National Safety and Quality Health Service (NSQHS) Standards

The National Safety and Quality Health Service (NSQHS) Standards were developed by the Australian Commission on Safety and Quality in Health Care (the Commission) in collaboration with the Australian Government, states and territories, the private sector, clinical experts, consumers, patients and carers. The primary aims of the NSQHS Standards are to protect the public from harm and to improve the quality of health service provision. The NSQHS Standards provide a quality assurance mechanism that tests whether relevant systems are in place to ensure that expected standards of safety and quality are met.

The eight NSQHS Standards cover high-prevalence adverse events including healthcare associated infections, medication safety, comprehensive care, clinical communication, the prevention and management of pressure injuries, the prevention of falls, and responding to clinical deterioration. Importantly, the NSQHS Standards provide a nationally consistent statement about the standard of care that consumers can expect from their health service organisations.

The NSQHS Standards embeds person-centred care and addresses the needs of people who may be at greater risk of harm. This includes patients with cognitive impairment.

People with intellectual disability are included within the existing definition of cognitive impairment used for the NSQHS Standards and therefore need to be supported under the specific cognitive impairment actions of 5.29 and 5.30 in the NSQHS Standards.

The Commission has developed this additional fact sheet series to provide specific, targeted strategies and resources for health service organisations to better respond to the specific needs of people with intellectual disability.
Intellectual disability

Intellectual disability is a lifelong condition that originates in the developmental period. It affects a person’s ability to learn, communicate, retain information and undertake everyday activities. People with intellectual disability have a wide range of capabilities and needs and their neurological, developmental and co-existing health conditions, circumstances and experiences vary considerably.

In Australia there have been decades of disability reform prior to and following the ratification of the 2008 United Nations (UN) Convention on the Rights of Persons with Disabilities. There have been State Disability action plans, the introduction of the National Disability Insurance Scheme (NDIS) and subsequent disability access and inclusion plans that have incorporated actions for the health sector. However, further work is needed to improve health outcomes for people with intellectual disability.

In 2020 the Disability Royal Commission provided research evidence and personal accounts of people with cognitive disability. They found people with a cognitive disability have been, and continue to be, neglected by the Australian health system. They can experience delayed diagnoses and misdiagnoses, and face barriers to appropriate treatment and management. They are at higher risk of hospital-acquired complications and avoidable and premature death.

The Disability Royal Commission used the term ‘cognitive disability’ as an umbrella term to describe a disability that results in actual and perceived differences in cognition and included people with intellectual disability, autism and acquired brain injury in its definition. The Commission has chosen to use ‘intellectual disability’ as it is a more familiar term to stakeholders, acknowledging that the strategies outlined in the fact sheet series are applicable more broadly.

Safety and quality issues in health care

People with intellectual disability can have high healthcare needs, often multiple health conditions, with frequent hospital admissions. A person with intellectual disability is at high risk of poor health, chronic disease and premature death from preventable illness.

The evidence and feedback on safety and quality issues suggests that health care can be improved by focusing on:

- Person-centred care
- Delivery of comprehensive care
- The inclusion of disability safety and quality issues in clinical governance systems.

Person-centred care

Person-centred care is fundamental to safe, high-quality healthcare. It is care that is respectful of, and responsive to, the person’s preferences, needs and values. The needs of the individual are considered in each interaction between the workforce (clinical and non-clinical) and the person, their carer and family and those providing support. The organisation’s systems and processes are designed to support the workforce to deliver person-centred care.

While some people with intellectual disability have good care experiences and outcomes, many do not. People with intellectual disability encounter problems such as:

- Not being accompanied by someone who is aware of their health issues
- Not being supported to be involved in decisions about their health care
- Not being provided information in accessible formats, particularly information on medicines
- Experiencing distress from the clinical environment and treatments
- Encountering clinicians who assume they lack capacity, not directly communicating with them and automatically talking to family members or support staff
- Not having their substitute decision-maker accurately identified and consulted when required
- Encountering clinicians who do not know how to effectively communicate with them or understand their specific communication or care needs.
Comprehensive care

Comprehensive care is the coordinated delivery of health care that is aligned to the person's goals of care and healthcare needs. It considers the effect of the person's health issues on their life and wellbeing, and is clinically appropriate. Key elements of comprehensive care include clinical assessment and diagnosis, goal setting, risk screening and assessment, care planning, care delivery and review.

When a person with intellectual disability is unwell, clinical assessments can be challenging for clinicians, particularly when a person has complex, urgent, high care needs. A person may not be able to describe symptoms or communicate pain, and emergency diagnostic procedures can be very stressful for the person.

Sometimes a comprehensive assessment is not undertaken and a person's symptoms are attributed to their disability and not fully investigated. This is known as diagnostic overshadowing. This can lead to delayed, missed or incorrect diagnoses.

A person with intellectual disability is at high risk of poor health, chronic disease and premature death from preventable illness. Clinicians may make negative assumptions about the person's quality of life and not discuss health goal setting or preventative health measures.

Not knowing the person, communication difficulties and lack of planning and preparation for a health care episode can create traumatic and stressful experiences, with escalating responses from the person that can impede investigations and the provision of care and may create a risk of harm to the person or others. These behaviours in turn can lead to restrictive practices and further complications.

The onset or escalation of behaviours may be an indication of underlying illness or health condition causing pain. For example, people with intellectual disability are more likely to have undetected oral health problems such as tooth decay, gum inflammation and mouth infections. Lack of investigation of possible pain and lack of recognition of the need for pain relief can be traumatic.

People with intellectual disability may have multiple health conditions with multiple medicines. Medicine-related harm can occur at any time but the risk is higher when people are on multiple medicines and not adequately monitored.

High risk medicines are another potential safety and quality issue. People with intellectual disability commonly take psychotropic medicines for co-existing mental health problems or to manage behaviours of concern, such as self-injury or aggression.

Psychotropic medicines can have a range of side effects, the worst of which is associated with death from neuroleptic malignant syndrome. People may experience nausea, weight gain and associated cardiovascular risks, increased risk of Type II diabetes, impaired cognitive functioning, abnormal movement disorder, liver problems, sexual difficulties, reduced bone density and a dry mouth that compounds their oral health issues.

People with intellectual disability are at greater risk of mental health disorders than the general population but can face significant barriers in accessing mental health services. People with dual diagnoses can have complex needs often requiring collaboration across mental health, health and disability sectors.

Difficulties in obtaining diagnoses, disputes about whether a person displaying behavioural or mental health issues when in crisis and which discipline should be responsible for the person's care have been reported. A lack of teamwork and poor communication can lead to contradictory treatment recommendations.

Communication and attitudinal barriers may mean that people with intellectual disability can be excluded from conversations about their own end of life or that of their loved ones. This includes not being given the opportunity to learn about death and dying or communicate their preferences for information and care if they are diagnosed with a life-limiting condition.
Governance

Good health outcomes rely on effective clinical governance and management processes and the existence of robust safety and quality systems. Negative assumptions by clinicians are a significant barrier to safe and high quality health care for people with intellectual disability. It leads to consumers reporting feeling devalued. Training and education for clinicians on how to support and care for people with intellectual disability can reduce this barrier.

Other organisational and systemic areas where barriers could be reduced include:

■ Consulting with people with intellectual disability, carers and families when designing and planning health service
■ Providing people with intellectual disability, carers and families with information on their right to and process for complaining
■ Addressing the health needs of people with intellectual disability in policies and procedures
■ Planning and coordinating health care with other services
■ Planning and coordinating care at transitions, particularly when moving from paediatric and adult services and between health, disability and aged care services
■ Maintaining records to keep important health information about the person up to date
■ Improving access to specialist disability care, particularly for First Nations people living in rural and remote areas and for people from culturally and linguistically diverse backgrounds
■ Addressing institutional racism for First Nations people
■ Collecting data on people with intellectual disability and their health care needs of people
■ Developing or adapting and using standardised measures of disability in patient data systems, to enable comparisons between services.

Fact sheet series

Other fact sheets in this series include:

■ Fact sheet 2: Intellectual disability – Person-centred care
■ Fact sheet 3: Intellectual disability – Comprehensive care
■ Fact sheet 4: Intellectual disability – Governance
■ Safe and high quality care for people with intellectual disability: Actions for clinicians.

The fact sheets provide more detailed information linked to the following NSQHS Standards.

Figure 1: The relevant NSQHS Standards

Resources

The Commission has developed a comprehensive range of resources to support the implementation of the NSQHS Standards that are available on the Commission’s website. The Commission website also includes fact sheets on attributes of high-performing person-centred healthcare organisations.

Cognitive impairment resources are available on the Commission’s website and on the Cognitive care website, including the NSQHS Standards user guide for health service organisations providing care for patients with cognitive impairment or at risk of delirium.
References

12. The Royal Children's Hospital Melbourne. Autism and developmental disability: Management of distress/agitation. [Internet].