



Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland

Summary of recommendations

About the review

People with intellectual or cognitive disability often have multiple and complex health needs and a high mortality rate compared with the general population. They also face significant barriers to accessing appropriate health care and experience poorer health due to poverty and social exclusion.

In Queensland, apart from the Coronial process for reviewing deaths in care, there is no specific process for systemically reviewing the deaths of people with disability. While all deaths in care must be reported to the Coroner and investigated, not all will result in an inquest or published findings. At the time this report was released, the number of deaths in care of people with disability were not published in Queensland.

A person was included in the sample if:

- they identified as having an intellectual impairment (intellectual disability or cognitive impairment) or 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 occurred between 2009 and 2014;
- their death was a death in care as defined in the Coroners Act 2003 (Qld) and they resided in a level 3 residential service or in an accommodation support service funded or provided by the Department of Communities, Child Safety and Disability Services; and
- their death was reported to the State Coroner and the available material included at least a Police Report, or Medical Practitioner's Report and Coroner's Findings, or Cause of Death certificate.

An Advisory Panel was formed to undertake a systemic analysis of the information received from the State Coroner and other agencies. The 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.

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.

A total of 73 cases were reviewed. The key findings of the review included:

- The median age at death was 53 years, approximately 25 years less than the general population.
- The median age at death for females (22 individuals) was 49 years, approximately 36 years less than the general population.
- More than half of all deaths reviewed (59%) were determined by the panel to be unexpected. Of those deaths deemed to be unexpected, 67% were also considered to be potentially avoidable.
- A high proportion of people in the sample (49%) were being administered psychotropic medication in cases where, based on available information, few seemed to have a diagnosis of mental illness.
- There was a large presence of undetected ill health noted in the review, with many people not diagnosed with the condition that led to their death until either just before their death or at autopsy.
- Many of the most common 'causes of death' identified in the sample involved conditions that were amenable to therapeutic treatments or evidence-based prevention such as vaccinations.



Recommendations for consideration by government to address overarching systemic issues

Governance

Improvements to the way that health care and end-of-life matters for people with disability are reported, recorded, monitored, and analysed.

- 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.

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.

- 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 the Queensland Centre for Intellectual and Developmental Disability (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.

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.

- The National Disability Insurance Scheme (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; and
 - 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.



Recommendations to address the risk factors and vulnerabilities of the leading causes of death for people with disability

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.



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 Sudden Unexpected Death in Epilepsy (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.

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.



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 dietitians 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.

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.



Choking/food asphyxia

- 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.

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.



Recommendations to address issues with provision of general health care and disability support

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 Comprehensive Health Assessment Program (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 Tele-health services should be extended to people with disability living in residential support



Identifying serious health conditions and responding to critical incidents

- 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.



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.

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.



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.

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.

