Intellectual disability

Governance

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.[1] People with intellectual disability have a wide range of capabilities and needs[2] and their neurological, developmental and co-existing health conditions, circumstances and experiences vary considerably.

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.[3]

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

- A person-centred approach
- Delivery of comprehensive care
- Inclusion of disability safety and quality issues in clinical governance systems.

Fact sheet 4

This fact sheet provides information to support better health care for people with intellectual disability. It identifies the clinical governance system essential for person-centred care for people with intellectual disability.

It is part of **a series of fact sheets** for health service organisations. The aim of the fact sheets is to support improvement in the quality of health care for people with intellectual disability. Reflective questions and suggested strategies are linked to actions in the **National Safety and Quality Health Service Standards (NSQHS) Standards**.

The importance of governance

Good health outcomes rely on effective clinical governance and management processes, as well as the existence of robust safety and quality systems. Person-centred care is only possible when governing bodies, managers and clinical leads support the workforce to implement well-designed safety and quality systems.[3] In person-centred clinical governance systems, consumers receive support to be involved at all levels of the organisation's governance structures, and models of care are designed around the person.[3]

How to support better health care in your organisation

The following reflective questions may be helpful for organisations to determine if its clinical governance system adequately supports people with intellectual disability, carers, family, support people, the workforce and key external agencies to provide person-centred care. Key areas of clinical governance include:

① **Governance, leadership and culture**
② **Patient safety and quality systems**
③ **Clinical performance and effectiveness**
④ **Safe environment**.

① Governance, leadership and culture

- Does the governing body provide leadership by driving improvements in safety and quality for people with disabilities?
- Are people with disability included in clinical governance structures responsible for safety and quality?

② Patient safety and quality systems

- Are the experiences of people with intellectual disability collected and is the information used to improve health outcomes?
- Are disability safety and quality issues included in health service planning, design and delivery?
- Are the health needs of people with intellectual disability considered in policies and processes?
- Are there flexible arrangements or alternative models of health care for people with disability, such as telehealth, outreach, home visits, after hours?
- Are there formal partnerships with relevant disability, First Nations and culturally and linguistically diverse background (CALD) organisations? Do these partnerships support well-planned and coordinated health, disability and aged service delivery?
- Are mental health services accessible or referral pathways in place for people with intellectual disability?
- Are palliative care services accessible or referral pathways in place for people with intellectual disability and a concurrent life-limiting condition?
- Are there processes in place for effective transfer from children to adult health services?
- Is data on people with disability collected, analysed and reported?

③ Clinical performance and effectiveness

- Is the disability education and training provided to the health workforce effective? The suggested topics for training and education are
  - person-centred care
  - communicating effectively and appropriately
  - use of communication aids
  - supported and substitute decision-making
  - comprehensive assessment
  - informed consent
  - behaviour support, de-escalation and non-pharmacological strategies
  - partnerships with carers, family and support people
  - culturally safe care for Aboriginal and Torres Strait Islander people
  - NDIS, access, health literacy of disability support workers
  - communication and coordination between health, disability and aged care services
- Are people with intellectual disability involved in the design or delivery of training?
- Is feedback from the experiences of people with disability included in workforce training? Does the workforce have access to disability health expertise and dual disability and mental health expertise?
- Is the organisation building the capability of its mainstream health services to be responsive to the needs of people with intellectual disability?
- Is data on people with intellectual disability used to identify variation in clinical practice and areas of patient risk?

④ Safe environment

- Does the physical environment support people with intellectual disability? Is it accessible and supportive?
- Does the physical environment offer flexibility and foster partnerships with people with intellectual disability, families, carers and support people? For example, are there flexible visiting or carer zones?

NSQHS Standards

Improving the health care of people with intellectual disability requires health service organisations to meet the NSQHS Standards. While all actions in the NSQHS Standards apply to people with disability these two standards are particularly important:

- Clinical Governance Standard
- Partnering with Consumers Standard.

Actions that warrant specific consideration are in **Table 1**.

Figure 1: The relevant NSQHS Standards

Table 1: Relevant actions in the NSQHS Standards

NSQHS Standard	Action	Item
	Governance, leadership and culture	
	1.01–1.06	Governance, leadership and culture
	Patient safety and quality improvement systems	
	1.07	Policies and procedures
	1.08	Measurement and quality improvement
	1.13, 1.14	Feedback and complaints management
	1.15	Diversity and high-risk groups
Clinical Governance	1.17	My Health Record System
	Clinical performance and effectiveness	
	1.20c	Safety and quality training
	1.28	Variation in clinical practice and health outcomes
	Safe environment for the delivery of care	
	1.29–1.33	Safe environment

NSQHS Standard	Action	Item
Partnering with Consumers	2.01c	Integrating clinical governance – identifying training requirement for partnering with consumers
	2.11–2.13	Partnering with consumers in organisational design and governance
	2.14	Consumer views and experiences in workforce training and education
Comprehensive Care	5.01	Integrating clinical governance – identifying training requirements to deliver comprehensive care

Learning from others

Suggested strategies and resources for improving the care of people with an intellectual disability:

1 Governance, leadership and culture

Person-centred healthcare organisations

- The Commission has developed a range of resources describing the **attributes of high-performing person-centred healthcare organisations** including a self-assessment tool which could be applied to assessing the organisation's response to people with intellectual disability.

2 Patient safety and quality systems

Self assessment

- NSW Agency for Clinical Innovation (ACI)'s guide **Building capability in NSW health services for people with intellectual disability: the Essentials** provides a self-assessment tool and links to a wealth of resources for health services to better meet the needs of people with an intellectual disability and their carers.

Planning

- The Victorian Health Association (VHA) has created a range of resources to support Victorian public hospitals, multi-purpose services and community health services in the development of **disability actions plans**. Resources include a **Disability action plan template and checklist** and a series of videos to assist building capacity to support the needs of people with disability and to ensure opportunities for greater representation on governing bodies, boards and committees, and support the workforce more broadly

- Improving access to autism assessment, diagnosis and early intervention is part of the **Victorian Government's autism plan 2019**

- As part of the Department of Health's **National Roadmap for Improving the Health of Australians with Intellectual Disability**, a Primary Care Enhancement Program is being piloted in four lead Primary Health Networks (PHNs) over four years, with a view to national rollout across all PHNs

- **Health Equity and Access Unit, Queensland Metro South Health** has people with disability as one of their priority populations.

Health pathways and access

- Metro South Health and the **Brisbane South Primary Health Network (PHN)** have developed a Health Assessment pathway for people with intellectual disability for local general practitioners

- NSW Agency for Innovation (ACI) has developed **Guidelines on the Pathways to Care for children and adolescents with intellectual disability and challenging behaviour and/or mental health problems** (2014)

- The Victoria government has created the **Disability Liaison Officer (DLO) Program** in response to the COVID-19 pandemic in Victoria. The service provides specialised disability information and support for people with a disability relating to COVID-19 including testing and vaccination as well as health advice and prevention through linking people to other health supports.

Inclusion in polices

- NSW Health's 2017 policy directive[4] **Responding to Needs of People with Disability during Hospitalisation** sets out guiding principles for responding to the needs of people with disability including inclusion, person-centred services, accessibility, communication, and reasonable adjustment

- **Western Australian Disability Health Framework 2015–2025: Improving the health care of people with disability** provides direction for WA Health and its partners on policy development and service delivery to achieve improved health outcomes for people with disability

- Western Australian Department of Health's **Hospital Stay Guideline for Hospitals and Disability Service Organisations**[5] provides guidance for disability service organisations and hospitals when managing the hospital experience of individuals with disability.

Flexible and alternative models of care

- The SA Intellectual Disability Health Service Model of Care recognises alternative models for health care that may suit the person's needs such as telehealth appointments for specialised services or home visiting.

Mental health system design

- The Department of Developmental Disability Neuropsychiatry's *Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers* is a guide to assist health services to provide equitable access, develop a skilled workforce and provide appropriate treatment for people with an intellectual disability and a mental health disorder

- CID has outlined a series of practical recommendations for improving the mental health system for people with intellectual disability in this **National Roundtable on Mental Health of People with Intellectual Disability 2018 Communique**.

Data

- The Australian, New South Wales, Victorian, South Australian and Queensland governments are working together with the National Disability Insurance Agency and the AIHW to pilot test the development of a **National Disability Data Asset**. This will bring together data from a range of domains relevant to people with disabilities and their carers, including health.

Transitions

- The Commission has published the **Transition Support Service, The Royal Children's Hospital Melbourne** as an exemplar practice supporting patients with complex chronic conditions, including those with neurocognitive and intellectual disabilities.

③ Clinical performance and effectiveness

Education and training

- Mater Intellectual Disability and Autism Service (formerly Qld Centre for Intellectual and Developmental Disabilities) provides access to a self-paced **ABLEx Series**, which aims to improve the health of people with intellectual disability. It looks at barriers and enablers to healthcare, and specific physical health and mental health issues

- Western Australian Department of Health has developed **Shared attitudes and behaviours in health care: A core capabilities resource for disability health**

- The Victorian Government has co-produced the **Allied health capability framework: disability and complex support needs** together with allied health professionals, professional bodies, disability services providers, academics, NDIS advisory bodies and consumers

- NSW Agency for Innovation (ACI) has developed a series of **training videos** to help clinicians understand the health needs of a person with intellectual disability including:
  - mental health
  - respiratory health
  - hospitalisation
  - diagnosis
  - working with health professionals – parent perspective
  - continuity of care
  - accessing care from a consumer perspective
- The Council for Intellectual Disability (CID) has **health fact sheets** covering 30 health topics that are relevant to health workforce
- Down Syndrome Australia has produced **resources** for health professionals to better understand how to support people with Down syndrome within the health system
- Inclusion designlab has produced *Your Dental Health: A Guide for People with a Disability, their Family Carers, Friends and Advocates* that outlines treatment pathways, information about communication and consent, and strategies for achieving better long term oral health outcomes for people with intellectual disability
- **The Living with Disability Research Centre at La Trobe University** has free online learning modules, seminars and resources to support person-centred care, social inclusion and participation of people with cognitive disabilities, in particular those with intellectual disability or acquired brain injury
- The University of Hertfordshire has a website on **Understanding Intellectual Disability and Health** that is a learning resource for everyone working in healthcare. The 'How to' articles provide practical advice about relevant clinical skills. An example is **Everybody's life has worth – Getting it right in hospital for people with an intellectual disability and reducing clinical risks**.

Clinical variation and appropriate care

- To ensure that the health care provided for people with intellectual disability is appropriate, health services can use the *NSQHS Standards User Guide for the Review of Clinical Variation in Health Care*. This guide outlines steps to implement **Action 1.28** of the NSQHS Standards. The Commission has also released a series of webinars about healthcare variation – the **Better Care Everywhere: Healthcare variation in practice program series.**

④ Safe environment

Physical environment

- The South Australian Intellectual Disability Health Service (SAIDHS)[1] is in a quiet and peaceful setting, with ample parking and telehealth facilities. Custom modifications support accessibility through including disability access ramps and restroom facilities, a lowered reception counter and wide access doors to clinic rooms for wheelchair access.

Fact sheet series

Other fact sheets in this series include:

- Fact sheet 1: **Intellectual disability – safety and quality issues**
- Fact sheet 2: **Intellectual disability – person-centred care**
- Fact sheet 3: **Intellectual disability – comprehensive care**
- **Safe and high quality care for people with intellectual disability: Actions for clinicians**.

References

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2. NSW ACI. Building Capability in NSW health services for people with intellectual disability: the Essentials. NSW Agency for Clinical Innovation; 2017.
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4. NSW Ministry of Health. Policy Directive Responding to Needs of People with Disability during Hospitalisation. [Internet] Sydney: NSW Ministry of Health 2017 [cited 14 January 2019] Available from: **https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2017_001**.
5. Western Australian Department of Health. Hospital Stay Guideline for Hospitals and Disability Service Organisations. Perth: Western Australian Department of Health; 2016.

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