Office of the Public Advocate (Qld)

Upholding the right to life and health:

A review of the deaths in care of people with disability in Queensland

A systemic advocacy report

February 2016

Queensland Government

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Foreword

Queenslanders with disability are dying unnecessarily. This needs to change.

Articles 10 and 25 of the United Nations *Convention on the Rights of Persons with Disabilities* articulate obligations to uphold a person's right to life and right to the highest attainable standard of health without discrimination on the basis of disability. This report provides evidence to suggest that relevant sectors within Queensland require improvement to ensure that the State effectively upholds these obligations.

It is well recognised that people with disability experience a broad range of medical conditions of varying complexity. While the range of conditions is akin to those experienced by the general population, the risk factors for some conditions can be more prevalent for people with disability.

There are a relatively limited number of health practitioners in Queensland with substantive experience in working with people with disability, particularly those with impaired capacity. However they do exist and where they do, the health outcomes for their patients are generally better than those achieved by many people with disability, particularly those living in residential care settings.

Unfortunately the health practitioners who lack the requisite knowledge and experience generally 'don't know what they don't know'. As a result, the diagnostic indicators for some conditions are often overshadowed by the presence of disability, which can impact the timeliness within which an accurate diagnosis is made and treatment provided. As stated by Brolan et al,

> *"…people with intellectual disability frequently experience unrecognised and poorly managed complex medical conditions, which detrimentally impact their mortality and morbidity rates."*[1]

People with impaired capacity and/or communication impairments are often further disadvantaged by the challenges they face in communicating their symptoms. In many cases, there is an over-reliance on families, carers and support staff (most of whom lack any form of medical training) to 'interpret' what the person with disability is experiencing.

Together with my fellow Advisory Panel members, I read every document that was provided in relation to the deaths in care of the 73 people who were the subject of this review. Both in reading these documents and during Panel discussions, I often reflected on how different the lives of many of these individuals could have been if their health needs had been better understood and attended to.

The issues that we identified in this review have historic origins just as much as they are perpetuated by the systemic challenges that plague human service delivery for many vulnerable persons. However that is not to say that they cannot be attended to.

We cannot ignore the fact that over half of the deaths in the sample were unexpected, and that (of that number) two thirds were also considered to be potentially avoidable.

The words 'potentially avoidable' clearly point to the need for action. They also indicate that change is possible.

With the implementation of the National Disability Insurance Scheme (NDIS) in Queensland imminent and the first NDIS participants due to begin accessing the scheme within months, the time to act is now.

Government has forecasted that the implementation of the NDIS in Queensland will result in an estimated increase in the number of people accessing funded disability supports from 45,000 to approximately 97,000. While this represents a significant improvement for Queenslanders with disability who require support, the findings from this review suggest that this may also increase potential risks.

The Queensland Government has estimated that the implementation of the NDIS will also herald 13,000 more jobs across multiple sectors. Many of these 13,000 people may lack background knowledge and expertise in providing services and supports to people with disability.

A targeted strategy to educate and inform people with disability, their families/carers, support staff, service organisations, health practitioners and the myriad of other relevant people and agencies in the broader community about health management and risk factors for people with disability is much needed. Without this, the lack of cohesion that is a notable feature in service provision for people with disability may result in catastrophic outcomes over coming years.

The evidence presented in this report highlights both opportunities and challenges associated with improving health outcomes for Queenslanders with disability. However, the information contained therein also highlights a number of important ways by which to reduce risk.

This review is the first of its kind in Queensland. Clearly we have the information that we need to make a difference… the next steps involve translating this information into action.

Jm Griffiths-Cook

Jodie Griffiths-Cook
Public Advocate (Qld)

Acknowledgements

Although my report is the first of its kind in Queensland, it is not unique. To this end, I would like to acknowledge the excellent work undertaken by the New South Wales Ombudsman in relation to ‘reviewable deaths’. The methodology underpinning this review was informed by the reports of reviewable deaths produced by the New South Wales Ombudsman.

I would like to thank the Office of the State Coroner; the Department of Communities, Child Safety and Disability Services; the Department of Health; and the Department of Housing and Public Works for providing access to data and documentation relating to the deaths of people with disability in care. I appreciate that the work involved in doing so was both time-consuming and resource-intensive, and I trust that this report will provide a resource to assist each of these agencies in further enhancing the services they provide to, and on behalf of, Queenslanders with disability.

A number of non-government organisations also assisted by providing information to support the Panel in undertaking case study analyses. I thank these organisations for the time spent in collating this information and, by extension, their contribution to the review.

Thank you also to the Queensland University of Technology and Tamara Rader for your assistance in guiding and undertaking research relevant to issues identified in this review.

Most importantly, I would like to acknowledge and thank my fellow Advisory Panel members (listed in Appendix One) for their dedication to this project. The Advisory Panel members contributed their time both during and outside of meetings to peruse countless pages of case file information, and to consider and discuss how best to respond to the findings of the review. I commend each of them for their commitment to improving outcomes for people with disability.

Finally, I would like to thank Ms Kim Chandler for her tireless work as Panel Secretariat and Project Manager. Without her efforts, this review and the resultant report would not have been possible.

Report structure

This report has been deliberately structured to enable both a high-level understanding of key issues, as conveyed in the Executive Summary, while also providing the necessary detail in the body of the report to demonstrate the evidence for change and guide the directions for reform.

The information and recommendations in this report have relevance for both State and Commonwealth Governments, non-government organisations, private providers, and health practitioner education and regulatory bodies.

Glossary

Causes of death	Those diseases, morbid conditions or injuries that either resulted in or contributed to death.
Core activity limitation	The Survey of Disability Aging and Carers (SDAC) describes four levels of core activity (i.e. communication, mobility and self-care) limitation. These include: profound; severe; moderate; and mild.
Death in care	A death will be a death in care if the person who died: • had a disability under the *Disability Services Act 2006* and lived in either a level three accredited residential service or a government funded or provided residential service • was subject to involuntary assessment or treatment under the *Mental Health Act 2000* or the *Forensic Disability Act 2011* and was either being taken to or detained in an authorised mental health service or the forensic disability service, detained because of a court order, or undertaking limited community treatment • was a child awaiting adoption under the *Adoption Act 2009* • was a child who lived away from their parents as a result of action taken under the *Child Protection Act 1999*.
ICD -10 **(International Statistical Classification of Diseases and Related Health Problems 10th Revision)**	The International Classification of Diseases (ICD) is the international standard classification for epidemiological purposes and is designed to promote international comparability in the collection, processing, classification, and presentation of causes of death statistics. The classification is used to classify diseases and causes of disease or injury as recorded on many types of medical records as well as death certificates and Coroner's findings. Currently the ICD 10th revision is used for classifying causes of death statistics in Australia.
Immediate cause of death	The disease or condition directly leading to death.
Other significant health conditions	Other significant conditions contributing to the death, but not related to the disease or condition causing it.
Potentially avoidable death	Potentially avoidable deaths comprise potentially preventable deaths and potentially treatable deaths.
Potentially preventable death	Potentially preventable deaths are 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.
Potentially treatable death	Deaths from potentially treatable conditions are those that are amenable to therapeutic interventions, and reflect the safety and quality of the current treatment system.
Profound disability	A person with disability who is unable to do, or always needs help with, a core activity task.
Sensory, Intellectual, Psychiatric and Neurological disabilities	For the SDAC, the Australian Bureau of Statistics (ABS) identifies four different groups based on the different type of disability. These four groups are: sensory, intellectual, psychiatric and neurological disabilities.
Severe disability	A person with disability who: • Sometimes needs help with a core activity task; and/or • Has difficulty understanding or being understood by family or friends; or • Can communicate more easily using sign language or other non-spoken form of communication.
Underlying cause of death	The disease or injury that initiated the train of morbid events leading directly to the death.
Unexpected death	A death that was not anticipated as a significant possibility 24 hours before the death.

Executive Summary

The United Nations *Convention on the Rights of Persons with Disabilities* (the Convention)[2] recognises that people with disability have the right to the enjoyment of the highest attainable standard of health, on an equal basis with others.[3] Queensland's transition to the National Disability Insurance Scheme (NDIS) presents a unique opportunity to review the extent to which Queensland is meeting its obligations under the Convention and to improve its performance accordingly.

This report seeks to assist this process by detailing the findings of a review of the deaths of 73 people with disability who died in care in Queensland between 2009 and 2014. This review was undertaken by the Public Advocate with assistance from an Advisory Panel.

The Advisory Panel comprised statutory authorities, whose functions were relevant to monitoring the provision of supports and services (including health services) to people with disability, and medical practitioners with specific expertise in health care for people with disability.

Summary of findings

People with disability who died in care between 2009 and 2014

Age, place and time of death

The median age at death for males was 53 years (approximately 25 years less than the general population), and 49 years for females (approximately 36 years less than the general population).

At the time of their death, most people (89%) were living in either disability supported accommodation operated by a non-government organisation (53%), or the government-operated Accommodation Support and Respite Services (AS&RS) (36%). Only eleven percent (11%) were living in a level three accredited residential service.

People with disability in the sample were slightly more likely to die while in hospital, with 58% of people dying in hospital and 42% dying in their usual place of residence. Most people (62%) died during the night between 6:00 PM and 6:00 AM.

Common underlying causes of death

The most common underlying causes of death were:

- Respiratory diseases (mostly aspiration pneumonia and pneumonia) (34%);
- Circulatory system diseases (mostly ischaemic heart disease) (22%);
- Diseases of the nervous system (epilepsy) (11%);
- Neoplasms/cancers (10%); and
- External causes/accidental threats to breathing (i.e. choking and food aspiration) (8%).

Unexpected and avoidable deaths

More than half of all deaths in care reviewed (59%) were determined by the Panel to be unexpected and over half of all deaths (53%) were considered by the Panel to be potentially avoidable. Of those deaths deemed to be unexpected, 67% were also considered to be potentially avoidable.

Addressing risk factors and vulnerabilities

A number of risk factors and vulnerabilities were identified when considering the leading causes of death for people with disability in this sample. Of note were key risks relating to respiratory disease, epilepsy, heart disease, choking, and the use of psychotropic medication; these are summarised below. Detailed information about these risks and the recommendations from this review is in the body of the report.

Respiratory Disease

While respiratory diseases account for about 9% of deaths in the general population, they are one of the major causes of death in people with intellectual disability. Although respiratory disease is often linked to age, people with disability may be at a higher risk due to a combination of factors such as limited mobility and dependence on others, swallowing difficulties, high use of psychotropic medication, and the presence of conditions such as epilepsy, Down syndrome and cerebral palsy. In this sample approximately 34% (or 25 individuals) died as a result of respiratory disease, notably aspiration pneumonia and pneumonia. Further, many people in this sample died only a short period of time after diagnosis and, in some instances, the condition was not diagnosed until after their death. Conditions such as pneumonia can, and should, be diagnosed quickly and treated urgently.

There is a clear need for enhanced education and increased awareness about heightened risks of respiratory disease (in particular pneumonia and aspiration pneumonia) for many people with disability. This should include information that alerts people with disability, their families/carers, and support staff to the 'red flags' that indicate the need to seek urgent medical assistance.

Service organisations must educate and train support staff to recognise and address risks associated with respiratory disease, in particular, swallowing difficulties, enteral feeding, epilepsy management, and the use of psychotropic medication.

Guidelines for health practitioners must clearly articulate comorbidities and other factors that indicate increased vulnerability/risk of respiratory disease for people with disability.

Epilepsy

The prevalence of epilepsy in people with intellectual or cognitive impairment is recognised as being much greater than the general population. Forty-nine percent (49%) of the sample for this review were identified to have epilepsy. Approximately 10% of the sample (or 7 individuals) died as a result of epilepsy, with Sudden Unexpected Death in Epilepsy (SUDEP) being the most common cause of epilepsy-related deaths.

This report highlights the importance of specialist medical advice and regular medical reviews for people with disability who also have epilepsy. It also points to the importance of support staff having the knowledge and skills to manage this condition.

There is also a clear need for further training to improve the skills of health practitioners in diagnosing and managing epilepsy in people with disability, understanding associated risks, and conveying relevant information to people with disability and families/carers.

Support staff must work closely with health practitioners to ensure the adequacy of their knowledge and skills in administering medication and emergency care, and in recognising the signs that indicate the need to seek urgent medical assistance.

Support staff and health practitioners must work together to ensure a coordinated approach to: risk assessment; epilepsy care and management planning; accurate monitoring and recording of seizures; and facilitating access to regular specialist and medication reviews.

Simple and non-invasive ways to reduce the risk of SUDEP for individuals at risk (e.g. seizure detection smart watches and pressure mattresses) should be used by all care providers.

Circulatory system diseases

Circulatory system diseases, in particular Ischaemic heart disease, have been found by this and other systemic studies of deaths of people with disability in care to be a leading cause of death. A number of risk factors, some of which can be modified through lifestyle changes (e.g. diet and exercise) were present for the 16 people in this sample (22%) whose death was attributed to circulatory system diseases.

Service organisations must support people with disability to make informed lifestyle choices by ensuring information is available in accessible formats and training staff to promote and actively support healthy lifestyle habits such as maintaining healthy diets, engaging in physical activity and exercise, and reducing/stopping smoking.

People with disability who have congenital heart disease (including those with defects corrected as children) should be supported to access specialist cardiologist treatment. They should also have regular medication reviews, particularly when being administered psychotropic medications given that this can also be a risk factor for cardiovascular disease. Monitoring regimes (e.g. of lipids, ECG and cholesterol) should be scheduled for every 3-6 months.

Decisions about treatment of congenital heart disease, including advance care planning, must be based on transparent criteria with the wishes of the person with disability given precedence in decision-making processes.

Choking/food asphyxia

Many people with intellectual or cognitive disability have difficulty with swallowing and eating. Of the five people in this sample who died due to choking/food asphyxia, swallowing assessments had been conducted and mealtime management plans developed for only three. Notably, there appeared to be a lack of compliance with those plans.

Service organisations and support staff must be alert to risks that indicate the need for further investigation of eating, drinking, swallowing and/or breathing difficulties.

Support staff must work closely with health practitioners to ensure that risks are appropriately assessed, and that mealtime management plans are developed, the resultant plans strictly complied with, and regular reviews undertaken. Factors such as resourcing and rostering must be considered and addressed in developing plans.

There is a clear need for increased understanding and training in relation to: the preparation of food; physical positioning, prompting and pacing during meals; maintaining close supervision; and in administering emergency care.

The potential for legal liability should diagnosed conditions or identified issues not be appropriately managed is an important matter for organisations and staff alike.

Psychotropic medication

Of significant concern in this review was the high number of people with disability (49%) being administered psychotropic medication in cases where, based on available information, few seemed to have a diagnosis of mental illness. It was also noted that polypharmacy (the use of multiple medications) was common, with, on average, three medications administered per individual. This was particularly concerning given that a number of negative health risks are associated with the use of psychotropic medication, including weight gain and sedation that, in turn, can lead to other health risks such as swallowing difficulties, aspiration (and aspiration pneumonia) as well as the risk of deep vein thrombosis.

Targeted educative resources are needed (particularly for health practitioners and support staff) to ensure that issues associated with efficacy, safety and the law in the administration of psychotropic medication for people with intellectual or cognitive disability are well understood.

Health practitioners should have access to clear guidelines addressing the dangers, and limited efficacy, of using psychotropic medications to control the behaviour of people with intellectual or cognitive disability. The guidelines should: promote adherence to standard pharmacy practices and procedures; actively discourage 'off-licence' use of such medications; and address issues associated with dosage, monitoring, and review.

Service organisations should prioritise comprehensive reviews of all people with disability who are being administered psychotropic medications, including those for whom these medications are being used for behaviour control. These reviews should include a full risk assessment to identify the potential for adverse side effects and contraindications.

Regular medication reviews by a specialist pharmacist and psychiatrist should be embraced as standard practice for all people with disability. These reviews should also inform screening practices (e.g. lipids, cholesterol, glucose, ECG) every 3-6 months, regular medical check-ups and comprehensive medical reviews (annually).

Addressing issues with health care and disability support

This review also highlighted key areas in the delivery of health and disability services that require reform to better address the health care and disability needs of people with disability, particularly those living in residential services. More detailed information about these issues and the associated recommendations can be found in the body of the report.

Improving primary care and prevention

Access to primary health care, including regular general health checks and annual comprehensive health checks, is integral not only to maintain the health and wellbeing of people with disability in residential care but also to identify preventable diseases in a timely way.

Service organisations should prioritise and allocate resources to ensure people with disability in residential care are supported to access regular medical check-ups (including dental), and annual comprehensive medical reviews.

Queensland's transition to the NDIS presents both opportunities and risks in respect of health matters for people with disability. Maintaining and improving health and wellbeing should remain a key priority in promoting quality service provision for people with disability.

Service organisations should support people with disability to undertake a Comprehensive Health Assessment Program (CHAP) review prior to transitioning to the NDIS. This will assist in identifying and addressing relevant health issues, and provide a baseline record of their health status prior to transitioning to new service arrangements.

Service organisations should ensure that staff receive regular education and training about behavioural indicators and other identifiable changes that may suggest an emerging health risk, including clear directions in relation to seeking medical advice.

Support staff should work collaboratively with health practitioners to ensure that people with disability in residential care access screening programs appropriate to their age and other risk factors, and should put in place strategies to actively attend to modifiable factors (e.g. diet, exercise, etc.) that may reduce risk.

Identifying signs of serious illness

There was a large presence of undetected ill health in this sample, with many people not having been diagnosed with the condition that led to their death until either just before their death or at autopsy. People with limited communication and/or who may have difficulties identifying the significance of the symptoms they are experiencing are particularly at risk.

Educative resources that target known health risks for people with disability, in particular those risks that are associated with potentially avoidable deaths, are urgently needed to ensure that these risks are readily understood by both health practitioners and support staff.

These resources should provide clear guidance to enable the identification of various risk factors, and highlight key issues in relation to timely assessment and the implementation of appropriate response strategies.

Many of the cases in this review highlighted the importance of people with disability being supported by staff who know them well and can identify when something is not right. Wherever possible, the use of agency, temporary or casual staff should be avoided, particularly when supporting people with disability whose condition places them at heightened risk.

Support staff and carers need to be aware of the signs of serious illness and be provided with the necessary education and training to be able to carry out basic observations of the person (including temperature, pulse, and heart rate).

Having access to specialist disability health advice to provide 24-hour a day guidance in response to adverse health matters is recommended for residential disability services (this could be established by working collaboratively with local Health and Hospital Services to set up 'on call' arrangements).

Improving access to health care and support

People with disability can have complex health needs that are often managed solely by general practitioners in their local community. This management would almost certainly be enhanced through greater involvement of specialist medical practitioners such as neurologists or gastroenterologists.

To ensure that people with disability get access to the necessary standard of health care, there is a need to improve the skills and competencies of current and future health professionals.

A multi-faceted strategy should be developed for health practitioners (through collaboration by Queensland Health, Health and Hospital Services and the Queensland Centre for Intellectual and Developmental Disability (QCIDD)) that includes changes to tertiary curriculums and accreditation competencies, the incorporation of health care for people with disability as a fundamental component of ongoing professional development, and up-to-date educative resources that highlight risks and response strategies for conditions associated with potentially avoidable deaths.

Specialist care and review is equally important for people with disability particularly those who have, or are at risk of, recurrent respiratory disease, circulatory diseases (e.g. heart disease), or epilepsy.

Where a person has specific conditions (e.g. epilepsy, chronic respiratory disease, heart disease, etc.) or where they are being administered regular medication (especially psychotropic medications), they must also be supported to access specialist medical care/reviews, including (where possible) having a specialist pharmacist and psychiatrist conduct annual medication reviews (at minimum), to identify issues that may put their health and wellbeing at risk.

Enhancing coordination of health care and disability services

Many of the people in this sample, like many people with disability who live in residential care, had complex health conditions and limited communication. Further, their primary health care was generally overseen by support workers who had minimal or no medical expertise. In present times, it should be expected that contemporary approaches to support for people with disability are inclusive of access to primary, secondary and tertiary health care as needed. A much greater degree of coordination and integration between disability and health care services is required to achieve this.

People with disability who live in residential care should have a designated person/role to take responsibility for coordinating and reviewing their health care (in consultation with the person themselves and/or their decision-maker).

The use of hand-held health records that ensure all relevant health care information for the person resides with the person should be used to promote communication between health care providers and those responsible for the person's everyday care.

End-of-life care and decision-making

Decision-making about medical care at the end of life involves complex medical, ethical and legal issues. Where a person lacks capacity to make decisions for themselves either in advance (in an advance health directive), or contemporaneously, the situation can be even more complex.

When substitute decision-makers make decisions about withholding or withdrawing treatment for people with disability, it requires them to make assessments about benefit to a person and their quality of life. This can be difficult when a person for whom the treatment decision is being made has a disability. As for any person, it is important that people with disability are not subject to futile and possibly burdensome life-sustaining treatment where doing so would be in conflict with the nature of their condition. This study highlighted the need for better end-of-life planning to ensure people with disability have a comfortable and dignified death.

As for any person, it is important that people with disability are not denied life-sustaining treatment because of prejudiced or misinformed views about their quality of life. A number of cases in this study 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.

This report emphasises the importance of appropriate end-of-life care and advance care planning activities that are empowering of people with disability and that ensure decision-making processes are robust and accountable at all times.

There is a clear need to promote and enhance understanding of the medical, ethical and legal elements associated with end-of-life decision-making and care.

The diagnosis of a long-term, chronic or terminal condition should prompt appropriate discussions and decisions around treatment and care at the end of life that involve the person with disability, their family/carers, and relevant health professionals.

A decision to withhold or withdraw treatment for people with disability should only be made by the relevant decision-maker after referral to a palliative care team or senior specialist who can provide appropriate professional advice.

The Department of Health's *Statewide strategy for end-of-life care 2015*[4] provides an important resource for health practitioners. Implementation of this strategy should ensure consideration for the specific needs of people with disability, particularly those with impaired decision-making capacity.

Systemic recommendations

Many people with disability have more complex health needs and a higher mortality rate than the general population. They can also face many barriers to accessing appropriate health care and a narrower margin of health due to poverty and social exclusion.[5]

As a result, systemic issues such as a lack of appropriate support (including support to access health care and appropriate responses by health care agencies) and ineffective coordination between disability and health services can have a serious effect on people with disability. For some, this includes the risk of premature death. Further, people with disability living in residential care have a much greater dependence on public agencies and funded non-government services to ensure their health and support needs are met.

> Without a deliberate strategy and concerted effort, these issues will not change with the introduction of the NDIS. If anything, there is a risk of a widening divide emerging for health (and other) services in the course of implementing the NDIS.

As articulated by the Council of Australian Governments, "the interactions of the NDIS with other service systems will reinforce the obligations of other service systems to improve the lives of people with disability, in line with the National Disability Strategy".[6] The health system is a notable party to the principles that will be used to determine the funding and delivery responsibilities of the NDIS versus the obligations that will be accorded to other systems.

> The current and future challenges in providing effective health care for people with disability must be recognised and attended to now.

Addressing the issues that impact the health and wellbeing of people with disability requires a coordinated effort and changes to both policy and practice. Ideally, policy and practice reform should be complemented by structural changes that capitalise on the likely shift in employment practices for allied health professionals currently working in the disability services sector.

> To close the gap in the delivery of health services and health outcomes for people with disability requires structural changes to current health policy, health programs and health practices in order to recognise and realise the health rights of people with disability.

Further to the condition-specific and issue-specific recommendations noted in the preceding pages, the following pages present overarching systemic recommendations for consideration by Government. The recommendations are grouped under the following three headings and while not all of the recommendations are specifically linked to the NDIS transition, both Government and people with disability alike will bear the consequences of inaction if the issues underpinning these recommendations are not addressed in the course of NDIS transition planning.

- ✓ **Governance –** Improvements to the way that health care and end-of-life matters for people with disability are reported, recorded, monitored, and analysed;

- ✓ **Health practices and standards –** Improvements in practice and standards for health services, inclusive of improvements in education and training and a focus on building capability in the delivery of health services for people with disability; and

- ✓ **Disability service practices and standards –** Improvements in practice and standards for disability services that should form part of the accreditation scheme for disability services regardless of whether this occurs at the state or commonwealth (NDIS) level.

Governance

Recommendations to improve governance:

- Report annually on deaths in care
- Review and update information resources and establish a targeted communication strategy to improve understanding about reporting requirements by both government, non-government and private providers
- Undertake regular systemic reviews with biennial reporting to Parliament

Improve reporting, investigation and systemic analysis

At present, the number of deaths in care in Queensland is not definitively known. While all deaths in care must be reported to the Coroner's office, a number of cases in the sample demonstrated a lack of understanding about these reporting requirements. There is therefore no way of determining whether the necessary reporting is happening in every case. In addition, there is no publicly available register of reported deaths in care.

In Queensland, apart from the coronial process for deaths in care, there is no specific process for systemic reviews of the deaths of people with disability. While all deaths in care must be reported to the Coroner and must be investigated, not all investigations result in an inquest and/or published findings/comments. Between 2009 and 2014 (the timeframe for this review), there was only one inquest into a death in care of a person with disability in Queensland.[7]

As a result of these limitations, there is no reliable information on the number of deaths in care each year in Queensland. This impacts the extent to which Queensland data can be compared with that of other states/territories, or with national data.

The potential data limitations and the lack of systemic review and analysis also hinders opportunities to identify systemic improvements that might assist to decrease the numbers of deaths in care. This reports highlights a number of ways in which this might be attended to.

The State Coroner should be required to report annually on deaths in care. Ideally, the numbers of deaths in care would be presented in the Annual Report and would be broken down against the categories associated with the definition of 'death in care'.

To promote more accurate reporting, and in view of proposed legislative amendments to support the transition to the NDIS, existing information resources about reporting deaths in care should be reviewed and updated to ensure accuracy and ease of understanding. To complement this, a targeted communication strategy should be developed to ensure that the reporting requirements in relation to deaths in care are understood by all relevant agencies, including hospitals.

Further, an appropriate agency should be resourced and tasked to carry out regular systemic reviews of people with disability who die in care in Queensland. A report detailing the outcomes of these reviews should be tabled in Parliament at least biennially.

Health Practices and Standards

Recommendations to improve health practices and standards:

- Develop a *Framework to Improve Health Care for People with Intellectual or Cognitive Impairment*
- Establish local, regional and state-wide networks, led by Health and Hospital Services in partnership with QCIDD, to provide clinical leadership, education and support to enhance the provision and coordination of health services to people with disability
- Establish an exemption from the need to live in a certain geographical area to be eligible for funded tele-health services for people with disability living in residential support services
- Develop and implement a multi-faceted education and information strategy to respond to identified gaps in knowledge in respect of providing health care support for people with disability
- Develop a multi-layered strategy for the training of health professionals, inclusive of that provided by tertiary institutions as well as that which is provided 'on-the-ground' in Health and Hospital Services

Develop a *Framework to Improve Health Care for People with Intellectual or Cognitive Impairment*

The transition to the NDIS makes the need for coordinated and integrated health and disability services even more critical to achieving improved quality of life outcomes for people with disability. There is a risk that the shift to a competitive 'marketplace' for disability services and the likely need to streamline costs will impact on the extent to which agencies are able to provide optimal support for preventative health care. Further, the interface principles between the Commonwealth and State/Territory Governments make a clear delineation between what NDIS will fund and what remains the responsibility of other parties.

While specialist disability services and health clinics alike play an important role in providing direct clinical services to people with disability and in educating and resourcing other health professionals, this is not enough. Ensuring that improvements in healthcare for people with disability are prioritised and that the capacity and responsiveness of the general health system is enhanced requires leadership, commitment and resources.

In accordance with the Queensland Government's commitment to improving "the capacity and accessibility of health services, including preventative services and health promotion to people with disability" as articulated in priority six of the *Queensland Disability Plan 2014-19*,[8] and in undertaking the necessary preparation to support transition to the NDIS, the Queensland Government (under the leadership of the Queensland Health) should develop a *Framework to Improve Health Care for People with Intellectual or Cognitive Impairment*.

The Framework should articulate both minimum standards and 'best practice' and have clear performance expectations that apply to all relevant agencies, particularly those under the auspice of the Health and Hospital Services network. Performance reporting against implementation of the Framework should occur through Disability Service Plan reporting processes.

The Framework should have the underlying goals of:

- Promoting better understanding of the health care needs of people with intellectual or cognitive impairment;
- Improving the quality, accessibility and integration of services needed to meet the health care needs of people with intellectual or cognitive impairment; and
- Improving coordination between disability services and health care services.

Consideration should be given to incorporating specific identifiers into data systems to enable information about relevant health issues and risk factors for people with disability to be collected and analysed so that Health and Hospital Services can identify opportunities to improve preventative health strategies, and enhance education and training needs for staff.

The Framework should also enable voluntary application by health care and disability providers in the broader sector (e.g. private providers), and provide a resource that can also be used by coroners to enable more robust investigations of reportable deaths in care.

Improve access to, and coordination of, health care services

Access to quality health services by health practitioners with a comprehensive understanding of the needs of people with disability has been a longstanding challenge for people with disability. This is even more challenging for people with intellectual or cognitive impairment and/or those who experience communication difficulties.

To date, these challenges have often been masked by the way in which disability supports have been funded and provided. For example, Accommodation Support and Respite Services (the government-provided disability service) and some larger non-government service providers have employed Health Liaison Officers with specialist knowledge and expertise to enable greater responsive to clients with complex health issues and/or comorbid conditions. In addition, there are numerous allied health professionals including speech and language pathologists, occupational therapists, psychologists, etc with significant expertise who also work in the disability services sector.

The impending implementation of the NDIS has already seen a number of allied health professionals from the disability services sector seek employment in the health sector, primarily due to concern that the services they provide will not be funded as ‘disability supports’ under the NDIS.

The likelihood that this trend will continue presents an opportunity for Health and Hospital Services to capitalise on the influx of health practitioners with disability-specific knowledge and expertise by establishing local, regional and state-wide networks that can provide clinical leadership, education and support to enhance the provision and coordination of health services to people with disability.

At the state-wide level, these networks could be supported by the Queensland Centre for Intellectual and Developmental Disability (QCIDD), an established and well recognised entity focussed on improving the health of people with disability through research, teaching and clinical activities.

Finally, given the challenges experienced by some people with disability in physically attending community health services, an exemption from the need to live in a certain geographical area to be eligible for funded tele-health services should be extended to people with disability living in residential support services.

Targeted education and information strategy

Building on the proposals to develop a *Framework to Improve Health Care for People with Intellectual or Cognitive Impairment*, and establish health practitioner networks with knowledge and expertise in working with people with disability, this report provides evidence to support the development of a range of information resources targeting specific risks in respect of health care for people with disability.

While it is acknowledged that the Department of Health's jurisdiction in respect of health care services in Queensland is not absolute, the opportunity exists to lead the development of a multi-faceted education and information strategy through collaboration with QCIDD, Health and Hospital Services, and those practitioners who have expertise in the provision of health care for people with disability. Such a strategy should be inclusive of evidence-based resources that:

- Target the causal factors underpinning potentially avoidable deaths by raising awareness about preventative health care and appropriate therapeutic options for identified conditions;
- Educate people with disability, and their families/carers about increased risk factors associated with specific types of disability, and how to recognise, assess and respond to them;
- Identify the 'red flags' (i.e. signs and symptoms) associated with specific illnesses that indicate the need to seek urgent medical assistance – this may be of value for families/carers and for health practitioners with limited experience in working with people with disability;
- Detail conditions and/or comorbidities that may indicate a need for health practitioners to explore potential risks more thoroughly, and/or that raise awareness about alternate diagnoses that may not have been considered (e.g. chronic constipation);
- Highlight the dangers (and limited efficacy) in using psychotropic medications to control the behaviour of people with intellectual disability or cognitive impairment, and that promote adherence to standard pharmacy practices, actively discouragement 'off-licence' use of such medications, and address issues associated with dosage, monitoring, and regular review; and
- Support coroners in conducting investigations into deaths in care, and assist them in deciding when to take a closer look at the circumstances behind a death in care.

Improved medical training

There is an obvious need for enhanced training and education of health professionals to better support people with disability. The Queensland Government, through relevant Departments, should work to further this by targeting universities, trainee General Practitioners (GPs) and ongoing professional education with consideration for:

- Including this topic in competencies for medical school accreditation and regulatory organisations;
- Committed curriculum time, with teaching and learning modules developed;
- Committed and skilled teaching staff to lead teaching and learning in this area; and
- Succession plans through the mentoring of more junior staff.

Health professionals should also receive further education and training (both in medical school and as part of continuing education) about the law that applies to end-of-life decision-making, within the wider context of medical ethics, including the ethical issues associated with making decisions about life-sustaining treatment and quality of life for people with disability.

Ideally, disability medicine should be embraced as a specialised area of training and practice.

Disability Service Practices and Standards

Recommendations to improve disability practice and standards:

- The NDIS Code of Conduct and/or registration/accreditation requirements must include minimum standards in relation to:
    - Health management guidelines (premised on article 25 of the Convention and drawing from available evidence such as this report and those of the New South Wales (NSW) Ombudsman that highlight known risks)
    - Risk management policies and practices
    - First aid and health observation training
    - Critical incident reporting and review
- Develop and implement a strategy for the sharing and/or transfer of disability-specific knowledge and skills across allied health and clinical service delivery

Ensure minimum standards for disability service providers

The quality and safeguarding framework for the NDIS is still under development however it is likely that the NDIS will seek to put in place a quality assurance scheme that builds upon existing screening, certification and accreditation systems. While the regulatory aspects of the Framework have not yet been confirmed, it has been suggested that, at minimum, providers of disability services will likely be bound by a NDIS Code of Conduct.

The NDIS Code of Conduct will form a crucial part of the National Disability Insurance Agency (NDIA) registration process and will be a key tool to measure the performance of providers of support as well as guide the culture of the NDIS.

As this review has highlighted, disability service organisations and support staff play a critical role in facilitating health outcomes for people with disability. To do so effectively requires appropriate knowledge and skills to ensure the adequacy of the support provided to people with disability in addressing health matters across the full spectrum of care, inclusive of preventative health care, risk identification and management, active day-to-day health monitoring, condition-specific health management, and responding to critical health events and emergency situations.

Given the Queensland Government is working closely with the Commonwealth to ensure that the transition to the NDIS effectively addresses the needs of Queenslanders with disability, the evidence provided in this report will assist the Queensland Government in advocating for the necessary standards for disability service provision.

The findings of this review highlight the need for minimum standards that require all disability service organisations to:

- Develop and implement health management guidelines for support staff that articulate core obligations associated with article 25 of the Convention in a manner that translates these to everyday practice. For example, the need to accord priority to regular general health checks, health screening practices as per recognised good practice intervals corresponding to age, etc., and annual comprehensive health assessments using evidence-based tools such as the CHAP.

- Develop and implement a risk management framework that articulates a clear process for identifying clients who have identified risk factors that may impact their health and wellbeing, including requirements for assessment and the development and implementation of response plans that attend to identified risks.
- Educate and train support staff in providing first aid (particularly in response to identified health risks such as choking, seizure management, etc.) and in taking basic health observations (such as temperature, pulse, and heart rate). Refresher training should be provided annually at minimum.
- Develop and implement critical incident reporting and review processes that mandate the requirement to internally review all critical incidents (especially those resulting in a person's death), the care and support arrangements, and any deficits related to the person's support and risk management. This should result in the development of recommendations for improving future practice and an implementation plan that seeks to reduce the risk of reoccurrence.

Knowledge transfer and skills retention strategy

The evolution of disability service provision in Queensland has seen a significant investment in the development of specialist knowledge and expertise across a range of allied health fields and clinical services. This has resulted in policy, program and practice frameworks, and collaborative service delivery approaches, that provide strong and effective guidance in many areas of support relevant to the findings from this review.

With only three years until Queensland reaches full implementation of the NDIS in 2019, there exists a unique opportunity to ensure the effective transition of the significant repository of knowledge, skills and resources currently residing within the Department of Communities, Child Safety and Disability Services (DCCSDS).

For example, in January 2012, the then Department of Communities undertook a practice review into dysphagia and mealtime support for individuals supported by the Department's Accommodation Support and Respite Services (AS&RS).[9] This review resulted in a suite of updated procedures, guidelines, resources and practices to ensure their alignment with contemporary best practice, accompanied by strengthened clinical governance and practice oversight processes.

This is just one of many areas of clinical expertise within DCCSDS for which there exists accessible and evidence-based resources, skills and knowledge that could be easily transferred to enhance the capability of health and disability services, while supporting sustainable long-term responsiveness to health care for people with disability post the transition to the NDIS.

However, without a clearly articulated and targeted strategy to ensure that these resources are appropriately considered in the transition process, Government's significant investment in the development and maintenance of its resources may well be lost or, at minimum, diluted to the point of losing its cohesion and effectiveness.

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1 Introduction and Background

1.1 Background

1.1.1 Objectives of this project

People with intellectual or cognitive disability often have multiple and complex health needs and a high mortality rate. Yet they also face significant barriers to accessing appropriate health care as well as a narrower margin of health due to poverty and social exclusion.[10]

In Queensland, apart from the coronial process for deaths in care, there is no specific process for systemic reviews of deaths of people with disability. While all deaths in care must be reported to the Coroner and investigated, not all investigations will result in an inquest and/or published findings and comments. At present, the number of deaths in care of people with disability is not published in Queensland.

The Public Advocate undertook this project to address the gap in information about the deaths in care of people with disability in Queensland by collecting and analysing available records held by the Coroner and other relevant departments.

The specific objectives of the project were to:

- Increase the transparency of the current system in reporting and recording deaths in care of people with disability;
- Assess and analyse the current reporting, recording and investigative processes for deaths of people with disability in care;
- Highlight key health and risk factors associated with deaths for people with disability in care, particularly in relation to deaths that may have been avoidable with access to enhanced supports, services and health care; and
- Identify the systems, practice and process issues associated with deaths of people with disability in care that are avoidable.

The practice in other jurisdictions of undertaking systemic reviews of deaths of people with disability in care and publishing data and reports has proven valuable in identifying common risks and vulnerabilities for people with intellectual or cognitive disability, as well as opportunities for improving health and wellbeing by enhancing the health and support service responses for people with disability.

These processes can also lead to improved knowledge of key health and other risk factors for people with disability, which can be addressed by support and health care services and, in turn, can maximise outcomes for people with disability, improve their overall health and wellbeing, and reduce the risk of premature illness and death.

Systematic recording, review and analysis of the details of the deaths in care of people with disability also leads to increased transparency and accountability in the service systems that support people with disability.

Oversight and review of support and health care services to people with disability is an important safeguard given they can be vulnerable not only to abuse and exploitation but also to neglect or discrimination in the way that supports and services are provided.

1.1.2 Findings from other systemic reviews

United Kingdom

There has been significant activity in the United Kingdom (UK) over the last decade in response to the above average death rate known to exist among younger people with learning disability.

Most recently the following reports have been published:

- In 2006, the report *Equal Treatment: Closing the Gap: A formal investigation into the physical health inequalities experienced by people with learning disabilities and/or mental health problems* by the Disability Rights Commission was generated in response to the evidence that people with learning disability and/or mental health problems were more likely than other citizen to die young and to live with health problems, many of which were preventable.[11]
- In 2007, Mencap's *Death by Indifference* report was published describing the circumstances surrounding the deaths of six people with learning disability while they were in the care of the National Health System (NHS).[12]
- In 2008, the Report of the Independent Inquiry led by Sir Jonathan Michael, *Healthcare for All*, identified the actions needed to ensure adults and children with learning disability received appropriate health services in the NHS.[13]
- In 2009, the Parliamentary and Health Service Ombudsman report *Six Lives*, investigated the deaths of the six people highlighted in the Mencap report.[14]
- In 2013, the *Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD) Final Report*, investigated the deaths of 247 people with learning disability over a two year period.[15]and
- In 2010 and 2013, two *Six Lives Progress Reports* by the Department of Health in response to the Health Service Ombudsman recommendations.[16]

Australia

In Australia to date, only the New South Wales (NSW) Ombudsman carries out regular systemic reviews in relation to deaths in care of people with disability.[17]

In NSW, the deaths of people with disability who die in care in that state have been subject to review for some time.

The *Community Services (Complaints, Reviews and Monitoring) Act 1993* requires the NSW Ombudsman to review the deaths of children and adults with disability who, at the time of their death, were living in department funded residential care or a licenced boarding house.[18] The Ombudsman has been undertaking these reviews for the past 12 years.

As part of the review process, the Ombudsman maintains a register of reviewable deaths and conducts reviews focused on identifying the procedural, practice and systems issues that may contribute to deaths, or that may affect the safety and wellbeing of people with disability in care and recommends relevant changes or new strategies that might ultimately help to prevent reviewable deaths.[19] The Ombudsman has published all such reports on the Ombudsman's website.[20]

Prior to the NSW Ombudsman undertaking this role, the Community Services Commission undertook reviews of the deaths of people with disability in accordance with the Act.[21]

1.1.3 Patterns of deaths and leading underlying causes

Life expectancy of people with intellectual and cognitive disabilities

The findings of reviews and research in the United Kingdom and Australia consistently find that people with intellectual or cognitive disability not only die at a much younger age than the general population but, in many cases, die from conditions that are treatable and avoidable.[22]

The reviews confirm the severe health inequities faced by this group that are caused by a number of factors including the severe disadvantage they face in their contact with the health system.[23]

For example, the UK Confidential Inquiry found a high likelihood of avoidable deaths of people with intellectual disability, attributable to untreated ill health and deficiencies in the delivery of health care to people with intellectual disability in England.

Close to a quarter of people with intellectual disability (22% - 54 individuals) in their study were younger than 50 years old when they died, with the median age being 64 years.[24] The median age at death of male individuals with intellectual disability was 65 years (13 years younger than the general population) and the median age at death of female individuals with intellectual disability was 63 years (20 years younger than the median age at death for the general population).[25]

The most common underlying causes of death for those with learning disability in the inquiry were heart and circulatory diseases (22%), neoplasms (20%), respiratory disorders (16%) and nervous system diseases (16%).[26]

In Australia, the NSW Ombudsman has found that the average age at death of people with disability in residential care in NSW was 25 years younger than the average age of the general population. Of the recorded deaths in care in 2012-13, on average the people that died in disability services were 55 years when they died and those in boarding houses were 59 years.[27] Of the people with disability who died in disability residential services, the leading underlying causes of death were respiratory diseases (24% - mainly pneumonia and aspiration pneumonia), nervous system diseases (17% - namely epilepsy and cerebral palsy), neoplasms (16% - mainly lung and breast cancer), and circulatory diseases (11% - primarily ischaemic heart disease).[28]

In 2012 and 2013, 239 people with disability died in residential care in NSW; in 2010 and 2011, 222 people died; and in 2008 and 2009, 193 people died.[29]

1.1.4 Risk factors and vulnerabilities

The UK Confidential Inquiry and the NSW Ombudsman inquiries, as well as other systemic reviews of the deaths of people with disability in residential care, have identified a number of common factors that can put certain people with disability at a greater risk of premature and preventable death.

Respiratory disease, risk factors, identification and response

People with disability have been found to be at greater risk of respiratory disease due to the presence of multiple risk factors, including swallowing and eating difficulties, a history of aspiration, use of psychotropic medications, limited mobility, dental problems, and the presence of conditions such as cerebral palsy, epilepsy or Down syndrome.[30] Reviews have noted the importance of early identification and monitoring of such risks.[31]

A number of reviews have also noted the short period of time between awareness of conditions such as pneumonia and the person's death, and have highlighted the importance of noticing early warning symptoms of respiratory disease and seeking urgent medical assistance.[32] In turn, this has highlighted the importance of caregivers and others being alert to the signs and symptoms of potentially serious illness and knowing when to seek urgent medical assistance.[33]

Swallowing and eating difficulties, aspiration and choking

Swallowing and eating difficulties are common in people with certain types of disability, which in turn places them at a high risk of choking as well as aspiration (which can also lead to respiratory disease).[34]

The NSW Ombudsman found that the most common factors in the choking deaths in the years 2010 and 2011, and 2012 and 2013, were a combination of eating and/or food-related behaviour problems and inadequate supervision,[35] or a failure by service providers to follow the recommended steps to reduce the risk of choking.[36] The importance of support staff being aware of the importance of identifying and mitigating choking risk has been identified by a number of reviews.[37]

Understanding that some people with disability are at a greater risk of aspiration, reducing the risk of aspiration, and being aware that repeated aspiration can lead to respiratory infections, has also been emphasised as important.[38]

Epilepsy

People with epilepsy have a high mortality rate,[39] and the risk of sudden death in epilepsy (SUDEP) in people with severe forms of epilepsy is high.[40]

The NSW Ombudsman found that of the 220 people with disability who died in 2010 and 2011, 93 people had been diagnosed with epilepsy and died from underlying causes such as respiratory illness and choking.[41] Similarly the UK Confidential Inquiry found that 43% of the people with learning disability who had died in their study had been diagnosed with epilepsy and, of those, 72% had experienced a seizure in the last five years.[42]

Recording and charting of seizure activity is important as it enables neurologists and GPs to review a person's progress and inform their treatment decisions.[43] The NSW Ombudsman identified systemic issues with poor recording and charting of seizure activity in 2010 and 2011, and a number of people identified in the Ombudsman's review had sub-therapeutic anti-convulsant medication levels.[44]

Medications

The UK Confidential Inquiry found that the vast majority of people with learning disability in their study (97%) were on some sort of medication prior to their death.

While the median number of medications prescribed was seven, it was noted that some people had up to 21 medications prescribed.[45] This is consistent with other literature that has found a high level of use of antipsychotic medication in this population, and that polypharmacy is not uncommon.[46]

Other systemic reviews, as well as the literature generally, have identified the potential risks of people with disability receiving medication such as antipsychotics, anticonvulsants, sedatives and muscle relaxants.[47] The use of certain medications, particularly antipsychotic medications, has been associated with an increased risk of swallowing and eating problems and aspiration (thus also increasing the risk of aspiration pneumonia) in both people with disability and the elderly.[48]

Lifestyle issues and heart disease

Being overweight, smoking, and high levels of alcohol consumption are important predictors of preventable and early deaths of people with learning disability.[49] The UK Confidential Inquiry found that a significant difference in the age at death of people in its study, with the median age at death higher for those at optimal weight (69.5 years) compared to those who were overweight (65 years), and lower still for those who were obese (62 years).[50] Similarly the NSW Ombudsman found that over half the people with disability who died in 2010 and 2011 in licensed boarding houses were overweight or obese.[51]

There was a correlation between obesity or severe obesity and underlying causes of death such as heart attack, heart disease and chronic obstructive pulmonary disease.[52] The NSW Ombudsman found that the people who died from ischaemic heart disease had a number of identifiable risk factors including hypertension, smoking, being overweight, and a lack of physical activity. [53]

The NSW Ombudsman emphasised the importance of assisting people with disability to develop healthy eating habits, reduce sedentary behaviour, and quit smoking.[54]

Cancer and screening programs

Despite the fact that neoplasms/cancer was the second highest cause of death in the UK Confidential Inquiry, the study found that little support was provided to people with learning disability to access screening programs and that no reasonable adjustments had been made to support their participation in screening programs.[55]

The NSW Ombudsman has similarly reported cancer to be the second highest underlying cause of death in their review of the deaths of people with disability, and that the median age at death from cancer (56.5 years) was almost 20 years younger than the median age at death from cancer in the general population.[56] The main form of cancer that caused death was bowel or colon cancer, with a very short time between diagnosis and death (ranging from two to nine months).[57]

Other risk factors

While having certain types of disability, such as Down syndrome, has in the past commonly been linked to an increased chance of early mortality,[58] more recent studies have emphasised a variety of factors such as level of mobility, communication, skills related to self-care (such as the ability to feed oneself) and adaptive functioning that may more accurately predict mortality risk in people with Down syndrome[59] as well as other disabling conditions. This indicates that mortality risks for people with disability are more complex than simply aetiologies such as the presence of Down syndrome.[60] Risk of early or preventable death relates more to the level and/or complexity of the support and care that a person requires for their disability.

Various systemic reviews of the deaths in care of people with disability have also confirmed that those who died were more likely to require support for their mobility, eating, drinking, continence and decision-making.[61]

Issues with health care and support

The life expectancy of people with intellectual or cognitive disability is a broad indicator of the wellbeing of people with intellectual or cognitive disability in the community, as it is for the general population.[62]

Numerous reports and other studies, including those reviews of deaths of people with disability in residential care, have highlighted the numerous inequities that people with disability face in their contact with the health system as well as the lack of coordination that often exists between disability services and health services.[63]

Diagnosis, early intervention and preventative care

The need for staff to be more aware and responsive to health changes – with some people with disability going from ill to critically ill within a short period of time – has been identified by a number of reviews.[64]

The UK Confidential Inquiry found considerable evidence of 'fragmented' care and a lack of holistic approaches to health and support needs.[65]

The Inquiry highlighted the importance of the involvement in the person's lives of health care workers who are trained in complexity and multi-morbidity, along with a professional consultant with ongoing (as opposed to episodic) responsibility for people with complex and multiple health issues.[66]

The NSW Ombudsman has also highlighted a lack of coordination between health and disability services and the need for more support to access medical treatment. Further, the need for more reasonable adjustments in the delivery of health care services to people with disability has also been noted.[67] The NSW Ombudsman found that many people with disability miss out on crucial health treatment because they are not supported to attend medical appointments, or to follow medical advice or other recommendations.[68]

Other people with disability missed out on treatment and/or received late diagnoses of life-threatening illness because of behaviours that affected their medical treatment and health (including people who refused to attend medical appointments or to allow physical examinations and other tests and procedures).[69] The review highlighted the importance of health and disability staff working together with the person with disability to minimise their resistance to health services and treatment and to support them to make informed decisions.[70]

A number of reviews have highlighted the lack of access to specialist care and involvement in the person's life, particularly respiratory specialists.[71] These reviews have emphasised the importance of specialist involvement in the management of chronic disease for people with disability.

Support in hospital

The UK Confidential Inquiry identified a number of issues with the diagnosis and treatment of illness for people with disability noting, in particular, a lack of reasonable adjustments being made for them and a lack of effective advocacy.[72] This study highlighted the importance of hospital-based learning disability specialist nurses who work to support the health needs of people with learning disability while they are in hospital.[73]

The adequacy of support for people with disability in hospital is raised consistently as an area of concern in the NSW Ombudsman's reviews. The reviews have repeatedly identified instances in which the health outcomes of people with disability have been adversely affected by hospital staff not adequately understanding the person's needs and by a lack of communication with support staff, including not heeding critical information provided by support staff about the person.[74]

End-of-life care and decision-making

Some reviews have found poor adherence to end-of-life decision-making policies and protocols for people with disability.[75]

The UK Confidential Inquiry identified concerns relating to a lack of transparency around decision-making, including incomplete documentation that failed to record the rationale for orders not to attempt cardiopulmonary resuscitation (CPR).[76] The Inquiry also found that the quality of care ahead of death was impacted negatively by a failure to recognise when end of life may be approaching and therefore not placing the person on an end-of-life pathway. The deaths of a number of people in the Inquiry were characterised by badly coordinated and poor quality care in the final days of their lives.[77]

Similarly the NSW Ombudsman's reviews have raised concerns about end-of-life care and decision-making, noting issues whereby:

- decisions to limit treatment, start palliative care, or not to perform CPR were often made by medical staff without the involvement of the person's family;
- the reasons for end-of-life decisions were either not documented or very limited;
- the person with disability was not involved in palliative care planning; and
- there was a lack of coordinated palliative care for assisted boarding house residents with advanced terminal illnesses.[78]

Misunderstanding, lack of knowledge and expertise in people with disability

Mencap's *Death by Indifference* report looked at the deaths of six people with disability, highlighting a culture of 'institutional discrimination' for people with learning disability in the UK NHS.

This included not designing systems, policies and procedures to meet the differing needs of patients with learning disability, and failing to deal with 'ignorance and prejudice within the workforce and culture of the organisation'.[79]

Contributing factors were:

- People with learning disability being seen as a low priority;
- Many healthcare professionals having limited understanding about learning disability;
- Many health care professionals do not properly consult and involve the families and carers of people with learning disability;
- Many health care professionals do not understand the law around capacity and treatment consent;
- Health care professionals rely inappropriately on their estimates of a person's quality of life; and
- Ineffectual, time-consuming complaints systems.[80]

Six years on, the UK Confidential Inquiry reviewed the patterns of care people with learning disability received before they died and found there was still much progress to be made in the provision of health care and social services to people with disability.[81]

Similarly, the NSW Ombudsman's review of the deaths of people with disability identified ongoing 'disadvantage and adversity' for people with disability in their contact with the health system.[82]

Standards of care in licensed boarding houses

The NSW Ombudsman also highlighted the need for improved standards in licensed boarding houses – with a Coroner's inquest into the deaths of six people in boarding houses finding they were "uncared for, poorly treated medically and neglected".[83]

It was identified that people with disability in boarding houses often had poor quality food and inadequate nourishment, a lack of appropriate support and access to health care and substandard accommodation.[84]

1.1.5 Reforms from previous reviews

Reforms in the United Kingdom

In the UK there have been many developments at a legislative, policy and practice level across the health and support service sector prompted by the systemic reports discussed above.[85]

For example, legislative changes have made it a legal requirement for public sector organisations to tailor the way they provide care (including health care) so that people with disability are not disadvantaged.[86]A number of reports and resources have been published detailing examples of 'reasonable adjustments' that have been made by health services to address the inequities faced by people with disability in the health care system. These are all made available on an online UK database so that good practice can be shared by all health professionals and to demonstrate progress.[87]

Since 2008-09, all NHS GPs in England are now paid to undertake an annual health check for people with learning disability who meet certain criteria. Progress reports reveal that increasing numbers of people with learning disability are now receiving health checks each year.[88]

Consultation by Mencap and the British Institute of Learning Disabilities (BILD) with people with learning disability and their families have confirmed that, while there is still much progress to be made, there have been many improvements from their perspectives.

These improvements include reports of significant improvements in several hospitals and GP practices in their care and treatment of people with learning disability. There was strong praise for the role of disability liaison nurses, and reports that many health professionals had received learning disability awareness training.

Reforms in NSW

In NSW, numerous changes and reforms have been introduced in the disability service sector, including the introduction of clinical nurse consultant positions to provide guidance to disability services staff and to act as intermediaries with health services in relation to people with disability and complex needs.[89]

In the boarding house sector, there have been changes to the screening tool for entry to licensed boarding houses to identify people with choking risks.[90]

The NSW Department of Ageing Disability and Home Care (DADHC) has undertaken substantial work to revise and simplify the guidance available for direct care staff in relation to supporting the health needs of people with disability in residential care, including developing the nutrition and swallowing guidelines, for example.[91]

The DADHC Clinical Innovation and Governance directorate also surveyed DADHC operated and funded supported accommodation services to identify the prevalence of the use of psychotropic medications to ensure adherence to policy guidelines in relation to the use of such medications.[92]

A number of positions currently funded by the NSW Department of Families and Community Services (FACS) play critical roles in improving the health and wellbeing of people with disability in NSW.

These positions include:

- Two specialist nurses funded in each district to assist with the coordination of health care needs of people with disability, particularly those with complex needs;
- Comprehensive health assessment program (CHAP) licence for use by FACS operated and funded disability services;
- Practice leader positions in nursing, speech pathology, occupational therapy, physiotherapy and psychology; and
- Nurse and dietician positions within dysphagia clinics at Westmead Hospital.[93]

The NSW Ombudsman released a series of simplified fact sheets to assist in reducing preventable deaths. Targeted at support staff and GPs, they address topics like breathing, swallowing and choking risks, and smoking, obesity and other lifestyle risks. They also cover the main causes of preventable deaths for people with disability in care.[94]

While significant progress has been noted, the NSW Ombudsman indicates that there is still progress to be made. In particular, the Ombudsman recently expressed serious concerns about the introduction of the NDIS and the significant and increased risks likely to be faced by people with disability without concerted and early action by State and Commonwealth Governments.[95]

1.2 Methodology for this project

1.2.1 The focus of this review and data requested

Focus of this review

The review undertaken by the Public Advocate focused on the deaths in care of people with disability in Queensland from 2009 to 2014. More specifically, the review considered those people with disability whose deaths were reported to the Coroner and who lived in either a:

- level 3 accredited residential service (i.e. a licenced hostel or boarding house); or
- disability residential service either provided or funded by the Department of Communities, Child Safety and Disability Services (DCCSDS).

Data and information requests

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 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.[96]

In accordance with these powers, the Public Advocate submitted data requests to a number of Government and non-Government agencies as detailed below.

Information received from the Queensland State Coroner

The State Coroner provided the Coroner's findings as well as the investigation documents for people with disability who died in care from 2009 to 2014. Investigation documents include coronial documents, police documents and other documents related to investigating deaths in care.[97]

In most cases, each individual file included a Form 20A Coroner's Findings and Notice of Completion of Coronial Investigation and either a Form 1 Police Report of Death to a Coroner or Form 1A Medical Practitioner Report of Death to a Coroner.

In some cases, if an autopsy was carried out, an Autopsy Report was included (which may or may not include a toxicology report) and, in some cases, extracts from a person's medical file were included, particularly if the person died while in hospital and a medical practitioner reported the death.

The State Coroner's Office provided the Public Advocate with investigation documents for 111 cases. Of these, 73 cases met the inclusion criteria and were considered in this review.

Information received from the Department of Communities, Child Safety and Disability Services

Initially the Public Advocate requested data on the number of deaths of people with disability in care in DCCSDS provided or funded services between 2010 to 2013, as well as any reports or documents detailing the thematic analysis of deaths in care or critical incidents for people with disability in receipt of DCCSDS provided or funded services.

DCCSDS provided the Public Advocate with aggregated data on the number of deaths in care of people with disability who may have had impaired capacity for a matter from 2011 to 2013. This is detailed in **Appendix Two**.

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.

Finally, DCCSDS provided copies of certain client files (upon request) for the Advisory Panel to use in conducting extended case reviews. In accordance with the requests made by the Public Advocate, DCCSDS provided either copies of full individual client files or extracts of files for nine individuals.

Information received from Queensland Health

Initially the Public Advocate requested data on the number of deaths of people with disability in care in Queensland Health provided or funded 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 receipt of DCCSDS provided or funded services.

The Public Advocate was informed that Queensland Health were not able to identify this information as disability was not recorded as an identifier. Queensland Health stated that, to ascertain this information, each individual hospital network would have to manually check through their patient files for those people who have died.

Once the review of the Coroner's findings and investigation documents commenced, the Advisory Panel sought further information to conduct extended case reviews. The Public Advocate sought the following further information from Queensland Health:

- For 14 people – 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.
- For 43 people – any clinical incident report, root-cause analysis, or SAC1 reportable event review for the person.

Information received from Department of Housing and Public Works

The Public Advocate requested data on 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.

While the Department of Housing does not collect this data from level 3 accredited residential services, the Office of the State Coroner provides the Coroner's findings to the Department of Housing after finalising its investigation and the Department provided a summary of this information to the Public Advocate. This is provided at **Appendix Two**.

Information received from non-government service providers

Copies of client files were also requested from a number of non-government service providers to support the Advisory Panel in undertaking extended case reviews. In all, four non-government service providers funded to provide disability services supplied the Public Advocate with copies of client files. These were usually restricted to copies of the files for the 12 months before their death.

Information received from the Public Guardian

The Public Advocate sought data from the Office of the Public Guardian on the number and nature of deaths of people with disability in care that were brought to the attention of Community Visitors. When a Community Visitor receives information about the death of a consumer at a 'visitable site', they provide the details of the client and location of the death (including whether the service provider reported the death to the Coroner) to the Community Visitor Program administration officer who then forwards this to the Coroner.

1.2.2 The Advisory Panel

Membership

An Advisory Panel was formed to assist the Public Advocate in the systemic analysis of the information received from the State Coroner and other agencies.

The Advisory Panel comprised the 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, in particular people with intellectual impairment.

The membership of the Advisory Panel is listed at **Appendix One**.

Role of the Panel

The role of the Advisory Panel was to assist in the systemic analysis of data and information received from the State Coroner and other relevant agencies about the deaths of people with disability in care.

More specifically, the Panel was engaged to:

- identify the most common leading underlying causes of death;
- identify demographic trends and patterns associated with these deaths in care;
- undertake an assessment of the sequence of events leading up to the death to identify any procedural, practice or systems issues associated with the death;
- identify any issues related to the provision of health care and support associated with the death; and
- identify risk factors for people with disability in relation to premature or preventable deaths.

The Advisory Panel also assisted in analysing current policies, procedures or guidelines relating to the reporting and analysis of critical incidents and deaths in care for people with disability to identify opportunities for improvements in the systematic reporting, collection, recording and analysis of deaths in care of people with disability. Finally, the Advisory Panel assisted in the development of the final report and its recommendations.

Process and schedule of meetings

The Advisory Panel met on a monthly basis over a period from February 2015 to August 2015 (with the exception of May 2015).

A final meeting was held in November 2015 to discuss and finalise the report.

1.2.3 The review methodology

Selection of cases

The following inclusion criteria decided the selection of individual cases for the project.

A person was included in the sample if:

- they identified as having an intellectual impairment (intellectual disability or cognitive impairment) or a person identified as having a disability who appeared to have a severe or profound disability that may result in a severe to profound impact on their intellectual or cognitive functioning (e.g. cerebral palsy);
- They were aged 18 years or over at time of death;
- their death was a death in care as defined in the *Coroners Act 2003* (Qld) 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;
- their death occurred between 2009 and 2014; 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.

In all, 38 cases provided by the State Coroner were excluded from consideration. Reasons for exclusion included, for example, if a case concerned an individual who:

- was under 18 years of age; or
- appeared to have a diagnosis of mental illness but no intellectual impairment; or
- resided in another health facility (such as an aged care facility).

Some cases were excluded because there were insufficient details contained in the file received from the Coroner for that person.

A total of 73 cases were reviewed.

Extraction of standard demographics

Standard demographic information was extracted from the files of each individual and placed in a template. This included:

- Name
- Date of birth
- Age at death
- Gender
- Cultural background
- Service type
- Postcode of service
- Primary disability (whether intellectual disability, intellectual impairment, acquired brain injury or not recorded)
- Other disabilities
- Date of death
- Time of death
- Place of death (hospital or service)
- Immediate cause of death
- Underlying cause of death
- Other significant health conditions.

Identification and classification of underlying cause of death

The analysis and reporting of causes of death in this Report uses the underlying cause of death as classified under the International Classification of Diseases (ICD-10).[98] The ICD-10 is the international standard classification system used to classify diseases and causes of disease or injury as recorded on many medical records as well as cause of death certificates and Coroner's findings. Currently the ICD 10th revision is used for Australian causes of death statistics.[99] See Glossary for more information.

The underlying cause of death is the cause of death usually recorded for statistical purposes. It is not the immediate cause of death (for example, heart failure) but rather the "disease or injury that initiated the train of morbid events leading directly to death" (for example, Ischaemic heart disease).[100]

Review of cases by advisory panel

Ahead of meeting to review the cases, the Advisory Panel were provided with:

- A template for each case containing the standard demographic information.
- The Coroner's investigation documents[101] for each case.
- Any critical incident reports available from the DCCSDS for each case.

For each individual case, the Panel:

- Validated the demographic information;
- Analysed the sequence of events leading up to death to determine if the death was:
  - An unexpected death; or
  - Either or both a potentially treatable death or potentially preventable death and so a potentially avoidable death;
- Identified issues in the provision of health care or support provided to the person; and
- Identified 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.

For all cases collectively, the Panel:

- Analysed the demographic patterns and trends in the data;
- 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.

Unexpected and potentially avoidable deaths

Following the review of available material, the Panel reached a conclusion (within the limitations of the information on hand) about whether each death was an unexpected death and/or a potentially avoidable death.

Applying generally accepted medical opinion, the Panel agreed to define an unexpected death as that which was not anticipated as a significant possibility 24 hours before the death.

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.[102]

Potentially avoidable deaths comprise potentially preventable deaths and potentially treatable deaths.[103] Deaths from potentially treatable conditions are those that are amenable to therapeutic interventions, and that reflect the safety and quality of the current treatment system.[104] Potentially preventable deaths are 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.[105]

Extended case reviews

At each meeting the Panel identified a number of cases where further information would be valuable in terms of generating a greater understanding of the systemic issues associated with the deaths of people with disability in care. For this purpose, further information requests were made of DCCSDS, Queensland Health and several funded non-government service organisations.

1.2.4 Limitations

There are a number of limitations to this review that must be acknowledged.

First, this is not a prevalence study in the sense that the sample of people's deaths reviewed in this study cannot be seen as representing all the people with disability who died in care during the period 2009-2014. It is widely acknowledged that there is a high degree of under-reporting, and while state agencies, including the Office of the State Coroner, develop and publish information on the requirements for reporting deaths in care, there remains a lack of awareness about obligations in this regard from many health service staff and disability support staff.

Second, the information available to the Advisory Panel was limited. In most cases, all that was available was the Coroner's findings (a two page document detailing the cause of death and a summary of any investigation carried out) and either a Police Report (with demographic details and a summary of the death of the person as described by witnesses at the scene) or a Medical Practitioner's Report (with demographic details and sometimes an attached discharge summary or cause of death certificate). If the person was a client of DCCSDS, the critical incident report from their death was provided by DCCSDS.

In some cases, as discussed above, the Panel requested and received further information from either DCCSDS, Queensland Health or a non-government service provider.

Nonetheless, the limited information available to the Panel impacted its ability to thoroughly review the person's medical history and current circumstances and must be taken into account in considering the findings.

1.2.5 Privacy and confidentiality

In the course of the study, the privacy and confidentiality of all information was considered and protected.

The *Guardianship and Administration Act 2000* provides the Public Advocate with a right to all information:

- necessary to monitor and review the delivery of services and facilities to adults with impaired capacity for a matter; and
- about the arrangements for the provision of services and facilities to a class of the adults; and
- about the policies and procedures of a service or facility that relate to the provision of services and facilities to the adults.[106]

The Public Advocate is also under a strict obligation not to publish confidential information, including information that is likely to lead to the identification of a person to whom the information relates.[107]

The Public Advocate must not disclose confidential information to another person except in the performance of the Public Advocate's functions under the Act.[108]

For the *Guardianship and Administration Act 2000*, confidential information includes information about a person's affairs not including—

- information within the public domain unless further disclosure of the information is prohibited by law; or
- statistical or other information that could not reasonably be expected to result in the identification of the person to whom the information relates; or
- information about a guardianship proceeding.[109]

For this project, all communications, documents, data, and other materials and information relating to the research, as well as discussion between members as part of Advisory Panel processes were treated as confidential information. The terms of reference for the Advisory Panel clearly articulated these confidentiality requirements and the basis on which confidential information was being shared.

Panel members were required to sign the terms of reference to show that they agreed to these requirements and also understood that the information provided to them must not be divulged to any person without the prior written consent of the Public Advocate. Communication between Advisory Panel members about confidential information in the course of undertaking their Panel functions was exempt from this.

While the *Guardianship and Administration Act 2000* empowers the Public Advocate to develop a systemic advocacy report based on the information obtained,[110] the report must not contain confidential information that is likely to result in the identification of an adult with impaired capacity.[111] For this reason where case studies are discussed, the person's real name is not used and sometimes other details are changed to ensure that the person is not identifiable.

1.2.6 Ethical framework

This project and the review of the cases by the Advisory Panel was informed by a rights-based ethical framework and approach to the provision of health care and social services.

The United Nations *Convention on the Rights of Persons with Disabilities*

Representing the first time that all international human rights Covenants have been brought together under one umbrella, the Convention emphasises the obligation of state parties to take a positive approach to rights – to protect people, rather than just refrain from discriminating against them.[112]

The Convention heralded a significant paradigm shift towards what is known as a social model of disability, recognising that disability is primarily a 'social construct', the result of a society that places physical, social and attitudinal barriers in the way of people with disability. It seeks to address this by requiring that 'in order to promote equality and eliminate discrimination, State Parties shall take all appropriate steps to ensure that reasonable accommodation is provided'.[113]

Reasonable accommodation is defined as:

> *'necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.'*[114]

Specifically Article 25 recognises that people with disability have the right to enjoyment of the highest attainable standard of health without discrimination on the basis of disability. This includes:

- Providing people with disability the same range, quality and standard of free or affordable health care and programs as provided to other persons.
- Providing those health services needed by persons with disability specifically because of their disability, including early identification and intervention as appropriate.

- Requiring health professionals to provide care of the same quality to persons with disability as to others, including on the basis of free and informed consent, by inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disability through training and the promulgation of ethical standards for public and private health care.
- Preventing discriminatory denial of health care/services or food/fluids on the basis of disability.[115]

Further, article 10 of the UNCRPD obligates state parties to reaffirm that every human being has the inherent right to life and to take all necessary measures to ensure its effective enjoyment by persons with disability on an equal basis with others.[116]

A theory of justice – valuing lives equally

A rights-based approach incorporates a theory of justice, recognising that all people, including those with intellectual impairment, have the capacity to engage in a valued way in society, and that doing so contributes to a society based on relations of mutual respect between free and equal members.[117]

Such an approach does not privilege the engagement of some (i.e. those who are able-bodied or -minded) over others (people with impairment). The end point in mind is a society based on mutual respect, where all members are considered equally worthy,[118] and where 'the life and health of each person matters as much as that of any other.'[119]

This entails an approach to the delivery of health care that involves a just allocation of health care resources that does not discriminate on the basis of disability, and provides that all people are entitled to equal consideration of their health needs on an equal basis.[120]

Some argue that such an approach ignores other pertinent issues, for example quality of life, and may seek to justify different treatment (including a lower prioritisation of health care resources) on the basis that people with certain disabilities are likely to have a much lower quality of life and the fact that there is a scarcity of health resources.[121]

A rights-based approach recognises however that concepts such as 'quality of life' can be very subjective and prone to prejudice and sometimes simply a lack of understanding.[122] At times, such concepts have been used to justify widespread discrimination in the provision of health care to people, including children with disability, based less on evidence-based approaches to prognosis and quality of life, and more on prejudice and misunderstanding.[123]

The Panel's approach

In line with the approach described above, the Panel implemented the 'but for' test when reviewing the available materials for each case. Essentially the Panel asked 'but for' the person's disability, would the health care and support that the person received in this instance for their particular health condition or symptoms seem reasonable.

Such an approach requires a comparison between how a person with a disability with a particular health condition or symptoms might be treated versus how a person without a disability with the same health condition or symptoms would be treated, with the objective to ascertain whether there has been a discriminatory approach.

In developing recommendations, the Panel applied the principles of reasonable accommodation in the context of a rights-based approach, and considered ways not only to stop discrimination against people with disability in the delivery of health care, but also the strategies for a positive approach and the implementation of accommodations to enable people with disability to access good health care and support services on the same basis as others.

This provided the ethical framework for the analysis of information by the Panel, which is demonstrated in the remainder of this report.

2 Review of people with disability who died in care in Queensland

Summary of Key Points

73 people

The total sample included 73 people with disability who died in care from 2009 to 2014.

53 years

The median age at death for males was 53 years (approximately 25 years less than the general population).

48.5 years

The median age at death for females was 49 years (approximately 36 years less than the general population).

Most people (89%) were living in disability supported accommodation at the time of death

When they died, most people (89%) were living in either disability supported accommodation operated by a funded non-government organisation; or the government operated AS&RS service. Only 11% were living in a level three accredited residential service.

People were slightly more likely to die in hospital

Both males and females were slightly more likely to die while in hospital, with 58% of people dying in hospital and 42% dying in their usual place of accommodation.

Most people died during the night

Most people (62%) died during the night (that is, between 6:00 PM and 6:00 AM).

Respiratory disease was the leading underlying cause of death

The most common underlying cause of death was respiratory diseases (34%) followed by circulatory diseases (22%); diseases of the nervous system (11%); neoplasms (10%) and external causes/ accidental threats to breathing (8%).

At the ICD 10 subchapter level, the most common underlying causes were: Influenza and Pneumonia (33%); Ischaemic heart disease (11%); Episodic and paroxysmal disorders (in this case epilepsy) (10%); and other accidental threats to breathing (in this case food aspiration and choking) (8%).

59% of deaths were unexpected

More than half of all deaths in care reviewed (59%) were determined by the Panel to be unexpected.

53% of deaths were avoidable

Over half of all deaths (53%) were considered by the Panel to be avoidable.

2.1 Characteristics of people who have died in care

2.1.1 Deaths in care (2009 to 2014)

This part outlines the findings of the review of deaths of people with disability in care from 2009 to 2014.

The total sample included 73 deaths of people with disability who died in care and met the inclusion criteria for the study between the year 2009 and 30 June 2014.

The breakdown of deaths in the sample by year is presented below.

Table 1 Deaths in care by year

Year	Total	Percentage of total
2009	12	16%
2010	8	11%
2011	7	10%
2012	20	27%
2013	19	26%
2014	7	10%
Total	**73**	**100%**

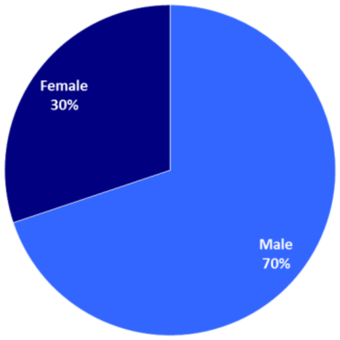
Importantly, these figures, and therefore the review as a whole, is unlikely to represent all the people with disability who died in care during that time. First, anecdotally, there is an acknowledged high rate of under-reporting of deaths in care. Second, only those cases that met the inclusion criteria were included (**see section 2.2.3**).

2.1.2 Gender and cultural background

Gender

The majority of the sample (51 individuals or 70%) of those people with disability who died in care were male. This result also reflects the prevalence of males living in supported residential disability accommodation services.[124]

Figure 1 Gender balance of the sample



Cultural background

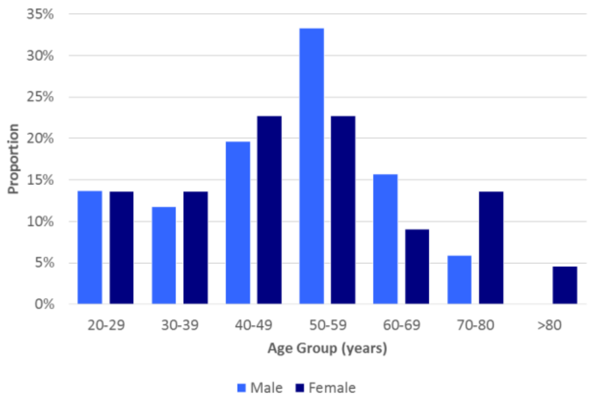
Of the 73 people with disability in the sample, 8 individuals (11%) were identified as Aboriginal or Torres Strait Islander while one individual was identified to be of Pacific Islander background.

2.1.3 Age at death

The age at death of people with disability who died while in care in the sample (Figure 2) ranged from 21 years to 81 years. The median age at death in the sample was 51. For males in the sample, the median age at death was 53 while for females, the median age at death was 49.

In 2013, the Australian Bureau of Statistics (ABS) reported that the median age at death for the general population was 78.4 for males and 84.6 for females.[125] This means that the median age at death for males in the sample for this review was approximately 25 years younger than the general population and for females in the sample for the review, the median age at death was approximately 36 years younger than the general population.

Figure 2 Age profile of the sample by gender



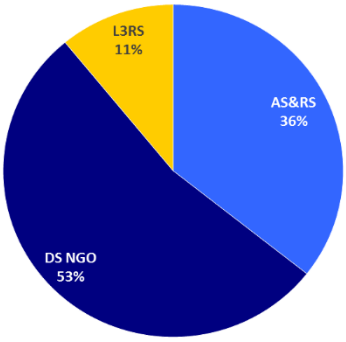
2.1.4 Residence at time of death

The majority of people with disability in the sample who died in care were living in disability provided or funded services at the time of their death (65 individuals or 89%).

Those living in supported accommodation provided by a non-government organisation (39 individuals) represented 53% of the overall sample while 36% (26 individuals) of the overall sample were supported by the government run AS&RS.

Eight of the people in the sample died while living in a level 3 accredited residential service.

Figure 3 Place of residence at time of death



2.1.5 Disability

A key inclusion criterion for this study was that the person who died was in some way identified as having an intellectual impairment (intellectual disability or cognitive impairment) or that the person identified as having a disability appeared to have a severe or profound disability that may result in a severe to profound impact on their intellectual or cognitive functioning (e.g. cerebral palsy).

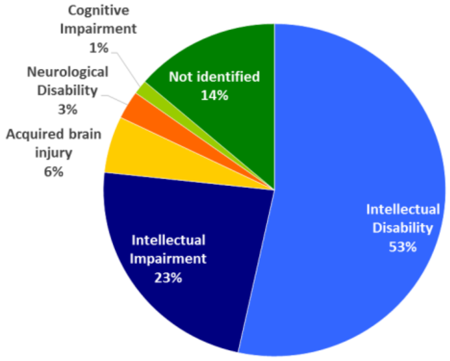
The person's primary disability (that is whether they were identified as having a form of intellectual impairment) was recorded for this study as it was recorded on the coronial investigation documents.

Primary disability (Figure 4)

Intellectual disability (53%) and intellectual impairment (23%) were identified as the primary disability types for the majority of the sample.

Other primary disability types that were identified included acquired brain injury (6%); neurological disability (3%); and cognitive impairment (1%). A primary disability was not recorded for 10 individuals (14%) in the sample.

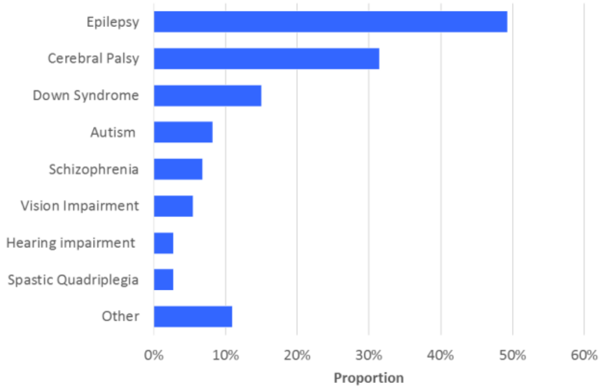
Figure 4 Profile of primary disability in the sample



Other disabilities (Figure 5)

Epilepsy (49%) and cerebral palsy (32%) were the most common other disability types in the sample, followed by Down syndrome (15%). The totals in this chart exceed the total number of cases due to many individuals in the sample being recorded as having multiple disabilities.

Figure 5 Profile of other disabilities in the sample



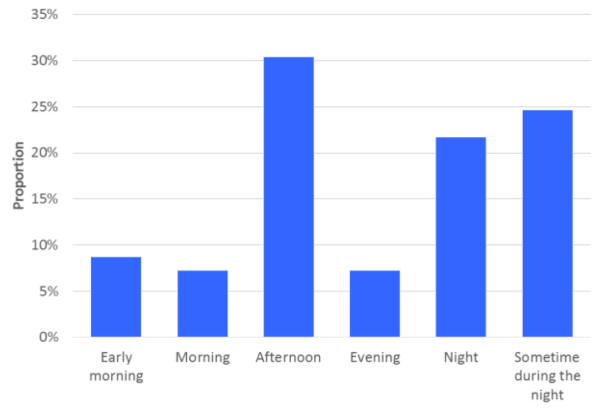
2.1.6 Time of death

Time of death

The majority of people in this sample (43 individuals or 62%) died during the night (i.e. between 6:00 PM and 6:00 AM) with morning being the least likely time of death. Not all people had their time of death recorded. In a significant number of cases (17 cases), the person's death was not discovered until the morning and so their time of death is recorded as 'sometime during the night'. The time of death for four individuals was not recorded at all.

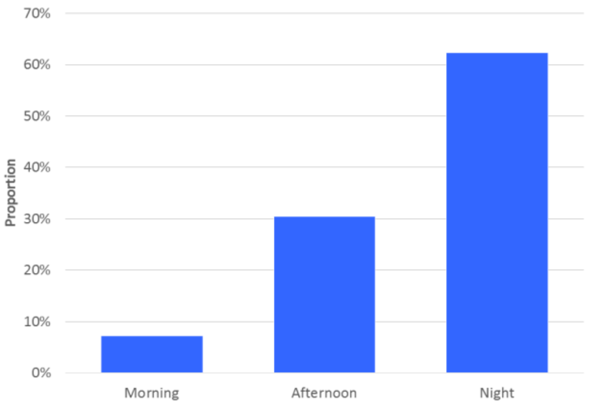
When the categories of time are expanded (Figure 6), almost a third of deaths are shown to have occurred in the afternoon (21 individuals or 30%), 9% (6 individuals) occurred in the early morning, and 7% (5 individuals) in the early evening. The recorded time of death for fifteen individuals (22%) was night and the recorded time of death for seventeen individuals (25%) was "sometime during the night".[126]

Figure 6 Recorded time of death (full categories) for the sample



Conversely, when the categories are collapsed (Figure 7), the data shows that 62% (43 individuals) died during the night, 7% (5 individuals) died during the morning and 30% (21 individuals) in the afternoon.[127]

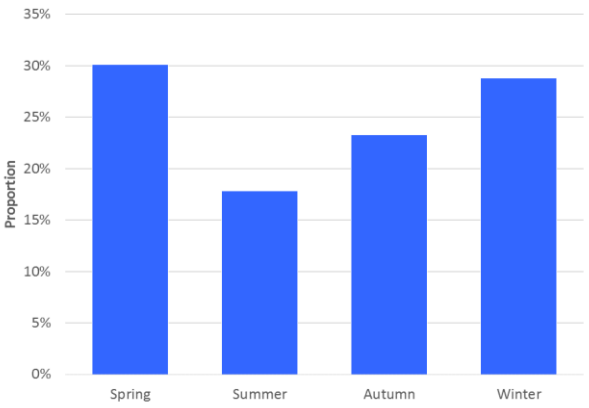
Figure 7 Recorded time of death (condensed categories) for the sample



Seasonality of death

There is insufficient data to make robust comment on the seasonality of death, but there may be a peak in the number of deaths in April and troughs in January and May (Figure 8). While the fewest deaths occurred in summer (18%) and the highest number in winter (29%) and spring (30%), the overall data indicates only a slight seasonal trend in deaths.

Figure 8 Seasonality of deaths in the sample



2.1.7 Place of death

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.

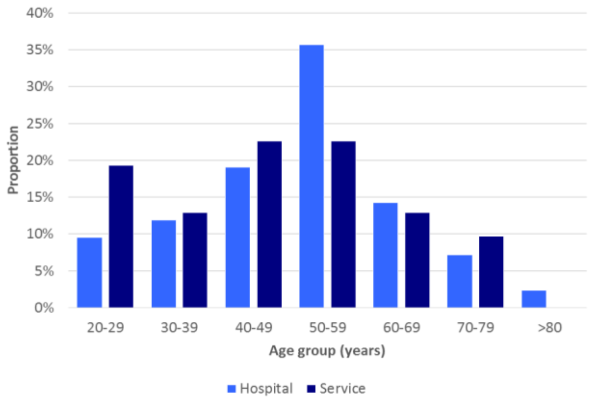
In the sample, 31 individuals (42%) died in the service in which they resided, while 42 individuals (58%) died in a hospital. Of the 22 females in the sample, 55% (12 individuals) died in hospital and 45% (10 individuals) died in the service. Of the 51 males in the sample, 59% (30 individuals) died in hospital while 41% (21 individuals) died in a service.

Age and place of death (Figure 9)

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.

Figure 9 Age profile of the sample by place of death

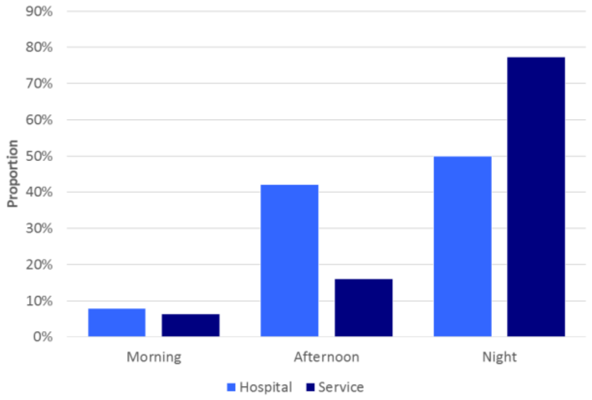


Time and place of death (Figure 10)

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.

Figure 10 Recorded time of death (condensed categories) for the sample by place of death



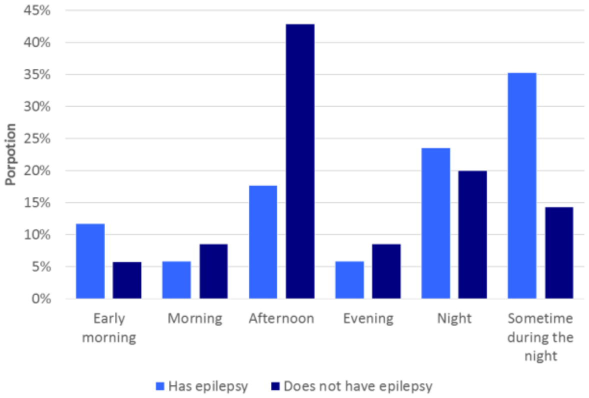
2.1.8 Time and place of death – Epilepsy

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.

Of the individuals with epilepsy, 77% died either in the early morning, evening or night (including ‘sometime during the night’) as opposed to 49% of the people without epilepsy having died during this time period.[128]

Figure 11 Recorded time of death (full categories) for the sample by recorded condition of epilepsy

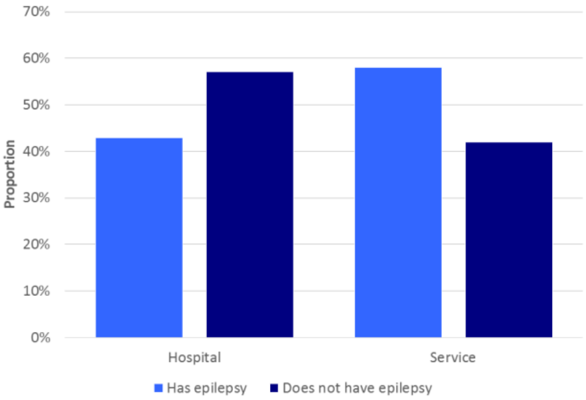


Place of death and epilepsy

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.

Of the 36 individuals with epilepsy, 58% died in the service in which they resided. By comparison, only 42% of people without epilepsy died in the service in which they resided.

Figure 12 Place of death by recorded condition of epilepsy



2.2 Causes of death

2.2.1 Leading underlying causes of death

The underlying cause of death is the cause of death usually recorded for statistical or reporting purposes. It is not necessarily the immediate cause of death (for example, heart failure) but rather the “disease or injury which initiated the train of morbid events leading directly to death”[129] (for example, Ischaemic heart disease).[130]

Except for six people, all people with disability in the study died from natural causes. The six deaths from unnatural causes were due to choking, food bolus inhalation, or aspiration of vomit.

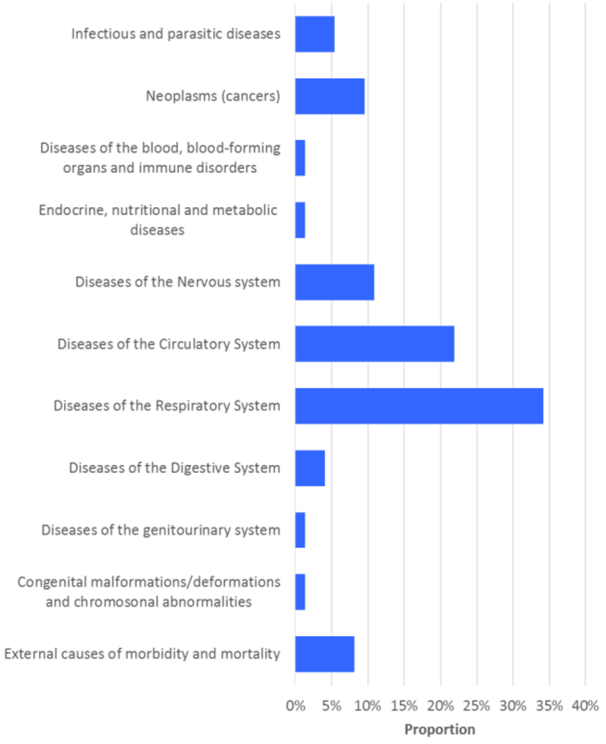
Leading underlying cause of death in the sample by ICD chapter

The most common underlying causes of death were diseases of the respiratory system (34%), circulatory system (22%), the nervous system (11%), neoplasms (10%), and external causes (8%).

When the underlying cause of death is classified by the ICD-10 Chapter, the most common underlying causes of death in this sample (figure 13) were:

- **Chapter X – Diseases of the respiratory system** (25 individuals - 34%): These included influenza and pneumonia (namely aspiration pneumonia, pneumonia, bronchopneumonia and HN1 Influenza) (24 individuals); and other respiratory diseases primarily affecting the interstitium (namely interstitial lung disease) (1 individual).
- **Chapter IX – Diseases of the circulatory system** (16 individuals - 22%): These included Ischaemic heart disease (8 individuals); pulmonary heart disease (1 individual); other forms of heart disease (5 individuals) and diseases of the veins and lymphatic vessels (namely deep vein thrombosis) (2 individuals).
- **Chapter VI – Diseases of the nervous system** (8 individuals - 11%): These included episodic and paroxysmal disorders (namely epilepsy) (7 individuals); and systemic atrophies primary affecting the central nervous system (Amyotrophic lateral sclerosis) (1 individual).
- **Chapter II – Neoplasms** (7 individuals - 10%): These included malignant neoplasms of the digestive organs (namely pancreatic, colorectal and oesophageal cancer) (3 individuals); 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); and malignant neoplasms of ill defined, secondary and unspecified sites (malignancy of unknown aetiology (1 individual).
- **Chapter XX – External causes** (6 individuals - 8%): These were all due to other accidental threats to breathing (namely choking, aspiration of vomit and food bolus asphyxia) (6 individuals).

Figure 13 Profile of underlying cause of death to report (ICD-10 chapter) in the sample

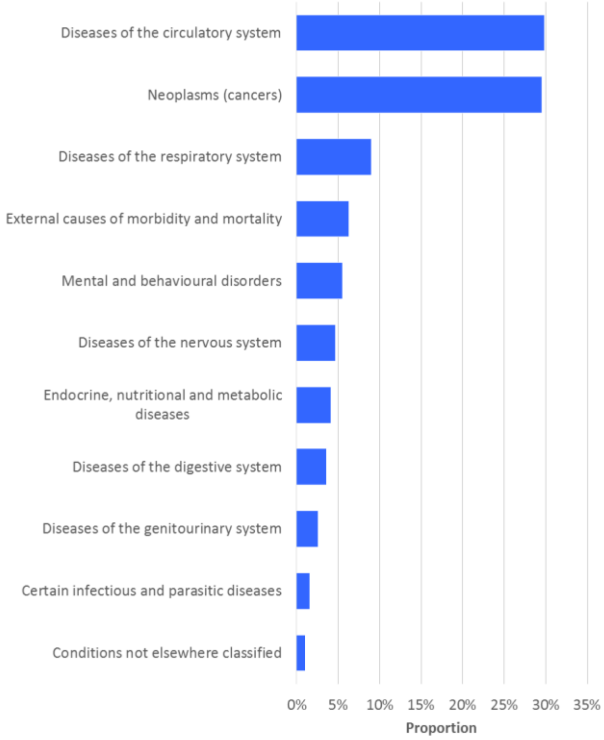


Leading underlying cause of death in the general population by ICD chapter

For the general population, the leading underlying causes of death, at the chapter level, were diseases of the circulatory system (I00-I99), chronic ischaemic heart disease (I25), acute myocardial infarction (I21) and stroke not specified as haemorrhage or infarction (I64). Chronic ischaemic heart disease was the cause of 7% all deaths registered in 2013.

For the general population, the second leading underlying cause of death, at the chapter level, were neoplasms (C00-D48), which includes neoplasms of the digestive, respiratory and haematopoietic organs. Malignant neoplasms of digestive organs was identified as the underlying cause of death of 8% of all deaths registered in 2012.[131]

Figure 14 Top ten underlying causes of death to report

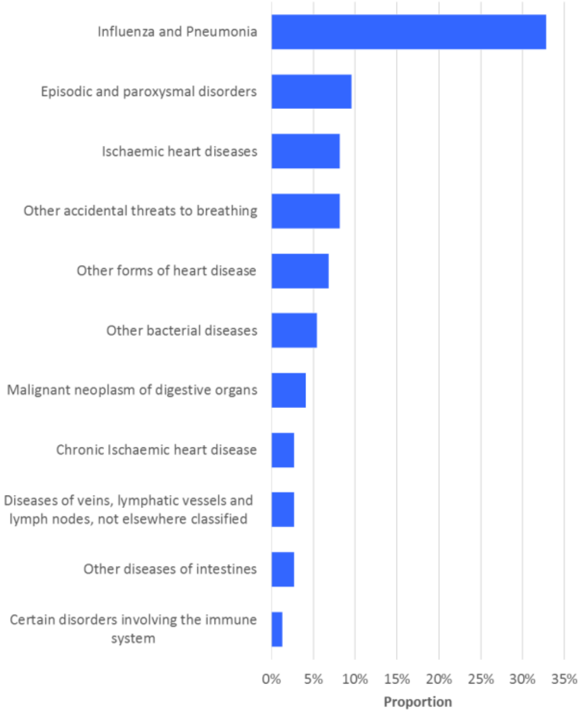


Leading underlying cause of death for the sample by ICD sub-chapter

The most common underlying causes of death when classified by ICD 10 sub-chapter were:

- Influenza and Pneumonia (J09-J18) (24 individuals - 33%)
- Ischaemic heart disease (I20-I25) (8 individuals - 11%)
- Episodic and paroxysmal disorders (in this case epilepsy) (G40-G47) (7 individuals - 10%)
- Other accidental threats to breathing (in this case food aspiration and choking) (W75-W84) (6 individuals - 8%)
- Other bacterial diseases (mostly septic shock) (A30-A49) (4 individuals - 5%)
- Malignant neoplasms of digestive organs (C15-C26) (3 individuals - 4%)
- Diseases of the veins, lymphatic vessels and lymph nodes, not elsewhere classified (Deep Vein Thrombosis) (2 individuals – 3%).

Figure 15 Leading underlying cause of death for the sample by ICD 10 sub-chapter



2.2.2 Underlying causes of death and gender

Table 2 shows the underlying cause of death classified by ICD 10 Chapters for males and females. 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).

Table 2 Underlying cause of death to report (ICD-10 chapter) by gender

	Male		**Female**		**Total**	
	n	**%**	**n**	**%**	**n**	**%**
Chapter I Certain infectious and parasitic diseases (A00-B99)	4	8%	0	0%	4	5%
Chapter II Neoplasms (C00-D48)	5	10%	2	9%	7	10%
Chapter III Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	1	2%	0	0%	1	1%
Chapter IV Endocrine, nutritional and metabolic diseases	1	2%	0	0%	1	1%
Chapter VI Diseases of the Nervous system (G00-G99)	5	10%	3	14%	8	11%
Chapter IX Diseases of the Circulatory System (I00-I99)	9	18%	7	32%	16	22%
Chapter X Diseases of the Respiratory System (JOO-99)	17	33%	8	36%	25	34%
Chapter XI Diseases of the Digestive System (K00-K93)	2	4%	1	5%	3	4%
Chapter XIV Diseases of the genitourinary system (N00-N39)	1	2%	0	0%	1	1%
Chapter XVII Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	1	2%	0	0%	1	1%
Chapter XX External causes of morbidity and mortality (V01-Y98)	5	10%	1	5%	6	8%
Total	**51**	**100%**	**22**	**100%**	**73**	**100%**

2.2.3 Disability and underlying cause of death

Table 3 shows the underlying cause of death classified by ICD 10 Chapters for people in the sample recorded as having cerebral palsy, Down syndrome and epilepsy, the three most common 'other disabilities' recorded. 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).

Table 3 Underlying cause of death to report (ICD-10 chapter) by select conditions

	Cerebral palsy		**Down syndrome**		**Epilepsy**		**Total**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Chapter I Certain infectious and parasitic diseases (A00-B99)	1	4%		0%	1	3%	4	5%
Chapter II Neoplasms (C00-D48)	0	0%	1	9%		0%	7	10%
Chapter III Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	0	0%	0	0%	1	3%	1	1%
Chapter IV Endocrine, nutritional and metabolic diseases	1	4%	0	0%	1	3%	1	1%
Chapter VI Diseases of the Nervous system (G00-G99)	3	13%	2	18%	7	19%	8	11%
Chapter IX Diseases of the Circulatory System (I00-I99)	3	13%	1	9%	8	22%	16	22%
Chapter X Diseases of the Respiratory System (JOO-99)	12	52%	5	45%	13	36%	25	34%
Chapter XI Diseases of the Digestive System (K00-K93)	1	4%		0%	2	6%	3	4%
Chapter XIV Diseases of the genitourinary system (N00-N39)	0	0%	1	9%	0	0%	1	1%
Chapter XVII Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	0	0%	1	9%	0	0%	1	1%
Chapter XX External causes of morbidity and mortality (V01-Y98)	2	9%	0	0%	3	8%	6	8%
Total	**23**	**100%**	**11**	**100%**	**36**	**100%**	**73**	**100%**

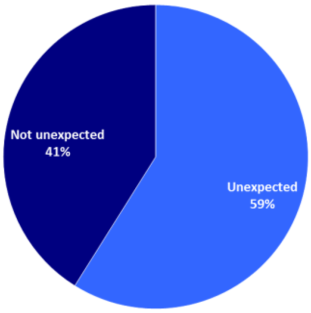
** Note that the total adds up to more than the total number of people with cerebral palsy, Down syndrome and epilepsy as it indicates the total number of deaths in the sample due to that cause. Some individuals had multiple other disabilities, and some individuals did not have cerebral palsy, Down syndrome and epilepsy recorded as another disability.

2.3 Unexpected and preventable deaths

2.3.1 Unexpected deaths

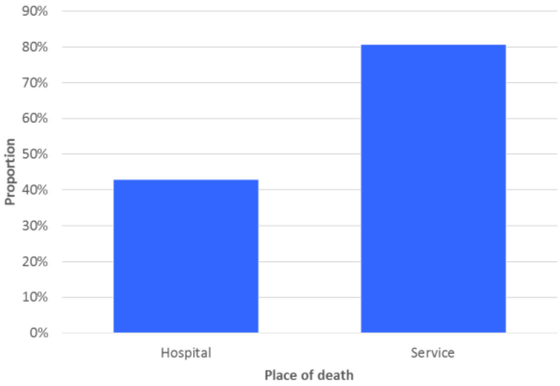
Using the available material for each person, the Panel determined (to the best of its ability given the sometimes limited information) whether the death was an unexpected or an expected death. More than half of all deaths in care reviewed (43 individuals or 59%) were deemed to be unexpected (Figure 16).

Figure 16 Unexpected deaths in the sample



Unexpected deaths were more likely to occur when the person was in their usual accommodation, rather than a hospital at time of death (Figure 17). 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.

Figure 17 Unexpected deaths in the sample by place of death



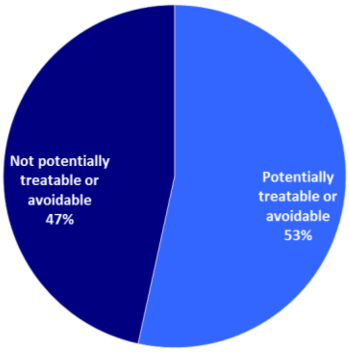
2.3.2 Potentially Avoidable deaths

The Advisory Panel also assessed whether the death could have been either or both a potentially treatable death or a potentially preventable death and so a potentially avoidable death.

Deaths from potentially treatable conditions are those that are amenable to therapeutic interventions, and reflect the safety and quality of the current treatment system.[132] Potentially preventable deaths are those that are amenable to screening and primary prevention, such as immunisation, and reflect the effectiveness of current preventive activities in the health sector.[133]

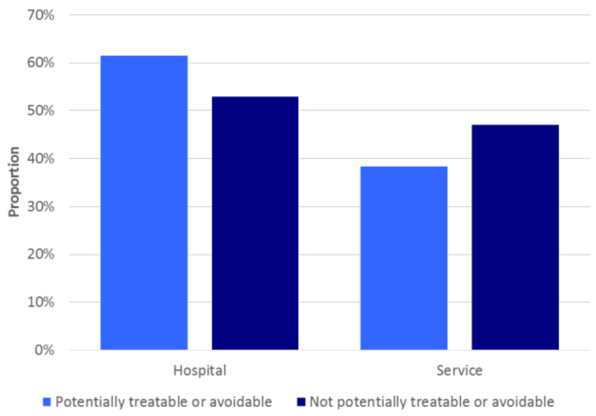
Over half of all deaths reviewed (39 individuals or 53%) were considered to be potentially avoidable (Figure 18).

Figure 18 Potentially avoidable deaths in the sample



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. The deaths of 15 individuals who died in their usual place of accommodation were considered to be potentially avoidable.

Figure 19 Potentially avoidable deaths in the sample by place of death



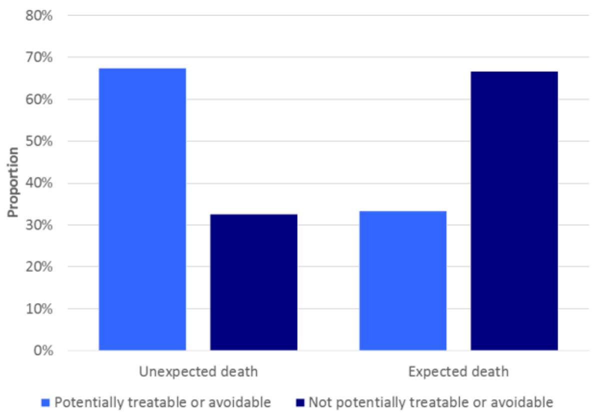
2.3.3 Deaths that are both unexpected and potentially avoidable

Of those deaths deemed by the Panel to be unexpected, approximately two thirds (67%) were also considered to be potentially avoidable; this represents approximately 40% (29 individuals) of all cases in the sample.

Diagnoses of epilepsy featured strongly in the case histories of those deaths that were deemed to be both unexpected and potentially avoidable (17 individuals), with epilepsy/SUDEP identified as the underlying cause of death for 4 individuals.

Of further note is that aspiration pneumonia was identified as the underlying cause of death for 8 individuals, 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.

Figure 20 Unexpected deaths in the sample by potentially avoidable deaths



3 Risks and issues – Deaths of people with disability in care

3.1 Risk factors and vulnerabilities

This section discusses the risk factors and vulnerabilities for people with disability living in residential care within the context of the leading underlying causes of death for this sample.

As previously identified, the leading underlying causes of death for people in this study were respiratory disease, circulatory system diseases, nervous system disease, cancer/neoplasms and choking/food asphyxiation.

Recommended strategies for disability organisations, health providers and others to reduce these particular health risks for people with disability are also proposed.

3.1.1 Deaths caused by respiratory diseases

Prevalence of respiratory disease as an underlying cause of death

While death as a result of respiratory diseases accounts for 9% of deaths in the general population,[134] respiratory diseases are one of the major causes of death in people with intellectual disability.[135]

Respiratory diseases were also found to be the most common underlying cause of death for the people in this sample. Approximately 34% of the sample (or 25 individuals) died as a result of respiratory disease – most commonly pneumonia, bronchopneumonia, aspiration pneumonia, or HN1 Influenza (24 individuals). One individual died from interstitial lung disease, which is notably different to the previous four conditions given that it occurs outside of the lungs as opposed to inside.

While in the general population, death from respiratory disease such as pneumonia is more common in the elderly,[136] people with intellectual disability or cognitive impairment may be at greater risk of developing respiratory diseases due to a combination of factors such as:

- Limited mobility and dependence on others;
- Epilepsy, Down syndrome and cerebral palsy;
- Swallowing difficulties (dysphagia);
- Recurrent pneumonia;
- High use of psychotropic medication;
- Gasto-oesophageal reflux disease;
- Receiving enteral nutrition; and
- Poor oral health (such as dental problems and gum disease).[137]

Late Diagnosis

A number of cases in this sample evidenced late diagnosis of the condition, resulting in treatment either not being provided or not being as effective as it could have been due to the infection having progressed significantly. As a result, many people died soon after diagnosis or sometimes before the pneumonia was even diagnosed.

It is important for carers and support staff to be aware of and alert to the signs and symptoms of pneumonia in the people with disability they support. Given the life threatening nature of pneumonia in people with disability, support staff should seek immediate medical assistance should signs and symptoms indicate this or any other serious illness.

People at risk of pneumonia should also be vaccinated against pneumococcal pneumonia as well as influenza to help reduce the risk of pneumonia.[138]

Symptoms of pneumonia may include:

- Rapid breathing
- Breathing difficulties
- Fever
- General malaise or lethargy
- Functional decline
- Increased confusion or agitation
- Incontinence (new onset)
- Loss of appetite
- Abdominal pain
- Headache
- Chest pain
- Tachypnoea (abnormally rapid breathing)
- Cough
- Blue colouration of the skin around the mouth.[139]

Case Studies: late diagnosis of pneumonia

A man in his 20's with intellectual disability, cerebral palsy and epilepsy lived in a disability residential service. He also suffered from gastro-oesophageal reflux and received enteral nutrition (via percutaneous endoscopic gastronomy or PEG feeding). He was put to bed by his carer but when subsequently checked on in the early morning, was found to have died sometime during the night. The Coroner found he had died due to aspiration pneumonia. It had not been diagnosed prior to his death.[140]

A 55 year old man with intellectual disability and cerebral palsy lived in a disability residential service. He was unable to communicate verbally. On the night that he died he had been in bed, with a carer noting that he appeared to be asleep 'on and off' and that he was snoring heavily. When his carer checked on him in the morning, she found that he had died sometime during the night. The Coroner found that he had died due to bronchopneumonia. It had not been diagnosed prior to death.[141]

A woman in her 60's with an intellectual disability and a history of recurrent pneumonia lived in a disability residential service. Upon noting the development of 'flu-like symptoms', she was taken to her GP. Two days later her condition deteriorated; she developed shortness of breath and laboured breathing. She was taken to hospital where she was diagnosed with pneumonia. Four days after noting her first symptoms, she died of pneumonia.[142]

Aspiration

Aspiration refers to the inhalation of food, saliva or gastric contents into the lower respiratory tract and larynx. Once aspiration occurs, this can lead to lung inflammation and infection.[143] Many people with intellectual disability or cognitive impairment are at a particular risk of aspiration due to:

- Problems with swallowing due to neuromuscular weakness, with loss of control of the larynx and pharynx;[144] and/or
- High use of psychotropic medications, which can cause sedation and decreased muscle coordination and in turn affects the muscles of the mouth throat and oesophagus,[145] potentially exacerbating swallowing difficulties.

The Panel identified a number of risk factors that could be addressed to prevent avoidable deaths of people with disability in residential care including diagnosing and addressing swallowing disorders that may lead to aspiration and infection; reducing the use of psychotropic medication; and the proper management of epilepsy.

Diagnosis of swallowing disorders (dysphagia)

Dysphagia means difficulty with eating, drinking and swallowing.[146] People with intellectual disability or cognitive impairment, as well as people with cerebral palsy,[147] may have difficulties with eating, drinking and swallowing due to a range of factors including:

- Central nervous system disorders;[148]
- Musculoskeletal deformities;[149]
- Poor oral health;[150]
- Mental health problems or psychiatric disorders;[151]
- Psychological effects of institutionalisation;[152]
- The effects of medication (such as sedatives or other psychotropic medications);[153]
- Gastroesophageal reflux;[154] or
- Deprivation of experiences needed for people to master mature swallowing skills.[155]

Given the risk of aspiration for some people with disability, it is crucial that swallowing disorders are recognised, that proper assessments by a speech pathologist or other qualified professional occur and, if appropriate, that a mealtime management plan is developed and implemented.

People with intellectual or cognitive impairment may not be able to communicate their difficulties with swallowing so support workers and health care providers need to be alert to some of the behavioural changes that may indicate deterioration in swallowing ability and the need for a professional assessment. These include:

- Increased coughing during meals;
- Increased congestion (especially if associated with feeding);
- Saliva accumulation and/or drooling;
- Refusal to self-feed;
- Self-restriction of selected food textures;
- Sudden or gradual weight loss;
- Increased duration of meals; and
- Other behaviour changes.[156]

It is important to discriminate between behaviours that are associated with the person’s disability and other behaviours, and not to attribute the symptoms of underlying swallowing disorder to the person’s disability.[157]

Studies have found that dependence for feeding was a significant predictor of pneumonia.[158] As a result, the use of ‘safe feeding’ techniques may directly decrease the amount of food, liquid or saliva aspirated and indirectly improve nutrition, which may in turn maximise resistance to infection.[159]

Reducing the risk of aspiration and aspiration pneumonia in people with swallowing problems:

- Minimise the use of sedative and anti-psychotic medication;
- Maintain good oral hygiene;
- Engage a speech and language pathologist to conduct a swallowing assessment; and
- Ensure that carers explicitly follow all recommendations with respect to feeding, food consistency and supervision while eating.

Percutaneous endoscopic gastronomy (PEG)

People who are provided with nutrition and hydration through percutaneous endoscopic gastronomy (PEG) may also be at risk of aspiration, and thus at risk of developing aspiration pneumonia.[160] Sometimes aspiration occurs due to aspirated refluxed gastric contents, and aspiration may also occur during the procedure when the PEG is inserted.[161] The level of sedation used in the procedure may increase the risk of aspiration.[162]

Aspiration resulting in pneumonia is one of the most frequently reported complications arising from PEG placement.[163]

Case Study: PEG Feeding, aspiration and aspiration pneumonia

A man in his 20's with intellectual disability, epilepsy and cerebral palsy lived in a disability residential service. He received nutrition and hydration via a PEG tube. He underwent day surgery to replace his PEG tube, which had broken, and returned home that day. On the same night during his night-time feed, his carer noted that his breathing was laboured, he was sweaty, and had a high temperature. The ambulance was called but he died on the way to the hospital. The Coroner found he died due to aspiration pneumonia.[164]

Use of psychotropic medication

Many people with intellectual disability or cognitive impairment are prescribed psychotropic medications, and the use of multiple psychotropic medications (polypharmacy) is common.[165]

In this sample, 49% of people (or 36 individuals) were being administered psychotropic medication. Polypharmacy was common with eight individuals being administered five or more different psychotropic medications. Notably, the average number of psychotropic medications administered per individual was approximately three. Of those administered psychotropic medications, 28% (or 10 individuals) died due to respiratory disease.

Given the high rate of psychotropic medication administered to people in this sample, the Panel considered the possible link between psychotropic medication and the risk of aspiration, and thus the associated risk of aspiration pneumonia.

There is an established link between the use of psychotropic medication and aspiration and aspiration pneumonia, particularly in older people.[166] Certain psychotropic medication may have an adverse effect on a person's swallowing, which may facilitate aspiration and increase the risk of acquiring pneumonia.[167]

Epilepsy

In some cases, the risk of aspiration (and, by association, aspiration pneumonia) may also be heightened by epilepsy and the experience of seizures.[168] 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.[169]

Case Studies: Epilepsy and aspiration pneumonia

A man in his 50's with Down syndrome and epilepsy lived in a disability residential service. He was not able to communicate verbally. He experienced seizures approximately once a month. On the day before his death he experienced a seizure after which he vomited. His carers subsequently noted that he seemed lethargic. When he did not improve, an ambulance was called and he was taken to hospital where he continued to deteriorate quickly. He died early the next morning from aspiration pneumonia.[170]

A man in his 50's with intellectual disability and epilepsy lived in a disability residential service. He had a history of pneumonia, for which he had been hospitalised in the past. His carer reported that he had not fully recovered from his last episode of pneumonia but that he had been discharged from hospital to his residence, where he was having continual seizures, during which he would sometimes aspirate. He was found by his carer at the service lying in a pool of vomit, an ambulance was called and he was taken to hospital where he was diagnosed with aspiration pneumonia. This time he did not respond to antibiotic treatment and died.[171]

Respiratory disease – Summary of findings and recommendations

In the sample, the most common underlying cause of death was respiratory disease, predominately pneumonia and aspiration pneumonia. A combination of factors may heighten the risk of respiratory disease for people with disability.

Many in the sample were not diagnosed with pneumonia until shortly before, and sometimes after, their death. This suggests that early signs of serious illness were either not noticed by support staff or health practitioners or potential indicators of the illness were not known or understood.

Support staff should have clear information about the heightened risk, and signs and symptoms, of pneumonia in people with disability.[172] This is particularly important for those supporting people who have limited verbal communication.

The 'red flags' that indicate a need to seek urgent medical assistance must be clearly understood. Support staff should have clear guidelines that articulate the need to seek urgent medical assistance if these signs and symptoms are present, regardless of how recently the person may have seen a doctor or other health practitioner.

People with disability, in particular intellectual disability or cognitive impairment, can be at greater risk of acquiring pneumonia due to a variety of factors. People with disability in residential care who are at greater risk should be identified and have strategies put in place to reduce their risk.

People with disability who are at risk of developing respiratory diseases and/or have had recurrent respiratory illness should also have access to respiratory specialist assessment and treatment.

There are many strategies that can be put in place in to reduce the risk of people with disability dying from respiratory illness.

Recommendations: Respiratory Disease

- People with disability in residential care at risk of developing pneumonia should be identified by the organisations responsible for their care and provided with appropriate support to minimise their risks. In particular:
    - signs and symptoms of dysphagia (swallowing difficulties) must be monitored closely, with assessments by appropriate professionals carried out, plans developed and implemented;
    - support staff need to be well trained in the importance of safe feeding techniques and following meal time management plans;
    - people who are administered enteral feeding (including PEG feeding) should be closely monitored for signs that aspiration could be occurring, and for early signs of respiratory infection;
    - people with epilepsy should have access to specialist attention and medication reviews;
    - the use of psychotropic medications should be regularly reviewed and kept to a minimum;
    - people at risk of pneumonia should be vaccinated against pneumococcal pneumonia as well as influenza; and
    - people with a history of recurrent respiratory infections should have access to specialist respiratory clinicians.
- Support workers and carers should be made aware of the signs and symptoms of pneumonia through easy to read, accessible documentation and training. These resources must be supported by organisational policies that mandate the need to seek urgent medical attention where those signs and symptoms appear (even when a person has recently seen a doctor).
- As part of a targeted education and information strategy, Queensland Health (in collaboration with QCIDD, Health and Hospital Services and expert practitioners) should develop resources that educate people with disability, their families/carers, support staff and health practitioners to the high risk of people with certain types of disabilities developing pneumonia, and the 'red flags' or signs and symptoms that a person may have pneumonia and that indicate the need to seek urgent medical assistance.
- As part of the above strategy, Queensland Health should develop evidenced-based guidelines for clinicians that take into account the risk factors for respiratory disease in the population of people with disability in care who often have comorbidities/multiple conditions that make them particularly vulnerable.

3.1.2 Deaths related to epilepsy

Prevalence of epilepsy as a disability and cause of death

The prevalence of epilepsy in people with intellectual disability or cognitive impairment is recognised as much greater than in the general population.[173] While estimates vary, it is generally recognised that one in five people with intellectual disability have epilepsy.[174] Not surprisingly there was a high prevalence of epilepsy in this sample (approximately 49% or 36 individuals).

Epilepsy is also noted as a common underlying cause of death for people with intellectual disability.[175] Sudden Death in Epilepsy (SUDEP) refers to a death without an obvious medical cause that happens unexpectedly and suddenly in an individual with a diagnosis of epilepsy. [176] In this sample, epilepsy was recorded as the underlying cause of death in approximately 10% of cases (7 individuals).

Management of epilepsy

The Panel found it difficult to ascertain whether the people in this sample with a diagnosis of epilepsy were getting access to the treatment, care and support they needed to manage their epilepsy.

In a number of cases, including in cases of severe epilepsy, the Panel deemed the people who died to have been administered sub-therapeutic dosages of their anticonvulsant medication. This highlighted the importance of people with epilepsy having access to a specialist neurologist for management and oversight of their epilepsy, including regular medication reviews.

It is also important for support staff who care for people with epilepsy to be vigilant about monitoring seizures in a consistent manner that enables comprehensive and useful information to be provided to the specialist/neurologist. There are a number of 'seizure diary' formats available,[177] including smart phone applications.[178]

People with intellectual disability are not only more likely to have adverse side effects from anti-convulsant medications,[179] but may also find it more difficult to report such side-effects. It is therefore important for support staff to be alert to changes in the person that may indicate negative side-effects, (e.g. behavioural changes), and to report this information to the person's specialist/neurologist. There are a number of tools available to assist support workers to prepare for a medical review appointment with the person with disability.[180]

Epilepsy management:

- Adults with a suspected seizure should be seen by a specialist in the diagnosis and management of epilepsy within two weeks.
- All adults diagnosed with epilepsy should have an agreed and comprehensive written care plan.
- Adults with a history of prolonged or repeated seizures should have an agreed written emergency care plan that provides guidance for support staff, carers or family members on how to administer emergency treatment.
- All adults with epilepsy should have an accessible point of contact with specialist services.
- All adults with epilepsy should have at least yearly reviews (or more regularly depending on how well their epilepsy is controlled).
- If seizures are not controlled in adults with epilepsy, or if there is treatment failure or side effects from their medication, they should be referred within 4 weeks to tertiary services for further assessment.

The presence of severe forms of epilepsy such as Lennox Gastaut Syndrome further raises expectations about the level of care that should be provided, including ongoing specialist attention and review. At least five people in the sample were recorded as having a diagnosis of Lennox Gastaut Syndrome, two of whom died due to aspiration/ aspiration pneumonia.[181]

As noted above, people with epilepsy are at a heightened risk of aspiration, and therefore a greater risk of developing aspiration pneumonia.[182]

The management of epilepsy should be a priority even when hospitalised for surgery or treatment for other medical issues. In one case a person was admitted to hospital for major surgery and his epilepsy medication was ceased despite having two seizures in hospital that were witnessed by staff.

Generally anti-epileptic medication should not be ceased on admission to hospital. Even if a patient is in receipt of palliative care, it is better to be seizure free. Medication can be given intravenously if necessary.

Case study: Epilepsy and hospital admission

A man in his 60's with intellectual disability and cerebral palsy and epilepsy was admitted to hospital for surgery. He had a diagnosis of epilepsy and a history of previous aspiration pneumonia. The surgery was carried out on the date of admission. His epilepsy medication was ceased upon admission although he was witnessed by staff to experience at least two seizures. He died in hospital two days after his surgery. The underlying cause of death was stated as pneumonia.[183]

Reducing the risk of SUDEP

Sudden Unexpected Death in Epilepsy (SUDEP) is the most common epilepsy-related cause of death, but the risk of SUDEP varies significantly across people with epilepsy,[184] tends to be underestimated by health practitioners,[185] and is often not raised by health practitioners in their interactions with the person, their support staff, or family.[186]

Significant action has been undertaken in the United Kingdom by the Department of Health, the National Institute for Health and Care Excellence (NICE), the Royal College of General Practitioners as well as non-Government organisations to raise awareness and educate health professionals, carers and persons with epilepsy about the condition and its management and, in particular, how to manage associated risks.[187]

Evidence-based checklists for the risks of SUDEP have also been developed.[188] An evidence-based checklist was utilised in the largest epidemiological study of SUDEP in England where it was found that in 90% of the deaths due to SUDEP there was an increase in seizure activity and/or intensity 3-6 months before death, and the presence of various modifiable risk factors 3-6 months prior to the person's deterioration accompanied by poor primary and tertiary health care.[189]

This points to the importance assessing risk factors for people with epilepsy to enable mitigation strategies and the incorporation of these strategies into a person-centred care plan. There are checklists[190] and other tools[191] that assist medical practitioners, support and care staff to undertake risk assessments of people with epilepsy and, where possible, reduce those risks.

Monitoring during the night for those at risk (with the use of seizure detection smart watches and/or pressure mattresses) is an effective prevention strategy.[192] If a monitoring system is used that can alert support staff to a seizure occurring, then support staff can immediately attend to the person, make sure their airways are clear, and position the person correctly.[193] Many easy to use monitoring systems are available.[194]

Risk factors for SUDEP:

- adolescent/young adults
- male gender
- early onset of epilepsy
- uncontrolled epilepsy
- duration of epilepsy (15-30 years)
- intellectual disability
- chronic epilepsy
- severe epilepsy
- tonic-clonic seizures (or grand mal seizures)
- seizures during sleep
- prone position
- treatment for depression
- use of numerous anti-epileptic medications
- non-compliance with medication
- reported alcohol problem
- no surveillance/monitoring at night
- unwitnessed seizures
- acquired epilepsy (e.g. head injury)
- Neurological disability or intellectual disability[195]

Case Studies: SUDEP

A woman in her 50's with Down syndrome and intellectual disability lived in a disability residential service. She had been diagnosed with epilepsy and had last experienced a seizure one month prior to her death, but it was noted that overall the rates of seizures were increasing. On the evening before she died she was put to bed as normal but when her carer checked on her in the morning it was found that she had died sometime during the night. The autopsy did not reveal a certain cause of death, but based on her medical history and condition the conclusion was that she had died due to sudden death in epilepsy.[196]

A man in his 30's with intellectual disability and autism lived in a disability residential service. He had a diagnosis of a severe form of epilepsy, and had been having frequent seizures. He was observed to have a seizure during the night and was settled back into bed. When his carer checked on him in the morning, it was found that he had died. The autopsy identified his death to be consistent with sudden death in epilepsy.[197]

Epilepsy – Summary of findings and recommendations

Given the prevalence of epilepsy in people with intellectual disability and cognitive impairment, it is important that staff/carers who support people with intellectual disability or cognitive impairment have the knowledge and skills to manage this condition.[198]

There are some easily implementable strategies that can be put in place for people with intellectual disability or cognitive impairment to reduce risk. If implemented, these strategies may mean that many people with epilepsy can be seizure free, and those with more severe forms of epilepsy can reduce their risks, including the risk of SUDEP.

Regular specialist input and review, together with education and training of health practitioners, carers and supporters in epilepsy management, monitoring and emergency care is critically important.

Recommendations: Epilepsy

- As part of a targeted education and information strategy, Queensland Health (in collaboration with QCIDD, Health and Hospital Services and expert practitioners) should publish guidelines for medical practitioners on the management of epilepsy that include:
  - A checklist for identifying risks for people with epilepsy;
  - Resources and guidance on how to discuss epilepsy and risks of SUDEP with the person, their carers and family members; and
  - The importance of continuing to manage epilepsy during any period of hospitalisation and how this can be achieved.
- Organisations that provide residential support to people with disability should work with general practitioners and specialists to ensure:
  - All people with epilepsy have a comprehensive epilepsy care plan;
  - A risk assessment is conducted of the person with epilepsy and all modifiable risks dealt with;
  - Seizures are accurately and comprehensively recorded in a seizure diary;
  - Monitoring aids, such as seizure detection smart watches and pressure mattresses, are used to alert support staff to the presence of a seizure;
  - People with epilepsy are monitored for any adverse side-effects from their medication;
  - People with epilepsy have at least annual access to specialist (neurologist) clinician (more often warranted by the severity of the epilepsy) and regular (six monthly) reviews of their epilepsy medication;
  - People with epilepsy should have someone who knows them well accompany them to appointments with their specialist, taking with them an accurate record of seizures and information about any side effects of medications;
  - Further specialist attention is sought as soon as possible if the epilepsy does not seem to be under control, if the seizures are worsening, or there is adverse effects from medication;
  - Staff are trained in the proper administration of medication for epilepsy; and
  - There is clear guidance available to support workers, as well as training in administering emergency care to people with epilepsy.

3.1.3 Deaths caused by circulatory system diseases

Prevalence of circulatory system diseases as underlying cause of death

Circulatory system diseases, in particular Ischaemic heart disease, has been found by this and other systemic studies of deaths of people with disability in residential care to be a leading underlying cause of death.[199] In the general population, circulatory system diseases are one of the leading underlying causes of death, accounting for 30% of deaths.[200]

Diseases of the circulatory system were the second most common underlying cause of death in this sample with 22% (16 individuals) dying due to circulatory system diseases, notably Ischaemic heart disease (8 individuals), other forms of heart disease (5 individuals), deep vein thrombosis (2 individuals), and pulmonary heart disease (1 individual).

Risk factors for Ischaemic Heart Disease

While remaining a leading cause of death, coronary heart disease mortality has declined in Australia over the past three decades driven by improved chances of survival after a heart attack and improvements to medical and surgical treatment, and also by the reduction in risk factors such as smoking, high blood cholesterol and high blood pressure.[201]

Such declines, however, are not evenly distributed across population groups, with a widening gap reported in the mortality decline between people from the highest and lowest socioeconomic status groups.[202] Mortality rates also remain high for Indigenous Australians.[203]

A number of risk factors, in particular risk factors that could have been modified with lifestyle changes and support, were present for some of the people in the sample who died due to Ischaemic heart disease.

In a number of cases, for example, the presence of obesity or morbid obesity was noted alongside the person having died due to heart disease or having been noted as having heart disease as a significant health condition. This raises concerns about the extent to which lifestyle issues such as diet, exercise and smoking are being attended to.

Risk factors for Ischaemic heart disease:

- physical inactivity
- smoking
- obesity
- high blood pressure
- risky alcohol consumption
- low vegetable consumption
- low fruit consumption
- diabetes[204]

Case Studies: Death due to heart disease

A young man with a cognitive impairment and autism lived in a disability residential service. At only 26 years of age he already had a history of high cholesterol and high blood pressure, and was obese. He was also being administered psychotropic medication (risperidone). He died due to a heart attack caused by coronary artery disease.[205]

A man in his 40’s with an acquired brain injury, epilepsy and obesity lived in a disability residential service with other residents receiving 24 hours a day support. Upon his death, the autopsy found him to have significant coronary artery disease (with a significant build-up of fatty material in the walls of his arteries) as well as an enlarged heart with significant cardiac dilation (an indication that his heart was under stress), physical changes that went undiagnosed until his death. It was found he died due to dilated cardiomyopathy.[206]

Health risk behaviours

Not only are the lifestyle issues identified above risk factors for coronary heart disease, but also for some cancers[207] as well as general ill health. It is therefore important for residential services that support people with disability to address health risk behaviours such as lack of exercise, obesity, smoking and poor diet for all people with disability and not just those with diagnosed heart disease.

There has been increasing concern about the presence of obesity and other health risk factors in people with intellectual disability,[208] with research indicating a high prevalence of obesity in adults with intellectual disability.[209] Low levels of physical exercise[210] is a particularly significant contributing factor along with poor diet.[211]

Case Study: Lifestyle risk factors

A man in his 30's with intellectual disability, epilepsy and mental illness lived in a private residence with drop in support provided by a funded non-government organisation. He had significant health issues including hypothyroidism, a peptic ulcer, ulcerative colitis and sleep apnoea. He was also obese, smoked and was taking a large number of psychotropic medications. On the night before he died, his support worker had taken him to a fast food restaurant for his dinner then stopped and had a smoke with him before putting him to bed. When he was checked on in the morning he was found deceased. The Coroner found he had died due to a seizure. [212]

Encouraging healthy eating patterns and physical exercise among residents of disability services should be a priority for health practitioners and support workers and is arguably part of their duty of care to people who are often dependent on them for their support and care overall.

The 'Walk and Talk' program developed by QCIDD and a non-profit disability support organisation encourages physical activity in adults with intellectual disability and social interactions with others while they exercise.[213]

Other successful programs involve multiple strategies including twice weekly education and exercise programs to increase knowledge, skills and self-efficacy regarding health, nutrition and fitness among adults with intellectual disability who were provided with peer mentors.[214]

Some programs reported barriers to interventions, including residents who do not have control over their diets being fed calorie-laden foods or having unhealthy fast foods purchase for them by support workers. It is therefore important that healthy living and eating initiatives are actively mandated and supported at an organisational level.[215]

Tips to support a person with obesity:

- arrange a health check with their medical practitioner to determine if there may be any underlying health causes for their obesity
- organise a dietician to provide advice on the kinds of food they should be eating to reduce their weight
- see a specialist fitness trainer who can advise on the types of exercises they can do and build these exercises into their daily routine
- organise fun and entertaining opportunities for exercise, like the walk and talk program.

Treatment of congenital heart disease

Four people in the sample were identified as having congenital heart disease (that is, a heart defect present at birth). Of those, three were diagnosed with ventricular septal defects (or holes in the heart) and all three had Down syndrome. All three also had concurrent respiratory chest infections at the time of their death and at least two had a recent history of recurrent bouts of pneumonia.

There is a high prevalence of congenital heart defects in people with Down syndrome (reported to affect anywhere between 40-60% of children born with Down syndrome).[216] While, in the past, it was the usual practice not to treat children or adults with Down syndrome for their heart defects,[217] changing attitudes as well as greater prospect of treatment success[218] has promoted improved treatment outcomes.

Radical increases in the life expectancy for people with Down syndrome have also been reported,[219] with one of the contributing factors believed to be provision of cardiac surgery for children with Down syndrome in circumstances where it may not have previously been provided.[220]

While congenital heart defects can be diagnosed early with routine screening (even prior to birth), so that appropriate care and treatment can be planned,[221] not all heart defects are diagnosed early or treated. This may particularly be the case for older or middle aged individuals with Down syndrome currently living in residential care who may have been born at a time prior to advanced treatments being offered. Left untreated, congenital heart disease (including ventricular septal defect) can lead to complications such as:

- repeated problems with respiratory infections including pneumonia;
- heart failure;
- high blood pressure (Pulmonary hypertension);
- pulmonary embolism; or
- bacterial endocarditis (a serious infection of the lining of the heart).[222]

Even people whose ventricular septal defects were repaired as children may have a lifelong risk of other heart problems.[223] It is therefore important for all people with congenital heart disease to receive specialist care from a cardiologist.

Case study: Congenital heart disease

A man in his 40’s with Down syndrome who lived in a disability residential service died due to pneumonia. He had been diagnosed with a congenital heart disease (a ventricular septal defect or a ‘hole in the heart’) and had a previous incident of cardiac arrest. He had a history of recurrent pneumonia, previously receiving intensive care for ‘double pneumonia’ earlier in the year. After developing a cough, he was prescribed antibiotics by his GP. He continued to deteriorate and was taken to hospital where he was again diagnosed with ‘double pneumonia’ and, despite intensive care treatment, suffered a number of cardiac arrests and died.[224]

Circulatory system diseases – Summary of findings and recommendations

A number of modifiable risk factors were found in individuals whose cause of death was due to heart disease, in particular the presence of obesity, poor diets and smoking.

It is important that organisations work with health practitioners to address the lifestyle issues that can put people at disability at high risk of heart disease.

People with congenital heart disease also need specialist attention from a cardiologist. Untreated congenital heart defects can put people at risk of a range of other life threatening conditions. Specialist reviews are also required for those born with a heart defects, even if corrected in their early years.

Recommendations: Circulatory System Diseases

- People with disability in residential care must be supported to make informed lifestyle choices by ensuring information is available in accessible formats and training staff to promote and actively support healthy lifestyle habits, including assistance to maintain healthy diets; engage in physical activity and exercise; and reduce/stop smoking.
- Further strategies may include:
    - engagement of dieticians to monitor the Body Mass Index of residents and develop healthy eating plans; and
    - active engagement in exercise programs, such as the walk and talk program.
- Service organisations should develop and maintain strategies to improve the health and wellbeing of support workers so that they can model healthy lifestyle behaviours and strategies.
- People with disability who have congenital heart disease (including those who had defects corrected as children) should have access to specialist cardiologist treatment.
- They should also have regular medication reviews, particularly when being administered psychotropic medications given that this can also be a risk factor for cardiovascular disease. Monitoring and review regimes should be scheduled for every 3-6 months.
- Decisions about treatment of congenital heart disease in people with disability, including advance care planning, should be based on transparent criteria with the individual patient's own needs and interests being given primacy in the decision-making process.

3.1.4 Deaths caused by choking/food asphyxia

The underlying cause of death for six people in the sample was accidental threats to breathing, specifically food bolus asphyxia or choking (five people) and aspiration of vomit (one person).

Of the five people who died due to choking on food or food asphyxia, in three cases the person had a previous swallowing assessment and a mealtime management plan developed. For all three, the choking incident occurred during mealtime at the disability residential service.

Choking and food aspiration has also been identified as a significant underlying cause of death in other systemic studies of deaths of people with disability in residential care.[225]

Identification of swallowing difficulties

As discussed in section 3.1.1 on respiratory diseases, many people with intellectual disability, and people with cerebral palsy, may have difficulties with eating, drinking and swallowing.

Because adults with intellectual disability or cognitive impairment may not be able to communicate difficulties with swallowing, support staff and health care providers need to be alert to the behavioural changes that may indicate a deterioration in their swallowing abilities such as:

- Increased coughing during meals;
- Increased congestion, especially if associated with feeding;
- Refusal to self-feed;
- Self-restriction of selected food textures;
- Sudden or gradual weight loss;
- Increased duration of meals; or
- Anorexia.[226]

Along with those risk factors identified in section 3.1.1, these signs and symptoms should be considered in assessing the risk of eating, drinking and swallowing difficulties.

If not identified, these difficulties can place people at risk of a range of health problems including food aspiration (leading to respiratory disease) and death due to choking or food bolus aspiration. People with disability at risk of dysphagia, or who have problems with eating, drinking and swallowing should be assessed by a qualified health professional.

The importance of complying with mealtime management plans and supervision

A number of people in the sample had identified eating and swallowing difficulties (including behavioural difficulties associated with eating). In a number of cases, although these difficulties had been appropriately identified, assessments carried out and mealtime management plans prepared, sometimes these plans were either not strictly followed or people had periods of non-supervision during mealtimes.

While assessments of swallowing/eating difficulties and the development of mealtime management plans are usually done by speech and language therapists, the implementation of mealtime management plans is highly reliant on family/carers and support staff. Carers and support staff must be aware of their important role in implementing and complying with mealtime management plans and the risks of not doing so.

Central to mealtime management plans will be strategies related to positioning the person while eating, preparing and providing food of correct consistencies, and supervision, prompting and supporting the person while eating.[227]

Studies have found that non-compliance with mealtime management plans may be due to staff turnover or a lack of training and skills in respect of implementing the plans. In addition, they can be due to errors and omissions in applying the plan, such as not prompting a person to slow down when they are eating and drinking independently, incorrect positioning, or incorrect food preparation (e.g. food consistency).[228]

Lack of compliance may also be influenced by poor staff to client ratios particularly during mealtimes, as well as time and resource constraints more generally.[229] In addition, support staff may feel that mealtime management plans are potentially inconsistent with service philosophy around maximising a person's choice and control over what they eat and how they eat.[230]

Case Studies: Choking and supervision by staff

A man in his 40's with intellectual disability lived in a disability residential service. He had been assessed by a speech therapist and a mealtime management plan had been prepared for him setting out the consistency of foods and fluids that he could consume safely, as well as strategies to support him at mealtime. This comprised having soft food cut up into very small pieces and given to him gradually. On a particular day he was provided with a piece of cake to eat. He started choking, lost consciousness and later died in hospital.[231]

A man in his 40's with intellectual disability lived in a disability residential service. He had numerous previous episodes of choking on food. In response to these repeated episodes of choking, he was assessed by a speech pathologist who confirmed his tendency to eat food too quickly. His mealtime management plan recommended soft textured food, cut into small pieces. It also advised close monitoring at mealtimes, encouragement to slow down while eating, and fluids in between each mouthful. On one particular day, residents were having an early lunch and the man was left unattended for a short time whereupon he put a sausage into his mouth and started choking. He died later in hospital without regaining consciousness.[232]

A man in his 60's with an acquired brain injury lived in a disability residential service. He had been assessed by a speech pathologist who recommended a soft food diet (moist food cut into small pieces) and particular positioning for eating. Despite multiple assessments with similar directions reinforced, he continued to have choking incidents, some resulting in the ambulance attending. On the day he died, he was provided with a burger and chips for his lunch after which he began choking. The ambulance was called but he could not be resuscitated.[233]

Caregiver compliance with mealtime management plans may be increased by training and education in:

- Preparing food and drinks to correct consistency;
- Techniques of correct positioning, prompting and pacing during meals;
- The importance of working alongside health professionals (e.g. speech therapists) in developing and implementing plans;
- The importance of close supervision; and
- The risks of non-compliance with plans.[234]

Compliance with mealtime management plans may also be increased if accessible information is made available to people with disability about the reasons for having diet and eating strategies that may differ to others with whom they reside.[235] This may also support more informed choices about compliance with mealtime management plans.

Health professionals who prepare mealtime management plans must alert service organisations to any potential resourcing impacts in implementing plans. Further, they must work with organisations to develop solutions, such as increasing the staff to client ratio at mealtimes or only using specifically trained staff to carry out certain tasks.[236]

Choking/food asphyxia – Summary of findings and recommendations

Some people with intellectual or cognitive disability (or cerebral palsy) may be at heightened risk of eating, drinking and swallowing disorders or dysphagia.

Failure to recognise and address these risks can have serious and life threatening health consequences including respiratory disease, poor nutritional status, choking, and aspiration.

While health professionals, in particular speech therapists, are typically responsible for the assessment and development of mealtime management plans, carers and support staff are primarily responsible for their implementation.

Carers and support staff must be adequately trained in the implementation of such plans and understand the risks of non-compliance.

Recommendations: Choking

- ❖ People with disability in residential care who are at risk of dysphagia, or showing signs and symptoms of dysphagia, should be assessed by qualified health professionals.
- ❖ Support staff and carers must be provided with training and education on the identification of potential eating, drinking and swallowing problems and the importance of comprehensively implementing mealtime management plans including:
  - Preparing food and drinks to the correct consistency;
  - Techniques of correct positioning, prompting and pacing during meals;

  - The importance of working alongside health professionals (e.g. speech therapists) in developing and implementing plans;
  - The importance of close supervision during mealtime; and
  - The risks of non-compliance with plans.
- ❖ Health professionals who develop mealtime management plans should discuss the implications of the plans with service organisations and ensure appropriate consideration for:
  - Resource and rostering issues;
  - Education and training; and
  - Potential risks of not following mealtime management plans.
- ❖ People with disability who are subject to mealtime management plans should be provided with accessible information about their plan to support understanding of and compliance with plans.
- ❖ Support staff and carers must be provided with training, including first aid training to respond promptly and confidently to critical incidents including choking and aspiration.

3.1.5 Deaths caused by neoplasms/cancer

Cancers or neoplasms were the underlying cause of death in approximately 10% of individuals in the sample. Seven people died due to cancer, with the leading type cancer of the digestive organs (three people). Other types of cancer included thyroid cancer, brain cancer, lung cancer and cancer of unknown origin.

In the general population, neoplasms/cancer is the underlying cause of death in approximately 30% of cases.[237]

Preventing cancer

Recent research confirms the role that lifestyle issues such as smoking, sun exposure, body weight, poor diet and exercise play in preventing cancer.[238]

About one-third of cancers in the general Australian population are attributable to modifiable risk factors and could be preventable (particularly by targeting issues such as smoking, diet, alcohol and sun exposure).[239]

Addressing lifestyle risks in people with disability in residential care were discussed in detail in part 3.1.3 in relation to preventing Ischaemic Heart Disease.

The importance of encouraging healthy eating patterns, exercise and addressing other lifestyle issues such as smoking and alcohol consumption was emphasised with respect to people with intellectual disability and cognitive impairment living in residential services.

Modifiable risk factors for preventing cancer:

- smoking
- being overweight/obese
- alcohol consumption
- inadequate fibre intake
- inadequate fruit intake
- inadequate vegetable intake
- red and processed meat consumption
- physical inactivity
- sun exposure.[240]

Case study: Lifestyle and preventative health

A man in his 50's lived in a level three accredited residential service. After suffering a stroke he had acquired a brain injury and went to live with his ageing father. He moved into the level three accredited residential service when his father could no longer care for him. He was described as a heavy smoker and a heavy drinker. He also had a history of hypertension and a number of complex medical problems. After suffering deteriorating ill health for some time, he was diagnosed with advanced pancreatic cancer and died three months later.[241]

Time from diagnosis to death – Screening and diagnosis of cancer

In a number of people in the sample there was a quite short time period between the diagnosis of cancer and death and, in one case, the diagnosis of cancer did not occur until autopsy.

Given many people with intellectual disability or cognitive impairment may have difficulty communicating changes in their health, it is important that carers and support staff are trained to be alert to changes in a person's behaviour or health and support them to seek medical advice.

It is also important that people with disability participate in screening programs that are appropriate to their age and the presence of any risk factors such as family history.

Case Studies: Time from diagnosis to death

A woman in her 40's with intellectual disability and Down syndrome lived in a disability residential service. She had suffered from general ill health associated with what was thought to be asthma for some time. Due to deterioration of her symptoms including laboured breathing an X-ray was carried out. Malignant tumours were discovered on her trachea, lymph nodes and chest. She died two days later.[242]

A man in his 30's with cognitive impairment and mental illness lived in a level three accredited residential service. He was described as being morbidly obese and suffering from a range of health problems including heart disease, osteoarthritis, gastro-oesophageal reflux disease and asthma. He was found deceased at his residence. An autopsy revealed he died due to a tumour of the brain.[243]

Neoplasms/cancer – Summary of findings and recommendations

In summary, addressing the modifiable risks for cancer (as well as other lifestyle related disease) associated with diet, exercise and smoking is important for people with intellectual and cognitive disability who are often dependent on others for their care. The importance of supporting people to access screening programs appropriate to age and/or risk must also be recognised.

The development of accessible information for people with disability about the risks they face to their health from poor diet, smoking and lack of exercise could assist support workers and carers in addressing this issue.

Recommendations: Neoplasms/Cancer

- Modifiable risks for cancer such as diet, exercise, smoking and alcohol consumption should be addressed by active interventions for people with disability living in residential care.
- Staff should be trained to ensure awareness of behavioural and other health changes that warrant seeking medical advice.
- People with disability in residential care should have access to screening programs appropriate to their age and other risk factors.

3.1.6 Use of psychotropic medication

Of significant concern in this study was the high number of people with disability being administered psychotropic medication, particularly given that, based on available information, few seemed to have a concurrent diagnosis of mental illness.

Of the total sample (73 cases), 36 people (49%) were being administered psychotropic medication. Polypharmacy (the use of multiple medications) was common. Of those individuals being administered psychotropic medication, most were taking between two to four different medications. The average number of psychotropic medications administered per individual was 3.2. Eight people were being administered five or more different psychotropic medications.

The most common types of psychotropic medications administered were anti-convulsant[244] medications (21 people) and anxiolytics[245] (20 people), followed by antipsychotics[246] (13 people) and anti-depressants[247] (11 people). Of the 13 individuals administered antipsychotic medication, the majority (85%) were administered second generation (atypical) types.

Use of psychotropic medication in people with intellectual disability

Over the past 20 years it has become well known that there is a high use of psychotropic medication in people with intellectual disability or cognitive impairment, including polypharmacy.[248]

An Australian study of adults with intellectual disability living in community settings found that, of the 117 participants, 35% were being administered psychotropic medications, most commonly antipsychotics and anti-convulsants.[249]

Psychotropic medications are often used in individuals who display what are known as “challenging behaviours” or “behaviours of concern”, that is behaviours that cause, or present a risk of, harm to the person or others. The efficacy associated with using such medications to reduce these behaviours is not clear, particularly in the absence of a diagnosed mental illness.[250]

Studies have shown positive results for the withdrawal of psychotropic medications used for behavioural purposes when alternative strategies such as behavioural assessments and interventions and environmental changes.[251] It is critical that psychotropic medication is not used in lieu of professional assessment and behavioural interventions for people with disability and challenging behaviours.

In Queensland, if medication is used to control a person’s behaviour and the person accesses funded disability services, it is considered chemical restraint and authority must be sought from a guardian appointed by the Queensland Civil and Administrative Tribunal (QCAT).[252]

Further, the *Disability Services Act 2006* requires the person to be assessed by an appropriately qualified person and a positive behaviour support plan prepared, focused on using more positive strategies to reduce and eliminate the need for such restraints over time.[253]

Health risks associated with use of psychotropic medication

A number of negative side effects are associated with the use of psychotropic medication, including weight gain, sedation and drowsiness, tachycardia (a faster than normal heart rate), tardive dyskinesia (or involuntary movements), tardive dystonia (involuntary muscle contractions), and a range of other potentially serious health risks. [254] The use of multiple medications increases the risks of adverse reactions and interactions.

As discussed earlier in this report, the use of psychotropic medication can also lead to swallowing and eating problems in people with intellectual disability or cognitive impairment, and potentially exacerbate existing problems.[255]

For example, the use of antipsychotic medication can result in symptoms such as a dry mouth and sedation that can exacerbate swallowing problems and lead to aspiration and aspiration pneumonia.[256]

A high incidence of deep vein thrombosis (including as a cause of death) has also been identified in people being administered antipsychotic medication.[257] It is important that health practitioners are aware of the possible relationship between the use of such medication and deep vein thrombosis and the dangers of pulmonary embolism.

The use of multiple psychotropic medications was noted in a number of cases of death in the sample where death was noted as being due to deep vein thrombosis and aspiration pneumonia.

Case studies: Use of psychotropic medication

A woman in her 60's with intellectual disability living in a disability residential service died due to pneumonia. Her files indicated that she had been administered 'anti-convulsant' medication since she was 12 years old but there was no indication that she had a diagnosis of epilepsy or any mention of when she might have last suffered a seizure. She had a history of recurrent episodes of pneumonia.[258]

A young woman with intellectual disability living in a disability residential service was administered a range of psychotropic medications to control her aggressive and self-harming behaviour despite no diagnosis of mental illness. She was taking anti-depressant medication as well as two different types of sedatives, one being a strong sedative used in treating psychosis. One of her medications was noted to be a first generation or typical antipsychotic medication. She reported to staff that her medications were making her feel tired, dizzy and anxious and she was also experiencing tremors. She was also described as morbidly obese. She died suddenly of a pulmonary embolism as a result of a bilateral deep vein thrombosis.[259]

A woman in her 30's with intellectual impairment living in a disability residential service had a history of recurrent pneumonia. She was prescribed a number of psychotropic medications, which it was reported were making her feel drowsy and sedated. She had been identified as having swallowing difficulties (dysphagia) and assessed by a speech pathologist. Following an incident of aspiration she contracted another bout of pneumonia but died when she did not respond to treatment on that occasion.[260]

A man in his 60's with intellectual disability was living in a disability residential service. He had been diagnosed with anxiety and depression and was being administered a range of psychotropic medications including Olanzapine, used for the treatment of schizophrenia and bipolar disorder. He died suddenly at the service and an autopsy revealed his death was due to a pulmonary embolism as a result of deep vein thrombosis.[261]

Use of psychotropic medication – Summary of findings and recommendations

Similar to other systemic studies, and as found in literature, there appeared to be a high use of psychotropic medication in the people in the sample. The use of medication for behaviour control brings with it legal issues for funded disability services, and support staff and health practitioners must be alert to the need to obtain appropriate authority, usually from a guardian appointed for restrictive practices. Further, the efficacy of the use of such medication in lieu of or in the absence of appropriate support, behavioural interventions and environmental changes is not clear.

Regardless of the reason for using psychotropic medication, it is important for people with disability to have their medication reviewed regularly (at least every three months), given the risks of adverse side effects, including serious health consequences.[262]

Given that many people with disability are administered multiple psychotropic medications, this review should be conducted by a specialist pharmacist or psychiatrist who can give consideration to the interactions that may exist between multiple medications.

Recommendations: Psychotropic medication

- Service organisations should prioritise comprehensive reviews of all people with disability being administered psychotropic medications, including medications used for behaviour management. As part of this review, attention should be given to ensuring that identified individuals are having a regular (e.g. three monthly) reviews of their medication and that risk assessments have been undertaken in relation to adverse side effects and contra-indications. Further, it should seek to confirm that individuals being administered multiple medications are regularly reviewed by a specialist pharmacist or psychiatrist.
- Service organisations should develop policies to ensure timely physical health, behaviour and mental health assessments are provided to people with intellectual disability being administered psychotropic medication.
- As part of a targeted education and information strategy, Queensland Health (in collaboration with QCIDD, Health and Hospital Services and expert practitioners) should develop and issue guidelines for health practitioners on the use of psychotropic medications for people with intellectual disability and cognitive impairment. The guidelines should address both the dangers of, and potential lack of efficacy in, using these medications for behaviour control, as well as guidance in relation to dosage and monitoring. The guidelines should promote regular reviews as well as adherence to standard pharmacy practices and procedures with active discouragement of ‘off-licence’ use of such medications for people with disability.

3.1.7 Chronic constipation

In a number of sections of this report, lifestyle issues such as diet and exercise have been discussed in the context of vulnerability to certain conditions (e.g. circulatory system diseases) and cancers.

Sedentary behaviours and poor diet can also lead to constipation, and a number of the people in this study were reported to have chronic and severe constipation. The use of medications such as psychotropic medications can also lead to chronic constipation.[263]

Chronic constipation is a potentially disabling and painful condition that can cause urinary and faecal incontinence, chronic nausea, rectal prolapse, anal fissures and haemorrhoids.[264] Hospitalisation may sometimes be needed for faecal impaction.[265]

One of the dangers of long-term and chronic constipation is the development of a 'floppy bowel' and the potentially fatal condition of a sigmoid volvulus (involving a blockage of the bowel, where a loop of the bowel - which may be stretched due to chronic constipation – twists, creating a blockage).

While people with intellectual and cognitive disabilities are prone to constipation for the reasons described above, they may not be able to communicate the typical symptoms to health practitioners, carers and supporters. Therefore it is very important that symptoms of chronic constipation are known by carers and that medical attention is sought for the management of this painful and potentially life threatening condition.

Case Study: Sigmoid volvulus due to chronic constipation

A man in his 50's with cerebral palsy lived in a disability residential service. He had a history of chronic constipation and had been experiencing consistent weight loss and vomiting. He attended an appointment with his GP who ordered a CT Scan, which indicated a blockage in the bowel and he was transported to the hospital by ambulance. He died later that day.[266]

To prevent constipation:

- For people who have difficulty with communication keep a bowel chart
- Contact the person's medical practitioner if they have not had a bowel movement in more than three days
- Provide a high fibre diet
- Encourage the person to drink lots of fluids, including warm soups
- Encourage the person to exercise daily and lead an active life
- Set aside time for a bowel motion after breakfast where the person does not have to rush
- Do not ignore the urge to have a bowel movement
- If constipation persists seek medical advice
- Seek urgent medical advice where a person has a history of constipation and has stopped eating, is nauseous and or vomiting or is complaining of pain.[267]

Recommendations: Constipation

- ❖ Carers and support staff should be informed about the signs and symptoms of chronic constipation (as well as the risks associated with chronic constipation) and actively seek medical advice and intervention. Where chronic constipation is a concern, appropriate tools (e.g. Bowel charts) must be used to monitor daily bowel motions.
- ❖ Health practitioners should be alert to the possibility of chronic constipation in patients with intellectual and cognitive disabilities who may not be able to describe the typical symptoms but may be experiencing behavioural changes, changes to sleeping patterns, refusal to eat, weight loss, nausea and vomiting.

3.2 Issues with the provision of general health care and support

This section discusses the issues that were identified in analysing the 73 cases of people with disability who died while in residential care in respect of the delivery of health and disability services to people with intellectual or cognitive impairment.

Some of the key areas in delivering health and disability services that require reform to better meet the health care and disability needs of people with disability living in residential services and to reduce the number of preventable deaths are presented on the following pages.

Many of the recommendations are aimed at not only promoting the need for better accommodation by health and disability services in responding to the needs of people with disability, but also the need for enhanced coordination and integration between disability and health services.

3.2.1 Access to health care

Regular check-ups and annual reviews

Due to the lack of information available, there was little evidence to confirm whether people in this sample (many of whom had multiple serious and complex health conditions) were having regular health checks from their general practitioner or annual health reviews utilising the Comprehensive Health Assessment Program (CHAP).

It is important that people with disability have regular check-ups with their general practitioner. Many people with disability who live in residential care environments have multiple and sometimes serious health conditions. In addition, many people with intellectual or cognitive disability may have difficulties communicating when they are ill or understanding the significance of symptoms that they may be experiencing.[268]

Comprehensive annual health reviews provide an opportunity to detect, treat and prevent emerging health conditions arising in people with disability, and/or address health risks, rather than waiting to treat health conditions that have become acute, chronic or advanced.[269]

Annual health reviews can also provide base-line information about a person's health, which can be compared from year to year to identify changes that may not otherwise be recognised, particularly when carers who see the person each day (or regularly) may not notice slow or incremental changes in health.[270] These reviews also provide an opportunity to enhance support worker and organisational knowledge and enhance their skills and confidence in dealing with day-to-day health issues.[271]

Health checks have been found to lead to the detection of both less serious conditions as well as those that might be considered serious and life threatening such as previously undetected heart disease,[272] hypertension,[273] cancer[274] and epilepsy.[275] They are also cost effective in that they can identify new and underlying medical conditions in a timely manner, which may mitigate the need for more expensive treatments.[276]

An Australian trial found that comprehensive health assessments by GPs not only led to improved health outcomes for people with disability but also that there was no significant difference in government costs for medical and pharmaceutical services between those who did and did not receive the health check. [277]

The Comprehensive Health Assessment Program

The CHAP was developed by QCIDD. In 2007, it was included as a Medicare Benefits Schedule item number.[278]

As a Medicare funded (bulk-billed) item, a GP is funded to obtain an extensive and thorough history of the person's health issues, conduct a full health check in a comprehensive way and review health issues that are common for many people with intellectual or cognitive disability.[279] A questionnaire must be completed prior to the GP visit to document the person's health history and provide the GP with prompts and guidelines in respect of health issues for people with disability.

Getting prepared for a CHAP review:

- Book a longer appointment time with the person's general practitioner
- Tell the general practitioner the person needs a comprehensive health assessment
- Download the CHAP document and complete the first part of the document (questions 1-24)[280]
- Ensure the support worker attending the appointment is someone who knows the person well
- Prepare the person for what will happen at the visit
- Prepare a list of questions that you may want the doctor to answer
- Remember to bring all the correct paper work including the CHAP document, the person's health records, including any personal hand held health record
- Take the person's current medications to the appointment.[281]

After the CHAP appointment:

- Complete the Action Plan attached to the CHAP document at the end of the visit
- Document any other results of the visit
- Keep the Action Plan and other documentation with the person's client file/ record and any personal hand held health record they might have
- Make sure all others involved in their care are aware of these documents, while also respecting the person's confidentiality
- Use team meetings, staff meetings and communication books to pass on important information about the person's health
- Put a date in their file for any follow up visits that need to occur and when their next annual review is due
- Ensure there is one person in the organisation who is responsible for collecting and maintaining all the person's health information.[282]

Deinstitutionalisation and service transition

Research has indicated that deinstitutionalisation of people with disability (moving from large intuitions to community living), and transition from one type of care to another, can make people with disability vulnerable to inadequate health care.[283] Changes in residences, support workers and carers risk reductions in care, often due to a lack of knowledge transfer. This can arise when new staff do not have sufficient knowledge of the person and their needs, and/or from communication difficulties (both ways) and inadequate health records being transferred.[284]

Over the next few years, it is likely that a number of people will transition out of large institutional environments into community living, or transition to different service arrangements in the course of becoming NDIS participants.

To alert current and new service providers to health issues that require attention and to provide baseline information that can be used to monitor changes in health, important for people with disability should be supported to access health care reviews prior to their transition. The results of such reviews must be recorded in organisational files and also in health records held by the person.

Specialist care

It is important for people with disability living in residential care to have access to the specialist medical attention and review that they need.

Many people in the sample had serious health conditions, most commonly heart disease, epilepsy, and recurrent respiratory disease (mostly recurrent pneumonia). To support optimal health outcomes, people need specialist medical attention and review.

In many cases, people with serious and chronic health conditions will also be administered a large range of medications. In these circumstances, specialist pharmacological review is also required to identify and resolve any possible negative interactions that could be occurring as a result of multiple prescriptions.

Making access to health treatment a priority

At times, visits to a medical practitioner or specialist can be difficult, particularly when there exists practical or behavioural issues associated with a person's disability.

A number of cases in this study reported delays in a person's planned visit to a medical practitioner due to lack of staffing resources or other issues that impacted on the scheduled appointment. Where a person lives in shared accommodation with other people with disability and there is a low staff to client ratio, extra staffing and resources may be required to enable a visit to a medical practitioner. In one of the cases studied, despite the person's deteriorating ill health, two previous doctor's appointments had not been kept, although the reasons for this were not clear.

Case study: Making health a priority

A woman in her 30's with epilepsy lived in a disability residential service. The staff at her service had noted that over the past several months there were signs that her health and wellbeing were deteriorating. She was sleeping more than usual, which was leading to decreasing mobility and she was having more falls than usual. A number of medical appointments had been made for her but the records state that they 'were unable to be kept' although the reason for this was not clear. She was put to bed as usual one night and when her carer checked on her in the morning it was found that she had died sometime during the night.[285]

Access to health services must be a priority for people with disability. Specialist behaviour support may be of value for those who get anxious and agitated when they have to visit a doctor or hospital.

Telehealth services

In some circumstances it may be possible to arrange a home visit or a telephone visit or video-conferencing via Telehealth.

At present Telehealth is only funded by Medicare for eligible areas outside of major cities, although residents of Aged Care Facilities or Aboriginal Medical Services or Community Controlled Health Services are exempt from these geographical requirements.[286] In order to provide adequate and appropriate health services, residents of disability residential services should also be exempt and able to access funded Telehealth services.

Access to health care – Summary of findings and recommendations

People with intellectual or cognitive disability often experience multiple serious health conditions. Alongside this exists many barriers that may prevent them from receiving the health care that they need, including both primary and specialist health care.

In many cases this may be due to difficulties in communicating health issues, including understanding the significance of any symptoms they might be experiencing. This is why regular check-ups and annual comprehensive health reviews are so important. Further, disability service providers must prioritise the allocation of resources (including extra staff and specialist behavioural support) that might be necessary to enable this to occur.

Health practitioners also need to be aware of common health issues for people with intellectual or cognitive disability. Although progress is evident, access to high quality integrated primary health care remains elusive for many people with disability.

The transition to the NDIS presents an opportunity to facilitate good quality, preventative and integrated health care for people with disability.

All people with disability should have comprehensive health assessments prior to becoming NDIS participants to identify health needs and issues and provide a baseline of health information before they commence new service arrangements.

Recommendations: Access to Health Care

- People with disability should have access to regular check-ups by their general practitioner and dentist, including annual CHAP reviews.
- A CHAP review should be conducted prior to transition to the NDIS for all people with disability.
- People with disability should have access to appropriate specialist medical care and reviews relevant and appropriate to the management and monitoring of any conditions they may have such as epilepsy, chronic respiratory disease and heart disease.
- Queensland Health should lead the development of a *Framework to Improve the Health of People with Intellectual or Cognitive Impairment* that aims to:
    - Promote better understanding of the health needs of people with intellectual or cognitive impairment;
    - Improve the quality, accessibility and integration of services needed to meet the health care needs of people with intellectual or cognitive impairment; and
    - Improve coordination between disability services and health care services.

- Health and Hospital Services should be required to report on the implementation of the framework.
- Health and Hospital Services should work to develop local, regional and state-wide networks of health practitioners with disability-specific knowledge and expertise (including clinical nurse consultants, allied health professionals, psychiatrists, physicians, general practitioners, dentists, etc.) to provide clinical leadership and enhance the provision and coordination of services.
- Resources and support should be made available to enable people with disability in residential care to access medical appointments, including specialist appointments as necessary. This may mean, for example, rostering on extra support staff or seeking specialist behavioural support.
- An exemption from the need to live in a certain geographical area to be eligible for funded Telehealth services should be extended to people with disability living in residential support services.

3.2.2 Identifying serious health conditions and responding to critical incidents

Identifying and responding to signs of deteriorating health

Undetected or undiagnosed serious illness in the sample was prevalent. In many cases, the person's death was due to a serious health condition that went undiagnosed until either just before, or sometimes following, their death.

Of the 24 people who died due to influenza or pneumonia in the sample, for example, six of those people were not diagnosed with the illness until after their death. A further four died within 24 hours of their diagnosis and a further four within one to three days of their diagnosis.

Where a person has difficulties with communication or cannot communicate verbally, support staff must be alert to signs of illness (such as coughing, sweating, vomiting and shortness of breath) and the potentially serious nature of these symptoms and other signs of illness (such as behavioural changes).

Behavioural changes (such as refusal to eat or drink) should also prompt further investigations including (at a minimum) taking of basic observations (including temperature, pulse, and heart rate) which are relatively easy and non-invasive procedures.

These cases indicate the importance of:

- Support staff being aware of the signs of serious illness ('red flags');
- Support staff carrying out basic observations of the person (including temperature, pulse, and heart rate); and
- Seeking medical advice urgently when 'red flags' are raised (even if the person saw a GP within the previous couple of days).

Given that many people with disability may have difficulty communicating the symptoms of their illness or understanding the significance of symptoms they may be experiencing, it is also important that people with disability are cared for by support staff who know them well. A support worker who is familiar with the person will be alert to behavioural changes and other signs that may indicate the person is unwell.

Support staff should also have access to on-call medical advice and assistance from a health practitioner such as a registered nurse/nurse facilitator. Having a nurse facilitator on-call, perhaps across a number of services, would ensure an appropriately trained person with a degree of familiarity with the people in the service was available for advice and information.

Case Studies: Short time between identifying illness and death

A man in his 50's with cerebral palsy lived in a disability residential service. He was unable to communicate verbally. He had been to the general practitioner a couple of days earlier for an unrelated illness. He had been coughing and vomiting in the evening and was sweating. He was put to bed as usual. When his carer checked on him in the morning it was found he had died sometime during the night. It was found he died due to bronchopneumonia.[287]

A woman in her 50's with cerebral palsy lived in a disability residential service. It was noted that she was not eating or drinking her usual amount. She was put to bed as normal and when she was checked on in the morning it was found she had died sometime during the night. An autopsy showed extensive pneumonia of both lungs.[288]

Responding to critical incidents

A number of deaths (6 individuals) were due to choking or aspiration of food or vomit. In the time before the person's death, support staff were in the difficult position of trying to save a person's life as a result of them choking. There was insufficient information available to allow the Panel to determine whether the staff on duty at the time of these incidents were trained in first aid or were confident in responding to critical incidents.

Staff caring for people with disability in residential services must be trained in first aid administration, including CPR and how to respond to choking.

In a number of cases, where a person died due to either choking or aspiration pneumonia, there had been repeated previous incidents of choking, including incidents requiring emergency medical care. Organisations must learn from previous critical incidents, provide opportunities for staff to be debriefed, and put strategies in place to avoid recurrences.

Management of risk factors for particular individuals

As discussed earlier, many people with disability living in residential care in this sample had multiple risk factors that put them at risk of life-threatening conditions such as pneumonia and aspiration pneumonia, choking, sudden unexpected death in epilepsy, and heart disease.

These multiple risk factors eventually lead to their death. As the Panel found, many of these deaths were either unexpected (59%) and/or potentially avoidable (53%).

Risk factors such as problems with eating and swallowing (dysphagia), recurrent respiratory illnesses, obesity, uses of multiple psychotropic medications, and risks to health associated with certain conditions such as cerebral palsy, epilepsy and Down syndrome must be identified and appropriately addressed.

All service organisations should ensure that they have a client risk policy in place to provide a framework for systematically identifying and responding to the risks to serious health conditions for individual clients. People identified as being at risk of serious illness must be given the support (including specialist medical attention and monitoring) that they need. When support staff feel that they are not adequately meeting the health care needs of a person with disability they must be encouraged to escalate this issue within their organisation as soon as possible.

Such a process is also particularly important for new clients entering a service, including for respite services. It is important that staff are well informed about the risks to particular clients and how to respond in the case of critical incidents and signs of deteriorating health.

It is important that this risk identification process is undertaken prior to the transition to the NDIS so that people with disability can have access to the disability support and health care that they need.

Identifying serious health conditions – Summary of findings and recommendations

Given the often complex health needs of many people with disability living in residential services there is a need for support staff to be aware of the 'red flags' that suggest serious illness and indicate the need to seek medical advice and attention. Being trained and encouraged to carry out simple observations (including temperature, pulse, and heart rate) should also be standard practice.

Organisations responsible for the care of people with disability must actively identify and respond to individual risk.

Recommendations: Identifying serious health conditions

- All service organisations should develop and implement a risk management framework that articulates a clear process for identifying clients who have identified risk factors, including requirements for assessment and the development and implementation of response plans that attend to identified risks.
- The planning phase for participants of the NDIS should give full consideration to their health care needs, identified risks and how their disability service/s will address these risks and coordinate with health practitioners to meet their health needs.
- As part of a targeted education and information strategy, Queensland Health (in collaboration with QCIDD, Health and Hospital Services and expert practitioners) should develop educative resources for support services and health practitioners about the risks certain people with disability face in terms of preventable death and how to recognise, assess and respond to various risk factors in individuals.
- Support workers should be trained to identify signs of deteriorating health, particularly in people with limited communication. This should be supplemented by simple guidance (e.g. in checklist form) in respect of signs and symptoms that indicate a need for urgent medical assistance.
- Support staff must be educated and trained in providing first aid (particularly in response to identified health risks such as choking, seizure management, etc.) and in taking basic health observations (such as temperature, pulse, and heart rate). Refresher training should be provided annually at minimum. This should be a mandatory requirement for the registration of disability residential and respite services.
- Having access to specialist disability health advice to provide 24-hour a day guidance in response to adverse health matters is recommended for residential disability services (this could be established by working collaboratively with local Health and Hospital Services to establish 'on call' arrangements).
- Support services should ensure that people with disability, particularly those with complex needs and/or communication difficulties, are supported by people who are familiar with them.
- Services should take effective action following a critical incident to reduce the risks of reoccurrence. This should include in addition to a report of the critical incident, this should include a mandated internal review of the incident (especially where this resulted in a person's death), the care arrangements, and any deficits related to the person's support and risk management. This should result in the development of recommendations for improving future practice and an implementation plan.

3.2.3 Coordination of health care and disability services

Integration between health and disability services

It is important that people with disability are supported in environments that implement a model of care consistent with contemporary knowledge about disability support (e.g. use of developmental strategies, environmental and structural modifications to ensure appropriate support, participatory engagement, etc.).

People with disability need access to models of care and support that help them to develop their capacity to actively participate in activities of daily living. They should also be part of their local communities.

Like all people who live in the community with serious health conditions, however, people with disability with serious health conditions also need access to appropriate health care, including primary health care, specialist care and tertiary (or hospital care) when it is needed. This does not mean they need to live in a hospital.

The people in this sample, like many people with disability who live in residential care, had complex and multiple health conditions. Many also had limited communication. Yet their primary care was often carried out by support workers who may have minimal or no medical expertise.

In some cases the lack of coordination and integrated care was evident in the transition from tertiary care (hospital) to disability care.

There is a real need for better coordination between the delivery of disability and health care services to enable people with disability to be included in the community and receive the health care they need.

Case Study: Transition from hospital

A young man with cerebral palsy and intellectual disability lived in a disability residential service operated by a non-government service provider. He had multiple serious health conditions (including epilepsy) and received his nutrition through a percutaneous gastrostomy tube (PEG). He entered hospital for day surgery to have his PEG tube replaced. He was discharged from hospital that same day. That night his carer noted that his breathing seemed laboured and that he had a high temperature, which led to an ambulance being called. He died on the way to hospital; his death was determined to be due to aspiration pneumonia.

Upon review, the Panel queried whether, given the severity of this man's health conditions, he was a suitable candidate for day surgery or whether he should have been kept in the hospital overnight for monitoring. The Panel also queried whether sufficient instructions were provided to his care staff about the need to monitor his vital signs on return from this procedure. For example, it was also noted that he didn't appear to have a Pulse Oximeter – which would have checked his respiratory rates and alerted staff more quickly to his deteriorating condition.[289]

Standards of care in accredited residential services

The availability of health care in level three accredited residential services raised particular concerns. Although there were only a relatively small number of deaths in care from these facilities reported during the period in which this sample was taken (8 people), a number of these cases raised concerns about the complexity of the health needs of those living in accredited residential services and whether they were getting the degree of care and support that they needed.

Case studies: Deaths in accredited residential services

An older woman with intellectual disability and schizophrenia lived in a level three accredited residential service. She also had multiple serious health conditions including epilepsy, Alzheimer's disease, Ischaemic heart disease and diabetes. She was being administered a range of psychotropic medications. She retired to bed early in the evening. Her roommate, a woman with an acquired brain injury said that that the older woman had fallen out of the bed onto the floor in the early evening soon after retiring to bed. But her roommate was affected by medication that she was administered every night to help her sleep and was too drowsy to raise the alarm. The older woman was found deceased on the floor of her room by a home visiting nurse in the morning. The autopsy found that she had extremely high levels of a particular anti-psychotic medication in her system.[290]

A woman in her 40's with Down syndrome and intellectual disability lived in a level three accredited residential service. She had multiple serious health conditions including heart disease and pulmonary hypertension. She collapsed at the service following what staff there described as a seizure. She died on the way to hospital in the ambulance.[291]

A man in his 60's with intellectual disability and schizophrenia lived in a level three accredited residential service. He had multiple serious health conditions including chronic obstructive airway disease, dementia and emphysema. He also had high cholesterol, skin cancers and had suffered a previous stroke. He had lived in the service for many years following his discharge from a mental health facility. An employee of the service entered his room one morning and found that he had died during the night.[292]

Coordination of an individual's health care

Given that many people with intellectual or cognitive disability may have multiple serious health problems, they may also need to consult a range of different health professionals. This means they also receive a significant amount of complex information that may not be easy to understand and remember.[293]

There is often little consistent family involvement in the lives of many people with disability who live in residential care. In particular, there may not be a consistent family member or members who know them well, accompany them to all their medical appointments, and keep all of their relevant health records and information ready to present to new health providers.

Instead, for many people with disability, it is the support worker who happens to be on duty. While this may be someone who is relatively familiar with them, they are not likely to have a full knowledge of their medical history and health issues.

For children with disability who live with their parents, this role is often played by the child's mother or father, a person who is motivated and concerned to coordinate their care, and collect and maintain all the relevant information support services and health professionals need to know about their medical history and current health issues. In the absence of a caring and supportive person to play this coordinating role, many people with disability in residential care can be very vulnerable.

Case Study: Complex health coordination

A woman in her 50's lived in a disability residential service. She died suddenly during the night as a result of sudden death in epilepsy. While she had been diagnosed with epilepsy and was continuing to experience regular seizures, it was noted that she was being administered 'sub-therapeutic' doses of her anti-convulsant medication, which it was considered might indicate that she had not been receiving specialist care or monitoring and review of her medication. This prompted the Panel to seek access to the person's case files in the hope of discovering further information about the nature of the specialist care and attention this person may have been receiving related to her epilepsy.

This woman had complex health issues, yet one of the most notable features of the information in the file was the lack of information about her health care including any communication or coordination between health and disability services. This lack of oversight was also evidenced by inconsistent spelling of her name throughout her files and evidence that her behaviour support plan, for example, might have been adapted from another client's plan (rather than developed specifically for her given there were inconsistent personal details, for example her gender was not correct. It was noted in the files that her health overall was deteriorating and that she may have early dementia. The time taken to provide care, in particular feeding at mealtimes (with staff required to feed her every 45 minutes) was becoming greater.

A medical professional on the expert Advisory Panel for this study expressed his opinion that her particular type of epilepsy should have been easily managed and that, with appropriate management, she could have been seizure free. Yet it was noted (in her record of seizures document) that over the past number of months her rate of seizures were increasing. This increase should have prompted a review of her medication and specialist attention.

This woman was also subject to restrictive practices (mechanical restraint) that were used primarily in response to risk behaviours relating to her handling of incontinence pads, which resulted in cross-contamination and infection. The Panel wondered at the attention paid to restrictive practices approval for this behaviour, yet the lack of attention paid to her potentially life-threatening epilepsy.[294]

It is important that there is a designated role responsible for the review and coordination of a person's care when they reside in a disability service. In some cases this may be the person's family member. Where this is not the case, however, it is important the service responsible for the person's care and wellbeing takes on this role in partnership with the person and/or their decision-maker (such as a personal guardian). This person needs to ensure health care strategies are being carried out, health appointments are booked and attended, annual health checks are carried out, that a hand-held health record is maintained.

There may also be a need to coordinate behavioural support to attend health appointments if necessary. Where the person has complex health conditions, that person should be a health professional.

Hand-held health records/health passports

A further positive strategy that should be employed by both disability and health services to facilitate the coordination of the person's health care is the use of hand-held health records. Health-held health records (or health passports or health diaries) for people with disability have been utilised in the United Kingdom for some time.

Numerous templates are used, but generally a hand-held health record is a document that is held by the person with disability or their carer. It is given to all health care providers (particularly hospitals). It is a record of the person's health conditions, current medications, and previous health consultations and interventions. It also contains information about the person themselves, how they communicate, things they like and don't like, and support for communication and decision-making.

Research indicates that hand-held health records generally lead to more discussion between primary health care providers and individuals about health problems, and increase health-related knowledge and awareness of personal health issues.[295] They can also be a useful tool to help people with disability advocate for themselves in the health system.[296]

The West Moreton Hospital and Health Service district in Queensland is in the process of developing a Health Passport for patients with intellectual or learning difficulties. It is inclusive of a smart phone application and is aimed at enabling ownership of health information for use across all health care settings including general practitioners, hospitals and community health care nurses.[297]

All health districts in Queensland should roll out this important initiative in partnership with regional offices of the Department of Communities, Child Safety and Disability Services in time for the full transition to the NDIS in Queensland.

Coordinated health and disability support – Summary of findings and recommendations

The need for coordination between disability and health services will only increase with the transition to full implementation of the NDIS in Queensland.

It is important that strategies are in place (prior to the introduction of the NDIS) that have identified a person's health care needs and risks, documented these in a way that stays with the person and is person-centred, and that there are established pathways for the person to obtain the health care they need.

Recommendations: Coordination of Health Care and Disability Services

- Disability residential services should have a designated person/role that takes responsibility for coordinating the health care of each resident with disability. This role should be responsible for ensuring health care strategies are being carried out, health appointments are booked and attended, annual health checks are carried out, hand-held health records are maintained, and coordinate behavioural support to attend health appointments if necessary.
- The Queensland Government (under the leadership of Queensland Health) should lead the development of a *Framework to Improve Health Care for People with Intellectual or Cognitive Impairment* that should include strategies to promote better coordination with disability services and better access to health care for people with disability.
- Hand-held health records should be implemented for all people with intellectual or cognitive disability. These should also be available as smart phone applications.

3.2.4 Improving health care and support

Providing specialist disability services and improving mainstream services

People with intellectual and cognitive disabilities with complex medical needs often spend a lot of time in hospital and going in and out of hospitals. In the sample, 58% of individuals died while in hospital. They may also have multiple and complex health conditions requiring ongoing medical attention and review. Therefore they are also frequently accessing a range of medical practitioners including general practitioners in their communities.

The Convention[298] recognises that people with disability have the right to the enjoyment of the highest attainable standard of health on an equal basis with others.[299] To ensure people with disabilities get access to the standard of health care to which they are entitled, improvements are required in the skills and competencies of health professionals working with people with disabilities in hospitals and other health services, including general practitioners.

Compared to countries such as the United Kingdom, the United States and some other European countries, there is a distinct lack of disability specialisation in the medical profession in Australia. More training and education of health professionals is needed on providing health care to people with disability in Australia, including common health conditions, the underlying risks and vulnerabilities to their health and skills for communicating with people with disability in the provision of health care.

Colleges of medical professionals should introduce further specific competencies in the care of people with disability.

As commentators have noted, such a role has usually fallen to ‘local champions’ who play an important role.[300] Yet, as has also been noted,[301] the commitment to addressing the health needs of people with disability cannot just rely on motivated and committed individuals, but must be supported by mechanisms to ensure the ongoing and sustainable nature of these initiatives, including the need for:

- Medical school accreditation and regulatory organisations to embrace the issue;
- Committed curriculum time, with teaching and learning modules developed;
- Committed and skilled teaching staff to lead teaching and learning in this area; and
- Succession plans through the mentoring of more junior staff.[302]

Nevertheless, specialist disability services and clinics play an important role not only in the provision of direct clinical services to people with disability but also in terms of educating and resourcing other health professionals.[303]

Queensland Centre for Intellectual and Developmental Disability

The Queensland Centre for Intellectual and Developmental Disability (QCIDD) supports people with developmental disability by providing clinical services to people with disability, teaching and educating other professionals, conducting research and providing resources.

The QCCID clinic provides clinical services at no cost to Queensland adults with intellectual or developmental disabilities including comprehensive health assessments, a psychiatric assessment service, and a telephone/email consultation service, including a behaviour support consultancy.

The website provides resources for people with disability, general practitioners and other health practitioners.

QCCID have led important research in a wide range of areas with respect to people with intellectual or learning disabilities, including developing the CHAP.

The CHAP provides for a Medicare funded (bulk-billed) extended period of time for a general practitioner to conduct a thorough history of the person's health issues, conduct a full health check in a comprehensive way and review health issues that are common for many people with intellectual and cognitive disabilities.

It was included as a Medicare Benefits Schedule item number in 2007.

Reasonable Adjustment

While specialisation and specialist clinics play a crucially important role in providing health care to people with disability as well as research and education of others, it is also important to enhance the capacity of the general health system to respond to the needs of people with disability.[304]

To ensure that people with disability get access to the health care and support they need, health services and hospitals may need to make changes or accommodations in the way they provide health care and support to people with disability. If these changes or accommodations are not made, then people with disability may miss out on the health care they need to treat their medical conditions and to ensure their ongoing good health and wellbeing.

In the United Kingdom, the *Equality Act 2010* (UK) requires public agencies (including hospitals and health services) to tailor the way they provide services to ensure that people with disabilities are not disadvantaged. The law applying to healthcare services is more explicit: it requires health care providers to avoid unlawful discrimination by making reasonable adjustments in service provision to meet the individual's needs.[305]

A publically available reasonable adjustments database has been set up providing examples of good practice in providing reasonable adjustment by National Health Service Trusts for people with learning disabilities within health services in England.[306]

The type of initiatives included vary widely and range from providing information in an accessible format to people with disability and their carers, to education materials or training of health provider staff to respond to specific health and support issues for people with disability, and providing general advice to health providers about disability, in particular intellectual and cognitive disabilities.

Making reasonable adjustments can take many different forms including:

- Making physical adjustments to the environment to ensure physical accessibility;
- Providing information resources targeted at people with disability and their carers;
- Allowing for extended consultation times including extended times to make decisions about treatment;
- Tools to assist the person with disability and their carers to engage in and make treatment decisions;
- Including the person's support person and carers; or
- Adjusting communication styles to suit the person with disability.[307]

Reasonable adjustment

An important overarching principle in the Convention is that of 'reasonable accommodation'. This refers to the support, modifications and adjustments that must be made so that people with disability can exercise their rights on the same basis as others.

Importantly, discrimination is now defined by article 5 of the Convention to also mean the failure to provide adequate accommodation. This broadens the concept of discrimination from the traditionally 'reactive' approach to providing a variety of remedies to discrimination in particular areas of life on the basis of disability, towards a positive obligation on state parties to ensure that people with disability have the information, assistance and support they need to exercise their legal rights.

Disability Liaison Nurses

In the United Kingdom, Learning Disability Liaison Nurses play an important role in facilitating reasonable adjustments in health care for people with intellectual or learning disability.[308] Learning Disability Liaison Nurses work with the treating team in hospital to support the person's care, assist the person with disability and their carers to be engaged in the treatment process and to make decisions about their treatment, and help plan their discharge and aftercare.[309] Importantly, because liaison nurses are experienced members of the health system, they also know how to influence the implementation of reasonable and achievable adjustments.[310]

Behavioural support

Sometimes the behaviour of a person with disability can be a barrier to receiving the health care they need, particularly where it may involve a visit to a health practitioner or a hospital. In such cases, either health care might be delayed or the person's behaviour, rather than their health issues, become the focus. It is important that people with disability who evidence behaviours that impact on their receipt of health care receive support from clinicians with appropriate expertise to address these behavioural issues and/or assist in ascertaining their underlying cause.

Case Study: Health and complex behaviour

A young woman with intellectual disability lived in a disability residential service. She had a history of depression as well as 'difficult' behaviour. Although she had not been diagnosed with a mental illness, it was noted that her 'behaviour had worsened' since moving to her current service, and worsened still when she was told that one of her family members had temporarily moved away.

In the six months preceding her death, there were a number of incidents of self-harming behaviour, threats to kill herself, and abusive behaviour with staff and other residents. She was placed on three different psychotropic medications. She reported her medication was making her feel tired, dizzy and anxious.

Approximately a week before her death, she began reporting that she could not feel her legs. She refused to get out of bed. She was taken to hospital where she was assessed and discharged. Back at the service she remained on a mattress all day refusing to eat and was incontinent of urine. She was again taken to hospital. She was assessed, and while nothing was found, she was kept in overnight because her carer was reported to be at 'the end of her tether' and could no longer manage her.

She was discharged the next day with a referral for a psychiatric appointment which she attended, and at which she continued to complain of the same physical symptoms. On return to her service that day, she collapsed and stopped breathing. She died on the way back to hospital. Autopsy revealed a large pulmonary embolus (clot in the lungs).

The Panel considered that she had many risk factors for the development of deep vein thrombosis, which caused the eventual pulmonary embolism that was the underlying cause of her death. She was morbidly obese, was being administered multiple psychotropic medications and had an extended period of physical inactivity. The Panel speculated that her behaviour might have been a significant distraction from a thorough examination of her health risks and symptoms.[311]

Improving health care and support – Summary of findings and recommendations

To ensure that people with disability get access to the health care and support they need, health services and hospitals will need to make changes and/or accommodations to the way they provide health care and support to people with disability.

Training and education of health professionals is also critically important to effecting long-term sustainable change to health care services for people with disability.

Recommendations: Improving health care and support

- There should be enhanced training and education of health professionals on providing health care to people with disability in universities, to trainee general practitioners and in ongoing professional education. The training must be underpinned by:
  - The inclusion of this topic as a competency in medical school accreditation and other regulatory organisations;
  - Committed curriculum time, with teaching and learning modules developed;
  - Committed and skilled teaching staff to lead teaching and learning in this area; and
  - Succession plans through the mentoring of more junior staff.
- All Health and Hospital Service Districts should collect data to ensure that people with disability can be identified in the health system to attend to identified risks and enable additional supports to be provided where necessary and appropriate.
- Queensland Health should engage with all Health and Hospital Service Districts to make it a requirement for ‘reasonable adjustments’ to be made to enable high standards of health care to be provided to people with disability.
- Health and Hospital Services should work to develop local, regional and state-wide networks of health practitioners with disability-specific knowledge and expertise (including clinical nurse consultants, allied health professionals, psychiatrists, physicians, general practitioners, dentists, etc) to provide clinical leadership and enhance the provision and coordination of services.
- Where a person is exhibiting behaviours that may impact on their ability to seek and receive medical attention (including hospitalisation), the respective health provider and disability service must work together to agree on what additional supports are needed and negotiate responsibility and resources for gaining these additional supports.

3.3 End-of-life care and decision-making

Decisions about the withdrawal and withholding of life-sustaining treatment must be considered carefully and be consistent with the law. Further, end-of-life care for people with disability must take account of the same medical and ethical issues as people without disability. People with disability must be accorded as much dignity at the end of their lives as possible by the medical profession and by carers. These considerations formed the framework for analysing cases in the study and underpin the issues discussed below.

3.3.1 Issues in making decisions about providing or withholding treatment

A number of cases in this sample described active decisions being made by medical professionals with substitute decision-makers (usually next of kin who would be the person's statutory health attorney) about the withdrawal and withholding of treatment, including life-sustaining treatment.

While the ability to draw conclusions was limited by the available information, in certain cases, the Panel queried whether more active intervention or treatment could have been provided.

Sometimes family members were given the choice between treating the person actively versus not treating them. In at least two cases, these concerned emergency situations where family consent is not normally needed to provide treatment, that is, where the person is at imminent risk of death and where active intervention could have potentially saved their lives.

The Panel noted that although in some cases the family may have agreed to 'not for resuscitation' orders, this should not mean that a person is not treated for a potentially treatable condition, but rather that life-sustaining treatment should not be provided if a person is at the end of their life and further treatment would be futile, or not in accordance with good medical practice.

The question should always be asked 'but for' this person's disability, would treatment be provided.

Case Studies: Withdrawal or withholding of treatment

A man in his late 50's with intellectual disability and Down syndrome was living in a disability residential service. After feeling unwell, complaining of having difficulty breathing, experiencing chills and refusing to eat and drink, he was taken by ambulance to the hospital where he quickly began deteriorating. He was transferred to the intensive care unit and placed on a life support system, but continued to deteriorate further. Following his second day in hospital, the hospital staff spoke to his family to advise that it was unlikely that he would recover. It was agreed with his family to withdraw life support and he died approximately 24 hours later. He was diagnosed with H1N1 (Influenza Virus).[312]

A man in his 50's with cerebral palsy lived in a disability residential service. On the day before his death, he attended a GP appointment. He had a history of chronic constipation and had been suffering consistent weight loss and vomiting. A CT scan was ordered and carried out that day, which found a blockage of the bowel. The radiologist requested that the man be transferred immediately to hospital. His statutory health attorney attended at the hospital and was reported to sign what was noted as a 'do not resuscitate order'. No surgical treatment was provided to remove the blockage in his bowel. The following morning, following a sudden deterioration in his condition, he died due to a sigmoid volvulus. The death certificate stated the cause of death was asphyxiation due to aspiration, due to a sigmoid volvulus and acute renal failure.[313]

A man in his 50's with Down syndrome and epilepsy was a resident of a disability residential service. On the day before his death, he had a seizure after which he had a large vomit. His carers became concerned when he remained lethargic. He was taken to hospital by ambulance where he experienced respiratory distress. The hospital considered that he has aspirated during or following the seizure. The hospital contacted his closest relative who stated that the patient 'would not want intubation' and only agreed to palliative care, so the hospital did not provide active treatment. Instead 'comfort care' (involving morphine and oxygen) was initiated in accordance with the statutory health attorney's directions. His treating team considered providing more active intervention (that is antibiotics) if he 'rallied' and if the family would consent, but he died early the next morning.[314]

Quality of life and assessing best interests

As for any person, it is important that people with disability are not subjected to futile and possibly burdensome life-sustaining measures when doing so would be in conflict with the nature of their condition. Further, people with disability should not be denied life-sustaining measures because of a prejudiced or misinformed view or assessment about their quality of life.

Depriving a person of life-sustaining measures simply because they have a disability such as Down syndrome or cerebral palsy, for example, or any other disability that sees them dependent on others for their care, is not a sufficient reason of itself to withdraw or withhold life-sustaining measures.

There is a risk that, in the context of discussions about costs and rationing of health care, the factors that are used to assess whether particular life-sustaining treatment is futile or not (such as quality of life and benefit) are used to make decisions that discriminate against people with disability.

The concepts of quality of life and benefit are enormously contested ones.[315] In cases where an adult has capacity, they are able to make their wishes known. However, when an adult lacks capacity, considerations such as quality of life and benefit to that person will usually need to be assessed by a substitute decision-maker.[316] That person needs to consider what quality of life would mean for the person with disability and "whether the life in prospect will be of sufficient quality (or 'value' or 'net benefit') for that individual, to justify continuing to sustain it".[317]

This is an inherently difficult exercise for a person without disability, as expressed by the following statement:

> *"To assess the quality of life of individuals who have severe impairment, we are forced to imagine what life would be like from their perspective. This sort of exercise may, however, implicitly bias our assessment… to imagine life as experienced by people with severe cognitive impairment is particularly difficult, as the fear of the loss of our own mental capacities is wide spread and deep rooted."* [318]

This demands that substitute decision-makers assess best interests in a way that is not relative to their own current quality of life, or the loss of mental or physical competencies that they think would remove benefit or quality from their lives. This is a very difficult task that can be more complicated if it is a family member who cares for the person with disability.

3.3.2 Planning for end-of-life

As described above, adults who have capacity can plan for their health care at the end of their life by executing an advance health directive and/or appointing an attorney to make decisions for them, including providing directions to that attorney about the decisions they want them to make.

Adults who have never had capacity to make an advance health directive do not have this opportunity.

The Panel identified a number of cases where end-of-life planning (prior to the critical event) would have been beneficial, in particular where, given the extent of a person's disease, that person's death would have been expected at some near stage.

In some cases, people with disability suffering from significant illness were subject to continual efforts to provide life-sustaining treatment (including resuscitation).

Case Study: Planning for the end of life – prolonged resuscitation

A woman in her 40's with intellectual disability and Down syndrome was a resident of a level 3 accredited residential service. She had a number of significant health conditions including Interstitial Lung Disease as well as a congenital heart disease. She was at the service when according to staff she had a seizure. An ambulance was called and the paramedics noted her weak cardiac output and difficulty breathing. She then arrested at the scene and CPR was administered by the paramedics who then transported her to the emergency department of the hospital. She arrested again during the transportation and upon arrival at the hospital and died shortly after arrival at the hospital. Four attempts were made at CPR each time she arrested, with the fourth attempt (despite prolonged resuscitation) being unsuccessful.[319]

Conversely, there were a couple of cases where there had been good consideration given to end-of-life planning, conducted in partnership with family and treating staff.

Case Study: Planning for the end of life – effective palliative care

A woman in her 20's with intellectual disability and serious medical conditions lived in a disability residential service. She was in receipt of palliative care and had end-of-life care planning undertaken with her parents after several admissions to hospital with aspiration pneumonia. She was admitted into hospital with laboured breathing and treated conservatively and palliatively over the next two weeks in accordance with her end-of-life plan and died after approximately two weeks in hospital.[320]

Confusion about the law

In a number of cases, there seemed to be confusion about end-of-life planning and the nature of statutory decision-makers. For example, in a number of cases the person's files noted that they had an enduring power of attorney, whereas it would have been unlikely that the person would have ever had the capacity to execute such a document. This may indicate a lack of awareness about the law and end-of-life in some cases.

Other studies have found significant knowledge gaps among health professionals who practice in the end-of-life field more generally.[321]

The law in relation to end-of-life decision-making is quite complex and is different for adults who have capacity versus adults who don't have capacity.

In considering adults who have never had capacity to make an advance health directive or execute an enduring power of attorney, advance planning for their end-of-life is more complex again, as there is no real legal framework (equivalent to an advance health directive) for this to occur. Guardianship legislation only allows for the authorisation of various substitute decision-makers to make decisions about withdrawal and withholding life-sustaining treatment for them. Such decisions have to be made on the basis of the person's best interests however, as has been briefly discussed above, this can be a problematic standard to apply.

While doctors receive some training about the law in this area as part of their medical education, some studies have thrown doubt on whether this training is adequate,[322] and whether it helps them to identify and deal with the complex ethical issues involved in making end of life treatment decisions with respect to people with disability.

3.3.3 Applying the law to decisions about medical treatment

Decision-making at the end of a person's life involves complex medical, ethical and legal issues. Where a person lacks capacity to make the decision for themselves either in advance (in an advance directive), or contemporaneously, the situation can be even more complex.

Capacity and advance directives

At common law, an adult with capacity has the right to refuse medical treatment,[323] even if that treatment will keep them alive and the reasons are "rational, irrational, unknown or even non-existent."[324] Therefore, a medical practitioner may be civilly or criminally liable for providing treatment to a competent adult who has refused their consent for that treatment. On the other hand, a competent adult does not have the right to demand treatment that is not in their best interests, including what is known as 'futile treatment'.[325]

This right of a competent adult to refuse treatment in advance is also recognised under Queensland's guardianship legislation.[326] A competent adult can make an advance health directive that provides for the withdrawal or withholding of life-sustaining treatment.[327]

In Queensland, a medical practitioner is generally required to follow this directive in making a decision about withholding or withdrawing life-sustaining treatment, if the directive is valid and applicable in the circumstances and the adult who made the directive lacks capacity[328] and has no reasonable prospect of regaining capacity.[329]

One of the following criteria also need to be met in following a direction to withhold or withdraw life-sustaining measures:

- The person has a terminal illness or condition that is incurable or irreversible as a result of which, in the opinion of a doctor treating the person and another doctor, the person may reasonably be expected to die within one year;
- The person is in a persistent vegetative state (i.e. a condition involving severe and irreversible brain damage) despite which some or all of the person's vital bodily functions to continue, including for example heartbeat or breathing;
- The person is permanently unconscious, that is, the person has a condition involving brain damage so severe that there is no reasonable prospect of the person regaining consciousness; or
- The person has an illness or injury of such severity that there is no reasonable prospect that the person will recover to the extent that the person will recover to the extent that the person's life can be sustained without the continued application of life-sustaining measures.[330]

Also, if the life-sustaining treatment involves the withdrawal of artificial nutrition or hydration, the commencement or continuation of these measures would be inconsistent with good medical practice.[331]

Where a person, at the time a decision needs to be made, lacks capacity to make medical treatment decisions themselves and has never made an advance directive, a medical practitioner must first obtain appropriate consent to either provide medical treatment, or withhold or withdraw medical treatment (except in an absolute emergency).

Impaired capacity

For adults with impaired capacity, the situation is complex.[332] In an emergency, the common law provides that a medical practitioner can provide medical treatment to an adult who lacks capacity without consent if the treatment is needed to save their life or prevent serious and imminent danger to their life or health.[333] This is reflected in Queensland's guardianship legislation so that health care of an adult without capacity may be carried out without consent to address imminent risk to the adult's life or health.[334]

Outside of actual emergency situations, a decision to withhold or withdraw life-sustaining treatment for an adult without capacity must have appropriate consent. There is no common law mechanism for medical treatment decisions to be made for adults who do not have capacity, including by their next of kin.[335] Further, Queensland's guardianship legislation makes it an offence to carry out health care on an adult with impaired capacity unless appropriate consent is provided, or otherwise authorised by law.[336] This includes the withholding and withdrawal of life-sustaining measures.

The decision must be authorised or consented to by one of the following substitute decision-makers:

- A guardian appointed for health care matters (this person is appointed by QCAT and may be a family member for example or a public official, the Public Guardian);[337]
- An attorney appointed under an enduring power of attorney or an advance health directive;[338]
- If there is not a guardian appointed for health care or an attorney appointed by the person, a statutory health attorney (generally the first person in a list of priority but generally the person's spouse with whom they are in a close relationship or the person's next of kin);[339]
- The Queensland Civil and Administrative Tribunal (QCAT);[340] or
- The Queensland Supreme Court (exercising its *parens patriae* jurisdiction).[341]

Limitations for substitute decision-makers

Queensland's guardianship legislation provides guidance for substitute decision-makers (including guardians, attorneys and QCAT) when making a decision about withdrawing or withholding life-sustaining treatment. Such decisions must be:

- consistent with the general principles and the health care principle in the *Guardianship and Administration Act 2000*;[342] and
- consistent with good medical practice.[343]

The medical practitioner must only withhold or withdraw medical treatment from a person without capacity whose substitute decision-maker has provided consent if the treatment is a life-sustaining measure as defined in Queensland's guardianship legislation; and the commencement or continuation of such measures would be inconsistent with good medical practice.[344]

A life-sustaining measure is defined as 'health care intended to sustain or prolong life and that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation."[345] This includes but is not limited to cardiopulmonary resuscitation, assisted ventilation, and artificial nutrition and hydration.[346]

Further, a medical practitioner cannot withhold or withdraw life-sustaining measures unless the practitioner also believes the commencement or continuation of such measures would be inconsistent with good medical practice.[347]

'Good medical practice' is defined as "good medical practice for the medical profession in Australia having regard to –

1. the recognised medical standards, practices and procedures of the medical profession in Australia; and
2. the recognised ethical standards of the medical profession in Australia."[348]

Duty to provide care and necessaries of life

Importantly, a health practitioner also has a duty of care to patients for whom they are providing medical care and treatment (including consultations). The health practitioner owes their patients a duty to exercise reasonable care and skill in their provision of medical care including examination, diagnosis, treatment and advice.[349]

In providing medical care, health practitioners have been found to be liable for a breach of their duty of care to a patient in a wide range of circumstances, including failure to refer patients to specialists for treatment or further investigation,[350] delayed diagnosis or misdiagnosis,[351] failure to follow up,[352] inadequate post-operative care,[353] and inadequate emergency care.[354]

There is also a positive duty to provide the necessaries of life to a person who is in your care.[355]

Euthanasia is unlawful

Importantly, while it may be lawful to withhold or withdraw life-sustaining treatment under certain circumstances, it is not lawful to perform euthanasia. The taking of active steps to end a person's life, including steps that merely hasten a person's death is illegal,[356] and would generally be considered murder in criminal law.[357] Performing euthanasia is a criminal act in Queensland and in all other Australian states and territories.[358]

Queensland's Criminal Code has provisions that allow for palliative care. A person is not criminally responsible for providing palliative care to another person if:

- the person provides the palliative care in good faith and with reasonable care and skill; and
- the provision of the palliative care is reasonable, having regard to the other person's state at the time and all the circumstances of the case; and
- the person is a doctor or, if the person is not a doctor, the palliative care is ordered by a doctor who confirms the order in writing.[359]

The above applies even if an incidental effect of providing the palliative care is to hasten the other person's death.[360] The provision of palliative care is only considered 'reasonable' if it is reasonable in the context of good medical practice.[361]

End-of-life care and decision-making – Summary of findings and recommendations

Providing care at the end of life for people with disability is an area fraught by significant legal and ethical uncertainties.

This was reflected in many of the cases in the sample where, perhaps because of the limited information available to the Panel in many circumstances, it was sometimes difficult to understand why certain decisions were made about withholding or withdrawing treatment to people with disability.

This was particularly the case where the person with disability had a treatable medical condition that, once treated, could have meant a return to their normal way of life.

In particular, it raises the importance of not confusing uninformed or even prejudiced assessments about the quality of life of people with disability with considerations of whether life-sustaining treatment would be futile.

There seems to be a need for both greater education of medical professionals and of substitute decision-makers in respect of both the law and ethical considerations in making end-of-life treatment decisions, as well as a consideration of how to better provide for appropriate end-of-life planning for people with disability who have terminal and life-threatening illnesses.

Recommendations: End-of-life care and decision-making

- A decision to withhold or withdraw treatment for people with disability should only be made by the relevant decision-maker after referral to a palliative care team or senior specialist who can provide professional advice.
- The diagnosis of a long-term, chronic or terminal condition should prompt appropriate discussions and decisions around treatment and care at the end-of-life that involve the person with disability, their family, supporters, carers and health professionals involved in their treatment and care.
- End-of-life care and advance care planning activities should be empowering of people with disability and ensure that decision-making processes are robust and accountable at all times.
- Health professionals should receive further education and training (both in medical school and as part of continuing education) about the law that applies to end-of-life decision-making, within the wider context of medical ethics, including the ethical issues concerning making decisions about life-sustaining treatment and quality of life for people with disability.
- The Department of Health's *Statewide strategy for end-of-life care 2015* provides an important resource for health practitioners. Implementation of this strategy should ensure consideration for the specific needs of people with disability, particularly those with impaired decision-making capacity.

4 Legislation, processes and practices

4.1 Coronial processes

4.1.1 Reporting of deaths in care – Legislative framework

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.[362]

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.[363]

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). [364]

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.[365]

This report is focused on people with disability who died in either a level 3 accredited residential service or were in receipt of disability accommodation services provided by or funded by DCCSDS.

4.1.2 Investigations and inquiries

How a death in care is reported

In most cases (56% of the sample), the documentation in relation to the death in care included a Form 1 Police Report of Death to Coroner). This usually occurs when the person dies at the residential service where they usually lived and the service reports their death to the police.

In some cases, the person died at the hospital and either the hospital or their usual service, rather than reporting the death directly to the Coroner, reported the death to the police.

In other cases where the person died in a hospital, the death was reported by the hospital using a Form 1A or Medical Practitioner Report of Death to a Coroner. This inconsistency in reporting practices suggests the need for enhanced understanding of reporting requirements for deaths in care.

Investigating a death in care

Once a death in care is reported to the State Coroner, a Coroner must investigate the death in accordance with the Coroner's broad powers under the Act.[366]

The Coroner has wide powers of investigation and can request additional reports, statements or information about the death from investigators, police, doctors and other witnesses.[367]

Preliminary investigations

While all deaths in care are reportable and must be subject to an investigation by the Coroner, the extent of that investigation will vary. The degree to which each death was investigated and the extent of the information and advice sought in each case was examined in this study for the 73 cases.

In some cases, particularly where the person has died in hospital, a preliminary cause of death certificate may be issued by the medical practitioner, which is then accepted by the Coroner if the Coroner does not believe the matter warrants further investigation. At this point, the final cause of death certificate is issued and the investigation ceases.[368]

The Coroner may also seek advice from the Clinical Forensic Medical Officer (CFMO), depending on the expert advice that might be needed.[369] The CFMO is located in Queensland Health and can provide clinical support and advice to the Coroner for health care related deaths and deaths in care. Advice from a CFMO was provided in 32% of cases in the sample.

Finally, the Coroner may request that an autopsy is performed. An autopsy may be performed whenever any of the following factors are an issue:

- the identity of the deceased;
- the need to identify any injuries or diseases that may have contributed to a person's death;
- the need to identify the effect of medical treatment on the deceased;
- to reassure carers that their action or inaction did not contribute to the person's death;
- to assist in evaluating the manner of the death; or
- to establish the cause of the death.[370]

An autopsy report was attached to 40% of the cases in the sample.

Determining whether to hold an inquest

Once a Coroner has completed these inquiries, the Coroner will determine whether to hold an inquest.

Not all investigations of deaths in care will result in an inquest. An inquest must be held if:

- The Coroner considers the death is a death in custody or a death in care in circumstances that raise issues about the deceased person's care;[371]
- The Attorney-General or directs the State Coroner to arrange for an inquest; or
- The State Coroner on their initiative or upon application by another person decides to hold an inquest.[372]

A Coroner may hold an inquest if the Coroner investigating a death is satisfied that it is in the public interest to do so.[373] In determining if an inquest may be in the public interest the Coroner may consider:

- the extent to which drawing attention to the circumstances of the death may prevent deaths in similar circumstances happening in the future; and
- any guidelines issued by the State Coroner about the issues that might be relevant in determining whether to hold an inquest.[374]

In conducting the inquest, a Coroner's court is not bound by the rules of evidence and may inform itself in any way it considers appropriate[375] as part of the Coroner's broad powers.[376]

A Coroner that has investigated a death at an inquest may make a comment related to issues of public health or safety, the administration of justice, or ways to prevent deaths happening in similar circumstances in the future in connection with the death investigated.[377]

An inquest was not held for any of the 73 cases in this sample.

Findings and comments

At the end of an investigation, the Coroner must make written findings that are provided to the family of the deceased; and if an inquest was held, to any person with sufficient interest in the inquest.[378] A Coroner must not make a finding of criminal guilt or civil liability.[379]

In conducting an investigation the Coroner must, if possible, find:

- Who the deceased person is;
- How the person died;
- When the person died;
- Where the person died; and
- What caused the person to die.[380]

If an inquest has been held, the findings (including any comments by the Coroner) must be published unless the Coroner orders otherwise.[381] If no inquest has been held, the findings may be published if the Coroner believes the findings are in the public interest and the Coroner has consulted with and had regard to the views of the family.[382]

For a death in care, regardless of whether an inquest has been held, the Coroner's findings must be provided to the Attorney-General, the appropriate chief executive and the appropriate Minister. [383]

Register of deaths

The State Coroner must establish a register of all deaths or suspected deaths investigated under the *Coroners Act 2003*.[384] The register must include the date on which the death was reported, a summary of any findings and comments made at an inquest.[385] At present in Queensland, the register is not publicly available.

4.1.3 Coroners' findings – Deaths of people with disability in care

Between 2009 and 30 June 2014, there have been findings from two inquests delivered into the deaths of adults with either intellectual disability or cognitive impairments in Queensland (not including people with mental illness). Only one of these was a 'death in care' as the person was a resident in a level 3 accredited residential service. The inquests that were conducted include that of:

- Stuart John Lambert who died 4 June 2009 (delivered 28 March 2013); and
- Leon Streader who died 22 February 2004 (delivered 1 October 2009).

The Coroner has also published the findings of two non-inquest findings into the deaths of adults with either intellectual disability or cognitive impairment including:

- The non-inquest findings of the investigation into the death of SM who died on 7 July 2014 (26 May 2015); and
- The non-inquest findings of the investigation into the death of Alison Ruth Copeland who died 18-19 November 2013 (28 July 2014).

The information below has already been published and has been summarised from the published findings of the Coroner available on the Queensland Coroner's website.[386]

Stuart John Lambert

Stuart John Lambert was 35 years of age at the time of his death, and was diagnosed with cerebral palsy, autism and epilepsy. He died while receiving respite services from a non-government organisation funded by 'Disability Services'. The services accessed by Mr Lambert were funded as 'in-home respite', so his death was not considered a 'death in care' under the *Coroners Act 2003*. Mr Lambert was, however, staying with his respite carer at her property in Lowood when he died. Mr Lambert's parents had agreed to him having overnight visits there.

The autopsy revealed that Mr Lambert had extensive fractures of his ribs and chest, which appeared to have been caused a few hours before his death. There was also evidence of old healed fractures.

Neighbours of the respite carer gave evidence at the hearing of having seen Mr Lambert being verbally and physically abused and assaulted by his carers; and being hosed in his underwear in the yard in winter time at night for his bathing arrangements. It was further noted that while his carers slept upstairs, Mr Lambert slept in an unsecured but enclosed area under the house.

During the time that Mr Lambert was accessing services from this carer, his carer was also charged and convicted of assault of another man with disability. The Coroner could not find any provable evidence, however, that Mr Lambert died as a result of criminal assault or that his death was due to criminal negligence.

Evidence was given that Mr Lambert died after falling onto a pot plant while having an epileptic seizure. The autopsy noted evidence of numerous previous injuries including fractures that seemed to have been caused a few hours before his death, concluding that his death was principally caused by chest injuries, with epilepsy and autism his underlying causes of death.

The Coroner made a number of remarks about the appropriateness of the care arrangements, including the lack of human dignity afforded Mr Lambert in his care arrangements, and the lack of oversight by Disability Services.[387]

Leon Streader

Leon Streader was 68 years of age at the time of his death. He lived in a level three accredited residential service and had epilepsy, intellectual disability and schizophrenia as well as a number of other health conditions. He had been in institutions all of his life.

On the day of his death, he and other residents had been sitting outside in severe heat conditions most of the day. Mr Streader returned inside and sat on the couch where he was later found to be deceased.

On arrival, the attending police found that the other residents were heat-affected and also appeared dehydrated.

The Coroner found that the cause of death was coronary atherosclerosis worsened by heat stroke. The Coroner also noted that the medications prescribed to Mr Streader, namely Benztropine (Cogentin) and Chlorpromazine (Largactil) were known to inhibit the body's ability to cope with extremes of heat and that, while they had been used for many years without apparent ill effect, the environmental conditions and temperatures inside his residence had been extreme on that day.

The Coroner noted the often complex medical, psychiatric and social conditions of many residents of level three accredited residential services as well as the low ratio of staff to clients (in this case, one person to 31 residents) and recommended a review of the appropriate ratio of residents to staff; training of staff; and procedures.

Given that there was no system in place for documenting the administration of medication to residents, the Coroner also recommended that level three residential service facilities be required to properly document this process as well as improve record-keeping generally with respect to medical history and care.[388]

SM

SM was 32 years of age at the time of his death. He had an intellectual disability and had been admitted to hospital with a two-day history of nausea and vomiting. These symptoms were initially attributable to food poisoning, but an abdominal CT scan revealed acute appendicitis. An emergency laparoscopic appendectomy was performed. Six days later he died while recovering in hospital as a result of a pulmonary embolism originating from deep vein thrombosis.

While the Coroner found that the identification and management of SM's risk of developing this venous thromboembolism was appropriate, there was a definite failure by the treating team to identify and appropriately investigate the cause of his persistent low oxygen saturations.[389]

Alison Ruth Copeland

Alison Copeland was 55 years of age at the time of her death, which was due to a cerebral aneurysm. She had lived with cognitive impairment, speech difficulties, blurred vision and blindness as well as limited mobility.

Ms Copeland had been on a waiting list for a Blue Care aged nursing facility for a number of years but was in receipt of care from a community mental health service for her depression. She experienced significant frustration as a result of the period of time she spent waiting for an aged care bed, as well as two years spent attempting to get assistance from 'Disability Services Queensland' (DSQ).

Although Ms Copeland had eventually been assessed as eligible for disability services in 2011, funding was not available for her and she was placed on a 'register of need', which recorded the details of those waiting for funding.

Ms Copeland's family contacted DSQ again in 2013, at which time Ms Copeland was assessed as in need of in-home support and accommodation support, but resources were still not available.

Despite being under 65 years of age, the Aged Care Assessment Team conducted an assessment and found her a temporary placement at Casuarina Lodge Rehabilitation Centre.

At the time that she died, Ms Copeland was in the care of her sister. Her sister discovered her deceased in the morning and the Coroner found that Ms Copeland had taken her own life.

The Coroner noted a systemic issue of insufficient housing as well as limited out-of-home accommodation support options for people under 65 years of age who have high needs, which may not necessarily be solved by the implementation of the National Disability Insurance Scheme.

The Coroner found that Ms Copeland had taken her own life in the context of depression and frustration with her life difficulties and residential circumstances.[390]

4.2 Expert examination and scrutiny of deaths in care

Overall the Advisory Panel felt there could have been further scrutiny and examination of the circumstances surrounding the deaths of many of the people who died in care in this sample. In particular, the Panel commented on the lack of advocacy in the coronial system for people who have died in care.

It may be that Coroners could benefit from further expert advice particularly with respect to the provision of health and support services to people with intellectual disabilities and cognitive impairments to enable the better identification of issues surrounding their care prior to their death.

4.3 Ongoing systemic reviews of deaths in care

It is well established that people with intellectual disability have more complex health needs and a higher mortality rate than the rest of society. They can also face many barriers accessing appropriate health care as well as a narrower margin of health, because of poverty and social exclusion and vulnerability to secondary conditions such as pressure sores or urinary tract infections.[391]

For this reason systemic issues such as a lack of appropriate support, including support to access health care and appropriate responses by health care agencies, as well as ineffective coordination between disability and health services can have a serious effect on people with disability (including the risk of premature death). Often people with disability living in residential care have much greater dependency on public agencies and funded non-government services to ensure their health and support needs are met.

The number of deaths in care in Queensland is not generally known. While deaths in care should be reported to the Coroner's office, there is no publicly available register of deaths in care.

The information on the register maintained by the Coroner is not made generally available for systemic monitoring and analysis, which if changed could enable trends and systemic issues to be identified.

In Queensland, apart from the coronial process for deaths in care, there is no specific process for systemic reviews of deaths of people with disability. As discussed above, while all deaths in care must be reported to the Coroner and investigated, not all investigations will result in an inquest and/or published findings and comments.

Between 2009 and 30 June 2014, there was only one inquest into a death in care of a person with disability in Queensland.[392] It is understood that two further inquests occurred in 2015.

The number of deaths in care that occur each year in Queensland is not definitively known. Nor is it known how this compares to other states and nationally, and whether there exist opportunities for systemic improvements to reduce the numbers of deaths in care.

The publishing of these figures and regular systemic analysis of deaths in care of people with disability should be an ongoing role for an appropriate agency with powers to request information and carry out further investigations if necessary.

The *Community Services (Complaints, Reviews and Monitoring) Act 1993* (NSW) requires the NSW Ombudsman to review deaths of children and adults with disability who at the time of their deaths were:

- living in residential care provided by services authorised or funded under the *Disability Services Act 1993*; or
- boarding houses licensed under the *Youth and Community Services Act 1973*.[393]

As part of this review function, the Ombudsman:

- maintains a register of reviewable deaths;
- conducts reviews focused on identifying the procedural, practice and systems issues that may contribute to deaths, or that may affect the safety and wellbeing of people with disabilities in care; and
- recommends relevant changes or new strategies that might ultimately help to prevent reviewable deaths.[394]

The Ombudsman publishes a report detailing the results of the reviews and highlighting the key systemic issues that are raised by the reviews.[395]

As discussed earlier, these publications play an important role in raising systemic issues related to the health care and support of people with disability, often leading to significant reforms and improvements.

An appropriately resourced public agency could perform a similar role in Queensland.

Recommendations: Systemic reviews of deaths in care of people with disability

❖ The State Coroner should be required to report annually on deaths in care. Ideally, the numbers of deaths in care would be presented in the Annual Report and would be broken down against the categories associated with the definition of 'death in care'.

❖ Coroners should be provided with further expert advice in relation to health and support issues for people with intellectual and cognitive impairments.

❖ There should be enhanced education and awareness raising about the reporting requirements in relation to the deaths of people with disability in care.

❖ An appropriate agency should be resourced and tasked to carry out regular systemic reviews of the people with disability who have died in care in Queensland. A report detailing the outcomes of these reviews should be tabled in Parliament at least biennially.

5 Conclusion

This review is a significant one on numerous levels. It is not only the first of its kind in Queensland but it offers a unique opportunity to consider and address important issues relevant to the health care needs of people with disability ahead of one of the most significant reforms to disability service delivery, that being the implementation of the National Disability Insurance Scheme (NDIS) in Queensland.

Given the significance of the issues highlighted by the Report, and the obvious benefits that would emerge for people with disability in addressing them, I urge the Queensland Government to consider the recommendations in the Report and to urgently prioritise an appropriate response as part of its transition planning for the implementation of the NDIS.

I strongly recommend immediate action that upholds Queensland's obligation to ensure the right to life and the right to the highest attainable standard of health for people with disability. Doing so will also serve to ensure improved health care outcomes for people with disability in Queensland while reducing the number of potentially avoidable deaths into the future.

In closing, I would like to once again thank my fellow Advisory Panel members for their efforts and commitment to this review, and for their support in advocating for change.

Jm Griffiths-Cook

Jodie Griffiths-Cook
Public Advocate (Qld)

6 Appendices

6.1 Appendix One – Advisory Panel members

Role	Member
Public Advocate	Ms Jodie Griffiths-Cook, Public Advocate
Public Guardian	Mr Kevin Martin (February 2015 – August 2015) Ms Julia Duffy (Acting Public Guardian) (August 2015 – December 2015)
Anti-Discrimination Commissioner	Mr Kevin Cocks AM
Health Ombudsman	Mr Leon Atkinson-MacEwen
Medical Practitioner	Professor Nick Lennox, Director Queensland Centre for Intellectual and Developmental Disability
Medical Practitioner	Professor Harry McConnell, Clinical Sub-Dean, School of Medicine, Griffith University
Medical Practitioner	Dr Paul White Consultant Physician in Psychiatry

6.2 Appendix Two – Data from Queensland Government

Department of Communities, Child Safety and Disability Services

Table 4 Number of deaths in care of people with disability who may have had impaired capacity for a matter in 2011

Year	Number of deaths	Gender	Mean age	Age range
2011	13	Male – 8	46	19-70
		Female – 5	50	19-74

Source: Department of Communities, Child Safety and Disability Services (2014)

In 2011, of the 13 deaths recorded, there were:

- 10 deaths in group homes – 5 in Accommodation Support and Respite Services facilities (AS&RS) and 5 in non-government service provider facilities; and
- 3 deaths in centre-based respite/respite homes (all AS&RS facilities).

Table 5 Number of deaths in care of people with disability who may have had impaired capacity for a matter in 2012

Year	Number of deaths	Gender	Mean age	Age range
2012	26	Male – 13	53	21-74
		Female – 13	49	21-61

Source: Department of Communities, Child Safety and Disability Services (2014)

In 2012, of the 26 deaths recorded, there were:

- 21 deaths in group homes – 7 in AS&RS and 14 in funded non-government service provider facilities;
- 1 death in own-home respite (provided by AS&RS); and
- 4 deaths in centre-based respite/respite homes (all AS&RS).

Table 6 Number of deaths in care of people with disability who may have had impaired capacity for a matter in 2013

Year	Number of deaths	Gender	Mean age	Age range
2013	13	Male – 8	46	19-70
		Female – 5	50	19-74

Source: Department of Communities, Child Safety and Disability Services (2014)

In 2013, of the 33 deaths recorded, there were:

- 28 deaths in group homes – 12 in AS&RS and 16 in funded non-government service provider facilities;
- 3 deaths in own-home respite (all funded non-government service providers); and
- 2 deaths in centre-based respite/respite homes (all AS&RS).

Department of Housing and Public Works

Table 7 Number of deaths of people with disability in level 3 accredited services

Year	Number	Gender	Age/range
2010	1	Male - 1	62 years
		Female - 0	NA
2012	7	Male - 5	37-81 years
		Female - 2	45-49 years
2013	3	Male - 2	56-63 years
		Female - 1	60 years

Source: Department of Housing and Public Works (2014)

7 Endnotes

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[83] New South Wales Ombudsman, *Report of Reviewable Deaths in 2010 and 2011: Volume 2: Deaths of People with Disabilities in Care* (May 2013).

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[92] New South Wales Ombudsman, *Report of Reviewable Deaths in 2012 and 2013: Volume 2: Deaths of People with Disability in Residential Care* (June 2015) 71.

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[98] World Health Organisation, *International Statistical Classification of Diseases and Related Health Problems 10th Revision* (http://www.who.int/classifications/icd/en/)

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[102] Australian Bureau of Statistics, *Causes of Death Australia 2012, Glossary* (Cat 3303.0,2014) Definition of Avoidable Mortality.

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[119] John Harris, "*QALYfying the value of life*" (1987) 13 Journal of Medical Ethics, 117-123, 120.

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[121] Julian Savulescu, "*Resources, Down's Syndrome, and cardiac surgery*" (2001) 322 British Medical Journal 87-876; Julian Savulescu, "*Kamm's Intricate Ethics: Chapter 13 A rough consequentialist response*" (Ethics Etc http://ethics-etc.com/2007/10/03/kamms-intricate-ethics-chapter-13-a-rough-consequentialist-response/)

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[123] See the *Report of the Independent Inquiries into Paediatric Cardiac Services at the Royal Brompton Hospital and Harefield Hospital* (April 2001) where it was found that doctors at the Royal Brompton Hospital in London and the Harefield Hospital in Middlesex failed to put patients first and offered parents a biased view of only some of the treatment options available for children with Down Syndrome. The inquiry found that many doctors were influenced by wider issues such as concerns for the family who would have to care for the child with Down syndrome and the likely fate of the parents and the child if lifesaving surgery was provided. This was in contrast to growing evidence that children with Down syndrome could benefit from potentially life-saving surgical intervention to correct cardiac abnormalities and the provision of such active surgical intervention by other medical centres.

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[127] Morning (6:00AM-12:00PM); afternoon (12:00PM-6:00PM); night (6:00PM-6:00AM, inclusive of those referenced to have died 'sometime during the night').

[128] Early morning (4:00AM-6:00AM); morning (6:00AM-12:00PM); afternoon (12:00PM-6:00PM); evening (6:00PM-8:00PM); night (8:00PM-4:00AM).

[129] World Health Organization, http://www.who.int/topics/mortality/en/.

[130] The analysis and reporting of causes of death uses the underlying cause of death as classified under the *International Classification of Diseases* (ICD-10). The ICD-10 is the international standard classification for epidemiological purposes and is designed to promote international comparability in the collection, processing, classification, and presentation of causes of death statistics. World Health Organisation *International Statistical Classification of Diseases and Related Health Problems 10th Revision* (http://www.who.int/classifications/icd/en/).

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[137] New South Wales Ombudsman, *Report of Reviewable Deaths in 2010 and 2011 Volume 2: Deaths of People With Disabilities in Care* (May 2013) 31; JJ Shepard, "Managing Dysphagia in Mentally Retarded Adults" (1991) (6) Dysphagia, 83, 84; Sharon Davis et.al "Respiratory medication use in an Australian developmental disability clinic population: messages for health care professionals" (2014) 20 Australian Journal of Primary Health 278, 278-9.

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[139] Lung Foundation Australia, *Fact Sheet: Pneumonia* (July 2014) www.lungfoundation.com.au; The Australian Immunisation Handbook.

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[144] Sharon Davis et.al "*Respiratory medication use in an Australian developmental disability clinic population: messages for health care professionals*" (2014) 20 Australian Journal of Primary Health 278, 278.

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[180] For example see Epilepsy Foundation Australia, My Epilepsy Medical Review Appointment, available at http://www.epinet.org.au/articles/epilepsy_review_appointment

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[245] This group of medications comprises preparations used in the treatment of neuroses and psychosomatic disorders associated with anxiety and tension eg. Benzodiazepines.

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