

Position statement

Upholding the right to life and health of people with disability

June 2019

The United Nations *Convention on the Rights of Persons with Disabilities* recognises that people with disability have the right to the enjoyment of the highest attainable standard of health, on an equal basis with others.

Key to fulfilling this obligation is the provision of preventative and coordinated health services and emergency interventions for people with disability. Health services need to adequately address the often complex health conditions and other risk factors experienced by people with disability. This includes early identification and intervention, and the provision of health services designed to minimise and prevent further disabilities or escalation in conditions.

In February 2016, the Public Advocate published a report – *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland* – which was the first systemic review of its kind in Queensland. The review investigated the deaths of 73 Queenslanders with intellectual disability living in disability and supported accommodation.

The review found that over half (53%) of the 73 the reviewed deaths were considered to be potentially avoidable.

The key issues identified in the review associated with the deaths included:

- The need to address risk factors and vulnerabilities for people with disability in care, including issues associated with respiratory diseases (mainly pneumonia and aspiration pneumonia), epilepsy, circulatory system diseases (including ischaemic heart disease), choking/food asphyxia and using psychotropic medications to manage challenging behaviours; and
- The need to improve the quality of health care and disability supports. This included improved primary care and intervention practices with regular general health and annual comprehensive health checks, identification of the signs of serious illness early, improved access to health care and support including medical specialists for complex conditions, enhanced coordination of health care and disability services, and end-of-life care and decision-making.

The National Disability Insurance Scheme (NDIS) presents the potential for significant positive change in the lives of people with disability. However, there are very significant risks for people with disability who have complex health issues. NDIS plans need to recognise people's health needs and include the supports necessary to routinely access health services for the management of multiple conditions.

At present, mainstream health services and the NDIS have no key points of connection that provide for engagement and follow up to coordinate care and services. This situation is further exacerbated by on-going unresolved issues between mainstream health services and

the National Disability Insurance Agency about funding for services that are critical to the health and wellbeing of people with disability.

While these issues remain unresolved, the health and wellbeing of people with disability is at risk.

This issue is not unique to Queensland. Both the New South Wales Ombudsman and Victorian Disability Services Commissioner have registered similar concerns following reviews of deaths in care in their respective states. The Disability Services Commissioner in Victoria has now issued notices requiring disability services to review the health care plans of all residents in care. These reviews will ensure that the health needs of every resident in care are documented, and that an associated health plan has been developed in consultation with the resident and is reviewed regularly.

The way forward

National responses

Medical and nursing degrees should include specific training on the health needs of people with disability

The Australian Government should:

- support the development and trial of curriculum content on the health needs of people with intellectual disability in university medical and nursing courses; and
- fund the employment of intellectual disability health workers as an information resource for GPs and to help people with intellectual disability find the right health professional.

NDIS plans

All of the available evidence highlights the need for NDIS plans to:

- acknowledge complex health issues and incorporate the disability supports necessary to address health care needs, provide for adequate coordination of essential health care supports, and support attendance at medical and therapeutic appointments; and
- include actions to improve the integration and communication between mainstream health services, registered NDIS service providers, and other disability support services to ensure people with disability with complex health conditions are accessing the health services they need.

State responses

Individual health care plans

People with disability who have complex health conditions need individual health care plans that are reviewed annually and used to inform the NDIS supports required to adequately coordinate access to health care.

Reviewing deaths in care

There should be regular systemic reviews of deaths of people with disability in care, similar to those undertaken by the New South Wales Ombudsman. This work should be coordinated with the NDIS Quality and Safeguards Commissioner, and focus on the real and necessary changes required to improve health and longevity outcomes for people with disability.

Best practice initiatives

The Queensland Government should encourage and fund pilot projects that:

- demonstrate best practice in coordination between health care providers and disability service providers; and,
- support improved training for health and disability workers about appropriate care for people with disability with complex health conditions.