5%) • **Autism: 4%** *Detailed breakdown:* Level 2- requiring substantial support (2%)**;** Level 3- requiring support (1%) • **Mental illness: 2%** *Detailed breakdown:* Other (2%) Total percentage of sample with intellectual disability as primary *or* additional disability: **74%** (Severe or profound- 37%; Mild or moderate: 60%; Unknown: 3%)
VIC **07-16**	Not Stated
QLD **09-14**	**Primary disability (as recorded on the person's coronial documentation):** • Intellectual disability: 53% • intellectual impairment: 23% • Acquired brain injury: 6% • Neurological disability: 3% • Cognitive impairment: 1% • Primary disability not recorded: 14%
NSW **12-13**	No distinction made between primary and additional disabilities; non-mutually exclusive disability types presented: • **Intellectual disability:** 84.5% (moderate or severe- 99%; mild-1%) • **Sensory disability:** 59% (The primary sensory impairment for people in disability services and assisted boarding houses was vision impairment.) • **Physical disability:** 49.4% (The people with physical disability most commonly had cerebral palsy, scoliosis, and/or ataxia.) • **Psychosocial disability:** 43.5% (All of the assisted boarding house residents who had a mental illness had schizophrenia or schizoaffective disorder. Most of the people in disability services who had a mental illness had a mood disorder, such as depression or bipolar disorder; schizophrenia or other psychotic disorder; and/or an anxiety disorder) • **Neurological:** 13.8% (Dementia, including Alzheimer's disease, was the primary neurological impairment of the people who died in 2012 and 2013) • **Acquired brain injury:** 9.6% (The brain injuries were acquired via a range of means, including alcohol-related brain damage, brain tumours, infection, and as a result of an accident.) • **Autism:** 5.4%
NSW **14-17**	No distinction made between primary and additional disabilities; non-mutually exclusive disability types presented: **For the 2014 and 2015 calendar years:** • Intellectual disability: 89.4% • Sensory disability: 73.3% • Physical disability: 53.8% • Psychosocial disability: 44.9% • Neurological: 25% • Acquired brain injury: 11% • Autism: 8.1% **For the 2016 and 2017 calendar years:** • Intellectual disability: 88.4% • Sensory disability: 72.9% • Physical disability: 53.1% • Psychosocial disability: 53.1% • Neurological: 23.6% • Acquired brain injury: 11.2% • Autism: 6.6%

Mental health concerns

Mental health concerns are outlined in Table 10. Across samples, people were noted to have high levels of co-occurring mental health concerns. In NSW, 43.5% of in-scope deaths that occurred in 2012-2013, and 53.1% of deaths that occurred in 2014-2017 involved people with a diagnosis of 'psychosocial disability'. Thirty-four percent of the 2017-2018 VIC sample were noted to have mental health concerns. The top 3 mental health concerns in this sample were depression (19%), self-harming behaviours (15%), and anxiety (14%). Schizophrenia was listed as an additional disability for 11% of the VIC 17-18 sample and 7% of the QLD 09-14 sample.

Table 10: Mental health concerns

Report ID	Mental health concern
VIC 17-18	In addition to primary cause of disability, 34% of sample also had a mental health concern: • Schizophrenia: 11% • Depression: 19% • Anxiety: 14% • Bipolar: 7% • Known history of self-harming behaviours: 15%
VIC 07-16	Not Stated
QLD 09-14	• 7% of the sample had "Schizophrenia" listed as an additional disability. • No other mention of mental health profile of sample made in the report.
NSW 12-13	43.5% of the sample were listed as having a 'psychosocial' disability: *"All of the assisted boarding house residents who had a mental illness had schizophrenia or schizoaffective disorder. Most of the people in disability services who had a mental illness had a mood disorder, such as depression or bipolar disorder; schizophrenia or other psychotic disorder; and/or an anxiety disorder"*
NSW 14-17	53.1% of the sample were listed as having a 'psychosocial' disability.

Physical health conditions

Physical health conditions are outlined in Table 11. Across samples, the vast majority of people who died were reported to experience multiple physical health problems in addition to their disability. The VIC 17-18 report was the only one that attempted to quantify the number of physical co-morbidities per person. They found that, in addition to their disability, 96% of the sample had a known physical health condition. On average, there were four physical health conditions per person. Across reports, common physical health problems included dental problems (impacting 51%- 83% of people) and epilepsy (impacting 28%- 49% of people across samples- with the exception of NSW assisted boarding house residents where epilepsy was not recorded). Constipation, urinary incontinence and Gastro Oesophageal Reflux Disease (GORD) were also commonly reported problems across samples.

Table 11: Physical health conditions

Report ID	Physical health conditions	
VIC 17-18	• Some teeth missing, no teeth or required dental aids: 51% • Urinary incontinence: 51% • Constipation: 40% • Faecal incontinence: 40% • Epilepsy: 28%	• History of respiratory infections: 27% • Heart problems: 21% • GORD: 19% • Hypertension: 19% • Diabetes: 14% • Diseases of the eye: 14%
VIC 07-16	-	-
QLD 09-14	• Epilepsy: 49% • Cerebral palsy: 32% • Down Syndrome: 15% • Vision impairment: 5%	• Hearing impairment: 3% • Spastic Quadriplegia: 3% • Other: 11%
NSW	**For disability service residents:**	**For assisted boarding house sample:**

12-13	• Incontinence: 71% • Constipation: 69% • GORD: 62% • Epilepsy: 48% • Recurrent respiratory infections: 46% • Osteoporosis: 36% • Hypertension: 29% • High cholesterol: 20% • Hypothyroidism: 19% • Heart problems: 19% • Arthritis: 41% • Urinary tract infections: 18% • Asthma: 16% • Diabetes: 15%	• Hypertension: 40% • High cholesterol: 40% • Constipation: 33% • GORD: 33% • Asthma: 33% • Diabetes: 27% • COPD: 27%
NSW 14-17	**For disability service residents:** • Constipation: 75% • Mobility problems: 70% • Incontinence: 69% • Dental problems: 67%	**For assisted boarding house sample:** • Dental problems: 83% • COPD/CAL/COAD: 50% • Overweight: 50% • High cholesterol: 33%

	• Swallowing difficulties: 65% • GORD: 62% • Eating problems: 51% • Epilepsy: 48% • Osteoporosis: 37% • Overweight: 37% • Vitamin deficiency: 36% • Hypertension: 30% • Aspiration pneumonia: 23% • Arthritis/osteoarthritis: 21% • Heart problems: 20% • Hypothyroidism: 20% • High cholesterol: 19% • Underweight: 17% • Urinary tract infection: 17% • Asthma: 15%	• GORD: 33% • Hypertension: 28% • Incontinence: 22% • Arthritis: 17% • Osteoporosis: 17% • Constipation: 17% • Ischaemic heart disease: 11% • Diabetes: 11% • Cellulitis: 11% • Hep C: 11% • Kidney disease: 11% • Hypothyroidism: 11% • Vitamin deficiency: 11%

Medication prescriptions

Medication patterns are outlined in Table 12. Only the QLD 09-14 report and the NSW 14- 17 report provided a detailed analysis of medication usage across their sample. Based on these two reports, it appears that psychotropic medications were commonly prescribed to people with disability who had died, often in the absence of a diagnosed mental illness. In the QLD sample, for example, 49% were prescribed psychotropic medications at the time of their death, most without a diagnosis of mental illness. In the NSW 14-17 sample, 87% were taking psychotropic medication at the time of their death. Notable, of these 87%, almost half (42%) had behaviours of concern but did not have a behaviour support plan- including 32 people who did not have any identified mental health condition.

High rates of polypharmacy were also noted in both reports. People in the QLD 09-14 sample were taking an average of 3.2 psychotropic medications per individual, and 11% were being administered five or more different psychotropics at the time of their death. In the NSW 14-17 sample, 84% were taking three or more medications at the time of their death, including 37% who received 10 or more medications, nine of whom were receiving 20 or more medications when they died.

Table 12: Number and types of medications

Report ID	Number and types of medications at time of death
VIC **17-18**	No specific information provided regarding numbers and/or type of medications prescribed at time of death.
VIC **07-16**	No specific information provided regarding numbers and/or type of medications prescribed at time of death.
QLD **09-14**	• 49% were prescribed psychotropic medication, most without a diagnosis of mental illness: ○ anti-convulsants: 29% ○ anxiolytics: 27% ○ antipsychotics: 18% (85% of which were atypical antipsychotics) ○ antidepressants: 15%. • The average number of psychotropic medications administered per individual was 3.2. • 11% were being administered five or more different psychotropic medications.
NSW **12-13**	No specific information provided regarding numbers and/or type of medications prescribed at time of death. The report does note, however, that “most” of the 10 people who had choking identified as a factor in their deaths were taking psychotropic medication, including three people who were taking two or more psychotropic medications.
NSW **14-17**	In 2014-2017 the following medication patterns were noted across the full sample (combining disability service and assisted boarding house groups): • 84% were taking three or more medications at the time of their death (This included 37% who received 10 or more medications, nine of whom were receiving 20 or more medications when they died) • 87% were taking psychotropic medication at the time of their death: ○ 30% antipsychotic medication ○ 22% antidepressant medication ○ 14% antianxiety medication ○ 8% sedatives. • Of the 206 people who were taking psychotropic medication at the time of their death, 42% had behaviours of concern but did not have a behaviour support plan, including 32 of these people who did not have an identified mental health condition.

Influenza and Pneumococcal vaccine status

The vaccination status of people whose deaths were in-scope are outlined in Table 13. A significant proportion of people did not have current vaccination protection. Across jurisdictional samples, between 14% and 48% of people had not received an influenza vaccination in the 12 months before their death. Where reported, it appeared that between 25% and 83% had not received a pneumococcal vaccination in the last 12 months.

Table 13: Influenza and Pneumococcal vaccine status

Report ID	Influenza and Pneumococcal vaccine status
VIC 17-18	**Influenza vaccine status:** Of the 72 people residing in shared accommodation, respite or a nursing home at the time of their death: • 22% had not received an influenza immunization in the last 12 months. **Pneumococcal vaccine status:** Of the 72 people residing in shared accommodation, respite or a nursing home at the time of their death: • 83% had not received a pneumococcal vaccination in the last 12 months.
VIC 07-16	Not stated
QLD 09-14	Not stated
NSW 12-13	**Influenza vaccine status**: • 73% of *Disability Services Sample* were vaccinated in the 12 month period before death. • 86% of the *Assisted Boarding House Sample* were vaccinated in the 12 month period before death. **Pneumococcal vaccine status:** • 37% of the *Disability Services Sample* were vaccinated in the in the 5 year period before death. • 21% of the *Assisted Boarding House Sample* were vaccinated in the 5 years period before death.
NSW 14-17	**Influenza vaccine status:** In 2014- 2017: • 76% of the *Disability Services Sample* were vaccinated in the 12 month period before death • 52% of the *Assisted Boarding House Sample* were vaccinated in the 12 month period before death. **Pneumococcal vaccine status:** In 2014- 2017: • 28% of the *Disability Services Sample* were vaccinated (recency of vaccination not stated in the report) • 75% of the *Assisted Boarding House Sample* were vaccinated (recency of vaccination not stated in the report).

Weight, smoking and other lifestyle risks

Identified lifestyle risks are reported in Table 14. No report systematically attempted to identify or report on the physical activity level of people whose deaths were in-scope. NSW was the only state that comprehensively considered the weight and smoking status of their sample. For people in the NSW *disability services* sample, less than half were in a healthy weight range (45.8% and 39.5% for the 2012-13 and 2014-17 respective reporting periods). For people living in *assisted boarding houses*, less than one-third were in a healthy weight range (28.6% and 27.8% across these periods). Access to dietitians was also noted to be limited. Weight was unknown for a significant minority, suggesting that regular monitoring of such data had not been occurring. Smoking was common among the assisted boarding house sample (NSW 12-13 & 14-17).

Table 14: Weight, smoking and other lifestyle risks

Report ID	Weight, smoking and other lifestyle risks
VIC **17-18**	Not stated
VIC **07-16**	Not stated
QLD **09-14**	Not stated
NSW **12-13**	**Weight status:** *Less than half (45.8%) of the disability services sample were in a healthy weight range:* • 9.8% were very underweight • 7.1% were underweight • 17.8% were overweight • 9.8% were obese. • 9.3% were severely obese • 4% had an unknown weight. *Less than one-third (28.6%) of the assisted boarding house sample were in the healthy weight range:* • 57.1% were overweight, obese or severely obese. • None were very underweight or underweight • 21.4% were overweight • 7.1% were obese • 28.6% were severely obese • 14.3% had an unknown weight. *Access to dietetic support:* Of the eight people in assisted boarding houses who were outside of the healthy weight range, only one person had seen a dietitian. The person had seen the dietician in the year before they died. **Smoking:** • 86% of *assisted boarding house* residents had smoked, and most (79%) were still smokers at the time of their death. • 15% of the *disability services sample* had smoked, and 9% were still smokers at the time of their death.

NSW 14-17	**Weight status:** For the period of 2014-2017: *Less than half (39.5%) of the disability services sample were in a healthy weight range:* • 9.7% were severely underweight • 5.9% were underweight • 21.2% were overweight

- 6.9% were obese.
- 9.0% were severely obese
- 7.8% had an unknown weight.

Less than one-third (27.8%) of the assisted boarding house sample were in the healthy weight range:

- 5.6% were severely underweight
- 5.6% were overweight
- 22.2% were obese
- 16.7% were severely obese
- 22.2% had an unknown weight.

Access to dietician: Only 33% of the nine boarding house residents who were outside of the healthy weight range had seen a dietitian. The one boarding house resident who was very underweight when they died in 2016-2017 had not seen a dietitian.

Smoking: for deaths in the 2014-2017 period:

- 61% of *assisted boarding house* residents had smoked, and 50% were still smokers at the time of their death.
- 13.6% of the *disability services sample* had smoked, and 8% were still smokers at the time of their death.

Date of the person's last comprehensive health assessment

No data regarding the date of the person's last comprehensive health assessment were recorded for the VIC 17-18 sample. In the QLD 09-14 report, the authors noted that there was a lack of available information to confirm if and when their sample had last had a comprehensive annual check-up. In NSW, for the 2012-13 reporting period, it was noted that 77% of the people in disability services and 36% of the assisted boarding house residents who had died had received a comprehensive health assessment in the 12 months preceding death. For the 2014-17 reporting period, numbers were similar with 81% of the disability services group, and 33% of the assisted boarding house residents reported to have a comprehensive health assessment in the 12 months preceding death.

Capacity to consent

Capacity to consent to medical/dental and other treatment was only reported in the NSW death reviews. For the 2012-2013 reporting period, it was found that the majority (85%) of disability services residents had other people, mainly family members (67%), provide consent to medical and dental treatment on their behalf. Just over half of the assisted boarding house residents (57%) provided their own consent in this same reporting period.

Likewise, in the 2014-2017 reporting period, the majority of disability services residents had other people who consented on their behalf (67%), while the vast majority (89%) of assisted boarding house residents provided their own consent across this period.

Nutrition, swallowing, mealtime support and dental health status

Nutrition, swallowing, mealtime support and dental health status of people whose deaths were in-scope are outlined in Table 15. These data were only comprehensively reported in the NSW reports (12-13 & 14-17). Of note is the considerable proportion of people with disabilities with dental problems such as missing teeth, as well as the significant minority of people with swallowing problems who had either not had a comprehensive risk assessment conducted, or whose mealtime management plan was lacking in detail.

Table 15: Nutrition, swallowing, mealtime support and dental health status

Report ID	Nutrition, Swallowing, mealtime support and dental health status
VIC 17-18	**Nutrition, swallowing and mealtime support:** Not stated **Dental: Health:** 51% had some teeth missing, no teeth or required dental aids
VIC 07-16	Not stated

QLD **09-14**	**Nutrition, swallowing and mealtime support:** No figures provided for overall sample. Specifically in relation to the five people in this sample who died due to choking/food asphyxia it was noted that swallowing assessments had been conducted and mealtime management plans developed for only three (60%). “Notably, there appeared to be a lack of compliance with those plans” **Dental Health:** Not stated
NSW **12-13**	**Nutrition, swallowing and mealtime support:** Since 2005, all disability accommodation services have been required to identify and address the nutrition and swallowing risks of the people in their care using an appropriate checklist. However: • Of the 52 people in *NGO services* with swallowing difficulties: o 12% did not have a risk assessment, and o 65% did not have a comprehensive assessment. • Of the 96 people in *ADHC services* with swallowing difficulties: o The majority had a comprehensive nutrition and swallowing risk assessment (69%), but o For almost one-third, staff had either not identified all of the person’s risks (23%), or had not recorded sufficient actions that needed to be taken to address the risks (6%), and o one person did not have a risk assessment. • Mealtime support guidance (such as a mealtime management plan or eating and drinking plan) was recorded for the majority (86%) of the people with swallowing difficulties in *disability services* who died.

	• For 20 people with swallowing difficulties, there was no written guidance to indicate to staff (or other services) what support the individuals required to minimise their swallowing risks. **Dental Health** • 24% of the people in disability services and 29% of assisted boarding house residents had all of their teeth. • Most (79%) of the people in disability services who died in 2012 and 2013 had seen a dentist. 64% had seen a dentist in the year before their death. • Less than half (43%) of the assisted boarding house residents had seen a dentist at any time. All of the six people had seen a dentist in the year before they died.
NSW 14-17	**Nutrition, swallowing and mealtime support:** Most of the people in *disability services* who died in 2014-2017 required assistance with meals, associated with swallowing difficulties, eating problems, or both. None of the assisted boarding house residents who died required this assistance. • Of the people in *disability services* who died in 2014-2017: o 54 (11%) relied on enteral nutrition (tube feeding), primarily via a percutaneous endoscopic gastrostomy (PEG) tube o The majority (85%) had seen a dietitian in the year before they died o Two thirds (65%) had swallowing difficulties o The majority (87%) had seen a speech pathologist and/or attended a dysphagia clinic in the year before they died o Just over half (51%) had eating and drinking mealtime behaviours, such as swallowing without chewing, eating too quickly, overfilling their mouth, and compulsive behaviour around food. **Dental Health** • 68% of the people who died in 2014-2017 were missing some or all of their teeth. • Dental health was worse for boarding house residents than disability services residents. • 69% of the people in disability services who died in 2014-2017 had seen a dentist in the year before their death. Only one-third 33% of the boarding house residents who died in the same period had seen a dentist.

Mobility and Communication

Table 16 summarises mobility and communication needs across samples. Of note is the high number of in-scope deaths that involved people who required communication support. The number of people requiring a communication plan who had one in place was either unknown or not investigated in QLD and NSW. In VIC, it was noted that, for the 2017-18 investigative period, 38% of the sample who needed a communication plan did not have one on record.

Table 16: Mobility and communication

Report ID	Mobility and Communication
VIC **17-18**	**Communication needs:** • Non-verbal requiring aides or gestures to communicate: 41% • Unable to communicate at all: 6% • Have verbal language but require communication support: 6% • Have verbal skills and no communication support required 47% *Communication plans:* 53% of deaths reported were for people whose reported level of communication indicated that a communication plan should have been in place. However, 38% of this cohort did not have any communication plan on record. *"We are deeply concerned by this preliminary data, which appears to indicate there is a lack of priority and focus on ensuring people with communication support needs have the necessary assessments and plans developed to assist staff to provide optimal care. Such information is critical to enable disability support staff to recognise and understand indicators of deteriorating health or illness of people in receipt of disability services"* **Mobility status:** • 70% required assistance with mobility including wheelchair, walking frame, walking stick or other aide.
VIC **07-16**	Not Stated
QLD **09-14**	**Communication needs:** • Approximately 6% of the sample had a vision impairment. • Approximately 3% of the sample had a hearing impairment. *Communication plans:* Number of people with communication plan in place was not stated in the report. The study authors did identify poor communication, and difficulties of interpreting communication as a contributing factor across many of these deaths. **Mobility status:** Not stated

NSW **12-13**	**Communication needs:** • Two-thirds (65%,) of people in *disability services* needed assistance to communicate, using mainly adjusted verbal language or other signing (such as gestures). • 21% of *assisted boarding house residents* were reported to need communication support (14%- required adjusted verbal support; 7%- required a hearing aid). *Communication plans:* Number of people with communication plan in place was not stated in the report. Authors do comment, however, "*Most of the people with disability whose deaths we have reviewed required help with communication – to both communicate their views and feelings, and to understand what was happening and the information relayed to them. However, while health records have frequently recorded the difficulties experienced by health staff in communicating with patients with disability, they have rarely identified the communication support the person required or received".* **Mobility status:** • Almost three-quarters (74%), of the people in disability services who died required help with mobility, and 50% required wheelchair support. • One assisted boarding house resident needed mobility assistance and used a walking stick.

NSW **14-17**	**Communication needs:** • Most of the *disability services residents* needed communication support, including 58% in 2014-2015 and 61% in 2016-2017. • 39% of the *disability services residents* who died in 2014-2015 and 38% in 2016-2017 communicated using verbal language. • None of the *assisted boarding house residents* who died required communication support. *Communication plans:* Number of people with communication plan in place was not stated in the report. **Mobility status:** • Most of the people in *disability services* who died in 2014-2015 (72%) and 2016-2017 (70%) required help with mobility. • 50% of the people in *disability services* relied on wheelchair support. • None of the *assisted boarding house residents* who died in 2014-2015, and one person who died in 2016-2017 required help with mobility.

Causes of death

This section of the review will focus on identifying patterns in broad, underlying, direct and contributing causes of death across samples.

Broad causes of death

Expected versus unexpected deaths

Across jurisdictions, the majority of deaths reported were considered to be 'unexpected'. Rates of unexpected deaths ranged from 59% in the QLD 09-14 sample to 71% in the VIC 17-18 sample. While all in-scope reports provided rates of 'expected' and 'unexpected' deaths, these terms were sometimes poorly defined or defined differently across reports. Table 18 summarises expected/unexpected death rates across samples, as well as differences in how these terms have been defined.

Table 18: Expected and unexpected deaths

Report ID	'Expected' and 'Unexpected' Deaths
VIC 17-18	• *29% (25 of 85 deaths) were reported as 'expected deaths' or category 2/ non-major impact incident.* • *71% (60 deaths out of 85) were reported as unexpected deaths or Category 1/major impact incident.* **Expected deaths:** Deaths reported to DHHS by **DHHS delivered services** used the following definition of "Expected death" as per guidance in the Critical Client Incident Management (CCIM) reporting system: ***"…**where the person was living in a disability residential service and the death was the progression of a diagnosed condition or illness"*. As of 15th January, 2018 deaths reported to DHHS based on incidents occurring in **non-government funded service providers**, used the following definition of an expected death of a person with a disability *"… people with a disability who die as the consequence of the progression of a diagnosed condition or illness".* **Unexpected Deaths:** Deaths reported by **DHHS delivered services** used the following definition of "Unexpected death" as per guidance in the Critical Client Incident Management (CCIM) reporting system: • the person's death was in unusual or unexpected circumstances • the person's death had a direct or obvious correlation to the service being received • the person's death is reportable, (for example, to the State Coroner or Commission for Children and Young People) • the death related to a child under the age of 18 years • the person resided in a residential facility or housing property where the condition of accommodation or standard of care provided may have been a contributing factor to the death. As of 15th January, 2018, deaths reported by DHHS based on incidents occurring **in non-government funded**

	service providers, used the following definition of "Unexpected death" and logged incidents per guidance in the Client Incident Management System (CIMS) reporting system: *"The CIMS guidelines advise that all deaths of clients in unexpected or unanticipated circumstances must be reported as a major impact incident.".* Deaths reported by the VIC state coroner use definitions 'unexpected'/'expected' set out in the *Coroners Act 2008.* All deaths considered to be 'unexpected 'are reportable to the state coroner.
VIC **07-16**	• Only unexpected deaths were in-scope for this investigation. • No definition of expected or unexpected deaths provided.
QLD **09-14**	• 39% of deaths were considered expected deaths. • 59% were unexpected. **Expected death:** not defined **Unexpected death:** defined as, *"A death that was not anticipated as a significant possibility 24 hours before the death"* Deaths reported by the QLD state coroner use definitions of 'unexpected'/'expected' set out in the QLD *Coroners Act.* All deaths considered to be 'unexpected 'are reportable to the state coroner.
NSW **12-13**	• No expected or unexpected death rates are reported. Deaths reported by the NSW state coroner use definitions of 'unexpected'/'expected' set out in the *NSW Coroners Act.* All deaths considered to be 'unexpected 'are reportable to the state coroner.
NSW **14-17**	• Most (64%) of the 494 deaths of people with disability in residential care in 2014-2017 were sudden unexpected deaths, including the deaths of 307 people (64%) in disability services, and the deaths of 11 people (61%) in assisted boarding houses. • The 176 people (36%) whose deaths were expected were typically in the final stages of a terminal condition or degenerative disease, and were receiving palliative care. Deaths reported by the NSW state coroner use definitions 'unexpected'/'expected' set out in the *NSW Coroners Act.* All deaths considered to be 'unexpected 'are reportable to the state coroner.

Where and when did people die?

QLD was the only state to conduct a detailed analysis of where and when deaths took place. Their report (QLD 09-14) demonstrated a higher number of deaths at night, particularly in cases where the person died in their usual place of residence rather than in hospital, and in cases where the person had a diagnosis of epilepsy. A slightly larger proportion of both genders died in hospital (58% of sample) than in the service where they had been living. While the fewest deaths occurred in summer (18%) and the highest number in winter (29%) and spring (30%), the overall data indicate only a slight seasonal trend in deaths. We commend this type of analysis to the Commission and note that inclusion of such data can help to identify time periods of higher risk and allow services to plan their care and staffing levels appropriately.

Natural versus unnatural (external) causes of death

The vast majority of deaths across samples were attributed to natural causes. Between 88% to 93% of deaths reported across samples were attributed to ‘natural’ causes (i.e. illness and disease). With the exception of the VIC 07-16 report (where only ‘unnatural’ causes of death were in-scope for investigation), unnatural or external causes of death accounted for between 5% to 8% of all other deaths investigated. The vast majority of these deaths related to accidental choking. According to the NSW Ombudsman (NSW 14-17) a higher proportion of people in disability services died from unnatural causes compared to residents in assisted boarding houses. A specific breakdown of deaths by natural and unnatural causes within each report is provided in Table 19.

Table 19: Natural versus unnatural causes of death

Report ID	Natural versus unnatural (or ‘external’) causes of death
VIC 17-18	• 6% of deaths were due to external or ‘unnatural’ causes– all related to choking on food. • ‘Natural’ causes were responsible for 88% of deaths. • For 6%, the cause of death was unascertained.
VIC 07-16	All 7 deaths investigated appeared related to external or ‘unnatural’ causes: • Accidental choking on food or other objects (4 deaths- 57%) • Physical restraint (1 death) • Inadequate supervision (1 death) • Inappropriate access to medication (1 death).
QLD 09-14	• 8% of deaths (6 people) died from ‘unnatural’ causes: These were all due to other accidental threats to breathing, namely food bolus asphyxia or choking. • 92% of deaths were from ‘natural’ causes.
NSW 12-13	• 89% of deaths of people with disability in residential care were due to ‘natural’ causes (illnesses and diseases). Natural causes accounted for the deaths of most of the people who resided in disability services (88%) and assisted boarding houses (93%). • Seventeen people (7%) died from external (unnatural) causes. All of these deaths were due to unintentional or accidental causes, mainly associated with choking on food. The vast majority (94%) of the 17 people who died from unintentional external causes resided in disability services; one person lived in an assisted boarding house. • There were no deaths due to intentional causes (such as suicide or assault) in 2012 and 2013. • For 10 people (4% of total sample), the cause of death was unable to be determined.
NSW 14-17	• 89% of the 494 deaths of people with disability in residential care in 2014- 2017 were due to natural causes (illnesses and diseases) • Twenty-seven people (5%) died from external (unnatural) causes: ○ The majority of these deaths (93%) were due to unintentional or accidental causes, mainly

	associated with choking on food or other substances. o Two deaths (7%) were due to intentional causes, both suicide. o Only one of the external cause deaths involved a person in an assisted boarding house – their death was due to a transport-related accident. • For 11 people (2%), the cause of death was unable to be determined • The underlying cause of death of 14 people (3%) had not yet been ascertained (still under investigation)

Potentially ‘avoidable’, ‘treatable’ and ‘preventable’ deaths

QLD (09-14) was the only state that systematically defined and reported these metrics. They based their definitions of these terms on data from the Australian Bureau of Statistics, Causes of Death in Australia (2012). A death was defined as *potentially avoidable* ”if, theoretically, it could have been avoided given an understanding of causation, the adoption of available disease prevention initiatives, and with available health care”. Potentially avoidable deaths include both *potentially preventable deaths* and *potentially treatable deaths*. *Potentially preventable deaths* are defined as, “…those that are amenable to screening and primary prevention, such as immunisation, and reflect the effectiveness of the current preventive health activities of the health sector”.

Within the QLD sample:

- Over half of all deaths reviewed (53%) were considered to be potentially treatable or avoidable.
- Potentially avoidable deaths were somewhat more common amongst those individuals who died in hospital. Sixty-two percent of those cases that the Panel considered to have been potentially avoidable died in hospital. The deaths of 21% of individuals who died in their usual place of accommodation were considered to be potentially avoidable.
- Of those deaths deemed by the Panel to be unexpected, approximately two thirds (67%) were also considered to be potentially avoidable
- Diagnoses of epilepsy featured strongly in the case histories of those deaths that were deemed to be both unexpected and potentially avoidable (23%), with epilepsy/SUDEP identified as the underlying cause of death for 4 individuals (5%

of the sample).

- Aspiration pneumonia was identified as the underlying cause of death for 8 individuals (11% of the sample), with a further 3 individuals having died from bronchopneumonia/pneumonia.
- Late (or no) diagnosis of relevant conditions was also noted in many of these deaths: Of the 24 people who died due to influenza or pneumonia in the sample, for example, 25% were not diagnosed with the illness until after their death. A further 17% died within 24 hours of their diagnosis and a further 17% within one to three days of their diagnosis.

Underlying causes of death

Underlying causes of death at the ICD-10 Chapter level

The four most common causes of death at the ICD Chapter level across samples were diseases of the respiratory, circulatory and nervous systems and neoplasms. Of the 901 deaths included across in-scope reports: respiratory diseases were the underlying cause for the most deaths - 173 (19%), diseases of the nervous system accounted for 126 deaths (14%), and circulatory disease was listed as the underlying cause of death of 121 people (13.42%). One hundred and eighteen people died due to neoplasms (13.09%).

Both in the VIC 17-18 and QLD 09-14 reports and in the disability services sample of the NSW 12-13 report, respiratory disease was the most frequent underlying cause of death, accounting for between 24% and 34% of all deaths in these samples. Respiratory disease accounted for a smaller proportion of deaths in the assisted boarding house sample in NSW - 14.3%, 12.5% and 10% respectively across the 2012-13, 2014-15 and 2016-17 reporting periods. Compared to the disability services sample, a greater proportion of assisted boarding house residents died from neoplasms and circulatory system diseases. Table 20 provides a more detailed breakdown of causes of death across samples.

Table 20: Underlying causes of death by ICD Chapter

Report ID	Underlying cause of death by ICD-10 Chapter
VIC **17-18**	Only 56% (n=48) of people had cause of death identified through a coronial finding, or information received from the medical inspection or examiner's report, or autopsy report for deaths in scope of review by the State Coroner. Of these, cause of death was as follows: • respiratory system diseases (33%): mainly aspiration and pneumonia. This was the most common category of death for males and females • circulatory system diseases (27%) – mainly ischaemic heart disease. Males overrepresented females for circulatory system deaths • neoplasms (8%) – mainly abdominal and bowel cancers • external causes (6%) – all related to choking on food • nervous system diseases (6%) – primarily sudden unexplained death in epilepsy • unascertained (6%).
VIC **07-16**	-
QLD **09-14**	• Diseases of the respiratory system (34%) • Diseases of the circulatory system (22%) • Diseases of the nervous system (11%) • Neoplasms (10%) • External causes (8%) • Diseases of the blood, blood-forming organs and immune disorder (3%) • Infectious and parasitic diseases (5%)
NSW **12-13**	**The leading underlying causes of death of people in *disability services* were:** • Respiratory diseases (24%) – mainly pneumonia and pneumonitis due to solids and liquids • Nervous system diseases (16.9%) – mainly epilepsy and cerebral palsy • Neoplasms (16%) – mainly lung and breast cancer • Circulatory diseases (11.1%) – primarily ischaemic heart diseases and other heart diseases • Congenital and chromosomal conditions (11.1%) • External causes (7%)- Mainly choking • Symptoms and signs NEC (4.4%) • Diseases of the digestive system (3.6%) • Diseases of the genitourinary system (2.7%) • Infectious and parasitic diseases (1.3%) • Endocrine, nutritional & metabolic disorders (1.3%) • Musculoskeletal and connective tissue (0.4%) • Mental & behavioural disorders (0%). **The leading underlying causes of death of people in *assisted boarding houses* were:** • Circulatory system diseases (42.9%) – mainly ischaemic and other heart diseases • Neoplasms (21.4%) – mainly liver cancer • Respiratory diseases (14.3%) – mainly chronic lower respiratory diseases and pneumonia • Diseases of the digestive system (7.1%) • External causes (7.1%) • Mental & behavioural disorders (7.1%).
NSW **14-17**	**The leading underlying causes of death for the full sample in residential care in 2014-2017 were:** • nervous system diseases (77 people; 16%) – mainly epilepsy and cerebral palsy • respiratory diseases (76 people; 15%) – mainly aspiration pneumonia

- neoplasms (68 people; 14%) – mainly lung and breast cancer
- congenital and chromosomal conditions (63 people; 13%) – mainly Down syndrome
- circulatory diseases (61 people; 12%) – mainly ischaemic heart diseases.

The leading underlying causes of death of people in *disability services* were:

- In *2016-2017,* the leading five underlying causes of death were:
    - Diseases of the respiratory system (17.34%); Congenital and chromosomal conditions (13.71%); Neoplasms (12.5%); Diseases of the nervous system (12.1%); Diseases of the circulatory system (11.69%)
    - 6.05% of deaths were due to external causes.
- In *2014-2015,* the leading five underlying causes of death were:
    - Diseases of the nervous system (20.6%); Neoplasms (14%); Diseases of the respiratory system (13.6%); Congenital and chromosomal conditions (12.7%); Diseases of the circulatory system (11.8%)
    - 4.8 % of deaths were due to external causes.

The leading underlying causes of death of people in *assisted boarding houses* were:

- In *2016-2017,* the leading underlying causes of death were:
    - Neoplasms (30%); Diseases of the circulatory system (20%); Diseases of the respiratory system (10%); Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (10%)
    - 10% of deaths were due to external causes.
- In *2014-2015,* the leading underlying causes of death were:
    - Diseases of the circulatory system (37.5%); Neoplasms (25%); Diseases of the respiratory system (12.5%); Certain infectious and parasitic diseases (12.5%)
    - No deaths had external causes listed as an underlying cause.

Underlying causes of death at ICD 10 Sub-Chapter level

At the ICD Sub-Chapter level, the leading underlying causes of *respiratory deaths* reported across samples were pneumonitis due to solids and liquids, and pneumonia. Ischaemic heart disease was the highest frequency cause of *circulatory* system deaths, while epilepsy was the leading cause of *nervous system* deaths across jurisdictions.

Down syndrome was the most frequently reported cause of *congenital and chromosomal* deaths. No report attempted to recode deaths due to congenital and chromosomal conditions to examine underlying causes of death. Malignant neoplasms of the digestive organs and malignant neoplasms of the trachea, bronchus and lungs were the most frequently reported types of neoplasms. Inhalation and ingestion of food causing obstruction of the respiratory tract was the most frequently reported *external* underlying cause of deaths across samples. Accidental choking was associated with 34 of the 901 deaths that were in-scope for this review (4%).

Pneumonitis due to solids and liquids, and pneumonia were the most common single categories of death in the VIC 17-18 and QLD 09-14 samples, and the NSW 12-13 sample, collectively accounting for between 15% to 33% of all deaths in these samples. A higher proportion of people residing in assisted boarding houses, died from circulatory diseases and neoplasms than from respiratory diseases (NSW 12-13 & 14-17). Ischaemic heart diseases and other heart diseases accounted for between 20% - 37.5% of all deaths in the NSW assisted boarding house samples between 2012-2017. Table 21 provides a more detailed picture of underlying causes of death at the sub-chapter level.

Table 21: Underlying causes of death by ICD Sub-Chapter

Report ID	Underlying causes of death by ICD subchapter or other level
VIC 17-18	ICD sub-chapter causes of death were not systematically or quantifiably described in this report. The following patterns relevant to the ICD Sub-chapter level deaths were described: • **respiratory system diseases**: mainly aspiration pneumonia (15%) and pneumonia (% not specified). This was the most common category of death for males and females • **circulatory system diseases**: mainly ischaemic heart disease (% not specified). Males overrepresented females for circulatory system deaths • **neoplasms**: mainly abdominal and bowel cancers (% not specified) • **external causes**: choking on food accounted for all external deaths (6%) • **nervous system diseases**: primarily sudden unexplained death in epilepsy (% not specified) • **unascertained** (6%).
VIC 07-16	• **Accidental choking** on food or other objects: cause of death noted in four of the seven deaths (57%) considered by the inquiry into abuse in disability services • **Physical restraint** (1 death) • **Inadequate supervision** (1 death) • **Inappropriate access to medication** (1 death)

QLD **09-14**	**Diseases of the respiratory system**: • influenza and pneumonia (namely aspiration pneumonia, pneumonia, bronchopneumonia and HN1 Influenza) (24 individuals/ 33%) • other respiratory diseases primarily affecting the interstitium (namely interstitial lung disease) (1 individual). **Diseases of the circulatory system**: • Ischaemic heart disease (8 individuals; 11%) • pulmonary heart disease (1 individual) • other forms of heart disease (5 individuals) • diseases of the veins and lymphatic vessels (namely deep vein thrombosis) (2 individuals). **Diseases of the nervous system**: • episodic and paroxysmal disorders (namely epilepsy) (7 individuals; 10%) • systemic atrophies primary affecting the central nervous system (Amyotrophic lateral sclerosis) (1 individual).
	Neoplasms: • malignant neoplasms of the digestive organs (namely pancreatic, colorectal and oesophageal cancer) (3 individuals; 4%) • malignant neoplasms of thyroid and other endocrine glands (thyroid cancer) (1 individual) • malignant neoplasms of eye, brain and other parts of the central nervous system (Gilomatosis Cerebri) (1 individual) • malignant neoplasms of the respiratory and intrathoracic organs (non small cell lung cancer) (1 individual) • malignant neoplasms of ill defined, secondary and unspecified sites (malignancy of unknown aetiology (1 individual). **External causes**: These were all due to other accidental threats to breathing, namely: • food bolus asphyxia or choking- 5 individuals • aspiration on vomit-1 individual. **Diseases of the blood, blood-forming organs and immune disorder:** • Diseases of the veins, lymphatic vessels and lymph nodes, not elsewhere classified (Deep Vein Thrombosis) (2 individuals – 3%). **Infectious and parasitic diseases:** • Other bacterial diseases (mostly septic shock) (4 individuals - 5%).

NSW **12-13**	**Across the full sample (combining both assisted boarding house and disability service residents) the leading 11 underlying causes of death at ICD sub-chapter level (which accounted for 51.9% of the underlying causes) were:** • Pneumonitis due to solids and liquids (9.2%) • Pneumonia (8.8%) • Cerebral palsy (6.7%) • Epilepsy (5.4%) • Ischaemic heart diseases (4.6%) • Inhalation and ingestion of food causing obstruction of respiratory tract (3.8%) • Other heart diseases (3.8%) • Down syndrome (3.3%) • Malignant neoplasm of trachea, bronchus and lung (2.1%) • Cerebrovascular diseases (2.1%) • Chronic lower respiratory diseases (2.1%). **The leading underlying causes of death of people in *disability services* were:** **Respiratory diseases**: • pneumonia (8.9%) • pneumonitis due to solids and liquids (9.8%). **Nervous system diseases:** • epilepsy (5.8%) • cerebral palsy (7.1%). **Neoplasms:** • lung and breast cancer. Malignant neoplasm of trachea, bronchus and lung accounted for 2.2%. **Circulatory diseases:** • ischaemic heart diseases (4%) • other heart diseases (2.7%).

	Congenital and chromosomal conditions: • Down syndrome (3.6%). **External causes:** • Choking - Inhalation and ingestion of food causing obstruction of respiratory tract (4%). **The only underlying causes of death of people in *assisted boarding houses* listed at ICD subchapter level were:** **Circulatory system diseases:** • ischaemic (14.3%) • other heart diseases (21.4%). **Neoplasms:** • mainly liver cancer (% not provided). **Respiratory diseases:** • chronic lower respiratory diseases (7.1%) • pneumonia (7.1%).
NSW 14-17	**The leading underlying causes of death of people in *disability services:*** **In 2014-2015:** • Cerebral palsy (7.46%); • Down syndrome (7.02%) • Epilepsy (6.14%) • Pneumonitis due to solids and liquids (5.26%) • Chronic ischaemic heart disease (4.39%) • Pneumonia, organism unspecified (4.39%). **In 2016-2017:** • Pneumonitis due to solids and liquids (9.3%) • Down Syndrome (8.1%) • Paralytic ileus and intestinal obstruction without hernia (4.4%) • Epilepsy (4.0%) • Pneumonia, organism unspecified (4.0%) • Severe mental retardation (3.2%). **The leading underlying causes of death of people in *assisted boarding houses*** **In 2014-2015:** • Chronic ischaemic heart disease (37.5%) • Emphysema (12.5%) • Malignant neoplasm of bronchus and lung (12.5%) • Other malignant neoplasms of skin (12.5%) • Other sepsis (12.5%). **In 2016-2017:** • Acute myocardial infarction (20.0%) • Malignant neoplasm of bladder (10.0%) • Malignant neoplasm of rectum (10.0% • Malignant neoplasm without specification of site (10.0%) • Other chronic obstructive pulmonary disease (10.0%) • Other ill-defined and unspecified causes of mortality (10.0%) • Pedestrian injured in collision with heavy transport vehicle or bus (10.0%).

Associated causes of death and other contributory 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. Unfortunately, details about the methodology and definitions relied upon to calculate these figures were not included in their in-scope reports. Analysis by the NSW Ombudsman has highlighted respiratory disease as the largest *contributory cause* of death for people in disability services (either as an underlying or associated cause of death). Respiratory disease contributed to approximately half of all disability service deaths in the 2012-2013, 2014-2015 and 2016- 2017 biannual reporting periods (50%, 46% and 46% respectively). This finding can, in part, be explained by the role respiratory diseases commonly play as a direct cause of death of people whose underlying cause of death are neoplasms such as lung cancer, nervous system diseases (such as cerebral palsy), or congenital and chromosomal conditions (such as Down syndrome). Mental and behavioural disorders were reported to contribute to 25% of disability service deaths in 2012-13 as an associated cause. For people in assisted boarding houses, circulatory diseases, neoplasms, mental and behavioural disorders and respiratory diseases were the leading contributory causes of deaths.

Stratified demographics, causes and contributors to death

Stratifying data can help to develop a more accurate picture of mortality data in specific populations. Particularly in relation to mortality data, such an analysis can help to isolate vulnerable populations and rationally target educational and other resources to populations most in need. Unfortunately, the way in which data were stratified across reports was highly varied. We were therefore unable to determine which, if any, patterns observed in each review were consistent across jurisdictions. We include the stratified analysis conducted in each review below in Table 22, since collectively they provide a guide for statistical analysis for the Commission to consider.

Table 22: Deaths stratified by characteristics

Report ID	Stratified analysis of deaths
VIC 17-18	**Age at death by severity of intellectual disability:** “We have observed that on average, people with a profound or severe intellectual disability died four years younger than those with mild or moderate levels of intellectual disability. This preliminary finding confirms research conducted in the United Kingdom, which found that people with a profound intellectual disability had a median age at death of 46 years, while people with a mild intellectual disability had a median age at death of 67.5 years.94”. **Choking or aspiration pneumonia as cause of death by: residence type, gender, age, disability and co-morbidities, swallowing status, meal assistance requirements, specialist visits in last 12 months:** All resided in shared supported accommodation; three were female, seven were male; ages at death ranged from 39 years to 77 years, and the average age at death was 54 years; eight people were described as having an intellectual disability; six people were known to have dysphagia; service providers were unsure if swallowing and eating issues were present for three people; six people were described as either always or sometimes requiring assistance with eating or drinking; the eating and drinking support needs for one person who was identified as having swallowing issues were not known by the service provider; three people were described as having no eating or drinking issues; two people were provided with a normal diet; five people required modified diets; the dietary needs for three people were not known by the service provider; four people had seen a dentist in the previous 12 months; five people had seen a dietitian in the previous 12 months; five people had seen a speech pathologist in the previous 12 months; none of the people had been to a specialist dysphagia clinic in the 12 months prior to their death. **People with a preliminary cause of death related to heart disease who were residing in shared supported accommodation by: gender, age, disability and co-morbidities, activity levels, smoking and drinking status, visits to cardiologist or dietitian in last 12 months (n=10):** All were described as having an intellectual disability; seven were male, three were female; age at death ranged from 46 years to 72 years, and the average age at death was 62 years; daily physical activity levels were low or unknown in most cases; three people were current or former smokers; three people consumed alcohol occasionally or weekly; five people had not seen either a cardiologist or dietitian in the previous 12 months.
VIC 07-16	Not Stated

QLD 09-14	**Place of death by gender:** “Both males and females were slightly more likely to die in hospital, although a significant proportion of individuals in the sample died in the service where they had been living”. **Age by place of death:** “Those individuals who died in their usual accommodation tended to be younger while those who died in hospital tended to be older individuals. This effect was much more pronounced in the 50-59 year age group and the 20-29 year age group.” **Time by place of death:** “Of the individuals who died in hospital, 50% (19 individuals) died during the night, 42% (16 individuals) during the afternoon, and 8% (3 individuals) during the morning. Of the individuals who died in their service, 77% (24 individuals) died during the night, 16% (5 individuals) during the afternoon and 6% (2 individuals) during the morning.” **Time of death and epilepsy:** “Individuals identified as having epilepsy were more likely to have a time of death during the night (6:00PM-6:00AM) than individuals who did not” **Place of death and epilepsy:** “Those people in the sample recorded as having epilepsy were more likely to die in their usual place of residence than those people without epilepsy”

	Underlying causes of death and gender: “Males and females had similar patterns of underlying causes of death except in the case of death due to diseases of the circulatory system, with 32% females in the sample dying due to diseases of the circulatory system and 18% of males in the sample. Male individuals in the sample were also slightly more likely to die due to external causes of morbidity and mortality (namely choking and food aspiration).” **Disability by underlying cause of death:** “The data shows similar patterns of underlying causes of death across people with cerebral palsy, Down syndrome and epilepsy (particularly with regard to the most common cause of death being diseases of the respiratory system). Some exceptions include, for example, that only people with epilepsy and cerebral palsy died due to external causes of morbidity and mortality (i.e. choking or food aspiration).” **Unexpected deaths by place of death:** “Unexpected deaths were more likely to occur when the person was in their usual accommodation, rather than a hospital at time of death. Of those people in hospital at time of death, 43% of deaths were considered unexpected. By contrast, of those individuals living in their usual accommodation, 81% of deaths were considered unexpected.” **Potentially avoidable deaths by place of death:** “Potentially avoidable deaths were somewhat more common amongst those individuals who died in hospital. 62% (24 individuals) of those cases that the Panel considered to have been potentially avoidable died in hospital.”

NSW **12-13**	**Death by service type (disability service versus assisted boarding house):** All data in the report were stratified within these categories **Age at death by accommodation type:** "On average, people in ADHC residential centres die at a slightly older age than the broader population in disability accommodation services – in 2012 and 2013, the average age at death of people in ADHC residential centres was 61 years, compared with 55 years in disability services." **Age by cause of death:** "*People in disability services*- Up to the age of 45 years, nervous system diseases were the leading cause of death of people in disability services in 2012 and 2013. Between 45 and 74 years, respiratory diseases were the leading cause of death. Circulatory diseases were the leading underlying cause of death for people over 75 years of age in disability services – similar to the general population. *People in assisted boarding houses*- All of the assisted boarding house residents who died in 2012 and 2013 were aged 46 years and older. For residents below 65 years, the leading causes of death were neoplasms and respiratory diseases. For people over 65 years of age, the leading cause of death was circulatory diseases." **Number and rates of deaths of people in disability services by underlying, associated and multiple causes of death; and rate ratios for multiple to underlying causes of death by ICD chapter:** See cause of death data above. **Choking by: accommodation type, location where choking occurred, food type or other substance choked on, known choking risk factors, presence of support plan:** "Unlike previous years, all of the people who died as a result of choking resided in disability services; most (8) resided in group home accommodation. Most (6) of the 10 people were at home at the time of the incident. Four people choked at other locations, including day programs (2), a car, or their family home. Three people died during celebratory meals – two people choked on their birthday at their day program, and one person choked during a meal at home to celebrate another resident's birthday. The deaths from choking in 2012 and 2013 were associated with a range of foods, including sandwiches (2), crepes, carrot, steak, cheese, and dim sims. Two people choked on vomitus. Most of the 10 people had known risk factors for choking, one person did not have prior risk factors for choking. For most of the other nine people, services had identified their

	choking risks (7) and documented strategies to address them (6). The gaps in the service response to identified choking risks primarily involved staff not following the requirements/ support plans.”
NSW 14-17	**Death by service type (disability service versus assisted boarding house):** All data in the report were stratified within these categories. **Age by cause of death:** *In disability Services:* “In the younger age groups, nervous system diseases featured as a leading cause of death of people in disability services in both periods. In 2016-2017, people aged up to 35 years also had additional leading causes of death, including respiratory diseases. While the leading cause of death of people aged 35-54 years in 2014-2015 was nervous system diseases, in 2016-2017 it was external causes and congenital and chromosomal conditions. For people aged 55-64 years, respiratory diseases were the leading cause of death. The leading causes of death for people aged 65 years and older were similar to the general population, including circulatory diseases and neoplasms. *In assisted boarding housing:* “For both two-year periods, similar leading causes of death featured in age groups 55-64 years and 65-74 years, including neoplasms and circulatory diseases.” **Number and rates of deaths of people in disability services by underlying, associated and multiple causes of death; and rate ratios for multiple to underlying causes of death by ICD chapter:** See cause of death data above. **Choking by: accommodation type, location where choking occurred, food type or other substance choked on, known choking risk factors, presence of support plan:** “Choking was a factor in the deaths of seven people in 2014-2015, and the deaths of four people in 2016-2017. This is a reduction on deaths from choking in the previous periods (10 deaths in 2012- 2013, and nine deaths in 2010-2011). All of the 11 people who died from choking in 2014-2017 lived in disability services, mainly group home accommodation (7). Most (7) were at home at the time of the critical event; three people choked while attending a day program; and one person choked while on an outing. Most (7) of the people choked on food – either during a meal (5), or while accessing food that they were not intended to have (2). Three people choked on vomitus, and one person choked on a latex glove. The majority (8) of the people who choked on food had identified eating and drinking behaviours and/or nutrition support needs (such as overfilling their mouth, swallowing without adequately chewing, eating too quickly, and missing teeth. In the main, the risks and management strategies had been identified and documented”**.**

Discussion:

Issues, risks and practice improvement strategies identified across reviews

Findings from this scoping review have highlighted a number of common causes and contributors to deaths of people with disability across jurisdictions. In this section of our review we explore reasons people with disability may be particularly vulnerable to premature mortality and mortality from potentially avoidable causes. We then explore common underlying causes of death identified in this scoping review that were potentially avoidable or amenable to treatment: namely respiratory deaths (including aspiration pneumonia), choking deaths, and nervous system deaths (particularly epilepsy related). Population vulnerabilities for each category of death are discussed, along with risks and potential areas of problematic practice. The contribution of lifestyle related risks to certain types of circulatory and neoplasm deaths will also be discussed. Finally, we highlight overarching contributors to poor practice that span jurisdictions and types of deaths.

Understanding broad patterns in mortality

Median age of death

The median age of death for people with disabilities whose deaths were in-scope for this review was substantially (20-36 years) lower than that of the general Australian population (ABS, 2018). This finding is consistent with the NSW Ombudsman's retrospective analysis of death data for people in residential care from 2003-2013 (cited in NSW 12-13) that found that, on average, people in disability services have died at 53 years of age – almost 30 years earlier than the general population, and that people in assisted boarding houses died at 63 years of age – a gap of almost 20 years. The greater gap in life expectancy for people receiving disability services, compared to assisted boarding house residents, is likely due to the more complex and severe diagnostic profile of people in receipt of disability services- crude mortality rates have been shown to increase with more severe levels of disability and higher support needs (Hosking et al., 2016). While mortality data from this scoping review cannot be considered representative, findings of reduced life expectancy among these cohorts are consistent with national and international trends.

Despite increases in life expectancy for people with intellectual disability (Patja, et al., 2000; Coppus, 2013) both nationally and internationally research highlights that a substantial gap in life expectancy persists. Nationally, Trollor and colleagues (2017) report a median age of death of 54 years in their representative sample of adults with intellectual disability in NSW. A smaller population-based study from one geographic region in NSW (Durvasala, et al., 2002) previously reported a standardised mortality rate of 4.9 for people with intellectual disability. Bittles and colleagues' (2002) analysis of data from an Australian service system database similarly found substantially reduced life expectancy for their population. Internationally, a recently published systematic review of 27 studies examining mortality among people with intellectual disability across countries reported a 20-year life expectancy gap (O'Leary et al., 2018).

A number of factors are likely to contribute to premature mortality for people with disabilities. These include high rates of physical and mental co-morbidities (Cooper et al., 2015). Consistent with findings from this scoping review that the people who died tended to have a high number of co-morbidities, a recently published study reported that 98.7% of their population-based sample with intellectual disability had multi-morbidities, with an average of 11.04 conditions per person (Kinnear et al., 2018). For certain groups of people with disabilities, increased mortality risk is also conferred by chromosomal abnormalities (Jørgensen et al., 2019; Bittles et al., 2002). Burdens associated with lower socio-economic status (Emerson & Hatton, 2007) and persistent stigma and discrimination (Wallace & Schluter, 2008) have also been associated with increased rates of morbidity and mortality among people with disability.

Poor access to preventative health care measures and barriers to receiving appropriately tailored quality health care (Heslop et al., 2014; Trollor, 2014) also contribute to excess morbidity and mortality among people with intellectual disability. The health care workforce has been noted to lack confidence and report feeling under-prepared to meet the needs of this population (Trollor et al., 2016). Chronic health conditions commonly go undiagnosed in this population (Draheim, 2006). In the Dutch Healthy Ageing in Intellectual Disability (HA-ID) study, for example, there were almost twice as many missed Metabolic Syndrome diagnoses in people with intellectual disability than in the comparable general population sample (45% versus 23%) (de Winter et al, 2012). Hypertension among people with intellectual disability was also undiagnosed in 50% of cases. A health screening study for people with intellectual disability (Beange et al., 1995), similarly reported that physicians had failed to detect almost 50% of diagnosable medical conditions in the cohort. A combination of all these factors is likely to contribute to the significantly lower median death age observed across samples in this scoping review.

Gender

The higher prevalence of male deaths across samples in this scoping review is unsurprising given that males outnumber females in all residential care accommodation and service types (NSW 14-17). Gender differences in this cohort may also relate to the higher prevalence of some disabilities among men than women. For example, the male-to- female ratio for autism spectrum disorders has recently been estimated as three to one (Loomes, et al., 2017), and most prevalence studies for intellectual disability report higher rates among men (McKenzie, et al., 2016).

The gender gap in median age of death reported in the QLD 09-14 and VIC 17-18 reviews appeared somewhat less substantial than what has been reported for the general population (ABS, 2018). Compared to general population data, the life expectancy gap in these samples appeared more substantial for women than for men. In their systematic review of mortality data among populations with intellectual disability, O’Leary and colleagues (2018) also noted a more substantial life expectancy gap for females than males. The reason for this gender difference is unclear. It is possible that women with specific types of disabilities may have vulnerability to death conferred by specific interaction of sex with hormonal, genetic or mortality related risk factors, for example, or may have comparatively more difficulty than men accessing preventative health care screenings (Trollor et al., 2017). Our previous work (Trollor et al., 2017) suggests that under-representation of deaths in young males with intellectual disability (compared to the general population) could be another driver of observed sex differences. Specifically, it is possible that men with intellectual disability are significantly less likely than aged matched non-intellectually disabled peers to die from injury and poisoning.

Broad causes of deaths

The majority of in-scope deaths for this review were classified as ‘unexpected’. Between 5-8% of deaths were attributed to external or unnatural causes. Unfortunately, it is difficult to estimate the number of deaths across samples that may have been potentially amenable to treatment or avoidable or both. The QLD review was the only in-scope report that attempted this quantification- within their sample they found that over half of all deaths were potentially treatable or avoidable. It is likely that rates of potentially avoidable deaths were also significant in the Victorian and NSW samples, given they recorded high rates of deaths from causes such as respiratory infections, choking and epilepsy, that are known to be amenable to treatment or potentially avoidable (Trollor et al., 2017).

The high rates of potentially treatable or avoidable deaths recorded in the QLD sample are consistent with our findings (Trollor et al., 2017) from representative population data in NSW in which 38% of deaths of people with intellectual disability were ‘potentially avoidable’. This rate was significantly higher than that of the matched general population (17%), pointing to ongoing gaps in the quality of health care people with disabilities are receiving. Findings from the UK (Hosking et al., 2016) have also highlighted an overrepresentation of deaths from causes amenable to health care intervention among adults with intellectual disability (37.0% compared with 22.5% in the matched general population).

Respiratory deaths

Prevalence

Respiratory disease was the major underlying cause of death for people with disability across reviewed reports. Out of the 901 in-scope deaths included in this analysis, respiratory diseases were the underlying cause for 173 deaths (19%). 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 (42%, n=72) of all respiratory deaths, and 8% of all in-scope deaths summarised in this synopsis. An overrepresentation of deaths from respiratory causes has been noted across a number of national and international intellectual disability mortality reviews (O'Leary et al., 2018; Trollor et al., 2017). A recent analysis of mortality data for adults with intellectual disability in the UK, (Hosking et al., 2016) reported rates of pneumonia and aspiration pneumonia deaths that were 10 times higher than those observed in the general population.

Demographics of people who died from aspiration pneumonia

Unfortunately, the jurisdictional death reviews did not allow for the development of a robust picture of the demographics of people whose death fell into this category. The VIC 17-18 report noted that all people in their sample who died from this cause lived in shared accommodation and none had been to a specialist dysphagia clinic in the 12 months preceding their death. The QLD 09-14 report noted that 2 of the 8 people whose underlying cause of death was aspiration pneumonia also had a diagnosis of Lennox Gastaut syndrome. The NSW Ombudsman noted that aspiration pneumonia was a more frequent underlying cause of death in the disability services sample compared to the boarding house sample across in-scope reporting periods.

Risk factors

A number of factors make certain groups of people with disabilities more susceptible to respiratory infections. These include greater risk of mobility limitations (Kinnear et al., 2018), dysphagia (Robertson, Chadwick, Baines, Emerson, & Hatton, 2018) and high rates of psychotropic medication use (Solmi et al., 2017). Relatively high frequency conditions among people with disabilities such as epilepsy, Down syndrome and cerebral palsy also confer increased risk for respiratory conditions. For example, physiological differences in the pulmonary cilia of people with Down syndrome increase their susceptibility to respiratory infection (Watts & Vyas, 2013).

Specifically in relation to risk of aspiration pneumonia, there are a number of factors that make certain people with disability more vulnerable to inhaling food, saliva or vomit into the lungs, and subsequently developing infections. These include:

Higher rates of psychotropic medication use: Some psychotropic medications can adversely impact swallowing function (Dziewas et al., 2007; Maddalena, et al., 2004) as well as increasing sedation and hypersalivation (Solmi et al., 2017). Prolonged use can lead to tardive dyskinesia, which in turn impacts feeding function (Dziewas et al., 2007). While robust studies are lacking, these side effects are thought to increase the risk for aspiration pneumonia (DiBardino & Wunderink, 2015) and other respiratory complications (Cicala et al., 2019).

Where recorded, samples in our scoping review were found to have high rates of psychotropic prescriptions and polypharmacy, including in the absence of a diagnosed mental health condition. These prescribing patterns are consistent with national and international research that finds that people with intellectual disabilities (the most common disability type identified across samples) are more likely than the general population to be exposed to psychotropic related risks. As a group, our work (Salomon et al., 2018) and that of others indicated that people with intellectual disability are more likely to be prescribed psychotropic medications, receive their first prescription at a younger age, to remain on psychotropic medications for longer time periods (Matson & Mahan, 2010), and to be prescribed two or more psychotropics simultaneously (Chitty et al., 2016). These prescribing patterns are in part explained by a combination of high rates of epilepsy (Robertson, et al, 2015a) and mental illness (Tong & Einfeld, 2000) in populations with intellectual disability. The common practice of using psychotropics ‘off-label’ to control behaviours of concern (de Kuijper et al., 2010) in the context of lack of access to appropriate behavioural supports, also contributes to these prescribing patterns. High rates of psychotropic prescribing and polypharmacy have also been described in Australian populations with autism spectrum disorder (Birch et al., 2018).

High rates of problematic feeding behaviours that increase aspiration risk*:* Particularly among some groups of people with intellectual disability, behaviours associated with aspiration risk such as gorging or pica (eating non-food items) are overrepresented (Samuels & Chadwick, 2006). Among cohorts of people with intellectual disability the prevalence of pica has been estimated at between 4% and 25% (Matson et al. 2011; Busch et al., 2018). Rates are higher for people with more severe levels of intellectual disability and/or co-occurring autism (Matson et al., 2011).

Higher rates of dysphagia: Dysphagia, one of the most common risk factors for aspiration pneumonia (DiBardino & Wunderink, 2015), is overrepresented among some groups of people with intellectual disability as well as people with cerebral palsy (Robertson et al., 2018). Prevalence rates for swallowing problems were high (62%) in the only cohort in our scoping review that included this information (the 2014-2017 NSW disability services cohort). Prevalence estimates for dysphagia in representative population samples with intellectual disability range from 8.1% (Chadwick & Jolliffe, 2009) to 14.4% (Kinnear et al., 2018). Dysphagia is thought to be an under-diagnosed condition among this population, however, and true prevalence may be higher (Robertson, et al., 2017)**.** Higher severity of cognitive impairment also increases the risk for dysphagia (Chadwick & Jolliffe, 2009) with some samples recording rates in excess of 50% (Robertson, Chadwick, et al., 2017).

Higher rates of GORD: GORD increases risk for respiratory infections including aspiration pneumonia (Thillai, 2010). People with intellectual disability are more likely than the general population to experience GORD. A recent population based cohort study reported that GORD affected 14.5% of their sample with various levels of intellectual disability (Kinnear et al., 2018). Rates of GORD have reported to be closer to 52% for people with more severe or profound levels of intellectual and motor disabilities (Van Timmeren et al., 2016). While not representative of the broader population, prevalence of GORD, where recorded in cohorts in this scoping review, was also significant, ranging from 19% to 62%.

Higher rates of percutaneous endoscopic gastronomy (PEG) to receive nutrition: Compared to the general population, people with intellectual and developmental disabilities experience a higher number of feeding difficulties and are more likely to require PEG feeding (Chennubhotla et al., 2019). PEG feeding is associated with increased risk for aspiration pneumonia (DiBardino & Wunderink, 2015). Aspiration of refluxed gastric contents can occur when the PEG is in place. Additionally, sedation used during the insertion procedure can increase aspiration risk. Approximately 50% of mortality in the 30 days post insertion is attributed to aspiration pneumonia (Laskaratos et al, 2013; Azzopardi & Ellul, 2013).

Dental problems and gum disease: Compared to the general population, people with intellectual disability have poorer oral health and a higher rate of dental decay, caries, tooth extractions and gingival inflammation. Paradoxically, despite poorer oral health they have comparatively less access to dental services including preventative care and fewer fillings (Wilson et al., 2018). Poor oral health contributes to feeding problems (Wilson et al., 2018) and has also been independently associated with aspiration pneumonia in the literature (Terpenning et al., 2001; Abe et al., 2008; DiBardino & Wunderink, 2015).

Significant dental problems were described across samples in this scoping review.

Higher rates of epilepsy: People with intellectual disability are significantly more likely to have a diagnosis of epilepsy than the general population (Robertson et al., 2015a). The QLD Public Advocate notes: *"While aspiration pneumonia is not a common complication of seizures in otherwise healthy adults, the increased incidence of aspiration in some people with intellectual disability may be heightened by factors such as increased oral secretions, impaired swallowing mechanisms, and difficulty in attaining adequate positioning"* (QLD 90-14). Day and colleagues (Day et al., 2005) found that people with co-occurring developmental disabilities and epilepsy were at increased risk for death from aspiration pneumonia.

Delays in detection and treatment of infection: In addition to the above factors, problems people with disability experience accessing quality health care in a timely manner may also contribute to the high rates of death from aspiration pneumonia. Pneumonia may be avoidable if aspiration risks are reduced, or treatment commenced in a timely manner (DiBardino & Wunderink, 2015). However, people with intellectual disabilities have been noted to experience delays and difficulties accessing quality health care. Recent research by our department (Trollor et al., 2017) has identified a large proportion of avoidable deaths from infections among a representative cohort with intellectual disability.

In addition to specific risks noted above, report authors identified a number of practice- related contributors to potentially avoidable respiratory deaths in their samples. These include:

- *Lack of comprehensive nutrition and swallowing assessments for at risk groups.* For example, the NSW Ombudsman noted that in 2012-2013 only one-third of the people in non-government disability services who died and who had swallowing difficulties had a comprehensive nutrition and swallowing assessment.
- *Increased risk of aspiration related to safe mealtime guidelines not consistently being adhered to or sometimes being disregarded all together* (i.e. VIC 17-18; VIC 07-16). Failure to adhere to guidelines was a major concern raised by multiple report authors in this scoping review.
- *Poor management of respiratory infection risk following surgery for falls and fractures*: In 2012 and 2013, the NSW Ombudsman noted that some of the people who died from pneumonia or aspiration pneumonia developed the infection following surgery to repair fractures, most of which were associated with falls.
- *Poor access to respiratory specialists and other chronic disease management and other out-of-hospital programs:* The NSW Ombudsman noted that in 2012 and 2013, only 26% of people in disability services with recurrent respiratory illness

and none of the boarding house residents with recurrent respiratory illness had seen a respiratory specialist.

- *Lack of timely access to influenza and pneumococcal vaccines:* Despite public health recommendations, and the known vulnerability of certain groups of people with disabilities to respiratory and other infections, a significant proportion of people whose deaths were investigated across reports, did not have current vaccination protection.
- *Late diagnosis:* For example, the QLD 09-14 report noted that many of the 25 people in their sample who died of respiratory causes died only a short period of time after diagnosis and, in some instances, the condition was not diagnosed until after their death.

External causes of death- choking

Prevalence

Across reports, accidental choking was highlighted as the leading external cause of death for people with disabilities- 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, 24 (83%) were related to choking on food
- 4 people (14%) choked on vomit
- 1 person (3%) choked on a foreign object (latex glove)

Analysis of longitudinal data from the NSW Ombudsman death reviews (see NSW 12-13) indicates that deaths associated with choking have increased in NSW residential services in recent years: 72% of people whose underlying cause of death was choking in the decade to 2013 died in the last four years. In their review of leading causes of deaths of people with disabilities in residential care between 2003-2017 (see NSW 14-17), the NSW Ombudsman found that 'inhalation and ingestion of food causing obstruction of respiratory tract' was the 10th most common cause of death, responsible for 38 (2.37%) of all in-scope deaths.

Comparative mortality research has highlighted different frequencies of certain types of 'external' deaths among cohorts with and without intellectual disability. The general population is more likely to die from external causes such as suicide and traffic accidents, for example (Hosking et al., 2016). Rates of death from choking, on the other hand, are overrepresented among people with intellectual disability. Dupont and Mortensen's study (cited in Sheppard et al., 2017) of causes of mortality among 9891 people with intellectual and developmental disability reported that this population was 100 times more likely to die from choking than the general population. Incidents of non-fatal choking were also reported by 40% of caregivers to adults with developmental disabilities in another study (Thacker et al., 2008). Choking has been reported to be particularly prevalent in certain sub-populations of people with disability. For example, people with Down syndrome experience problems chewing due to poor tongue control, an inefficient tongue thrust and an underdeveloped jaw (Hennequin et al., 1999). People with cerebral palsy are at increased risk for choking on food due to impaired swallowing and coughing reflexes (Pilla et al., 2018). Rates of choking have also been noted to be elevated in populations with mental illness and in populations with dementia (Guthrie & Stansfield, 2017).

Demographics of people who died from choking

A lack of consistent and detailed stratification of cause of death by demographics across reports limits insight into the characteristics of people with disability who were most at risk for this type of death. In the NSW (12-13 & 14-17) and VIC 17-18 reports it appeared that most people whose underlying cause of death was choking lived in shared accommodation. More than half of the NSW 12-13 sample were also noted to have choked at home. In 3 of the 10 cases reviewed people choked during celebratory meals: two people choked on their birthday at their day program, and one person choked during a meal at home to celebrate another resident’s birthday. This may highlight an issue regarding lack of consistency with mealtime guidelines on ‘special’ occasions. The QLD 09-14 report noted that in their sample men were slightly more likely than women to die due to choking and food aspiration. In both the NSW reports it was noted that most of the people who died from choking had known risk factors prior to their death including problems swallowing, missing teeth, and problematic eating and drinking behaviours (such as eating too quickly, overfilling their mouth, swallowing without adequately chewing).

Risk Factors

As highlighted previously in our discussion of aspiration pneumonia, there are a number of risk factors for choking that are overrepresented in certain groups of people with disabilities. These include high rates of psychotropic medications and polypharmacy, dysphagia, risky food related behaviours such as gorging or pica, GORD, poor oral health and impaired muscle control or weakness (Sheppard et al., 2017).

Additionally, the following areas of *problematic practice* related to choking risk were reported by death review authors:

- Expert advice regarding mealtime requirements provided by a dietitian or speech pathologist not being adhered to (VIC 17-18; VIC 07-16; QLD, NSW). This included periods of non-supervision during mealtimes and inappropriate food types and textures being offered.
- Potentially inappropriately high use of antipsychotics (VIC 17-18).
- Failure by service providers to proactively reduce the risk of choking: For example, the NSW Ombudsman (NSW 14-17) highlighted cases where the person had had previous non-fatal choking events prior to death but insufficient action had been taken to reduce future incidents from occurring.

Deaths related to Epilepsy

Prevalence

Diseases of the nervous system were a common underlying cause of death across jurisdictions, accounting for 126 of the 901 deaths included in this scoping review (14%). Epilepsy was listed as the leading cause of death in 46 (37%) of these cases, and 5% of all deaths included in the review. These data are consistent with the NSW Ombudsman's longitudinal review of cause of death for people with disability in residential care between 2003-2017 that found epilepsy accounted for 5.35% of all in-scope deaths (see NSW 14- 17). Epilepsy was reported as the third most common cause of death across this time period.

Demographics of people with epilepsy who died

Only the QLD 09-14 report on disability included an in-depth analysis related to the deaths of people with epilepsy. They noted that a higher proportion of people with epilepsy in their sample died at night and died in their usual place of residence, compared to people without epilepsy. This likely reflects a known association between sleep and increased risk of seizures, a higher chance of breathing impairment related to lying prone, as well as the fact that a person is less likely to be under direct observation during sleep (Purnell et al., 2018).

Risk Factors

Compared to the general population, deaths from epilepsy related causes are overrepresented among people with disabilities. This can largely be explained by the overrepresentation of epilepsy among people with certain types of disabilities, such as intellectual disability. While population prevalence estimates vary between studies, approximately 16%-30% of people with intellectual disability are thought to have epilepsy, compared to 0.5-1.0% of the general population (Robertson et al., 2015a). More severe levels of disability are associated with higher prevalence rates (Robertson et al., 2015b). A recent meta-analysis (Robertson et al., 2015b) of 38 studies in general populations with intellectual disability reported a pooled epilepsy prevalence of 22.2% (95% CI 19.6–25.1).

Populations with co-occurring intellectual disability and epilepsy have a substantially increased mortality risk, particularly in cases where the seizure activity is ongoing (Robertson et al., 2015a). Although the reason is unclear, recent research indicates a growing trend in the number of people with an intellectual disability dying as a consequence of epilepsy (Kiani et al. 2014). It is possible that problems people with intellectual disability experience accessing quality health care, as well as issues related to recognising and communicating health concerns may also contribute to poorer epilepsy management in this population (Robertson, Baines, et al., 2017)

In their analysis of epilepsy related deaths, the QLD Office of the Public Advocate (QLD 09-14) identified the following areas of problematic practice:

- Some people who died appeared to have been administered sub-therapeutic dosages of anticonvulsant medication.
- In some cases it was not clear whether people had access to a specialist neurologist for management and oversight of their epilepsy, including regular medication reviews, prior to death.
- In one case, the person's epilepsy medication was ceased in hospital prior to surgery and despite staff witnessing seizures, the medication was not recommenced.
- Sub-optimal recording and charting of seizure activity was noted. Poor charting of seizure activity is an issue of concern, especially given recent research indicating that in 90% of the deaths due to sudden unexpected death in epilepsy (SUDEP) there was an increase in seizure activity and/or intensity 3-6 months before death (Shankar, 2015).

Deaths due to neoplasms and circulatory disease: Understanding and addressing lifestyle related risks

Neoplasms

Across the 901 deaths included in this scoping review, neoplasms were the underlying cause of death for 118 people (13.09%). Malignant neoplasms of the digestive organs and malignant neoplasms of the trachea, bronchus and lungs were the most frequently reported neoplasm types. Previous research has highlighted higher rates of cancer mortality in the general population, compared to groups with intellectual disability (Patja et al., 2001; Trollor et al., 2017). Consistent with this finding, people in this scoping review appeared more likely than the general population to die from other causes. However, neoplasms were still a cause of death for a significant proportion of the sample and neoplasm death rates in people with intellectual disability have not been presented as

age-adjusted statistics. Given that the risk for certain cancers has been linked to lifestyle factors including diet, exercise, smoking and alcohol (Orenstein et al., 2016), and that cancer re-occurrence among cancer survivors is noted to be lower with healthy lifestyle behaviour (Schwedhelm et al., 2016), a proportion of neoplasm related deaths in this sample may be potentially avoidable or amenable to intervention. Further research is required in this area.

Malignant neoplasms of the bronchus and lungs are one type of cancer considered potentially amenable to lifestyle interventions such as smoking reduction (Torre et al., 2015). Significantly, the NSW Ombudsman's longitudinal analysis of in-scope deaths from 2002-2017 (see NSW 14-17) identified this type of neoplasm as the leading cause of cancer related deaths in both assisted boarding house and disability service samples. In the assisted boarding house sample, malignant neoplasms of the bronchus and lungs were the 4th most common cause of death overall, accounting for 5.03% of all in-scope deaths. In the disability services sample they were the 9th most common cause, accounting for 2.1% of all in-scope deaths during this period.

Circulatory deaths

Circulatory disease was listed as the underlying cause of death of 121 of the 901 cases included in this scoping review (13.42%). In both the QLD 09-14 and VIC 17-18 reports, circulatory disease was the second most common underlying cause of death at ICD Chapter level. In the NSW in-scope reports, circulatory disease was the leading cause of death in assisted boarding house samples but not in the disability service samples.

At ICD sub-chapter level ischaemic heart disease featured as the leading underlying cause of circulatory deaths across reports. Ischaemic heart disease was the cause of 50% of all circulatory deaths in the QLD 09-14 sample, and 35% and 31% of all circulatory deaths in the 2012-2013 and 2014-2017 NSW samples respectively. Mortality from ischaemic heart disease, as well as other types of circulatory disease, has been noted in the literature to be amenable to lifestyle intervention (O'Doherty, et. al.)

Differences in analysis between reports limits insight into overall demographic patterns of people who died from this cause. In the QLD 09-14 sample, women were noted to be slightly more likely than men to die from circulatory disease, however the sample size was small. In the NSW 12-13 report, it was noted that people in assisted boarding houses tended to have more relevant risk factors for circulatory deaths such as smoking, hypertension, and obesity, compared to people in disability services. Circulatory deaths were more common in the older age brackets analysed in the NSW samples.

While rates of circulatory deaths are also high in the general population, they have been falling in recent years, potentially as a result of health promotion initiatives and improved access to healthy living supports (O'Flaherty et al., 2012). Rates of deaths from circulatory diseases have not declined in a similar fashion for people with intellectual disability, however, suggesting that health promotion messaging and initiatives may not be accessible to these populations.

Identifying lifestyle related risks across the samples

Report authors identify a number of lifestyle related risks that potentially contributed to circulatory and neoplasm related deaths in their samples. These include:

Obesity: For example, over one-third of the people in disability services in NSW who died in 2012-2013 and over half of the people in assisted boarding houses, were overweight or obese. The NSW Ombudsman notes that the leading causes of death for this sample who were obese or severely obese included heart attack, heart disease, pneumonia, COPD and cancers. For eight of these people, the Coroner specifically identified obesity as a significant contributory factor in their death. In the 2014-2017 review period the Ombudsman notes that over one-third of the people who died in disability services and almost half of the residents who died in assisted boarding houses were overweight or obese. Obesity was identified as a significant condition or contributory factor in the deaths of eleven people over this time period.

Smoking: For example, 30% of the people who died from circulatory disease in the VIC 17-18 sample were smokers. In NSW between 2014-2017 61% of the assisted boarding house residents who died were reported to have smoked, including one-third who were smoking more than 10 cigarettes a day at the time of their death.

Low or unknown levels of physical activity: For example, all people who died from circulatory disease in the VIC 17-18 sample had low or unknown levels of physical activity.

Hypertension: For example, 19% of the VIC 2017-18 sample were known to have hypertension. For the NSW 2012-2013 review period, 29% of disability service residents and 40% of assisted boarding house residents had a diagnosis of hypertension prior to their death. For the 2014-2017 review period, 30% of disability service residents who died and 28% of assisted boarding house residents were noted to have hypertension.

Diabetes: For example, 14% of the VIC 17-18 sample was known to have diabetes. In NSW, 27% of assisted boarding house residents who died in 2012-13 and 11% who died in 2014-17 had a diagnosis of diabetes.

Poor management of lifestyle related risks: For example, in the VIC 17-18 sample, 50% of people who died from circulatory disease had neither seen a cardiologist or dietitian in the previous 12 months (despite the fact that many had identifiable risk factors such as hypertension, being overweight, a lack of physical activity, and smoking). In the QLD sample, it was also noted that some of the people who died from circulatory disease were obese, but there was little evidence to show how this health issue had been attended to, prior to death. Similarly, in the NSW 12-14 report it was noted that almost half of the people in disability services who were outside of a healthy weight range had not seen a dietitian. In the NSW 14-17 report it was noted that only 33% of the boarding house residents who were outside of the healthy weight range had seen a dietitian.

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

residential care: The NSW Ombudsman notes that in many cases people did not seem to receive care based on the guidance policies issues by ADHC in their ‘Health care policy and procedures’ (ADHC, 2007-ammended 2010 and 2012). For example, many people who were overweight were not referred to their GP or a dietician to obtain an individual eating plan and individualised dietary advice for weight loss, despite a requirement that they should have been. It was also noted that some disability staff encouraged unhealthy eating practices by taking residents to ‘fast-food’ restaurants (NSW 14-17).

Lack of care co-ordination between services to address identified risk factors: The NSW Ombudsman (NSW 14-17) notes, “*A range of reviews identified individuals whose weight was adversely affecting their health, such as their respiratory function. However, other than recording the significant risks for the person and telling them they needed to lose weight, no support was provided. In some cases, we did not see an attempt to adopt a coordinated and person-centred approach to helping the person to address their weight risks, even when their obesity was noted to be limiting the treatment options for their chronic conditions.”*

High rates of psychotropic prescriptions and polypharmacy and insufficient specialist review of medications: High rates of polypharmacy and antipsychotic use in the absence of a mental illness diagnosis were noted in a number of the in-scope death reviews. Psychotropic medications can contribute to lifestyle risks including weight gain, hypertension and diabetes (Correll et al., 2015) and thus place clients at increased risk for certain types of deaths. A lack of specialist input and medication reviews were noted by several report authors.

While dietary risk factors and levels of physical activity were not extensively examined in the reports included in this scoping review, we know from the literature that these factors also contribute to preventable morbidity and mortality and are overrepresented in people with disabilities. Compared to the general population, for example, people with intellectual disability are significantly less likely to meet physical activity recommendations and significantly more likely to live sedentary lifestyles (Einarsson et al., 2015; Dixon-Ibarra et al., 2013). They are also more likely to consume a diet that is higher in calories and lower in nutrients (Crawley, 2009).

Overarching problems spanning jurisdictions and types of deaths

In addition to lifestyle and disease specific risks identified above, a number of areas of poor practice were noted across death types and jurisdictions. These include inadequate facilitation of preventative health care measures, difficulties identifying and responding to health concerns and health care emergencies, and lack of clarity around end of life planning. In this section of the review we highlight the contribution of these factors to the sequence of events leading up to the person’s death.

Access to preventative health care

Across jurisdictions report authors noted a lack of proactive support for preventative health care measures, including recommended vaccinations, dental check-ups and annual comprehensive health examinations. Across populations, preventative health care measures play a significant role in reducing potentially avoidable complications and deaths. In the context of known high rates of potentially avoidable deaths among certain groups with disabilities (Trollor et al., 2017), it is of significant concern that many deaths that were in-scope for this review involved people whose preventative health care needs had not been fully met.

Influenza and pneumococcal vaccinations**,** for example, are encouraged for vulnerable populations with complex health needs. The majority of people whose deaths were in- scope for this review fell into this category. Influenza and pneumococcal vaccinations reduce the risk of certain types of respiratory infections and complications (Kraicer- Melamed et al., 2016), and combined vaccination has been shown to reduce pneumonia related mortality (Christenson et al., 2004). Across samples, however, compliance with vaccination recommendations was not as high as it could have been. Where reported, between 14% and 48% of people whose deaths were in-scope for this review had not received an influenza vaccination in the 12 months prior to their death and between 25% and 83% had not received a pneumococcal vaccination.

As noted previously, most disability providers are also expected to support clients to attend a ***comprehensive annual health examination*****.** Annual health check-ups are an evidence-based intervention for improving primary care for people with intellectual disability (Robertson et al., 2014). They assist in early detection of new diseases and improve monitoring of pre-existing diseases (Buszewicz et al., 2014; Lennox et al., 2007). Such examinations are particularly important for populations with disabilities who have multiple co-morbidities and may struggle to identify or communicate changes in their health status (Cooper et al., 2014). In this scoping review, however, we found that the date of the person’s last comprehensive health assessment was either unknown or unreported in the VIC 17-18 and QLD 09-14 samples. Data from NSW (NSW 12-13 & 14-17) highlighted that a significant minority of people who died during the in-scope reporting periods had not had access to this important preventative health care measure. In the 2012-2013 reporting period, for example, 26% of deaths involved people who had not had a comprehensive health check in the preceding 12 months. In the 2014-2017 period, 20% of deaths involved people who had not had a comprehensive health check in the preceding 12 months.

The significant proportion of people across these samples whose health assessment status was unknown, or who had not had a comprehensive check-up in the last 12 months, is striking, given that disability accommodation services are generally mandated to support clients to undertake an annual GP assessment. Financial burden is unlikely to be a factor, given the Medicare Benefits Schedule (MBS) provides for extended consultations for annual comprehensive health assessments for people with known health risks- this includes people with a diagnosis of intellectual disability and people aged between 45-49 who are at risk of developing chronic disease. While it is impossible to determine the number of deaths that could potentially have been avoided if more people attended annual health reviews, we note that late (or no) diagnosis was described as a contributing factor across a number of cases.

Regular dental check-ups are another important preventative health care measure. Poor oral health has been linked to an increased risk of death from causes such as choking on food and aspiration pneumonia (DiBardino & Wunderink, 2015). Tooth loss and self-rated poor tooth and gum health are also markers of increased risk for ischaemic heart disease, peripheral vascular disease and all-cause mortality (Joshy et al., 2016). Despite the fact that people with disabilities are at increased risk specifically from causes such as choking and aspiration pneumonia, and are known to have poor oral health (Ziegler & Spivack, 2018), a significant proportion of people in this review did not appear to be receiving regular dental check-ups. In NSW, for example, 37% of the deaths in the 2012-2013 period and 32% of deaths in the 2014-2017 period involved people who had not seen a dentist in the last year. Lack of accessible dental care contributes to this picture, particularly for people with complex needs who may need highly specialised dental services including extensive preparation to tolerate dental visits or in some situations, dental examination under general anaesthetic.

Poor engagement in preventative health care reported in this scoping review is consistent with previously published disability research (Weise et al., 2017).

Populations with disabilities have been shown to have poorer access to, and lower uptake of preventative health measures such as oral health checks (Ziegler & Spivack, 2018) and cholesterol screenings (Havercamp & Scott, 2015). Women with intellectual disability have been noted to have poor uptake of cervical and breast cancer screenings (Parish et al., 2013; Parish & Saville, 2006). A combination of person-related and environmental barriers are likely to contribute to these preventative health utilisation patterns (Williamson et al., 2017).

Identifying and responding to emerging health concerns

Report authors also raised concerns about how well emerging health risks and chronic conditions were identified and managed by services. Limited use of communication plans and other communication accommodations may have curtailed some clients' ability to express emerging health concerns to staff. Additionally, a lack of proactive management of emerging and chronic health risks was noted. Finally, concerns were raised about inadequate or delayed staff response to emergency situations. In general, these problems highlight a need for additional staff training, supported by organisational best practice policies and procedures.

Facilitating and interpreting client communication: In order for any person to share their health concerns with others, they must have a method of communication available to them. Many people with disabilities have cognitive and/or sensory impairments that impact communication. For example, they may struggle with abstract ideas and may require support to express and/or receive information (Boardman et al., 2014). Additionally, 50- 60% of people with intellectual disability will have a hearing impairment, and approximately 40% may have vision problems (Boardman et al., 2014; Emerson et al., 2001).

Despite legislation and health care policies highlighting the importance of tailored communication for this population (UN General Assembly, 2007), this scoping review has identified that in some cases, people's basic right to supported communication adjustments may not have been met. The VIC 17-18 authors, for example, noted that 53% of in-scope deaths were of people whose reported level of communication indicated that a communication plan should be in place, yet, 38% did not have any such communication plan on record. The NSW Ombudsman, in the 2012-2013 review period similarly notes, "…*while health records have frequently recorded the difficulties experienced by health staff in communicating with patients with disability, they have rarely identified the communication support the person required or received".* Developing communication plans should be a priority for disability services: Early detection and intervention of emerging health threats is far more likely when staff have plans in place to support them to understand the client's verbal and/or behavioural communication cues.

Taking action when chronic health risks or other diagnosis are detected: Across reviews, report authors raised concerns about service providers failing to proactively manage emerging and chronic health risks. As we highlighted in our discussion of lifestyle related risks, a significant portion of people across samples were noted to be outside of a healthy weight range, yet many were not referred to specialists for follow-up and support. Similarly, people with recurrent respiratory infections and other known risks for aspiration were not uniformly referred to specialist clinics for assessment and follow-up. Many of the people across samples who smoked did not appear to have access to preventative supports such as nicotine replacement therapy or involvement in quit smoking programs. These data highlight a need to improve staff awareness of the risks associated with chronic untreated health conditions and the importance of early proactive intervention.

In some cases, it was noted that follow-up care was not sought due to client reluctance to attend medical or dental appointments. Even potentially life-saving treatment such as chemotherapy, was noted to be refused in some cases (NSW 12-13). In such cases, the NSW Ombudsman (NSW 12-13) has highlighted the importance of making reasonable adjustments to practice, and working with the person's team to decrease anxiety and maximise co-operation with appointments.

Identifying and responding to medical emergencies and identifying medical urgency: Across reviews, it was noted that 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, it was noted that staff had difficulty distinguishing between an urgent and a non-urgent health situation, thus leading to delays in treatment that in some cases contributed to death. Given the short window between illness and death that has been reported in many of the in-scope deaths, training staff to respond promptly to deteriorations in health is essential. In their 2012-2013 and 2014-17 reports, for example, the NSW Ombudsman identified incidents of staff documenting deteriorations in health conditions, but not interpreting this as a prompt to seek medical review. Some workers appeared particularly reluctant to seek medical assistance, in cases where the person had recently been reviewed by a doctor. This reluctance may highlight a lack of understanding of how quickly a health problem may deteriorate into a crisis situation. In other cases, workers were unsure how to check for a pulse, or were noted to call their manager before calling emergency services, despite a clear need to call emergency services immediately.

While a number of tools, such as ‘Between the Flags’ (NSW Government, 2013) and ‘ISBAR’ (Introduction, Situation, Background, Assessment and Recommendation) (Thomas, Bertram, & Johnson, 2009), have been implemented in some disability services to improve responses to critical situations, the NSW Ombudsman raised concerns in their 2014-2017 report about how well staff in disability services actually understand such tools. They recommend, instead, educating disability staff (including nurses) not to make professional or clinical judgements about a person’s health. Instead, if they have *any* concerns or doubts or notice any changes or concerns, they should seek urgent medical help.

The importance of direct care staff receiving regular refresher information on responding to critical health incidents was also highlighted (NSW 12-14). Specifically in relation to preventing epilepsy related deaths, the QLD (09-14) report emphasises that all people with a history of prolonged or repeated seizures should have an emergency care plan in place and that all staff should be familiar with this plan. Support staff and family members should also receive regular training about emergency management of epileptic seizures, as well as administration of emergency medication, if required, prior to arrival of emergency services.

Supporting end of life care

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 procedures indicated by the persons presenting conditions and treatment options. The QLD (09-14) authors noted that a number of their cases, "…*raised questions about whether more active treatment could have been provided for treatable illness, particularly where 'not for resuscitation' orders were provided by substitute decision-makers".* The NSW Ombudsman's report (NSW 12-13) also raised a number of problematic practices and concerns regarding end of life planning for people with disabilities. These include the following instances:

- *"decisions to limit treatment, start palliative care, or not to perform CPR were made by medical staff without the involvement of the person's family,*
- *the reasons for end of life decisions were either not documented or were very limited,*
- *the person with disability was not involved in the palliative care planning, and*
- *there was a lack of coordinated palliative care provided to assisted boarding house residents with advanced terminal conditions." (NSW 2012-13*)".

Report authors highlight the importance of advance care planning activities that include the person with disability to the utmost extent possible. Health care staff, disability staff and family members, may also require additional support to enhance their understanding of legal, ethical, and medical considerations pertaining to end of life decision making for people with disabilities. A decision to withhold or cease treatment should only be made in conjunction with all relevant parties. We note that NSW was the only jurisdiction that specifically reported on who provided consent to treatment for people whose deaths were in-scope for review. We recommend the Commission collect this information as part of their minimum dataset for NDIS death investigations. This information may help to clarify how end of life decisions are being made, and identify where future education initiatives could best be targeted.

Issues raised across these death reviews regarding end of life planning for people with disabilities, are consistent with findings from national and international research.

Specifically in relation to end of life care for people with intellectual disabilities, for example, problems with accessing palliative care (Friedman, Helm, & Woodman, 2012), and lack of confidence among palliative care staff to tailor their practice to the needs of this population (Ryan, McEvoy, Guerin, & Dodd, 2010) have been noted. Additionally, medical staff and family members have identified confusion regarding their roles in facilitating advanced care plan discussions with people with intellectual disability (Voss et al., 2017). Hospice staff describe struggling with ethical dilemmas pertaining to informed consent when capacity is lacking or difficult to determine (Friedman et al., 2012).

Difficulties pertaining to pain assessment and management have also been raised (Friedman et al., 2012; Read, 2006), particularly in cases where people may be non-verbal. Reviews have highlighted that people with intellectual disability are often excluded from participation in end of life planning, despite the fact that some level of inclusion is generally possible, with creativity and skilful use of communication accommodations (Kirkendall, Linton, & Farris, 2017).

Conclusion

This scoping review has highlighted the significant gap in life expectancy experienced by people with disabilities in Australia. Across include jurisdictions, people with disabilities died approximately 20 to 25 years earlier than the general population. Analysis of the demographic data of people whose deaths were in-scope highlighted the complex health presentations of this population, that included multiple physical and mental health co- morbidities, and in many cases communication and mobility challenges. High rates of psychotropic use and polypharmacy were also noted across samples. Compared to the general Australian population, deaths from respiratory causes (mainly aspiration pneumonia and pneumonia) appeared to be overrepresented, as did nervous system deaths (especially epilepsy related). Deaths from particular types of external causes (specifically choking on food) were also overrepresented.

It was not possible to quantify the exact number of in-scope deaths across reports that were potentially treatable or avoidable. Certain categories of deaths that were overrepresented in this sample, however, such as deaths related to respiratory infections, choking, and epilepsy have been demonstrated to be potentially avoidable or amenable to intervention. Additionally, certain categories of circulatory and neoplasm deaths described across samples, have been shown to be sensitive to lifestyle intervention.

Across jurisdictions report authors identified a number of areas of poor practice that contributed to overall premature mortality. These included failure to comprehensively support client access to preventative health measures such as recommended vaccinations, annual physical examinations and dental appointments. Despite observed high rates of lifestyle related risks such as obesity and hypertension, a significant proportion of people whose deaths were in-scope for this review had not been supported to access the services of dietitians or exercise physiologists prior to their deaths.

Concerns were also raised by report authors that people with known health risks such as dysphagia, epilepsy, re-current respiratory infections or cardiac conditions, were not referred in a timely manner for specialist assessment and support. It was also unclear to what extent accommodations were being made by health and disability services to support clients to communicate their experiences and health concerns effectively.

Systematic problems related to both health and disability staff training and expertise were also noted across jurisdictions. For example, even in cases where the person had a mealtime management plan in place, multiple cases of staff not adhering to the plan were noted as a contributing factor in choking deaths. Emerging chronic health concerns were not always proactively followed up by staff, and it was noted that staff were unsure at times of how to appropriately respond to acute changes in the person’s health, or how to respond to a medical emergency. Lack of clarity around end of life care and decision- making was also described.

A number of limitations should be kept in mind when interpreting the results of this scoping review: Firstly, the five in-scope reports spanned significantly different time periods and had noted differences in their terms-of-reference and inclusion criteria. The overall sample therefore cannot be assumed to be representative of the broader population of people with disabilities in Australia. Secondly, methodological differences in data collection and data analysis techniques meant that in many cases it was not possible to directly compare results across jurisdictions. For example, QLD was the only state that attempted to define and quantify the number of potentially avoidable deaths in their sample. Thirdly, specifically in relation to cause of death, methodological constraints and differences between reports limit the insights that can be drawn. Cause of death could not always be established, for example, particularly in cases where the person’s death was not ‘reportable’ to the state coroner. For a significant minority of in-scope deaths, underlying cause of death was listed as the disability itself, thus limiting the insight we could draw into potentially avoidable factors that may have also contributed to these deaths. Finally, limited and varied stratification of demographics by cause of death across reports meant that it was not possible to build up a clear picture of exactly who was more likely to die from which types of causes.

The introduction of the NDIS Quality and Safeguards Commission offers a substantial opportunity to develop a more comprehensive national picture of causes and contributors to deaths of Australians with disability. Despite the limitations outlined above, we are hopeful that the findings and analysis offered in this scoping review will provide the Commission with insight into core patterns related to deaths of people with disabilities in Australia, as well as potential methodological pitfalls to avoid when establishing an investigative methodology for their own death reviews.

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